DATA LABEL: Public

West Lothian Integration Strategic Planning Group

West Lothian Civic Centre
Howden South Road
LIVINGSTON
EH54 6FF

31 March 2016

A meeting of the **West Lothian Integration Strategic Planning Group** of West Lothian Council will be held within the **Strathbrock Partnership Centre, 189(a) West Main Street, Broxburn EH52 5LH** on **Thursday 7 April 2016** at **2:00pm**.

BUSINESS

1. Apologies for Absence

2. Order of Business, including notice of urgent business

3. Declarations of Interest - Members should declare any financial and non-financial interests they have in the items of business for consideration at the meeting, identifying the relevant agenda item and the nature of their interest.

4. Confirm Draft Minutes of Meeting of West Lothian Integration Strategic Planning Group held on Tuesday 23 February 2016 (herewith).

5. IJB Finance Arrangements

   (a) Presentation by Chief Finance Officer (herewith)

   (b) IJB Financial Arrangements - Report by Chief Finance Officer (herewith)

6. Joint Commissioning Plans Update - Report by Director (herewith).

7. Localities Groups - Terms of Reference - Report by Director (herewith).

8. Participation and Engagement Strategy - Report by Director (herewith)

9. Timetable of Meetings 2016-17 (herewith)

10. Workplan (herewith)

NOTE **For further information please contact Val Johnston, Tel No.01506 281604 or email val.johnston@westlothian.gov.uk**

MINUTE of MEETING of the WEST LOTHIAN INTEGRATION STRATEGIC PLANNING GROUP of WEST LOTHIAN COUNCIL held within STRATHBROCK PARTNERSHIP CENTRE, 189(A) WEST MAIN STREET, BROXBURN EH52 5LH, on 23 FEBRUARY 2016.

Present – Jim Forrest (Chair, Health Professional), Marion Barton (Health Professional), Carol Bebbington (Health Professional), Alan Bell (Social Care Professional), Ian Buchanan (User of Social Care), Margaret Douglas (Health Professional), Jane Houston (Unison Health), Mairead Hughes (Health Professional), Jane Kellock (Social Care Professional), Pamela Main (Social Care Professional), Martin Murray (Unison Public Sector), Charles Swan (Social Care Professional) and Robert Telfer (Commercial Provider of Social Care)

Apologies – Jacqui Campbell, Elaine Duncan, David Farquharson, James McCallum and Mary-Denise McKernan

1. DECLARATIONS OF INTEREST

No declarations of interest were made.

2. MINUTE

The Group confirmed the Minute of its meeting held on 4 February 2016. The Minute was thereafter signed by the Chair.

3. STRATEGIC PLAN

A report had been circulated by the Director providing an update on the development of the Strategic Plan, a copy of which was attached to the report.

It was recognised that there was still work to be done to finalise the plan however it was anticipated that the final draft of the plan would be presented to the March meeting of the Integrated Joint Board (IJB).

The report continued to advise that there were 23 National indicators agreed to measure performance of Integration of Health and Social Care. A baseline performance report had been prepared which provided a summary position for West Lothian based on the data available. The West Lothian performance was compared to Scotland for each indicator except for indicator 22 which was compared to the other three Lothian partnerships.

Additionally the Scottish Government had made a strong recommendation that the localities within integration areas should be based on 2011 datazones instead of 2001 datazones. Therefore in line with this recommendation a revised map of the West Lothian localities was circulated at the meeting.

It was also reported that the Performance Data would continue to be updated and it was proposed that it would form an integral part of the Strategic Plan.

The group were also advised that the Strategic Plan contained a number of Strategic Priorities but it was intended that these would be expanded to provide more details on how each of these would be addressed as part of the integration of health and social care.

Finally the group were advised that the Locality Groups would start to be populated once the Strategic Plan had been finalised and signed off by the IJB.

Decision

1. To note the contents of the draft Strategic Plan;
2. Agreed to include the revised localities in the Strategic Plan;
3. Agreed to include the Performance Data, including targets in the Strategic Plan; and
4. Agreed to further develop the Strategic Priorities to provide a detailed brief for each one along with an explanation on how it would be addressed as part of the integration of health and social care.

4. JOINT COMMISSIONING PLAN UPDATE

A report had been circulated by the Director providing an update on the schedule of the development of care group commissioning for specific plans.

The report explained that the joint commissioning of health and care services within West Lothian was well established under the auspice of the former West Lothian Community Health and Care Partnership (CHCP). As a result of this the West Lothian IJB was well placed to meet the requirements for strategic commissioning under the new legislation.

The previous joint commissioning plans developed within the remit of the CHCP had been developed by the management group appropriate to the client care group. This same general structure was also being proposed within the draft Strategic Plan. It was also being recommended that the terms of reference including membership be drafted to cover the remit of these commissioning groups and be presented to the IJB for approval.

The report then provided a summary of the various commissioning groups noting that a Needs Assessment was still to be completed for some of them and that this would require to be tendered for as the resources were not available elsewhere.

Therefore it was recommended that the Group :-

1. Note the progress of the development of various care group

commission plans;

2. Agree that a report on the progress of the various care group commissioning plans be presented to the Integrated Joint Board (IJB) meeting on 23 March 2016; and
3. Agree that terms of reference including membership be drafted to cover the remit of the commissioning groups who would be responsible for drafting the relevant commissioning plan for approval by the IJB.

Decision

To approve the terms of the report.

5. ORGANISATIONAL DEVELOPMENT AND WORKFORCE PLAN

A report had been circulated by the Head of Health outlining the plan for organisational and workforce development to support the integration of health and social care and contribute to the achievement of the national health and well-being outcomes.

The purpose of the Organisational Development and Workforce Plan was to ensure that a planned and systematic approach was adopted to support the organisational change required to contribute fully to improving healthcare and reducing inequalities in West Lothian.

West Lothian had a proven track record of successful partnership working across health and social care boundaries and it was planned to build on this foundation to ensure services were developed and delivered more innovatively and effectively and were designed to meet local needs and priorities.

There would be a clear emphasis on person-centred planning and delivery ensuring that those who used services got the right care and support whatever their needs, at any point in their care journey.

For integration of health and social care to be successful it was essential that those working in health and social care were equipped to make best use of their collective skills and resources to improve outcomes. This would require individuals, teams and organisations to develop new ways of working together to deliver the vision underpinned by strong leadership, evolving management arrangements, processes and relationships.

The plan for workforce development would focus on five key outcomes :-

- Understand, promote and achieve better outcomes for people;
- Engage in meaningful co-production with people and communities;
- Affirm professional values and identity and to take responsibility for career long development;

- Demonstrate authentic and collaborative leadership behaviours; and

- Actively engage in locality planning and service improvement.

Local support networks would be put in place to ensure staff were engaged and support to continually improve the information, support, care and treatment they provided. The development plan focussed on a number of themes including; locality planning, change management and joint strategic commissioning.

A series of road shows had been held across health and social care to provide information to staff on the integration of health and social care and to provide an opportunity for staff to discuss and raise any questions they had. These events had been successful and well attended by staff across the partnership.

The plan would be considered a working document and would evolve over time to reflect strategic developments, responsiveness to local needs and availability of resources.

The group continued to be advised that challenges remained with workforce planning particularly as the workforce got older. A dialogue with education providers would need to be had to ensure that workforce planning for the future was underway. It was noted that a similar situation within the private sector also existed with the recruitment and retention of staff.

As the integration of health and social care progressed engagement with staff would continue to be central to the whole process to ensure resources were used effectively and efficiently in the provision of services.

The Strategic Planning Group were asked to :-

1. Note the contents of the report; and

2. Support the key activities required for delivery of the organisational development and workforce plan.

Decision

1. Noted the contents of the report;

2. Noted that challenges remained with regards to workforce planning in both the public and private sector; and

3. Noted that engagement with staff as integration progressed was crucial.

6. WORKPLAN

A workplan had been circulated which provided details of the work of the

Strategic Planning Group over the coming months.

It was agreed to also include the following items :-

- Strategic plan priorities
- Joint commissioning plans progress report
- Budget update
- Locality Group update

It was also noted that the item concerning Oral Health Strategy would be delayed beyond the April meeting due to a member of staff being on long-term absence.

Decision

1. Noted the contents of the workplan;
2. Agreed to include a number of additional items; and
3. Noted that the Oral Health Strategy would be delayed.

West Lothian
Council

NHS
Lothian

West Lothian Integration Joint Board

INTRODUCTION TO IJB BUDGETS

7TH APRIL 2016

Content

- Components of IJB budget
- How the IJB budget is derived
- The differences between the IJB and the HSCP
- Resource Allocation to and from the IJB
- Budget responsibilities
- Operational Budget Management of IJB delegated functions / services
- Questions

Components of the IJB Budget

Budget Component	Delegated by	Budget Element
Adult Social Care	West Lothian Council	Payment
Delegated Core Health Services	NHS Lothian	Payment
Share of Delegated Pan Lothian Hosted Services	NHS Lothian	Payment
Share of Delegated Acute Services	NHS Lothian	Set Aside

- Includes
    - Direct Services Budgets
- Excludes
    - Facilities and Property Overhead Budgets
    - Corporate Support Services Budgets

How is the IJB Budget Derived

- Adult Social Care budget – discrete budget
- Delegated Health Budgets -
  - Derived using cost centres that relate to delegated services (list of delegated cost centres agreed)
  - Proposed method of calculating West Lothian's share of Pan Lothian Hosted and Acute Services (largely based on Primary Care NRAC model with a few exceptions)
  - Proposed method of calculating West Lothian's share of Pan Lothian Prescribing budget (currently based on PBSG model)

IJB budget differs from HSCP budget

Services in HSCP not in IJB	Reason for variation
Children’s Services, Criminal Justice	West Lothian Council services not Delegated to WL IJB
Specific Children’s Services * Regional / National Services	West Lothian Core Health Services not Delegated to WL IJB
Children’s Psychology	West Lothian Hosted Health Services not Delegated to WL (or any other) IJB
Dental Services, Adult Psychology, Podiatry and Orthoptics	West Lothian HSCP Hosted Services with only a share delegated to WL IJB
Services in IJB not in HSCP	**Reason for variation**
Examples include Dietetics, Complex Care, LUCS, Rehab Medicine, Sexual Health	Services Hosted by other Health Operational Units with a share delegated to WL IJB
Examples include Geriatric Medicine, General Medicine, Rehabilitation Medicine, A&E	Acute Services with a share delegated to the IJB

* It should be noted that Primary Care (including GMS and Prescribing) and Dental Services are delegated for adults and children

Resource allocation to and from the IJB

Resources from the parties to the IJB	West Lothian Council and NHS Lothian advise WL IJB of the value of the payment and set aside budget and the method of deriving those budgets.
IJB Actions	After undertaking appropriate due diligence on the value of the payment and set aside budget, WL IJB will, in line with its Strategic Plan, allocate budgets to functions / services to be delivered by the council and the health board.
Resources from the IJB to the parties	WL IJB will issue directions to the Chief Executives of the council and health board advising the value of the resources they have been allocated for each function / service and what outcomes they are required to delivering in utilising those funds.
Payments between the parties	Where resources allocated back to each party differs from the resources allocated by each party, a balancing payment will be required to be made between the parties.

Budget Management Responsibilities

- IJB Budget Responsibilities
  - Making decisions on how resources will be used and directing the parties accordingly.
  - Monitoring financial performance against IJB budgets
  - Working with operational managers to develop recovery plans if overspend is forecast

- Operational Management Budget Responsibilities
  - Delivering outcomes directed by the IJB within the allocated resources
  - Monitor financial performance against operational budgets for their business unit
  - Developing financial recovery plans in conjunction with IJBs if overspend is forecast

Operational Budget Management – Delivering Delegated Functions / Services

There are a number of operational units involved in the delivery of the functions / services delegated to West Lothian IJB. The table below sets out the directors involved in that operational delivery across the council and NHS Lothian.

	Adult Social Care	**Delegated Core Health Services**	**Delegated Pan Lothian Hosted Services**	**Delegated Acute Services**
Director(s) responsible for Operational Delivery	Joint Director, West Lothian	Joint Director, West Lothian	Joint Director West Lothian Joint Director East Lothian Joint Director Mid Lothian Joint Director Edinburgh NHSL Corporate Directors	Chief Officer, Acute Services, NHSL Site Director RIE Site Director SJH Site Director WGH

It should be noted that the operational managers also have operational remit above and beyond the services they deliver for the IJB.

Questions

West Lothian Strategic Planning Group

Date: 7/04/2016

Agenda Item: 5

IJB FINANCIAL ASSURANCE

REPORT BY CHIEF FINANCE OFFICER

A PURPOSE OF REPORT

The purpose of this report is to set out the outcome of the financial assurance process on the currently proposed resources to be delegated to the IJB for 2016/17.

B RECOMMENDATIONS

It is recommended the Strategic Planning Group:

1. Notes the financial assurance work undertaken to date;
2. Notes the agreed allocation of the Social Care Fund resources, taking account of Scottish Government requirements;
3. Notes that approved council resources and indicative NHS Lothian resources are allocated back to Partners, via Directions, to operationally deliver and financially manage IJB delegated functions from 1 April 2016; and
4. Notes that a further report on financial assurance will be provided to the IJB following the conclusion of the NHS Lothian 2016/17 budget process

C TERMS OF REPORT

C.1 Background

A key aspect in the ability of the IJB to deliver its Strategic Plan and improve health and social care outcomes is the level and adequacy of resources available. This report considers the level of 2016/17 resources delegated to the IJB, as approved by West Lothian Council, and indicative resources currently assumed by NHS Lothian.

The content of the report was agreed by the IJB at its meeting on 31 March 2016. This report considers assumptions, risks and budget saving plans incorporated within the 2016/17 resources set out for IJB delegated functions.

C.2 Purpose and Approach to Financial Assurance

As noted in the Scottish Government guidance and approved IJB Financial Regulations, the purpose of undertaking financial assurance is to allow the IJB to understand the assumptions and risks associated with the annual resources allocated by West Lothian Council and NHS Lothian. The council and NHS Lothian are, in accordance with legislation, responsible for agreeing the functions delegated to the IJB and setting their respective budgets including the level of payments and set aside resources to the IJB.

Previous reports to the IJB on 20 October 2015 and 16 February 2016 set out the proposed approach to financial assurance which is based on Scottish Government and Audit Scotland guidance. The matters to be taken into account s part of this assurance process are:

- Assessment of actual expenditure for IJB functions in 2014/15 and forecast year end spend for 2015/16
- Information on assumptions regarding estimated budget to be delegated to the IJB for 2016/17 and comparison against previous year spend and anticipated 2016/17 demands
- Information on key budget risks associated with functions that will be delegated to the IJB
- Information on approved budget savings for 2016/17 that relate to IJB functions
- Details of any non-recurring funding included in the budget resources delegated to the IJB

The above approach forms the basis of reviewing the 2016/17 resources identified in this report by West Lothian Council and NHS Lothian, subject to the status of each bodies 2016/17 budget plans and information available. In addition, the approved West Lothian IJB Integration Scheme also informs the approach taken on financial assurance.

C.3 West Lothian Council Resources

West Lothian Council approved its 2016/17 budget on 23 February 2016, including the 2016/17 level of resources associated with functions delegated to the IJB of £66.685 million. This took account of Scottish Government funding to IJBs, provided in the first instance to Health Boards, of £250 million specifically for social care. For West Lothian, the share of this funding has been confirmed as £7.130 million.

C.3.1 Social Care Fund

In terms of allocation of the £250 million provided to Health Boards, the Scottish Government confirmed that the sum is not intended to mitigate any Health Board pressures and Ministers have directed IJBs to use the money to protect and support social care. The Scottish Government have confirmed the funding is to be used as follows:

- £125 million is provided to support spend on protecting and increasing social care capacity to support the objectives of integration, including through making progress on charging thresholds for all non-residential services to reduce charges and help address poverty.
- £125 million is provided to help meet a range of existing cost pressures faced by local authorities in the context of reduced budgets. In addition, it is to be used to meet the cost of councils introducing the Living Wage of £8.25 per hour for all social care workers, including in the independent and third sector. This is to be implemented from 1 October 2016.

As part of the council's approved budget, the following has been assumed in terms of the £7.130 million:

- £2.275 million to meet the costs of additional social care capacity requirements, in terms of additional clients and care hours, which reflects increasing pressures to meet delayed discharge targets and reduce emergency admission to hospital. This will also be used to meet the additional cost of increasing charging thresholds for non-residential care clients
- £1.635 million to protect social care provision by retaining eligibility criteria at existing levels and retaining charging at the current low levels;
- £2.240 million to address low pay in the care sector by introducing a living wage of £8.25 per hour for all external care sector workers contracted by the council, to be implemented from 1 October 2016. The actual cost of this remains uncertain and will be subject to the outcome of discussions with care providers;
- One-off preventative care investment of £980,000 reflecting the additional amount estimated to meet the full year cost (from 2017/18) of introducing the Living Wage, which will not be required for this purpose in 2016/17. This will allow the purchase of new telecare units to replace approximately 2,000 units which are at the end, or nearing the end, of their useful life. In addition, housing with care and sheltered housing improvements are required as a priority in a number of units. Housing based solutions are a key element of ensuring the overall sustainability of the health and social care system and provide a necessary level of support that helps to prevent care home and hospital admissions.

As part of the agreement on the overall local government budget for 2016/17 with the Scottish Government, councils were required to agree to the conditions of the Social Care funding and, as a result, take account of it in their budget plans for 2016/17.

The Scottish Government also stipulated that to ensure transparency for the flow of Social Care funding support for local authorities and delivery of the Living Wage commitment, the arrangements for West Lothian's allocation of the Social Care fund will require to be signed off by the West Lothian IJB Section 95 officer.

C.3.2 Financial Assurance

The table below summarises the 2014/15 outturn, forecast 2015/16 outturn and approved 2016/17 budget associated with council functions delegated to the IJB.

West Lothian Council – Resources Associated with Delegated IJB Functions

	2014/15 Actual £'000	2015/16 Forecast Spend £'000	2016/17 Budget £'000
WLC Delegated Functions	59,849	62,545	66,685
Growth in Resources		2,696	6,836

Appendix 1 shows further details on the split of the above resources against the various adult social care functions/services in each year.

2015/16 Budget Position

The forecast spend of £62.545 million represents an overspend of £321,000 against the 2015/16 budget of £62.224 million. The overspend is largely due to pressures within council care homes and reablement services where client demands continue to increase. Pressures in these areas are being partially offset by savings across a range of areas including purchased care home placements and staffing. For 2015/16, the £321,000 pressure is being met as part of the overall council Social Policy budget.

2016/17 Budget

The 2016/17 budget resources total £66.685 million, of which £7.130 million relates to West Lothian's share of the Social Care fund. In addition £48,000 of this relates to time limited investment to support dementia, with the remainder being directly received recurring council funding.

This level of resource provides for the estimated additional costs associated with staff pay awards, single tier pension costs, demographic and demand led pressures and contractual inflation, including the estimated cost of introducing the Living Wage from 1 October 2016. The 2016/17 budget also reflects approved council savings of £1.604 million which will require to be delivered to manage within the resources of £66.685 million delegated to the IJB. While comprehensive budget planning has been undertaken to realistically assess the additional cost demands to be budgeted for in 2016/17, and savings required as a result, there are a number of key risks and uncertainties that will require to be closely monitored during 2016/17. This also shows current assumptions regarding savings for 2017/18.

Key Risks and Uncertainties

- Increasing demands in social care capacity. West Lothian has the fastest growing elderly population in Scotland and while the budget resources assume £2.275 million to meet growth in demand and meet delayed discharge targets, there is a risk that demand will outstrip the assumptions and resources available.
- Increasing demand to shift the balance of care from a hospital setting to a community / social care setting. As well as elderly clients this also particularly relates to high cost adult complex care clients
- The introduction of the Living Wage for all independent and third sector providers. This will require significant discussion and negotiation with a range of care providers. A sum of £2.240 million has been estimated but there remains uncertainty over the actual cost of introduction which will not be known until contractual uplifts have been agreed
- Delivery of 2016/17 Savings. Substantial saving totalling £1.604 million will be required to be achieved. Ongoing monitoring of progress towards delivery will be required on a regular basis.
- Funding Risks. The council's contribution to the IJB assumes various sources of Scottish Government funding received via NHS Lothian. The NHS Lothian budget is still to be finalised and the impact of Scottish Government funding allocations for a number of areas, including ADP, is still being assessed.

C.4 NHS Lothian Resources

Updates to the 2016/17 financial plans have been presented to the NHS Lothian Finance and Resources Committee, most recently on the 9 March 2016. NHS Lothian continue to progress their 2016/17 budget planning. This report showed gross 2016/17 pressures of £136.7 million across NHS Lothian. After taking account of additional funding, financial recovery plans (low and medium risk savings only) and in year flexibility, the remaining gap to be funded was reported indicatively as £46.4 million.

The most recent version of the draft NHS financial plan indicates a reduced remaining gap of £31 million across an overall NHS Lothian budget of approximately £1.5 billion. It is important to note that NHS Lothian financial planning is undertaken at Business Unit level, rather than IJB level, and the focus of NHS Lothian is to balance its budget at Business Unit level in the first place, which will then feed through to IJBs. NHS Lothian is continuing to work with its Business Unit management teams to agree further options to balance the remaining £31 million gap. A significant element of this remaining gap relates to IJB delegated set aside acute services and non delegated acute services.

C.4.1 Financial Assurance

Given the ongoing work to progress and balance the NHS Lothian 2016/17 budget, the West Lothian IJB position is indicative at this stage. Full financial assurance of the 2016/17 NHS Lothian contribution to the IJB is not possible at this time and given information of IJB related spend in previous years is not fully available, the focus of the assurance will be on the current 2016/17 indicative IJB budget and assumptions attached to these resources. The table below shows the indicative 2016/17 budget position in respect of functions to be delegated to the IJB by NHS Lothian. The NHS Lothian figures do not include the Social Care Fund as the assumption made, based on Scottish Government guidance, is that this will not impact directly on NHS Lothian 2016/17 budget plans.

West Lothian IJB Indicative 2016/17 NHS Contribution		
	£'000	£'000
Base Budget Brought Forward		**130,494**
Funding Adjustments		
Proposed Share of NRAC Funding	1,998	
Base Budget Funding Uplift	1,501	
Other Misc. Adjustments	(422)	**3,077**
Updated Indicative 2016/17 Contribution		**133,571**

The table shows an indicative 2016/17 contribution of £133.571 million for the IJB from NHS Lothian, reflecting a £3.077 million increase from the 2015/16 base budget associated with IJB delegated functions.

The split of the £133.571 million between the three elements of the NHS Lothian contribution to the IJB is shown in the table below.

Components of Indicative 2016/17 NHS Contribution	
Indicative Payment to IJB	£'000
Core West Lothian Health Services	87,694
Share of Pan Lothian Hosted Services	16,686
Indicative Payment to IJB - Total	**104,380**
Share of Acute Set Aside	29.191
Total Indicative Contribution	**133,571**

Further details on the indicative £133.571 million is shown in Appendix 2, including the split of functions between the payment to the IJB and the share of Acute set aside.

In respect of the NHS payment (excluding acute set aside) there is an assumption that £2.287 million of low to medium risk savings will be achieved. In addition, further measures of approximately £2.5 million would also require to be identified to manage anticipated spend within the £104.380 million payment to the IJB.

In respect of overall acute services, substantial savings are required to ensure a balanced budget position can be achieved in 2016/17. For the purposes of IJB strategic planning a notional share of resources totalling £29.191 million has been estimated as West Lothian's share of resources associated with delegated acute functions.

A number of areas are being considered by NHS Lothian to identify options to manage the remaining pressures both within the NHS overall shortfall and the West Lothian IJB payment element of approximately £2.5 million. These include sources of additional funding, in year flexibility funds and West Lothian IJB related Financial Recovery Plans categorised as high risk. These plans are being developed further to ascertain the scope for savings in 2016/17 and beyond.

Key Risks and Uncertainties

The key risk at this stage in terms of the NHS Lothian contribution is clearly that the budget contribution is still indicative and further work requires to be progressed to identify saving options that will provide for a balanced 2016/17 budget. In addition, the following specific risks will require to be closely monitored.

- Prescribing. A key change to the budget setting arrangements for next year relate to the move to a 'PBSG' based budget setting approach. The result of this change means that additional resources of just under £3.2 million is transferred to Edinburgh's prescribing budget from East, Mid and West Lothian Business Units. In order to support transition to PBSG, and giving due recognition to concerns expressed by IJBs on this issue, a principle of nil detriment will be applied from 2016/17. This will be achieved through the use of £3.2 million of NRAC funding. However, even allowing for this nil detriment, prescribing will remain a key risk as inflation and demands continue to grow in this area
- Delayed Discharge. Pressures in this area continue to be a budget risk and will require continued joint working to reduce bed days lost
- ADP Investment. Scottish Government funding for ADP investment has been reduced by 20% for 2016/17. The implications of this are being considered by NHS Lothian as part of their 2016/17 budget plans and discussions are ongoing with councils, including West Lothian Council, as a substantial element of this funding is transferred to councils
- Delivery of savings required to ensure spend is managed within available 2016/17 resources

C.5 Financial Assurance – Key Points

As noted the purpose of the financial assurance process is to set out the assumptions and risks associated with the contributions agreed by NHS Lothian and the council. The council and NHS Lothian are, in accordance with legislation, responsible for agreeing the functions delegated to the IJB and setting their respective budgets including the level of payments and set aside resources to the IJB.

The IJB is then responsible for allocating the resources it has been provided back to partners to operationally deliver services. This will be through Directions issued to the council and NHS Lothian who remain operationally responsible for delivering services within the resources available. As noted in the approved West Lothian Integration Scheme in respect of financial assurance, 'if any such (financial assurance) review indicates that the projected expenditure is likely to exceed the initial payments to the Board, then the relevant party will be notified. The relevant party will be required to take action to ensure that services can be delivered within the available budget.'

Based on the financial assurance undertaken to date, it is clear that NHS Lothian have further action to take to agree a balanced budget for 2016/17 and financial assurance of their budget contribution cannot be fully completed until this has been achieved. Given this position, the current indicative resources will be required to form the basis of the directions back to NHS Lothian who will then be operationally responsible for managing within these resources, or any subsequently amended resource level following the finalisation of their 2016/17 budget plans.

Similarly, the council, whilst approving a balanced budget position, will also be responsible to manage within the resources available. Taking account of the budget resources identified in this report the table below shows the indicative level of 2016/17 resources associated with IJB functions.

West Lothian IJB – Indicative 2016/17 Delegated Resources	
	£’000
Adult Social Care	66,685
Core Health Services	87,694
Share of Hosted Services	16,686
Indicative IJB Payment	**171,065**
Indicative Acute Set Aside	29.191
Total Indicative IJB Resources	**200,256**

C.6 Ongoing Monitoring and Review

A further report on financial assurance will be provided to the IJB following NHS Lothian having finalised their 2016/17 budget plans. Any amendments required to the NHS Lothian budget contribution to the IJB will be taken account of as part of this report, and reflected in revised Directions as necessary.

In addition, financial assurance will be ongoing during the year as part of regular financial reporting on the 2016/17 resources associated with IJB functions. As noted in this report, there are a number of risks across health and social care that will require to be closely managed.

D CONSULTATION

Relevant officers in NHS Lothian and West Lothian Council.

E REFERENCES/BACKGROUND

Public Bodies (Joint Working) (Scotland) Act 2014

Local Government (Scotland) Act 1973

F APPENDICES

Appendix 1 – West Lothian Council Delegated Resources

Appendix 2 – NHS Lothian Delegated Resources

G SUMMARY OF IMPLICATIONS

Equality/Health	The report has been assessed as having little or no relevance with regard to equality or the Public Sector Equality Duty. As a result, equality impact assessment has not been conducted. The relevance assessment can be viewed via the background references to this report.
National Health and Wellbeing Outcomes	The 2016/17 budget resources delegated to the IJB will be used to support the delivery of outcomes.

Strategic Plan Outcomes	The 2016/17 budget resources delegated to the IJB will be used to support the delivery of the Strategic Plan.
Single Outcome Agreement	The 2016/17 budget resources delegated to the IJB will be used to support the delivery of the Single Outcome Agreement.
Impact on other Lothian IJBs	None.
Resource/Finance	The indicative 2016/17 budget resources relevant to functions that will be delegated to the IJB from 1 April 2016 have been estimated at over £200 million.
Policy/Legal	None.
Risk	There are a number of risks associated with health and social care budgets, which will require to be closely managed.

H CONTACT

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31 March 2016

Appendix 1

SOCIAL CARE SERVICES DELEGATED TO WEST LOTHIAN IJB

2014/15 Spend (£'000)		2015/16 Budget (£'000)	2015/16 P9 Forecast (£'000)	2015/16 Variance (£'000)	2016/17 Budget (£'000)
11,204	Learning Disabilities	12,425	12,478	53	13,565
5,259	Physical Disabilities	5,926	5,814	-112	6,255
2,609	Mental Health	2,954	2,951	-3	2,941
24,464	Older People Assess & Care	25,164	25,159	-5	27,903
7,207	Care Homes & HWC	6,927	7,406	479	7,090
5,893	Contracts & Commissioning Support	5,987	5,784	-203	5,841
3,215	Other Social Care Services	2,841	2,953	112	3,090
59,851	**Total Adult Social Care Services**	**62,224**	**62,545**	**321**	**66,685**

NHS DELEGATED FUNCTIONS AND INDICATIVE RESOURCES

	2016/17 £'000
Core Health Services	
Community Hospitals	2,200
Mental Health	11,537
District Nursing	2,870
Community AHPS	3,220
GMS	22,173
Prescribing	32,146
Resource Transfer	6,886
Other Core	6,662
Total Core Health Services	**87,694**
Hosted Health Services	
Sexual Health	902
Hosted AHP Services	2,260
Hosted Rehabilitation Medicine	876
Learning Disabilities	3,290
Mental Health	610
Substance Misuse	1,049
Oral Health Services	2,130
Hosted Psychology Service	1,070
Hosted GMS	1,522
Public Health	283
Lothian Unscheduled Care Service	1,924
UNPAC	807
Strategic Programmes	944
Other Hosted Services	-981
Total Hosted Health Services	**16,686**
TOTAL INDICATIVE NHS PAYMENT TO IJB	**104,380**
Acute Set Aside Services	
A & E (outpatients)	4,116
Cardiology	5,797
Diabetes	513
Endocrinology	405
Gastroenterology	1,728
General Medicine	7,345
Geriatric Medicine	5,069
Infectious Disease	3,015
Rehabilitation Medicine	727
Respiratory Medicine	177
Therapies/Management	299
TOTAL SET ASIDE	**29,191**
OVERALL TOTAL	**133,571**

WEST LOTHIAN STRATEGIC PLANNING GROUP

Date: 7 April 2016	
Agenda Item: 6	

JOINT COMMISSIONING PLANS UPDATE

REPORT BY DIRECTOR

A PURPOSE OF REPORT

To provide an update to the Strategic Planning Group on the Needs Assessments for Physical and Learning Disabilities Commissioning Plans.

B RECOMMENDATION

To note the Needs Assessments for Physical and Learning Disabilities Commissioning Plans.

C TERMS OF REPORT

In August 2011 the West Lothian Community Health and Care (CHCP) Board noted the development of an overarching strategy for the joint commissioning of health and care services within West Lothian. Since then, strategic commissioning has become central to the Scottish Government thinking in respect of the integration of health and social care services and the Public Bodies (Joint Working) (Scotland) Act 2014 made it a requirement of the new partnerships to produce strategic commissioning plans covering all activities within the scope of the partnership.

The strategic commissioning process is circular with four main stages:

1. Analyse
2. Plan
3. Do
4. Review

The process starts with a comprehensive assessment of needs, preferences and intended outcomes, including the mapping and reviewing of existing service provision to inform future commissioning.

Needs assessments have recently been carried out in respect of Adults with Physical Disabilities (Appendix 1) and Adults with Learning Disabilities (Appendix 2). These are provided for the information of the Strategic Planning Group. The IJB has agreed Terms of Reference and membership of the planning groups who will progress the development of the relevant care group commissioning plans.

D CONSULTATION

- Relevant council and health board officers
- Relevant service users groups
- Independent sector providers and representative bodies
- Third sector providers and representative bodies

E REFERENCES/BACKGROUND

- Public Bodies (Joint Working) (Scotland) Act 2014, and related statutory instruments and guidance
- Scottish Government Guidance and Advice - http://www.gov.scot/Topics/Health/Policy/Adult-Health-SocialCare-Integration/Implementation/ImplementationGuidance
- West Lothian CHCP Commissioning Strategy 2011 – 2021
- Commissioning Plan Groups Terms of Reference, report to West Lothian IJB, 5 April 2016

F APPENDICES

1. Needs Assessments for Adults with Physical Disabilities
2. Needs Assessments for Adults with Learning Disabilities

G SUMMARY OF IMPLICATIONS

Equality/Health	This report has been assessed as having little or no relevance with regard to equality or the Public Sector Equality Duty. As a result, an equality impact assessment has not been conducted. Note that the commissioning plans will be subject to an equality impact assessment.
National Health and Wellbeing Outcomes	The commissioning plans will address relevant National Health and Well-Being Outcomes
Strategic Plan Outcomes	The commissioning plans outcomes will be aligned to relevant Strategic Plan outcomes
Single Outcome Agreement	The commissioning plans outcomes will be aligned to relevant Single Outcome Agreement outcomes related to health and social care

Impact on other Lothian IJBs	None
Resource/finance	None
Policy/Legal	Public Bodies (Joint Working) (Scotland) Act 2014 and statutory regulations and guidance
Risk	None

H CONTACT

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7 April 2016

FIGURE 8
CONSULTANCY SERVICES LTD

2015

LEARNING DISABILITY AND AUTISM NEEDS ASSESSMENT

Report prepared for West Lothian Community Health Care Partnership

Figure 8 Consultancy Services Ltd
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EVIDENCE INTO PRACTICE

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TABLES AND FIGURES

CHAPTER 1: INTRODUCTION

1.1 Introduction and background

Figure 8 Consultancy Services Ltd. was commissioned by West Lothian CHCP in April 2015 to carry out a comprehensive learning disability and autism needs assessment project; and fieldwork took place between May 2015 and June 2015.

1.2 Definitions and concepts

For the purposes of this report we use the following terms:

1.2.1 Learning disability (disabilities)

For the purpose of this needs assessment, the definition of learning disability in the Scottish Governments' '*The Same as You?*' report is used.[1] That is, people with learning disabilities have a significant, lifelong condition that started before adulthood that affected their development and which means they need help to:

- understand information;
- learn skills; and
- cope independently.

This definition was mirrored in the 2001 Department of Health's White Paper '*Valuing people: a new strategy for learning disability for the 21st century*'[2]; and maintained in the updated 2013 Scottish Government '*The Keys to Life*'[3] strategy.

Some people with learning disabilities also have physical and/or sensory impairments, mental health problems or other neurodevelopmental disorders such as autism. People who have these conditions are included in the definition, providing that they also have a learning disability as in *The Same As You* definition above.

The World Health Organisation International Classification of Diseases (ICD) divides learning disability into four main categories: mild, moderate, severe and profound, depending on the level of cognitive impairment. People with profound learning disability have an IQ of less than 20, compared to an IQ of 50 to 69 for people with a mild learning disability. Figure 1.1 below provides the ICD codes, with their classification and IQ levels:

---

[1] Scottish Government (2000). *The Same as You? A Review of Services for People with Learning disabilities*. Edinburgh: Scottish Government.

[2] Department of Health (2001). *Valuing people: a new strategy for learning disability for the 21st century*. London: Department of Health.

[3] Scottish Government (2013). *The Keys to Life: Improving Quality of Life for People with Learning Difficulties.* Edinburgh: Scottish Government.

Figure 1.1: ICD Learning Disability Classification

ICD Code	Learning disability Classification	IQ Levels
F70	Mild	50-69
F71	Moderate	35-49
F72	Severe	20-34
F73	Profound	<20

There are a number of known causes of learning disabilities which can be subdivided into those conditions that arise at conception (prevention lies before conception), and those that arise during pregnancy, labour and after birth. Aetiology agents fall into three main categories: genetic, infective and environmental, as shown in the Figure below:

Figure 1.2 Major aetiological factors that cause learning disabilities[4]

Aetiological Factor	Timing of Injury/Exposure		
	Antenatal		
Genetic	**Chromosome aberrations**	**Secondary Neurological Damage**	
	Trisomies: • Down's syndrome, Edwards' syndrome, • Patou syndrome • Sex linked (e.g. fragile X syndrome)	• Disorders of protein metabolism, • lipid metabolism, • mucopolysaccaride metabolism, • hormone system	
	Antenatal	**Perinatal**	**Postnatal**
Infective	• Rubella • HIV • Toxoplasma • Cytomegalovirus	• Herpes Simplex	• Meningitis • Encephalitis • Encephalopathies • Whooping cough
	Antenatal	**Perinatal**	**Postnatal**
Environmental	• Nutritional deficiencies • Rhesus incompatibility • Drugs/alcohol • Irradiation	• Birth injury	• Trauma • Lead • Nutrition

---

[4] Rees S, Cullen C, Kavanagh S, Lelliott P. Chapter 17 Learning disabilities. In: Stevens A, Raftery J, Mant J, Simpson S. (eds.) *Health Care Needs Assessment. First Series*. Second. Oxford: Radcliffe Publishing Ltd; 2004. pp451–540.

However, research suggests that in between 40%-80% of cases no specific cause can be determined.[5]

Autistic spectrum disorders are also commonly associated with learning disabilities (see section 1.2.3 below).

1.2.2 Learning difficulties

In UK education services, the term 'learning difficulty' includes children and young people who have 'specific learning difficulties', for example dyslexia, but who do not have a significant general impairment of intelligence. The Special Educational Needs codes also use the terms 'moderate learning difficulty', 'severe learning difficulty' and 'profound multiple learning difficulty', which relate to general impairments in learning of different severity. These could be seen as interchangeable with the term 'learning disability' which is used in health and social care, and the groups of mild, moderate, severe and profound learning disabilities.

1.2.3 Autism and Asperger's Syndrome

'Autism' (sometimes referred to Autistic Spectrum Condition [ASC] or Autistic Spectrum Disorder [ASD]) can be described as a neurodevelopmental disorder. It is a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. It is a spectrum disorder meaning all people diagnosed with the condition will share certain behaviours and traits to different extents. There are no evidenced biological markers to identify and diagnose autism; so the following three behavioural descriptions are used, known as the 'triad of impairment' (Wing and Gould, 1979)[6], which all people with autism share:

- Social communication (e.g. using and understanding verbal and non-verbal language such as appropriate use of eye contact, gestures, facial expressions and tone of voice; using appropriate language skills such as initiating and turn taking during conversation; those with good language skills may nevertheless interpret language in a literal manner, and may struggle to understand idiom, metaphor or sarcasm);
- Social interaction (e.g. recognising, understanding and empathising with other people's feelings and managing their own; a lack of ability to adapt behaviour accordingly; problems in developing and maintaining friendships);
- Social imagination (e.g. preferring a fixed routine and finding change hard to cope with; having a narrow range of interests; poor imaginative skills).

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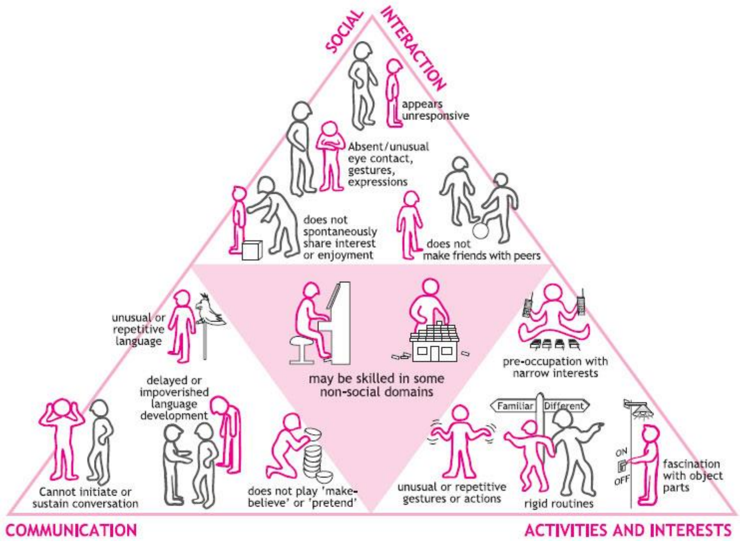
[5] Gates and Barr (2009). Oxford handbook of learning and intellectual disability nursing, OUP.

[6] Wing, L and Gould, J (1979). Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9(1): 11–29.

Figure 1.3: Diagram of the 'triad of impairment' (adapted from the National Autistic Society)



The area of most difficulty for those with a diagnosis of an Autistic Spectrum Disorder is social interaction. Many of those diagnosed on the autistic spectrum can learn to compensate for their difficulties with social communication and social imagination but cannot compensate for their difficulties with social interaction – their impairment will still be evident in this area.

Other symptoms of Autistic Spectrum Disorders are: favouring routine, sensory sensitivity, having specific interests. Furthermore, co-morbidity with other disorders such as attention deficit hyperactivity disorder, a learning difficulty, dyslexia, and dyspraxia are common.

Whilst a substantial proportion of people with autism have a learning disability more than half don't.[7] People with Asperger's syndrome (and those with higher functioning autism) are included in the definition of those with ASD, and although having higher IQ's may still suffer many of the characteristics of autism above. People with Asperger's syndrome commonly experience difficulty communicating with others and can have difficulty forming and maintaining friendships and relationships. Whilst they may be interested in forming relationships attempts at doing so may be awkward or inappropriate.

This can make the person prone to bullying or social isolation, and at risk of mental health difficulties.[8] A person with Asperger's syndrome may have difficulty with eye contact, and may find it difficult to understand non-verbal interaction such as body language and facial expression. People with Asperger's syndrome often have a need for routines, and may have very specific interests, which can impact on other areas of their lives, including maintaining employment. The needs and difficulties of people with Asperger's syndrome may not be immediately or fully obvious, and so they may have difficulty accessing support.

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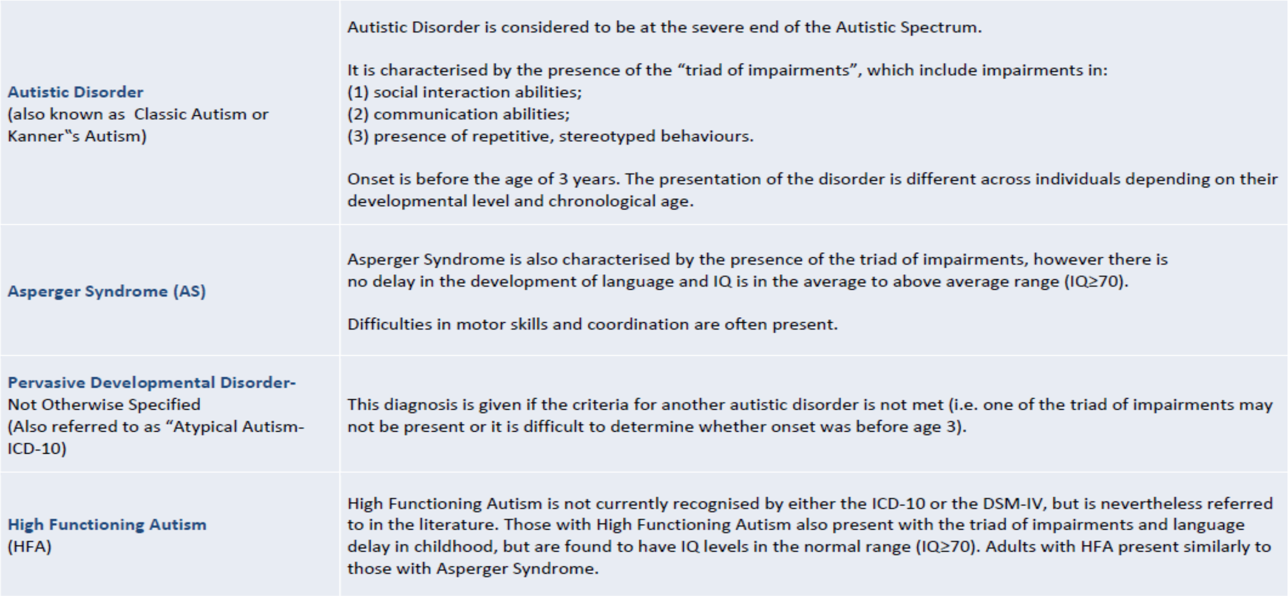
[7] HM Government (2010). 'Fulfilling and rewarding lives': the strategy for adults with autism in England. Available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113405.pdf [Accessed on 28th September 2015].

[8] http://www.gosh.nhs.uk/medical-information/search-medical-conditions/aspergers-syndrome [Accessed on 28th September 2015].

In general, people with Asperger's Syndrome have fewer problems with speaking and are often of average intelligence or above average intelligence, although they may have specific learning difficulties such as dyslexia and dyspraxia.

A range of conditions are grouped under the banner ASD, these are broadly outlined in Table 1.4 below:

Table 1.4: ASD Classifications

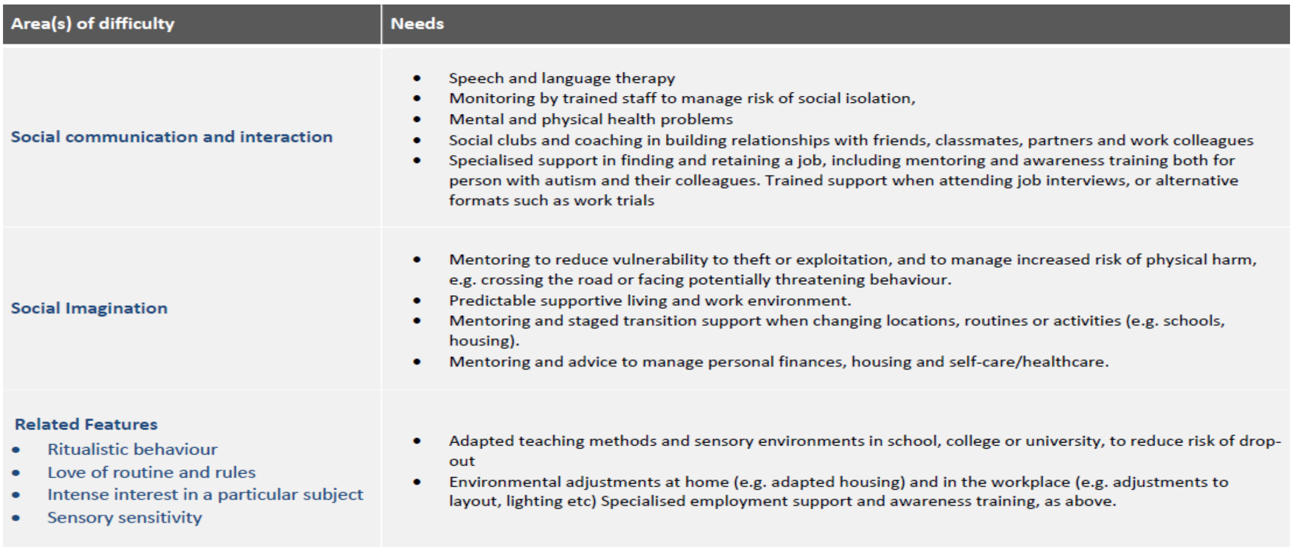


Autistic Disorder (also known as Classic Autism or Kanner‟s Autism)	Autistic Disorder is considered to be at the severe end of the Autistic Spectrum. It is characterised by the presence of the "triad of impairments", which include impairments in: (1) social interaction abilities; (2) communication abilities; (3) presence of repetitive, stereotyped behaviours. Onset is before the age of 3 years. The presentation of the disorder is different across individuals depending on their developmental level and chronological age.
Asperger Syndrome (AS)	Asperger Syndrome is also characterised by the presence of the triad of impairments, however there is no delay in the development of language and IQ is in the average to above average range (IQ≥70). Difficulties in motor skills and coordination are often present.
Pervasive Developmental Disorder- Not Otherwise Specified (Also referred to as "Atypical Autism- ICD-10)	This diagnosis is given if the criteria for another autistic disorder is not met (i.e. one of the triad of impairments may not be present or it is difficult to determine whether onset was before age 3).
High Functioning Autism (HFA)	High Functioning Autism is not currently recognised by either the ICD-10 or the DSM-IV, but is nevertheless referred to in the literature. Those with High Functioning Autism also present with the triad of impairments and language delay in childhood, but are found to have IQ levels in the normal range (IQ≥70). Adults with HFA present similarly to those with Asperger Syndrome.

(Adapted from ICD-10, Diagnostic Statistical Manual IV and the National Autistic Society website).

Needs reflect the range of behaviours shown in Table 1.5 below, adapted from Lorna Wing's '*The Autistic Spectrum: A Guide for Parents and Professionals*'.[9]

Table 1.5: Area(s) of ASD difficulty and associated needs



Area(s) of difficulty	Needs
Social communication and interaction	• Speech and language therapy • Monitoring by trained staff to manage risk of social isolation, • Mental and physical health problems • Social clubs and coaching in building relationships with friends, classmates, partners and work colleagues • Specialised support in finding and retaining a job, including mentoring and awareness training both for person with autism and their colleagues. Trained support when attending job interviews, or alternative formats such as work trials
Social Imagination	• Mentoring to reduce vulnerability to theft or exploitation, and to manage increased risk of physical harm, e.g. crossing the road or facing potentially threatening behaviour. • Predictable supportive living and work environment. • Mentoring and staged transition support when changing locations, routines or activities (e.g. schools, housing). • Mentoring and advice to manage personal finances, housing and self-care/healthcare.
Related Features • Ritualistic behaviour • Love of routine and rules • Intense interest in a particular subject • Sensory sensitivity	• Adapted teaching methods and sensory environments in school, college or university, to reduce risk of drop-out • Environmental adjustments at home (e.g. adapted housing) and in the workplace (e.g. adjustments to layout, lighting etc) Specialised employment support and awareness training, as above.

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[9] Wing, L. (1996). *The autistic spectrum: a guide for parents and professionals*. Constable: London.

There are a number of similarities between those with high functioning autism and Asperger's syndrome. However the main differences between those with a diagnosis of high functioning autism and those who present with Asperger's syndrome are:

- Those with Asperger's syndrome tend to display fewer difficulties with language;
- Have average or above average intelligence;
- Age of diagnosis - unlike autism, which would most likely be diagnosed below the age of three, those with Asperger's syndrome, might not be diagnosed until adulthood; and
- High-functioning autism and Asperger's syndrome: it is debated that difference between these two conditions is language development, those with Asperger's syndrome, will NOT have delayed language development when younger.

1.2.4 Health Inequalities and the Social Determinants of Health

Health inequalities are the 'differences in health status or in the distribution of health determinants between difference population groups'.[10] Those differences are *inequitable* when they can be determined as being unfair or unavoidable.

The social determinants of health are the collective set of conditions in which people are born, grow up, live and work. These include housing, education, financial stability, and the built environment as well as the health system. The World Health Organisation (WHO) notes that in turn, these conditions are shaped by a powerful over-riding set of forces: economics, social policy and politics.[11]

It is now widely accepted that these social determinants are responsible for significant levels of unfair health 'inequalities'. So, whilst some health inequalities are the result of natural biological differences or free choice, others are beyond the control of individuals or groups and could be avoided.

1.2.5 Wellbeing

This report examines not just learning disability and autism, but also considers what promotes and supports mental and emotional wellbeing. The concept of 'wellbeing' has gained a wider public airing following the decision to embark on a national measurement programme developed by the Office for National Statistics (ONS), introduced in 2011. At a personal level wellbeing is "a positive physical, social and mental state" at a population, or national level, a range of indicators are being included, individual wellbeing but also the quality of the environment, equality, sustainability and the economy. Research indicates that 'wellbeing' comprises two main elements: feeling good and functioning well. Feelings of happiness, contentment, enjoyment, curiosity, and engagement are characteristic of someone who has a positive experience of their life. Equally important for wellbeing is our

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[10] http://www.who.int/social_determinants/en/

[11] http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/

functioning in the world. Experiencing positive relationships, having some control over one's life and having a sense of purpose are all important attributes of wellbeing.[12]

In a review of the evidence on how individuals can improve wellbeing, the New Economics Foundation (nef)[13] identified five actions to improve wellbeing that individuals could be encouraged to build into their lives:

1. Connect ... With the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community. Think of these as the cornerstones of your life and invest time in developing them. Building these connections will support and enrich you every day.
2. Be active ... Go for a walk or run. Step outside, cycle, play a game, garden, or dance. Exercising makes you feel good. Most importantly, discover a physical activity you enjoy and that suits your level of mobility and fitness.
3. Take notice ... Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you.
4. Keep learning ... Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Set a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun.
5. Give ... Do something nice for a friend, or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out, as well as in. Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you.

Aked et al (2009) contend that it is vital to combine consideration of the structural factors affecting the circumstances of individuals' lives, together with the psychological and social aspects of their wellbeing. Only by taking this 'twin track' approach is it possible to account for the dynamic nature of wellbeing, where positive experiences ('feeling good') and outcomes ('doing well') arise through the interplay between external circumstances, inner resources, and capabilities and interactions with the surrounding world.[14]

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[12] Huppert F (2008) *Psychological well-being: evidence regarding its causes and its consequences* (London: Foresight Mental Capital and Wellbeing Project 2008).

[13] Aked, J. and Thompson, S. (2011). *Five ways to wellbeing – new applications, new ways of thinking*. New Economics Foundation: London.

[14] Aked, J., Steuer, N., Lawlor, E. and Spratt, S., (2009), *Backing the Future*. See also Foresight Mental Capital and Wellbeing Project (2008), *Final Project report – Executive summary*, London: The Government Office for Science; and Thompson S, & Marks N (2008) *Measuring well-being in policy: Issues and applications,* New Economics Foundation: London.

1.3 Risks and resilience - factors impacting the mental health and wellbeing of those with learning disabilities and/or autism

People with learning disability are not only at increased risk of developing physical and mental health conditions[15] but they also face prejudice and discrimination in health services, social care, education and employment; often, they have substantial unmet health needs and little control over their lives.[16,17] The vulnerability of this population was demonstrated in recent research reports of negligence and premature deaths.[18] The need to improve health and promote wellbeing in this population has been regularly acknowledged, including through the Scottish Government's 'Keys to Life' strategy.[19,20,21]

Resilience, a dynamic process of positive adaptation in the context of significant adversity[22], is seen as a key element in maintaining wellbeing.[23] Adverse life-events can negatively affect wellbeing in the learning disability population[24] but resilience, well researched in a general population, is still under researched in the learning disability population.

The mental health of those with a learning disability and/or autism is not just a function of an individual's characteristics or attributes, it is also affected by a wide range of social, economic and environmental factors. These have been summarised in Table 1.6 below.

- At an individual level people may be affected by biological or genetic factors or may have specific difficulties, for example communication difficulties, increasing vulnerability to mental health problems, by affecting their ability to engage, participate or understand aspects of daily living.

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[15] Royal College of Nursing (2013). Meeting the health needs of people with learning disabilities. RCN Guidance for Nursing Staff, London: RCN.

[16] Department of Health (2001) Valuing People: a New Strategy for Learning disability for the 21st Century. London: Department of Health.

[17] Department of Health (2009) Valuing People Now: a new three-year strategy for people with learning disabilities 'Making it happen for everyone'. London: Department of Health.

[18] Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A. and Russ, L. (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLEARNING DISABILITY). Available at: http://www.bris.ac.uk/cipolearning disability/fullfinalreport.pdf

[19] Op. cit. Scottish Government (2013)

[20] Op. cit. Department of Health (2009)

[21] Improving Health and Lives, Learning disability Observatory (2012). Improving the Health and Wellbeing of People with Learning disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGS). Available at: http://www.rcgp.org.uk/revalidation-and-cpd/centre-for-commissioning/~/media/Files/CIRC/LEARNING DISABILITY%20Commissioning/RCGP%20LEARNING DISABILITY%20Commissioning%20Guide%20v1%200%202012%2009%2024%20FINAL%20pdf.ashx

[22] Luthar, S.S., Cicchetti, D. and Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. Child Development, 71(3), 543-562.

[23] Lightsay, O.R. Jr. (2006) Resilience, Meaning and Well-being. The Counseling Psychologist, 34(1), 96-107.

[24] Hulbert-Williams, L., & Hastings, R.P. (2008). Life-events as a risk factor for psychological problems in individuals with intellectual disabilities: a critical review. Journal of Intellectual Disability Research, 52(11), 883–895.

- There are numerous socio-economic circumstances which impact on mental health and wellbeing; The Marmot Review[25] highlighted the issue of employment and education; but specific events can also affect mental wellbeing including bereavement, family or relationship breakdown and exposure to violence or abuse. When considering a life course, people may be more exposed to risks at different ages; for example older people are more likely to experience bereavement of partners/friends and may become more socially isolated whereas younger adults may be more at risk of homelessness and unemployment.
- It is recognised that experience in childhood is important and resilience in adulthood may relate to the experiences and skills developed in childhood.
- At a higher level wider factors such as basic access to services, economic recession or exposure to widespread violence or insecurity also impact mental health; these factors can be considered as the prevailing environment or conditions in which people live.

Table 1.6: Risk factors and resilience

LEVEL	ADVERSE FACTORS	PROTECTIVE FACTORS
Individual attributes	**Low self-esteem**	• **Self-esteem, confidence**
	Cognitive/emotional immaturity	• **Ability to solve problems & manage stress or adversity**
	Difficulties in communicating	• **Communication skills**
	Medical illness, substance use	• **Physical health, fitness**
Social Circumstances	**Loneliness, bereavement**	• **Social support of family & friends**
	Neglect, family conflict	• **Good parenting / family interaction**
	Exposure to violence/abuse	• **Physical security and safety**
	Low income and poverty	• **Economic security**
	Difficulties or failure at school	• **Scholastic achievement**
	Work stress, unemployment	• **Satisfaction and success at work**
Environmental Factors	**Poor access to basic services**	• **Equality of access to basic services**
	Injustice and discrimination	• **Social justice, tolerance, integration**
	Social and gender inequalities	• **Social and gender equality**
	Exposure to war or disaster	• **Physical security and safety**

(Taken from Risks to Mental Health: An Overview of Vulnerabilities and Risk Factors WHO 2012)

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[25] The Marmot Review (2010). *Fair Society, Healthy Lives*. Available at: http://www.ucl.ac.uk/whitehallII/pdf/FairSocietyHealthyLives.pdf [Accessed on 5th November 2014].

1.4 Purpose

The purpose of this project is to assist West Lothian CHCP in:

- Identifying and profiling service users with learning disabilities and/or autism in West Lothian;
- Assessing and describing the current strengths, gaps and inequities in such service provision;
- Identifying and describing the prevalence of people with learning disability and/or autism in West Lothian;
- Profiling current service delivery to people with a learning disability and/or autism;
- Improving the number, quality, consistency, accessibility and integration of services appropriate for the needs of people with a learning disability and/or autism;
- Promoting a broader understanding of their needs and their right to effective services;
- Promoting equitable care through the promotion of positive values and attitudes;
- Reducing the inequalities experienced by people with a learning disability and/or autism.

1.5 Objectives

The specific objectives of this project are as follows:

- To provide a comprehensive assessment and mapping of specialist and non-specialist services and support for those with a learning disability and/or autism;
- To conduct an assessment of local need for such services and support;
- To identify gaps and areas of unmet need in current provision;
- To examine the current use of services, both community and inpatient;
- To examine the accessibility, appropriateness and location of current services;
- To identify any areas with over-provision;
- To provide evidence based recommendations as to how services could be extended or adapted to meet need including relationship and any overlap between agencies; and
- To suggest locality pathways for intervention and support for those with a learning disability and/or autism.

1.6 Scope

This document presents the findings of the needs assessment and reports on the future requirements for learning disability and autism services across West Lothian. Evidence from the Needs Assessment will assist:

- In providing evidence on the extent to which current services and support are meeting demand;
- In the commissioning of new services and support;

- In identifying gaps in existing service provision and support;
- In identifying areas of over provision;
- In providing evidence on the extent to which services and available support are accessible and in the right location; and
- In suggesting ways as to how West Lothian CHCP and its partners could extend / adapt services and support to meet need.

Conducting needs assessments in such a complex environment requires a great deal of understanding and flexibility on the part of the project team, and it is essential to engage as broad a range of interests as possible in the assessment process. To this end, the research team sought the views of a wide range of different learning disability, autism and mainstream services, people who use services, families and carers; advocates and other stakeholders. The qualitative element of the study in particular aimed to consult with staff from specialist learning disability and autism services, together with a sample of the following groups which support people with a learning disability and/or autism:

- Those who have a learning disability and/or autism, and who currently use West Lothian learning disability and/or autism specialist services;
- Those not currently using specialist learning disability and/or autism services, but who may benefit from doing so;
- Advocates;
- Families and Carers;
- Services for young people with a learning disability who are / will be in transition to adult services;
- Local Area Coordinators;
- Strategic Planners;
- GP’s and Public Health Consultants;
- Mental Health Services;
- Criminal Justice and Youth Justice;
- Police Scotland;
- Health and Social Care Practice Teams;
- Third Sector and Independent Sector providers; and
- Mainstream services such as:
    - Primary healthcare (inc. A&E);
    - Older People’s services;
    - Adult education/training;
    - Employability/Careers service;

  - Housing/Homelessness Services; and
  - Leisure and recreation.

Discussions with the project steering group and key strategic planners took place at several points during the fieldwork, and this acted as a helpful 'sounding board' for the emerging findings of the study.

1.7 Data Sources

The needs assessment incorporates data from a wide variety of sources, detailed throughout this report as footnotes; and includes evidence collated from an extensive consultation process with services users, local organisations and professionals. A note of data sources used for the Literature Review and the Epidemiology sections are provided at **section 2.4** and **section 3.2.2**. A full bibliography of data sources used is provided in **Appendix I** and full details of those consulted as part of the study is provided in **Appendix II**.

1.8 The Health Needs Assessment Process

In broad terms, health needs assessment (HNA) is the systematic approach to ensuring that the health service uses its resources to improve the health of the population in the most efficient way. It involves methods to describe the health problems of a population, identify inequalities in health and access to services, and determine the priorities for the most effective use of resources.

Health needs assessment has become important as the costs of health care are rising and resources for health care are, at the same time, limited. In addition, there can be significant variations in availability and use of health care by geographical area and point of provision (Andersen and Mooney, 1990).[26]

Another force of change is consumerism. The expectations of members of the public have led to greater concerns about the quality of the services they receive, from access and equity to appropriateness and effectiveness.

The health needs assessment (HNA) process has been defined, in guidance from the National Institute of Clinical Excellence (NICE), as:

> *"A systematic method for reviewing the health issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities."*[27]

The assessment process involves identifying need from four different perspectives (see Figure 1.5):

- **Epidemiological needs** – the use of health information based on the population, including demographic trends, health status and risk, as well as evidence of clinical effectiveness of services and interventions.

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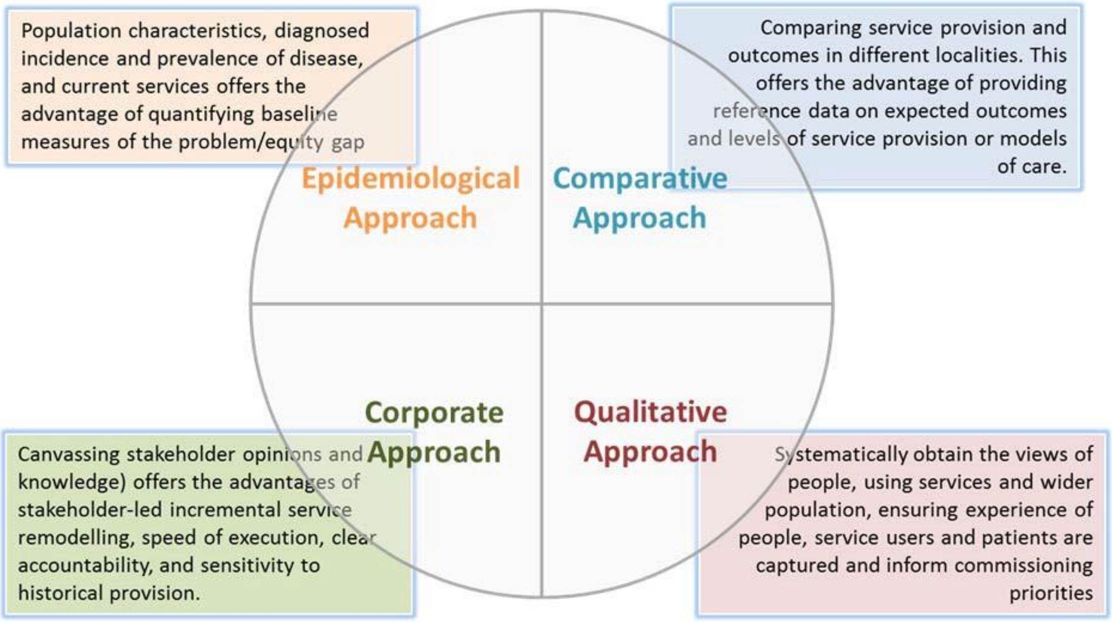
[26] Andersen, T.F. & Mooney, G. (Eds) (1990) *The challenges of medical practice variations.* MacMillan Press: London.

[27] Cavanagh S and Chadwick K (2005), "Health needs assessment: A practical guide". London: NICE. Available at: http://www.nice.org.uk/

- **Felt and expressed needs (Qualitative)** – the views of the public, from surveys, focus groups and the like, often using participatory appraisal methods.
- **Normative or expert needs (Corporate)** – as identified by professionals or experts.
- **Comparative needs** – the scope and nature of services available to the population and how these compare with services elsewhere.

Figure 1.7: Diagram of health needs assessment



The study methods used in this health needs assessment (outlined in section 1.9 below) were designed to capture each of these four different approaches/perspectives and are identified in Table 1.6 below.

1.9 Summary of Study Methods

The study was conducted in four stages. Each stage was tailored to the needs of the study, requiring a mix of data collection methods and sample populations. These are set out in Table 1.6 below. All questionnaires and interview schedules were approved by commissioners prior to use. Copies of these are available upon request.

Table 1.8: Summary of Data Collection Methods

Stage 1	**Method**		**Link to approaches / perspectives on need**
Review of Existing Literature/Datasets	Desk-based review of national and local literature and datasets and any local specialist service data available.		• Epidemiological • Comparative
Stage 2	**Method**	**Sample**	
Quantitative Survey	Online Surveys	• Managers of all specialist LEARNING DISABILITY and Autism services • Staff in all specialist LEARNING DISABILITY and Autism services.	• Normative/Expert (Corporate) • Comparative
Stage 3	**Method**	**Sample**	
Quantitative Surveys	Online and paper-based surveys	• Service users • Non (potential) service users • Carers, family members, advocates	• Felt and Expressed (Qualitative)
Stage 4	**Method**	**Sample**	
Existing Service Review	Case Studies	• Those with Learning disabilities, and/or autism	• Felt and Expressed (Qualitative)
Stage 5	**Method**	**Sample**	
Stakeholder Event / Working Group / Qualitative Interviews / Focus Groups	Stakeholder Event	All key stakeholders invited to a half-day event in relation to Learning disabilities and Autism	• Normative/Expert (Corporate) • Felt and Expressed (Qualitative)
	Working Group	Sample of key stakeholders recruited via approaches from the Research Steering Group, and via the stakeholder's event above. The working group to meet twice to explore Learning disability/Autism issues.	• Normative/Expert (Corporate) • Felt and Expressed (Qualitative)
	Semi-structured interviews	• All specialist services • A range of non-specialist services • Other relevant stakeholders	• Normative/Expert (Corporate)
	Focus Groups	• Service users • Non (potential) service users • Carers, family members, advocates	• Felt and Expressed (Qualitative)

1.10 Terminology

When quoting individual respondents or citing literature sources we will use the terms they have chosen for accuracy of representation.

1.11 Considerations and limitations

There are a number of factors which should be taken into account when reading this report. These are:

- The views of those interviewed and surveyed were taken and reported in good faith and are their own, not necessarily those of Figure 8 Consultancy Services Ltd. or the organisations they represent. It cannot be assumed that the views of the participants in interviews or surveys are representative of all similar stakeholders.
- Making comparisons with other areas of similar population and/or geography, as well as prevalence of learning disabilities and/or autism, allows for a degree of 'benchmarking' to observe the relative position of West Lothian. It should be noted that there may be variations between areas in the way in which this data is collected.
- The views of service users are drawn from those currently engaged with the services. This "self-selecting" group are more likely to be positively disposed towards the service, its staff and the interventions that they provide.
- In health care, need is commonly defined as 'the capacity to benefit'. If health needs are to be identified then an effective intervention should be available to meet these needs and improve health. There will be no benefit from an intervention that is not effective or if there are no resources available (Wright, Williams & Wilkinson, 1998).28 The definition of need used in this study is 'the number of individuals in the general population with learning disabilities who could benefit from intervention'. There are several challenges in estimating the prevalence of learning disabilities and autism in the general population involving the definition of 'problems' and the methods used to obtain the estimate.

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[28] Wright, J., Williams, R., & Wilkinson, J.R. (1998). Development and Importance of Health Needs Assessment. *British Medical Journal,* 316; 1310-1313.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The aim of this section is to present and summarise relevant, existing literature in relation to learning disability and/or autistic spectrum disorder. This will provide a backdrop for the later sections of the Needs Assessment whilst situating the current project into the wider context.

2.2 Considerations and limitations

- The abbreviation of learning disability is used throughout this document. learning disability is used to describe a learning disability.
- At times the term disability is used as this was the term used in the article, rather than a specific learning disability.

2.3 Method of data collection

A literature review was conducted which included local, national and international databases. The articles included mixed-methods, quantitative and also qualitative designs. To obtain a focussed, comprehensive overview and to identify all the available, relevant literature, a search of 'grey' literature was also conducted.

2.4 Data sources

The various data sources utilised in this report include:

- Centre for Learning disability Research http://www.lancaster.ac.uk/fhm/research/centre-for-disability-research/
- Centre for Welfare Reform http://www.centreforwelfarereform.org/
- Department of Health https://www.gov.uk/government/organisations/department-of-health
- Google Scholar http://scholar.google.co.uk/
- Information Services Division Scotland http://www.isdscotland.org/
- National Records for Scotland http://nationalrecordsofscotland.gov.uk/
- National Skills Forum http://pol1-003-olearning disability.live.atomicant.co.uk/nsfapsg
- NHS Health Scotland http://www.healthscotland.com/
- Office for National Statistics http://www.ons.gov.uk/ons/index.html
- Public Health England https://www.improvinghealthandlives.org.uk/
- Scottish Consortium for Learning disability http://www.sclearning disability.org.uk/

- Scottish Government http://www.gov.scot/
- Social Care Institute for Excellence http://www.scie.org.uk/
- ProQuest Central
- SAGE Journals
- Web of Science (Core Collection)
- Wiley Online Library

2.5 Definitions

See section 1.2 for the definitions of 'Learning Disabilities' and 'Autism' that we are using for the purposes of this report.

2.6 Policy context

Scottish policy for people with a learning disability is underpinned by the principles of choice, control, independence and human rights. Supporting people with a learning disability demands tackling the inequalities people with learning disability face which are key priorities for the Scottish Government as demonstrated in *'The Keys to Life'* strategy.[29] One focus of the 10 year strategy is to advance the major health inequalities which people with a learning disability face. The strategy reviewed the progress of 'The Same as You?' recommendations and challenges Local Authorities and Health Boards to work towards improved opportunities for people with a learning disability and provision of quality supports to people and to family carers.

The strategy stands on the shoulders of a previous strategy, 'The Same as You?' [30] which sets out 7 key principles, namely:

People with a learning disability should:

- Be valued and have the same rights;
- Be seen as individuals and receive appropriate help;
- Be asked about services and have advice;
- Be helped and supported and achieve freedom;
- Be able to use the same local services;
- Have special services as well as general services; and
- Have services which take account of age.

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[29] Op Cit. Scottish Government. 2013.

[30] Scottish Executive (2000) *The same as you? A review of services for people with learning disabilities.* The Stationery Office, Edinburgh. Available at: http://www.gov.scot/Resource/Doc/1095/0001661.pdf [Accessed 10 June 2015].

This report was promoting a major shift in the balance of care and support services, for children and adults with a learning disability and people with Autism. In terms of quality of life, the report heightened the need for action against harassment and bullying and action to improve access to health services, reducing health inequalities, and the Scottish Government specifically then commissioned a 'Scottish Health Needs Assessment of People with Learning Disabilities' (2004)[31] Prominent in both strategies are the health issues which those with a LD face and improving health practice and outcomes so a person with a LD's human rights are respected and upheld. Both of these policies promote good practice in relation to autism. The Same as You? Strategy promoted autism sitting within the LD strategy, however this was not widely accepted by local authorities and health boards across Scotland and as a result the national Autism strategy emerged.

The Scottish Strategy for Autism[32] covers the full spectrum of Autism disorders and in the same vein as the Keys to life strategy, the Scottish strategy for autism is underpinned by 6 key values:

- Dignity: people should be given the care and support they need in a way which promotes their independence and emotional well-being and respects their dignity;
- Privacy: people should be supported to have choice and control over their lives so that they are able to have the same chosen level of privacy as other citizens;
- Choice: care and support should be personalised and based on the identified needs and wishes of the individual;
- Safety: people should be supported to feel safe and secure without being over-protected;
- Realising potential: people should have the opportunity to achieve all they can;
- Equality and diversity: people should have equal access to information assessment and services.

The Scottish Government's vision is that individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives.[33]

2.7 Self-directed Support

There have been major developments in Scotland's social care landscape in recent years with the introduction of Self-directed Support (hereinafter referred to as 'SDS') legislation, an approach first introduced by the Scottish Government with their Self-Directed Support National Strategy (2010).[34] This 10 year strategy aims to improve outcomes for people and gives people greater choice and

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[31] NHS Health Scotland (2004). Health Needs Assessment Report – People with Learning Disabilities in Scotland. Available at: http://www.healthscotland.com/uploads/documents/1676-LD_summary.pdf [Accessed on 29th September 2015].

[32] Scottish Government. 2011. *The Scottish Strategy for Autism.* Available at: http://www.gov.scot/Resource/Doc/361926/0122373.pdf [Accessed 1 June 2015].

[33] Op Cit. Scottish Government. 2011.

[34] Scottish Government. 2010. *Self-Directed Support: A National Strategy for Scotland.* Available from: http://www.scotland.gov.uk/Resource/Doc/329971/0106962.pdf [Accessed 1 June 2015].

control in deciding, where they are eligible how they want their personal outcomes to be met. The approach is further cemented with the introduction of the Social Care (Self-directed Support) (Scotland) Act 2013 which came into force in April 2014. This new legislation is underpinned by all Councils reshaping their current delivery of social care services so that they offer people using services, for example adults and children with a learning disability, more choice and control over how they meet their outcomes. [35] The Act promotes an outcomes focused approach which is person centred and asset & strengths based.

2.7.1 Social Care (Self-directed Support) Scotland Act 2013 (SDS)

The *Social Care (Self-directed Support) Scotland Act 2013* cements SDS into statute. The Act provides a new legal framework to which all Councils must adhere; guaranteeing that adults, children, young carers and adult carers assessed as requiring social care provision, will receive the support which is personal to them. Previously, the long-established approach has involved the Local Authority arranging services (Option 3); whereas now an individual can choose from four options when deciding on how their individual budget is to be managed. People with a Learning Disability, who are eligible for support may manage their individual budget by way of 4 options:

- Option 1 - have a Direct Payment and arrange their own support;
- Option 2 - direct the Local Authority in how they wish their allocated budget to be utilised (an Individual Service Fund), working with a provider directly;
- Option 3 - have the Local Authority arrange any support needs; or
- Option 4 – a combination of the above.

2.7.2 Self-directed Support - outcomes for people with a Learning Disability

The reviewed literature reveals that for people with a learning disability, not only is there currently limited evidence available, it would seem elements of SDS are not being considered an option for some people within this client group, particularly where there are capacity issues.[36] Confidence is growing however as knowledge and experience of SDS grows nationally. The Outcomes focused and SDS approach together offer real opportunities for people with a learning disability to design innovative ways of achieving what is important and essential to their wellbeing. [37,38] This issue of choice and control was touched upon recently with the authors suggesting that in relation to people

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[35] Scottish Government. 2014. *Statutory guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013.* Available at: http://www.scotland.gov.uk/Resource/0044/00446933.pdf [Accessed 29 May 2015].

[36] This could be explained by reference to capacity issues as individuals without capacity need a family member or carer to legally manage their finances and this may not be possible for all.

[37] Harkes, M. A., Brown, M., and Horsburgh, D. 2012. Self-directed support and people with learning disabilities: a review of the published research evidence. *British Journal of Learning disabilities*, 42(2): 87-101.

[38] Carr, S., and Robbins, D. 2009. *The implementation of individual budget schemes in adult social care.* Available from: http://www.scie.org.uk/publications/briefings/files/briefing20.pdf [Accessed 10 June 2015].

with a LD *the autonomous choice of whether or not to take a Direct Payment must be offered* for this to become apparent.[39]

2.7.3 Direct Payment value per client group (aged 18-64)

Current statistics demonstrate disparity between service user groups and uptake of option 1, Direct Payments. The table below illustrates the value of direct payments for those with a learning disability and those with both a learning disability and a physical disability aged 18-64.

Table 2.1: Number of Clients Aged 18 to 64 and Value of Direct Payments, by Client Group, 2013[40]

Client Group	Number of Clients	Expenditure (£ thousands)	Average £ per client
Learning disability Only	884	£14,052	£15,896
Learning disability AND physical disability	182	£2,672	£14,680

2.7.4 SDS value per client group (aged 65+)

The table below illustrates the value of direct payments for those with learning disability and those with a learning disability and physical disability aged 65 and over. It must be noted for this age category that direct payments are not eligible to purchase residential care.

Table 2.2: Number of Clients Aged 65 and over, and Value of Direct Payments, by Client Group, 2013[41]

Client Group	Number of Clients	Expenditure (£ thousands)	Average £ per client
Learning disability Only	28	£614	£21,932
Learning disability AND physical disability	5	£85	£17,061

2.8 Health needs and inequalities

The term 'health inequalities' describes the poorer health experienced by some of our population in comparison with their neighbours. Those who experience social disadvantage because of low income, social position, gender, ethnic origin, age or disability are likely to have poorer physical and mental health than the rest of the population. By far the commonest reason for people to experience health inequalities is low income. The poorest in our society die earlier and have higher rates of

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[39] Op Cit. Harkes, M., A., Brown, M., and Horsburgh, D. 2013.

[40] Op Cit. Scottish Government. 2013.

[41] Ibid.

disease and people struggling with poverty and low income have poorer mental health and wellbeing than those with higher incomes and positive life chances.

A review of the literature shows that when compared to the general population, both adults and children with a learning disability experience significant health related inequalities. Research from the UK[42] and further afield suggest that individuals with a learning disability have worse health outcomes, are disadvantaged socially with reduced social networks, are more likely to have other chronic health conditions, have a shorter life expectancy and are more likely to die 20 years before the general population.[43],[44],[45] The main causes of death for those with learning disability are respiratory disease, cardiovascular disease (related to congenital heart disease) forms of cancer (mainly connected with the gullet, stomach and gall bladder).[46] People with a learning disability also have greater occurrences of dementia, sight and hearing loss and epilepsy. [47],[48]

For individuals with profound and multiple learning disability life prospects are limited, with evidence to suggest 20% of those with a profound and multiple learning disability die within a ten year period, the main issues being breathing problems, epilepsy and difficulties in eating and drinking.[49] Research suggests health inequalities can begin in early life and result in many barriers in accessing not only suitable healthcare but in day to day tasks the general population take for granted.[50] Individuals with a learning disability can have other complex health needs such as additional physical or mental health issues, challenging or offending behaviour, and have other unmet health needs due to lower rates of access at health services such as oral health care and immunisations. People with a learning disability could have other physical and/or emotional conditions including Autism and, Cerebral Palsy, Down's syndrome, Fragile X syndrome and Global development delay resulting in more than one diagnoses given. People with a learning disability are further compounded compared to the general population they are more likely to experience marginalisation, poverty and abuse. Furthermore, of those who live in the community there is evidence to suggest people with a learning disability experience a variety of aggravation, mistreatment and related crime.[51]

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[42] Op.Cit. NHS Health Scotland (2004)

[43] Op Cit. Scottish Government. 2013.

[44] Tyrer, F., Smith, L. K., and McGrother, C. W. 2007. Mortality in adults with moderate to profound learning disability: a population based study. *Journal of Intellectual Disabilities research*, 51(7): 520-527.

[45] Patja, K., Iivanainen, M., Vesala, H., Oksanen, H., Ruoppila, I. 2000. Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of Intellectual Disabilities Research, 45(5):* 591-599.

[46] Op Cit. Scottish Government. 2013.

[47] NHS Health Scotland. 2004. *People with Learning disabilities in Scotland: The Health Needs Assessment Report.* NHS Scotland. Available at: http://www.gla.ac.uk/media/media_63872_en.pdf [Accessed 1 May 2015].

[48] Scottish Government. 2014. *See Hear. A strategic framework for meeting the needs of people with a sensory impairment in Scotland.* Available at: http://www.gov.scot/Publications/2014/04/7863/0 [Accessed 10 June 2015].

[49] Hogg, J., Juhlberg, K. and Lambe, L. 2007. Policy, service pathways and mortality: a 10-year longitudinal study of people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, 51(5): 366-376.

[50] Emerson, E., and Baines, S. 2010. *Health Inequalities & People with Learning disabilities in the UK: 2010.* London: Department of Health. Available at: http://strathprints.strath.ac.uk/34862/1/vid_7479_IHaL2010_3HealthInequality2010.pdf [Accessed 01 May 2015].

[51] Gravell, C. 2012. *Loneliness and Cruelty: People with Learning disabilities and their Experiences of Harassment, Abuse and Related Crime in the Community*. London: Lemos and Crane.

The public sector duties on equalities included in the Equality Act (2010) place a requirement on all public bodies to consider the impact of policies and services on the needs of individuals with these 'protected characteristics'. There is also a legislative requirement that human rights are considered by public bodies and this has some crossover with equality legislation (NHS Health Scotland, 2011).

West Lothian Council alongside NHS Lothian have a duty to address such inequalities that may exist for people with a learning disability and with autism. NHS Lothian in its Strategic Plan (2013-2020) state, as one of the key priorities:

> *'Prioritise prevention, reduce inequalities and promote longer healthier lives for all.'*

Everyone should have the same opportunities to enjoy good health as a matter of fairness. The NHS provides health care to everyone free at the point of need and has a role to play in:

- providing services designed to prevent future illness;
- taking opportunities to provide advice and support to people to help them to take care of their own health; and
- working with partners to promote the health and wellbeing of communities and the whole population.

Addressing health inequalities is a complex challenge and requires actions to be taken by many different agencies working closely with communities. West Lothian CHCP need to make sure that people with a learning disability, vulnerable to or experiencing inequality, have good access to all public services. By working closely across all agencies, people with a learning disability can be supported to better health. The West Lothian Community Planning Partnership supports reducing health inequalities for all (Audit Scotland Report Oct 2014 with CPP's priorities). Addressing health inequalities is a major challenge and one which the new West Lothian Health and Social Care Partnerships is expected to make a significant contribution to.

2.9 Accidents and injuries

Adults with a learning disability are more likely than the general population to have accidental injuries, as much as 22% when self-inflicted injuries are included.[52] This trend is echoed in younger populations with research in the USA and Australia providing evidence that young people with intellectual disabilities have higher rates of injuries compared to the general population.[53] For older people with a learning disability it appears that the side effects of medication increases the risk of falls and accidental injuries.[54] Recent evidence from the 2014 Learning disability Census, which looks at English NHS and independent inpatient services, found that 55% of those with a learning disability

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[52] Finlayson, J., Morrison, J., Jackson, A., Mantry, D., and Cooper, S. A. 2010. Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study. *J Intellectual Disabilities Research,* 54(11): 966–80.

[53] Dunne et al. 1993; Sherrard et al. 2001a, as cited in Finlayson, J., Morrison, J., Jackson, A., Mantry, D., and Cooper, S. A. 2010. Injuries, falls and accidents among adults with intellectual disabilities. Prospective cohort study. *J Intellectual Disabilities Research,* 54(11): 966–80.

[54] Smulders, E., Enkelaar, L., Weerdesteyn, V., Geurts, A. C., and van Schrojenstein Lantman-de Valk, H. 2012. Falls in older persons with intellectual disabilities: fall rate, circumstances and consequences. Journal of Intellectual Disability Research, 57(12): 1173-1182.

had one or more incidents (self-harm, accident, physical assault, restraint or seclusion) in the three months before census day which highlights the non-accidental injuries those with a learning disability face.

2.10 Harm and neglect

Compared to the general population, it appears that people with a learning disability are also at a greater risk of physical, emotional and verbal harm and/or abuse, ill treatment and neglect.[55] The sustained ill treatment of those with a learning disability was recently highlighted in a Department of Health review of Winterbourne View hospital, a scandal initially aired on the BBC's *Panorama* documentary.[56] The review highlighted a widespread failure to the design, commission and provision of services, in line with best practice guidelines. Reporting of other forms of harm is also documented; those with a learning disability appearing to be at more risk of sexual assault and robbery when compared to the general population.[57],[58] Communication problems, dependence issues, comprehension and compliance issues all appear to increase the vulnerabilities to ill treatment.[59] Research also suggests that the risk of abuse appears to be greater for those with a learning disability who display challenging behaviours.[60]

2.11 Mental health and challenging behaviour

An individual's behaviour can be defined as 'challenging' if it puts them or those around them (such as their carer) at risk of harm, or leads to a poorer quality of life. It can also impact on their ability to join in everyday activities. Challenging behaviour can include aggression, self-harm, destructiveness and disruptiveness.

The needs of adults and children who display challenging behaviours, in addition to a learning disability, are complex.[61] Emerson and colleagues provide a worthy definition stating '*challenging behaviour refers to behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit*

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[55] Hogg, J., Campbell, M., Cullen, C., Hudson, W. 2001. Evaluation of the effect of an open learning course on staff knowledge and attitudes towards the sexual abuse of adults with learning disabilities. *Journal of Applied Research in Intellectual Disabilities*, 14(1): 12-29.

[56] Department of Health. 2012. *Department of Health Review. Winterbourne View Hospital.* Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf [Accessed 10 June 2015].

[57] Kebbell, M.R., Hatton, C., Johnson, S.D., and O'Kelly, C.M. 2001. People with learning disabilities as witnesses in court: What questions should lawyers ask? *British Journal of Learning disabilities*, 29(3): 98–102.

[58] Peckham, N. G. The vulnerability and sexual abuse of people with learning disabilities. *British Journal of Learning disabilities*, 35(2): 131-137.

[59] Ibid.

[60] Emerson, E., McGill, P., and Mansell, J. 1994. *Severe Learning disabilities and Challenging Behaviours: Designing High Quality Services.* Chapman and Hall: London.

[61] Op Cit. Scottish Government. 2013.

or delay access to and use of ordinary community facilities'.[62] Challenging behaviour is a presenting issue for some people with learning disability and many forms of challenging behaviour can result from issues such as communication, lack of understanding, pain, stopping unwanted attention or attracting attention.[63],[64] Research suggests the prevalence of challenging behaviours is suggested to be anywhere from 10%-15% in those with a learning disability. In a systematic review which looked at challenging behaviour in people with a learning disability the authors highlight evidence suggesting the most common challenging behaviours to be aggression, destructive behaviour and self-injury, going on to state that the most challenging of these appear to continue as life goes on .[65] The authors also found associations between challenging behaviours and visual impairment, enduring sleep problems, urinary incontinence, and pain related to cerebral palsy. The risk of abuse appears to be greater for those with a learning disability who display challenging behaviours.[66] A variety of interventions may be needed for people with learning disabilities who display challenging behaviour. Of particular note here would be the approach of 'Positive Behaviour Support' (PBS). PBS is defined as, 'an approach that is used to support behaviour change in a child or adult with a learning disability. Unlike traditional methods used, the focus is not on 'fixing' the person or on the challenging behaviour itself and never uses punishment as a strategy for dealing with challenging behaviour. PBS is based upon the principle that if you can teach someone a more effective and more acceptable behaviour than the challenging one, the challenging behaviour will reduce.'[67]

2.12 Transport

If those with a learning disability are to be truly independent, it is important that transport is accessible, affordable and available[68], however, the literature reveals access to travel and transport is a significant barrier for many with a learning disability. Heller and colleagues, for example, found high costs and the availability of transport appeared to be a key barrier for full inclusion into the community for those with Down's Syndrome.[69] The accessibility of transport is highlighted as a

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[62] Emerson, E., Barrett, S., Bell, C., Cummings, R., McCool, C., and Toogood, A. 1987. *Developing services for people with severe learning difficulties and challenging behaviours.* Canterbury: Institute of Social and Applied Psychology.

[63] Foundation for People with Learning disabilities. 2015. *Challenging behaviour.* Available at: http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/c/challenging-behaviour/ [Accessed 21 June 2015].

[64] Op Cit. Emerson et al. 1987.

[65] de Winter, C. F., Jansen, A. A. and Evenhuis, H. M. 2011. Physical conditions and challenging behaviour in people with intellectual disability: a systematic review. *Journal of Intellectual Disability Research*, 55(7): 675–98.

[66] Emerson, E., McGill, P., and Mansell, J. 1994. *Severe Learning disabilities and Challenging Behaviours: Designing High Quality Services.* Chapman and Hall: London.

[67] http://www.challengingbehaviour.org.uk/learning-disability-files/03---Positive-Behaviour-Support-Planning-Part-3-web-2014.pdf

[68] Op Cit. Scottish Government. 2013.

[69] Heller, T., Hsieh, K., and Rimmer, J. 2003. Barriers and supports for exercise participation among adults with Down syndrome. *Journal of Gerontological Social Work*, 38 (1-2): 161–178.

barrier to exercise for adults with Cerebral Palsy[70], whereas the lack of transport is highlighted as a barrier to community inclusion especially in regards to leisure activities for both adults[71] and adolescents[72]. Taken together these findings not only raise questions of inclusion and community participation for those with a learning disability, but are worrying given the prevalence of obesity among persons with a learning disability.

2.13 Employment

Assisting people with a learning disability to find work in mainstream employment, which is suitable to their particular skills, is a key aim for the Scottish Government, and a recommendation in the Keys to Life strategy is that more supported employment opportunities be available for those with a learning disability who want to work. Those with a learning disability, however, are more likely to be exposed to social determinants of poor health, one of which is unemployment. [73] Being employed can have many positive benefits to those with a learning disability as well as the general population in term of increased self-esteem[74], confidence and social inclusion[75], and also positive benefits to physical and mental health[76] and evidence suggests these benefits of employment are evident for those with a learning disability with reporting of higher levels of self-esteem and lower rates of depression.[77] Research focusing on supported employment, which promotes participation and integration for people with a learning disability into wider society, suggests it enhances the quality of life of people and has a positive effects on well-being for those with a learning disability. [78] Recent UK evidence of employment rates for those with a learning disability are low [79] and evidence suggests that of people with a learning disability currently are in paid employment, this work is usually less than 16 hours per week. The working life of those with a learning disability appears to be characterised of short periods of employment in between longer periods of unemployment, and

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[70] Heller, T., Ying, G., Rimmer, J., and Marks, B. 2002. Determinants of exercise in adults with cerebral palsy. *Public Health Nursing*, 19(3): 223– 231

[71] Verdonschot, M. M. L., De Witte, L. P., Buntinx, W. H. E., and Curfs, L. M. G. 2009. Impact of environmental factors on community participation of persons with an intellectual disability: A systematic review. *Journal of Intellectual Disability Research*, 53(1): 54–64.

[72] Buttimer, J., and Tierney, E. 2005. Patterns of leisure participation among adolescents with a mild intellectual disability. *Journal of Intellectual Disabilities*, 9(1): 25–42.

[73] Op Cit. Scottish Government. 2013.

[74] Dunn E. C., Wewiorski N. J. and Rogers E. S. (2008) The meaning and importance of employment to people in recovery from serious mental illness: results of a qualitative study. Psychiatric Rehabilitation Journal 32(1): 59–62.

[75] Carew, D., Birkin, R., and Booth, D. 2010. Employment, policy and social inclusion. *The Psychologist*, 23: 28–30.

[76] Butterworth, P., Leach, L. S., Strazdins, L., Olesen, S. C., Rodgers, B., and Broom, D. H. 2011. The psychosocial quality of work determines whether employment has benefits for mental health: results from a longitudinal national household panel survey. *Occupational and Environmental Medicine*, 68(11): 806–812.

[77] Jahoda, A., Kemp, J., Banks, P., and Williams, V. 2008. Feelings about work: a review of the socio-emotional impact of supported employment on people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21 (1): 1–18.

[78] Cramm, J.M., Kuijsten, R., Finkenflügel, H., and van Exel, N. J. A. 2009. How employment support and social integration programs are viewed by the intellectually disabled. *Journal of Intellectual Disabilities Research*, 53(6): 512–520.

[79] Dempsey, L., and Ford, J. 2009. Employment for people with intellectual disability in Australia and the United Kingdom. *Journal of Disability Policy Studies*, 19(4): 233–243.

when in employment it is characterised by low wages and a low level of skill.[80] Although not evaluated, there is evidence emerging of social enterprises which offer support and help to build the skills of people with a learning disability. One example is the Healthy Gourmet Café, Lambeth College which has been in operation since 2007. The café's aim is to provide a quality catering service to staff and students as part of a social enterprise for students with a learning difficulty and/or disabilities.[81]

2.14 Housing

If people with a learning disability are to live independently, access to requisite housing is paramount. Many people with a learning disability want to live more independent lives[82], however, it appears they are often exposed to poor housing and face barriers to housing in relation to adequate resources, planning, and a lack of housing which meets their needs. This has resulted in people with a learning disability living in housing far from friends and family or staying in accommodation which restricts independent living.[83]

2.15 Transition

Transitions in life can be difficult whether someone is an adult or child. People with learning disabilities go through many changes during their life and transition periods such as moving from primary to secondary school or moving from a children to adult service appear to be particularly difficult, with confusion and uncertainty common.[84] Research suggests adjusting to the transition from primary to secondary school appears to play a significant role in mental wellbeing in young people[85]; however, this period appears to be of particular importance for those with learning disability with Beattie noting that '*young people with learning disability are at risk of social exclusion and difficult transition on leaving school and during subsequent transitions*'. The transition from primary to secondary school is a particularly vulnerable time for those with a learning disability due to communication and social skill impairments[86] and knowing staff members has been found to be an important factor for a positive transition during this period, whereas staff characteristics such as being kind and/ or understanding was found to make the process smoother. Making and/or maintaining friendships also appears to be an important issue during this transition for both those

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[80] Banks P., Jahoda A., Dagnan D., Kemp, J., and Williams, V. 2010. Supported employment for people with intellectual disability: the effects of job breakdown on psychological well-being. *Journal of Applied Research in Intellectual Disabilities*, 23(4): 344–54.

[81] National Skills Forum. 2009. *Doing things differently: Step changes in skills and inclusion – people with disabilities Policy Connect.* Available at: http://pol1-003-olearning disability.live.atomicant.co.uk/nsfapsg/research [Accessed 19 August 2015].

[82] Op Cit. Scottish Government. 2013.

[83] Mencap. 2014. *Housing for people with a learning disability.* Available at: https://www.mencap.org.uk/sites/default/files/documents/2012.108%20Housing%20report_V7.pdf [Accessed 18 June 2015].

[84] Heslop, P., Mallett, R., Simons, K., and Ward, L. 2002. B*ridging the divide at transition: what happens for young people with learning difficulties and their families?* Kidderminster, British Institute of Learning disabilities.

[85] West, P., Sweeting, H., and Young, R. 2010. Transition matters: pupils' experiences of the primary–secondary school transition in the west of Scotland and consequences for well-being and attainment. *Research Papers in Education*, 25, 21–50.

[86] *Dillon, G. V., and Underwood, J. D. M. 2012. Parental perspectives of students with autism spectrum disorders transitioning from primary to secondary school in the United Kingdom. Focus on Autism and Other Developmental Disabilities, 27(2):111–121.*

with ASD and their parents.[87] Moving from children to adult services is also highlighted as a difficult transition phase resulting in heightened anxiety for many, with family members and carers describing this phase as the '*the black hole of transition*'.[88] Research has shown that the absence of accessible information, a lack of co-production and young people not having an input into their future appear to be a barrier for a successful transition for young people with a learning disability and their parents.[89] Moreover, inadequate preparation for transition, and services not being fully established appear to further worsen this period[90]; whereas limited resources such as funding streams, physical support and training opportunities also appear to hinder transition processes.[91]

A method for assisting young people with a learning disability to effectively communicate their views during transition periods is 'Talking Mats®'[92] which appear to foster both choice and control in the young person, giving them a 'voice' during an otherwise troubled period. [93] Heslop et al (2002) suggests five good elements are key to a smooth transition process are exemplified in the '5c's' which are communication, co-ordination, comprehensiveness, continuity, and choice:

- Communication: which is open, honest and respectful between agencies, and between agencies and families; independent advocacy for young people;
- Coordination: effective inter-agency working; joint training initiatives; joint assessment procedures and a cohesive strategic approach to service provision;
- Comprehensiveness: an effective transition plan for all young people; appropriate race and disability equality training for all staff; expectation that young people with learning difficulties will have access to the same opportunities to realise their aspirations as their peers;
- Continuity: key workers to support individual youngsters and their families throughout the transition process; a seamless transition from children's to adult services; a range of options for young people to move into and between;
- Choice: more and better involvement of young people and their families in the transition process; access to appropriate information on potential options; development of a range of local post-school alternatives in housing and employment.

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[87] Dann, R. 2011. Secondary transition experiences for pupils with autistic spectrum conditions (ASCs). *Educational Psychology in Practice*, 27(3): 293–312.

[88] Op Cit. Scottish Government. 2013.

[89] Heslop, P., Mallett, R., Simons, K., and Ward, L. 2002. B*ridging the divide at transition: what happens for young people with learning difficulties and their families?* Kidderminster, British Institute of Learning disabilities.

[90] Beecham, J., Clarke, S., Franklin, A., Moran, N., and Cusworth, L. 2010. *Models of Multi-agency Services for Transition to Adult Services for Disabled Young People and Those with Complex Health Needs: Impact and costs.* Social Policy Research Unit, University of York.

[91] Martin, K., Hart, R., White, R., and Sharp, C. 2011. Young people with special educational needs/learning difficulties and disabilities: Research into planning for adult life and services. Available at: http://www.nfer.ac.uk/publications/SENT01/SENT01.pdf [Accessed 23 November 2015].

[92] Talking Mats is registered as a Trademark. For further information please see http://www.talkingmats.com/

[93] *Cameron, L., and Murphy, J. 2002. Enabling young people with a learning disability to make choices at a time of transition. British Journal of Learning disabilities, 30(3): 105-112.*

2.16 Local Area Coordinators

Local Area Coordination is a person-centred preventative approach to support disabled people and their families to have a fulfilled life within the community in line with the principles of independent living.[94] Local Area Coordinator's work in a variety of ways including supporting adults and children with a learning disability, assisting those with a learning disability to find support and access services, and evidence suggests those with a learning disability and their families are favourable towards Local Area Coordinator's. [95] The role of a Local Area Coordinator was first introduced in the 'Same as You?' (2000) strategy which defines a Local Area Coordinator as "*a specialist worker dedicated to working with a small number of people using services in one area (to) help people and their families through the current maze of systems*". [96] The Local Area Coordination is flexible in its approach and current statistics reveals Local Area Coordinators are available in 26 out of the 32 local authority areas in Scotland.[97] Local Area Coordinator's appear to be a valuable resource with Broad (2012) highlighting evidence of the benefits of a Local Area Coordinator for older people, their carers and for building more connections within the community.[98] Guidelines to support the implementation of Local Area Coordination across Scotland have recently been introduced with the development of the '*Values into Practice: A Framework for Local Area Coordination in Scotland*'.[99]

2.17 Families and carers

Recent statistics from Learning Disability Statistics Scotland reveal that over a third of adults with learning disabilities, who are known to local authorities, live with a family carer (34.8%; n=9,142). [100] The role that family carers have in the lives of people with a learning disability is crucial in supporting the health and wellbeing of the individual with a learning disability; the literature reveals, however, that support for carers' needs is, at times, lacking. The Scottish Government are aware of the impact carers have, not only in the lives of those with a learning disability, but carers overall, and the need to identify and support carers is a key priority in the Carers Strategy for Scotland which aims to

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[94] Scottish Consortium for Learning disability. 2015. *Values into Practice: A Framework for Local Area Coordination in Scotland.* Available at: http://www.sclearning disability.org.uk/?publications=values-into-practice-a-framework-for-local-area-coordination-in-scotland [Accessed 19 August 2015].

[95] Stalker, K. O., Malloch, M. and Barry, M. A. 2008 Local area co-ordination: strengthening support for people with learning disabilities in Scotland. *British Journal of Learning disabilities*, 36(3): 215-219.

[96] Op Cit. Scottish Government. 2013.

[97] Scottish Consortium for Learning disability. 2015. *Values into Practice: A Framework for Local Area Coordination in Scotland.* Available at: http://www.sclearning disability.org.uk/?publications=values-into-practice-a-framework-for-local-area-coordination-in-scotland [Accessed 19 August 2015].

[98] Broad, R. 2012. *Local Area Coordination: From service users to citizens.* London: Centre for Welfare Reform. http://www.centreforwelfarereform.org/uploads/attachment/340/local-area-coordination.pdf [Accessed 19 August 2015].

[99] Scottish Consortium for Learning disability. 2015. *Values into Practice: A Framework for Local Area Coordination in Scotland.* Available at: http://www.sclearning disability.org.uk/?publications=values-into-practice-a-framework-for-local-area-coordination-in-scotland [Accessed 19 August 2015].

[100] Scottish Consortium for Learning disability. 2015. *Statistics Release: Learning disability Statistics Scotland 2013 (eSAY).* Available at: http://www.sclearning disability.org.uk/wp-content/uploads/2015/05/statistics_release_learning_disability_statistics_scotland_2013.pdf [Accessed 24 July 2015].

ensure carers are supported to manage their caring responsibilities with confidence and in good health, whilst having a life of their own outside of caring. [101]

Research reveals that those caring for someone with a learning disability often take on more responsibilities compared to other families, which results in increased levels of exhaustion, stress and depression.[102,103] This is often exacerbated with the needs of the carers not being met. That said reporting of the positive aspects the caring role brings include being supportive of family dynamics and educating people about specific learning disabilities.[104] In early 2015 The Carers Bill was presented to the Scottish Parliament which aims to guarantee improved and more constant support for carers and young carers so that they can continue to care, if they so wish, in better health and to have a life alongside caring.[105]

The Bill will:

- Introduce the Adult Carer Support Plan;
- Introduce a Young Carers Statement to recognise the unique needs of young carers;
- Place a duty on local authorities to provide support to carers and young carers based on local eligibility criteria
- Ensure that carers and young carers will be at the centre of decision making on how services are designed, delivered and evaluated;
- Place a duty on local authorities to create an information and advice service.

2.18 Parents with a learning disability

There are growing numbers of parents now living in the community who have a learning disability and the research suggests that this group are often deprived on several levels such as in contact with child welfare systems, in child protection cases and are at a greater risk of having their children taking into social care.[106] Furthermore, parents with a learning disability are more likely to experience barriers such social exclusion, poverty and discrimination. Additionally, if parents with a learning disability are judged as inadequate in their parenting role by social services.[107] A recent study in

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[101] Scottish Government. 2015. *Caring Together: The Carers Strategy for Scotland 2010 – 2015*. Available at: http://www.scotland.gov.uk/Publications/2010/07/23153304/0 [Accessed 1 May 2015].

[102] Green, S. E. 2007. "We're tired, not sad": benefits and burdens of mothering a child with a disability. *Social Science & Medicine* 64(1): 150–163.

[103] Baker, B., Blacher, J., and Olson, M. 2005. Preschool children with and without developmental delay: behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research*, 49(8): 575–590.

[104] Chadwick, D. D., Mannan, H., Iriarte, E. G., McConkey, R., O'Brien, P., and Finlay, F., et al. 2013. Family voices: life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities*, 26(2):119–32.

[105] Scottish Government. 2015. Carers (Scotland) Bill. Available at: http://www.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers/CarersBill [Accessed 20 August 2015].

[106] McGhee, J., and Hunter, S. 2011. The Scottish children's hearings tribunals system: a better forum for parents with learning disabilities? *Journal of Social Welfare and Family Law,* 33(3): 255-266.

[107] Murphy and Feldman, 2002; Booth and Booth, 1996, as cited in MacIntyre, G., and Stewart, A. 2011. For the record: the lived experience if parents with a learning disability-a pilot study examining the Scottish perspective. *British Journal of Learning Disabilities*, 40(1): 5–14.

Scotland found that the parents with a learning disability were disadvantaged, felt stigmatised by social work and child protection services and would have benefitted from earlier interventions to help deal with the issues faced. The authors go on to highlight that their evidence echoes findings from further afield which suggests more support is offered to the child of the parent with a learning disability rather than the parent which can result in a cycle of crisis, then intervention then crisis. Although this study was small scale in nature (in-depth interviews with 5 parents) it appears to reveal the unmet needs of this particular group.[108]

2.19 Advocacy

Advocacy can help people with a learning disability to understand their choices, their human rights and specific information which they might otherwise not comprehend and at its heart are principles of choice, empowerment and inclusion.[109] Advocacy can take many forms or processes including giving a voice to those with learning disability, enabling them to speak up for themselves, and can be provided to help those with a learning disability attain the rights afforded to them and/or enable them to make their own decisions. This can be in small matters or can be when those with a learning disability are involved in the criminal justice system or parents with a learning disability are at risk of losing their children into care.[110],[111] Indeed, advocacy is a right secured in statute for people with learning disabilities within the Mental Health (Care and Treatment)(Scotland) Act 2003. Advocacy has also been found to play an empowering role in supporting people with a disability to self-build 'safe havens'.[112] This recent evidence appears to show the benefits of advocacy work with people with a learning disability influencing their own inclusion into the community with what is described as processes of 'self-building' safe communities. Places such as allotments and marinas are being used by people with a learning disability providing them with a sense of security, safety, and belonging and connecting them to non-disabled people within the community. From these examples it appears the role of advocacy fits neatly within the principles underpinning Self-directed Support.

2.20 Summary

- When compared to the general population, both adults and children with a learning disability experience significant health related inequalities, are disadvantaged socially with reduced social networks, are more likely to have other chronic health conditions, and have a shorter life expectancy than the general population.

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[108] MacIntyre, G., and Stewart, A. 2011. For the record: the lived experience if parents with a learning disability-a pilot study examining the Scottish perspective. *British Journal of Learning Disabilities*, 40(1): 5–14.

[109] Op Cit. Scottish Government. 2013.

[110] Op Cit. Scottish Government. 2013.

[111] Bauer, A., Dixon, J., Wistow, G., and Knapp, M. 2013. *Investing in advocacy interventions for parents with learning disabilities: What is the economic argument?* Available at: http://eprints.lse.ac.uk/51114/1/Investing%20in%20advocay.pdf [Accessed 20 June 2015].

[112] Power, A., and Bartlett, R. 2015. Self-building safe havens in a post-service landscape: how adults with learning disabilities are reclaiming the welcoming communities agenda. *Social and Cultural Geography.* Doi: 10.1080/14649365.2015.10316.

- Of those with a learning disability who live in the community evidence suggests they experience a variety of aggravation, mistreatment and related crime.
- Adults and children with a learning disability are more likely than the general population to have accidental injuries.
- Compared to the general population, people with a learning disability are at a greater risk of physical, emotional and verbal harm abuse, ill treatment and neglect.
- Challenging behaviour is an issue for some people with a learning disability and forms of challenging behaviour may result from issues such as communication, lack of understanding, pain, stopping unwanted attention or attracting attention.
- The risk of abuse appears to be greater for people with a learning disability who display challenging behaviours.
- Access to travel and transport is a significant barrier for many people with a learning disability.
- People with a learning disability are more likely to be exposed to social determinants of poor health, one of which is unemployment. Of those in employment it is usually less than 16 hours per week, with low wages with short periods of employment in between longer periods of unemployment.
- People with a learning disability are often exposed to poor housing and face barriers to housing in relation to adequate resources, planning, and a lack of housing which meets their individual requirements.
- The transition from primary to secondary school, or moving from children to adult services, is a particularly vulnerable time for those with a learning disability which can be exacerbated due to communication and social skill impairments. Knowing staff members appears to be an important factor for a positive transition during this period. Making and/or maintaining friendships is also an important issue during this transition for both those with Autism Spectrum Disorder and their parents.
- The absence of accessible information, lack of co-production and young people not having an input into their future appear to be a barrier for a successful transition for young people with a learning disability and their parents.
- Limited resources also appear to hinder the transition processes and for those with additional communication impairments these times can be extremely difficult.
- A method for assisting young people with a learning disability to effectively communicate their views during transition periods is 'Talking Mats®'[113] which appear to foster both choice and control.
- Local Area Coordination (LAC) is a person-centred preventative approach to support disabled people and their families to have a fulfilled life within the community in line with the principles of independent living.

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[113] Talking Mats is registered as a Trademark. For further information please see http://www.talkingmats.com/

- Those caring for someone with a learning disability often take on more responsibilities compared to other families, which can result in increased levels of exhaustion, stress and depression.
- Parents with a learning disability are more likely to experience barriers such as social exclusion, poverty and discrimination and appear to be judged as inadequate in their parenting role by social services.
- Advocacy can help people with a learning disability to understand their choices, human rights and specific information which they might otherwise not comprehend and at its heart are principles of choice, empowerment and inclusion.

CHAPTER 3: EPIDEMIOLOGY

3.1 Introduction and Aims

After considering first the overall demographic make-up of West Lothian, this section is broken into a number of sub-sections. Under each of these, it examines the general research on learning disabilities and autism, then at the national statistics, and then the local figures where they are available.

3.2 Data Collection

3.2.1 Method of data collection

Information was identified and drawn together from a range of local and national sources on prevalence and trends in the patterns of learning disabilities and autism in Scotland over the past ten years. In order to provide comparative analysis on a range of health and social indicators three local authority areas were identified from similar socioeconomic deprivation backgrounds as West Lothian[114], as well as using information from the Local Government Benchmark Framework (LGBF).[115] The LGBF considers the many differences between local authorities that contribute to variations in performance, including: population; geography; social and economic factors; and the needs and priorities of local communities.

Falkirk, Renfrewshire and South Lanarkshire were chosen as comparators as they have similar characteristics as West Lothian (such as the size, density and composition of the population, unemployment, housing, ethnic diversity and wealth).

3.2.2 Data sources

The various data sources utilised in this report include:

- Audit Scotland http://www.audit-scotland.gov.uk/
- Centre for Learning disability Research http://www.lancaster.ac.uk/fhm/research/centre-for-disability-research/
- Google Scholar http://scholar.google.co.uk/
- Information Services Division Scotland http://www.isdscotland.org/
- National Records for Scotland http://nationalrecordsofscotland.gov.uk/

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[114] Scottish Government. 2013. *Deprivation- Scottish index of multiple deprivation.* Available at: http://www.scotland.gov.uk/Topics/Statistics/Browse/Social-Welfare/TrendSIMD [Accessed 21 July 2015].

[115] http://www.scotborders.gov.uk/info/691/council_performance/1352/local_government_benchmarking_framework

- NHS Health Scotland http://www.healthscotland.com/
- Office for National Statistics http://www.ons.gov.uk/ons/index.html
- Public Health England https://www.improvinghealthandlives.org.uk/
- Scottish Consortium for Learning disability http://www.sclearning disability.org.uk/
- Scottish Government http://www.gov.scot/
- Scottish Index for Multiple Deprivation http://www.gov.scot/Topics/Statistics/SIMD
- Scottish Public Health Observatory http://www.scotpho.org.uk/
- Social Care Online http://www.scie-socialcareonline.org.uk/
- West Lothian Council http://www.westlothian.gov.uk/
- World Health Organisation http://www.who.int/en/

3.2.3 Data issues

Data relating specifically to people with learning disabilities can be difficult to find and often there are problems with the data which mean that it does not give a completely accurate picture. This said the data which is available is still useful in providing information regarding the needs of this population as long as it is interpreted with certain caveats in mind.

In all data sets relating to people with learning disabilities it is likely that a significant number of people will be missed due to the fact that their learning disability is not recorded. This is most likely to affect those with milder learning disabilities who are less likely to need specialist health or social care services and who live independently. This is also likely to be a problem in data sets where the focus of the information is not on learning disability specifically, such as hospital episodes statistics. In this case only conditions which impact directly on the primary reason for admission to hospital are recorded, meaning that the presence of a learning disability is likely to be recorded inconsistently and are again less likely to be recorded if the disability is mild. This is also the case in recording on death certificates, where only conditions relating directly to the cause of death will be recorded.

The main national sources of data relating to the number of adults with learning disabilities are Learning disability Statistics Scotland (LDSS) and adult social care records (recorded via SWIFT database). There are some known issues with both of these data sets as detailed below:

- Learning disability Statistics Scotland (LDSS):
    - The severity of learning disability may not be coded correctly or consistently.
    - Some people with physical disabilities may be miscoded as having learning disabilities People with Down's syndrome may not be included.
    - While data completeness has been steadily improving, there is missing data both within individual records and in discrete data items. At present, no weighting or imputation is undertaken on missing data. However, in July 2013, the Methodology Advisory Service from the Office for National Statistics carried out a feasibility study

on the data to determine whether or not statistical weighting and imputation would be appropriate measures to improve the quality of the data. The study found that the data are currently not suitable for statistical weighting or imputation and recommended that the quality of the data be improved at source. The LDSS statistical team are currently working with the data providers (Scottish local authorities) to improve the quality of the data they provide.

- Adult Social Care Data (SWIFT)
    - Only the primary social care need is recorded meaning that people with learning disabilities who have another more prominent need may be missed from the data set.

3.3 Demography of West Lothian

Present and future need for services and assets to address learning disability and autism needs across West Lothian depends in part on the demography of the county. In this section basic population data is therefore briefly assessed.

3.3.1 Area Profile

West Lothian is an area of 165 square miles (428 square km) situated in the east of Scotland, positioned between Glasgow and Edinburgh, and surrounded by the council areas of Edinburgh, Falkirk, North Lanarkshire, South Lanarkshire and the Scottish Borders. Livingston, Bathgate and Linlithgow are the main centres of population in this local authority.

Figure 3.1: Map of West Lothian[116]

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[116] West Lothian Map, Google Map 2015. Available at: https://www.google.co.uk/maps/place/West+Lothian/@55.8546737,-3.7929644,10z/data=!4m2!3m1!1s0x4887c514c305f6ff:0x9f54bb6a8afceff3. [Accessed on: 17 June 2015].

According to National Records of Scotland, the 2014 population for West Lothian was 177,150[117]; this is an increase of the whole population figures reported in 2011 Census (175,118). In relation to the comparison areas, the table below shows West Lothian has a higher population than Falkirk (157,640) and Renfrewshire (174,230), and lower than South Lanarkshire (315,360). Scotland's overall population is also shown (5,347,600).

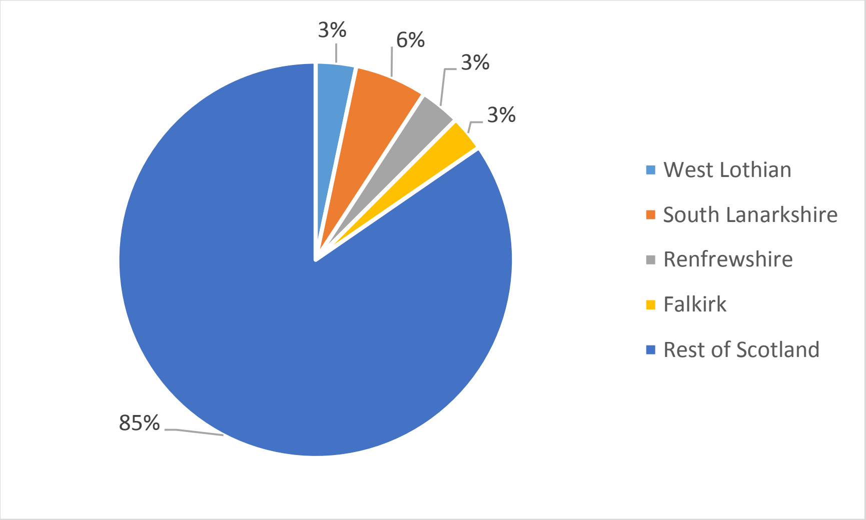
Table 3.2: Whole Population Figures for West Lothian, Scotland and Comparison Areas[118]

	West Lothian	South Lanarkshire	Renfrewshire	Falkirk	Scotland
2014 Mid-Yr Estimate	**177,150**	315,360	174,230	157,640	5,347,600

*NRS = National Records of Scotland

Further analysis of these figures is demonstrated below which shows population percentages of West Lothian, South Lanarkshire, Renfrewshire and Falkirk compared with the rest of Scotland. The figure reveals that West Lothian, Renfrewshire and Falkirk have a similar population percentages (3%), with South Lanarkshire double this (6%). The rest of Scotland accounts for 85% of the population.

Figure 3.3: Population Breakdown of West Lothian, Comparison Areas and Rest of Scotland[119]



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[117] National Records of Scotland.2015. *West Lothian Council Area- Demographic Factsheet. Available at:* http://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/west-lothian-factsheet.pdf. *Accessed on: 17th June 2015.*

[118] National Records of Scotland, 2015. *Council area profiles*. Available at: http://www.nrscotland.gov.uk/statistics-and-data/statistics/stats-at-a-glance/council-area-profiles [Accessed 17 June 2015].

[119] National Records of Scotland, 2015. *Council area profiles*. Available at: http://www.nrscotland.gov.uk/statistics-and-data/statistics/stats-at-a-glance/council-area-profiles [Accessed 22 June 2015].

3.3.2 Population: Sex

There are more females than males in West Lothian (90, 394 compared to 86, 756). As can be seen in the table below there are similarities between West Lothian figures, Scottish figures and comparison areas when male and female statistics are put in percentages.

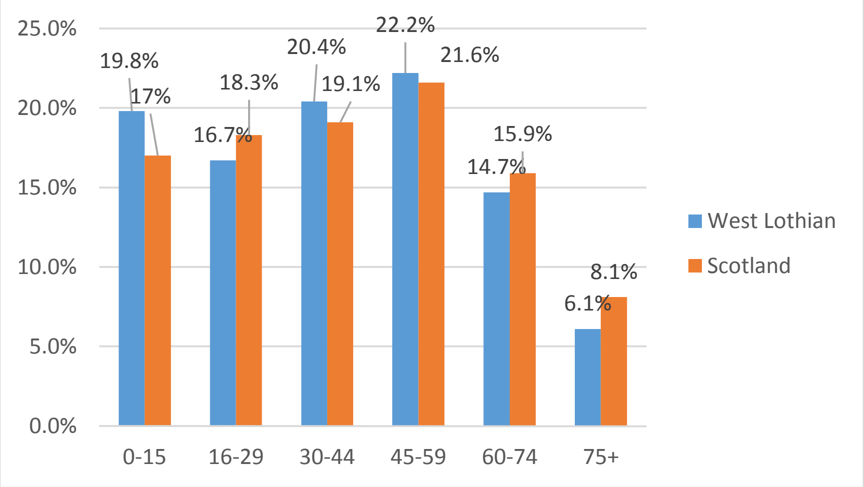
Table 3.4: Breakdown of population by Gender (for West Lothian, Scotland and Comparison Areas)[120]

	West Lothian	South Lanarkshire	Renfrewshire	Falkirk	Scotland
Male	**48.9%**	48.1%	48.1%	48.8%	48.5%
Female	**51.1%**	51.9%	51.9%	51.2%	51.5%

3.3.3 Population: Age

The population of the West Lothian is largely aged between the age brackets of 30-44 and 45-59 years of age, with 20.4% and 22.2% of people in West Lothian belonging to these age categories. This is more than the Scottish averages for these age categories (19.1% and 21.6% respectively). The graph below shows comparisons of age categories in West Lothian compared to the Scottish average.

Figure 3.5: West Lothian Population Breakdown by Age, Compared to the Scottish Average[121]



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[120] National Records of Scotland, 2011 *Census*. Available at: http://www.scotlandscensus.gov.uk/ods-web/area.html. [Accessed 16 June 2015].

[121] National Records of Scotland. 2015. *West Lothian Council Area- Demographic Factsheet.* Available at: http://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/west-lothian-factsheet.pdf [Accessed 1 July 2015].

3.3.4 Population: Projected Population

Current projections for West Lothian are estimating an overall population increase of 11.7 % by 2037 (n=196,664). From the table below the projected population of West Lothian until 2037 can be seen.

Table 3.6: Projected Population in West Lothian- 2017, 2022, 2027, 2032, 2037[122]

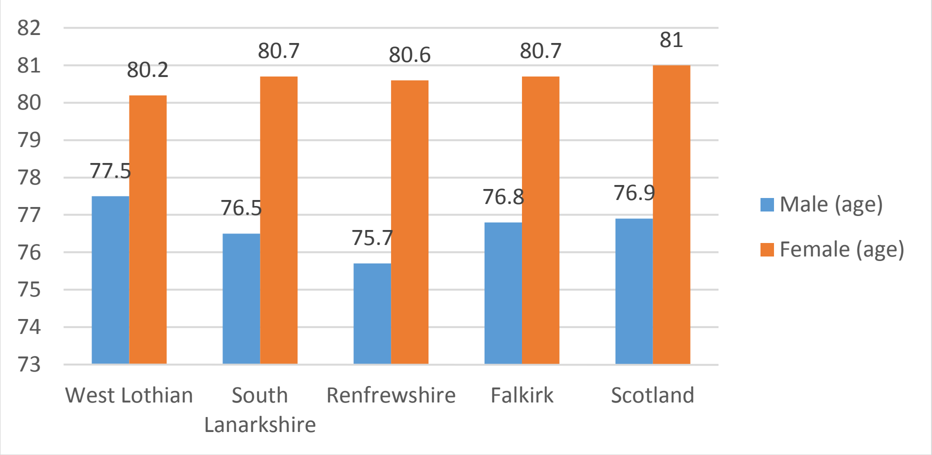
Projected years	**2017**	**2022**	**2027**	**2032**	**2037**
Projected population	180, 252	184,774	189, 208	193,254	196,664

3.3.5 Population: Life expectancy

Female life expectancy at birth (80.2 years) is greater than male life expectancy (77.5 years) in West Lothian, with male life expectancy higher than the Scottish average (77.5 years compared to 76.9 years) and female life expectancy lower (80.2 years compared to 81 years). Male life expectancy at birth in West Lothian is improving more rapidly than female life expectancy.

Further analysis is revealed in the graph below and it can be seen that life expectancy at birth for males in West Lothian is higher than all other areas (South Lanarkshire 76.5 years, Renfrewshire 75.7 years Falkirk 76.8 years). Life expectance at birth for females is slightly lower than all other areas (South Lanarkshire 80.7 years, Renfrewshire 80.6 years Falkirk 80.7 years).

Figure 3.7: West Lothian Life Expectancy at Birth by Sex, Comparison Areas and Scotland, 2010-2012[123]



3.3.6 Population: Ethnicity

The 2011 Census reveals 97.5% of the people in West Lothian consider their ethnic group to be ‘white’ which is higher than national figures (96.1%). Further analysis of these figures demonstrates

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[122] Ibid.

[123] National Records of Scotland, 2015. *Council area profiles*. Available at: http://www.nrscotland.gov.uk/statistics-and-data/statistics/stats-at-a-glance/council-area-profiles [Accessed 22 June 2015].

that 87.8% of people within West Lothian consider their ethnic group to be 'White Scottish', which, again, is higher than the national average (84%), but lower than all comparison areas (South Lanarkshire 91.6%, Renfrewshire and Falkirk both 91.3%). The table below demonstrates further analysis of 2011 census data on ethnicity.

Table 3.8: Ethnicity Breakdown for West Lothian, Comparison Areas and Scotland[124]

	West Lothian	South Lanarkshire	Renfrewshire	Falkirk	Scotland
White- Scottish	87.8%	91.6%	91.3%	91.3%	84%
White- Other British	5.8%	3.8%	3.3%	4.5%	7.9%
White- Irish	0.7%	1%	0.9%	0.6%	1%
White-Gypsy/Traveller	-	0.1%	-	0.1%	0.1%
White-Polish	1.9%	0.4%	0.7%	0.7%	1.2%
White- Other	1.3%	0.8%	0.9%	0.9%	1.9%
Asian, Asian Scottish or Asian British	1.7%	1.6%	1.8%	1.3%	2.7%
Mixed or multiple ethnic groups	0.3%	0.2%	0.2%	0.2%	0.4%
African	0.3%	0.2%	0.5%	0.1%	0.6%
Caribbean or Black	0.1%	0.1%	0.1%	0.1%	0.1%
Other Ethnic group	0.1%	0.1%	0.2%	0.1%	0.3%

3.4 Deprivation

It is documented that individuals from deprived areas have lower overall mental well-being compared to those from more affluent areas, with national and international research demonstrating that those in deprived areas are more likely to have higher rates of hospital admissions, increased risk of premature death[125], are twice as likely to have anxiety problems than those in the least deprived areas, and also have higher rates of suicide.[126] Almost 53% (n=12,945) of adults with learning disabilities for whom Scottish Index of Multiple Deprivation (SIMD) information is known, live in the 40% most deprived areas in Scotland.[127] It is worth noting that recent research indicates

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[124] National Records for Scotland. 2013. *2011 Census: Key Results on Population, Ethnicity, Identity, Language, Religion, Health, Housing and Accommodation in Scotland - Release 2A. Available at:* http://www.scotlandscensus.gov.uk/documents/censusresults/release2a/StatsBulletin2A.pdf [Accessed 22 July 2015].

[125] Office of the Deputy Prime Minister. 2004. *Mental health and social exclusion: Social Exclusion Unit report.* Available at: http://www.socialfirmsuk.co.uk/resources/library/mental-health-and-social-exclusion-social-exclusion-unit-report[Accessed 22 July 2015].

[126] Audit Scotland. 2012. *Health inequalities in Scotland.* Available at: http://www.audit-scotland.gov.uk/docs/health/2012/nr_121213_health_inequalities.pdf [Accessed 22 July 2015].

[127] Scottish Consortium for Learning disability. 2015. *Statistics Release: Learning disability Statistics Scotland 2013 (eSAY).* Available at: http://www.sclearning disability.org.uk/wp-content/uploads/2015/05/statistics_release_learning_disability_statistics_scotland_2013.pdf [Accessed 24 July 2015].

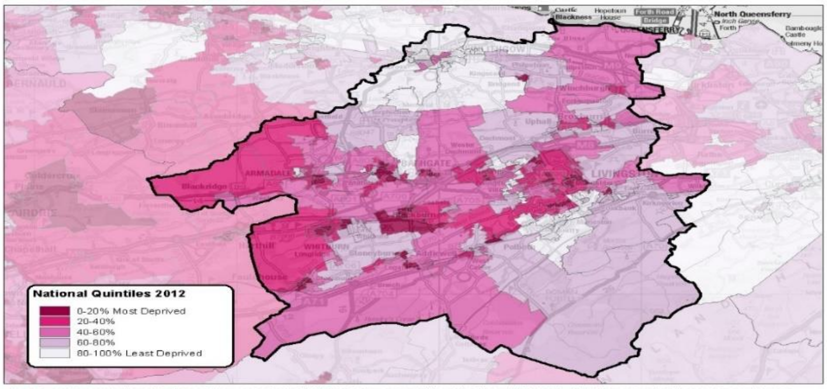
that health inequalities for people with learning disabilities are present regardless of SIMD; that is to say, people with learning disabilities who live in affluent areas experience the same levels of health inequalities and social isolation as those from poorer areas (Professor Anna Cooper, Scottish Learning Disabilities Observatory Team).

The SIMD is a Scottish Government tool which includes different aspects of deprivation to combine them into a single index. Specifically, the index incorporates seven domains to measure the multiple aspects of deprivation and the overall index is a weighted sum of the seven domain scores as follows: income (28%), employment (28%), health (14%), education (14%), geographic access (9%), crime (5%) and housing (2%). There are a total of 6,506 datazones (small areas) within Scotland to which the SIMD offers a relative ranking for each datazone from 1 (most deprived) to 6,506 (least deprived). The datazones contain approximately 350 households/800 people. Current SIMD (2012) figures for Scotland show that 742,200 people live in the 15% most deprived areas of Scotland. Figures also shows that multiple deprivation has become less clustered over time with 2004 figures highlighting approximately half of all datasets in the most deprived 10% across Scotland were in Glasgow City, whereas 2012 figures highlights that this has fallen to 35.8%. Currently Ferguslie Park, Paisley, is the most deprived area in Scotland, whereas the least deprived datazone is the Craiglockhart area of Edinburgh.[128]

3.4.1 Deprivation within West Lothian

Within West Lothian there are 211 datazones. The SIMD 2012 reveals that 13 (6.2%) of West Lothian's 211 datazones were found in the 15% most deprived datazones in Scotland, compared to 19 (9%) in 2009, 14 (6.6%) in 2006 and 9 (4.3%) in 2004. The most deprived datazone in West Lothian in the overall SIMD 2012 is S01006416, which is found in Bathgate East. It has a rank of 440, meaning that it is amongst the 10% most deprived areas in Scotland. The figure below shows the national quintiles for West Lothian.

Figure 3.9: Levels of Deprivation in West Lothian in SIMD 2012 by quintile.[129]



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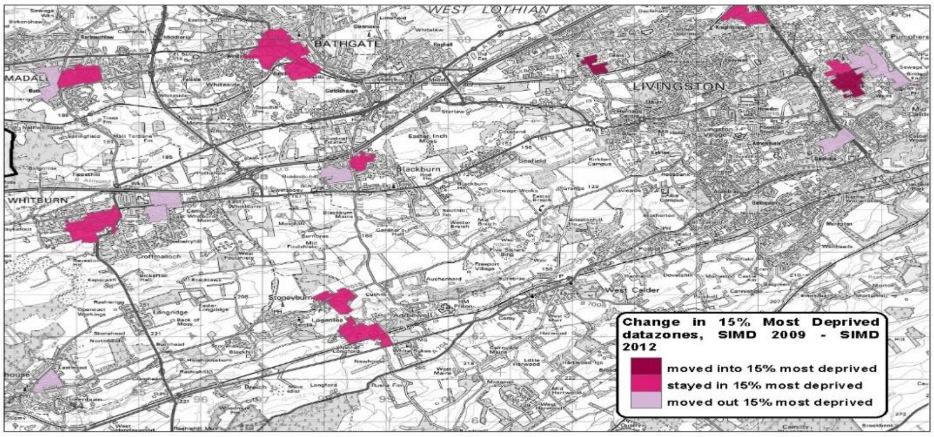
[128] Scottish Government. 2012. *SIMD 2012 Results.* Available at: http://simd.scotland.gov.uk/publication-2012/simd-2012-results/ [Accessed 22 July 2015].

[129] Ibid.

The figure below shows changes in deprivation within West Lothian with areas which have moved into the 15% most deprived, areas which have stayed in the 15% most deprived and areas which have moved out the 15% most deprived areas between SIMD 2009 and SIMD 2012.

Figure 3.10: Datazones in West Lothian Which Have Stayed in or Moved Out of the 15% Most Deprived in Scotland.[130]



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SIMD mages courtesy of the Scottish Government

Further analysis of the SIMD (2012) figures is presented in the table below which shows West Lothian as having 6.2% of the 211 datazones in the 15% most deprived datazones in Scotland. This figure is lower than South Lanarkshire (13.3%), Renfrewshire (22.4) and also Falkirk (9.1%).

Table 3.11: Percentage of Most Deprived Zones in West Lothian and Comparison Areas According to SIMD 2012.[131]

West Lothian	South Lanarkshire	Renfrewshire	Falkirk
6.2% (13 out of 211)	13.3% (53 out of 398)	22.4% (48 out of 214)	9.1% (18 out of 197)

3.5 Employment (Working age)

Current figures show that there are approximately 89,000 people employed within West Lothian. The figure below shows employment rates and levels in West Lothian and comparison areas from April 2014- March 2015. It can be seen in the figure that employment rates in West Lothian, as an overall percentage, are higher than all three comparison areas (Falkirk 72.5%; Renfrewshire 73.8%; South Lanarkshire 75.2%).

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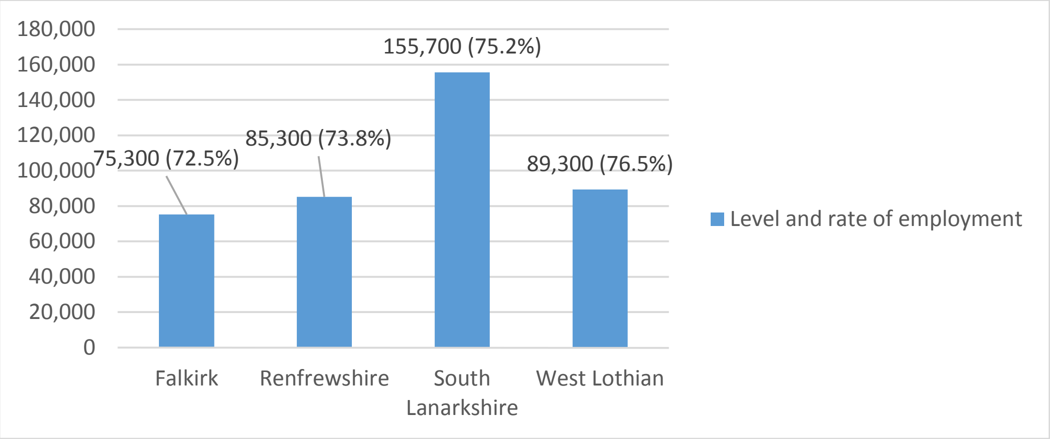
[130] Scottish Government. 2012. *SIMD 2012 Results.* Available at: http://simd.scotland.gov.uk/publication-2012/simd-2012-results/ [Accessed 22 July 2015].

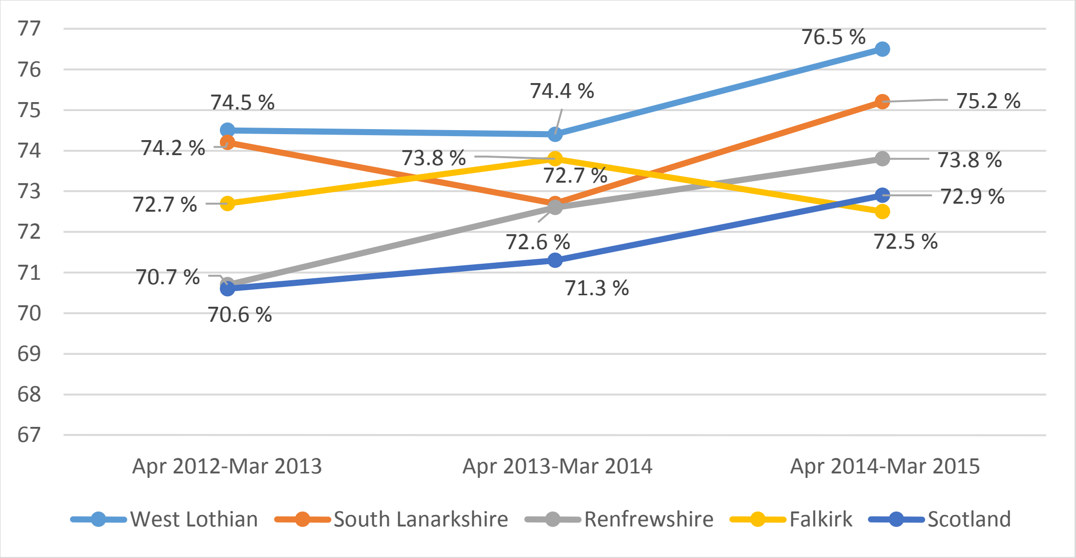
[131] Ibid.

Table 3.12: Employment Rates and Levels in West Lothian and Comparison Areas, April 2014 - March 2015.[132]



In further detail, the figure below shows employment rates and levels in West Lothian, comparison areas and Scotland in years 2012-2013, 2013-2014, and 2014-2015. The figure reveals that employment rates in West Lothian have increased in the three years with current figures for the year April 2014- March 2015 (76.5%) higher than South Lanarkshire (75.2%), Renfrewshire (73.8%), Falkirk (72.5%) and Scotland (72.9%).

Figure 3.13: Percentages of Employment Rates in West Lothian, Comparison Areas and Scotland, 2012-2013, 2013-2014, 2014-2015. [133]



3.6 Unemployment

Overall unemployment figures include people who are out of work and not only those claiming unemployment benefits. From the table below it can be seen that the unemployment figures in West

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[132] Scottish Government. 2015. *Annual population survey, results for year to March 2015- summary tables.* Available at: http://www.gov.scot/Topics/Statistics/Browse/Labour-Market/Publications/APSAMTables [Accessed 20 July 2015].

[133] Scottish Government. 2015, op. cit.

Lothian are lower than the Scottish average (5.6% compared to 6.2%). Furthermore, West Lothian has lower unemployment figures than South Lanarkshire (5.9%), Renfrewshire (6.4%) and Falkirk (6.4%).

Table 3.14: Unemployment Figures for West Lothian, South Lanarkshire, Renfrewshire and Falkirk Compared to Scotland, April 2014-March 2015.[134]

West Lothian numbers	**%**	**Scotland**
5,300	5.6 %	6.2%
South Lanarkshire numbers	**%**	
9,900	5.9%	6.2%
Renfrewshire numbers	**%**	
5,8000	6.4%	6.2%
Falkirk numbers	**%**	
5,200	6.4%	6.2%

Recent labour market profile figures show the breakdown of key benefit claimants who are of working age within West Lothian and from the table it can be seen that there were a total of 16,140 working age clients claiming key benefits from April 2014-March 2015.

Table 3.15: Working-age Client Group - Key Benefit Claimants in West Lothian, April 2014-March 2015.[135]

	West Lothian numbers	**(%)**	**Scotland %**
Total claimants	16,140	14	14.3
Job seekers	1,980	1.7	2.2
ESA and incapacity benefits	9,030	7.9	7.8
Lone parents	1,290	1.1	1
Carers	1,690	1.5	1.5
Others on income related benefits	350	0.3	0.3
Disabled	1,530	1.3	1.2
Bereaved	280	0.2	0.2
Main Out-of-Work Benefits	12,650	11	11.4

*Main out-of-work benefits includes the groups: job seekers, ESA and incapacity benefits, lone parents and others on income related benefits

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[134] Office for National Statistics. 2015. *Local authority profile.* Available at: http://www.nomisweb.co.uk/reports/lmp/la/contents.aspx [Accessed 25 July 2015].

[135] Office for National Statistics. 2015. *Local authority profile.* Available at: http://www.nomisweb.co.uk/reports/lmp/la/contents.aspx [Accessed 25 July 2015].

3.7 Welfare Sanctions

With the introduction of the new Welfare Reform Act in 2012, a new system of sanctions was implemented which has resulted in the number of unfavourable sanctions increasing for jobseekers. However, such sanctions can have negative outcomes for claimants.[136] The graph below highlights sanctions under the old regime and the higher level of sanctions since the new regime was implemented in 2012.

Figure 3.16: Annual Number of Adverse JSA Sanction Decisions in Scotland, 2001-2013[137]

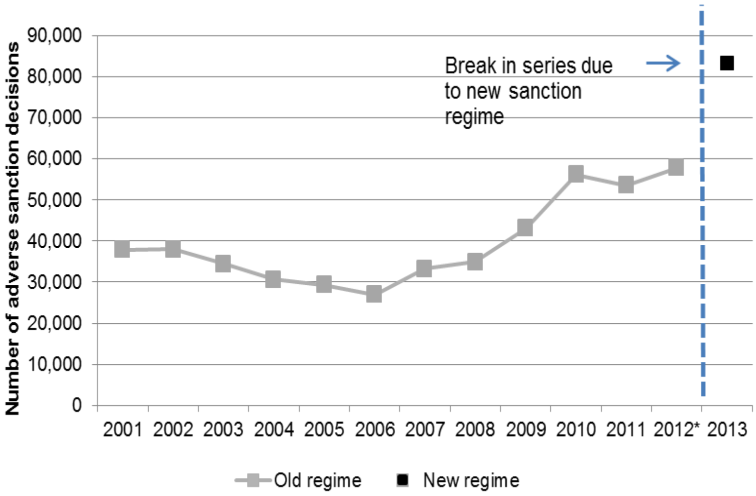

Image courtesy of the Scottish Government. 2014. Welfare Reform (Further Provision) (Scotland) Act 2012 Annual Report – 2014.

3.8 Homelessness

Efforts to prevent homelessness require an understanding of the underlying causes and early indicators of risk. Evidence highlights that childhood learning disabilities are over-represented among homeless adults with complex comorbidities and predict a range of poor health outcomes in adulthood; including mood and anxiety disorders, suicidal ideation, early and severe substance use and physical health problems.[138,139]

The childhoods of homeless adults are disproportionately characterised by persistent poverty, residential mobility, school problems and other stressful and/or traumatic experiences.[140,141] While a growing body of research has examined the relationship between adverse childhood events and subsequent homelessness,[142,143] few studies have examined the role of childhood learning

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[136] Scottish Government. 2014. *Welfare Reform (Further Provision) (Scotland) Act 2012 Annual Report – 2014.* Available at: http://www.scotland.gov.uk/Resource/0045/00454504.pdf [Accessed 29 July 2015].

[137] Scottish Government. 2014, op. cit.

[138] Shinn M (2007). *International homelessness: policy, socio-cultural, and individual perspectives.* J Soc Issues 2007;63:657–77.

[139] Sullivan G, Burnam A, Koegel P (2000). Pathways to homelessness among the mentally ill. Soc Psychiatry Epidemiol 2000;35:444–50.

[140] Herman D, Susser ES, Struening EL, *et al* (1997). *Adverse childhood experiences: are they risk factors for adult homelessness?* Am J Public Health 1997;87:249–55.

[141] Koegel P, Malamid E, Burnam MA (1995). Childhood risk factors for homelessness among homeless adults. Am J Public Health 1995;85:1642–9.

[142] Herman, op. cit.

[143] Koegel, op. cit.

disabilities. There is growing evidence that academic problems in school foreshadow later educational and employment difficulties and may affect multiple domains of functioning.[144]

From a public health perspective, early interventions in childhood might change or moderate the cycle of homelessness across generations because early risk factors are often longstanding and drive a trajectory of cumulative risk, potentially leading to severe psychopathology and social exclusion. Learning problems may contribute to challenges with print and financial literacy, obtaining and maintaining housing and employment and a wide range of daily living skills.[145]

From the table below it can be seen that in the year to March 2015 there were 1,331 applications made under the Homeless Persons Legislation in West Lothian, which was a 3.2% increase from 2013-14 figures (1,290) but a 5.7% decrease from 2012-13 (1,412). This is in contrast to the 10.7% decrease in homeless applications made in Scotland from 2012-13 (40,051) until 2014-15 (35,764).

Figure 3.17: Number of Applications under the Homeless Persons legislation by Local Authority 2010-11 to 2014-15[146]

	2012-13	2013-14	2014-15
West Lothian	1,412	1,290	1,331
Falkirk	1,087	1,046	1,206
Renfrewshire	1,103	975	825
South Lanarkshire	2,101	2,129	1,904
Scotland	40,051	37,234	35,764

3.9 Health Inequalities

The term 'health inequalities' describes the poorer health experienced by some of our population in comparison with their neighbours. Those who experience social disadvantage because of low income, social position, gender, ethnic origin, age or disability are likely to have poorer physical and mental health than the rest of the population. By far the commonest reason for people to experience health inequalities is low income. The poorest in our society die earlier and have higher rates of disease and people struggling with poverty and low income have poorer mental health and wellbeing than those with higher incomes and positive life chances.

People with a learning disability are also at high risk of having poorer health, as a result of poor knowledge, access to health services and propensity to having health conditions.

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[144] Masten A, Long JD, Roisman G et al (2005). *Developmental cascades: linking academic achievement, externalizing and internalizing symptoms over 20 years.* Developmental Psychology, 2005; 41:733–46.

[145] Patterson, M.L. et al (2012). *Missed opportunities: childhood learning disabilities as early indicators of risk among homeless adults with mental illness in Vancouver, British Columbia.* BMJ Open 2012;2:e001586 doi:10.1136/bmjopen-2012-001586.

[146] Office for National Statistics. 2015. *Operation of the homeless person's legislation in Scotland: 2014-15. Available* at: http://www.gov.scot/Resource/0048/00480524.pdf [Accessed 9 August 2015].

People with learning disabilities have higher rates of many health needs, including respiratory disease and aspiration/choking, being born with heart disease (especially people with Down syndrome), reflux disorder, constipation, obesity, epilepsy, sensory impairments, incontinence, movement disorders, and mental health needs.

People with learning disabilities have shorter life expectancy than other people. They also have poorer physical and mental health. These things are not inevitable. They are examples of health inequalities that can, to a significant extent, be avoided.

The public sector duties on equalities included in the Equality Act (2010) place a requirement on all public bodies to consider the impact of policies and services on the needs of individuals with these 'protected characteristics'. There is also a legislative requirement that human rights are considered by public bodies and this has some crossover with equality legislation (NHS Health Scotland, 2011).

West Lothian Council alongside NHS Lothian have a duty to address such inequalities that may exist for people with a learning disability and with Autism. NHS Lothian in its Strategic plan 2013-20, state as one of the key priorities:

> *'Prioritise prevention, reduce inequalities and promote longer healthier lives for all.'*

Everyone should have the same opportunities to enjoy good health as a matter of fairness. The NHS provides health care to everyone free at the point of need and has a role to play in:

- providing services designed to prevent future illness;
- taking opportunities to provide advice and support to people to help them to take care of their own health; and
- working with partners to promote the health and wellbeing of communities and the whole population.

Addressing health inequalities is a complex challenge and requires actions to be taken by many different agencies working closely with communities. West Lothian Partnership need to ensure that people with a learning disability vulnerable to or experiencing inequality have good access to all public services. By working closely across all agencies, people with a learning disability can be supported to better health. The West Lothian Community Planning Partnership supports reducing Health inequalities for all. (Audit Scotland Report Oct 2014 with CPP's priorities). Addressing Health Inequalities is a major challenge and one which the new West Lothian Health and Social Care Partnerships is expected to make a significant contribution.

3.10 Mental Health and Wellbeing

Mental wellbeing is an essential part of a person's capacity to lead a satisfying life which includes the capacity to make informed choices, study, pursue leisure interests, as well the ability to form relationships with others.[147] The nation's mental health is a key priority for Scottish government

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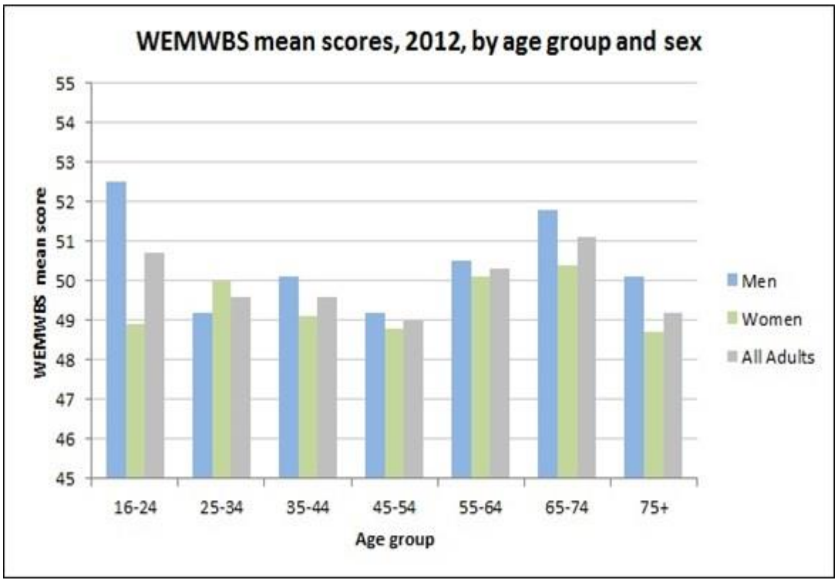
[147] World Health Organisation. 2012. *Risks to mental health: An overview of vulnerabilities and risk factors.* Available at: http://www.who.int/mental_health/mhgap/risks_to_mental_health_EN_27_08_12.pdf [Accessed 31 July 2015].

policy. In Scotland, mental health is measured within the Scottish Health Survey which adopts the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS). This scale is made up of 14 separate statements regarding mental health and wellbeing to which respondents answer. A score is then created to determine the person's state of mental wellbeing. The maximum score is 70 and the minimum score is 14, with the higher the score the better level of mental wellbeing.[148] At present there are no results for each local authority, with results available at a national level only. That withstanding, from the figure below it can be seen that for all adults, the age bracket of 65-74 had the greater level of wellbeing. Updated Scottish Health Survey results for 2013 will be released in December 2014.

Figure 3.18: Warwick Edinburgh Mental Wellbeing Scale Mean Scores (2012) by age group and sex[149]



Wellbeing results for each local authority are available from data in the UK Annual Population Survey.[150] To asses personal well-being in the UK the survey uses responses from approximately 165,000 people across the UK, and the publication includes the four following key questions to measure well-being which are answered on a scale from 0 to 10 with 0 the lowest and 10 highest.

The questions are as follows:

- *Overall, how satisfied are you with your life nowadays?*
- *Overall, to what extent do you feel the things you do in your life are worthwhile?*
- *Overall, how happy did you feel yesterday?*
- *Overall, how anxious did you feel yesterday?*

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[148] Scottish Government. 2012. *The Scottish health survey*. Available at: http://www.scotland.gov.uk/resource/0043/00434590.pdf *[Accessed 25 July 2015]*.

[149] Scottish Government. 2012, op. cit.

[150] Office for National Statistics. 2014. *Personal well-being in the UK, 2013/14*. Available at: http://www.ons.gov.uk/ons/dcp171778_377460.pdf [Accessed 09 August 2015].

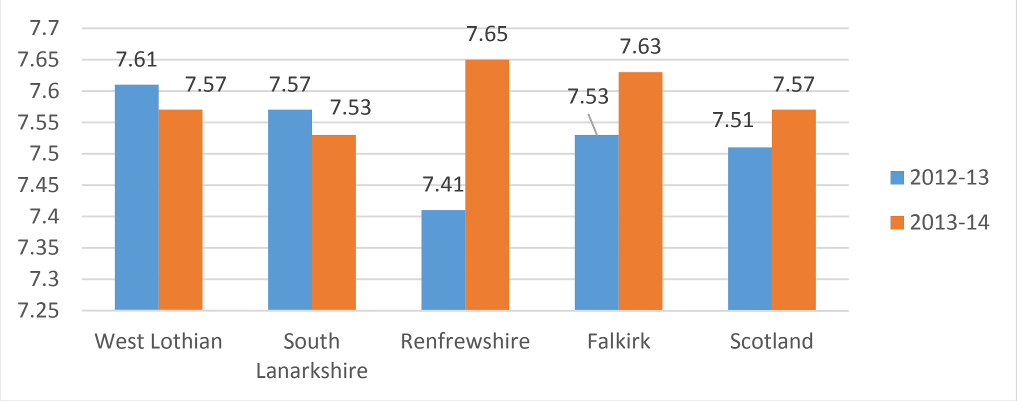
An overview of the well-being estimates is that there have been year on year improvements in reported average personal well-being ratings in the UK across each of the four measures of well-being, with the greatest gain being in the reduced anxiety levels. It should be noted that the survey should be interpreted as giving an estimate of well-being in the UK, rather than an exact measure.

There are mixed results for personal well-being in West Lothian with estimated average figures showing a slight decrease from 2012/13 to 2013/14 in reporting of life satisfaction (2012/13=7.61; 2013/14=7.57) and worthwhile (2012/13=7.83; 2013/14=7.81). Reporting on happiness measures have slightly increased (2012/13=7.46; 2013/14=7.49), whereas overall levels of anxiety have seen a reduction (2012/13=3.15; 2013/14=2.71). Further analyses of personal well-being ratings are presented below.

3.10.1 Life satisfaction

How satisfied a person is with their life is an important aspect of their overall well-being and from the figure below it can be seen that estimates of life satisfaction from 2012-13 to 2013/14 have increased in the Renfrewshire, Falkirk and Scotland, whereas ratings in West Lothian and South Lanarkshire have decreased.

Figure 3.19: Estimates of Life Satisfaction From the Annual Population Survey (APS) Personal Well-being 2012/13 and 2013/14[151]



3.10.2 Worthwhile

In regards to the worthwhile question, it can be seen from the figure below that ratings from 2012-13 to 2013/14 have increased in South Lanarkshire, Renfrewshire, Falkirk, and Scotland, whereas ratings have decreased in West Lothian.

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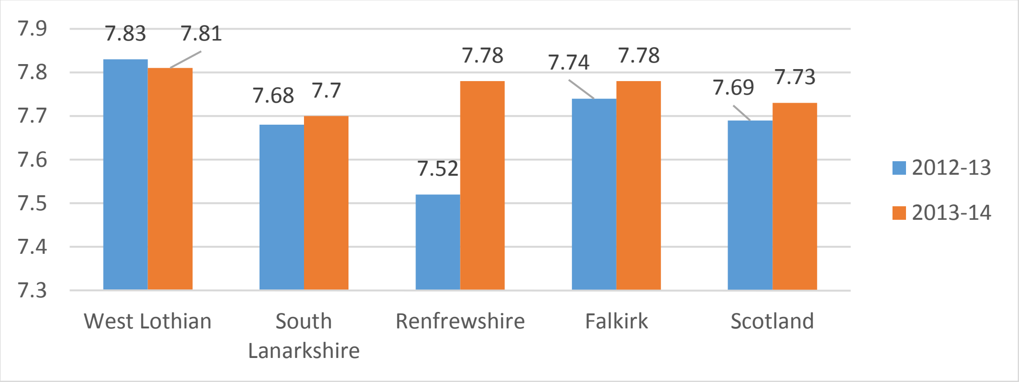
[151] Office for National Statistics. 2013. *Measuring National Well-being, Personal Well-being Across the UK, 2012/13.* Available at: http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-327124 [Accessed 10 August 2015].

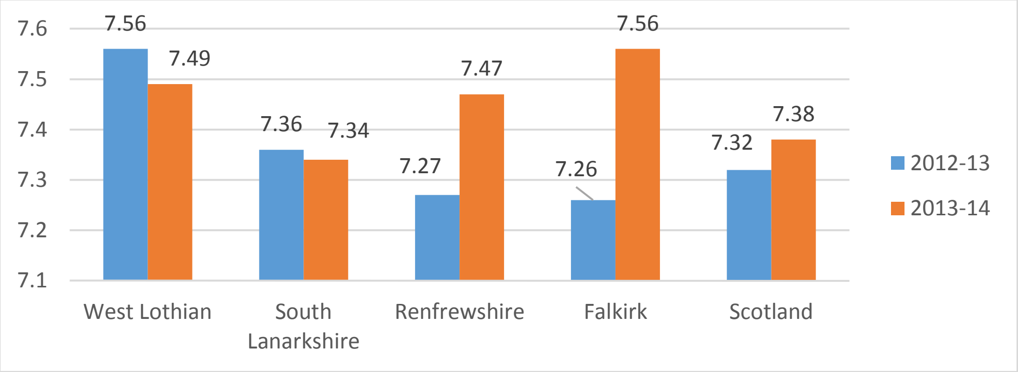
Figure 3.20: Estimates of Worthwhile From the Annual Population Survey (APS) Personal Well-being 2012/13 and 2013/14[152]



3.10.3 Happiness

In regards to happiness ratings there has been an increase from 2012/13-2103/14 in the Renfrewshire, Falkirk and Scotland, whereas ratings for West Lothian and South Lanarkshire have decreased.

Figure 3.21: Estimates of Happiness From the Annual Population Survey (APS) Personal Well-being 2012/13 and 2013/14[153]



3.10.4 Anxiety

In regards to anxiety ratings there have been reductions in West Lothian, South Lanarkshire, Falkirk, and Scotland, whereas there has been an increase in anxiety ratings in Renfrewshire.

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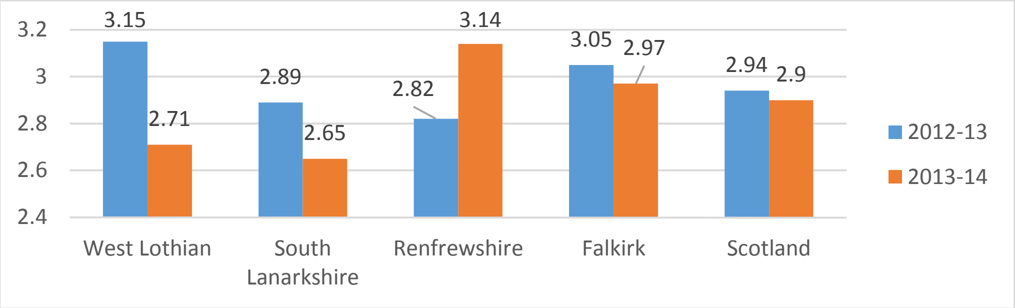
[152] Ibid.

[153] Ibid.

Figure 3.22: Estimates of Anxiety From the Annual Population Survey (APS) Personal Well-being 2012/13 and 2013/14[154]



3.10.5 Mental health and wellbeing for people with learning disabilities

Recent guidance for commissioners of mental health services for people with learning disabilities[155] purports that *'many people with learning disabilities live full and rewarding lives as part of their local communities.'* The key message of the guidance report is that support is needed for those with learning disabilities to have good mental health and wellbeing. The guidance makes for following points (pp.3), which commissioners in West Lothian should take cognisance of:

- The prevalence of mental health problems in people with learning disabilities is considerably higher than the general population.
- In addition to mental illness, people with learning disabilities often have coexisting autistic spectrum disorders, behaviours that challenge services, offending behaviour, or physical health conditions. It is often hard to distinguish between these conditions especially when people have more severe intellectual impairments.
- It is often difficult for people with learning disabilities to access generic and specialised mental health services.
- The quality of mental health services should be measured from the perspective of the individual with learning disabilities and their family. Clinical effectiveness and outcomes, and patient safety, are also key.
- A positive experience for the individual with learning disabilities and their family is achieved by building a partnership through early involvement in service planning, delivery and evaluation as well as the provision of timely and seamless advice and support especially during periods of transition. Involving people with learning disabilities, their families and advocates in service planning, enables the provision of individualised services, one of the key characteristics of exemplary care or support.
- Successful services provide individualised pathways of care, based on a thorough understanding of the individual and their experience. It should be person-centred and consist of a coordinated assessment of need, agreement of expected outcomes, provision of care

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[154] Ibid.

[155] Joint Commissioning Panel for Mental Health (2013). *Guidance for Commissioners of Mental Health Services for People with Learning Disabilities*. Available at: http://www.jcpmh.info/wp-content/uploads/jcpmh-learningdisabilities-guide.pdf [accessed on 23 November 2015].

and treatment, followed by a joint review of achieved outcomes with the people receiving services and their carers.

- Commissioners should work in partnership with provider services in primary and acute care, and with local authorities including public health. This is a crucial first step to a better understanding of the needs of the population with learning disabilities and achieving an improvement in overall health and wellbeing.
- Commissioning of mental health services should support the development of local, person-centred services, leading to the development of skilled local providers.
- Commissioners should evaluate the outcomes of the service models they are providing, checking for evidence of effectiveness, safety and user satisfaction. They should use this to agree priorities for investment as the commissioning landscape changes and personal budgets become more popular.

3.11 Prevalence of learning disabilities

The World Health Organisation (2001) estimates that the overall prevalence of learning disabilities is between 1-3%, further suggesting that prevalence is higher in developing countries for reasons such as higher incidence of injuries and anoxia, early childhood brain infections and deprivation of oxygen at birth.[156] The Same as You? (2000)[157], suggests that 20 people for every 1,000 will have a mild or moderate learning disability; whereas 3 to 4 people for every 1,000 have a profound or multiple disability.[158] These figures have been used in subsequent large-scale Scottish publications.[159, 160] Figures from the 2011 Census reveal that 23,016 people in Scotland have a learning disability, whilst 102,136 have a learning difficulty.[161]

Information provided by General Practitioners suggest a prevalence rate of 0.5% per 100 patients registered to general practices in 2014.[162]

Although estimates for learning disabilities vary, work by Emerson and Hatton[163] is cited throughout the literature on learning disabilities and/or autistic spectrum disorder. Adapting these prevalence

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[156] World Health Organization. 2001. *Fact Sheet: the World Health Report 2001. Mental and Neurological Disorders.* Available at: http://www.who.int/whr/2001/media_centre/en/whr01_fact_sheet1_en.pdf [Accessed 2 August 2015].

[157] Scottish Government. 2000. *The same as you? A review of services for people with learning disabilities.* Available at: http://www.gov.scot/resource/doc/1095/0001661.pdf [Accessed 25 July 2015].

[158] Scottish Government. 2000, op. cit.

[159] NHS Scotland. 2004. *People with learning disabilities in Scotland.* Available at: http://www.gla.ac.uk/media/media_63872_en.pdf [Accessed 2 August 2015].

[160] Scottish Government. 2008. *The population of learning disabilities in Scotland: A review of existing data*. Available at: http://www.gov.scot/Resource/Doc/1095/0076896.pdf [Accessed 2 August 2015].

[161] Table CT_0033f_2011 - Long-term health condition by sex by age- retrieved by going to Scotland census tables index and searching http://www.scotlandscensus.gov.uk/ods-web/data-warehouse.html

[162] Information Services Division Scotland. 2014. *Quality & Outcomes Framework (QOF) of the GMS contract - achievement, prevalence and exception reporting data 2013/14*. Available at: http://www.isdscotland.org/Health-Topics/General-Practice/Quality-And-Outcomes-Framework/ [Accessed 2 August 2015].

[163] Emerson, E., and Hatton, H. 2004. *Estimating the current need/demand for supports for people with learning disabilities in England.* Available at:

estimates for adults in West Lothian, the tables below reveal prevalence estimates across the lifespan, based on mid-2014 population figures.

Table 3.23a: Prevalence of Learning disability in West Lothian by Age Group

Age	**Total Population**	**% prevalence of learning disability**	**No. prevalence of learning disability**
0-4	10,855	0.15%	16
5-9	11,566	0.97%	112
10-14	10,423	2.26%	236
15-19	10,928	2.67%	292
20-24	10,301	2.6%	268
25-29	10,653	2.4%	256
30-34	11,424	2.41%	275
35-39	11,202	2.38%	267
40-44	13,594	2.4%	326
45-49	14,676	2.25%	330
50-54	13,514	2.12%	286
55-59	11,120	2.09%	232
60-64	9,764	1.97%	192
65-69	9,373	1.8%	169
70-74	6,894	1.72%	119
75-79	5,150	1.52%	78
80+	5713	1.43%	82
TOTAL	**177,150**	2%	**3543**

Source: applying assumption from Emerson and Hatton (2004) to West Lothian Mid-Year 2014 Estimates (accessed via www.nomisweb.co.uk).

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http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7008_Estimating_Current_Need_Emerson_and_Hatton_2004.pdf [Accessed 2 August 2015].

Table 3.23b: Prevalence of Learning disability in West Lothian by Age Group and Gender

Age	Male	% prevalence of learning disability	No. prevalence of learning disability	Female	% prevalence of learning disability	No. prevalence of learning disability
0-4	5,597	0.19%	11	5,258	0.11%	6
5-9	5,927	1.21%	72	5,639	0.72%	41
10-14	5,240	2.76%	145	5,183	1.73%	90
15-19	5,673	3.22%	183	5,255	2.1%	110
20-24	5,266	3.09%	163	5,035	2.11%	106
25-29	5,187	2.84%	147	5,466	1.98%	108
30-34	5,526	2.87%	159	5,898	1.97%	116
35-39	5,547	2.82%	156	5,655	1.95%	110
40-44	6,538	2.86%	187	7,056	1.95%	138
45-49	7,135	2.66%	190	7,541	1.84%	139
50-54	6,699	2.51%	168	6,815	1.74%	119
55-59	5,465	2.44%	133	5,655	1.74%	98
60-64	4,672	2.34%	109	5,092	1.62%	82
65-69	4,526	2.17%	98	4,847	1.46%	71
70-74	3,212	2.08%	67	3,682	1.42%	52
75-79	2,353	1.89%	44	2,797	1.25%	35
80+	2,193	1.86%	41	3,520	1.23%	43
TOTAL	**86,756**	2.41%	**2090**	**90,394**	1.62%	**1464**

Source: applying assumption from Emerson and Hatton (2004) to West Lothian Mid-Year 2014 Estimates (accessed via www.nomisweb.co.uk).

Emerson and Robertson (2011)[164] have combined information collected by government departments on the presence of learning disabilities among people using particular services, overall population predictions and results of epidemiological research. Using these data Emerson and Robertson have applied the prevalence estimates from previous research to estimate:

- The likely number of adults with learning disabilities that should be known to learning disabilities services; and
- The likely number of adults with learning disabilities in the general population.

Emerson and Robertson suggest there are likely to be 87,500 adults (aged 20 years+) with a learning disability in the general Scottish population, with 18,400 of these known to services. This equates to

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[164] Emerson, E., and Robertson, J. 2011. *The Estimated Prevalence of Visual Impairment among People with Learning disabilities in the UK*. Available at: http://www.rnib.org.uk/sites/default/files/Learn_dis_small_res.pdf [Accessed 3 August 2015].

21.03% of the adult population with a learning disability (i.e. 18,400 divided by 87,500) who *should* be known to services.

By comparing the figures of adults in the general Scottish population that are likely to have a learning disability (87,500) to the whole population figures from the 2011 Census for those aged 20+ in Scotland (4,118,317), this suggests a prevalence rate of 2.125% (i.e. 87,500 divided by 4,118,317).

By applying this formula (i.e. a prevalence rate of 2.125%) to the 2011 Census results for West Lothian of Adults 20 years + (n=131,119), it would suggest that there will be 2786 adults with a learning disability (i.e. 131,119 multiplied by 2.125%) in the general population.

Finally, by applying Emerson and Robertson's 21.03% ratio (as stated above), to the West Lothian population figures, 586 adults *should* be known to learning disability services in West Lothian.

Table 3.24: Prevalence of Adults with a learning disability Known to Services and in Population

West Lothian	Total Adult Population (20+)	Adults known to LEARNING DISABILITY services	Adults with LEARNING DISABILITY in population
Adult population	131,119	586	2786

Source: applying assumption from Emerson and colleagues to West Lothian Census 2011 figures

Approximately half of people with severe learning disabilities also have some kind of autistic spectrum disorder.

Research evidence suggests that there may be patterns in the prevalence of learning disabilities in various demographic groups. Socio-economic deprivation is positively associated with mild and moderate learning disabilities; this is not the case however with more severe learning disabilities.[165]

Males have been shown to be more likely to have both mild and severe learning disabilities than females.[166] This may be due in part to the fact that some learning disabilities have a genetic element which is more commonly passed to male children.

There are also patterns in the prevalence of learning disabilities and ethnicity. There are higher rates of learning disability in South Asian groups compared to the general population, particularly younger people with severe learning difficulties. This may be due to numerous factors such as inequalities in access to maternal health care.

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[165] Emerson, E., Hatton, C., Felce, D. and Murphy, G. (2001). *Learning disabilities: The Fundamental Facts*, The Foundation for People with Learning disabilities.

[166] Rees S, Cullen C, Kavanagh S & Lelliott P (2004). *Learning disabilities*. In Health care needs assessment: the epidemiologically based needs assessment, Volume 2 Radcliffe Publishing.

3.11.1 Prevalence estimation limitations

There is no conclusive figures of the number of people with learning disabilities:

- There are difficulties in estimating the prevalence of learning disabilities at a global, national and local level, therefore it is not possible to present an accurate figure for people with a learning disability.
- Data generated for the Quality and Outcomes Framework is based on individuals aged 18 and over and is also based on GPs' interpretation of a specific learning disability therefore the numbers provided will not be a reliable measure.
- The various measurements, classification and definitions used to gauge the prevalence of learning disabilities makes presenting accurate figures challenging.

3.12 Prevalence of Autistic Spectrum Disorders

The prevalence estimates in the Public Health Institute of Scotland (PHIS) ASD Needs Assessment Report[167] suggested 60 in every 10,000 people are affected by ASD. However, the Scottish Strategy for Autism (Scottish Government, Nov 2011[168]) reports that more recent studies estimate that the prevalence of autism in children and adults in Scotland is around 1 in 100.

The Strategy details the estimated figures by local authority areas in 2005 (using a prevalence rate of 90 in 10,000 people, which is taken from the Office of National Statistics survey of the mental health of children and young people in Great Britain, 2004). In West Lothian in 2005 the population was 163, 780[169] which would indicate approximately 1474[2] individuals having an ASD.

According to The General Register Office for Scotland[170] the population of West Lothian in mid-2014 is 177,150. Using the estimated prevalence of 90 per 10,000 detailed in the Scottish Strategy for Autism (Scottish Government, 2011) there would be an estimated 1594 people with an ASD in West Lothian.

The latest prevalence studies of autism indicate that 1.1% of the population in the UK may have autism. This means that over 695,000 people in the UK may have autism, an estimate derived from the 1.1% prevalence rate applied to the 2011 UK census figures. In respect of West Lothian this prevalence rate would indicate 1949 individuals with an ASD off all age groups based on the mid-2014 population estimates (see Table 2.1 and Table 2.2 below for a breakdown of the adult these estimations based on adults 16+).

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[167] Public Health Institute of Scotland (2002). *Autistic Spectrum Disorders Needs Assessment Report 2001.* Scottish Executive: Edinburgh. Available at: http://www.scottishautism.org/autism-knowledge-services/autism%20-%20policy/needs-assessment-report-2001/

[168] Scottish Government. 2011, op. cit.

[169] National records for Scotland. 2015. *Results for administrative areas.* Available at: http://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/archive/mid-2005-population-estimates-scotland/results-for-administrative-areas [Accessed 30 July 2015].

[170] GROS. 2013,op. cit.

The prevalence rate is based on two relatively recent studies, one of children and the other of adults. The prevalence study of children, (Baird G. et al., 2006)[171] looked at a population in the South Thames area. The study of adults was published in two parts, Brugha et al (2009)[172], and The NHS Information Centre, Community and Mental Health Team, Brugha et al (2012)[173]. This is the only known prevalence study to have been completed based on an adult population.

Table 3.25a: Estimation of Adults (16+) with an ASD – West Lothian

West Lothian	Adult Population (16+)	% prevalence of autism	No. prevalence of autism
Adult population	**142,086**	**1.1%**	**1563**
Male	68,842	2%	1376
Female	73,244	0.3%	220

Source: applying assumption from Brugha et al.'s (2012) report to GROS 2014 Mid-Year Estimates.

Table 3.25b: Age breakdown of people with ASD – West Lothian

West Lothian	Total Adult Population (16+)	% prevalence of autism	No. prevalence of autism
16-29	29,662	1.1%	326
30-44	36,220	1.1%	398
45-59	39,310	1.1%	432
60-74	26,031	1.1%	286
75+	10,863	1.1%	119
TOTAL	**142,086**	**1.1%**	**1563**

Source: applying assumption from Brugha et al.'s (2012) report to GROS 2014 Mid-Year Estimates.

The Additional Support for Learning and Young Carers Report to Parliament (2013)[174] reports that in West Lothian there are 2994 (recorded) children and young people in education who have additional support needs. The report highlights that 321 (recorded) children and young people in education have autism in West Lothian.

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[171] Baird, G. et al (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet* 368(9531): 210-215.

[172] Brugha, T. et al (2009). *Autistic Spectrum Disorders in Adults Living in Households throughout England – Report from the Adult Psychiatric Morbidity Survey 2007*. NHS Information Centre for Health and Social Care: Leeds.

[173] Brugha, T. et al (2012). Validating two survey methods for identifying cases of Autistic Spectrum Disorders among adults in the community. *Psychological Medicine* 42(3): 647-656.

[174] Scottish Government (2013). *Additional Support for Learning and Young Carers: Report to Parliament.* Available at: http://www.scotland.gov.uk/Publications/2013/02/7808/0 [Accessed 30 July 2015].

3.12.1 Prevalence estimation limitations

This needs assessment has included commonly used prevalence estimates (above), but these are used with the knowledge of a number of caveats. The quality of the available literature must be taken into account in any analysis and any figures calculated should be considered indicative for the following reasons:

- Limited sample and low response rates.

  Brugha et al.'s studies (2009, 2012)[175,176] used limited samples and received fairly low response rates. Brugha et al.'s later (2012)[177] piece of work collated data from 83 private households (response rate of 20%) and 207 from communal care establishments (response rate 69%).

- Geography

  Brugha et al. (2012)[178] focused on specific geographical areas (Leicestershire, Lambeth, Sheffield) and, although a sensitivity analysis was conducted to test if the results could be applied nationally, it is clear that there may be local variations. In addition, as Census 2001 data was used (as well as case studies), it is debatable as to whether or not this gives an accurate national picture.

- Social Determinants

  Brugha et al. (2012)[179] focused on urban areas and over-represented specific ethnic groups (including South Asian) although there is little evidence to show whether or not these factors correlate with prevalence of autism. In addition, the evidence shows that males are more likely to have autism than females. However, there is suggestion in the literature that this figure may be masking the true picture, such as females are better at hiding it, they are less likely to be diagnosed or that they may display certain behaviours that are excluded from the traditional methods of diagnosis.

- There are a number of problems estimating the number of young people and adults who have autism:-
  - There is no single source or register, and setting one up would be difficult to maintain.
  - Not all people will have been diagnosed and some people may have been 'mis-diagnosed'.
  - There are inconsistencies in how agencies record autism.
  - Much of the existing work on prevalence has been undertaken in relation to children, there may be enduring problems of childhood misdiagnosis or some people only being diagnosed in adulthood.

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[175] Brugha (2009), op.cit.

[176] Brugha (2012), op.cit.

[177] Ibid.

[178] Ibid.

[179] Ibid.

    - There is some evidence of poor identification of adults with autism compared with children. A GP practice audit in Brighton and Hove in 2010 found that prevalence amongst patients under 18 was approx. 1-2% but was around 0.1% for patients aged 18+.

Even where a diagnosis has been made, it is important to note that different conditions are likely to be diagnosed at different ages, and there are some common mis-diagnoses:

- Frith (1989)[180] found that, in relation to autism, the average age of diagnosis was within primary schools years (often by age of 6).
- Atwood (1997)[181] found Asperger's syndrome diagnosis not until secondary school (by 14 years) or early adulthood.
- Many adults do not receive a diagnosis or maybe mis-diagnosed; mis-diagnoses including depression, personality disorder, psychosis or schizophrenia.

3.13 Adults known with a Learning disability and/or Autistic Spectrum Disorder in West Lothian

Data regarding those known to have a learning disability and/or autistic spectrum disorder is provided by Learning disability Statistics Scotland which collates information given from all 32 local authorities across Scotland.[182] Individual level information is collected on people:

- aged 16 and 17 who are not in full time education;
- age 18 and over;
- who have had contact with the local authority in the last 3 years.

As this data set pertains to adults with learning disabilities who are known to local authorities, the information provided describes the administrative prevalence (prevalence determined by service use or clinical diagnoses), therefore it is likely that many people with learning disabilities are not captured in this data set. For example, people with mild forms of learning disability and/or autistic spectrum disorder who do not access local authority services or who live independently will not be presented.

The local authorities provided information on 26,786 adults with a learning disability across Scotland in 2014, which equates to 6.0 people with a learning disability per 1000 people in the general population.[183] This data also reports that there are 4,048 in Scotland with an ASD diagnosis who are known to local authorities, with most of these adults (n=3,018; 74.6%) having a learning disability.

Recent figures, based on the 2014 West Lothian return to Learning disability Statistics Scotland shows that there are 706 people who have a learning disability currently known to services in West Lothian. 18 individuals are recorded as having no learning disability (so will therefore have an Autistic

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[180] Frith, U. (1989). *Autism: Explaining the Enigma.* Basil Blackwood: Oxford.

[181] Attwood, T. (1997). *Asperger's Syndrome: a Guide for Parents and Professionals.* Jessica Kingsley Publishers: London.

[182] Scottish Consortium for Learning disability. 2014, op. cit.

[183] Ibid.

Spectrum Disorder), whereas for 54 individuals recorded on the system it is 'not known' whether they have a learning disability or not. The total number of individuals reported to Learning disability Statistics Scotland in 2014 was 778 individuals.

The following tables show the breakdown of information provided to Learning disability Statistics Scotland by West Lothian Council.

Table 3.26a: West Lothian Council Frequency Tables for Learning disability Statistics Scotland, 2014

Learning disability	**Frequency**		
	2012	**2013**	**2014**
Total	821	774	778
Adults known per 1,000 population	5.9	5.5	5.5
Change in rate (from previous year)	-0.7	-0.4	0.0

Table 3.26b: West Lothian Council Frequency Tables for Learning disability Statistics Scotland, 2014

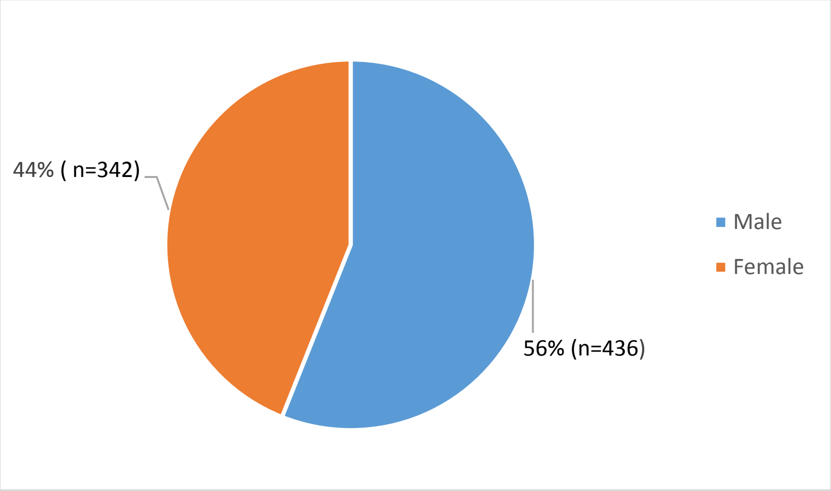
ASD diagnosis	**Frequency**		
	2012	**2013**	**2014**
Asperger's Syndrome	25	27	28
Other Autistic Spectrum Diagnosis	49	44	60
No Autism Spectrum diagnosis	8	29	95
Not known/ not recorded	739	674	595
Total	**821**	**774**	**778**

The following sections present a detailed breakdown of this information based on 2014 figures. This data pertains to adults with a learning disability and/or autism who are known to services. It should be noted that the figures presented below are based on a breakdown of the total figure of 778.

3.13.1 Gender of people with a learning disability and/or autism who are known to services in West Lothian

Of the 778 people known to services, 436 are male and 342 are female, which is presented in the figure below.

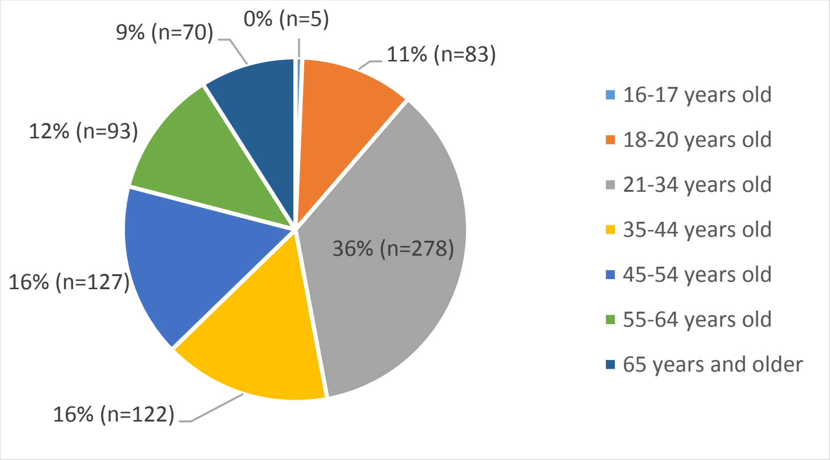
Figure 3.27: People with a learning disability and/or autism known to services in West Lothian – by gender



3.13.2 Age of people with a learning disability and/or autism who are known to services in West Lothian

Figure 2.27 indicates that, of the people known to services, most are from the age bracket 21-34 years (36%; n=278). The ages of all known individuals are presented in the chart below.

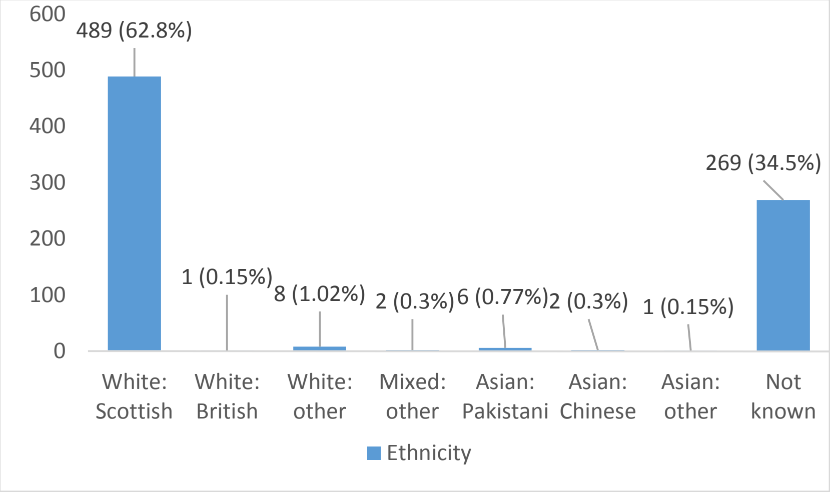
Figure 3.28: People with a learning disability and/or autism known to services in West Lothian – by age



3.13.3 Ethnic background of people with a learning disability and/or autism who are known to services in West Lothian

Of those known with a learning disability most are described as ‘White Scottish’ (n=489; 62.8%). For 269 (34.5%) individuals ethnicity is not known. Figure 2.28 below illustrates the further breakdown of ethnicity for those in West Lothian.

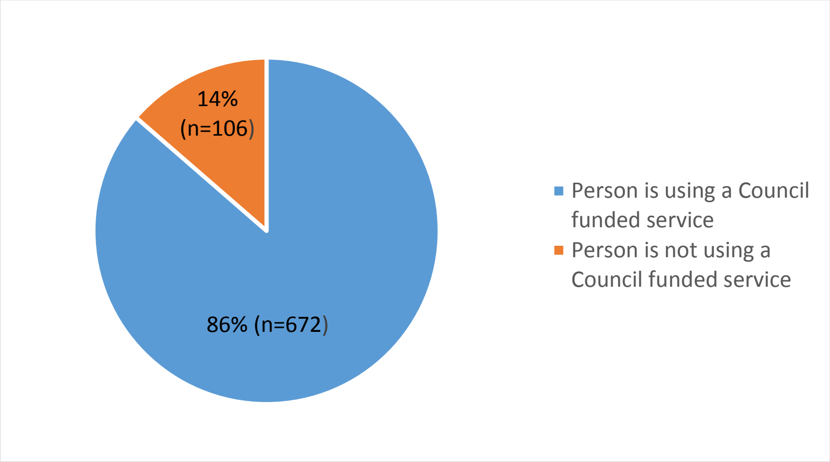
Figure 3.29: People with a learning disability and/or autism known to services in West Lothian – by ethnicity



3.13.4 Type of service used by people with a learning disability and/or autism who are known to services in West Lothian

The figure below reveals that most individuals in West Lothian use a service which is funded by the council (86%; n=672), whereas 14% (n=106) use a service which is not funded by the council.

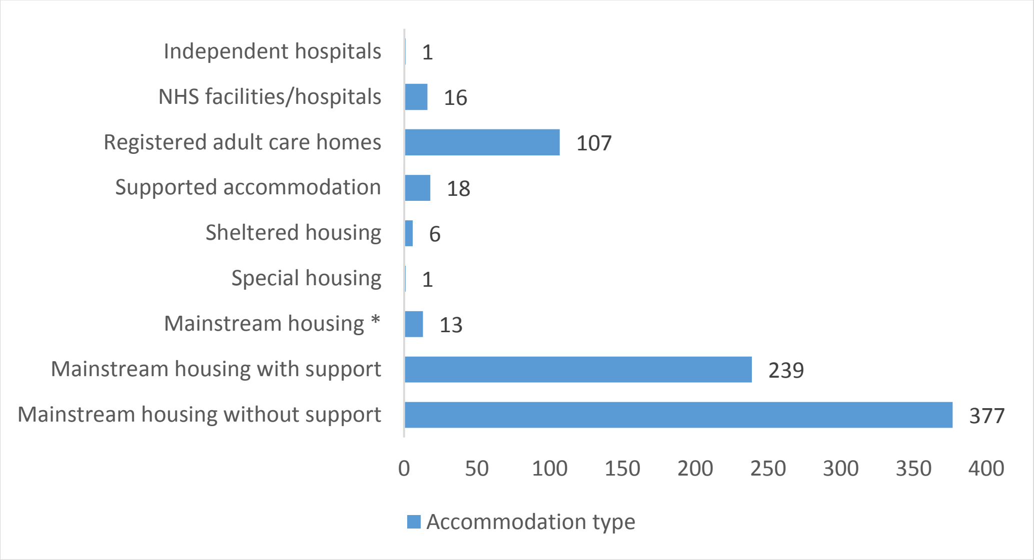
Figure 3.30: People with a learning disability and/or autism known to services in West Lothian – by type of service



3.13.5 Accommodation type used by people with a learning disability and/or autism who are known to services in West Lothian

The figure below shows that the accommodation type used by most people known to services in West Lothian is 'Mainstream housing without support (n=377; 48%).

Figure 3.31: People with a learning disability and/or autism known to services in West Lothian – by type of accommodation



*Mainstream housing, support status unknown

3.13.6 Day centre and alternative opportunities used by people with a learning disability and/or autism who are known to services in West Lothian

20% (n=169) people with a learning disability and/or autism who are known to services in West Lothian, attend a day centre which mirrors figures at the national level (20%; n=5,287). When it comes to alternative opportunities, the figure rises with 33.5% of these adults in West Lothian having access to alternative opportunities, which again is slightly lower than national figures (35.2%, n=9,250).

3.13.7 Employment of people with a learning disability and/or autism who are known to services in West Lothian

Of those people with a learning disability and/or autism who are known to services across West Lothian, 48 are currently in employment or training for employment which is demonstrated in the figure below. There are also 21 people in volunteer roles. Nationally, there are currently 3,444 adults with learning disabilities in employment or training for employment, which is an increase of 1.5% from 2013 figures (3,393).[184] The figure below reveals that of those in employment in West Lothian, 16 of these are in 'open employment'[185], whereas 23 are in 'non-open employment'.[186]

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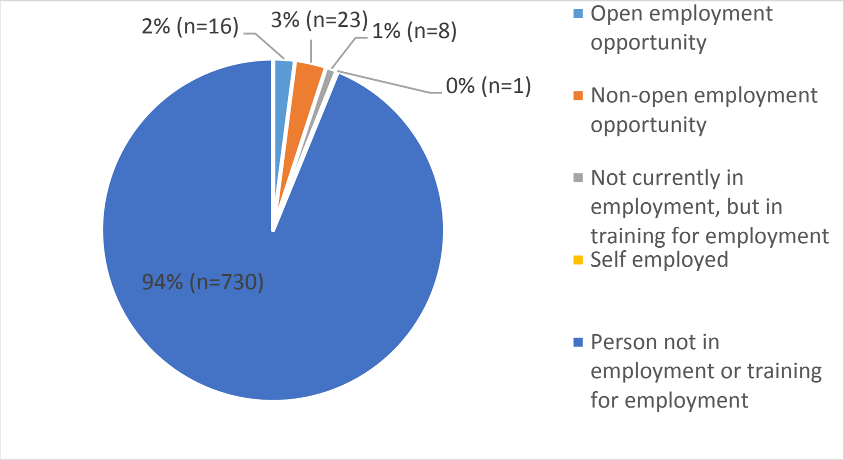
[184] Scottish Consortium for Learning disability. 2014, op.cit.

[185] The workplace is specifically set up for people with learning disabilities. Non-open posts are not usually advertised.

[186] Employment in a workplace that is not specifically set up for people with learning disabilities. People with learning disabilities are paid the going rate for the job.

Figure 3.32: People with a learning disability and/or autism known to services in West Lothian – by employment



3.13.8 Further education of people with a learning disability and/or autism who are known to services in West Lothian

A total of 28 people (3.6%) with a learning disability and/or autism who are known to services across West Lothian are in further education in West Lothian. In Scotland, 2,224 adults (8.5 %) with a learning disability and/or autism who are known to services were known to be enrolled in further education in 2013, which is a decrease of 7.6% from 2012 figures (2041). Of those in further education, 994 adults with attend further education for 2.5 days per week a 22% decrease from 2012 figures (1,279), whereas 915 attend further education for 3 days a week or more.[187] The table below reveals a breakdown of hours in education for the identified adults in West Lothian.

Table 3.33: People with a learning disability and/or autism known to services in West Lothian – by hours in education

Time in Education	Frequency
In education, amount of time not specified	1
In education, 0.5 days per week	6
In education, 1.5 days per week	5
In education, 3 days per week	1
In education 3.5 days per week	15

3.13.9 Local Area Co-ordination (LAC)

Of those people with a learning disability and/or autism who are known to services across West Lothian, 6.8% (n=53) use a LAC service. When compared to national figures, West Lothian figures are

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[187] Scottish Consortium for Learning disability. 2014, op.cit.

much lower with 12.6% (n=2,470) of adults in Scotland, who had access to a LAC service, using this service.[188]

3.14 Key Findings

In West Lothian:

- The 2014 mid-year population estimates is 177,150. Current projections are estimating an overall population increase of 11.7 % by 2037 (n=196,664).
- Female life expectancy at birth (80.2 years) is greater than male life expectancy (77.5 years).
- 97.5% of the people consider their ethnic group to be 'white' which is higher than national figures (96.1%).
- 13 (6.2%) of West Lothian's 211 datazones are found in the 15% most deprived datazones in Scotland according to the Scottish Index of Multiple Deprivation (SIMD). The most deprived datazone is S01006416, which is found in Bathgate East. It has a rank of 440, meaning that it is amongst the 10% most deprived areas in Scotland.
- Approximately 89,000 people employed, with unemployment figures lower than the Scottish average (5.6% compared to 6.2%).
- In the year to March 2015 there were 1,331 applications made under the Homeless Persons Legislation, a 3.2% increase from 2013-14 figures (1,290) but a 5.7% decrease from 2012-13 (1,412).
- Reports on personal wellbeing are mixed with estimated average figures showing a slight decrease from 2012/13 to 2013/14 in reporting of life satisfaction (2012/13=7.61; 2013/14=7.57) and worthwhile (2012/13=7.83; 2013/14=7.81). Reporting on happiness measures have slightly increased (2012/13=7.46; 2013/14=7.49), whereas overall levels of anxiety have seen a reduction (2012/13=3.15; 2013/14=2.71).
- Based on a prevalence rate of 1.1% in respect of West Lothian this prevalence rate would indicate 1949 individuals with an ASD off all age groups based on the mid-2014 population estimates.
- 31 local authorities provided information on 26,786 adults across Scotland in 2014 to Learning disability Statistics Scotland, which equates to 6.0 people with a learning disability per 1000 people in the general population.
- The Scottish Consortium for Learning disabilities (SCLEARNING DISABILITY, eSay 2014) reports that there are 4,048 in Scotland with as ASD diagnosis who are known to local authorities, most of these adults (n=3,018; 74.6%) have a learning disability and/or autism.
- There are at least 706 people who have a learning disability currently known to services in West Lothian. 18 individuals are recorded as having no learning disability (so will therefore

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[188] Ibid.

have an Autistic Spectrum Disorder), whereas for 54 individuals recorded on the system it is 'not known' whether they have a learning disability or not. The total number of individuals reported to Learning disability Statistics Scotland in 2014 was 778 individuals.

- Of the 778 individuals reported:
    - 436 are male and 342 are female;
    - Most are from the age bracket 21-34 years (36%; n=278);
    - Most are described as 'White Scottish' (n=489; 62.8%);
    - Most individuals in West Lothian use a service which is funded by the council (86%; n=672), whereas 14% (n=106) use services which are not funded by the council;
    - The accommodation type used by most people known to learning disability services in West Lothian is 'Mainstream housing without support' (n=377; 48%);
    - 20% (n=169) people in West Lothian attend a day centre which mirrors figures at the national level (20%; n=5,287). When it comes to alternative opportunities, the figure rises with 33.5% of adults in West Lothian having access to alternative opportunities, which again is similar to national figures (35.2%, n=9,250);
    - 48 are currently in employment or training for employment. There are also 21 people in volunteer roles across West Lothian;
    - A total of 28 (3.6%) are known to be in further education;
    - 6.8% (n=53) use an LAC service.

CHAPTER 4: PROFILE OF CURRENT SERVICE PROVISION

4.1 Introduction

This chapter sets out information on current service provision and is drawn from a variety of sources including data supplied from West Lothian Council, NHS Lothian and information provided (via an online survey), by managers of learning disability and autism services in West Lothian. An online questionnaire was sent to all specialist learning disability and autism service managers in May 2015.

4.2 Current learning disability and autism service provision in West Lothian

Responses to the online questionnaire were received from 23 individuals and correspond to the following organisations:

- Autism Assessment Team;
- Autism Initiatives;
- Ark Housing;
- Barony Housing Association (Waverly Place);
- Community Inclusion Team;
- Community Integrated Care (Lismore);
- Eliburn Support Service;
- Enable (West Lothian Housing Support and Care at Home Service);
- Employment Service (Learning disability Independence Team);
- Housing Support Service (Learning disability Independence Team);
- Key Community Supports (Close Care and Support for Learning disabilities);
- Learning disability Service;
- Leonard Cheshire Disability;
- Livingston Homereach Ltd.;
- Local Area Coordination Service;
- Mears Group Ltd (Edinburgh , Lothian , Borders and Dundee Housing Support Service);
- New Directions West Lothian;
- Pathways;
- Penumbra Supported Living Service;
- Real Life Options (Care home for adults with learning disabilities and housing support and care at home);
- The Action Group;
- The Richmond Fellowship (West Lothian Supported Living Service); and
- West Lothian Befriending Scheme.

Table 4.1 below provides a breakdown of the commissioned services provided by the above organisations across West Lothian. Responses to the online survey were from the managers of these services.

Table 4.1: Breakdown of specialist learning disability and autism services across West Lothian

West Lothian CHCP Services (West Lothian Council and NHS Lothian)	
West Lothian Council	Day Support Services: • Community Inclusion Team • Eliburn Day Centre • Pathways
	Residential Services: • Burnside Residential • Deans House • Letham Court
	Other services: • Autism (Assessment) Team • Learning disability Independence Team – Employment Service • Learning disability Independence Team – Housing Support • Learning disability Service • Local Area Coordination
NHS Lothian	Community Learning disability (Nursing) Team
NON-STATUTORY (COMMISSIONED) PROVIDERS/SERVICES	
Ark Housing	Housing support, care at home and care home services
Autism Initiatives UK	West Lothian services
Barony Housing Association	Waverley Place
Community Integrated Care	Lismore, Millroad and Muir Court Residential Care Homes
Elm Cottage	Residential Care Home
Enable	West Lothian housing support and care at home services
Homereach	Supported accommodation service
Key Housing	Close care and support for learning disabilities (key community supports)
Leonard Cheshire Disability	Respite services
Mears Care Ltd (Glasgow)	Housing support service
New Directions West Lothian	Vision Community Support service and Access2Support service
Penumbra	Supported Living Service

Real Life Options	Care home for adults with LEARNING DISABILITY's and housing support and care at home
The Action Group	Community, tenancy, social, and personal care support
The Richmond Fellowship	Supported living service
Voluntary Sector Gateway	West Lothian befriending scheme

4.3 Response Rate

There was a total of 27 responses. Four responses were deleted; two respondents had repeated attempts at responding to the survey; one respondent only completed the personal information section and one response was deleted as the respondent was answering the question from the same organisation/service as another survey participant.

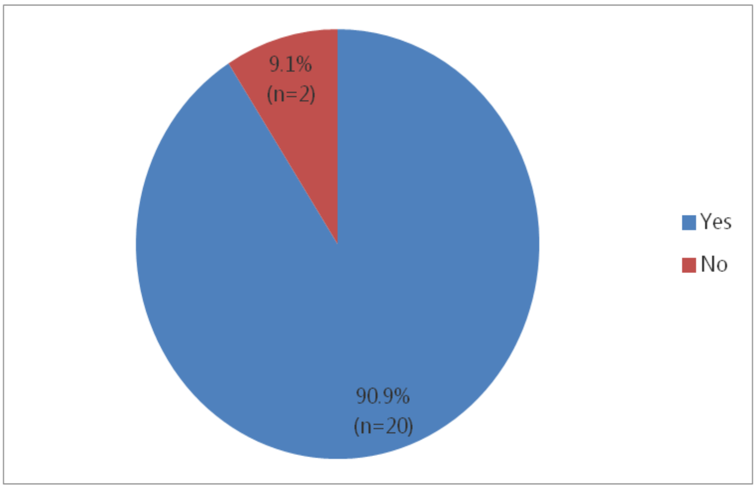
4.4 Service Profile

This section of the report provides factual data on specialist learning disability and autism services currently commissioned in West Lothian.

4.4.1 Locality of services

Respondents were asked to specify whether their service covered all of West Lothian. It can be observed in the figure below, the majority of services covered the whole of West Lothian, with 90.9% (n=20) respondents stating 'yes' in response to this question and only two respondents stated that their service did not cover all of West Lothian.

Figure 4.2: Locality of services



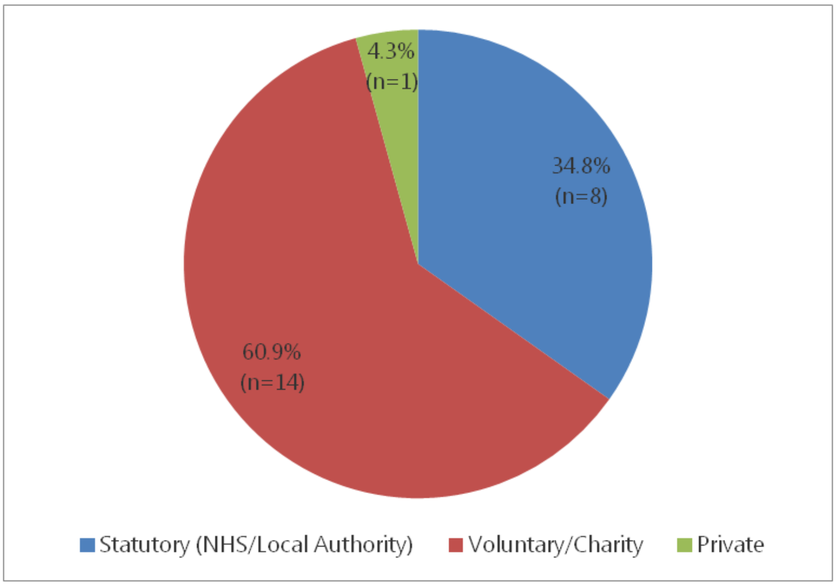
Respondents that answered no this question were asked to provide further details. Their comments are presented below:

> *'Not at present. This is a specific two person service however KEY can and would like to offer services West Lothian wide.'* (Key Community Supports)
>
> *'We are solely based in Armadale.'* (Community Integrated Care - Lismore)

4.4.2 Type of service

Respondents were asked what 'type of service' they were manager of. Just over 60% (60.9%; n=14) of respondents were responsible for a Voluntary/Third Sector/Charity service and just under 35% (34.8%; n=8) were based in Statutory services (NHS/Local Authority). One respondent specified that they worked in a 'Private' organisation.

Figure 4.3: Type of service



4.4.3 Description of service

Managers were asked to provide a brief summary on what their service provides. Their descriptions are presented in the table below:

Table 4.4: Brief description of each service[189]

Service	Service description
Autism Assessment Team	*'Provision of information and consultation on Autism information - assessment of needs and care management for people with a diagnosis of Autism age 16-65 within the West Lothian area.'*

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[189] Source: Management survey conducted by Figure 8.

Autism Initiatives	*'We offer support to people with Autism from the age of 14. We offer varied packages of support. These are personalised to meet individual needs. We support people in their own homes, access community resources such as college, day opportunities and other recreational, employability based programs and social based programmes.'*
Ark Housing	*'Housing Support, care at Home and Care Home Services.'*
Barony Housing Association	*'An intensive housing support and care at home service providing 24 hour support to one man (including waking night cover) and outreach support to another man living upstairs. The rationale for the service is to allow these men to live independently and integrate with their local community whilst keeping them safe, healthy and preventing hospital admission. We would welcome the opportunity to extend our service to support service users throughout West Lothian.'*
Community Inclusion Team	*'CIT provides day support/activities for Adults with Learning disabilities. We are community based utilising a range of community resources i.e. Sports Centre, Libraries and Community Centres. We also have a main admin. Base which also provides 2 Sheltered Workshops. We are viewed as one of the possible alternatives to traditional Day Centres in the area.'*
Community Integrated Care (Lismore)	*'To provide 24 hr support to 4 older individuals with LEARNING DISABILITY in a community based setting.'*
Eliburn Support Service	*'Eliburn Support Service aims to provide a day care service for adults who have a learning disability, associated physical disabilities and complex levels of needs including health care needs the service is for anyone aged between 16 and 65 years old, living in West Lothian who meets the criteria for Eliburn. The service is for people seeking day respite for themselves and/or their family.'*
Enable	*'We support adults with learning disabilities in a variety of ways including support with person care, administration of medication, socialising. Everyone we support has outcomes which we support them with.'*
Employment Service	*'The employment service was created in order to support adults who have a learning disability into paid employment. The service also supports service users to sustain their employment and to look for alternative employment opportunities. The service was initiated to support people with learning disabilities to overcome the additional barriers they encounter when attempting to secure employment.'*
Housing Support Service	*'Housing support, including personal care where required, is provided to adults with a learning disability who have their own accommodation and who need support to continue to live at home. The housing support team can also help adults who have been assessed as needing to move to their own accommodation by supporting them to establish themselves in their new home.'*
Key Community Supports	*'The service KEY provides is designed around the complex needs of two people who had resided in a long term health facility. They both have a learning disability and*

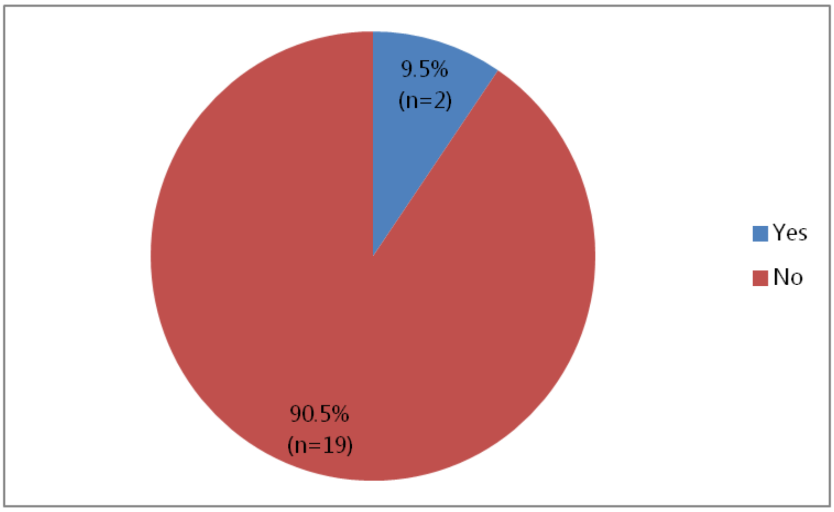
	are on the Autism Spectrum and have been known to challenge services. This service was tendered by West Lothian Council with KEY appointed as the support provider. The service has been operational since early 2014, providing support to the two people in their own home since May 2014.'
Learning disability Service	*'Undertakes assessment and care management for those aged 16 yrs up to 65 who have a learning disability.'*
Leonard Cheshire Disability	*'Respite service for adults with physical and learning disabilities.'*
Livingston Homereach Ltd	*'Livingston Homereach is a Charitable Company set up to offer supported accommodation to adults who have a learning disability. Our overall aim is to ensure that those who use our services have a good quality of life and achieve as many as possible of the things that are important to them.'*
Local Area Coordination Service	*'Working with individuals who have a mild/moderate learning disability to integrate them into their own communities.'*
Mears Group Ltd	*'Support Service for people with learning disabilities to support with all aspects of housing support and to achieve outcome based support.'*
New Directions West Lothian	*'We are registered as a support service without care at home for people aged 16 years - 65 years. We deliver support through 2 different services: 1. Vision Community Support - for people with a learning disability, physical disability, mental health conditions, and acquired brain injury and autism. It is a skills development service teaching independent living-skills, self-travel and group work. 2. Access2Support - for people with a learning disability. This service provides 1:1 support and also offers the opportunity to take part in a 'hub' of social group activities.'*
Pathways	*'Pathways provides a range of meaningful day time activities for a range of adults who have a learning disability and who require additional structure and support to make choices, enjoy life and learn new skills. Activities are carried out both at Quigley House and within the community. The service provides a respite element by providing a regular break for families and carers. The service operates five days per week Monday through to Friday and is open 50 weeks per year closing for Christmas and New Year along with West Lothian Councils designated Public Holidays.'*
Penumbra Supported Living Service	*'To support people who have Mental health/ Learning disabilities in the community to maintain their tenancies. To assist people who use our service to engage with the wider community. To assist people to gain new skills by working in a Recovery focused way which promotes independence.'*
Real Life Options	*'We have one 24 hour registered care home. We support vulnerable adults with disabilities and other service users in care at home basis.'*

The Action Group	*'We provide community, tenancy, social, and personal care support to adults (and children) with any type of support need. We are a voluntary organisation with charitable status.'*
The Richmond Fellowship	*'This service offers a range of supports to individuals with a Learning disability to meet individually specified outcomes. The service delivery ranges from intensive 1 to 1 24/7 support packages supporting individuals to live at home, keep healthy, safe & well and develop independence and enhance community presence to smaller levels of support designed and tailored to support individuals to engage in community activities and education.'*
West Lothian Befriending Scheme	*'Provide trained befrienders for adults (16+) with learning disabilities. To enable them to go out and enjoy the facilities in their local community.'*

4.4.4 Formal partnerships with other organisations

Managers were asked whether their service was in any formal partnership with other organisations. Only two (9.5%) respondents indicated that their service was in any formal partnerships with other organisations, with the remaining stating 'no' to this question (90.5%; n=19).

Figure 4.5: Formal partnerships with other organisations



Respondents that answered yes to this question was asked to provide details, their answers are presented below:

> *'We will be working with West Lothian College in the near future on Project Search. Information can be found on this later in the survey.'* (Employment Service)
>
> *'We work with Health, education and other local based charities and groups.'* (Autism Initiatives)

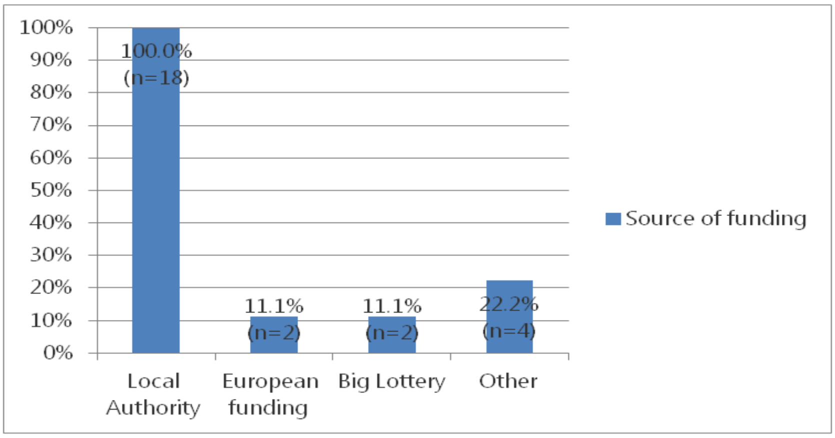
One respondent that indicated 'no' to this question also provided the following commentary:

> *'The team does have partnerships with other organisations but not formal funded agreement. Did have formal partnership with Autism Initiatives and education department within a project called the Autism Transition Project which ended this month (June 2015).'* (Autism Assessment Team)

4.4.5 Sources of Funding

Respondents were asked to specify the funding source(s) of their service. 18 respondents indicated their primary funding comes from the local authority. Four respondents indicated that their primary source of funding is not from the list of options presented to them. One of these respondents reported that approximately 20% of their income comes via service user charging.

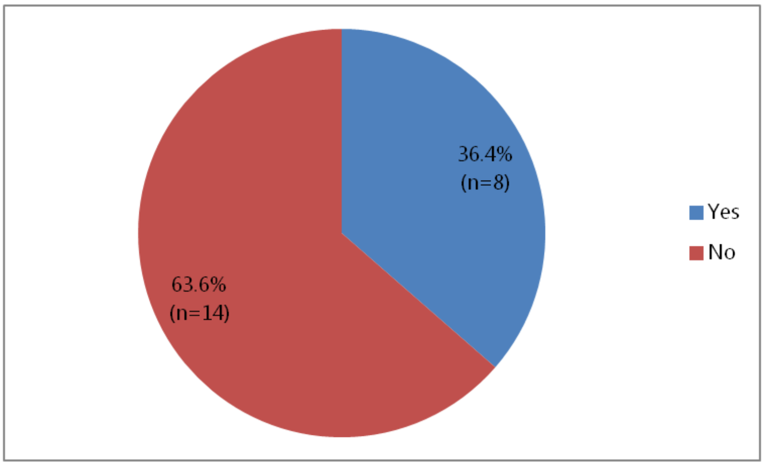
Figure 4.6: Primary source(s) of funding



4.4.6 Service user charging

Respondents were asked to specify whether their service currently charges its service users. Almost two-thirds (63.6%; n=14) of respondents indicated that their service does not charge its service users. Eight respondents (36.4%) indicated that their service does charge service users.

Figure 4.7: Number of services currently charging service users – by percentage



4.4.7 Referral pathways into services and services referred to

Figure 4.8: Referral pathways and services referred to

Service	Referral Pathways and Service referred to
Autism Assessment Team	*'Referral pathway is: first contact and referral is made via the Contact and Referral Team, which then gets passed to the Adults Duty Screener, which then gets passed to myself to screen and place on the Autism Team waiting list, if appropriate. Organisations who refer to the team are: Community Learning disability Team Autism Initiatives Education department West Lothian College No.6 One Stop Shop for Autism Signpost Community Adolescent Mental Health Service Community Education GP's Parents and carers.'*
Autism Initiatives	*'99% of referrals come through social work, we sometimes get referrals from health and from families with own budgets.'*
Ark Housing	*'Social Work Health Board / N.H.S. Self-Directed Support Self-Referral.'*
Barony Housing Association	*'Via West Lothian Council, although we would accept self-referrals from individuals, or their representatives, who have opted to manage their own SDS budget.'*
Community Inclusion Team	*'All referrals are as a result of Community Care Assessments carried out by Social Work Team. We have no self-referral system or drop in type service.'*
Community Integrated Care (Lismore)	*'When vacancy arises, social work dept. are aware and they match up person requiring support to the service and people currently being supported.'*
Eliburn Support Service	*'Referrals can be made via Social Work and in conjunction usually with health or education.'*
Enable	*'Referrals come from social work or through ENABLE direct which receives direct referrals from people requesting a service.'*
Employment Service	*'Self-referrals can been made to the service however it is more common that a referral is made from a support worker or other organisation. Initial contact can be made in person, by post, email and telephone. An information pack is then sent to the person and if they wish to proceed, they will return an application form. The majority of referrals are currently made from social policy staff members.'*
Housing Support Service	No comment provided.
Key Community Supports	*'KEY will accept referrals for direct support through any pathway – WLCHCP, direct referrals via Individual Budgets (SDS or referrals from individuals with direct payments. We are also registered to support people with disabilities under the age of 16 years. KEY provides highly personalised, flexible services therefore would*

	design a service around the needs and wishes of the person and the information provided by their other key stakeholders.'
Learning disability Service	*'Referrals are made via: contact and referral team (social work) by letter.'*
Leonard Cheshire Disability	*'Referrals come from West Lothian Council.'*
Livingston Homereach Ltd	*'Notify vacancy to WLC Social Policy.'*
Local Area Coordination Service	*'All referrals are received through the Social Policy Contact and referral team and screened by team managers.'*
Mears Group Ltd	*'Social Work referrals.'*
New Directions West Lothian	*'VCS - Referral is made through social work.* *A2S - Referral is made through social work, through individuals who under SDS have opted for own control over their budget and also through a private arrangement.'*
Pathways	*'All referrals to Pathways are made through West Lothian Councils Social Policy Community Care Assessment Team. Any informal enquiries made by Parents/Carers to Pathways are directed to the Assessment Team.'*
Penumbra Supported Living Service	*'All referrals come to us through Social Work department at the present time.'*
Real Life Options	*'Local Authority Referral.'*
The Action Group	*'Most of our business in West Lothian is from the Social Work Department. We also have service users who come us directly with ILF, DP, and trust funds.'*
The Richmond Fellowship	*'Referrals received are from Social Workers, Community teams, individuals, families and SDS.'*
West Lothian Befriending Scheme	*'Users can self-refer but 99% are referred through the social work department.'*

4.5 Service User Profile

Data was sought from all commissioned services (period April 2014 – March 2015), in relation to:

- Referral activity;
- Numbers engaged with the service;
- Number of 'Did Not Attends'; and

- Discharge activity.

Local Authority and NHS services were unable to provide the data in the format requested. Local Authority data is kept on the SWIFT database. The Social Policy Team, who maintain the SWIFT database, were able to provide a series of reports, which have been used in the following sections and previously, in Chapter 3 (Epidemiology).

The data received from the commissioned services is presented in the table below:

Table 4.9: Referral, Engagement, DNA and Discharge Activity – by commissioned service

	Ark Housing	Autism Initiatives	Barony Housing	CIC Lismore	Enable	Homereach	Key Housing	Leonard Cheshire Disability	Mears Care Ltd	New Directions- VCS*	New Directions- A2S**	Penumbra	Real Life Options	The Action Group	The Richmond Fellowship	Voluntary Sector Gateway
1a. Total no. of referrals	4	4	0	0	5	0	2	3	0	47	17	1	0	17	7	18
1b. Of which how many were appropriate referrals?	4	4	N/A	N/A	4	N/A	2	3		47		1	0	4	6	18
1c. How many were self-referrals?	1	0	0	N/A	0	N/A	0	0	0	0	0	0	0	1	0	2
1d. How many were 'returning' contacts?	N/A	0	0	N/A	0	N/A	0	0	0	9	0	1	0	1	0	0
2. Total no. of individuals engaged with the service?	4	54	2	N/A	28	5	2	38	14	58	34	16		78	18	41
3. Total no. of DNA's?	N/A	0	0	N/A	0	N/A	0	N/A	0	3	1	0	0	3	0	0
4a. No. of planned discharges from the service?	N/A	0	0	N/A		N/A	0	N/A	0	7	0	2	0	6	2	12
4b. No. of unplanned discharges from the service?	N/A	0	0	N/A	0	N/A	0	N/A	0	5	2	0	0	3	0	5

* New Directions - Vision Community Support

** New Directions – Access 2 Support

Blank spaces in the table represent unanswered questions

4.6 Service Provision

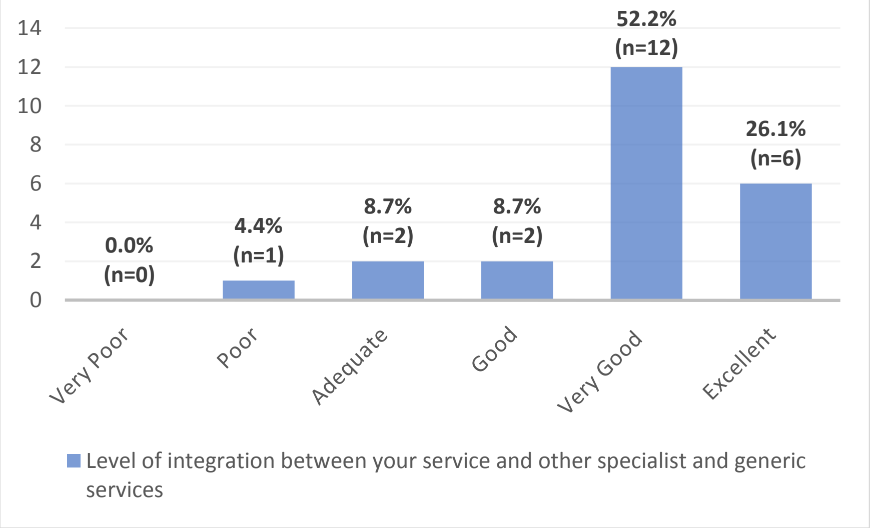
4.6.1 Integration between services and other specialist and generic services

Respondents were asked to rate the level of integration between their service and other specialist and generic services using a six point Likert scale:

- 1= Very Poor
- 2= Poor
- 3= Adequate
- 4= Good
- 5= Very Good
- 6= Excellent

The majority (52.2%; n=12) of respondents rated their service as having a 'Very Good' level of integration between their service and other services. Six (26.1%) respondents rated their service as having 'Excellent' integration, whereas one respondent (4.35%) rated their service as having a 'Poor' level of integration.

Figure 4.10: Level of perceived integration of services with other specialist services and generic services[190]



4.6.2 Involvement of families, carer or significant others

Respondents were asked to rate the level at which their service involved families, carers or significant others in supporting people with Learning disabilities and/or Autism using a six point Likert scale:

- 1= Very Poor

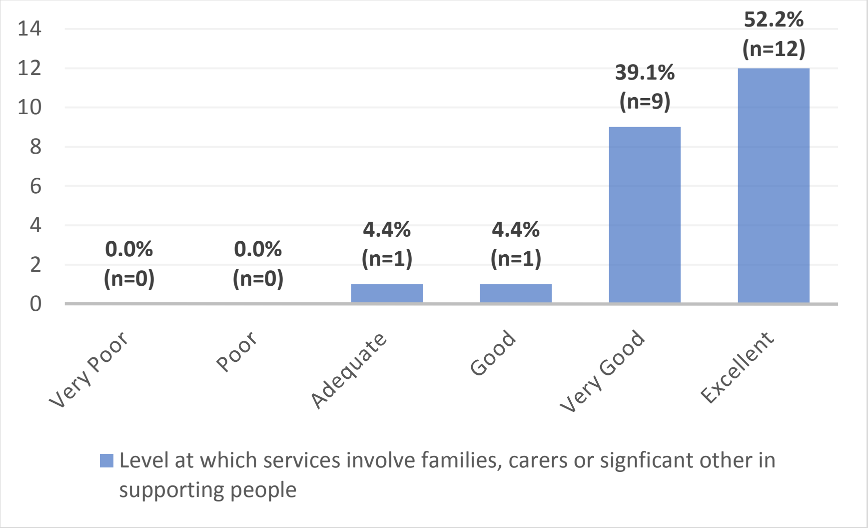
---

[190] Source: Source: Management survey conducted by Figure 8.

- 2= Poor
- 3= Adequate
- 4= Good
- 5= Very Good
- 6= Excellent

The vast majority (91.3%) of respondents rated the involvement of families, carers and significant others as either 'Very Good' (n=9) or 'Excellent' (n=12). Only two respondents out of 23 (8.8%) rated the involvement of families, carers and significant others in their service as being 'Adequate' or 'Good'.

Figure 4.11: Level of involvement of families/carers [191]



4.6.3 Involvement of service users

Respondents were asked to rate the level at which their service involves servicer users using a six point Likert scale:

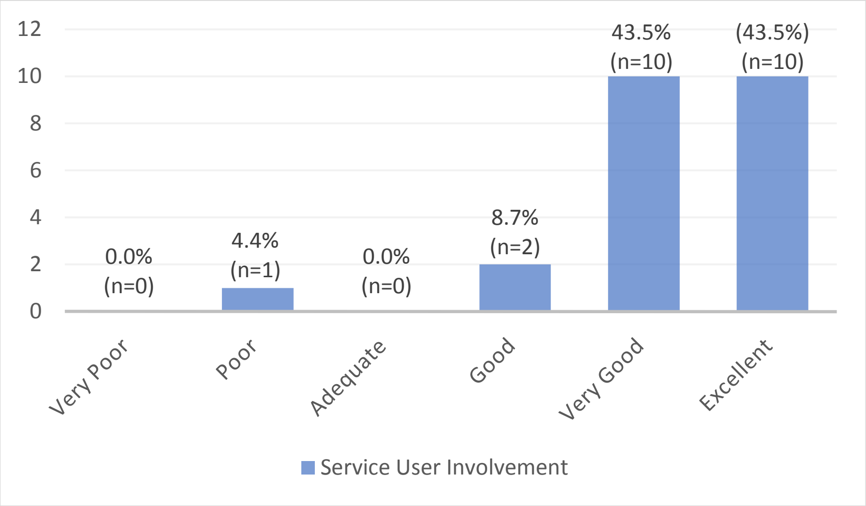
- 1= Very Poor
- 2= Poor
- 3= Adequate
- 4= Good
- 5= Very Good
- 6= Excellent

---

[191] Source: Source: Management survey conducted by Figure 8.

The vast majority (87%) of respondents rated the level of service user involvement in their service as being either 'Very Good' (n=10) or 'Excellent' (n=10), with a further two respondents rating it as 'Good'. Only one respondent (4.4%) rated service user involvement as 'Poor'.

Figure 4.12: Level of involvement of service users[192]



4.6.4 Gaps in services

100% of respondents indicated that there are gaps in services for people with Learning disabilities and/or Autism.

Respondents were asked to provide commentary on the reasons for stating this:

> *'Support to people with very complex needs in the WLCHCP area who still live in health facilities or outwith authority. Further to the above one of the barriers appears to be Housing which meets the very specific needs of people with the most robust and complex needs.'*
>
> *'Evening activities/groups.'*
>
> *'Only one specialist provider for people with Autism in the West Lothian area.'*
>
> *'There are no services for adults with learning disability or complex needs when they are "retired" from day services at 65. This leaves a huge gap in most individual's lives and often struggle to cope without the day to day routine and meaningful purpose that Day centre service provide. It is difficult for current support staff to fill this void in a person's life.'*
>
> *'For people with more complex needs there could be more services.'*
>
> *'We require to better develop our knowledge to respond better to people who have a learning disability but whose dominant requirement might be Autism or as health declines those who have started on the Dementia process.'*
>
> *'Some Service Users have support packages that are too small for their actual needs.'*

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[192] Source: Source: Management survey conducted by Figure 8.

> *'Insufficient advocacy resources due to demand for services. Work placement/supported work type activity.'*
>
> *'Activities in the local area in the evenings and at weekends would be of benefit to a lot of service users.'*
>
> *'People living independently in their own tenancy are very often inadequately supported.'*
>
> *'No services for older people with Autism (social groups) housing services for people with Autism Limited access to further education (Autism specific) college is not suitable for everyone Respite for people with Autism.'*
>
> *'Evening and weekend activities.'*
>
> *'There seems to be a need for more respite services.'*
>
> *'Employment, Placements either voluntary or skill/time specific. College provision.'*
>
> *'There is no designated service for adults with learning disabilities post 65yrs when they retire from Day Services and this can cause isolation and detachment form their community. Here at Eliburn, service users may not reach retirement age due to their medical conditions. There is a lack of health provision for Respite in West Lothian. There could be more support given to families/carers who have their dependant in hospital. Feedback from families and carers have indicated that they have not been supported or listened to when caring for their son/daughter in hospital. More provision for LEARNING DISABILITY nurses to work in General Hospital to care for service users with complex medical care needs. More planning for future living arrangements/residential service for service users moving from family home post a crisis or bereavement of parent.'*
>
> *'I believe that a be-friending service would be useful.'*
>
> *'More provision is required for alternative day opportunities.'*
>
> *'Not enough activity based events/ venues for people to attend.'*
>
> *'Young people in transition.'*

4.6.5 Overprovision of services

When asked if there are any areas of overprovision of services for those with Learning disabilities and/or Autism, only one respondent (5.26%) who answered the question answered affirmatively. This respondent feels there is overprovision in relation to:

> *'Small groups for children with learning disability and Autism.'*

4.6.6 Views on future priorities

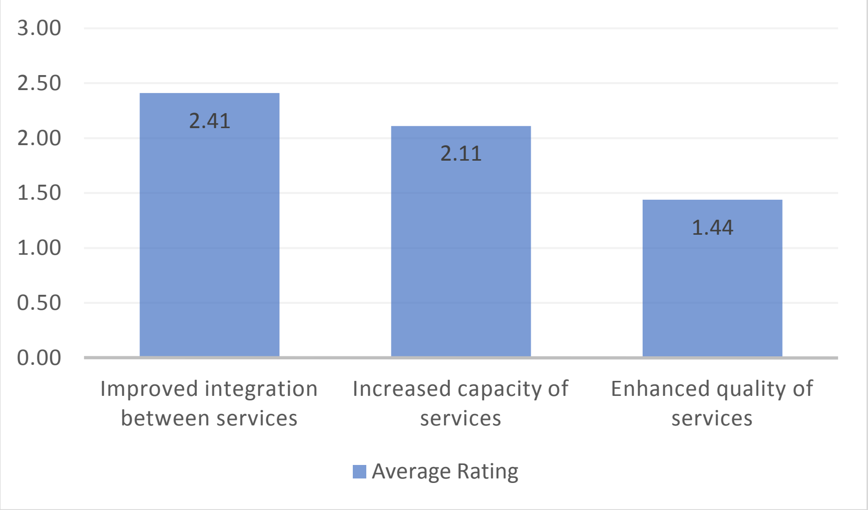
Respondents were asked to rate some statements in order of importance in relation to preferred future priorities. Statements were in regard to integration, capacity and quality of services.

The rating scale was:

- 1= Most important
- 3= Least important

The statement which was rated the most important was ‘Improved integration of specialist services and other services’ (65%; n=11). The statement rated the least important was ‘Enhanced quality of specialist services (41%; n=7).

Figure 4.13 Future priorities - statements rated in order of important: 1= Most important; 3= Least Important [193]



Additional comments provided were:

> *‘I believe that services should provide a high quality and should not act alone dovetailing between all services that an individual may access with this in mind each individual would not be dependent on one service on its own and as a result support given through a wide network not to the extent of increasing the capacity of one service alone.’*
>
> *‘Funding pressures are putting increasing strain on providers and endangering both quality and capacity of services.’*
>
> *‘Workers are often frustrated by poor communication between services and hampered by delays in accessing services.’*
>
> *‘Public transport in west Lothian needs looked at. Especially connecting the small towns and villages around is a nightmare. Because of transport network people with learning disability will always struggle to self-travel. There are no direct connections between towns or links with Edinburgh the bust to Edinburgh takes 2 hrs from some areas in west Lothian. Too much time for someone who struggles with public transport.’*
>
> *‘There are real issues with recruitment and being able to recruit suitable qualified and competent staff to develop a credible work force. Transport links also affect this as staff are unable to commute to and from work. The use of block contracts and service users not being*

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[193] Source: Source: Management survey conducted by Figure 8.

individually assessed creates a culture that does not support individualism and person centred approaches. There is a need for more placements in West Lothian so people do not have to move out of their chosen area.'

CHAPTER 5: CORPORATE APPROACH (NORMATIVE OR EXPERT)

5.1 Introduction

The purpose of this element of the research was to seek the views from key professional stakeholders on the current provision of specialist learning disability and autism services across West Lothian. Specifically, study informants were asked to provide their views on the quality of services, key issues, gaps and areas for improvements.

Findings in the first part (**5.2-5.7**) of this chapter derive from quantitative online surveys which were distributed to learning disability and autism service staff across West Lothian during June 2015.

Findings in the second part of this chapter (**5.7-5.14**) primarily derive from the main qualitative elements of the study:

- A stakeholders event held on 20th May 2015 with 42 participants;
- Two Working Group sessions held on 27th May 2015 and 5th June 2015;
- 12 interviews with professional and wider stakeholders held between May and June 2015; and
- One focus group held with staff from the WLCHCP Community Learning disability Team.

5.2. Response rates

There were 92 responses to staff survey, of which three were discarded as respondents completed less than 25% of the survey. The overall total of responses used for analysis was therefore 89, broken down as follows:

- 9 out of one 89 (10.1%) responses were deemed ‘complete’, as 100% of questions were answered by respondents.
- 80 out of one 89 (89.9%) responses were considered ‘incomplete’, as:
    - 24 of 80 respondents completed 50%-99% of the survey;
    - 56 of 80 respondents completed 25%-49% of the survey.

5.3 Limitations

- All the services listed in the previous Chapter (Table 4.1, Section 4.2) were sent the link to the online staff survey and invited to participate. Varying levels of responses were received as shown in Figures 5.1 and 5.2 below.
- The services completing the survey represent a broad range of organisations (statutory and non-statutory), type of service (community based and residential) and size of service (from small to large), so results need to be read with these variances in mind.
- It should also be noted that some of the residential services are located outwith West Lothian.

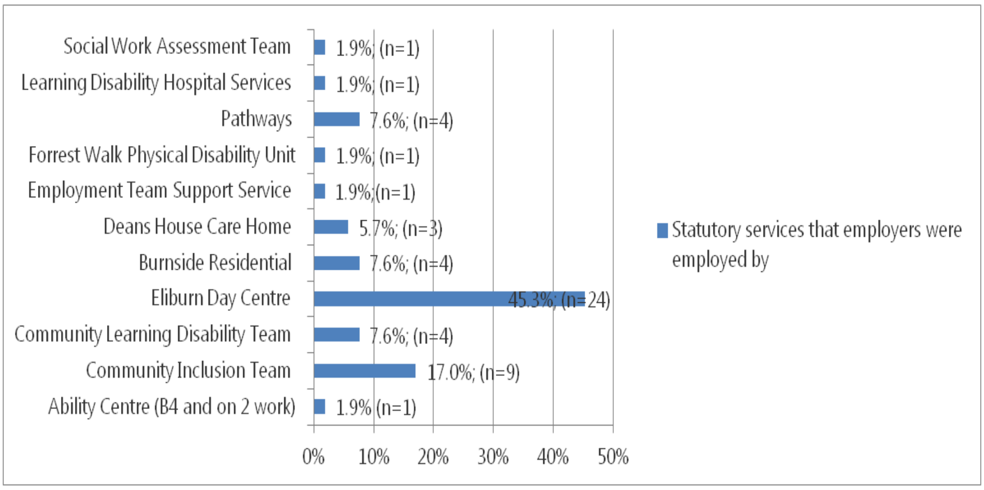
- Care needs to be taken when interpreting findings as there were a number of questions which had varying levels of response rates.

5.4 Service Information

5.4.1 Statutory Services

Respondents were asked to indicate what statutory services they were employed by. The majority of respondents were employed by Eliburn Day Centre (45.3%; n=24) and 7.6% (n=9) of respondents were employed by Community Inclusion Team.

Figure 5.1: Breakdown of respondents by employment in Statutory Services



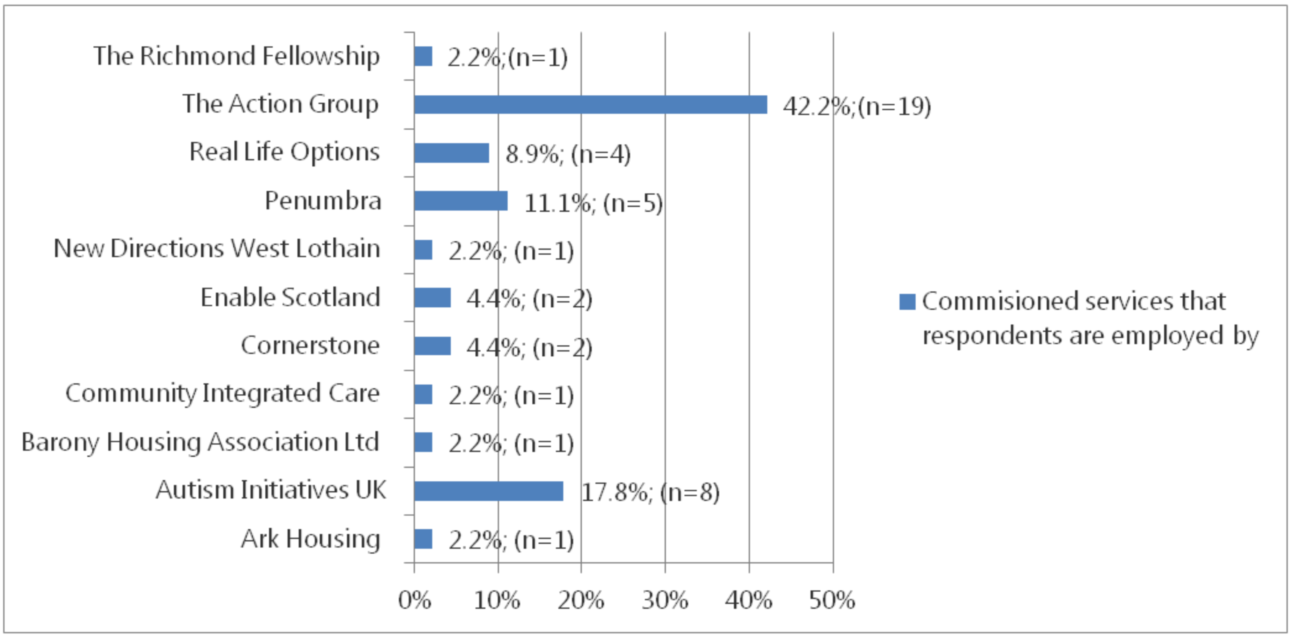
There were no respondents employed by the following services:

- Letham Court; or
- Local Area Coordination Team.

5.4.2 Commissioned services

Respondents were asked to indicate what commissioned services they were employed by. Just over 40% of respondents were employed by 'The Action Group' (42.2%; n=19). Responses are presented in the figure below.

Figure 5.2: Breakdown of respondents by employment in Commissioned Services



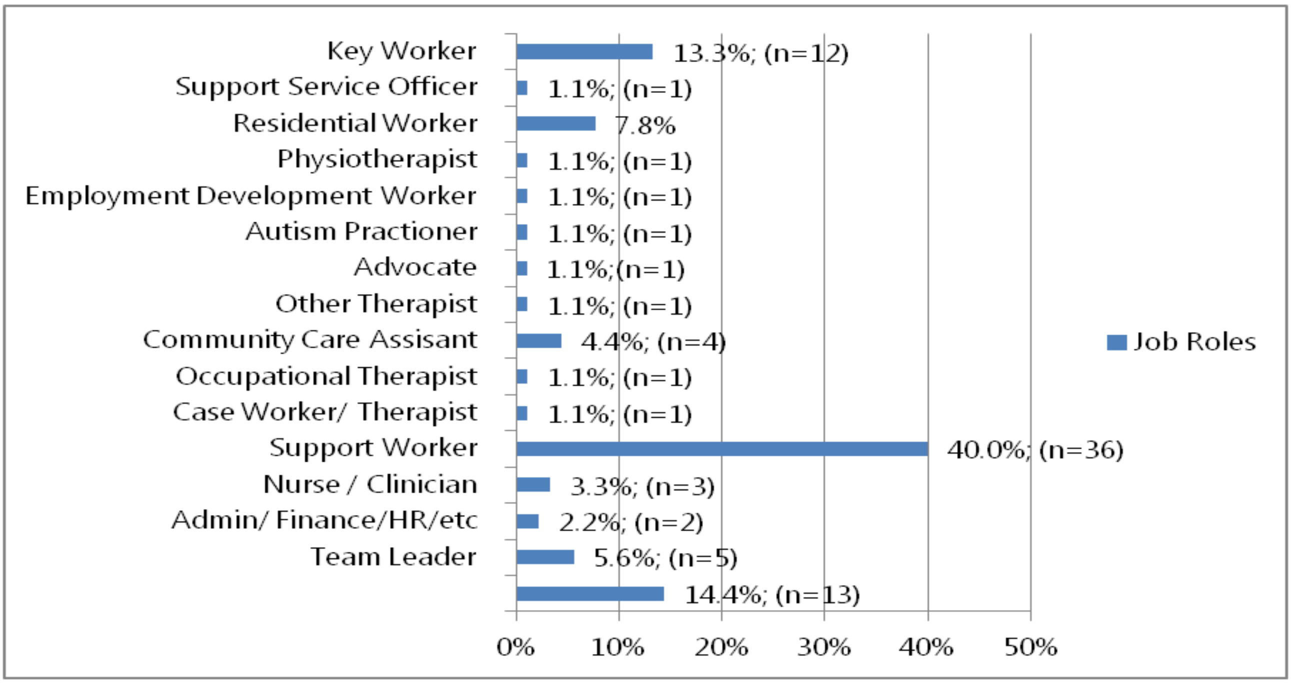
There were no respondents from the following services:

- Homereach;
- Key Housing Association;
- Leonard Cheshire Disability Ltd;
- Place for People;
- Quarriers;
- Scottish Autism; or
- Voluntary Sector Gateway - Befriending Service.

5.4.3 Job Role

Respondents were asked to indicate what their job role was in the service which they work for. The majority of respondents were support workers. (40%; n=36) and 12 (13.3%) respondents indicated that they were key workers.

Figure 5.3: Breakdown of respondents by job role



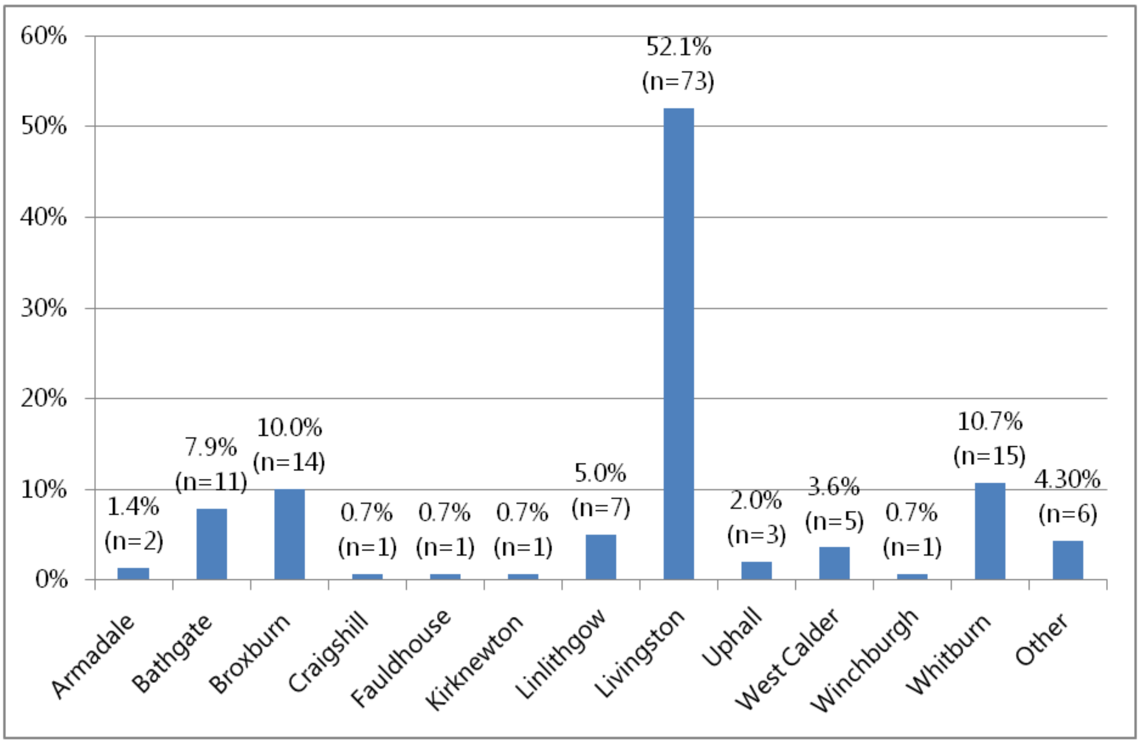
There were no respondents who indicated that they were in the following job roles:

- Social Worker
- Psychologist
- Counsellor
- Speech and Language Therapist
- Occupational Therapist Assistant
- Art Therapist
- Music Therapist

5.4.4 Locality

Most of the services for learning disabilities and/or Autism Disorders are located in Livingston (n=73), this was followed by Whitburn, with 11.2% (n=15) of respondents indicating that their services are in this locality. Respondents were able to choose more than one option.

Figure 5.4: Services by locality in West Lothian



Of the six respondents that that indicated that their service locality was in another area:

- Five respondents had stated that their service covered all of West Lothian; and
- One respondent stated that their service is based in Edinburgh and Lothian.

5.5 Quality of Services

5.5.1 Service ratings

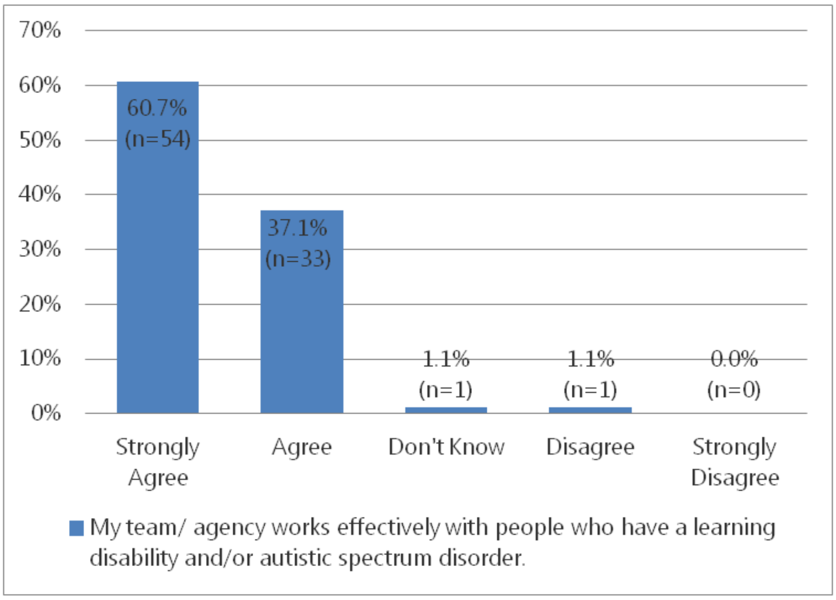
Respondents were asked to specify how much they agreed or disagree with a set of 13 statements. A breakdown of respondent's agreement/disagreement is presented in the figures below:

Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/ agency works effectively with people with a learning disability and/or autistic spectrum disorder.'*

The majority of respondents strongly agreed (60.7%; n=54) or agreed (37.1%; n=33) with this statement.

Figure 5.5: Statement 1

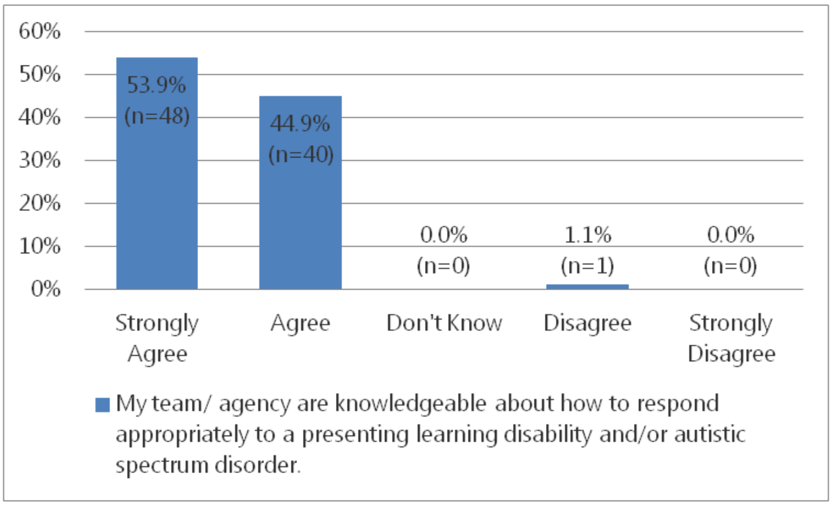


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency are knowledgeable about how to respond appropriately to a presenting learning disability and autistic spectrum disorder.'*

The majority of respondents strongly agreed (53.9%; n=48) or agreed (44.9%; n=40) with this statement. One (1.1%) respondent disagreed with this statement.

Figure 5.6: Statement 2

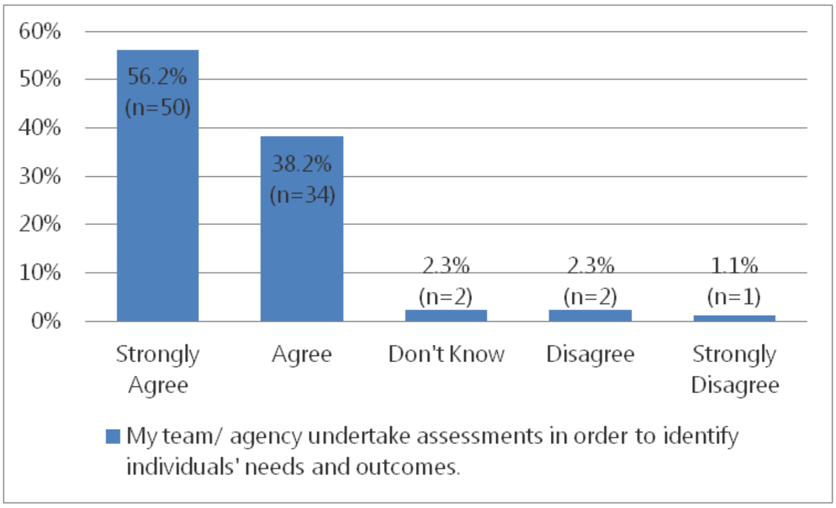


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency undertake assessments in order to identify individuals' needs and outcomes'.*

The majority of respondents strongly agreed (56.2%; n=50) or agreed (38.2%; n=34) with this statement. Two respondents (2.3%) responded 'Don't Know', two (2.3%) respondent stated that they disagreed and one (3.6%) respondent strongly disagreed with this statement.

Figure 5.7: Statement 3

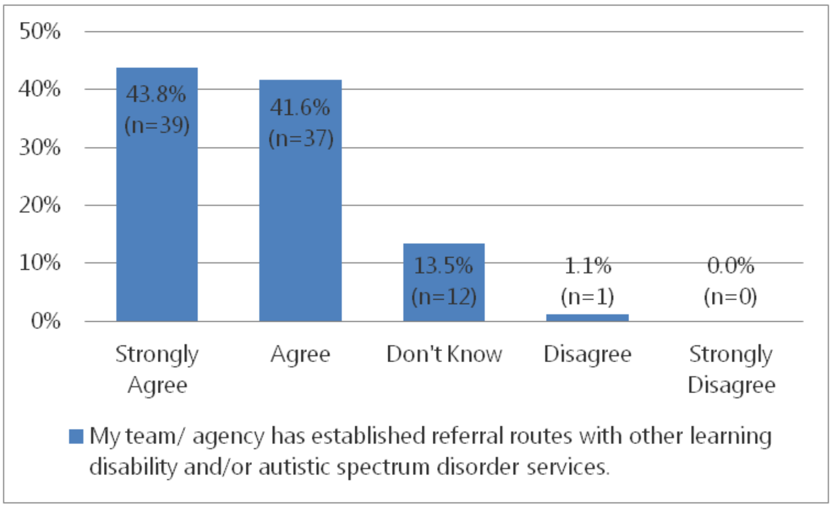


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency has established referral routes with other learning disability and/or autistic spectrum disorder services.'*

The majority of respondents 'Strongly Agree (d)' (43.8 %; n=39) or 'Agree (d)' (41.6%; n=37) with this statement. 12 respondents (13.5 %) responded 'Don't Know'.

Figure 5.8: Statement 4

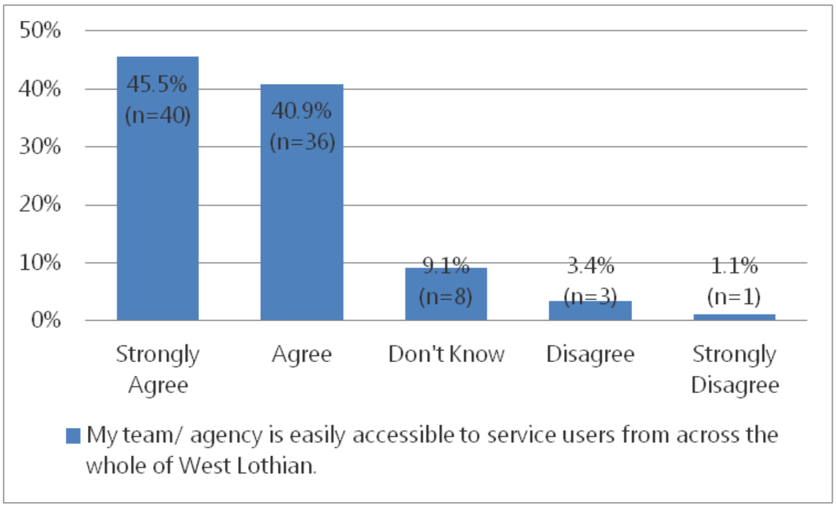


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency is easily accessible to service users from across the whole of West Lothian.'*

The majority of respondents strongly agreed (45.5 %; n=40) or agreed (40.9 %; n=36) with this statement. Eight respondents (9.1 %) responded 'Don't Know'.

Figure 5.9: Statement 5



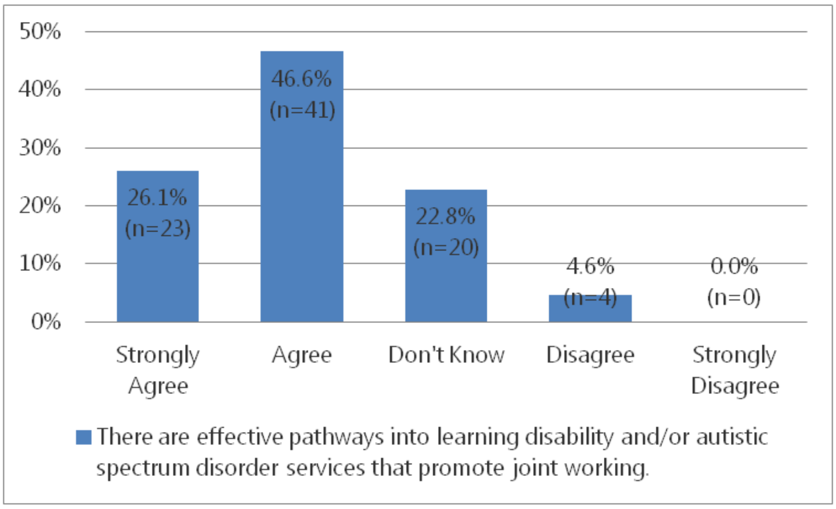
Respondents were asked how much they agreed or disagreed with the statement:

> *'There are effective pathways into learning disability and/or autistic spectrum disorder services that promote joint working.'*

Respondents were asked how much they agreed or disagreed with the statement:

A large (46.6%; n=41) proportion of respondents stated that they agreed with this statement. 22.8% (n=20) of respondents responded 'Don't Know'.

Figure 5.10: Statement 6

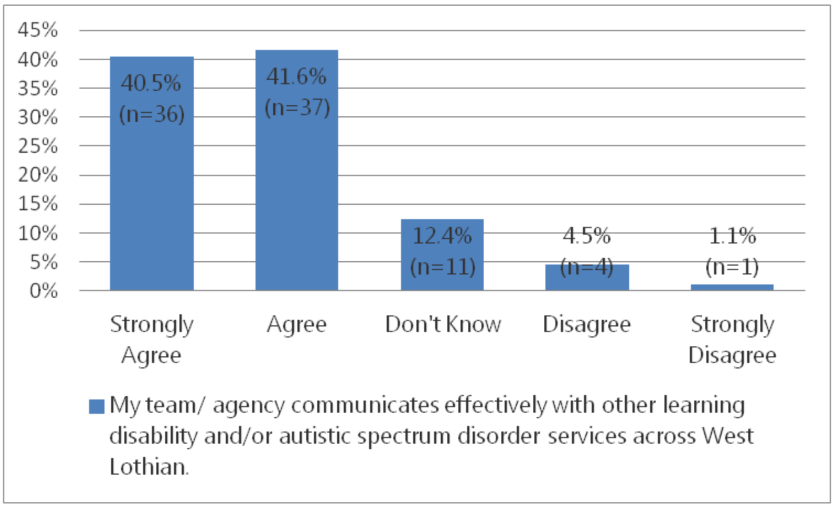


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency communicates effectively with other learning disability and/or autistic spectrum disorder services across West Lothian.'*

40.5% (n=36) of respondents strongly agreed with this statement, with a similar (41.6%; (n= 37) percentage of respondents also indicating that they agreed with this statement. 11 respondents responded 'Don't know' to this statement.

Figure 5.11: Statement 7

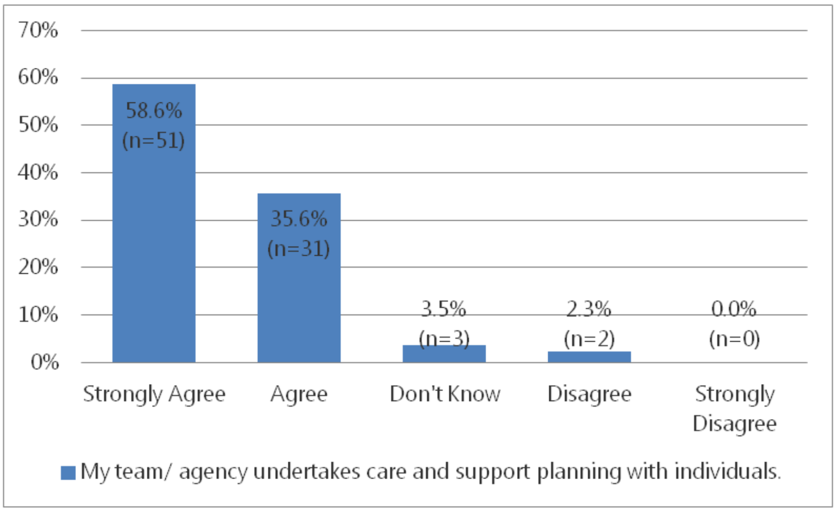


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency undertakes care and support planning with individuals.'*

Almost 60% (58.6%; n=51) of respondents strongly agreed that their team agency undertakes care and support planning with individuals. Just over 35% (35.6%; n=31) of respondents agreed with this statement and a further three (3.5%) stated they didn't know and two (2.3%) respondents disagreed with this statement.

Figure 5.12: Statement 8

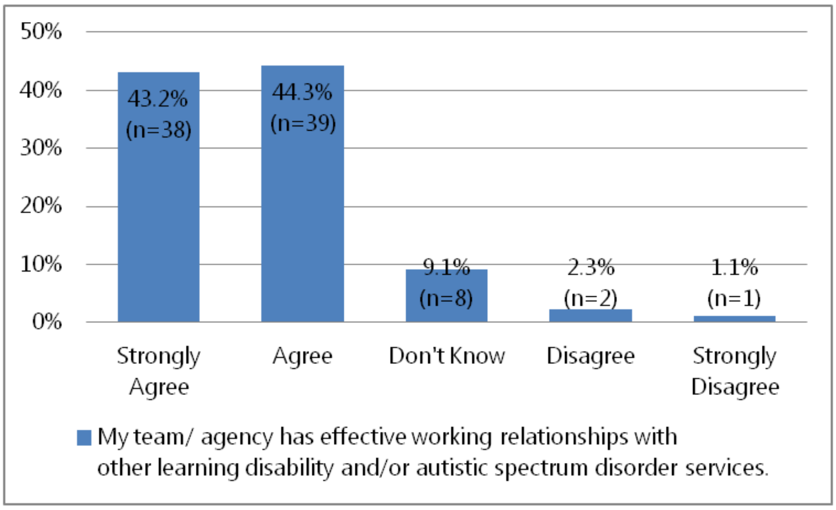


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency has effective working relationships with other learning disability and/or autistic spectrum disorder services.'*

There was a similar proportion of respondents that strongly agreed (43.2%; n=38) and agreed (44.3%; n=38) with this statement. Eight respondents stated that they didn't know and two (2.3%) respondents disagreed with statement. One (1.1%) respondent strongly disagreed.

Figure 5.13: Statement 9

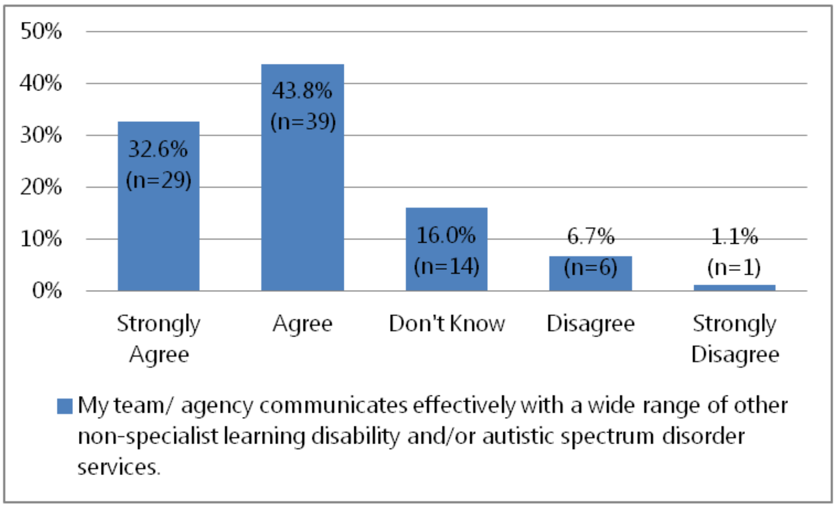


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency communicate effectively with a wide range of other non-specialised learning disability and/or autistic spectrum disorder services.'*

There were some discrepancy between respondents with the extent to which they agreed/disagreed with this statement, though the vast majority of respondents either strongly agreed (32.6%; n=29) or agreed (43.8%; n=39) with this statement. 14 (16%) respondents stated they didn't know, six (6.7%) respondents disagreed and one (1.1%) respondent strongly disagreed.

Figure 5.14: Statement 10

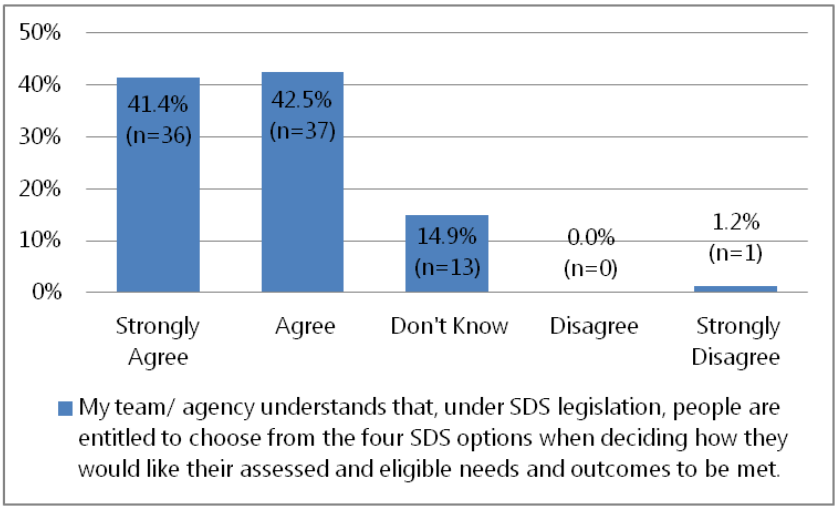


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/ agency understands that, under SDS legislation, people are entitled to choose from the four SDS options when deciding how they would like their assessed and eligible needs and outcomes to be met.'*

Most respondents either strongly agreed (41.4%; n=36) or agreed (42.5%; n=37) with this statement. 13 (14.9%) respondents stated 'Don't Know'. One (1.25) of respondents strongly disagreed with this statement.

Figure 5.15: Statement 11

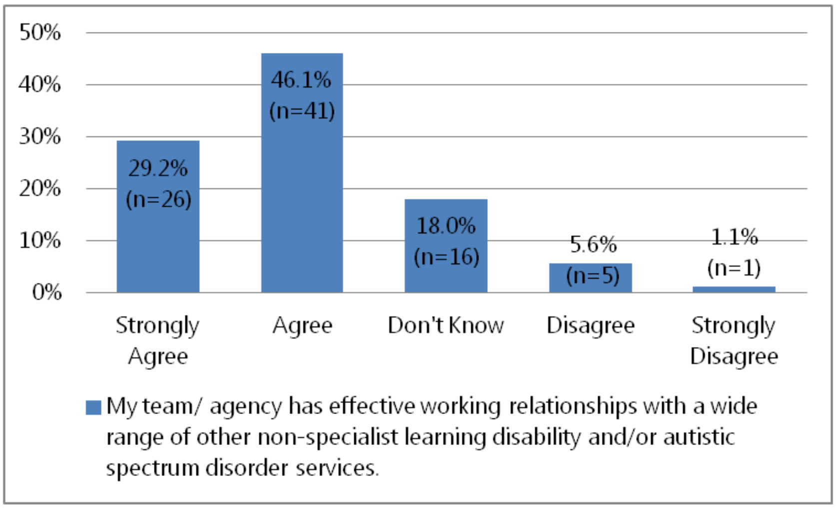


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency has effective working relationships with a wide range of other non-specialist learning disability and/or autistic spectrum disorder services.'*

From figure below, it can be observed that there was difference in the extent to which respondents were in agreement/disagreement with this statement. The majority of respondent were in agreement with this statement, with 46.1% (n=41) agreeing and a smaller proportion of respondents strongly agreeing with this statement. However, 5.6% (n=5) respondents disagreed and one (1.1%) respondent strongly disagreed. 16 respondents were not sure about this statement and stated 'Don't Know'.

Figure 5.16: Statement 12

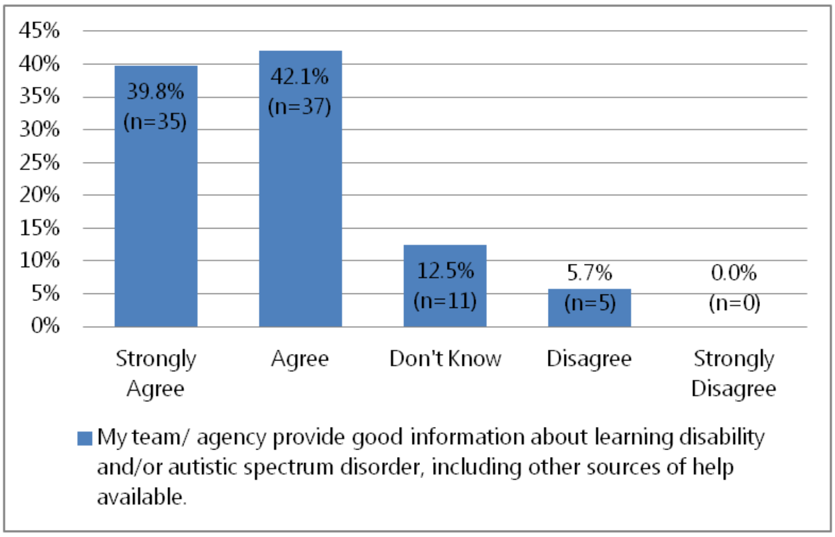


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency provide good information about learning disability and/or autistic spectrum disorder, including other sources of help available.'*

37 (42.1%) respondents agreed with this statement, a further 35 (42.1%) respondents strongly agreed. Five (5.7%) respondents disagreed with this statement.

Figure 5.17: Statement 13



5.5.2 What services do well?

Respondents were asked what they thought their team/agency did particular well. There were 62 responses and responses are broken down by the services respondents were employed by:

Figure 5.18: What services do particularly well

Service Name:	Comments:
Ability Centre (B4 and on 2 work)	*'Meets the needs of the client group treats all fair and with respect.'*
Action Group	*'Organises support, keeps clients connected to community.'* *'At home and social support.'* *'My team is particularly good at promoting the independence of every service user, in a way that's appropriate for them as individuals. My team is effective at delivering a wide range of caring support to our service users in a way that consistently promotes their dignity, rights and their choices.'* *'Support is very person centred. Support staff work very hard to build up trust and good relationships with service users.'* *'Providing a great quality of support to service users and families, listening to individual needs and promoting independence. Showing compassion to those we work with and striving to enhance quality of life and the development of social skills. Our team is flexible in accommodating service user's needs, and is always keen to try new ideas to better support.'* *'I feel we meet the individual needs of a service user well. We also know each service user very well to.'* *'Provides a regular support team to each person so they have a strong group of people they trust.'* *'Be supportive in communication with the staff.'* *'I think we communicate well with our service users well with newsletters, service user lead groups and service user lead group planning. Service user files are person centred as is their support.'* *'I think that my team is incredibly flexible in responding to the needs of the individuals we support. We change the way we work to meet the changing needs of the people we support. We work well with other support providers often in conjunction with the same service user. We also offer additional opportunities for individuals we support out with their regular support. We have an events committee run by service users who come together and organize outings and events on a monthly basis. If required the events committee will carry out some fundraising to help with the cost of some of the chosen outings. We also run a Weekly Healthy Living group to give people more opportunities to meet others, socialize and learn how to take care of themselves. This is open to anyone who receives support.'* *'Providing support the user needs and wants.'*
Autism Initiatives	*'Provides great training, has a fantastic approach in dealing with people with autism ('the autism initiatives way').'* *'I feel our team listens to the Needs of Service Users. We understand what needs to be identified by communicating with our service users to ensure*

	they set goals that They want to achieve in small easy steps which make it more manageable.' *'Listens to the service user and their families.'* *'Helps young people with Autism to feel valued.'* *'Helping our service users take ownership of their own package of support and to maintain that they are continuously learning and developing new skills.'* *'Specialist support and care Sharing of knowledge.'*
Burnside Residential	*'Communicating with other agencies.'* *'Promote independence.'*
Community Inclusion Team	*'Person centred planning/care/support.'* *'Supporting and offering activities to our clients.'* *'Provide a safe environment. Offer a good variety of activities.'* *'Work together in order to provide a consistent approach and level of day service provision to our service users that meet individual needs. We also strive to empower our service users to realise and achieve realistic goals towards meeting their individual personal development and skills.'* *'Promotes service users choice.'* *'Provides a wide range of activities for service users.'*
Community Learning disability Team	*'We provide specialist services and work well as a close MDT. We also have good informal links with SW. We aim to meet a wide range of client's needs (complex, PMLEARNING DISABILITY).'* *'Makes sure people we look after can have as fulfilled and meaningful life as possible.'* *'Work with clients and other agencies in a person centred way.'* *'Provide health care treatment and assessment to people with learning disabilities and learning disabilities.'*
Cornerstone	*'We have a good working relationship with local G .Ps, District Nurses, etc., work and involve family members of the people we support and try to provide a range of inside /outside activities.'* *'We provide a high standard of care to the people we support.'*
Deans House Care Home	*'Listen to the individuals, promotes and maintain good links with in the multi-disciplinary team. Have excellent relationship with carers and parents.'* *'Promotes independence.'* *'Helps promote independence.'*
Eliburn Centre	*'Team offers a variety of activities in social settings.'* *'Promotes Service Users to be as independent as possible.'* *'Physical care and management of people with PMLEARNING DISABILITY.'* *'Takes a holistic view of the client. Has a good team ethos.'* *'Communicates effectively.'*

	'Person-centred planning, adapting to Service Users needs changing.' *'Advocate on client behalf.'* *'Advocate well for Service Users- respecting choices and their needs.'* *'Communication, working with families and with Community Learning disability Team.'* *'Our team agencies work well with other healthcare professionals- providing a holistic approach to care. Ensuring we are meeting the needs of our Service Users.'* *'Provide high standards of care to our Service Users. Advocate on behalf of Service Users.'* *'Advocating for Service Users, person-centred planning.'* *'Excellent service/ quality of care provided by the staff team, who are very knowledgeable about service users' needs/ health care.'*
Employment Team Support Service	*'Links with other services well.'*
Penumbra	*'Works towards the recovery of the individual, to introduce new skills and activities.'* *'Providing person centred support.'* *'Assisting people to live safely in the community with a minimum amount of support while retaining as much independence as possible.'*
Real Life Options	*'Support individuals in a variety of activities at home and in the community, and on a daily living basis.'* *'Provides day care variety of outdoor activities/ trips and indoor craft, music and art activities Residential support 24hr in small house groups 3-4 and also supported living and housing support Supporting making own decisions and involvement in how would like individual support delivered.'* *'As a team we provide support to individuals with learning disabilities and mental health disabilities. We work closely to provide a service where our residents feel safe and secure and are treated with respect, dignity and each individual's support plans are devised working with our service user.'*
Richmond Fellowship	*'My team builds support around the person's wishes and needs. Focusing on what is important to them to have a meaningful and enjoyable life. We gather information from the individual, family and other stakeholders and use this information as resource, to build on our existing community networks and partnerships. We do not fit individuals into a service model.'*
WLC Pathways	*'Encourages people to socialise in a non-structured way.'* *'Provide structured and safe learning base for people with disabilities on needs led basis.'*

5.5.3 Services/support needed in West Lothian

Respondents were asked to provide details about any services or support they thought were needed for those with a learning disability and/or autistic spectrum disorder and not currently provided in West Lothian. There were 49 responses. There were a number of key themes which emerged from respondents answers. They were:

- Eight respondents indicated that they there should be more social activities/groups/available for those with a learning disability and/or autistic spectrum disorder.

> *'We strongly need a place where the young people we support can be part of the community and enjoy some socialising in Disco's either weekly or monthly , this is very important to us and there is nothing like this in West Lothian.'*
>
> *'Yes. More and appropriate groups to attend and courses to attend which would be beneficial and enjoyable to service users which would enhance their lives.'*
>
> *'Accessible clubs in the evening and at weekends.'*
>
> *'There is always a need for more services and activities for People with Learning disabilities and ASD. I feel most of these need socialisation groups as there are a lot of people who feel very isolated and lonely and out-casted from the community.'*
>
> *'I think there isn't enough activity based groups for service users and most groups in west Lothian are attended by the same people.'*
>
> *'Yes, more groups i.e. discos or drawing for all groups.'*
>
> *'Evening and week end activities, social and fun where people could meet in safe area, club night music, dancing also educational /learning activities Specialist services for those with autism.'*
>
> *'I think more social opportunities are required for people that are on the spectrum as not everyone gets support or the little time they do they have no time to socialise which can cause them to become isolated.'*

- There were eight respondents that stated there were no other services or support needed.

> *'No there is a good variety of support and services in West Lothian.'*

- There were a number of respondents (n=7) that stated there should be more respite services available.

> *'Respite services for complex needs.'*
>
> *'Respite services for adults.'*
>
> *'Respite services for PMLEARNING DISABILITY in local area.'*
>
> *'Respite services for adults with health needs in West Lothian.'*
>
> *'Respite service in West Lothian for health care need.'*
>
> *'Specialist respite services that meet the needs of client's with PMLEARNING DISABILITY.'*

'Respite services.'

- Respondents (n=5) also stated that there should be services aimed at the elderly with learning disabilities and autism spectrum disorders.

    'Services for elderly people with learning disabilities.'

    'What happens after 60/65 years?

    'More services for older people with learning disabilities.'

    'There are not a lot of activities for older adults with learning disabilities.'

    'Care of the elderly for people with learning disabilities and place that can be home for life in later years.'

- Three respondents felt that there should be more choice of services available in West Lothian.

    'There are a lot more agencies and wider choice with city of Edinburgh, sometimes lack of services can be frustrating.'

    'More services/choices for people with autistic spectrum disorder.'

    'Feel there could be more on offer in West Lothian.'

- A further three respondents stated that there should be employment related services available in West Lothian.

    'More employment related support specific to Learning disability and ASD.'

    'More long term supported work/training placements need to be funded for service users. Capability Scotland provides a training environment in a cafe however no further funding is available for this after 2015.'

    'More opportunities for work / occupational experiences.'

- Three respondents also stated advocacy services were need in the West Lothian area.

    'Advocacy services.'

    'Advocacy Service.'

    'Increased independent advocacy support.'

- Two respondents thought that staff and the general public should be made more aware and better educated on autistic spectrum disorders.

    'More education and understanding of ASD to ALL staff BEFORE working with clients.'

    'Worthwhile education public understanding of Autism.'

- Two respondent's comments stated accessibility should be improved to public facilities to make it easier for those with a learning disability and/or autistic spectrum disorders.

    'Easier access to some venues, bus parking.'

> *'I find that public accessibility facilities are lacking when out and about in West Lothian and it can be difficult to provide the level of care that every person deserves when there isn't the means to facilitate this.'*

- Other (n=6) comments provided by respondents are presented below :

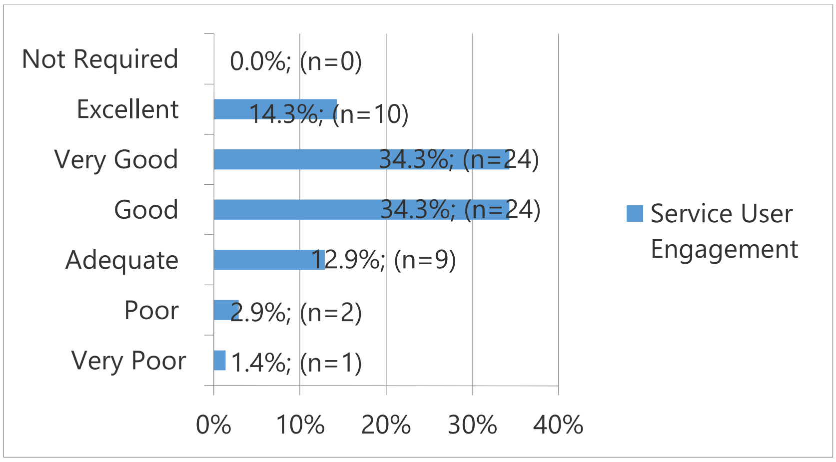
> *'Suitable supported housing options.'*
>
> *'More core and cluster type facilities. Specialist residential care for clients who need specific health care i.e. dementia.'*
>
> *'More support groups required maybe drop in.'*
>
> *'I think Livingston shopping centre could adjust one of the empty units to a place accessible and fun for people with a disability.'*
>
> *'It would be great if we had access to a community sensory room. These are fantastic for supporting individuals who have autism with their sensory needs, unfortunately once people leave school if they don't have access to a day centre they can no longer access a sensory room. There is one in Falkirk, however they give priority to Falkirk residents and it is very expensive, plus if people don't have access to a car they would struggle to get their using public transport. In addition to this some sort of hydrotherapy/sensory pool accessible to people in the community. Swimming is a great activity for people. It helps stay fit and healthy and also provides some therapeutic support. However, during school holidays individuals who have sensory support needs and Autism are unable to access local pools as crowds, noise, lots of children make life very difficult for them.'*
>
> *'Weight management service and other client based health promotion.'*
>
> *'I think that autism specific day centres would be beneficial to individuals with autism so they can be around people with similar needs and feel more comfortable.'*
>
> *'More Units like Deans.'*
>
> *'More support for parents with Learning disabilities. Good if there were support groups and drop in centres. Some parents only get services when their family is in crisis and are in the children's hearing system.'*

5.5.4 Level of service user engagement

Respondents were asked to rate the level of service user engagement within their service. Service user engagement was defined as 'the active participation of those with a learning disability and/or autistic spectrum disorder in shaping their own needs and outcomes'.

Respondents stated their services were either very good (34.3%; n=24) or good (34.3%; n=24) in terms of service user engagement. 10 (14.3%) respondents felt that their service was excellent. However two (2.9%) respondents stated that their services was poor and one (1.4%) respondent felt that their service was very poor at engaging services users.

Figure 5.19: Service user engagement



Respondents were able to provide commentary. Their remarks are presented below:

> *'Due to communication difficulties and high healthcare needs this can be [ ] at times however we do attempt to involve the Service User.'*
>
> *'Depends on each individual service user and their level of understanding.'*
>
> *'Difficult to fully engage due to the high complex levels of needs of service users however we do engage/communicate with one or two individuals who have the ability with communication.'*
>
> *'Service users have an annual review, a 6 month interim review, we have an informal open door policy, client forum. Customer satisfaction questionnaires.'*
>
> *'The service users we provide support to have severe learning disabilities, we work closely with their families and close friends to meet their needs and outcomes.'*

5.5.5 Groups that are not well catered for

Respondents were asked if there are any particular groups that they felt were not well catered for in terms of those with a learning disability and/or autistic spectrum disorder and the reason why respondents thought these groups were not well catered for. Respondent's answers are presented below:

Figure 5.20: Groups that are not well catered for and reasons why respondents thought those groups were not well catered for

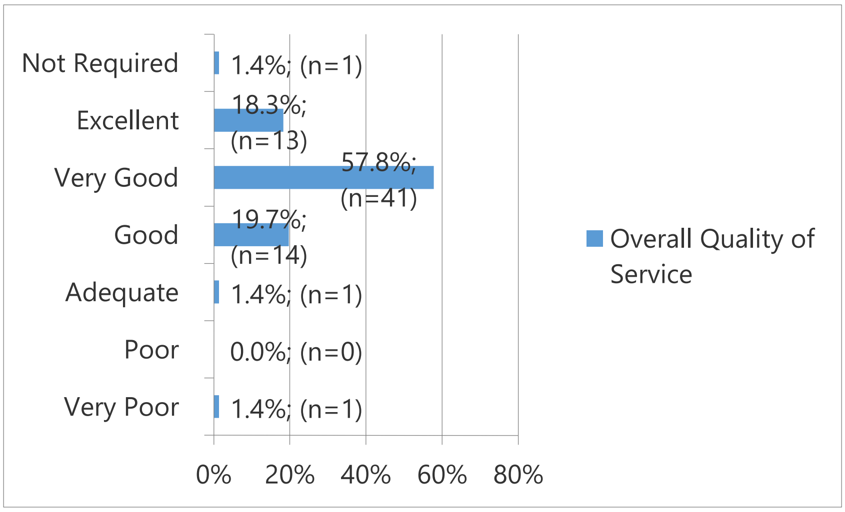
Groups that are not well catered for:	Why they thought this group was not well catered for:
Ten respondents stated that a group that are not well catered for are the elderly with learning difficulties. Sample of comments: *'Elderly community of people with learning disabilities. Lack of specialised care i.e. a care home is not a good option in my opinion. Also there is a lack of resources for the ageing population of people with a learning disability i.e. clubs etc. not all want to sit and do nothing.'* *'Elderly people with learning disabilities.'*	*'No available resources.'* *'Lack of resources and funding.'* *'Lack of specialist units i.e. learning disability dementia.'* *'Some older people with learning disabilities do not have activities to attend for their age group. Or there are no appropriate groups on which they would enjoy. And older people can become socially isolated, whereas if there were various activities which older people would enjoy provided in the local area then this can alleviate social isolation.'* *'Not sure but there does seem to be a gap in general for services for older people.'*
Five respondents indicated that there were no groups that were not well catered for.	*'I think all the groups are well catered for.'* (Only one respondent indicated why they thought there were no groups that were not well catered for).
Four respondents felt that a group that was not well catered for are those with learning difficulties and mental health issues. Sample of comments: *'Clients with mental health issue.'* *'People with depression.'* *'Hard to place individuals i.e. adults with learning disabilities and associated health/mental health/disorders/dementia.'*	*'Money.'* *'Not sure...no one to speak up for them...isolated?...hard to reach?...specialist input required?'* *'I feel it is a disability that can be overlooked at times and I feel professionals struggle to find reasons and solutions to help people with a mental illness.'*
Three individuals mentioned that people with profound multiple learning disabilities are group that are not well catered for in West Lothian. Sample of comments: *'Respite and residential placements for clients with profound and multiple LEARNING DISABILITY.'* *'Residential and respite care for PMLEARNING DISABILITY clients. There is no residential or respite services for PMLEARNING DISABILITY clients with additional healthcare needs.'* *'PMLEARNING DISABILITY.'*	*'Resources and demands on time.'* *'Finance.'* *'Lack of inward investment by NHS Lothian and a lack of identifying numbers.'*

Two respondents indicated that those who had survived abuse were a group that was not well catered for. Sample of comments: *'People who survive abuse.'* *'Victims of abuse.'*	*'Services tend to have HQ in city.'* *'Don't know.'*
Other comments from respondents were: *'Deaf.'* *'Younger People in general. Once leaving school activities are very hard to come by and cause lots of issues with socialisation and criminal behaviour.'* *'Gender identity groups.'* *'Nothing worthwhile for any disabled adult.'* *'Adults.'* *'Some clients in the borderline rage of LEARNING DISABILITY sometimes seem to fall between services, but can be a vulnerable group.'*	Other comments from respondents were: *'Less and less support workers are learning sign language.'* *'Lack of community based resources that are well run and well-advertised.'* *'Experience from working with a service user.'* *'Because it an easy way to save money.'* *'Lack of funding.'* *'Resources and demands on time.'*

5.5.6 Overall quality of service

Respondents were asked to rate the overall quality of their service. There was total of 71 responses to this question with the majority (57.8%; n=41) of respondents stating that the overall quality of their service was very good. 13 (18.3%) respondent stated that overall quality of service was excellent. One (1.4%) respondent, however, indicated that that the overall quality of their service was very poor.

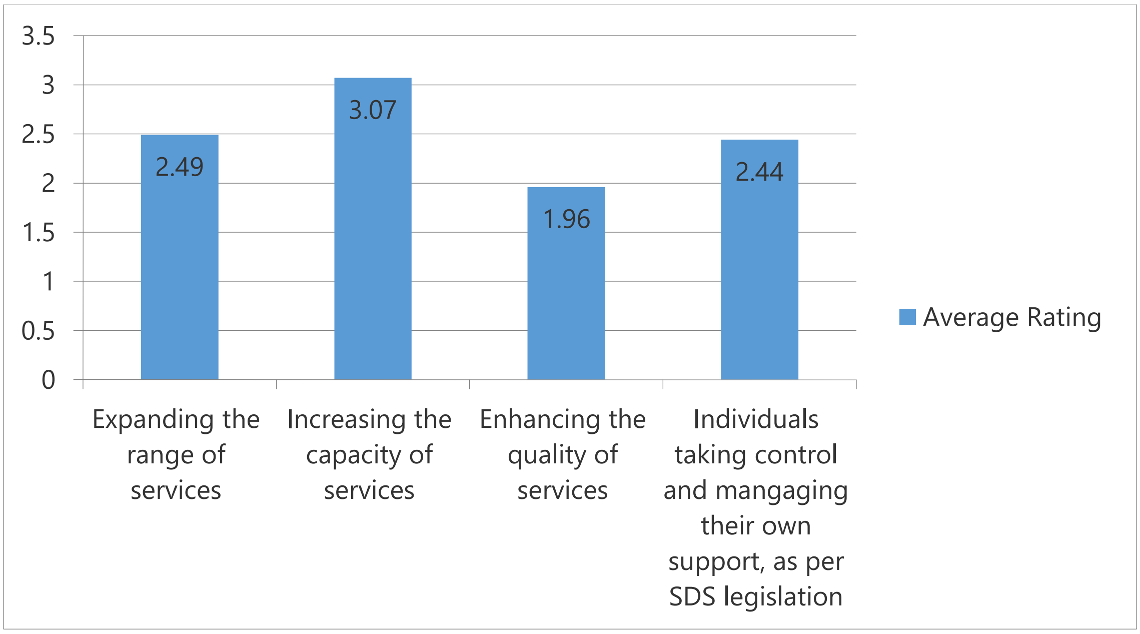
Figure 5.21: Overall quality of services



5.5.7 Service related importance ratings

Respondents were asked to put four statements in order of importance with the rating of 1 indicating the most important and rating of 4 indicating the statement as being least important. The statements were in regards to where respondents would like future investment to go. Respondents rated the statement '*Increasing the capacity of services*' the highest, with this statement receiving the highest average rating (n=3.07) from respondents. The statement that received the lowest rating was '*Enhancing the quality of services*' with the average rating being 1.96.

Figure 5.22: Future Investment



5.5.8 Other assets, resources, groups, individuals and opportunities for those with learning disabilities and/or autism

Respondents were asked what other assets, resources, groups, individuals, and opportunities are available across West Lothian to support mainstream services in meeting the needs of those with a learning disability and/or autism spectrum disorder. Respondents gave more than one asset, groups, individuals and opportunities. Respondent's comments are presented below:

- Leisure centres (West Lothian and Livingston)
- Local colleges
- Community Learning disability Team
- Community Inclusion Team
- Carers of West Lothian
- Employment Development
- New Direction
- Ability Centre

- Penumbra
- Pathways
- Music group
- Dance group
- Healthy living group run by Action Group
- Craft group
- Cycling group
- Sport group
- Day Services
- ASD Cinema
- FAB club
- Tree club
- Yellow Tea Pot Club
- ABE classes

Respondents were asked if there were anything else they would like to add or if they had any gaps they wish to identify or improvements. Respondent's answers are presented below:

> *'More choice and options. No health respite for adults in West Lothian.'*
>
> *'I think there should be a health respite centre for families in West Lothian.'*
>
> *'Music/ art therapy groups out with centre. Beauty treatments at local college.'*
>
> *'Individuals housing tenancies and residential housing.'*
>
> *'Accessing other centres out-with my workplace for other groups etc. (beauty, gardening).'*
>
> *'Service users with high level of support needs, complex health needs and communication difficulties require increased support- so taking control and managing their own support will prove difficult. Increased independent advocacy can improve ensuring individual voices are heard. Also provision (or lack of) areas designated in community for assisting people with personal care requirements and require hoists/ changing facilities. This would enable individuals to access community based activities.'*
>
> *'It may be aspirational, but in my service I would like to see more learning disability specific training for staff. I would like modern interactive technology to be available to use in service user groups, e.g. iPads.*
>
> *'While there is good close working between health and SW OT's, there is limited OT specific learning disability cover for the size of the population.'*

'I think there should be more service provision in the evenings and at weekends for service users i.e. clubs, social outings, to enable people with a learning disability/autism to meet up with friends etc.'

'Information to be given in a non-written form using easy read/language/pictorial to aid individuals understanding.'

'More support hours and shifts. Longer shift times are sometimes needed. Sometimes the support hours and shift times are not long enough in which to support the service user and some tasks may have to be carried over to the next shift or the support worker may choose, if possible, to work longer shifts without being paid and in their own time.'

'All of my concerns are with evening and weekend activities in general for the whole spectrum, from elderly through to learning disabilities'.

'More specialised care for 1:1 and for the ageing population of service users.'

'There needs to be more in terms of public accessibility for those with additional needs - places they can go that aren't just centred towards children. Places like The Yard in Edinburgh or Number 6, also in Edinburgh. There needs to be more to fulfil their lives and give them the same choices and opportunities afforded to those without additional support needs. The Action Group West Lothian set up their own group for service users which has been incredibly rewarding and valuable for our service users, and allows them a forum to learn new skills and socialise with their peers. There needs to be more of these.'

'I feel more resources are needed within the community. I feel there is a huge gap in terms of Young people who are leaving education because the education system is failing the individuals. After this has happened there is not much support in terms to people who have left education to become more active in their communities and to give these people opportunities to better themselves.'

'In my short experience of SDS I feel like the principle of choice, control and flexibility is great, however, in reality it brings the issue of money to the forefront of services for people with complex needs. Rather than quality the main focus is cost, driving down cost and getting a cheaper service. We already work in a very underpaid and undervalued industry. Wages are near minimum wage yet our workers have the responsibility of caring for the most complex and vulnerable people in society and still we have to drive down costs. Recruitment and retention are big problems in this sector due to the low pay vs high stress and responsibility. Staff can literally get paid more to stack shelved in Tesco. It is all very well giving people choice, control and flexibility but my fear is that people will have a very limited choice with a budget too low to buy a good quality service.'

'Learning disability specialist health team must be ring - fenced and maintained to meet the needs of the clients whilst allowing for access to mainstream service where appropriate.'

'Sometimes difficult to provide support individual may require or want as funding for staff insufficient.'

'I believe that each individual should be treated equally and that their care reflects this. I believe as a whole you should be re-evaluating care services to best support individuals that need support and don't have any.'

'I think there should be more housing support services available as service users within a service are getting made to stay there even when it doesn't meet there needs and there is issues between the service users because there is nowhere else for them to go as there isn't enough services.'

'There is a definite need for a central point of information on what services and support is available for potential service users and carers.'

'Yes within my service we have just been told we can no longer take service users out in our cars, due to Council cut backs, and only essential journeys. What is essential to our service users maybe not essential to others but it is important to them. How do some of our service users understand about cut backs, they have been used to getting outings to spend their money when in for respite. It upsets me when our service users get their services cut.'

5.6 Key Findings

- There were 92 responses to staff survey, of which 3 were discarded as respondents completed less than 10% of the survey.
- Respondents were asked to indicate what statutory services they were employed by. The majority of respondents were employed by Eliburn Day Centre (45.3%; n=24). There were no respondent employed by Letham Court and the Local Area Coordination Team.
- Respondents were asked to indicate what commissioned services they were employed by. Just over 40% of respondents were employed by 'The Action Group' (42.2%; n=19). There were no respondents from the following services: Homereach, Key Housing Association, Leonard Cheshire Disability Ltd, Place for People, Quarriers, Scottish Autism, and Voluntary Sector Gateway- Befriending Service.
- Respondents were asked to indicate what their job role was in the service which they work for. The majority of respondents were support workers. (40%; n=36) and 12 (13.3%) respondents indicated that they were key workers.
- Most of the services for learning disabilities and/or Autism Disorders are located in Livingston (n=73), this was followed by Whitburn, with 11.2% (n=15) of respondents indicating that their services are in this locality. Other respondents indicated that their service covers all of West Lothian and one respondent stated that their service was based in Edinburgh and Lothian.
- Respondents were asked to specify how much they agreed or disagree with a set of 13 statements.

- The majority of respondents strongly agreed (60.7%; n=54) or agreed (37.1%; n=33) with the statement, ‘My team/agency works effectively with people with a learning disability and/or autistic spectrum disorder.’
- The majority of respondents strongly agreed (53.9%; n=48) or agreed (44.9%; n=40) with the statement, ‘My team/agency are knowledgeable about how to respond appropriately to a presenting learning disability and autistic spectrum disorder.’
- The majority of respondents strongly agreed (56.2%; n=50) or agreed (38.2%; n=34) with the statement, ‘My team/agency undertake assessments in order to identify individuals’ needs and out comes’. Two (2.3%) respondent stated that they disagreed and one (3.6%) respondent strongly disagreed with this statement.
- The majority of respondents strongly agreed (43.8 %; n=39) or agreed (41.6%; n=37) with the statement, ‘My team/agency has established referral routes with other learning disability and/or autistic spectrum disorder services. ’
- The majority of respondents strongly agreed (45.5 %; n=40) or agreed (40.9 %; n=36) with the statement, ‘My team/agency is easily accessible to service users from across the whole of West Lothian’
- A large (46.6%; n=41) proportion of respondents stated that they agreed with the statement, ‘There are effective pathways into learning disability and/or autistic spectrum disorder services that promote joint working’. 22.8% (n=20) of respondents they didn’t know whether there were effective pathways into learning disability and/ or autistic spectrum disorders.
- 40.5% (n=36) of respondents strongly agreed with the statement, ‘My team/agency communicates effectively with other learning disability and/or autistic spectrum disorder services across West Lothian’, with a similar (41.6%; (n= 37) percentage of respondents also indicating that they agreed with this statement. 11 respondents responded ‘Don’t know’ to this statement.
- Almost 60% (58.6%; n=51) of respondents strongly agreed that their team/agency undertakes care and support planning with individuals. Just over 35% (35.6%; n=31) of respondents agreed and a further three (3.5%) stated they didn’t know and two (2.3%) respondents disagreed that their team/ agency undertakes care and support planning with individuals.
- There was a similar proportion of respondents that strongly agreed (43.2%; n=38) and agreed (44.3%; n=38) with the statement, ‘My team/agency has effective working relationships with other learning disability and/or autistic spectrum disorder services’. Eight respondents stated that they didn’t know and two (2.3%) respondents disagreed with statement. One (1.1%) respondent strongly disagreed.
- There were some discrepancies between respondents with the extent to which they agreed/disagreed with the statement, ‘My team/agency communicate effectively with a wide range of other non-specialised learning disability and/or autistic spectrum services.’

However, the vast majority of respondents either strongly agreed (32.6%; n=29) or agreed (43.8%; n=39) with this statement. 14 (16%) respondents stated they didn't know, six (6.7%) respondents disagreed and one (1.1%) respondent strongly disagreed.

  - There was difference in the extent to which respondents were in agreement/disagreement with the statement, 'My team/agency has effective working relationships with a wide range of other non-specialist learning disability and/or autistic spectrum disorder services.' The majority of respondent were in agreement with this statement, with 46.1% (n=41) agreeing and a smaller proportion of respondents strongly agreeing with this statement. However, 5.6% (n=5) respondents disagreed and one (1.1%) respondent strongly disagreed. 16 respondents were not sure about this statement and stated 'Don't Know'.
  - Respondents were asked how much they agreed or disagreed with the statement, 'My team/agency provide good information about learning disability and/or autistic spectrum disorder, including other sources of help available.' 37 (42.1%) respondents agreed with this statement, a further 35 (42.1%) respondents strongly agreed. Five (5.7%) respondents disagreed with this statement.
- Respondents were asked to provide details about any services or support they thought were needed for those with a learning disability and/or autistic spectrum disorder and not currently provided in West Lothian.
  - Eight respondents indicated that they there should be more social activities/groups/ available for those with a learning disability and/or autistic spectrum disorder.
  - There were eight respondents that stated there were no other services or support needed.
  - Five respondents also stated that there should be services aimed at the elderly with learning disabilities and autism spectrum disorders.
  - Three respondents felt that there should be more choice of services available in West Lothian.
  - A further three respondents stated that there should be employment related services available in West Lothian.
  - Three respondents also stated advocacy services were need in the West Lothian area.
  - Two respondents thought that staff and the general public should be made more aware and better educated on autistic spectrum disorders.
  - Two respondent's comments stated accessibility should be improved to public facilities to make it easier for those with a learning disability and/or autistic spectrum disorders.
- Respondents were asked to rate the level of service user engagement within their service. Service user engagement was defined as 'the active participation of those with a learning disability and/or autistic spectrum disorder in shaping their own needs and outcomes'. Respondents stated their services were either very good (34.3%; n=24) or good (34.3%; n=24) in terms of service user engagement.

- Respondents were asked if there are any particular groups that they felt were not well catered for in terms of those with a learning disability and/or autistic spectrum disorder:
    - Ten respondents stated that a group that are not well catered for are the elderly with learning difficulties.
    - Five respondents indicated that there were no groups that are not well catered for.
    - Three individuals mentioned that people with profound multiple learning disabilities are a group that are not well catered for in West Lothian.
    - Two respondents indicated that those who had survived abuse were a group that are not well catered for.
- Respondents were asked to rate the overall quality of their service. There was total of 71 responses to this question with the majority (57.8%; n=41) of respondents stating that the overall quality of their service was very good.
- Respondents were asked to put four statements in order of importance with the rating of 1 indicating the most important and rating of 4 indicating the statement as being least important. The statements were in regards to where respondents would like future investment to go. Respondents rated the statement 'Increasing the capacity of services' the highest, with this statement receiving the highest average rating (n=3.07) from respondents. The statement that received the lowest rating was 'Enhancing the quality of services' with the average rating being 1.96.
- Respondents were asked what other assets, resources, groups, individuals, and opportunities are available across West Lothian to support mainstream services in meeting the needs of those with a learning disability and/or autism spectrum disorder. Examples of assets, resources, groups mentioned were: ASD cinema, leisure centres, local colleges, Yellow Tea Pot Club, FAB clubs. Respondents also mention craft, sports, and music and dance groups but didn't specify exact names.

5.7 Background to Stakeholder Event 20th May 2015

The Stakeholder event was held in the Howden Park Centre in Livingston on 20th May 2015. It was divided into two separate events. The invitations were sent out to representatives from each of the stakeholder groups identified by the commissioners. The attendees were made up of service users, parent/carers and professional staff from a whole range of organisations operating in West Lothian and delivering services to those with Learning disabilities or someone affected by them.

This report will focus on the morning session which was devoted to the Learning disability Needs Assessment and which consisted of a short introductory session and three separate workshops. Each of the three workshops addressed four questions each and the following paragraphs accurately represent the views of those taking part in the workshops.

As there were a significant number of people booked to attend the event, with 42 eventually attending, each person arriving was allocated a coloured name badge which indicated which workshop they were to attend. For the purposes of continuity each workshop group answered the same questions.

5.7.1 Questions addressed by each workshop group

- What are the needs of people with and affected by a Learning disability in West Lothian?
- How are these needs currently being met?
- What is currently going well?
- What is not going well and how can this be improved?

5.7.2 The specific needs discussed in all three workshops

- Health.
- Specific learning disability team with universal remit.
- Health & Safety education (how to be safe in various environments).
- Activities which enhance a person's life.
- Peer support/councils.
- Long-term solutions – future planning/transition.
- Choices.
- More opportunities.
- Skills development.
- Safe and secure housing.
- Support to live independently if they can/want.
- Better accessibility to service.
- More accessible means of travel.
- Improved service user involvement.
- Service user involvement in service/recruitment.
- Service Users/Carers need to know what's available.
- Regular reviews.
- Structured programmes.
- More respite and residential respite.
- Consistency in support staff – need to be able to trust/rely on support staff.
- Being considered a valued citizen.

- Volunteering.
- Employment (paid work).
- Valued roles.
- Integration/access to the community.
- Awareness regarding services/ entitlements/ benefits/ legislation etc.
- Staff need regular training to remain up-to-date with current legislation/policy/procedures.
- Less jargon and more easy to read information leaflets.
- Somewhere to go in the evenings – clubs etc.
- In terms of housing people get isolated, they want and need maximum independence but also someone to be there when they need them.
- Public transport is a joke – there are no buses to Glasgow, and the buses all seem to come at the one time. There is also no supervision on the buses.
- If you take time to train someone on a particular route and then that route is changed, then to have to start all over again. People who run the buses don't take account of how just a small change can affect someone. Buses are late and sometimes people can't get on with wheelchairs as those with prams won't shift. There needs to be improvement in the accessibility of buses.
- There are not enough things for people to do, they don't just want to go to a shopping centre all the time.
- Reliance on charities, groups wouldn't be there if parents are not involved.
- More support from West Lothian Council – not enough funding.
- If a small budget was given to help people set up groups they wouldn't be so reliant on services. Parents need to do it all the checks on helpers with no support.
- Worthwhile, purposeful, educational activities or social activities allowing interaction with people.
- Support for individuals and carers: Carers needs more support and training – not fair that they don't get that.
- Support is a need for carers along with support workers. People allocating funds should have a better idea of disability.
- Sibling service – Is there one? Someone can be disadvantaged by having a disabled sibling – according to Carers of West Lothian.
- Training for staff – Council HNC – like to see specific training for learning disabilities for staff who work with people with Learning disabilities. There could be input from specialist services e.g. speech and language therapists.

- Group activities – not everyone wants to be associated with groups or a day centre etc., people therefore fall through the net.
- Forums for views – there is not enough opportunity. Resource centres have provision for people who use the resource - no consultation for people who do not use these services.
- There should be 1-1 services, social groups. A model of funding is being looked at. Drop in facilities really important to meet a friend, or getting some advice and relax. Funded opportunities, socialisation really important.

5.7.3 How are these needs currently being met?

The following points are representative of the views expressed from all three groups:

- Pathways Day Service;
- Advocacy through 'Our voice Our choice';
- Community Learning disability Team workshops;
- Advice shops providing advice on Benefits, money/budgeting, housing;
- Independent living team, although this was regarded as being short staffed at present;
- Life skills such as cooking; travel training; socialisation;
- Respite services provided at Letham Court; and
- Employment support to engage in volunteering and/or paid work.

5.7.4 What is currently going well?

The following points are representative of the views expressed from all three groups:

- People have opportunities and choice;
- Services listen to service users;
- Good communication;
- Learning disability forum (although not currently operational – to be reinstated soon);
- Widespread services updates;
- Peer Advocacy service 'Our Voice Our Choice';
- Liaison nurse if you have to be admitted to hospital; and
- Plenty of volunteering opportunities.

5.7.5 What is not going well and how can this be improved?

The following points are representative of the views expressed from all three groups.

In mainstream services:

- There is a lack of specially trained staff to deal with the specific challenges those with a Learning disabilities sometimes present with. For example in phlebotomy – diabetics with a Learning disability may find the process of having bloods taken very stressful.
- There is an insufficient number of professionals with the relevant experience.
- There is insufficient provision of services such as weight management for those with a Learning disability.

Generally:

- Perhaps more smooth joint working/ smoother referrals would be beneficial especially if there is no social work involvement.
- One carer reported that *'Social work is the gateway to everything.'* [N.B. Her experience was many years ago. This may not be the case today.]

5.8 Background to the two working group meetings held in The Pathways Centre, Craigshill

A critical part of the information gathering methodology was to establish a working group which would meet twice within the fieldwork component of the project. Recruitment for the working group would be both through invitation from the research team using a stakeholders list provided by the commissioner and by self-nomination at the Stakeholders Event. It was stressed that those who wished to attend the Working Group should be available for both meetings, however due to work commitments and other pressures not everyone could attend both sessions.

5.9 Working Group Session 1: 27th May 2015 Venue The Pathways Centre, Craigshill, Livingston

Total Attended: 14

Break Down: 11 Professional Staff, 2 Parent/Carers and 1 Service User

Agencies Represented:

- West Lothian Social Work Department (Autism and Learning disability Team);
- West Lothian Council (Equalities Department);
- The Action Group;
- New Directions West Lothian;
- Carers of West Lothian;
- Disabilities West Lothian;
- Social Work Department (Looked after Children Team); and
- Enable.

The focus of the business of the first meeting was to address the following:

- The key messages that had arisen from the Stakeholders event.
- The current service provision.
- Choice of Services in West Lothian.
- Are some groups not well catered for?
- What works well for services.
- How effective is the identification and assessment process?
- How accessible are services?
- How well do services integrate and work together?
- How good is accessibility to and integration with mainstream health and social care services?

The group was given a hard copy of the key findings from the Stakeholders Event, this is given below:

- ACCESSIBILITY: Once in the system there is support but getting into the system is an issue. If you are not in the system knowing what information and assistance is available appears to be a barrier to support.
- HOUSING: There appears to be a gap in supported living provision in West Lothian.
- TRANSITION: The transition from children to adult services seems to be weak, with more services for children and apparent limited continuity from children to adult services.
- JOINT WORKING: There are good examples of joint working and information sharing in West Lothian, however there is room for improvement.
- FUNDING: there seems to funding issues when conducting projects. Short-term ism- not sufficient amount of time as learning disability in a long-term issue, "it's not a broken leg".
- CHOICE: There may not be genuine choice for those with a learning disability.

On the whole the group felt that this was a fair reflection of the current position in West Lothian.

On the subject of accessibility, it was felt that the change to the availability of bus passes, created issues for people being able to go to services. Benefit entitlement was seen as key to the problems of accessibility as some services were only available if you received a certain type or level of benefit.

The issue of housing was raised, as this was universally agreed as being a significant problem. There are gaps in the provision of supported living accommodation, this is also seen as being part of wider shortage of housing for one person households. It was felt that there was a particular shortage of housing for those with mild learning difficulties.

One of the key message which the group felt was not highlighted enough within the Stakeholders event was that of respite, both in terms of availability and also flexibility. A carer stated that:

> *'Some families may use it because they are desperate, rather than because it actually fits.'*

It was suggested by the group that the increasing roll out of SDS might help with being more creative but the costs involved in this might be preventative.

5.9.1 Current service provision

In terms of current provision the Working Group felt that:

- There are a range of services, but not enough.
- There is insufficient information re providers for carers and service users.
- Lack of provision for those with an ABI. Those with an ABI don't fall into traditional categories. Many supports that are put in place are very short-term/through-put services i.e. 6-8 weeks in duration.
- 1:1 support is only ever short-term, but many individuals flourish with this support → there are services, but not sufficient in length of provision.

On the question of there being a genuine choice available in relation to range, consistency and quality of services there were 2 specific themes which were raised:

The ageing Learning disability population was a particular concern to both professionals and parents/carers, and a lack of transition services

> *'When you hit 65 there are no services.'*

The other concern raised was in relation to a lack of transition services.

The consensus was that this will become an ever increasing problem with an ageing society however others in the group argued there is lots available in the community e.g. Aging Well; the Food Train; Cyrenians; Guardian Angels; 50+.

5.9.2 Transition

It was agreed that there is a lack of availability support when you move from child services to adult services.

The representative from the Social Work Department Autism Team noted that any young person transitioning should have an assessment as early as possible so that the relevant services can be in place in a timely fashion (particularly important for those with an ASD as change/long waits etc. causes them anxiety). Carers WL in conjunction with Signpost offer a transition course for parents to explain processes/things to consider including guardianship etc.

It was noted that to access many adult services you need a 'label', but many potential service users are told to avoid getting a diagnosis as this will 'pigeonhole' them. It was noted that there needs to be a Signpost service for adults.

5.9.3 Are there any particular groups that you feel are not well catered for?

- People with more profound/complex needs. The opinion was that the cost to support this group is high thus services have stopped tendering for contracts dealing with this demographic. Staff capability/training is lacking to deal with these needs. Respite for this particular group is very limited.

- Those with an Acquired Brain Injury.
- Black and Minority Ethnic Communities, few services pay attention to people's religious/cultural diversity even within their support.
- Young adult services.
- Those with offending behaviours as a result of their condition e.g. some with a Learning disability exhibit challenging/violent behaviour/have sensory issues that make them feel vulnerable to attack/have paranoia and therefore may carry offensive weapons etc. If they are not effectively represented or supported this group can fall into a cycle of trouble with the police. If they are not reminded/supported to attend appointments they can inadvertently be in breach of sentence etc. (e.g. Drug Testing and Treatment Order). Furthermore due to risk assessments etc., services are unlikely to take on a service user with an offending background

5.9.4 What works well for services?

- Flexibility of service around people's needs.
- Voluntary services can be flexible; social work flexible re crisis management.
- As a provider it was noted that there needs to be a mixture of both flexibility to respond and continuity so the provider know where its staff are etc.

5.9.5 How effective is the identification and assessment process for people with a learning disability?

- It can provide a key to many doors BUT people can slip through the net.
- There may be an issue re 'labelling' people, but often you can only access relevant services with a diagnosis.
- The identification and assessment process is effective if the person "fits easily" within a category/need type; if not, it can be difficult e.g. if you have good and bad days etc.
- West Lothian recognise those with an ASD don't fit easily into either Mental Health or Learning disability.
- The assessment process for those with an ASD is getting better, but it's not perfect because there is such a wide range of level of need.
- Work needs to be done across the lifespan and reassessments need to be made regularly.
- Assessment needs to see both good and bad days.
- There needs to be day-in/day-out individuality.
- New assessment within Health & Social Care introduced 01/04/2014 and is still bedding in.

5.9.6 How accessible are services?[194]

- Most statutory services require professional referral.
- Most third sector services accept walk-ins or professional referrals.
- It takes between 12-14 weeks to get an initial assessment.
- It takes 4-6 weeks to undertake the assessment.
- Care Plan – from first point of contact to full implementation it can take a year.
- Enabling/1:1 support takes a long time to implement because recruitment etc. needs to take place too.

5.9.7 How well do services integrate and work together?

- Joint Assessment: The more complex the need the more likely it is that there will be a joint health/social care assessment.
- Adult Support and Protection Legislation. It was reported that the courts are very good at supporting those with a Learning disability through the process.
- The 'Safe and Sound' Forum is quite dynamic – addressing issues such as: harassment, hate crimes, online vulnerability. Internet safety is a particular issue for those with a learning disability because of the question of capacity.
- There is a mechanism for reviewing of Carers, although one carer did report to never being invited. ASD service/provision is reviewed on an annual basis (following a review at 4-6wks following implementation). Sometimes the Service User is invited, however this depends on individual. If there is no Social Work involvement often a liaison worker provides input.
- In terms of communication, information sharing isn't bad. It could be better but there are no major issues. Social Work liaison and communication with GPs is somewhat "hit or miss" – GPs can put up barriers to sharing information due to patient confidentiality concerns. On the whole the group agreed that communication between other organisations is built on trust.
- Local Authorities can use the Scottish Council's Equality Network to have open discussions re policy/practice and to learn from each other.
- Professionals felt that generally the council were very good at sharing information. Within the council there is an ongoing challenge to get people engaged with equalities across everything/all policies/agendas.

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[194] Treatment Time Guarantee - The Scottish Government have set national waiting times standards for the maximum time that patients should have to wait for NHS services in Scotland. A 'Treatment Time Guarantee' means that, from the 1 October 2012, the Patient Rights (Scotland) Act 2011 established a 12 week maximum waiting time for the treatment of all eligible patients who are due to receive planned treatment delivered on an inpatient or day case basis.

5.9.8 How good is accessibility to and integration with mainstream health and social care services?

- The group as a whole agreed that mainstream services are not generally accessible to those with a learning disability. There is a lack of awareness among mainstream services, together with the fact that the way in which mainstream services are provided is not always appropriate for those with learning disabilities.
- In terms of integration of those with learning disabilities the Police and the Criminal Justice System in general was felt to be less than satisfactory. Individual officers can be very good, but there is a lack of training across the board (PCs upwards). One carer reported that in her experience the Procurator Fiscal often throws out cases with witnesses who have a Learning disability as they are considered 'unreliable'.
- It was noted however that there are some very good solicitors available who understand the particular issues those with learning disability present with.
- The group also discussed what they saw as the health inequalities experienced by those with a Learning disability. There are some FAiR brochures on health issues/healthy lifestyles (easy-read/accessible), but unfortunately they are not widely known about and don't appear to be in GP practices.
- Specifically in relation to dental services, the dentist who works specifically with those with Learning disabilities is very good, but comes in on set days/times (Monday-Friday) and some patients don't want to miss their day service to attend i.e. there is limited access.
- Access to mainstream dentist is sometimes difficult (problem with free treatment being dependent on the type of benefit you're on. Many with a learning disability will be on Incapacity Benefit and need to complete particular forms to be eligible for free treatment. Dentists don't routinely have these forms on hand).
- Sexual health services are not easily accessible.
- Women's health - very few women with a learning disability have a smear test. This could be due to a lack of understanding regarding what's involved; or that many GPs are reluctant to perform the procedure. Given the anxiety it produces amongst patients with a learning disability they may require anaesthetic, which can raise issues of consent.

5.10 Workshop 2: 5th June 2015 Venue The Pathways Centre, Craigshill, Livingston

Total Attended: 11

Break Down: 7 Professional Staff, 2 Parent/Carers and 2 Service User

Agencies Represented:

- West Lothian Social Work Department (Autism and Learning disability Team);
- New Directions West Lothian;
- Carers of West Lothian;

- Disabilities West Lothian;
- Social Work Department; and
- Enable.

The focus of the business of the second meeting was to address the following:

- Service User Involvement;
- Transition;
- Integrated Care Pathways;
- Current Gaps in Service Provision for those with a Learning disability;
- Future Investment; and
- Asset Mapping.

5.10.1 Service User Involvement

- There are many examples discussed of good practice involving Learning disability service users in service design across West Lothian These included user-led fora/focus groups and user consultation in the early stages of new projects such as Pathways.
- However, there appears to be a discrepancy between those in receipt of structured services and those in receipt of direct payments. The latter feel more disenfranchised; there is a perception that there is not a two-way dialogue – that there is no way to challenge current provisions/find new ways of working. An example was given however, which highlighted innovative practice from across Scotland e.g. DP recipients getting together to investigate and instigate services e.g. in Irvine a group of parents got together to source childminders for children with ASN and the LAC got a small pot of money to help fund this provision. Circle Care Support in Edinburgh was also mentioned.

5.10.2 Transition

- The group clearly recognised and identified this as a gap in current service provision.
- There are examples of good transition from child to adult health services, for example Carers of West Lothian and Signpost offer a transitions course for parents of children aged 14-16. Covers a range of topics such as SDS, guardianship etc.
- One carer spoke of her daughter's experience which was fantastic in her view. For one year prior to transition, adult health services 'piggy-backed' appointments with the Sick Kids Hospital. She would attend an appointment at the Sick Kids Hospital and then the following week one at the associated consultant from adult health services. By the end of the year she was comfortable attending the variety of consultants required as an adult.

- It was felt by the group that health, social care and education should work more effectively together in the transition process.
- The need to begin the process/conversations/dialogue early was stressed.
- A named person to coordinate between professionals in adult services was one example of where this transition period could be improved.[195]
- It was felt that teachers and staff in colleges lacked training in engaging with students with learning disabilities and an improvement in this may help make the transition from school to college a little bit easier.

5.10.3 Integrated Care Pathways

- The group on the whole didn't see much evidence of Integrated Care Pathways in their day to day work or caring responsibilities. Their view was that if services worked together and achieved an outcome it was more by chance than design.
- One of the key gaps in the functioning of the Care Pathways model for those with Learning disabilities was that those not in receipt of services have no care plan/pathway and for those who were in receipt of services the care pathway provided:

  > *'An idea of what we want to achieve long term.'*

- It was felt the role of Person Centred Planning Officer should be reinstated and extended as this had been a key asset in the Integrated Care Pathway.
- ASD SW service is now going into college to work on pathway planning with young people with an ASD. They aim to upskill young people, because they recognise there is a gap for many with a Learning disability/ASD post college.
- The need for support through the benefits appeals process was discussed and seen as vital with a care pathway, especially given that legal aid is no longer accessible to challenge decisions about benefits etc.
- It is now harder and harder to challenge decisions, but at the same time it is becoming more and more important to have the right 'label' / benefit to access services.
- One of the Social Work Department representatives noted that he often meets those with an ASD (particularly Asperger's) in their 30s and they've never had services. Often they are deemed combative if they don't attend appointments/are reluctant to go to new places/services. Their emotional and behavioural issues are not taken into account.
- Many suitable services are in Edinburgh, but how do they get there? – There is a lack of support to access these services.

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[195] This function is catered for through the Children and Young Persons (Scotland) Act 2014 – and is protected in statute for all of Scotland's children.

- One of the carers present noted that his brother has both physical disabilities and learning disabilities; his learning disabilities are given the priority even though it is actually PD services that would help more.
- Budgets are also an issue when users have both physical disabilities and learning disabilities – which budget pays for what?

5.10.4 Gaps in current service provision

- Transition services were seen as a major gap in provision.
- Services for those with mild to moderate learning disabilities.
- Early intervention / preventative services.
- MH services for those with learning disability, – high prevalence of OCD / paranoia / depression / anxiety amongst those with a learning disability and there are currently very few learning disability-specific MH services.
- Integrated travel.
- An information hub.

5.10.5 Future Investment

- In terms of whether future investment should focus on expanding the range of services, increasing capacity of current services or enhancing the quality of current services, there was some disagreement amongst the group, the majority favoured increasing the range of services offered.
- It was noted however, that there needs to be increased security and sustainability of services – a view was raised that funding decisions are based on *'short-termism'* needs and not with the long-term in mind.
- The competitive nature of tendering was discussed and it was noted that quality of service provision is not always known in advance.

5.10.6 Asset Mapping

- It was agreed that the voluntary sector in WL is thriving; there is a massive range and variety of voluntary organisations in WL, but all the small groups are not always known about.
- Short-term funding was noted as a constant stress; projects are constantly required to come up with new/innovative projects to attract funding rather than just ones that have proven effective.
- Social services sign-post to the voluntary sector.

- College consult heavily to identify gaps and as a result of feedback some suggest that it is becoming more acceptable for students to bring a carer/enabler with them (volunteer or PA). However it was noted that the College doesn't generally use/involve the voluntary sector.
- Parents as assets. It was felt by some carers however that parents are left to their own devices too much.
- Suggestion that mainstream services could better support voluntary/carer/parent organisations by providing access to HR/finance/legal/IT/H&S etc. thereby freeing them to focus on Service users.
- The introduction of Direct Payments (SDS Option 1) was considered an asset by some and as a welcome development by others, some felt it allowed service users more choice but others felt it placed too much of a burden on parents/carers in terms of organisation.

5.11 Background to interviews

A total of 14 professional and wider stakeholders participated in qualitative interviews and one staff team participated in a focus group in West Lothian in June 2015. The qualitative methods of the West Lothian Learning Disability Needs Assessment study targeted managers from statutory (NHS and Local Authority) and commissioned learning disability services. Of the 14 interviews undertaken, 13 were conducted on a face-to-face basis; broken down, as follows:

- West Lothian Council (n=8);
- NHS (n=3);
- Voluntary Sector (n=1); and
- Further Education (n=1).

The full interview scheduled is outlined at **Appendix II**

5.12 Purpose of interviews

The purpose of interviews was to find out:

- Views on current provision of treatment services;
- Gaps in current provision;
- Views in relation to the nature and extent of future requirements; and
- Assets (groups, networks, individuals, etc.) across West Lothian.

5.13 Limitations of interviews

A challenge was the time limitations of the study and having to identify interviewees from a list of stakeholders and providers provided by the commissioners.

Whilst acknowledging that the research team has autonomy of decision making in terms of participant selection; indeed, the team and commissioners worked cohesively to identify and agree who would be the key figures to interview, the time limitations of the study did impact upon this selection as some were not available due to workload, holiday and other commitments compounded by the short notice of interview dates available.

5.14 Interview key findings

<u>5.14.1 Is there sufficient provision of services to meet presenting needs and what are the main gaps in provision?</u>

Provision

There appears to be some consensus amongst managers of services that there are a good range of services for people with learning disabilities in West Lothian; however, there appears to some divided opinion on whether they are sufficient to meet the ever changing needs and demographic profile of the Learning disability population. From a Primary Care perspective there is probably sufficient provision for people with learning disabilities who have significant support needs; however for those people with lower level needs, for example people with Asperger's and ADHD, there is little support. For those people who do not meet the eligibility criteria, it will be important that they have access to voluntary and community resources for guidance, information and support. It will be important therefore that staff across health and social care services have sufficient knowledge of where to signpost people.

In terms of capacity there are issues with staffing of learning disability services in terms of maternity leave etc.; however, the closer integration of health and social work services in West Lothian may allow for more consistency in service provision. There is a general perception that health and social care services are stretched in West Lothian and that West Lothian is slower to progress integration than other areas. Learning disability nurses are currently challenged to have the breadth of 'integrated' knowledge being expected of them today - for example, having confidence to advise / signpost on social care matters. The issue of some of the specific learning disability services being pan-Lothian, such as the AHP provision, can at times reduce the service in West Lothian, if demands are higher elsewhere. Management of health and social care teams is fragmented with multiple managers across social work, nursing and Allied Health Professionals. The third sector provide a good range of services and the CLDT provide training and support for them. At Pathways and in the Eliburn Centre there is a Band 6 nurse and a part-time Band 5 nurse (who is funded by West Lothian Council), both of whom attend to the significant physical health needs of the people who attend these services; thus providing the clinical expertise to support the medical needs of service users of these two day services.

From a commissioner's perspective, again the issue is not around the number of services but the fact that they appear to be very static and are therefore not very able to adapt to the changing demographics of the learning disability population, such as the growth in the younger population and also the ever increasing older population with learning disabilities.

Services, particularly transition services for children with learning disabilities are not resourced by way of a dedicated team, therefore young people are shared out within the generic staff base, and this may lead to a lack of consistency of practice and expertise within the care pathway. There was some concern over the flexibility of current children's services in relation to Self-directed Support. Although children's services are taking responsibility to progress the implementation of SDS, there exists a barrier in the shape of the commissioned support services which remain in block contracts, so limiting flexibility, innovation and person-centred responses.

In terms of community inclusion the picture of services is on the whole very positive, policy drivers such as "The Same as You" challenged Local Authorities to do things differently and to establish many more community based activities and opportunities. To provide a counter balance to that however, third sector services who work specifically with Autism suggest that they are only scratching the surface of requirements, for example they do not have a group for adults with autism, the fear is that older people with autism are placed within mainstream older people's accommodation, which may be inappropriate for their ongoing needs.

In a Further Education setting there is a perception that there is too little integration of people with different abilities and needs. There also appears to be a pattern of the same people coming to the same courses, indicative perhaps of a lack of alternatives within this sector. There lacks a clear pathway post further education. From the commissioner's point of view it has been noted that there has been extensive work done with the local College to extend choice and develop pathways.

The major centres for day service provision, including Pathways and Eliburn are having to adapt their services to meet the needs of the changing population. These needs can be at different ends of the scale, for example there may be a group of young people with lower intensity support needs attending a day service but this can be offset by a growing number of people with dementia who require a much higher level of support and indeed attending a day service may not be the best option for them going forward.

From a Commissioning aspect, the following challenges are recognised:

- Making progress on Outcomes focused Commissioning - measuring and evidencing progress and meeting of outcomes - monitoring contracts in an outcomes focused way. How does commissioning link to the individual and their outcomes. Link to operational outcomes focused assessment. GAP is at the individual level - measuring change.
- Ensuring people know what they should be getting for their hourly rate and get it.
- SDS - option 2 - Providers achieving flexibility.
- Bringing in-house into the framework agreement from arm's length positioning.
- Autism Strategy sits with young people services on the basis that it is a lifelong condition. Ensuring collaboration across adult and children services and key partners.

- Children and Families – the challenges with young people in transition. SDS is currently only for children with a disability, although there are plans afoot to implement across all children. Children's services are not on the Integration Joint Board - so not within consistency of planning approach. Commissioning services for children with disabilities has some current limitations. There is a Lothian-wide arrangement for purchasing Action for Children, supported by NHS Lothian, which provides Lothian-wide access to crisis children's respite/support services. There are additional services spot purchased over and above this, although this can be very expensive. There is a need to review the current approach. There is critical work to be done in terms of the differences between current arrangements against the expectations of families in children services and adult services. There is a commonly held view that this should be approached as life planning as opposed to the current 'children-transition-adult' processes and system. This needs to be worked through carefully given that adult services will be accountable to a new body (IJB) and children's service will not.

Choice

In relation to whether there is a great choice of services available, the introduction of Self Directed Support has provided an opportunity for individuals to access different services in a more flexible way. To a greater or lesser degree this has allowed services to adapt to the needs of their clients and has led to a greater choice of services.

Self-directed Support (SDS) became the mainstream approach in West Lothian in April 2014. One year on West Lothian has in place a senior manager lead – Head of Service, a Project Board providing governance, has developed an Assessment tool for Adults, Financial framework for Adults and is continuously progressing on these. For children and families, there is a commitment to progress all aspects of SDS to the wider Children and Families groups, not just children with a Disability.

Commissioning approaches reflect a desire to offer a genuine choice and encourage the market to develop.

The recent Care at Home tender has been shaped in lots to reflect geographical areas sitting within a framework agreement. This will give some predictability and opportunity for growth and security. Probably will be used through option 3 in the main. There is also a specialist care framework for adults with a disability, which offers lots of opportunities.

West Lothian is aiming for flexible services with for example virtual transactions with in house provision for the use of Individual Budgets - for example the purchase a service from Pathways.

The issue of block funding for support services was raised as a brake on the choice of services available and it was suggested that providers sometimes demonstrated a degree of inflexibility within their block. This can lead to waiting lists for certain services as once the block of hours are exhausted there is no capacity for any new demand. It should be noted that the agreed approach is to move away from block contracts in favour of framework agreements. Linked to this was the view that some services lacked innovation and still relied heavily on the traditional model of risk aversion, which can hamper an individual's desire to develop skills they may have such as starting their own business, with attendant mentoring support.

In terms of how a choice of services has allowed for more support in the community and enhanced inclusion, the continuing focus on providing care for those with 'special needs' may have isolated some people. There does appear to be a lack of choice for those with autism, which is made worse by a perceived lack of understanding amongst staff providing assessments as some are assessed as being "high functioning" and are then denied support.

The day services have offered a great deal of choice for people, however this is curtailed by their lack of ability to provide services in the evening.

From a Provider perspective, for a Local Authority of the size of West Lothian, there is a reasonable range of services but the geography of the area results in services being centralised in Livingston area. The general view is that there is a relatively poor transport infrastructure in West Lothian and subsequently, for those in outlying local communities, there is limited opportunity and access (for example, transport networks) - inequalities result.

Hidden Populations

A significant issue in relation to services is identifying and reaching hidden populations. There seems to be a slightly lost generation who have been cared for by parents and through being protective of them have to an extent been restricted in their aspirations and achievements. This may include older people with autism and school leavers who, having not accessed transition services are unaware of where they want to go.

Learning disabilities and mental health was also an issue which some saw as a significant population who slip under the radar. They become visible after incidents of self-harming without previously receiving a service for their mental health issues.

One hidden population from a primary care perspective is those with mild Asperger's or lower level ADHD. In truth they are not a priority for GPs, however they do seem to fall within gap between the services provided. Minorities such as Travellers and new migrants are not fully understood.

Although the population itself is not "hidden" as such, people with autism don't always find the day centre environment easy to be in, therefore any specific services have to be developed uniquely, the costs of this can prove restrictive.

There are young people with a learning disability getting involved in crime/on the edge of crime/no court orders but out of control and falling under influence of criminals. The number is increasing. There is a gap in provision of 'forensic learning disability services' in West Lothian. This needs to be quantified and should perhaps be better addressed within the Criminal Justice Strategy.

Resources

When discussing resources the interviewees predictably to a degree differed widely in their opinions. Those representing the 3rd sector felt that there was very little resources available especially for those with autism. On a wider issue there is an ongoing discussion/review within West Lothian Council regarding eligibility criteria. West Lothian Council do not presently seek financial contribution for services. The Council will be making a decision on this later in the year, and it is acknowledged that this may have a significant impact on the people of West Lothian. Indeed, it may result in an increased, perceived, tension between efficiency and quality. The perception is that this tension may impact upon the maintenance of a competent, well trained workforce who can work well within families, as the costs of maintaining this are at odds with efficiency savings.

When asked about what works particularly well for services for people with learning disabilities, a number of key good practice examples were given; including Muir's Court in Uphall/Broxburn. The West Lothian Community Learning disability Team is a much focussed committed service (for more see details of CLDT see specific Focus Group later in this chapter). They provide a whole range of services including:

- Health surveillance.
- Epilepsy management.
- Treatment and monitoring of mental ill health.
- Sexual health issues.
- Behaviour management and supports for parents with a learning disability.
- For people with a learning disability in general, there is the practice of having a learning disability community nurse as a link with one, or a group, of GP practices – this could be built on and social work/LAC included in the communications and learning.
- People with learning disability and dementia - screening of people with learning disability who have Down's syndrome is core practice for Psychology and nursing. A tool for the use of Carers to assess for dementia in someone with Downs has been developed.

In terms of the co-ordination of learning disability services from a social work perspective, it was felt that there are some competent and knowledgeable workers locally who take a social inclusion approach; a model which could be expanded to other areas such as physical disability and autism.

In relation to working specifically with autism, the third sector recognise the contribution made by some parents in setting up very small but effective groups; however, there were some fears expressed over the sustainability of these groups, unless they are supported by the local authority.

In a general sense the provision of respite and opportunities for people to socialise with their friends is a positive component of service provision.

Identification and Assessment

On a more systems approach the assessment process is considered to be fairly robust by local authority managers and despite some previous misgivings about the separate components of someone's care package those responsible for commissioning services appear to suggest that these are in fact working well together. In terms of appropriateness, from a community inclusion perspective, the referrals they receive correctly match up with the services they can provide. On very few occasions does an individual need to be re-assessed. This view is reinforced by the view from Social Work Management that assessment workers are very skilled and have a robust understanding of needs and with the promising start of the roll out of Self-directed Support, service users now have more choice and with that more power in directing the care they receive. Monitoring and managing budget spend is critical. Devolved authorisation is in place, with authorisation at levels from CCA upwards – where the IB will be higher than what would be the equivalent, management approval is needed. Group managers are close to Team Leaders and offer support and close working.

The Outcomes focused SDS Assessment tool, 'All about me: what I need' appears to work well but the need for continuous improvement is well acknowledged. Views from practitioners using the tool are mixed, indeed the Adult SDS tool is not universally popular but with experience and confidence staff are beginning to see the benefits. The tool requires thinking which focuses on Outcomes and not 'hours' and 'tasks'. Staff need to regain skills of analysis within the assessment process. It is recognised that the assessment tool needs to:

- Takes account of the family/informal care provided.
- Can be easily translated onto financial spreadsheet which calculates amount of Individual Budget (IB).
- Assessor can evidence why certain box is not ticked – all based on evidence.
- Capacity decisions should be incorporated under 'Making decisions' section.
- Staying safe section and Complex needs and risks have been kept as two discrete sections intentionally.

An Outcome focused review tool is being developed - the quality of life indicators established at point of support planning will be reviewed and difference recorded – so evidencing meeting of outcomes.

A Carers assessment is also being developed.

In line with the discussion around previous aspects of service provision, there does appear to be a significant difference between the identification and assessment of children and that of adults and also between those with certain learning disabilities and those with autism.

The assessment of children is carried out with the framework of the Getting It Right for Every Child[196] policy driver from the Scottish Government, which has its limitations for the assessment of children with disabilities, as lower level needs may not be identified and therefore the incorrect assessment made. The appropriate service needs of the child may not be picked up until they are assessed as an adult. For those who provide services within a day centre environment the key to assessment and identification is to work with the families from an early age, involving family visits and multi-agency planning. Ongoing assessment is also key to meeting people's needs, as those who attend the Pathways centre for example do so for quite a considerable length of time, during which their needs will change as they get older for example.

From an NHS standpoint the ongoing issue of identification and assessment stem from the lack of diagnosis of a learning disability for children. The NHS staffed Community Learning Disability Team therefore use the criteria as a flexible way which best meets the needs of service users. From the perspective of primary care delivery, the assessment of children with Learning disabilities appears to be better than it is when you reach 18, this does fit well with the overall discussion of transition and

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[196] Getting it Right for Every Child, Scottish Governement, 2006

especially the view of services user (See Chapter 6), that services tend to be few and far between when you leave school, with the exception of college. From the Colleges' viewpoint this transition is supported by referrals, processed through the schools, identifying needs and meeting those. This is true for full time placements, the part-time course are perhaps not so well advertised therefore awareness and take-up has been poor.

From a Third Sector perspective, West Lothian teams provide quality assessment. The NHS Community team provide a range of services but lack of 'positive behaviour support 'team type resource. There are limitations in close working between Council and NHS teams - the pathway is not streamlined for person and their family.

At direct odds with the view that, notwithstanding certain limitations, identification and assessment is fairly good; stands the view of services that work directly with autism, who view assessment as being *'horrendous'*. There was a general view expressed in relation to a perceived lack of understanding of autism by social work assessment staff, which has only been compounded by the introduction of Self-directed Support, which instead of offering the choice it was supposed to, has led to inadequate assessment; thus, in practice, meaning that almost 90% of the clients of an Autism third sector organisation have had their budgets for support reduced.

Accessibility

As with most services within the health and social care field, there are a number of routes through which someone can access the services, whether that be through a GP, self-referral or social work assessment. There are certain services which most people know about, for example Eliburn and the Pathways Centre. In terms of physical access they are both well catered for in terms of transport to them. Pedestrian access from the main road is an issue for the Pathways Centre as there are no obvious footpaths to the building's entrance.

The main challenges in relation to accessibility for those managing teams covering children with a range of disabilities was one of covering the whole spectrum in a consistent way and that without a robust input from health services, either financially or professionally, accessibility for some people was restricted. This aspect must also be set aside the fact that services can be quite dispersed, and don't always work in a co-ordinated fashion. In addition to the systems based accessibility issues there are also the transport related ones, an especially important issue for those with Learning disabilities.

Communication is a fundamental aspect of service accessibility and this is highlighted more predominantly within the forthcoming chapter which details the view of service users and parent/carers, however there does appear to be a lack of effective marketing of available services which would thus reduce the number of individuals with learning disabilities who use them. This was alluded to in the previous section on Identification and Assessment for the perspective of the College.

In relation to the College one important issue relating to accessibility is that due to the lack of available space for parking a motorised scooter for example, those with profound learning and physical disabilities not particularly well catered for. The College for their part however are willing to expand their provision within the community.

Service Integration

The whole issue of services integration must be seen within the context of the Health and Social Care Integration agenda nationally, however from a clinical standpoint there could be more integration with social work at present. This may improve the further established health and social care integration becomes, however with the reduction in the financial resources available, this process will need to be handled very carefully to avoid unnecessary duplication. Evidence exists of good collaborative practice, the smaller size of West Lothian Council, in comparison to others, does allow joint working due to services being familiar with each other, but systems still seem to be separate. There is and agreed Data Sharing Protocol in place which should enhance the joint working between services; although not everyone is aware of this.

Where integration appears to be flawed is in respect of reconciling the health and social care models of care. From the perspective of some a team should be built around the person and their needs and not fitting the person into the team.

The third sector, especially services who work with autism, do appear to work very well with health (CAMHS) and Social Work, primary, secondary and further education; however, they do feel that their clients do require more information about services in order for them to fully integrate in terms of a care pathway. Despite a public consultation being conducted by West Lothian Council on their recent Autism Strategy, Autism Initiatives reported that they were unaware of the consultation and so were those who use their services.

Accessibility and Integration into Mainstream Services

A crucial aspect of community inclusion is the use of mainstream services by people with a learning disability as and when required, and not just in an emergency or crisis situation, as informants reported is often the case. With respect to children it would appear that access to Community groups are not widely supported for children and young people with a disability. Improvements here could lead to opportunities for children and their parents to benefit from increased confidence and further respite for the parents.

From the perspective of health care there are some good examples of people with learning disabilities accessing mainstream services; such as access to mainstream mental health beds, a learning disability liaison nurse and a forensic team who will work directly with mainstream criminal justice services. There is a full ‘health passport’ in practice, which will play a key role in integration, and is supported by a systems-wide policy instructing on the care and support of people with learning disabilities in acute hospital settings. There is also the eKIS (electronic Key Information Summary), which is held at GP level and corresponds with systems across the full spectrum of service tiers (GP, secondary, tertiary care, A & E and NHS 24). This is also part of the current Enhanced Service Contract with Lothian GPs.

A limitation to the use of mainstream services by those with a learning disability is perceived to be the skills and knowledge of the staff in these services. For example, a local GP noted, it is important that people receive the best care and that may be best delivered by people with knowledge of the issues affecting people with learning disabilities rather than by mainstream services. In a way supportive of this practice is the view from those delivering large scale day services that many of their clients are not screened annually and that GPs take advice from parents and carers, which may not always be in the best interests of the patient but may be based on the assumption that they know what’s best.

There is a view that older people with a learning disability are do not have equitable access to older people services, particularly Dementia services. The National Dementia strategy and 8 Pillars talk of access for all, but in practice there are still barriers for people with a learning disability.

In terms of community access there are some ongoing developments such as leisure facilities which are being improved and day services for those with learning disabilities are being consulted upon how best these can be available for the use of individuals with learning disabilities.

5.14.2 View on what services should look like in the future

Gaps in current provision

In general terms there was consensus (from all perspectives: health, social care, third sector and further education), that there are significant gaps in current service provision.

Pressure on resources of course can accentuate gaps and establish a culture of the ‘revolving door’. The main gaps identified throughout the interviews were:

- Transition;
- Severe autism and challenging behaviour;
- Local opportunities for those with complex and challenging needs to live in West Lothian to prevent being dispersed to other areas of the country;
- A range of opportunities for people with mild learning disabilities which are community based and promote being valued - e.g. training for work/ employment/being active citizens ;
- Communication of information about knowledge and development of community based resources;
- Improved inter agency collaboration regarding assessments;
- The range of respite opportunities;
- Housing support for those who wish to live independently;
- Advocacy services;
- Training and skills development in mainstream health care;
- Specialist services (one has had recently to close) for children with autism at the point of transition;
- Services such as a central information point for people with milder learning disabilities;

- Specific services for those children in the community who have limited resilience such as internet safety;
- Opportunities which integrate and prepare young people for life as an adult;
- Employment opportunities;
- Evenings and weekend services and with associated opportunities to interact; and
- Integration of the existing further education provision into courses that can lead to a qualification.

Future Investment

In an age of austerity and shrinking resources, the answer to the question of where future investment should be focused is always prone to significant limitations. However, during the interviews there seemed to a leaning towards using any available resources to enhance existing services, with increasing the capacity and range of services following on.

In the context of reducing resources the suggestion was made that opportunities and services to increase independence were required more and more to reduce the need for services in the long term by building upon personal skills and strengths to develop and change lifestyles, whilst meeting their needs. This could also be achieved by investing in more independent living opportunities but investing at the same time in promoting skills development and positive risk taking. Currently there is a significant investment in Core and Cluster type new build accommodation which may allow those opportunities to be offered.

From a specific perspective of those with Asperger's or adults with autism, a useful way of allocating future resources which was suggested, was the co-ordination of the various parent led groups in order to provide a more needs based provision with a clearer direction and purpose. For the embedding of SDS there are recognised challenges:

- Further change for practitioners from the Transfer from SWIFT to new information system – AIS – Adult Integrated System. This will require learning and readjustment.
- Getting away from the tick box assessment practice, replacing with an emphasis on 'conversations' with people.
- Continuous improvement on 'assessment recording tool' to make as streamlined as possible – this needs to be suitable and appropriate for all client groups.
- People who do not have capacity to make decisions – we cannot assume that SDS will not be an option. For example, people with complex and multiple needs. West Lothian need to consider SDS being for all and make best use of use of circles of support, for example, to protect human rights. Choice and decision should be based on good information and engagement.
- Making pooled budgets work where a desire and appropriate.
- Where multiple occupancy and receiving one provider as per commissioning arrangement – enabling one person to opt out for another provider.

- Having the capacity for reviewing and transition to SDS with people having an Individual Budget, where eligible, and choice.
- Need to focus on complex care needs in the Community – where do NHS resources fit in. Need for engagement with partners in NHS with regard to shared funding.
- With integration (change), principle of shared assessment and recording – NHS staff will need knowledge and understanding – WL proposing eLearning for NHS staff initially. Within integration, need for full workforce development programme, including Communities of practice.
- Commissioning and Framework agreement – pre- dates the current learning disability and physical disability needs assessments, so commissioning structure will not be fully informed.
- SDS and eligibility criteria – Charging policy - West Lothian demand no contribution at present but COSLA leading and looking for consistency across Scotland. Eligibility thresholds need to be reviewed. Early intervention/prevention versus eligibility of critical/substantial levels - do not sit comfortably together.

Asset Mapping

The vast majority of assets which were identified have been mentioned elsewhere in this chapter under current service provision, one important service, the NHS Community Learning disability Team, is the subject of the next section of this Chapter.

A service in Edinburgh called Number 6, which operates as a drop-in service for those with autism, is a very good asset. Informants reported that it is currently underutilised by those living in West Lothian, although performance statistics suggest good usage by West Lothian residents especially those not known to social work. This will be worth checking out given this contradiction in reporting.

There is a joint accommodation strategy being developed which addresses how housing can be woven into the overall health and social care agenda, this may well provide additional assets.

Lothian Public Health are currently working on data sharing protocols and there is a Data Sharing Protocol Working Group in place. There is a lack of clarity re the ownership of data. The Lothians Caldicott Guardian has a focus on secondary care data. GPs are their own guardians regarding primary care data. Getting sharing of information right is essential to health improvement.

SPIRE is the tool to enable interrogation of primary health practices via the extraction of data electronically. GP's will have to give consent to the data being extracted. This has not been agreed as yet, although national work continues and is supported by SPHO. This is being piloted in two Health Board areas, in order to inform the development of a national database – as per 'Keys to Life' Action plan.

Through the implementation of the NHS Lothian Strategic Plan, there are two 'House of Care' Pilots being conducted - in Midlothian and Edinburgh. One pilot, working on improving the knowledge of people with learning disability and the health services they receive. GPs and Community Learning Disability Teams are working to develop an integrated care pathway, focusing initially on those most at risk and with complex needs - and particularly looking at multiple morbidity:

- learning disability and epilepsy;
- learning disability and dementia; and
- learning disability and mental health.

The other pilot, in Midlothian, is working on supporting people to access services in addition to GP's. Link workers are based at the GP practice and offer services of advice, signposting and connecting.

5.14.3 The Community Learning Disability Team

The structure of this section will mirror that of the previous one in so far as the question asked and the discussion ensuing from that will be given using similar headings. The focus group was conducted in the CLDT premises at Fairbairn House in Livingston. The vast majority of the team's personnel were present.

Current Service Provision

In relation to the provision currently and whether it is sufficient to meet presenting needs, 25% of those with a learning disability have a profound PD. There is no equivalent team working with those with Physical Disabilities. The CLDT work equally with people with complex needs, and those with profound and multiple learning disabilities (PMLD).

There appears to be no consistent understanding across health & social care of terms such as complex needs. The team stated that they hope this Needs Assessment will provide this clarity.

Services have not developed to meet the increasing needs of the population. The continuing existence of waiting lists highlight this, even when fully staffed there are lists. The waiting list for Learning disability nursing is around one year. learning disability nurses also work with children. The rest of the team is just for adults.

- SLT can't run a waiting list for those with Dysphagia – these people are seen within 5 days.
- Learning disability Dietician no longer offers weight management services because the waiting list would be too long.
- There is no waiting list for acute post-op physio. There was a plan in 1995 to increase/expand the physio service to keep up with predicted demand. The main problem is recruitment there is currently a FT vacancy for a physio.
- Psychiatry – no waiting list. Urgent cases seen within 2 weeks; 4-6 weeks for non-urgent cases.
- Psychology – no waiting list.
- Art therapy is very thinly spread across the whole of Lothian.

It was universally agreed that the team has never had the opportunity to plan/develop the service to meet increasing future need. But they were adamant that whatever/however the team is developed they'd want to ensure the current service is ring-fenced and that when the team moves forward and developed it is done so with appropriate resources.

> *'Budgets need to be realistic.'*

This team work with a demographic of those who live in day-to-day crisis. This group are just surviving and going through the motions. These people won't necessarily have the time or energy to give their opinions.

Health care respite is available for those with PMLD at Murraypark. Any other health care respite is not considered as a feature of NHS services for people with learning disabilities. The team suggested that social care respite is fantastic, but places are very limited. There is only one emergency bed and it is always occupied.

Those with mild learning disabilities, but complex MH needs are often pushed into hospital; but this is not appropriate however there appears from their perspective to be no other option though.

> *'There is an insufficient breadth of models of respite.'*

The level of respite for adults with learning disability is significantly lower than for children with learning disability. For instance, some children with learning disability get 20 nights per month respite; the maximum level for adults with learning disability is 42 nights per year; many clients only get around 15. Levels are based on a Social Work assessment; carers need to ask for review if they want more.

Any form of residential care is lacking in WL – some in need are told they have to move out of the area (often in to nursing homes). This affects their entire life – they can't maintain friendships etc. Poor residential placements for PMLD (4 places, 50 applicants).

The current provision of Day Services is considered to be good, with an exception that there is none for the Insulin dependent population. Day service carers are not permitted to give insulin; but more than that, these carers are not permitted to make the decision to call the district nurse to say they think a client needs injecting. Policy dictates this. The same is true of 'as and when' medications for anxiety. This is a complex area of work and will require careful consideration to find appropriate solutions.

Choice

In respect of choice the team's view was very much in line with those of managers within the different strands of service provision, however they made special mention of Day Care provision and applauded their commitment to helping and supporting people who use their services. In respect of Self-directed Support they recognised the potential it has for providing more choice to recipients, however their experience also of people being overwhelmed with the amount of work which accompanies the process.

Hidden Populations

Other than those populations noted within other sections of this report, the team identified the following groups as being potentially 'hidden' and therefore not always able to receive the services they need:

- Profound and Multiple Learning disabilities;
- Forensic (i.e. offenders or potential offenders);
- Mental health;

- Some with learning disability often also experience multiple mental health issues such as trauma/anxiety/psychosis;
- CLDT only see patients when Mental Health conditions are externally manifest – they don't see the long-term depressed etc.;
- Weight management;
- Borderline Range of Intellectual Functioning (i.e. those with mild learning disability); and
- Under 65's with Dementia.

It was noted that often self-harm and psychiatric damage is directly linked to lack of purposeful activity.

It was further noted that the level of service can often be diluted by the *'coffee-club culture'* – lots of those with learning disabilities spending their time at the Livingston Centre having coffee and cake. Aside from the physical health implications, mental wellbeing can also be affected.

The Local Area Coordination team deal with this demographic. Some informants were of the opinion that there is a significant waiting list for this service for those with less severe learning disability. An example given was that the time lapse between an initial referral letter for a patient being sent to the LAC team and then being seen can be up to two years. This demographic may also misuse substances and/or self-medicate with alcohol and/or illegal drugs.

Resources

Whilst the team, as non-budget holders felt unable to comment on this in detail, they did express a concern that with the forthcoming integration of health and social care, that their budgets would remain as it was and not been subsumed with social care. They felt very strongly that the dilution of learning disability services would be very much a retrograde step.

What works particularly well

In terms of their own team they saw autonomy as a major strength. They consider themselves to be individual practitioners who work closely as a team, with good communication between themselves and other services. Linked to this is the feeling that there is a good understanding of different roles and responsibilities within the team. The CLDT consider themselves to be very committed because all team members have chosen this specialism/role. In relation to working with mainstream health services, there are some really good interactions between the CLDT and health. They work closely with Day Services and various sections of Social Work such as the SW Adult Learning Disability Team and Occupational Therapy.

The Learning Disability Epilepsy Service is considered to be a very efficient team and operates across the Lothians. It is a unique service. It is based in the community and neurology refer complex cases (those involving behavioural/psychological issues) as well as cross-referring.

West Lothian has a specialist ASD team based within Social Work.

Identification and Assessment

In their view and in line with other professional they do see a gaps in identification in childhood, partly perhaps as a result of no specialist Paediatricians.

This could also be a result of a cultural issue – the notion that it is wrong to label people for life. There is also confusion re terms used e.g. Global Developmental Delay (GDD)/Development Delay (DD). Some come into the CLDT with non-specific diagnoses like GDD – this is not sufficient to access resources etc. This team have resources within our team to carry this out and do so. There are robust screening processes for new referrals within the team.

A nurse with another professional does an initial Risk Assessment and screening to see whether the referral is appropriate, and if it is, who is best placed to take the lead. If it is not clear whether the referral has a learning disability, St Johns do the assessment.

Accessibility

In the team's opinion accessibility has improved in recent years, perhaps again due to this services open referral system. GPs often refer and the relationship between the team and primary care services is key. There is a liaison within every GP practice. The alternative side to this however, is that the CLDT doesn't promote itself for fear that it will not be able to deal with the increased demand. They also believe that the referral system for Social Work could be improved. In practice we have waiting lists, these vary within specialisms. An inability to discharge affects them in certain areas, e.g. Epilepsy, PT, EDS, and PMLD. Culturally, it is assumed that discharge is the measure of success, however for some in this demographic, discharge actually creates more problems.

Often Social Work referrals are diverted to LACs and may sit with them for some time. Any referrals to SW OT need to go through the client's named SW / duty SW. This can add to the time the client has to wait to receive a service.

Service Integration

This team do not do joint assessments; however OT's do on an individual basis. There are occasions where health and social care perspectives are at odds in respect of joint care planning. Paradoxically this can sometimes be good for the patient, but sometimes it is viewed as being dangerous.

> *'Sometimes the common sense approach is lost in the system.'*
>
> *'The system can't be circumvented.'*

For joint reviews, there appears to be a robust system for this team to share their views with other teams and disciplines; through such areas as Case Conferences, Professional Concerns meetings, and Core Groups. Social Work attend their team meetings.

In terms of communication, at a personal level are considered to be extremely good. Communication at the informal/local level is based on mutual respect. The team felt that communication is much better than it was.

The team shared a concern regarding the standard of IT equipment available and the challenges faced through integration of joining up IT systems.

As for information sharing, there can be problems accessing notes – often practitioners in the other service just get formal reports which don't provide the necessary/useful background. There was a generally acknowledged fear that the H&SC budget could be spent on IT.

Form this team's perspective, joint premises was seen to be the answer to integration.

Accessibility to and integration with other mainstream services

The team's view was that there are a small number of their clients who would be able to access some of these services but only with support. PMLD & Complex Needs clients would struggle to access these. Liaison nurses are a very necessary support to enable this.

Gaps in Provision

In summary the team identified, in line with their previous comments the following:

- PMLD– Respite & Residential/Supported Living services;
- Young people with early onset dementia – Residential;
- Changing needs of the Learning disabilities population as they live longer;
- Staffing – Increasing population/decreasing staff;
- An effective integrated care pathway; and
- Better links and pathways for Forensic & Mental Health clients.

Resources

Perhaps not surprisingly for a front line team, in terms of priorities for any future resources, increasing capacity, namely increasing staffing, was seen as the first priority, as they felt the range and quality of the services provided was already good. They also felt a need for more respite provision for those with increasing healthcare need would be an important target to resource.

Asset Mapping

In terms of other assets the team suggested clearly that they need Health Specialist services to continue as they support the mainstream services, furthermore they need more health/social care support workers to work along with CLDT's. In their opinion if staff and training levels were increased in social care they would be able to support the client better to access the mainstream services.

This team provide a significant amount of training to other teams and mainstream services, which helps protect these assets for service users in the future.

In summary the group's views were very clear of where they saw their role within the provision of specialist services to those with Learning disabilities of all levels with West Lothian. Their concerns over the dilution of their funding as a result of health and social care integration, are based solely on their desire to continue to provide the best service possible. As a front line service they identify issues such as 'end of life' care as being a particular area which needs to be reviewed, given the ageing Learning disability population.

5.15 Key Findings

- Communication needs to be improved not only between services but also with services users and parent/carers.
- More housing for independent living is increasingly required as the demographic changes.
- A range of specialist training events should be developed for staff in mainstream services to aid better integration.
- There is not a genuine choice of services available although there may be a number of services, people very often are required to fit the available provision.
- Generally service user involvement is good, with opinions being asked and ideas implemented.
- Joint working between services is generally good but could be better particularly in relation to integrated care pathways.
- Transport is a key area of concern, in terms of accessibility to services.
- Services do offer a degree of flexibility but require to adapt more to the changing profile of the Learning disability population.
- The Assessment process needs to be reviewed in order to increase access to services.
- Opinions are divided over the efficacy of Self Directed Support, perhaps compounded by what parents/carers and those staff supporting them, see as lack of information.
- Any future resources should be focussed on expanding the range of services available.
- The services offered by The Community Learning disability Team are a key component of service provision in West Lothian as are the services provided by the Social work teams. The weakness is the lack of joined up thinking and close working.
- There are gaps in services to people with a learning disability and people with Autism who offend. It has been suggested these issues need to be understood and included within the Criminal Justice Strategy. There needs to be collaboration between Criminal Justice Strategy and Learning disability/Autism Strategies.
- SDS poses a number of key challenges to staff across the partnerships and to lead officers and commissioners - these are referred to within the Future investment element of this Section.

CHAPTER 6: QUALITATIVE APPROACH (FELT AND EXPRESSED)

6.1 Introduction

The purpose of this element of the research was to seek the views from service users and carers on the current provision of specialist learning disability and autism services across West Lothian. Specifically, service users and carers were asked to provide their views on the quality of services, key issues, gaps and areas for improvements.

Findings in the first part (**6.2-6.9**) of this chapter derive from quantitative surveys which were distributed to service users across West Lothian during June 2015; with the aid of learning disability and autism service providers. There were two identical versions of the survey used; namely an online version and a hard copy version.

Findings in the second part (**6.10-6.15**) of this chapter derive from quantitative surveys which were distributed to families and carers across West Lothian during June 2015; with the aid of learning disability and autism service providers. There were two identical versions of the survey used; namely an online version and a hard copy version.

Findings in the third part of this chapter (**6.16-6.19**) derive from five service user and family/carer focus groups held in June 2015 (two groups were held with service users only; two groups were held with family members and carers only; and the final group was a mixed group).The views of service users and carers expressed through the stakeholders event (20th May 2015) and the two working group sessions held on 27th May 2015 and 5th June 2015 are also captured in this section.

6.2 Service user survey - response rates

There were 43 responses to the service user survey, of which one response was discarded as the respondent completed only a few fields (personal information) of the survey. The overall total of responses used for analysis was therefore **42**, broken down as follows:

- 21 out of 42 (50%) responses were deemed ‘complete’, as 100% of questions were answered by respondents.
- 21 out of 42 (50%) responses were considered ‘incomplete’, as:
    - 17 of 21 respondents completed 50%-99% of the survey;
    - 4 of 21 respondents completed 20%-49% of the survey. These six respondents did not complete the optional questions regarding demographic information.

6.3 Limitations

One limitation concerning analysis of the service user survey element of the Needs Assessment centres on the low number of responses to the survey (n=42).

A second limitation is in respect of the varied quality and depth of responses given the nature of the learning disabilities of respondents.

The final limitation is that 50% of surveys were only partially completed; therefore some care should be taken when interpreting these findings.

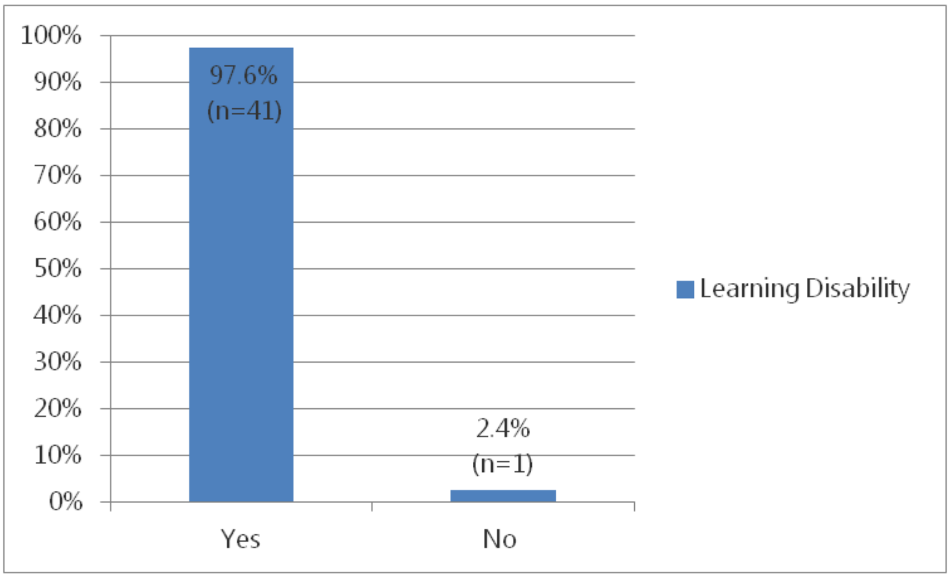
Although, the survey was an important element of the study, the above limitations mean that the strength of the evidence gained through the survey is restricted. In light of this, the evidence gathered from service users through the varied qualitative elements of the study is deemed to be stronger and has been given greater consideration when forming the conclusions and recommendations of the study.

6.4 Demographics

6.4.1 Diagnosis

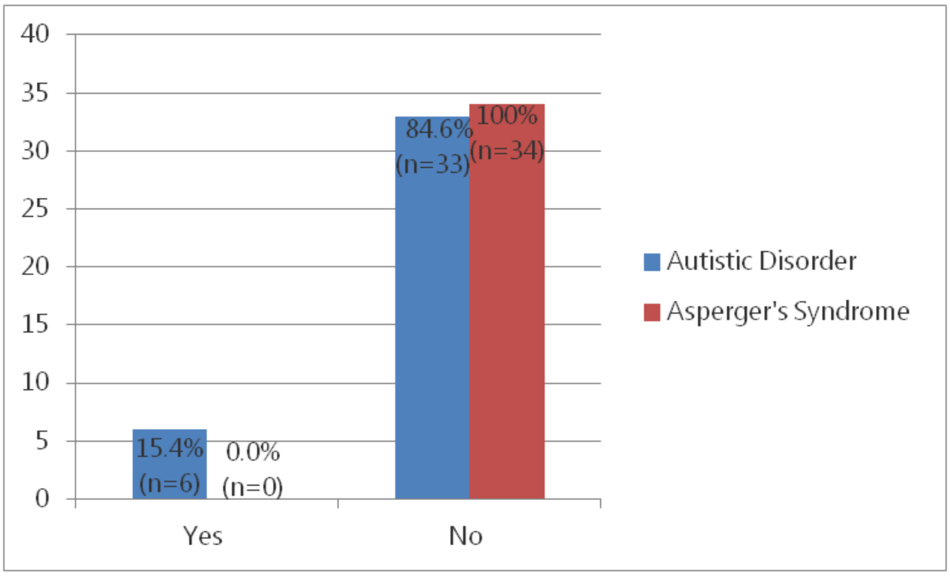
Respondents were asked whether they had a learning disability. The majority of respondents (97.6%; n=41) indicated that they a learning disability. Only one (2.4%) respondent did not have a learning disability.

Figure 6.1: Breakdown of respondents by diagnosis of Learning disability



Respondents were asked to indicate whether they have an Autistic Spectrum Disorder or Asperger's Syndrome. Six respondents (15.4%) indicated that they do have an Autistic Spectrum Disorder, whilst there were no respondents (0%) who indicated that they have Asperger's Syndrome. The majority of survey respondents indicated that they do not have an Autistic Spectrum Disorder (84.6%; n=33) or Asperger's Syndrome (100 %; n=34).

Figure 6.2: Breakdown of respondents by a diagnosis of Autistic Spectrum Disorder or Asperger's Syndrome

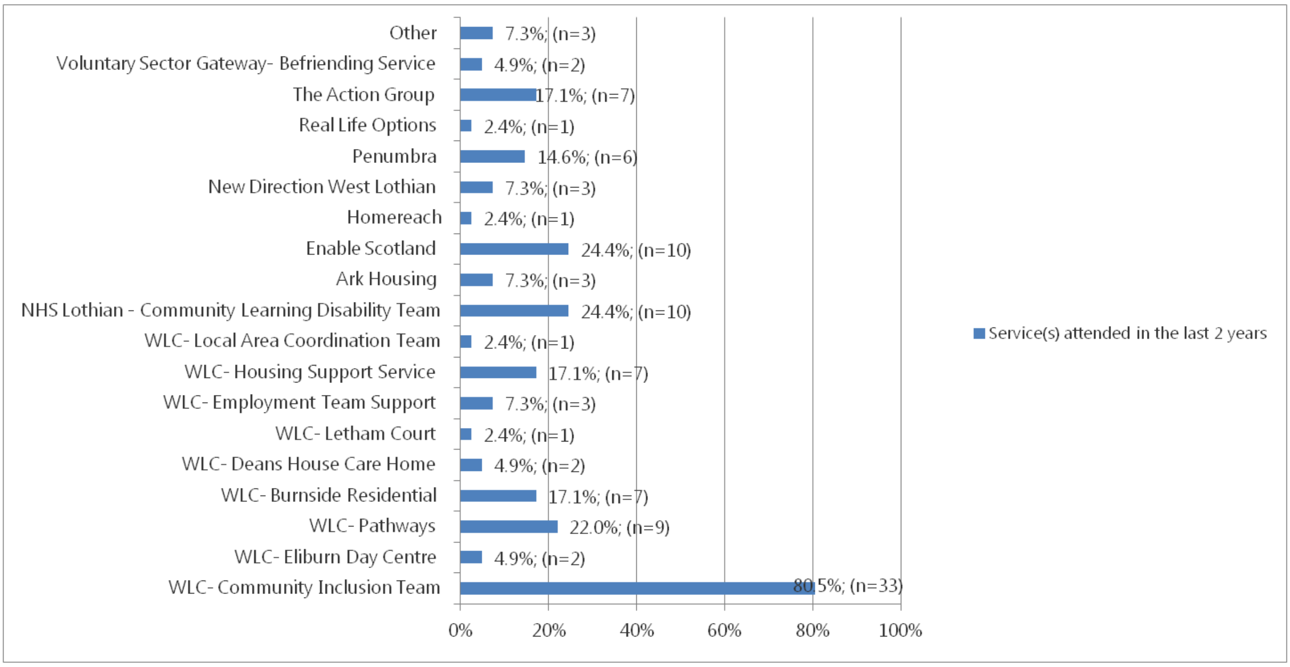


6.5 Services

6.5.1 Services recently attended (within the last 2 years) or currently attending

Respondents were asked to specify what services they have attended within the last 2 years. The majority of respondents had attended the Community Inclusion Team, with just over 80% of respondents ticking this option. Following this, the services with next highest responses rates were Enable Scotland (24.4%; n=10) and NHS Lothian – Community Learning disability Team (24.4%; n=10).

Figure 6.3: Services that were attended by respondents in the last two years



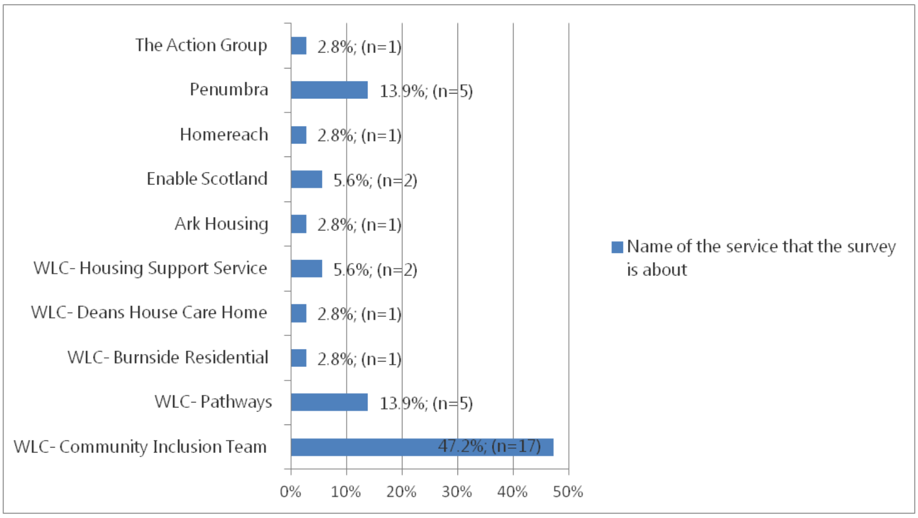
There were no respondents indicating attendance at the following services within the last two years:

- Autism Team (West Lothian Council);
- Social Work Assessment Team (West Lothian Council);
- Autism Initiatives UK;
- Barony Housing Association;
- Key Housing Association;
- Leonard Cheshire Disability;
- Mears Care ltd (Glasgow);
- Place for People; or
- Quarriers.

6.5.2 Service which survey response is in relation to

Respondents were asked to specify the service which they were answering the remainder of the survey questions about. The majority of respondents were answering the survey about the West Lothian Council Community Inclusion Team (47.2%; n=17).

Figure 6.4: Services that respondents were answering the survey about



There were no respondents who answered the survey about the following services:

- Autism Team (West Lothian Council);
- Social Work Assessment Team (West Lothian Council);
- Autism Initiatives UK;
- Barony Housing Association;

- Leonard Cheshire Disability;
- Mears Care Ltd (Glasgow);
- Place for People;
- Quarriers;
- Scottish Autism; or
- The Richmond Fellowship.

6.5.3 Extent that respondent agreed/disagreed with statements about service(s)

Survey respondents were asked indicate whether they agree or disagree with a number of statements about the service which they are answering the survey about by using the following rating scale:

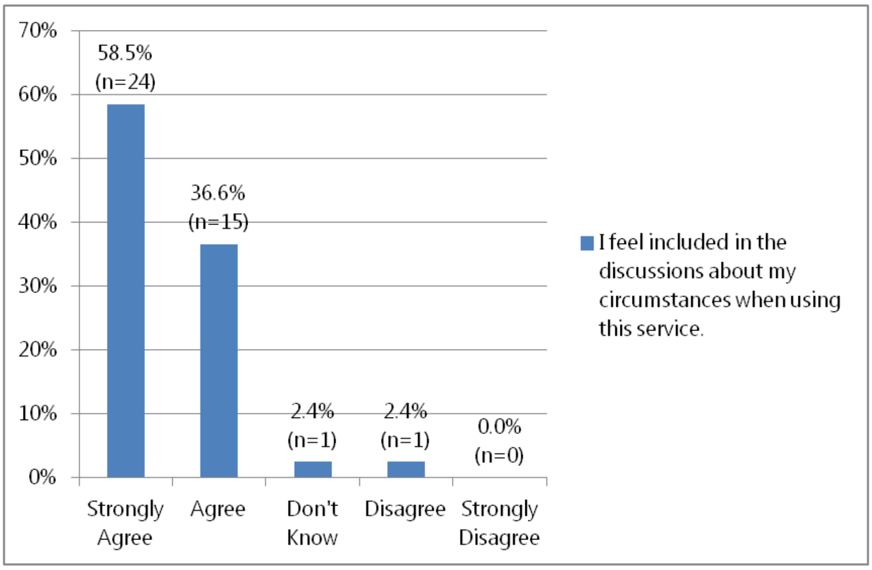
- Strong Agree
- Agree
- Don't Know
- Disagree
- Strongly Disagree

The following figures provide breakdowns of the extent that respondents agreed or disagreed with the following statements:

- 'I feel included in the discussions about my circumstances when using the service.'
- 'The staff treat me with care and concern.'
- 'I have confidence and trust in the staff of this service.'
- 'I feel safe using this service.'
- 'Overall, I feel that my experience of using this service is good.'

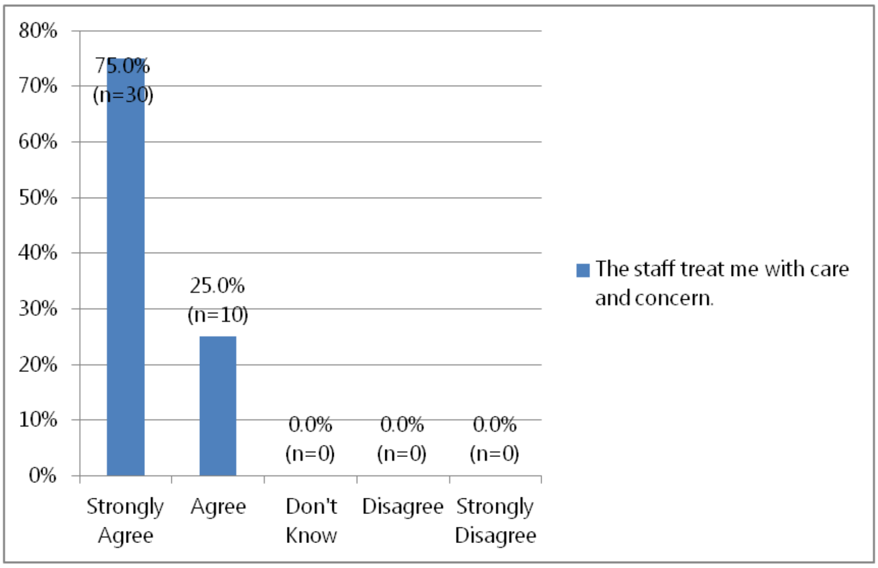
Respondents were asked to what extent they agreed with the statement *'I feel included in the discussions about my circumstances when using this services*'. 24 (58.5%) respondents 'strongly agreed' with this statement, this was followed by 15 (36.6%) respondents stating that they 'agree' with that statement. Only one (2.4%) respondent 'disagreed' with this statement and one (2.4%) respondents stated that they 'Don't know'.

Figure 6.5: Extent that respondents agreed with the statement 'I feel included in the discussions about my circumstances when using this service'



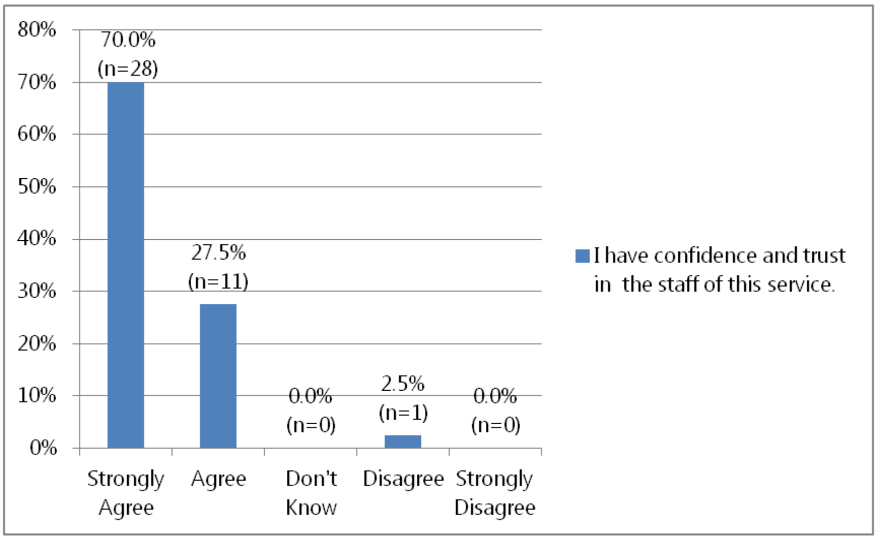
Respondents were asked to what extent they agreed with the statement *'The staff treat me with care and concern.'* Three quarters (75%; n=30) of respondents 'strongly agreed' with this statement and one quarter of respondents 'agreed with this'. There were no respondents that disagreed or strongly disagreed with this statement.

Figure 6.6: Extent that respondents agreed with the statement 'The staff treat me with care and concern'



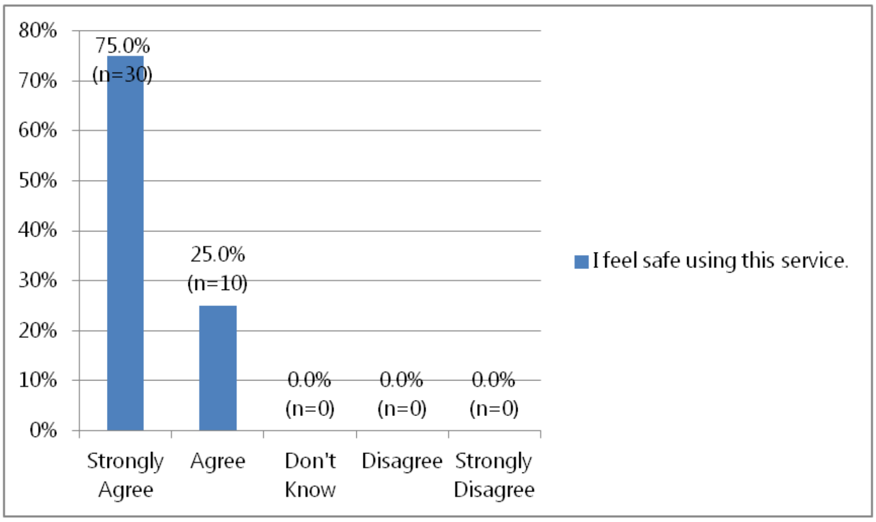
Respondents were asked to what extent they agreed with the statement *'I have confidence and trust in the staff of this service.'* The majority (70%; n=28) of respondents 'strongly agreed' with this statement and just under 30% (27.5%; n=11) of respondents 'agree' with this statement. One (2.5%) respondent 'disagreed' with statement.

Figure 6.7: Extent that respondents agreed with the statement 'I have confidence and trust in the staff of this service'



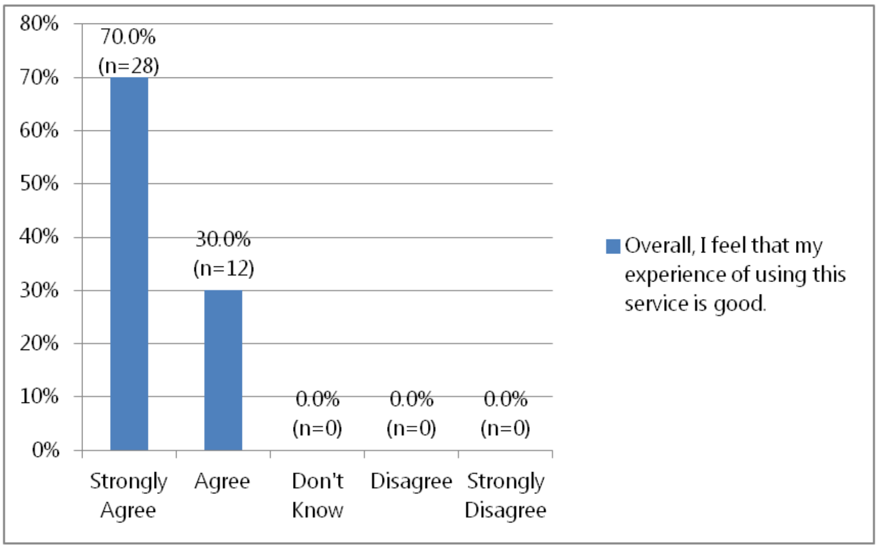
Respondents were asked to what extent they agreed with the statement *'I feel safe using this service.'* 75% (n=30) of respondents stated that the 'strongly agree' with the statement '*I feel safe using this service*'. A quarter (25%; n=10) of respondents 'agree' with this statement. There were no respondents that disagreed or strongly disagreed with this statement.

Figure 6.8: Extent that respondents agreed with the statement 'I feel safe using this service'



Respondents were asked to what extent they agreed with the statement *'Overall, I feel that my experience of using this service is good.'* 70% (n=28) of respondents strongly agreed with this statement and 30% (n=12) of respondents 'agreed'. There were no respondents that disagreed or strongly disagreed with this statement.

Figure 6.9: Extent that respondents agreed with the statement 'Overall, I feel that my experience of using this service is good'



6.6 Quality of Services

6.6.1 What respondents like about services

Service users were asked if there was anything they liked about the service they were answering the survey about. There were a number of key themes that emerged; which are presented below:

- 12 respondents indicated that they liked the staff that worked at the service:

> *'The staff are friendly and helpful.'* (WLC- Burnside Residential)
>
> 'Staff *are very good and helpful.'* (Service Unknown)
>
> *'I like my key worker [name] because she helps a lot and [name] and [name]. I like everyone in the inclusion team and all my pals.'* (WLC – Community Inclusion Team)
>
> *'I like my key workers and the people in my group'.* (WLC – Community Inclusion Team)
>
> *'Staff help me in my house.'* (Enable Scotland)
>
> *'[name] is now in the early stages of dementia at the moment. Grateful to all who help her with kindness and caring.'* (WLC – Community Inclusion Team)
>
> '*They look after me well.'* (WLC- Pathways)
>
> *'Friendly staff look after me.'* (WLC- Pathways)
>
> *'I like the staff who work with me in Burnside and Pathways. They help me when I need. [name] helped me when my mum died. He also helped my dad. People know what I need to help me.'* (WLC- Burnside Residential and WLC Pathways)

'I *like all the staff that visit me. They come at the right time for my support. I sometimes get other workers when they are on annual leave. Staff always make me feel better about myself.'* (Penumbra)

'Friendly staff. Have given me support to be as independent as I can live in my own home.' (Penumbra)

'I like my keyworker and cooking my lunch. I sometimes like bowling.' (WLC – Community Inclusion Team)

- Seven respondents stated that they liked the activities that were offered by the service:

'Interesting things to do, exercise and learn skills.' (WLC – Community Inclusion Team)

'Zumba Class.' (WLC – Community Inclusion Team)

'I like meeting people. I like my activities, most of all Art.' (WLC- Pathways)

'I go to the clubs and meet my friends. My mum helps out and there is tea and coffee.' (Enable Scotland)

'I enjoy the weights. [name] in the workshop. [name] doing cooking with me. Bowling Tournaments.' (WLC – Community Inclusion Team)

'Like going out places. I like walking with them. Like doing exercises with [name] and the gym. They are fun. I learn self-travel.' (WLC – Community Inclusion Team)

'Activities are made for me.' (WLC – Community Inclusion Team)

- Four respondents specified they liked the service because of the help/support they offer:

'Making sure I pay my bills and advice on direct debits. I want to cancel, making sure I have gas, electricity, food and encourage me.' (Penumbra)

'The care home I live in provides the necessary support and seeks other. I have input from various people, social work and learning disability teams and specialist.' (The Action Group)

'Getting nagged at with support! It's all good - if people are in need, if the support isn't there, where do they go?' (Penumbra)

'Very helpful.' (Service Unknown)

- Three respondents indicated that other people/service users were what they liked about the service they attend:

'Meeting other people. Working with other people.' (WLC – Community Inclusion Team)

'I go to the clubs and meet my friends.' (Enable Scotland)

'It helps me with my reading and writing and meeting new people.' (WLC – Community Inclusion Team)

- Two respondents stated they liked everything about the service:

'Everything.' (WLC – Community Inclusion Team)

> *'It all.'* (WLC- Housing Support Service.)

- Two respondents like the outings offered by the service:

> *'I like outings.'* (WLC – Community Inclusion Team)
>
> *'I like going there because we go out and about to different places.'* (WLC – Community Inclusion Team)

- Other responses given by respondents were:

> *'The service does a lot for me.'* (WLC – Community Inclusion Team)
>
> *'Quiet.'* (WLC- Deans House Care Home)
>
> *'I am content with the service supplied.'* (Service Unknown)
>
> *'The fact that everything I do, I am able to take part in, and I am happy doing so, therefore I look forward to my time with the inclusion team and my respite time at Burnside.'* (WLC- Burnside Residential and WLC Inclusion Team)

6.6.2 What respondents dislike about services

Service users were asked if there was anything they disliked about the service they were answering the survey about. There were a number of key themes that emerged; which are presented below:

- 17 respondents indicated that there was nothing they disliked about the service.
- 3 respondents stated that they like everything about this service:

> *'I am happy with service.'* (Penumbra)
>
> *'Content with the service.'* (Service Unknown)
>
> *'I like it all.'* (WLC – Community Inclusion Team)

6.7 Improvements

6.7.1 Improvements to service/s attended

Service users were asked to specify what improvements they would like in the service they were answering the survey about. There were a number of key themes that emerged; which are presented below:

- 11 respondents stated that there were no improvements needed in the service.
- Four respondents stated that they were happy with the service:

> *'Happy with all services.'* (Unknown Service)
>
> *'I am very happy with this service.'* (Enable Scotland)
>
> *'I am not sure as I like my time in Pathways.'* (WLC Pathways)

'I am happy going to the club and meeting my friends.' (Enable Scotland)

- Two respondents felt that there should be more activities offered:

'More activities offered. More frequently.' (WLC - Community Inclusion Team)

'More different things to do.' (WLC - Community Inclusion Team)

- Other comments specifying improvements needed in services are presented below:

'They could find somewhere better for us like a gym because where we go isn't a gym.' (WLC - Community Inclusion Team)

'A cafe for lunch.' (WLC - Community Inclusion Team)

'Could do with more support.' (Penumbra)

'I'd like to see support workers paid a lot more for the work they do.' (Penumbra)

'Wi Fi.' (WLC- Deans House Care Home)

'Would like the inclusion team to stay at Fairburn road and not move out to the community centres.' (WLC - Community Inclusion Team)

'Replacement staff could improve their time keeping.' (Service Unknown)

'To be supported in holidays/days out.' (Penumbra)

'Would be good if there were a lot more support workers.' (Penumbra)

6.8 Supplementary comments

Service users were asked if there were anything else you would like to say about the service or about improvements you would like to see across West Lothian for supporting people with a learning disability and/or Autistic Spectrum Disorder:

- Six respondents stated that was nothing further they would like to comment on.
- Four respondents felt there should be more clubs/groups/activities across West Lothian:

'More clubs to meet other young people.'

'I would like to see more cooking courses for people with support.'

'More activity clubs etc. Keep fit classes. Drama groups and art groups (West Lothian).'

'Easier ways to get gym memberships not needed to renew every 6 months. Evening clubs to attend more social activities to go to.'

- Two respondents indicated they would like to see more supported/accompanied trips/holidays/outings:

'I would like more summer trips.'

'To be supported/ accompanied on holidays/days out.'

- Two respondents indicated that though transport should be improved:

'Bus routes improved.'

'Better bus services for all.'

- Other comments are presented below:

  'The service is there for me if I need them. If I have any problems I can talk to [name] or [name] or [name].'

  'I would like a job.'

  'More staff to help.'

  'I am happy with it all. I have lots of fun at the club. I go to the club on a Monday and Tuesday night and a Saturday in the day time.'

  'Wi fi.'

  'Not sure what is available.'

  'More befrienders for people.'

6.9 Service user survey - key findings

- The majority of respondents (97.6%; n=41) indicated that they have a Learning disability.
- Six respondents (15.4%) indicated that they have an Autistic Spectrum Disorder.
- The majority of respondents (over 80%) had attended the Community Inclusion Team.
- The majority of respondents were answering the survey about the West Lothian Council Community Inclusion Team (47.2%; n=17).
- 24 (58.5%) respondents 'strongly agreed' with the statement 'I feel included in the discussions about my circumstances when using this services'.
- 30 (75%) respondents 'strongly agreed' with the statement 'the staff treat me with care and concern.'
- The majority of respondents (n=28, 70%) 'Strongly agreed' with the statement 'I have confidence and trust in the staff of this service.'
- 75% (n=30) of respondents 'strongly agreed' with the statement 'I feel safe using this service'.
- The majority of respondents (n=28, 70%) 'Strongly agreed' with the statement 'Overall, I feel that my experience of using this service is good.'
- Comments regarding what respondents liked about the services included:

  'The staff are friendly and helpful.' (WLC- Burnside Residential)

- Comments regarding what activities respondents liked about the activities offered by services included:

  'Interesting things to do, exercise and learn skills.' (WLC – Community Inclusion Team)

> *'I like meeting people. I like my activities, most of all Art.'* (WLC- Pathways)

- Many respondents indicated that there was nothing they disliked about the service, whilst 3 respondents stated that they like everything about this service.
- Comments regarding improvements to services included:

> *'Happy with all services.'* (Unknown Service)
>
> *'More activities offered. More frequently.'* (WLC - Community Inclusion Team)

6.10 Carer survey - response rates

There were 31 responses to the carer survey. Eight responses were not used for analysis as the data was received after the deadline however the qualitative responses were used and are included within the following section. Three were discarded as the survey was not completed by a family member or carer. The overall total of responses used for analysis was therefore **20**, broken down as follows:

- 1 out of 20 (5%) responses were deemed 'complete', as 100% of questions were answered by respondents.
- 19 out of 20 (95%) responses were considered 'incomplete', as:
    - 16 of 19 respondents completed 50%-99% of the survey;
    - 3 of 19 respondents completed 25%-49% of the survey.

The optional questions regarding demographic information were completed to various degrees by respondents with 15 respondents responding to this section. Five respondents did not complete this part of the survey.

6.11 Limitations

One limitation concerning analysis of the service user survey element of the Needs Assessment centres on the partial completion of surveys by 78.3% of respondents; therefore some care should be taken when interpreting these findings.

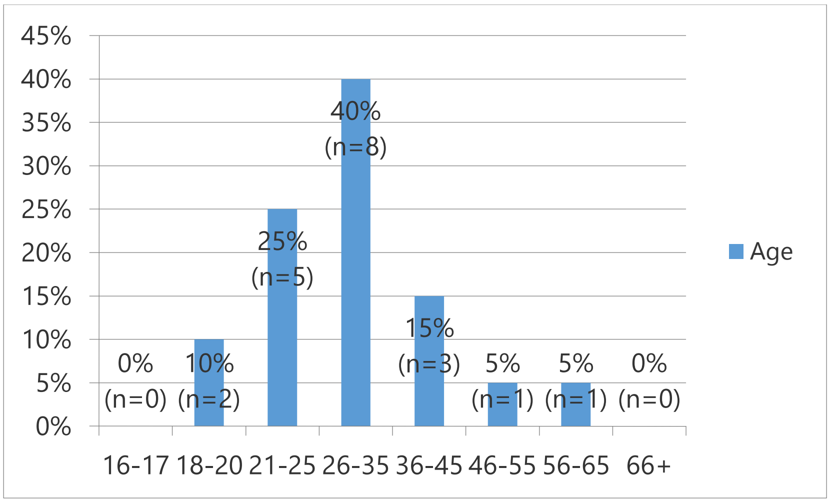
6.12 Demographics of person cared for

Family and carers were asked to provide basic demographic information about the person for whom they care.

6.12.1 Age of person cared for

Firstly, respondents were asked to provide the age of the person they care for. The majority of respondents reported that the person they care for were aged between 26-35 years (40%; n=8). No respondents indicated that the person they care for was below 18 (16=17) or aged 66 + years.

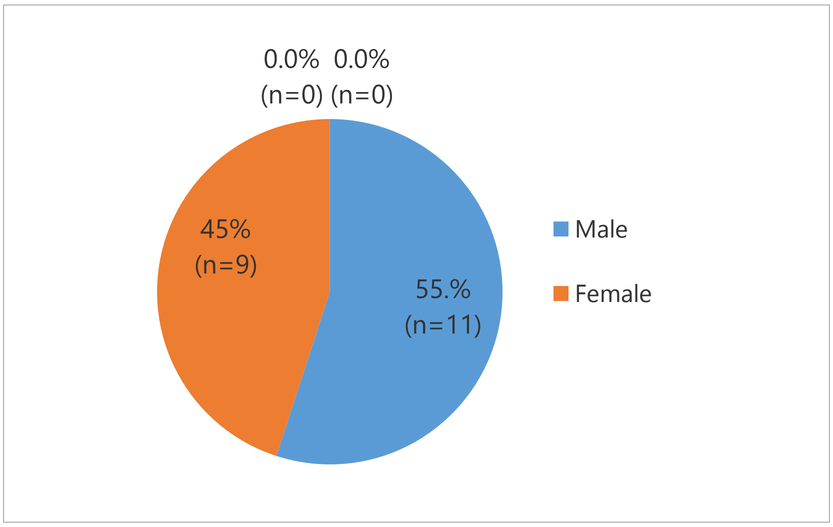
Figure 6.10: Breakdown of ages of persons cared for



6.12.2 Gender of person cared for

Respondents were asked what gender the person they care for was. 55% (n=11) of the persons cared for were male and 45% (n=9) reported the gender as female.

Figure 6.11: Breakdown of gender of persons cared for



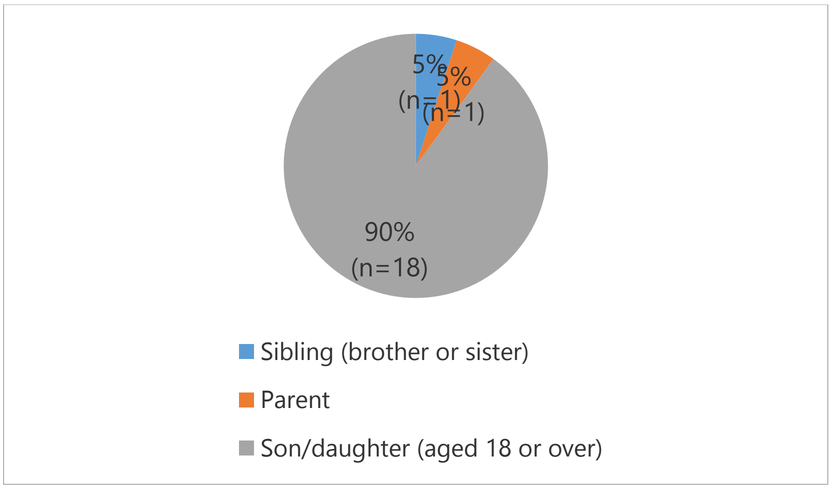
6.12.3 Relationship to the person cared for

Respondents were asked to specify what their relationship was to the person they cared for. 90% (n=18) respondents indicated that the person they cared for where their son/daughter (aged 18 and over). One respondent (5%) was a parent and another (5%; n=1) indicated that the person they cared for was their sibling (brother or sister). No respondents specified their relationship to the person they cared for as:

- Husband/wife/partner;
- Guardian;

- Child (Under 18);
- Other relative (e.g. grandparent);
- Named person;
- Power of Attorney;
- Friend; or
- Neighbour.

Figure 6.12: Relationship to person cared for



6.12.4 Specification of type of learning disability and autism

Respondents were asked to specify the type of learning disability and autism which the person they care for experienced. From responses, it can identify that some respondents were caring for individuals with multiple needs. Furthermore, from the responses, the research team were able to identify types of learning disability and autism:

- Seven respondents stated that that the person they care for have learning disability/difficulties:

> *'Our son has a complex learning disability due to his extreme premature birth. First of all he has a learning disability which is compounded by his lack of speech. His lack of speech is helped through the use of a communication aid. He also has a visual disability where he is blind on his lower left side and has no 3D, he also has problems with special awareness and he has a cerebral vision disability where the messages going back to his brain do not process properly. He has physical disabilities, poor balance, poor function in his right arm and hydrocephalus.'*

- Six respondents indicated that the person they care for experiences epilepsy.
- Five respondents stated that the person they care for has autism.

- Respondents (n=4) also noted Cerebral Palsy as a condition which the person they care for experience:

> *'Quadriplegic profound cerebral palsy with epilepsy, mental health problems, hiatus hernia, on the autistic spectrum.'*

- Three respondents stated that the person they care for has Down Syndrome.
- One stated that the person they cared for was 'mentally handicapped':

> *'Mentally handicapped, takes seizures.'*

- Other conditions that were reported were: Cerebral Atrophy (n=1); Nicolaides–Baraitser syndrome (n=1); Patou's Syndrome (n=1).

> *'Born with Cerebral Atrophy resulting in brain matter had not developed causing severe learning disability. IQ level between 45 - 53 to put this into perspective across the whole population less than 1-1000 would perform at this level according to the British Psychological Society classification system.'*

6.13 Local services and sources support

6.13.1 Services and support which family/carers have had contact with in last two years/ service they are were answering survey about

Respondents were asked to provide details about the services/sources they have been in contact with in their role as a carer within the last two years. Respondents were able to choose more than one option, with all 20 answering this question. West Lothian Council's Community Inclusion Team (n=7) and Eliburn Centre (n=7) are the services most respondents had contact with. For presentation purposes the answers provided are split into statutory and non-statutory services.

Figure 6.13: Breakdown of statutory services respondents were in contact with

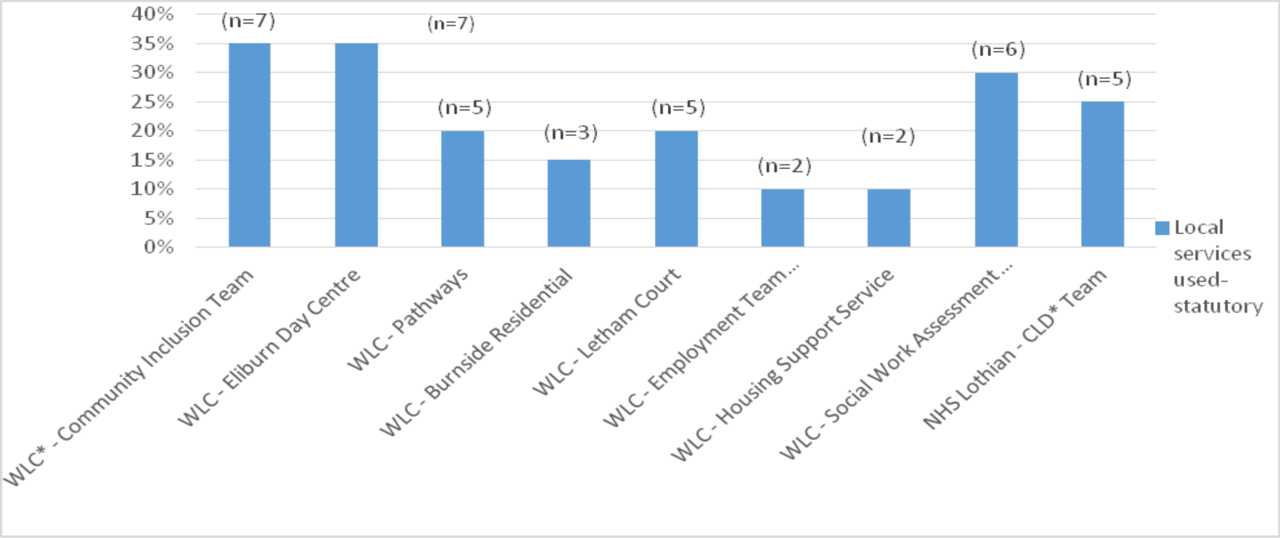
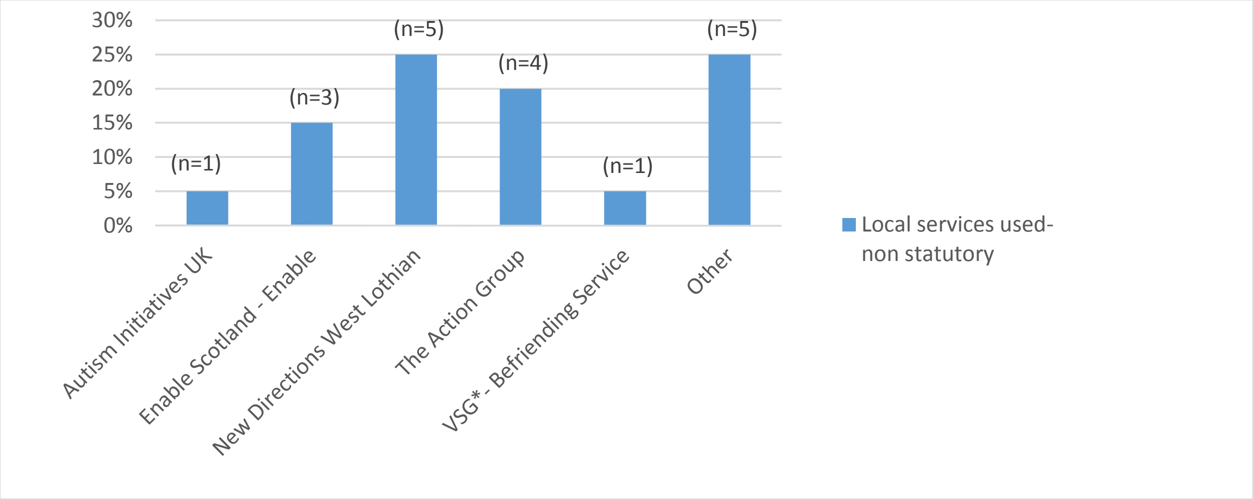


Figure 6.14: Breakdown of non-statutory services respondents were in contact with



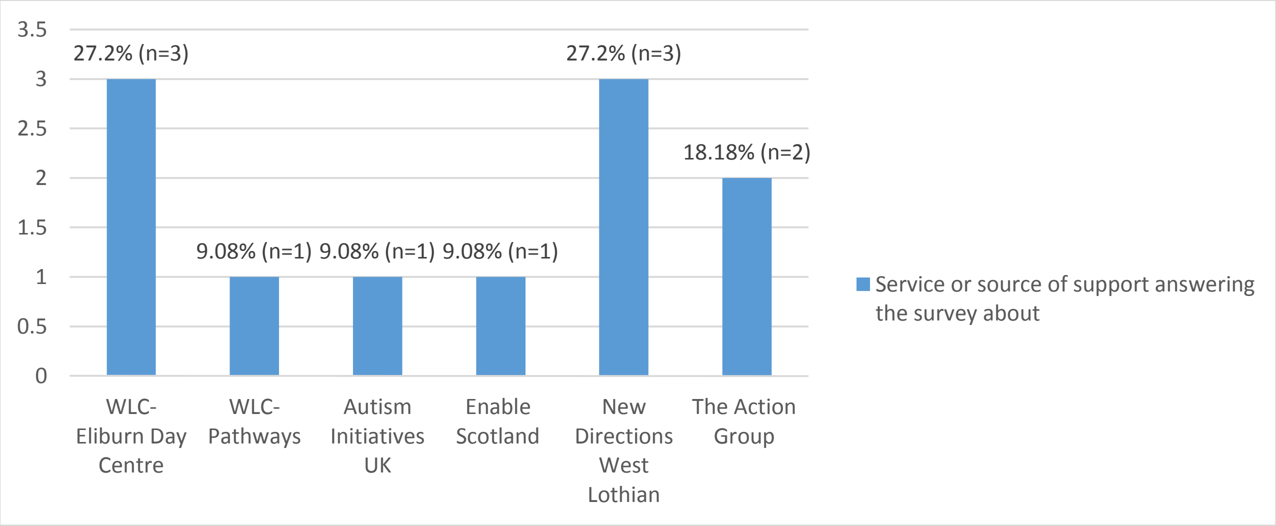
* The following abbreviations have been used in figures above: VSG- Voluntary Sector Gateway; WLC- West Lothian Council; CLEARNING DISABILITY- Community Learning disability.

Other services respondents had been in contact with are as follows:

> *'For the Social worker review of use of Direct Payments.'*
>
> *'Access2Support maybe this is part of New Direction?'*
>
> *'No Limits, Nickirian, Beats of Brazil.'*
>
> *'West Lothian Council Learning disability Social Work Team.'*
>
> *'Signpost, Carers of West Lothian.'*

Furthermore, respondents were asked to provide the name of the service or sources their answers were regarding, with WLC Eliburn Centre and New Directions West Lothian named the most (n=3).

Figure 6.15: Service or source of support which respondents' answers are based on



* The following abbreviation has been used in figure above: WLC- West Lothian Council.

Other services provided in comments are as follows:

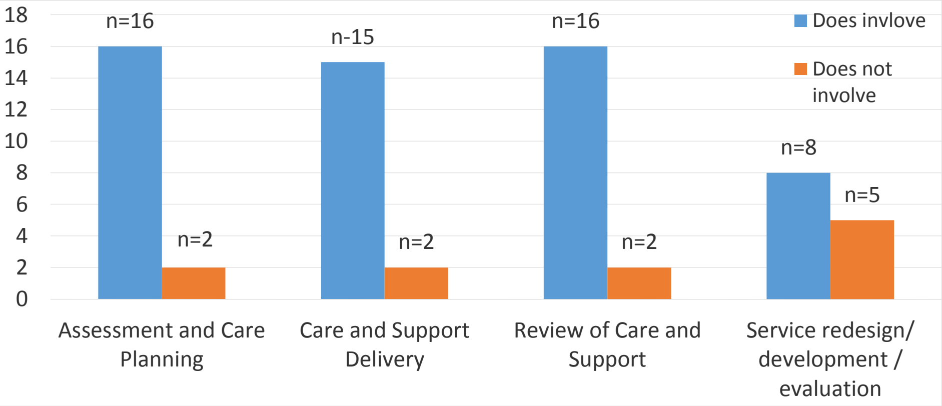
> *'Social Worker.'*
>
> *'Social Work and Direct Payments.'*
>
> *'Forrest Walk.'*
>
> *'Access2Support.'*

6.14 Carer/ Family member support

6.14.1 Carer/ Family member involvement with service implementation

Respondents were asked if the service directly involves them as a carer/family member in the following processes: Assessment and Care Planning, Care and Support Delivery, Review of Care and Support, Service Redesign/ Development/ Evaluation. Overall, respondents indicated that the service they are involved with does directly involve them in the four processes, with Assessment and Care Planning, and Review of Care and Support Delivery rated most (n=16).

Figure 6.16: Breakdown of carer/ Family member involvement in service process



Respondents were also asked to elaborate in terms of the nature, scope and any benefit(s) of such involvement with 11 respondents doing so. From the comments below it can be seen that there are a rich and diverse range of comments demonstrating good practice. Comments are as follows:

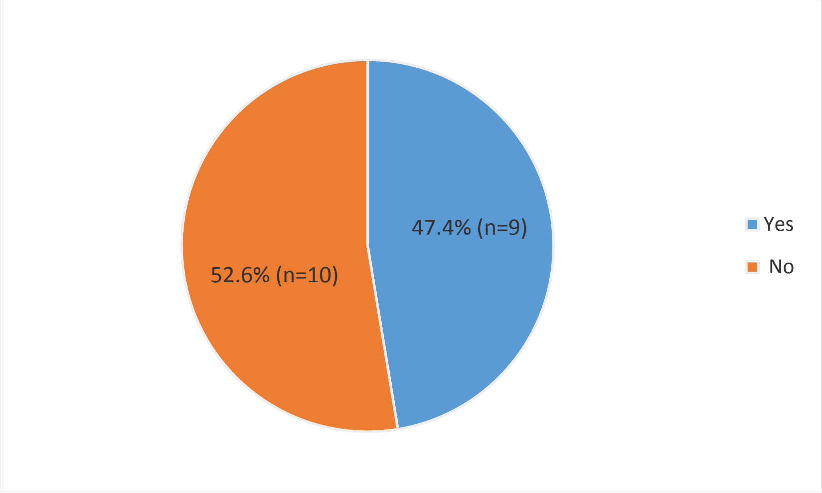
> *'Keep in touch regular and if any concern contact us.'*
>
> *'Takes daughter out for 3 hours on Monday night, Thursday night and 4 on Saturday afternoon.'*
>
> *'Kept involved at every stage. Very person centred.'*
>
> *'I am always involved in any decision made about my daughter.'*
>
> *'After a year at Access2support this service has proved invaluable. We have periodical reviews to access Lee's support. They have open days were the clients can participate in what they would like to see as a service to the end user.'*

> *'See services that are available.'*
>
> *'I have found Pathways to be very good on all 3 areas I have answered yes to. The last however I have had very little involvement with, I find the manager of Pathways to be very set in his ways and not open to new ideas. I do not think the rest of the management team are similar. I took my son's computer in to show how he accesses the Internet through a special program called the grid 2 (I know Pathways could access outside funding to support this and other ideas) but although the support worker was very enthusiastic about it, her manager looked bored and uninterested. There are trust funds out there which could fund initiatives like this and other ideas, the council needs to have more vision and train their staff to open to be more proactive.'*
>
> *'It is beneficial that we are all working to the same goal & by regular communication this enables this to happen.'*
>
> *'The travel support team at New Directions communicate with us very well and ensure that even if there is a minor change, we are consulted at every stage. This gives us peace of mind.'*
>
> *'Regular contact and discussion about Stephen's needs and how best to meet them within support. Excellent communication and dialogue.'*
>
> *'Reviews held yearly to make sure support giving is effective and meets her needs.'*

6.14.2 Involvement with family or carer support groups

Respondents were asked if they had any involvement with any family/ carer support groups within the last two years. Just over half (52.6%; n=10) had done so as demonstrated in the chart below.

Figure 6.17: Breakdown of Involvement with Family or Carer Support Groups within the Last Two Years



Details of the family/ carer support groups respondents had contact with are provided in the comments below. Carers of West Lothian was mentioned in five comments:

> *'Annual review of my son's progress.'*

'Enable Scotland.'

'Carers of West Lothian.'

'Just with other parents whose young adults also attend Autism Initiatives.'

6.14.3 Support received

Respondents were asked what support they received from a family /carer service/group in the past two years. There were eight responses to this question. They were:

- Two respondents said they got information from the group/service:

  'Information and training.'

  'Information about claiming help with heating cost.'

- Two respondents said that they got a newsletter from the support group/service

  'Newsletter.'

  'None specific, just regular news letters.'

- Other comments are:

  '6 hour day service 2 X 3 hours. Social activity.'

  'Advice, a friendly ear.'

  'Annual review of my son's progress.'

  'Discussion and general sharing of experiences.'

6.14.4 Other sources of information and/or support

Respondents were asked if they had any other sources of information and/or support available to them as family members/carers of someone with a learning disability and/or autism spectrum disorder in West Lothian. There were 11 responses and the research team identified some key themes. They were:

- Two respondents stated that a social worker was a source of information and/or support:

  'Social worker input for Self-directed Support.'

  'Social Worker - very supportive and reliable, excellent at providing information I need.'

- Two respondents mentioned the service Signpost.
- Two respondent said that other sources of information and/or support were friends and acquaintances:

  'I do have a friend/acquaintance that I have known thru Lee being at Pinewood who has special needs daughter who has helped guide in a very small way. The majority off help I have to research and struggled to find myself before social became involved.'

> *'Yes, through our social network of other families who have a disabled member.'*

- Two respondents stated there were no other sources of information and/or support available.
- Another respondent (n=1) stated Disability West Lothian as a source of information and/or support.

> *'Disability West Lothian and word of mouth from parents/families.'*

- Lastly, one respondent stated that they are able to access information due to the nature of their employment:

> *'I work with adults with autism so can access information from there.'*

Furthermore respondents were asked if there were any other sources of information or support (groups, clubs, etc.) they knew of in West Lothian. Their answers are presented below:

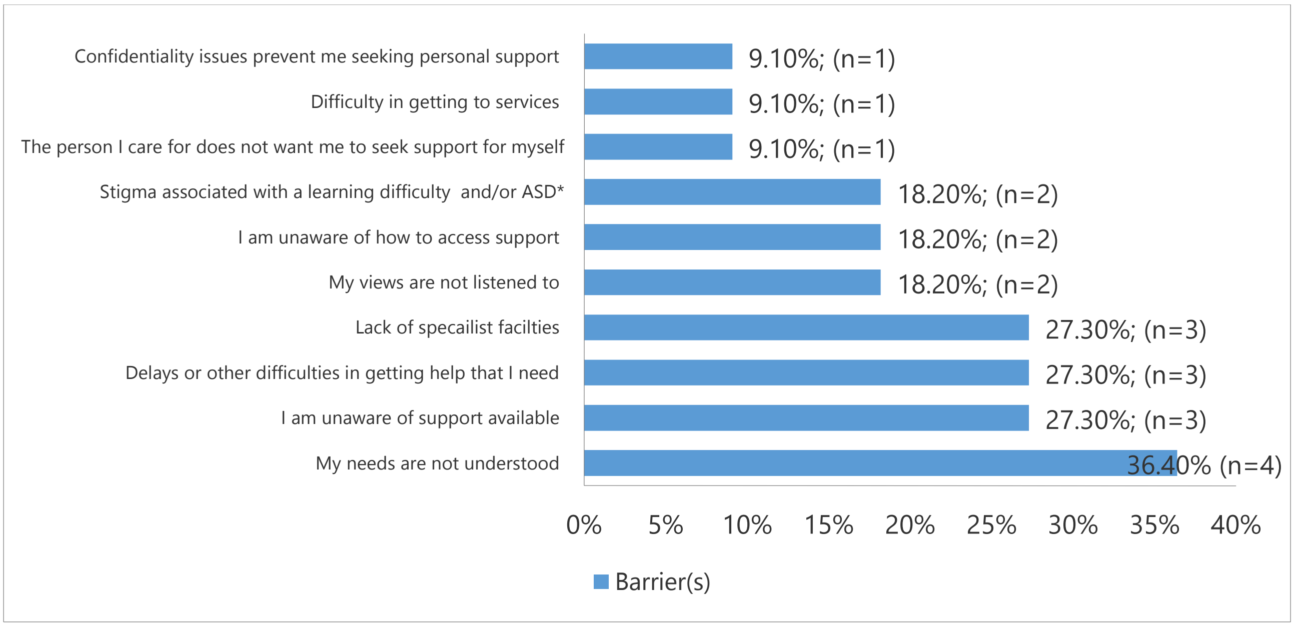
- Six respondents stated that they did not know of any other sources of information or support groups.
- Respondents mentioned the following services/groups/clubs:
  - Enable (n=2);
  - Signpost (n=2);
  - No Limits (n=2);
  - (A) music group (n=2);
  - The FABB club (n=1);
  - Yellow Tea Pot Group (n=1);
  - Mime and Drama Group (n=1);
  - Friends of Jesus (Prospects) (n=1); and
  - Church (n=1).
- Two respondents also stated that the groups/services/clubs they have found was through their own research/only knew about support available due to support received via social work:

> *'Some but often have to search out this information ourselves.'*
>
> *'No not until social work got involved. Did find Enable myself - this was the only one.'*

6.14.5 Barriers preventing family/carers seeking support

Respondents were asked to identify possible barriers that could prevent them from seeking support in their role of as a carer/ family member. There were 11 responses to this question and respondents were asked to select a maximum of the three most significant barriers. The barrier which had the highest response rate was 'My needs are not understood', with four (36.4%) respondents stating this as a barrier. Respondents were presented with a list of barriers to choose from, the results are displayed in the Figure 6.18 below:

Figure 6.18: Barrier(s) to seeking support as a carer/family member



No respondents listed the following two options as barriers:

- 'A significant other does not want me to seek support.'
- 'Confidentiality issues prevent me getting involved in decisions about care or services.'

Respondents were asked to specify any other barriers that prevented them from seeking support. One respondent noted the difficulty accessing support outwith working hours:

> *'I work and find it hard to access services outwith working hours.'*

Furthermore, respondents were asked to provide details of the barriers which they noted. Their responses are recorded below:

> *'Daughter won't mix with other people so won't go to groups.'*
>
> *'The complexity of the need does not fit into any of the provision council have available.'*
>
> *'After [Name] left pinewood school and college we were left with no support. We had knowledge of support that was on offer and for many years relied on family to enable me to work. We moved to Cyprus as well, so for 4 years had no support as sole carer. It's only since moving back to Scotland a year ago at Christmas that we are now getting help. Waiting a very long year and bit for this but slow but surely things have improved.'*
>
> *'I don't feel that I need this kind of support just now.'*
>
> *'Generally very happy with the services provided by the voluntary sector services once the Council commission them to provide support, and also with Council run respite and day services. However, the Social Work referral and allocation process is lengthy, inefficient and stressful for a carer trying to access the service. The lack of communication by the service is frustrating, and the Council policy of discharging clients*

> *for short periods of time until changes occur does not work when it takes months to be referred back in again.'*
>
> *'I am worried about the lack of opportunities longer term for [Name] in employment due to funding cuts.*
>
> *'Lack of assigned social worker.'*

6.14.6 Help needed in order to care

Respondents were asked to provide details of any help they need in order to support the person they care for. Their responses are listed below:

- Three respondents stated that they did not need any help
- Two respondents felt they needed some sort of respite/ break from their caring role:

> *'Getting older would like to be able to do things and go places without problems, need to have a break now and again.'*
>
> *'Now looking at respite for me. Stress that build up between my son and me needs fixed so look to be working on this now.'*

Other responses were:

> *'I need and have a comprehensive care package but I can't get the help I need after 10pm at night. Service providers in private sector will not respond.'*
>
> *'Help with personal care.'*
>
> *'I need help in terms of having things put in place for my son to allow me to balance full time work with my role as carer.'*
>
> *'Need to know the full range of services available.'*
>
> *'The Action group provides support Mon-Fri and my Mum assists with the care of my daughter too.'*

6.14.7 Improvements in support for carers and family members

Respondents were asked what improvements they would like to see in the support available for family members and carers of individuals with a learning disability and/or autistic spectrum disorder across West Lothian. A varied range of suggestions were provided as demonstrated below:

> *'Respite locally.'*
>
> *'Some kind of help that lets you see that you have some kind of support and that you are not on your own. There is support for the individual but not for the carer.'*
>
> *'None.'*
>
> *'More choice in recruitment of carers who would be involved in my sons support.'*

> *'More in door inclement weather facilities.'*
>
> *'Appropriate help with recruitment of staff, training available for staff.'*
>
> *'I would have liked some kind of support network when my son left school/college. I feel if I knew then what was available it would have helped the whole family to cope better. His diagnoses also was very slow to be recognised was over 10 years before MRI was done far too late this also caused us stress to Lee and whole family. As difficulties continued feel as if we fell down thru the cracks thru out his life not sure if he ever got the help that he should have had. I feel that a lot off the family and Lee's anxiety has been exacerbated due to lack meaningful structure and activity and the lack of full understanding on Lee's intellectual impairment.'*
>
> *'More choices for leisure and sport.'*
>
> *'In general I would like west Lothian to be a more disabled friendly place. My son needs guidance when walking and that means we are virtually walking side by side, what I find is that paths in parks and cycle paths are never wide enough, wheel chairs and push chairs can get around but we always have stop and let other people by. Hospital car parks never enough disabled spaces, I cannot open my door and let my son out and tell him to wait until I find a space. Please just make it easier to do the simple things.'*
>
> *'More information when there's an initial diagnosis, if you don't ask no-one offers help.'*
>
> *'Better communication from, and quicker access to, Social Work dept. when referrals back into the service are required. Ideally, I would prefer that the Social Work team did not discharge clients for short periods of time while temporary arrangements are in place. It takes too long to re-engage with the service. I would like to see an open door policy where the person with the learning disability, or their carer, can quickly access the service as needed. At the moment we have been waiting for over two months for any kind of acknowledgement of our referral.'*
>
> *'I think there is a lot of good support available.'*
>
> *'Would like a named social worker that we could go to for information and in times of need, this is not available at the moment. We need to know the full range of services out there and information on how to access them.'*
>
> *'Don't know.'*

6.14.8 General improvements across West Lothian

Respondents were asked what improvements they would like to see more generally across West Lothian for supporting people with a learning disability and/or autistic spectrum disorder. Respondents who stated they would like to see improvements provided commentary which are presented below:

> *'We need: greater choice of supported housing provision, supported work placements, more opportunities for developing independence and more befriending services.'*

‘More activities that are of interested to young adults - more social activities like discos held in pubs etc. Ask the opinions of the young people more.’

‘None.’

‘See services continuing. I think we are well served in West Lothian.’

‘More changing facilities with hoists.’

‘Appropriate interesting respite opportunities - where the staff/team who know the individual can continue to support and care for the individual.’

‘Early diagnoses. Full team awareness across the whole disability spectrum for parents to understand what will be available for their child. The parents to have a whole learning experience of what they are entitled to and what is available for child thru to adult both in learning, financial and going forward to legal and so on.’

‘Healthy eating habits - too many suffer from obesity.’

‘Provide more clubs especially for adults. A weekly disco on a Friday night would be great and please don't get a charity to run it, get volunteers to help with it, you would find them if they didn't have to do any paper work. Help the small local charities already out there providing services, have one council worker to go round them all to do paper work like police cheques, or find auditors for their accounts, or just be a point of contact. The volunteer centre is ok but what these charities need is someone to come to them someone who knows what they are doing and can get it done quickly.’

‘More accessible information.’

‘Opportunities within the employment sector - supported employment.’

6.14.9 Gaps in service provision or support

Respondents were asked if there are any gaps in service provision and/or support across West Lothian for those with a learning disability and/or autistic spectrum disorder. Comments are as follows:

‘Could be doing with more social events in evening.’

‘None.’

‘N/A.’

‘Purposeful/meaningful activities which give achievement and enable contribution to society.’

‘Big gap knowledge and who to go to gain the things you require. Also transportation if you cannot self-travel less activities are available unless you spend a large portion for money on transportation.’

‘Service operate 9-5 instead of 24h.’

> *'Not enough contact between those with more profound disabilities and those more able. E.g. Eliburn and Pathways.'*
>
> *'Yes there needs to be some form of lifelong learning. This should be a theme which runs through all the services provided for adults with a learning disability. No one should be allowed to unlearn anything with has taken.'*
>
> *'As previously mentioned, the Council policy of discharging clients each time their care plan has been implemented, regardless of how short term part of that care plan may be, and resulting in long delays upon re-referral, is not a good policy.'*
>
> *'Supported employment. Epilepsy training (AI are fine) for staff in clubs so that young adults with epilepsy can be left with staff who are trained.'*
>
> *'Social activities for the over 25's, there seems to be little funding available.'*
>
> *'Yes, there is hardly any groups that my daughter would wish to attend as they're not of interest to her. She enjoys pop music, going to concerts, going to the pub, taking photos, dancing, meeting up with her friends. If there were more just social groups where her and her friends could go and hang out then this would be welcome.'*

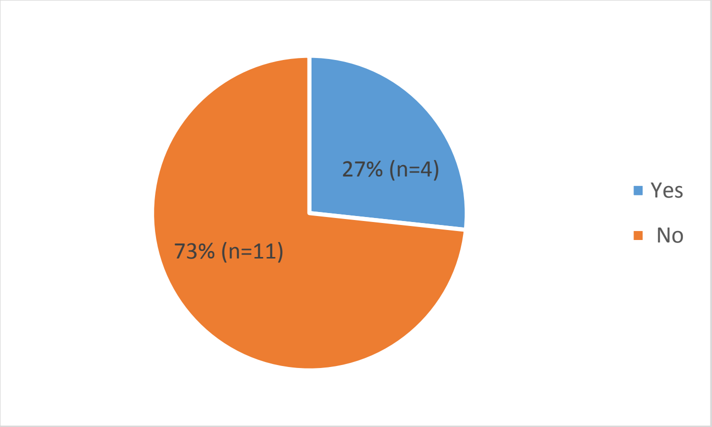
6.14.10 Gaps in service provision or support for carers and family members

Respondents were asked if there are any gaps in service provision and/or support across West Lothian for family members and carers of those with a learning disability and/or autistic spectrum disorder. 10 answered and 10 skipped. Comments are as follows.

> *'As above.'*
>
> *'More support groups.'*
>
> *'Information points and up to date information on what is happening/available.'*
>
> *'Yes when your child leaves school or college what the next step or help for them would be.'*
>
> *'It can take time to get any help such as community nurses and social workers, once you are in the system it is better but you do feel that you have to be falling apart at the seams to access them quickly or else you just need a great deal of patience.'*
>
> *'My son has epilepsy and Autism Initiatives are the only organisation who are actually trained to administer emergency medication. For all other clubs, I or another adult has to support my son for the duration of the clubs when they meet - this causes extra stress on myself and my husband. There seems to be a general disregard for those with epilepsy and no club is prepared to pay for the necessary training and insurance.'*
>
> *'Carers need to know that our young people will be appropriately supported later in life when we are not around, this is a constant worry.'*
>
> *'Don't know.'*

6.14.11 Opportunities to influence service development and improvement

Figure 6.19: Breakdown of Respondents Opportunities to Influence Service Development



If respondents believed they have opportunities they were asked to specify how they have been involved. If they did not they were asked to indicate how they think this can be improved. Comments are as follows:

> *'People who are unconnected to a day centre/service provided by the council are ignored and left out of news of what is happening/ consultations / events / appropriate support.'*
>
> *'More surveys or advice from other carers to improve the system would be help full. No one else except for the Carer has the most knowledge so taking the time to ask them the questions am sure would be beneficial.'*
>
> *'Learning disability forum. Membership of CHCP.'*
>
> *'I have already said above how I believe lifelong learning should be a theme going through all services, but I find it difficult to see that any idea I have would be taken on board by those who work in the council. There seems to me to be an awful lot of individual services for various degrees of disabilities and none of these come together to collaborate on ideas. Indeed they are little empires guarded by their management who are probably petrified they could lose their jobs if they didn't over emphasis how good they are. I volunteer at a small group who provide craft classes for 14 severe to complex needs adults, who all attend with their carer and although it is only for a few hours a week, I feel that what achieve on a very small budget could well be done by those in the council who have access to more information and help.'*
>
> *'Through my employment.'*
>
> *'It is important for young adults to be able to experience employment situations in however small their role may be. This is ultimately a normal part of life for their peers who do not have any form of disability.'*
>
> *'Maybe through surveys like this? Being personally consulted to give your opinion.'*

6.15 Carer survey - key findings

- The majority of respondents reported that the person they care for was aged between 26-35 years (40%; n=8).
- 55% (n=11) of the persons cared for were male.
- 90% (n=18) respondents indicated that the person they cared for was their son/daughter (aged 18 and over).
- Most respondents stated that that the person they cared for has a learning disability/difficulty, six respondents indicated that the person they care for has epilepsy, five respondents stated that the person they care for has autism. Other conditions reported were 'mentally handicapped', Down's syndrome, Cerebral Palsy, Cerebral Atrophy, Nicolaides–Baraitser syndrome and Patou's Syndrome.
- West Lothian Council's Community Inclusion Team and the Eliburn Centre (n=7) are the services most respondents had contact with.
- Most carer/family members indicated that the service they are involved with does directly involve them mostly with the Assessment and Care Planning, and the Review of Care and Support Delivery rated most (n=16).
- Just over half (52.6%; n=10) of respondents have had involvement with any family/ carer support groups within the last two years.
- Support respondents received from a family /carer service/group include:

  > *'Information and training.'*
  >
  > *'Information about claiming help with heating cost.'*

- The barrier which had the highest response rate to preventing respondents from seeking support was 'My needs are not understood', with four (36.4%) respondents stating this.
- Improvements respondents would like to see more generally across West Lothian for supporting people with a learning disability and/or autistic spectrum disorder include:

  > *'We need: greater choice of supported housing provision, supported work placements, more opportunities for developing independence and more befriending services.'*
  >
  > *'Healthy eating habits - too many suffer from obesity.'*

- Gaps in service provision and/or support across West Lothian for those with a learning disability and/or autistic spectrum disorder include:

  > *'Could be doing with more social events in evening.'*
  >
  > *'Purposeful/meaningful activities which give achievement and enable contribution to society.'*

- Gaps in service provision or support for carers and family members of those with a learning disability and/or autistic spectrum disorder include:

> *'Information points and up to date information on what is happening / available.'*
>
> *'Yes when your child leaves school or college what the next step or help for them would be.'*

- Comments on respondent's opportunities to influence service development and improvement include:

> *'More surveys or advice from other carers to improve the system would be help full. No one else except for the Carer has the most knowledge so taking the time to ask them the questions am sure would be beneficial.'*

6.16 Background to carer and service user focus groups

There were a total of five carer and service user focus groups held in various locations throughout West Lothian:

- New Directions West Lothian Bloom House, Livingston Village (n=2);
- Blackburn Library (n=1);
- Pathways Centre Livingston (n=1); and
- Bathgate Partnership Centre (n=1).

A total of 39 people attended. The breakdown of participants per focus group is as follows:

- New Directions West Lothian – Service User Focus Group (n=7);
- New Directions West Lothian – Carers Focus Group (n=8);
- Blackburn Library – Service User Focus Group (n=3);
- Bathgate Partnership Centre - Carers Focus Group (n=4); and
- Pathways West Lothian – Service Users and Carer Focus Group (Carers n= 3; Service Users n=14).

6.17 Purpose of focus groups

The purpose of carer and service user focus groups was to find out:

- Their views on current learning disability services in West Lothian;
- What they saw as the gaps in current provision;
- Their views on accessibility and integration of services;
- Their views on service user involvement;
- Their views on transition services; and
- Their views on what services should look like in the future.

6.18 Limitations of focus groups

The strict time limitations of the study, in particular on its qualitative methods, restricted the number of focus groups that could be held and therefore the breadth of the service user and carers' views solicited through this method. Such constraint is further amplified by low levels of service user participation in two of the three service user focus groups held. There appeared to be a rather ad-hoc communication mechanism, which was relied upon to invite participants along to the focus groups resulting in two service user focus groups being cancelled. One was subsequently rearranged and was attended very well.

6.19 Focus group key findings

6.19.1 Are there enough services in West Lothian for people with Learning disabilities?

There appeared to be quite a difference in opinion between the different service user focus groups. In one group it was generally agreed that there was "lots of stuff" to do, however it was not that well-advertised. Those who went to Pathways felt that there was enough to do, as they attended or had the opportunity to attend activities such as:

- A walking club;
- Football;
- The library;
- Swimming; and
- Zumba

Certain other services were frequently mentioned such as Eliburn, Community Inclusion and Autism Initiatives.

The one point that nearly all of the services users who attended the focus groups agreed on was that there is very little to do in the evening. One service user, who attended college during the day, commented that, *'I have to stay in the house and play on the computer'* in the evening.

Carers on the other hand, who attended the focus group in Bathgate, were of the opinion that the answer to that question depends on what you are expecting of services: *'It's very individual whether you think you have enough services'*. That said, overall, carers in all groups did feel that in relation to other areas, there are lots of services in West Lothian, but fewer than in Edinburgh

Carers also stated that any evening activities that are offered, with the exception of Enable and the FABB Club, are usually run by parents. In effect, parents *'provide the icing'*. Those carers that attended the Focus Groups did mention that there were a number of very good services operating in West Lothian; however the ones that allowed people with learning disabilities to socialise were parent run.

Hours of enabling support was also raised as an issue in discussion on current service provision. Hours of such support do not always match the time of particular activities or services that those with learning disabilities want to attend. The support workers noted that whilst they try to be flexible with times of personal support, because they enable several different people, it is not always possible to the meet the needs/wants of all.

One example is Enable, who employ lots of casual support staff. They are flexible and work well together, covering each other's shifts if necessary and to more effectively meet the needs of their clients, however they cannot always cover everything.

6.19.2 Is there a genuine choice of services across West Lothian for those with a Learning disability?

There was a clear difference between the views of those accessing services and their carers/advocacy staff. Generally, those who use services think there is a lot to do, although one noted that *'lots of people are disabled; there aren't enough groups.'* In contrast, carers/advocacy staff noted there is not enough choice.

A service user stated the college runs a range of courses including cooking and catering and most recently a course for people with learning disabilities who want to work as volunteers. The importance of the college courses for both the social and educational development of the service users attending was highlighted throughout the focus group. Of the three service users who attended the focus group two of them attended the college. Currently it runs a number of specific courses for those with a Learning disability including photography, art, cooking, mechanics, and life skills. However, it was very difficult to find out specific details about the courses, they aren't available online and they are very poorly advertised.

Two service users went on a tour/introduction to the college and had their lunch, but there was no literature available on their courses for them to take away (to show family etc.) and they were shown around the whole college, not just the bits they'd be going to on a daily basis. One of the service users' support worker said this was a bit confusing. It was felt that perhaps they need staff more familiar with the particular needs of those with a learning disability.

The issue of knowing what is available was raised. The advocacy staff noted that if you do not live in the community houses, you very often do not know what is going on. One of the very active and vocal parent/carers echoed the point that those who use Direct Payment (i.e. do not access structured services), are often left out of communications and rarely know about everything that is happening or the scope of services available.

From the carers' perspective, one noted that "there might be services, but often only one or two fit", which reduces the choice of what is available to specific families. Certain therapies are available such as Music Therapy, but must be on the whole self-funded, unless a medical need has been established and funding can be secured from the NHS.

There are a number of very specific services and activities which people would like to attend, such as Mill Farm in Livingston and mini golf, however, again, the hours available for enabling support often restricts access to these activities (**see 6.19.1 above**).

6.19.3 Are there any other types of services needed?

There were number of gaps identified in the service provision for those with learning disabilities in West Lothian. The services users who attended the focus groups mentioned a number of areas:

- Cooking classes – linked to independent living skills.
- Computer / IT classes.
- Entertainment / dancing / music classes.
- Opportunities to volunteer – some organisations are known to offer placements to those with a learning disability e.g. Superdrug, Tesco, Charity Shops (Red Cross/Sense). However, many places cannot accommodate a support worker too. One of the service users was interested in volunteering in a care home, but their support worker didn't know how to get them involved in such a venture.
- A befriending service for those with learning disabilities offering someone to do things in the community with e.g. football. One of the service users knew about a service in Edinburgh called 'Best Buddies' and stated that they would like to see a service like that in West Lothian.
- A better route for communication of opportunities was also identified by service users as a gap in provision. For instance it was noted that courses for those with learning disabilities at West Lothian College did not appear online with the other courses on offer.

The focus of the discussion on gaps in provision from a carer's perspective revolved around service quality and the lack of spot-checking to maintain standards and ensure effective communication between management and staff. The longevity of services also appeared to be an issue. Some interventions are only available for only a short, pre-determined period of time, before they are withdrawn and the service user expected to 'progress'. Carers also highlighted an issue surrounding socialisation and meeting other people, especially for adults with learning disabilities. The lack of evening events was seen to inhibit this, and furthermore, it was noted that if you are not in receipt of services you remain ignorant of any social events. The carers felt that this was a significant gap as mixing with and meeting new people is vital.

One of the comments consistently made was that existing services are not fully utilised. For instance, although The Pathways Centre is seen as a very important service, the fact that it does not open in the evening and is therefore unavailable to local groups to use outwith the normal daily opening hours is a major gap in local service provision.

6.19.4 What do West Lothian services do particularly well?

The Pathways service was seen to offer a lot of choice and is generally highly thought of, as is the Burnside Centre. The continuity of staff within services in West Lothian was also seen as a major advantage, together with the strong bond between staff and service user which was subsequently built up. This was seen to be particularly important for those with Autism, for whom lack of continuity is a key factor in increasing stress.

6.19.5 How easy is it to get help from learning disability services in West Lothian?

Service users and carers were generally consistent in their opinion on this question. The overall consensus was that it was not always easy to get help. One of the main reasons given for this was waiting lists. The FABB Club for example has a waiting list of around two years and an age restriction of 30 years.

Some service users found emergency access easy to get, such as on call services, however some relied solely on siblings or parents to provide them with help.

An outstanding fear for one parent/carer was the introduction of Self-directed Support (SDS). She stated that she had made an application/enquiry into receiving SDS for her son, but that she was terrified that the budget he will be awarded will not be sufficient to cover the cost of the services already in place. She has been given no indication as to what the final situation will look like – in her words she "hasn't heard a dicky-bird" throughout the course of the process. Other opinions on SDS were:

> *'It's all money driven, and that's sad.'*
>
> *'On paper these things are great, but unless parents organise 'stuff' it won't work.'*
>
> *'They want you to be creative, but its parent's who'll make it happen.'*

One of the carers advised that New Directions have published an 'Access to Support' booklet which tells you how much specific services cost under SDS, but not everybody know about this resource. She noted:

> *'It's about the information. Some people are being dissuaded [from applying for SDS] because they think it's all down to them.'*

6.19.6 How easy is it to get to learning disability services in West Lothian?

The topic of transport was one which received much attention during all the focus groups. The general opinion was that it caused difficulties – especially for those who were travel trained and travelled independently. If buses are late for instance, if the routes are changed or the numbers of the buses are altered, this can cause a great deal of confusion. One parent stated that her son could not read so he knew which bus to take solely by the number, therefore if the number changes he has to learn to recognise a new number – essentially he has to be re-trained. In terms of how transport can impinge on accessing services, one carer stated that it used to be easy to access the Community Inclusion Team. People could get off the bus at the hospital and just walk there. It has now moved 'off the beaten track' and you can only get a bus there in the morning. This, the group noted, will have a severe impact on service availability/access. To attend this service you have to be able to self-travel, but the new location makes this difficult.

Living in more remote locations in West Lothian and trying to access services via public transport was also an issue for some service users. Some locations such as Addiewell appear to have no direct bus links to any of the main services and travel from, for example, Stoneyburn to Bathgate is restricted due to the hourly bus service.

Bus passes were also a key point of discussion. The benchmark/criteria to receive a bus pass has been raised so high, many with a learning disability no longer qualify. This, the focus group noted, is a shame because people with a learning disability are often more vulnerable than those with physical disabilities. Moreover, the plus-one bus pass is only available if you meet the right criteria (highest rate of mobility DLA). Without it support workers/carers have to pay full fare. This added cost impacts on the ability of those with a learning disability to get out in the community if they need support.

The assessment process does not always accurately reflect need. For example, one of the service users lives with his sister, and because of the way he answered the questions posed during the assessment process he was not deemed eligible for a plus-one bus pass. It can be difficult to appeal these sorts of decisions. His support worker has taken him to the advice shop in Bathgate for help. Support staff noted, *'benefits shouldn't dictate bus passes.'*

Enable are running a campaign to extend the free bus pass scheme and one of the service users who contributed to a focus group is actively involved in gathering signatures for the petition.

Lack of parity between those with learning disabilities and those with physical disabilities was also highlighted. For example, members of the Focus Group were of the understanding that 'dial-a-bus' and 'taxi-cards' are available to those with a physical disability, but not to those with a learning disability.

One of the parents noted that although their daughter self-travels, as a parent they aren't happy for her to do so at night.

In terms of feeling comfortable travelling on buses or taxis, some of the parent/carers were concerned that some of the bus drivers/taxi drivers are not always understanding towards those with a learning disability, and some drivers who do not have English as a first language are difficult for those with learning disabilities to understand.

The enablers and advocacy staff present felt that some service users with learning disabilities do not feel comfortable travelling or attending services or activities on their own.

One of the parent/carers also expressed some concern over the ruling that support staff apparently could not use a service user's mobility vehicle. The parent argued that the car belonged to the individual and not the family and therefore should be available for the service user's needs when required. This situation is made worse in her view with regard to communication about insurance and who can be put on the policy as an additional driver.

In has also to be noted however, that some service users felt that it was easy to get to services.

6.19.7 How well do learning disability services work together in West Lothian?

From a carers' perspective services do not always work well together. An example given was that although Pathways is used for activities other than daily groups, these activities are always health based; therefore not fully exploiting available resources for perhaps other non-health based activities.

One person who cares for both a person with physical disabilities and someone with learning disabilities felt that West Lothian had one of the best records of Health and Social Integration over recent years. In their opinion the secret is to know who to speak to and in what service.

On the whole however, it was felt by parent/carers that there needs to be *'much more co-ordination.'* This is sometimes compounded by a lack of information about what is available. An example given by carers was the existence of a learning disability specific Occupational Therapist. If parents were routinely informed that you could contact this individual and request that they come out and assess for the necessary adaptations, it was felt that this would make things a bit easier for them.

One of the advocacy workers did say:

> *'As an advocate attending meetings, the problem is often that social work is on one side and health are on the other.'*

The advocate noted that this is not always a bad thing, but that sometimes there is a problem regarding who pays for what.

6.19.8 Service User Involvement

Generally it was felt by both service users and parent/carers that their views were sought by many of the services they attended or accessed. Most of these services send out service user surveys for completion. One carer did however express concern that a comment she made was referred to in relation to them specifically and she is now reticent to give her views and will only do so in future if it is anonymous. Service users did feel that certain services did seek their opinion but not all of them. One commented, *'Some people don't answer my questions.'* The Care Inspectorate does ask service users and parent/carers about their views on a specific service.

6.19.9 Transition from young people's services to adult services

The general consensus across all of the focus groups was that on the whole the period of transition from school to college or school to young adulthood, was not well catered for in West Lothian. There appears to be a lack of services available to young people once they have left schools, irrespective of whether these were mainstream or specialist educational establishments. There appears to be concern about the age range from 16 to 18, where the young person does not qualify for services through school but does not qualify for adult services either.

Specific examples given to illustrate this gap include one service user who attended a mainstream school but received 1:1 support with reading. When she left school there were no specific services available to her. A service user who was in foster care received quite a lot of help from his foster mum through the transition process. This was indicative of the transition services received by young people, in so far as the majority received help and support from parents, aunts, uncles etc. The type of services which service users and carers highlighted as being important at this time, were help to fill in applications for colleges and sourcing information on courses etc. One service user suggested that if you were not eligible for college there does not appear to be many other services available to you after you leave school. One service – the Yellow Teapot Club – was mentioned as providing help for children and young adults.

One aspect of transition which was highlighted by carers as being particularly problematic was the move over from school which is a five day a week service to a three day a week service, which their assessment may suggest they require. If the parent/carer works five days a week, how do they manage the other two days? It may even lead to some parents either losing or having to give up their jobs. The expression used by one carer to sum up how they felt about this was they were left "juggling custard". The feeling was some employers can be very flexible and understanding and others not so. One carer stated this period was, *'not so much of a transition; it's more of a zap!'*

There was also a feeling that due to restrictions on what young people with learning disabilities can or cannot do, not imposed by the parents/carers but by organisations that provide services and outdoor activities, the range of services offered to young people when they leave school is curtailed. One young person with a learning disability had clearly not had a good experience of transition services as his impression was, *'once you're older, you're on your own.'*

The problems related to transition of course do not stop when moving from school to college, they are equally as important when someone leaves college. One parent reported that:

> *'He [son with learning disability] was at Pinewood until he was 18 and then he went into Bathgate College. Then, after college, nothing – everything stopped after college and I didn't know where to go for help.'*

6.19.10 Services required in the future

There were a number of services which those present at the focus groups wish to see in the future, however there was also some discussion about services which currently exist. Furthermore, some of those present at the focus groups noted that existing services are in danger of closing because they are not used sufficiently. Some attributed this to the fact that people just do not know about them.

One of the areas in which service users and carers feel improvement is required is better communication. It was noted that someone is needed to join up knowledge regarding all services. One comment being:

> *'There is just one Communication Officer for West Lothian Council, but this isn't enough – it's a big job.'*

In line with other comments regarding choice and availability, one service user wanted to do *'more things outside.'*

Some service users noted they would like more to do in the evening, but they do not want to go to Pathways in the evening because they are there during the day, therefore there needs to be somewhere else to go. Interestingly this comment was at odds with the predominant view from parents/carers, featured previously in this chapter, that opening Pathways in the evening would give a great place to go. One parent/carer added that although the Bathgate Partnership was purpose-built there are no rooms suitable for the FABB Club – they are all too small.

Another parent/carer noted there are facilities which are not fully utilised. For instance the café at Pathways could be used for social events. He noted that many community centres etc. are not fully accessible (difficult to get to/expensive to hire) but Pathways' is. He noted this also applies to the Bathgate Partnership/community School.

An expansion in the provision of advocacy services was identified as a service which was required, again the emphasis here being on improving the capacity of existing services. The current workshop provision for those with disabilities was mentioned, one parent commenting:

> *'It seems very little skill is imparted; I'm not sure it's purposeful'.*

This parent's wish was to see social enterprises working with this demographic, however there were concerns voiced that as social enterprises were aiming at eventually being self-funded, those with Learning disabilities would not be in a good position to achieve this, therefore rendering them an unattractive option.

Although generally respite services were highly thought of by service users and carers alike, the consensus was that they still require some improvement. It was noted that respite is especially important for carers as they get older. The need for more choice in provision was highlighted. Good respite, it was suggested, has to fit the client, be purposeful, and allow for socialisation/inclusion. A specific need for respite for families with a child on the autistic spectrum also was noted. Those who are high functioning/in mainstream school are rarely eligible for respite, but they often present with very challenging behaviour which parents struggle to deal with.

In line with comments previously made regarding restrictions on staff using their own cars to transport clients, where there is no pool car, public transport has to be relied upon, and often timetables etc. do not fit in with personal care routines etc. Effectively this means that staff cannot take respite clients out anywhere which led to the comment that, *'respite becomes institutionalisation in the community.'*

One carer whose daughter has profound learning disabilities expressed the need for more hydrotherapy services. There is a high demand for theses but they are very expensive. St John's Hospital is the only place locally that offers this service although there are locations in Edinburgh who offer it. The only way to access it is to go through health to get a referral and then the individual only receives a short course of therapy.

There was also a view expressed that as we are now at a time when the first generation of those with learning disabilities are living into their 50s and beyond, the requirement for adult services to continue after 65 is becoming more and more important. One parent felt that:

> *'Learning disability service should be for life,'*

and not as they are currently, age limited.

6.20 Key Findings

- Communication of what is available and where, is not consistent or effective.
- There is a severe shortage of services in the evening and most that do exist are run by parents, so are therefore small and poorly resourced.
- Service users generally feel that there are enough services during the day, whilst parents/carers generally do not.
- Services don't offer enough variety or purposeful activity for service users.
- Existing services are underutilised, perhaps due to communication and information gaps.
- There is mixed opinion between parent/carers on the benefits of Self Directed Support and Direct Payments.
- Transport in general and bus services in particular could be better, with more thought being given to the effect on passengers with learning difficulties when changing routes and numbers.
- Assessment processes could be improved through more awareness by staff, to avoid some individuals with milder forms of Learning disability missing out on service provision.
- Services need to be more co-ordinated to provide a more holistic service.
- Transition services need to be improved for not only those with learning difficulties leaving school but also those leaving college.

CHAPTER 7: KEY FINDINGS AND RECOMMENDATIONS – WHAT THIS MEANS FOR WEST LOTHIAN

7.1 Introduction

The limited published evidence base and research in this filed suggests that learning disabilities, of all kinds, often goes under reported nationally; and the limited prevalence data obtained through the course of this needs assessment suggests this is the case in West Lothian too. Although psychology services are able to (and do) use reliable diagnostic testing in adult services, formal diagnosis testing is rarely done in children's services. We also know that learning disabilities place a considerable lifelong challenge on the individual as well as family, friends and carers with markedly worse health than the population as a whole, overall shorter lifespan and a host of health conditions unequally experienced.

The NHS and health and social care partners have a statutory duty of care to respond appropriately and considerately in meeting the needs of people with learning disabilities with dignity and compassion. This challenge is given even more of an acute focus by the predicted rise in the prevalence of learning disabilities across Scotland over the next decade and beyond.

It is reassuring then, that in West Lothian there is generally positive corporate feedback from service users on the range of services provided locally, although attention still needs to be maintained on improving communication in all its forms.

Of course, much work and vigilance is still needed to further improve and provide excellent local and appropriate services, which are accessible for all people with learning disabilities.

This section sets out a summary of the key findings from all elements of the study, along with a series of recommendations. There are 17 recommendations in total for deliberation by West Lothian Community Health and Care Partnership and their partners. Recommendations are derived from evidence gathered and analysed from the review of literature, surveys and fieldwork, including study informants; and have been grouped under the following five key themes:

- Ambition, Strategy and Communication (recommendations 1-3)
- Accessibility and Transport (recommendation 4)
- Service Response to Evolving Needs (recommendations 5-10)
- Integrated Practice (recommendations 11-16)
- Workforce development (recommendation 17)

7.2 Key findings and recommendations

The overall environment in West Lothian is generally regarded as excellent, with a varied landscape with diverse cultural and leisure opportunities contributing to a high quality of life for many residents.

From the outset of this research contract being commissioned, the research team has been highly impressed with the commitment and desire of the majority of stakeholders to strive for significant improvements to both service provision and commissioning of services for people with learning disabilities and/or autism. The following ambitious set of recommendations have been developed to match the level of commitment and desire demonstrated. The research team believe that a genuine focus on these recommendations will lead to a comprehensive programme of change and improvement over the next 5-10 years.

7.3 Ambition, Strategy and Communication

Ambition, Strategy and Communication (recommendations 1 -3)

7.3.1 Integrated Learning Disability Strategy

RECOMMENDATION 1: An Integrated Health & Social Care Learning Disability Strategy should be developed with a broad range of stakeholders; considering and agreeing a set of joint principles for action to be addressed through the lifetime of the strategy. The strategy should be inclusive of people who have both autism and a learning disability, and should be cross-referenced to the existing 2015 Autism Strategy for West Lothian.[197]

By embedding an agreed set of joint principles it will be possible to avoid duplication or simply reinventing ways of tackling existing challenges. All relevant commissioners should be asked to consider how they will contribute to these principles. The principles agreed should be used to judge and challenge future commissioning plans and we would encourage commissioners to use them as an integral part of developing their plans.

The broad set of principles listed below are suggested as a starting point for discussion. Any agreed set of principles should be based on lifestyle and risk factors that impact on the wellbeing of people with a learning disability (inclusive of those who also have autism) in West Lothian; and that might limit their choice, control and independence.

The suggested list of joint principles for action are:

- Demonstrating engagement with service users, families and carers and their participation in the design of services;

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[197] Available at:
http://www.autismstrategyscotland.org.uk/index.php?option=com_docman&Itemid=&gid=361&lang=en&task=doc_download

- Identifying not only financial and resource constraints but also assets and strengths;
- Being clear on improved outcomes;
- Demonstrating improved collaboration and integration (between health and social care commissioning);
- Identifying contributions to reduce health inequalities, increased service user access, choice and control and more seamless care and support pathways;
- Being transformational and innovative where necessary;
- Providing local opportunities and services wherever possible
- Removing barriers to change that would have an early impact;
- Shifting the focus towards all aspects of early assessment and prevention; and
- Identifying the potential interaction with other services such as housing, transport, community planning and education.
- Promoting full involvement of all stakeholders, modelling practice on the new national Charter for Involvement for people and creating real opportunities for third and Independent Sector services to be in practice 'equal' partners.

Good Practice Reference

'The Voluntary Sector is key to Health & Social Care integration, not an optional extra' Community Care June 2014.

Check out: *http://thirdsectordumgal.org.uk/integration/*

7.3.2 Integrated Autism Strategy

RECOMMENDATION 2: An Integrated Health and Social Care Autism Implementation/Action Plan should be developed, in order to fully operationalise the existing 2015 Strategy[198].

The current West Lothian Council Autism Strategy sits with Young people services. Wherever the responsibility and leadership is located to implement the strategy, good and effective connections between children, young people and adult services across every aspect of the partnership are vital.

The Integrated Autism Implementation/Action Plan needs to prioritise the promotion of good awareness of Autism in every aspect of the Spectrum. An awareness raising plan to ensure good levels of knowledge and skill within each Community will result in a better experience for people with Autism and their families.

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[198] Available at: http://www.autismstrategyscotland.org.uk/index.php?option=com_docman&Itemid=&gid=361&lang=en&task=doc_download

The Implementation/Action Plan needs to be linked and cross-referenced to current Scottish Government Autism priorities and strategic outcomes (2015-2017)[199] to ensure a consistent direction of travel.

Good Practice References

Scottish Autism are a Centre for Practice Innovation and provide a focus for practitioners, researchers and organisations to come together and collaborate, share ideas and shape innovative autism practice. A virtual support network for people with Autism, their friends and families has been established in Dundee.

www.autismnetworkscotland.org.uk. This website also has a well-developed events calendar for Scotland and links in with the Keys to Life.

7.3.3 Communication

RECOMMENDATION 3: In order to involve all relevant stakeholders as equal partners in meeting Recommendations 1 & 2, it is recommended that commissioners develop a full Communications Strategy, with one workstream targeted at professionals and one workstream targeted at service users and their families/carers. Consideration should be given, to developing (operationally) a locality-based approach to achieving excellent communication across the partnership; with cognisance taken of, and links to, the local integration plan.

Whilst there is an overall acceptance that there are a good range of services in West Lothian available to individuals with Learning Disabilities and those who care for them, the one issue that was raised time and time again was a lack of knowledge regarding services available. Many parents/carers and those who work with Learning Disabilities knew little if anything at all about many of the services which were available and there appeared to be no central point of contact to find out about them.

The need for better communication highlights the importance of the service recently commissioned from Capability Scotland and the opportunity that exits for this contract to establish itself as the central point of information and contact that people are looking for. Capability Scotland should be used as a key partner in developing the Communications Strategy.

Capability Scotland should be enabled to act both as an information resource, and also as a signpost for professionals, service users and their parents/carers. This, in our opinion, would significantly increase access to services, improve their effectiveness, and contribute to developing community capacity. Emphasis needs to be given to information being made accessible to people with a learning disability. The use of digital routes need to be considered, such as Twitter and Social Networking.

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[199] Autism Outcomes and Priorities 2015-2017. Available at: http://www.autismstrategyscotland.org.uk/index.php?option=com_docman&Itemid=&gid=451&lang=en&task=doc_download [Accessed on 28th September 2015].

In addition the West Lothian Health and Social Care Partnership should ensure best use of Locality Hubs as information and advice points and maximise on the knowledge and skill of the Local Area Coordination local networks.

Responses and comments from the West Lothian workforce across the partnerships reflect a significant lack of knowledge about local communities and their resources. This is indeed a surprising result. Investment in embedding a culture of Community, through developing a knowledgeable and confident staff group, would contribute to streamlining and improving the Care pathway for people with a learning disability and people with Autism.

Good Practice Reference

Midlothian Partnership have developed through the House of Care, a pilot of locating a post in a number of Health centres to provide accurate information about local resources, services and opportunities. This in effect prevents valuable time being taken up with the GPs in particular.

Edinburgh have developed an interactive map showing all the services and opportunities for older people: *http://www.jitscotland.org.uk/resource/edinburgh-live-well-in-later-life-interactive-map/*

NHS Western Isles – Learning Disability Pages - *http://www.wihb.scot.nhs.uk/LD/index.html*

7.4 Transport

Accessibility and Transport (recommendation 4)

7.4.1 Transport consultation and strategy

RECOMMENDATION 4: The development of an inclusive strategy which needs to address accessibility of services within West Lothian (Recommendation 2); must include a conversation around transport provision to and from services, as well as access to community activity and work, for people with Learning Disabilities and/or Autism across the whole of West Lothian. There is a current opportunity for all stakeholders to engage in a current West Lothian Transport Policy consultation (which is at the early stage of updating the previous 2001 West Lothian Transport strategy).

There are a number of challenges and opportunities which drive the need for developing an inclusive Transport Strategy for people with Learning Disabilities and/or Autism in West Lothian:

- The growing demands of a learning disability population who wish to travel more, both in frequency of journey but also more independently.

- The geographical challenges which an area of urban/rural mix produces, including the necessity to use public transport for longer journeys than would be the case in a predominantly urban setting.
- The requirement for individuals to be accompanied by family and friends or support staff more regularly than those without a learning disability or autism.
- Supporting people in their independence and ability to make their own choices about which services they access and where, should also include taking cognisance of the impact of changes to bus routes, numbers, bus stopping points etc. on people with a learning disability and/or autism.

There is therefore work to be done in addressing the transport needs of West Lothian people with a learning disability and/or autism, particularly in regard to inequalities in service access across the area. It is recommended that any conversation regarding service accessibility should be framed within the assessment of someone's ability to travel independently.

The priorities in all strategies and commissioning plans must be informed by the voices of service users, families, and carers; as well as by an outcome focused framework. By using the collective influence gained through the development of a joint strategy, it will be possible to secure improved outcomes through the other factors that impact on the accessibility and therefore the wellbeing of people with a learning disability and/or autism; including access to services pertaining to housing, education and employment.

Good Practice Reference

"**Sustrans** makes smarter travel choices possible, desirable and inevitable. We're a leading UK charity enabling people to travel by foot, bike or public transport for more of the journeys we make every day. We work with families, communities, policy-makers and partner organisations so that people are able to choose healthier, cleaner and cheaper journeys, with better places and spaces to move through and live in. It's time we all began making smarter travel choices." *www.sustrans.org.uk*

7.5 Service Response to Evolving Needs

Service Response to Evolving Needs (Recomendations 5-10)

Based on the strength of findings in this study, a crucial element which should be taken into account in all future commissioning, monitoring and evaluation planning, is the range of services which match up to the changing demographic of the Learning Disability and Autism Population. This population are ageing, have different aspirations, are pursuing different avenues of activity and are experiencing dementia in greater numbers than in the previous ten years. As such, the requirement for services to adapt and provide for these changing needs is increasing.

7.5.1 Transition

RECOMMENDATION 5: Commissioners are encouraged to consider reviewing and strengthening the availability and profile of transition services within West Lothian.

The general consensus gained from the fieldwork was that on the whole the period of transition from school to college or school to young adulthood, was not well catered for in West Lothian. Although there is evidence of commitment and collaboration between services, with individual planning being done within the framework of Positive Destinations and the work of the Transitions Internal and External Hubs, there is no dedicated resource for Transitions. The Care pathway is not integrated and different expectations, lack of consistency of message, double doing and loss of focus can result.

There appears to be a lack of choice of supports and services available to young people and their families from age 12 - 18 and then again once they have left schools, irrespective of whether these have been mainstream or specialist educational establishments. There also appears to be concern about the age range from 16 to 18, where the young person does not qualify for services through school but does not qualify for adult services either. This appears to be a gap which can be particularly problematic for young people and their families and requires some careful thought from commissioners. Provisions within the Children and Young People (Scotland) Act 2014[200] extend the age group which the Children and Families department, as well as the Education department, have responsibility for; and this, along with named persons, must underpin the consideration for any remodelled pathways.

Good Practice Reference

Case studies about young people with Autism and involving The Richmond Fellowship Scotland can be found at:

http://www.autismstrategyscotland.org.uk/sub-groups/group-2.html#sthash.qfqNy0nQ.dpuf

The Scottish Transitions Forum aims to improve the experience of people with additional support needs, particularly those with high support needs, as they go through life transitions. The forum has a focus on the transition of young people from school or college to adult life.

http://arcuk.org.uk/scotland/scottish-transitions-forum/

Foundation for People with Learning Disabilities 'Prepared for the Future?' booklet - *http://www.learningdisabilities.org.uk/content/assets/pdf/publications/prepared-for-future-rebrand.pdf?view=Standard*

Better Info, Better Lives - *www.scld.co.uk*

Project Search in Blackpool:

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[200] Available at: http://www.legislation.gov.uk/asp/2014/8/pdfs/asp_20140008_en.pdf [Accessed on 23 November 2015].

https://www.learningdisabilitytoday.co.uk/blackpool-council-project-search-helps-learning-disability-students-employment-pathways.aspx

Money course for people in New Zealand:

http://www.stuff.co.nz/business/71110710/money-course-for-people-with-learning-disabilities-is-a-new-zealand-first?dm_t=0,0,0,0,0

7.5.2 Ensuring good quality care co-ordination and effective partnership working

RECOMMENDATION 6: Commissioners should review the pattern of service provision and contracting for those with learning disabilities who are over 55 to ensure that it strengthens the co-ordination of care and effective partnership working and communication and provides appropriate care and end of life provision.

There was concern expressed by staff in Social Services, the NHS Community Learning Disability Team and also within primary care, that as the learning disability population ages and their needs become ever more complex, the traditional older people's residential facilities will not be a suitable place for those over 55 (163 people in 2014) either as they get older but also as they approach the end of their lives. Thus commissioners should actively engage with current service providers to address this issue and give thought to providing flexible provision to enable people to live at home as long as possible.

The 'Rebalance of Care' agenda driven in Older People's services is key to planning for older people with a learning disability. Planners, operational managers and commissioners, from each section should be having conversations about the opportunities for people with a learning disability to access mainstream older people services (for example, extra care housing, intermediate treatment post-discharge from hospital/reablement services); and have the discussion about the pros and cons of mainstream older people care homes providing for people with a learning disability (in some cases younger people). In all older people mainstream supports and services, the knowledge and skill of staff on supporting people with a learning disability will be a critical factor. This is also true of the needs of older people with autism.

Good Practice References

Community Links Project for Older people in Midlothian *http://www.jitscotland.org.uk/examples-of-practice/*

NICE draft guideline for older people with a learning disability – in consultation http://www.nice.org.uk/guidance/gid-scwave0776/resources/care-and-support-of-older-people-with-learning-disabilities-draft-scope-for-consultation2?dm_i=6N7,3LC23,KIQWTQ,CXEHI,1

End of Life project - *http://www.skillsforcare.org.uk/Document-library/NMDS-SC,-workforce-intelligence-and-innovation/Workforce-integration/5Champions.pdf*

Joseph Rowntree Foundation and Edinburgh University (2010) - "Supporting Derek" is a practice development guide to support staff working with people who have an intellectual disability and dementia. http://dementia.mvm.ed.ac.uk/

Report of the National Task Group on Intellectual Disabilities and Dementia Practices (2012) – "My Thinker's Not Working" - http://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf

NHS Lothian and City of Edinburgh Joint Strategy (2014) – 'Ageing in Place' to support people with learning disabilities and dementia

7.5.3 Future joint planning

RECOMMENDATION 7: This needs assessment has added to the existing evidence (Learning Disability Statistics Scotland (e-SAY) data; the pan-Lothian Models of Care project (South East Scotland Managed Care Network for Learning Disability)[201]; and a recent briefing paper on the Integration of Learning Disability Health and Social Care Services), which demonstrates a wide range of levels of need of people with a learning disability in West Lothian. Future joint planning for services needs to take account of the research into prevalence, the local knowledge of each known person, whilst at the same time seeking as much information about 'hidden' populations.

Planning for services and opportunities needs to be on the principles of these ideally being provided locally and, as far as possible, accessible in terms of geography.

7.5.4 Housing strategy

RECOMMENDATION 8: A Housing strategy for people with a learning disability is developed in collaboration with Housing Strategy and Community Planning partners.

For example, there is no specific supported living service for people with a learning disability with forensic needs. The further development of a core and cluster model of support would enable a better opportunity for reduced offending and reduce the vulnerability of individuals. The West Lothian Housing Allocations Policy allows for a number of vacant properties to be allocated to young people and adults with learning disabilities and/or autism and the current West Lothian Housing Strategy 2012 – 2017 puts great emphasis on promoting independent living. This proposed housing strategy, for people with a learning disability and/or autism, could comfortably fit within these streams and allow a more focussed approach to accommodation in line with other community planning priorities. It is recognised that some good work has already been completed to consider the needs of people with learning disabilities within the local housing strategy, and the purpose of this recommendation is to encourage further development of this work.

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[201] NHS Scotland SEAT Region (2012). *The full spectrum of care for people with a learning disability who have complex care needs.*

Good Practice Reference

Scottish Offenders with learning disabilities - a network to reduce offending and increase support *http://arcuk.org.uk/scotland/sold-supporting-offenders-with-learning-disabilities/*

RECOMMENDATION 9: The West Lothian Partnership should work with the local Housing Strategy group to seek opportunities which will provide a core and cluster for permanent living and a resource for short breaks which can be purchased on a flexible basis for others (for example, older people, people with sensory needs).

Murraypark Hospital provides a much valued resource for respite and short breaks for people with profound and multiple needs. The Learning Disability Pan-Lothian Collaboration is currently deliberating on future planning. There is no provision locally for people with profound and multiple needs. Family Carer messages within the scope of this needs assessment have highlighted the Carer view of having reliable responsive services locally.

Good Practice References

Edinburgh "Break Away" services and community short breaks - http://www.edinburgh.gov.uk/site/scripts/home_info.php?homepageID=60&recordID=5797

NHS Lothian – Lanfine; Short Breaks for Carers of People with Progressive Neurological Conditions

7.5.5 Daytime Opportunities

RECOMMENDATION 10: Commissioning strategies and plans should be reviewed in respect of Daytime Opportunities.

Daytime opportunities was seen by nearly all service users, parents/carers and professional support staff, as key to the well-being of those with Learning Disabilities in West Lothian. There was little doubt that The Pathways Centre was regarded as an essential facility for people with learning disabilities within West Lothian and in particular those residing within Livingston, by service users, parents and carers and professionals. The role Pathways plays within the community was evidenced on many occasions within the fieldwork component of this assessment, not only as a place of learning and socialisation for those using the facility but also as a provider of 'respite' for parents/family carers whose relative attended the centre. Indeed one of the most commonly reported criticisms of the facility was that it was not able to be utilised in the evening as a means of providing facilities more in line with needs of those service users who either didn't attend during the day or wished to socialise in the evening. The use of the centre as a community facility was also discussed, due to its location and café facilities. The Eliburn Centre, whilst providing a different type of service was also highly regarded by services users, parents/carers and professionals. We therefore believe that commissioners should review any existing plans for those day services in light of the role they play within the Learning Disability Community in West Lothian as highlighted by this needs assessment.

A review of daytime opportunities for people with a learning disability will inform in full the spectrum of opportunities people in West Lothian are wanting. This spectrum should include those opportunities within each community which offer solutions for people which prevent the need for an association with a service, so enhancing at an individual level independence, valued status and community presence and involvement. The review would also take into account training for work and supported employment and open employment opportunities for people with a learning disability. This applies to people with high functioning autism as well. Continuous learning and development opportunities are important and crucial to independent living. A review, and resulting planning, needs to see collaboration between the Health and Social Care Partnership with West Lothian College, West Lothian Community Planning and Business partners in terms of potential employment.

Good Practice References

SCLD have reviewed their Values into practice guidance for Local Area Coordinator services. *http://www.scld.org.uk/?publications=values-into-practice-a-framework-for-local-area-coordination-in-scotland*

SCLD have written a report on Further Education opportunities - ‘‘Achieving our potential’. https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=0CCcQFjABahUKEwixrKvq96_IAhVBUhoKHVqlB6A&url=http%3A%2F%2Fwww.scld.org.uk%2Fwp-content%2Fuploads%2F2015%2F06%2FAchieving-Our-Potential.pdf&usg=AFQjCNGhRQoI_I4VVFzvTuCP2X-2JB3LOw

Scottish Borders have reviewed their Learning Disability Day opportunities provision. A report and DVD are available. SBCares - a Limited Liability Partnership now provides Day Opportunity services for people with a learning disability in Scottish Borders – see:

http://www.sbcares.co.uk/info/4/day_services/14/day_services_for_people_with_a_learning_disability

The approach of Intensive Interaction - http://www.intensiveinteraction.co.uk/about/

Supporting people with a learning disability to use their skills and engage with the community:

https://www.mencap.org.uk/sites/default/files/documents/2015.058_RYG%20Community%20Impact%20Project%20v5.pdf

7.6 Integrated Practice

Integrated Practice (recommendations 11-16)

Integration represents a seismic change for services, in terms of operations, governance and workforce development. It demands a change of mindset and a maximisation of use of resources in an efficient and effective way. Services and individual professionals working closely together will bring about improvement and better outcomes for each person. This cultural journey needs to start now at all levels of services. Engagement by the workforce with this agenda is paramount and support from West Lothian Organisational development resources within NHS and West Lothian Council may be a source of support to learning disability and autism services alike.

7.6.1 Integrated working across all partner agencies and stakeholders

RECOMMENDATION 11: Construct an integrated working guide involving learning disability and autism services and mainstream service provision in housing, health care and other relevant services (e.g. criminal justice)

The integration of health and social care demands closer working across professionals and services to optimise the experience for the person and their family. This study has highlighted inconsistencies in integrated working within, between and across specialist learning disability services and other crucial linked services such as health care, assessment teams and employability.

For example, despite the work of such groups as the ‘Transitions Life Stage’ group, which focuses on young people with links to Criminal Justice, mainstream Children and Families services and Homelessness, there seems to be in general (for both young people and adults), little consistent understanding or progress towards establishing Integrated Care Pathways for people with learning disabilities and people with autism. The experience of parents/family carers is patchy at best. In the longer-term there would be great benefit in developing and agreeing an integrated care pathway working guide involving all relevant stakeholders.

Good Practice Reference

Bringing the NHS and Local Government together - A practical guide to integrated working:

http://www.wales.nhs.uk/sitesplus/documents/829/ICN%20Practical%20Guide%20to%20Integrated%20Working.pdf

King Fund article on achieving Health and Social Care Integration through collective transformation *http://www.kingsfund.org.uk/publications/quest-integrated-health-and-social-care?gclid=CI3U5vCksMcCFZHHtAoduRUFew*

Draft guidelines to help transform the care of people with a learning disability in England: *http://www.england.nhs.uk/2015/07/28/ld-transforming-*

care/?utm_source=feedburner&utm_medium=email&utm_campaign=Feed%3A+NHSCBoard+%28NHS+England%29&dm_i=6N7,3K45X,KIQWTQ,CSIQO,1

Equal access, equal care – Working with people with a learning disability in prison:

http://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/08/equal-access-equal-care-guidance-patients-ld.pdf?dm_i=6N7,3LC23,KIQWTQ,CWNZ9,1

7.6.2 Responsive and proactive respite services

RECOMMENDATION 12: Respite Services & Short Break opportunities need to be further developed to be more responsive to the needs of an ever changing population including ensuring that staff and parents/carers understand what services are available and how to appropriately refer and access.

Whilst it was recognised that within West Lothian the available respite services are generally very good, it was also identified that there was a need for respite services to be more person centred, responsive, accessible, joined up/coordinated and effective to meet assessed needs and changing needs. This will require a review of what services provide, matched to the expectations and needs viewed primarily from the perspectives of service users and their carers.

A full review of short breaks and respite opportunities for both people with a learning disability and people with autism is recommended. Collaboration with key partners and the involvement of people with a learning disability and people with Autism is paramount. Listening to what works well and what could be done better, acknowledging the financial constraints will inform a plan of development.

Self-directed support has become the mainstream approach for people who are eligible for funding to meet their outcomes. This review would need to take account of the different ways people might want to use to meet their agreed outcomes and commissioning of services would need to reflect this.

Good Practice Reference

'Wee breaks' in Midlothian is run by VOCAL and provides advice and support to Carers in Midlothian: *www.weebreaks.org*

7.6.3 Self-directed Support

RECOMMENDATION 13: Support for all staff in SDS development is essential to progress. A stronger message of the SDS approach being the mainstream approach and there being no choice in its use would be beneficial.

Responses from both people and staff suggest that Self-directed Support in West Lothian is developing in practice and as experience of using this approach increases so does the knowledge and confidence. Self - directed Support is a 'golden' thread running alongside the outcomes focused approach. Our research suggests that assessing staff are not embracing SDS fully or indeed across all care groups. For example, there is evidence of gaps within young people services and for people with complex needs. For people with a learning disability and for people with Autism, SDS offers increased control of choice and decision making and should be offered an equitable opportunity to achieve this. The agreement on the final aspects of the Assessment tool and the associated systems will enable confidence and strength for the workforce to enable people with a learning disability widely, including people with complex needs, to have an individual budget and support plan to meet their outcomes. As with any change programme, strong leadership from Senior and Operational managers will support confidence in embedding this approach into practice.

In Children Services, choice of service is currently limited by block contracting. West Lothian managers have positive plans for developing SDS for children with disability as well as children with other areas of need.

7.6.4 People with a Learning Disability who have complex needs

RECOMMENDATION 14: West Lothian CHCP need to continue being a full partner in the pan-Lothian plan regarding provision for those people with a Learning Disability who have complex needs.

Regular comment and concern was expressed throughout the course of the needs assessment project in relation to the challenge of establishing an appropriate level of support and service provision for those people with a Learning Disability who also have complex needs. The report authors are aware of the pan-Lothian plan for provision for this population and would encourage West Lothian CHCP to take a leading role in ensuring the plan is fully supported across West Lothian.

7.6.5 Strengthening the Third Sector and Statutory Service Integration across West Lothian

RECOMMENDATION 15: Enhance the role and availability of the third sector and peer support services and networks to support integrated care and outcomes for people.

The third sector, including both voluntary organisations and commissioned services, is a fundamental element of any solution concerning support provision across West Lothian. There are a mix of experiences across commissioned Third Sector organisations in West Lothian, with some stating their satisfaction with local arrangements; whilst others, including parent/carers groups, did express some 'issue' type sentiments such as being under-funded, under-utilised and under-valued. It is evident that the third sector can continue to make a vast impact on results at an individual, family, local community and wider societal basis.

Working together with commissioners with commonly identified and agreed goals, third sector organisations must do better at demonstrating their effectiveness in providing support to those with learning disabilities; critically within the framework of Self Directed Support.

The Learning Disability Providers forum - including West Lothian Council Learning Disability providers - is a real opportunity for sharing good practice and building trust and strength in knowledge and understanding.

Currently, family/carer support networks, activities and initiatives in West Lothian are largely sporadic; notwithstanding the endeavours and successes to date of a few third sector organisations and parent led groups and activities. However, there needs to be heavier investment including financial backing to developing family/carer support/mutual aid models and practices to complement more conventional services. Support for Parent/Carer lead initiatives, both financially but also systemically will not only improve the variety of services but also their impact on service users well-being and quality of life.

Good Practice References

VOCAL provide a service to Carers across the Lothians - Examples of good practice at: www.vocal.org.uk

Edinburgh Joint Carers Strategy: *http://www.jitscotland.org.uk/example-of-practice/edinburgh-joint-carers-strategy/*

7.6.6 Increasing the profile of Service Users and their Families/Carers

RECOMMENDATION 16: Consideration should be given to developing a clear framework for how service users and their families/carers could and should be involved in the delivery, development and commissioning of Learning Disability services.

The evolution, planning and development of services, models of support and commissioning processes should be built around the ambitions of service users and their families within a self-directed support and outcomes focused system of care. Developing services in this way will provide benefits to people who use the service but will also help develop community based mutual aid and peer support networks, thereby enhancing the ability for people to move on from services.

The National Charter for Involvement[202] details clearly the view of people using services in terms of participation and involvement.

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[202] Available at: http://arcuk.org.uk/scotland/files/2011/09/ARC-final-charter-297mmx297mm-12.12.14.pdf

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Good Practice References

National Charter for Involvement: *http://arcuk.org.uk/scotland/files/2011/09/ARC-final-charter-297mmx297mm-12.12.14.pdf*

Stirling University – Talking Mats® - *www.talkingmats.com*

National Standards for Community Engagement - *http://www.scdc.org.uk/what/national-standards/* and *http://www.gov.scot/Topics/People/engage/NationalStandards*

7.7 Workforce Development

Workforce Development (recommendation 17)

7.7.1 Developing an experienced, flexible, responsive and hopeful workforce

RECOMMENDATION 17: There is a clear need for a comprehensive training needs analysis to inform the development of a long-term programme of workforce development opportunities.

The transition to Self-directed Support has opened up demand for new skills and competencies in the workforce and is influencing the understanding of the scope of that workforce.

In short, consideration should be given to undertaking a training needs analysis and development of a learning and development schedule for specialist and generic staff and other stakeholders (including carers/families) who work with/care for people with learning disabilities and/or autism. This workforce development programme would play a significant part in further developing the profile of Self-directed Support, assessment processes and would augment the very good training interventions carried out by the Community Learning Disability Team.

The full picture of sources of learning needs to be understood with all opportunities for learning being included in a scoping exercise and resulting map. The Voluntary, Third and Independent Sectors need to contribute to this as well. As previously referred to, this would bridge the gap in terms of closer working across the partnership.

Engagement with staff and opportunities to learn about role and remit across the professions will result in closer, more trusting and confident working relationships.

The West Lothian Autism Strategy group have identified within their Action plan a need to develop local training plans which incorporate both local and national developments.

We would suggest that a vision is drawn together for the establishment of a 'Learning College' (or Resource Centre) in West Lothian; staffed and run by service user-educators and linked to the delivery of a local recovery strategy. The centre would train and support people with lived experience of learning disabilities and/or autism, to tell their stories and to promote awareness of learning disabilities and/or autism among staff and other service users. It would also begin to train people as ‘peer professionals’ to provide direct care within the services. It would need to work with local education providers to ensure that the training is of a consistently high standard and begin to offer accredited courses. A beneficial offshoot of this development would be the general promotion of an ‘educational’, rather than a ‘therapeutic’, model within the services, which would place an emphasis on learning from one another and assist in promoting self-determination and self-management.

There are emerging examples of ‘Recovery Colleges’ in Scotland, particularly within the Mental Health field, which focus on peer education and dissemination of good practice. Obviously, given the permanence of Learning Disabilities, the use of the word ‘recovery’ is not appropriate in this setting; but if the example of ‘recovery colleges’ could be seen as ‘learning colleges’ then the approach is definitely worth looking at.

Good Practice References

Midlothian Voluntary Action Training plan and newsletter: *http://mvacvs.org/index.php/our-services/training*

Mindspace Recovery College covering Perth & Kinross – information available at: *http://www.mindspacepk.com/recovery-college/*

NHS Education for Scotland – Mental Health and Learning Disabilities E-Learning: *http://www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/mental-health-and-learning-disabilities/publications-and-resources.aspx*

APPENDICES

Appendix I: References

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Appendix II: Interview Schedule

	Stakeholder	Title / Position
1	**Alastair Murdoch**	Senior Physiotherapist, NHS Community Learning Disability Team
2	**Alexander**	Autism and Learning Disability Social Worker
3	**Alison**	NHS Community Learning Disability Team
4	**Alison Nicol**	Literacy Development Worker, West Lothian Council
5	**Allistair Littlejohn**	Clinical Services Development Manager, NHS Lothian
6	**Alistair Welsh**	Support Provider, Key Community Support
7	**Andrew**	Psychologist, NHS Community Learning Disability Team
8	**Anne Quinn**	West Lothian Council
9	**Calum Robson**	Learning Disability Team, West Lothian Council
10	**Caroline Johnston**	Local Area Coordinator, Social Work, West Lothian Council
11	**Chen Zinoro**	Area Manager, Autism Initiatives
12	**Christene Nealy**	Projects abd Development Manager, New Directions West Lothian
13	**Christopher Nelson**	Senior Advisor, Advice Shop, West Lothian Council
14	**Claire**	Psychologist, NHS Community Learning Disability Team
15	**Claire Pagani**	Learning Disability and Autism Team Manager, West Lothian Council
16	**Clare Coyle**	Action Group
17	**Clare Hickie**	Carers of West Lothian
18	**Deborah Paton**	Transport Policy Officer, West Lothian Council
19	**Diane Robertson**	Pathways
20	**Duncan McGowan**	GP and CHCP Lead for West Lothian Council, NHS Lothian
21	**Elaine McKenna**	Depute Manager, Eliburn Centre
22	**Gail**	Art Therapist, NHS Community Learning Disability Team
23	**Gill Burns**	Carers of West Lothian
24	**Gillian Alexander**	Disability West Lothian
25	**Gillian Johnston**	West Lothian Council
26	**Gwen Smeaton**	Barony Housing Association
27	**Gwyn Morrison**	Head of Service, Mears Group
28	**Helen Doctor**	Director of Corporate and Customer Services, Capability Scotland

29	**Jane Dalrymple**	Assistant Strategic Programme Manager, Learning Disability, and Physical and Complex Disability, NHS Lothian
30	**Jane Kellock**	Interim Head of Social Policy, West Lothian Council
31	**Jane Stewart**	Clinical Psychiatrist, NHS Community Learning Disability Team
32	**Jean Michaels**	Chief Executive, New Directions West Lothian
33	**Jill Derby**	Self-directed Support Lead, West Lothian Council
34	**Jim Herron**	Area Manager, the Richmond Fellowship
35	**John Cassidy**	Activity Manager, West Lothian Community Inclusion Team
36	**Joy Tomlinson**	NHS Lothian
37	**Joyce Orminston**	Group Manager, Social Work (Adults), West Lothian Council
38	**Katy McBride**	Planning and Co-ordination Officer, Housing Strategy and Development, West Lothian Council
39	**Kayley Travers**	Enable
40	**Kenneth Stein**	East Regional Co-ordinator, Share Scotland
41	**Laura Smith**	Learning Disability Nurse, NHS Community Learning Disability Team
42	**Leona Jackson**	Contracts and Commissioning Officer, West Lothian Council
43	**Lesley Broadley**	Service Development Officer, West Lothian Council
44	**Linda Blackie**	Dietitian Learning Disability Service
45	**Linda Sanders**	Team Manager, Children with Disabilities Team
46	**Linda Smith**	Learning Disability Nurse, NHS Community Learning Disability Team
47	**Lorna Kemp**	Equalities Officer, West Lothian Council
48	**Lorna Smith**	Dietitian Learning Disability Service
49	**Lorna Thomson**	Advice Services Manager, Capability Scotland
50	**Margaret Forisky**	Centre Head (Hospitality/Assisted Programme) West Lothian College
51	**Mhairi Flannigan**	Community Charge Nurse, NHS Community Learning Disability Team
52	**Michael Davis**	West Lothian Council
53	**Nicola Smith**	Enable
54	**Pamela Main**	Senior Manager, Community Care Assessment and Prevention, West Lothian Council
55	**Pauline Cochrane**	Team Manager, Children with Disabilities Team
56	**Rachel Mackay**	Group Commissioning Manager, West Lothian Council

57	**Rhoda Taylor**	Real Life Options
58	**Rona Laskowski**	Strategic Programme Manager – Disabilities, NHS Lothian
56	**Rosalind Keogh**	West Lothian Council
60	**Rosemary Willox**	West Lothian Council
61	**Rosie Fleming**	Manager of Dean House / Burnside respite
62	**Sam Abdulla**	Community Staff Nurse, NHS Community Learning Disability Team
63	**Stuart Pretswell**	Employment Development Worker, West Lothian Council
64	**Susan Jackson**	Community Charge Nurse, NHS Community Learning Disability Team
65	**Tom Ullathorne**	Autism Initiatives
66	**Yvonne Lawton**	Service Development Officer, West Lothian Council
67	**Wendy Kelly**	Team Manager, The Richmond Fellowship

During the course of the research, the team at Figure 8 spoke also spoke with 13 parents/ carers and nine service users, in addition to the stakeholders detailed above.

FIGURE 8
CONSULTANCY SERVICES LTD

2015

PHYSICAL DISABILITY, SENSORY IMPAIRMENT AND ACQUIRED BRAIN INJURY NEEDS ASSESSMENT

Report prepared for West Lothian Community Health Care Partnership

Figure 8 Consultancy Services Ltd
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EVIDENCE INTO PRACTICE

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CHAPTER 1: INTRODUCTION

1.1 Introduction and background

Figure 8 Consultancy Services Ltd. was commissioned by West Lothian CHCP in April 2015 to carry out a comprehensive physical disability, sensory impairment and acquired brain injury needs assessment project; and fieldwork took place between May 2015 and June 2015.

1.2 Definitions and concepts

For the purposes of this report we use the following terms:

1.2.1 Physical Disability (Disabilities)

According to the Equality Act (2010) "*a person has a disability if s/he has a physical or mental impairment which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities*."

1.2.2 Sensory Impairment

According to the Scottish Government's *'See Hear'* Strategy a sensory impairment includes individuals with a variety of impairments such as hearing loss, sight loss, and loss of both these senses combined. Sensory loss can be present from an individual's birth, however, for most, a sensory loss happens later in life.[1]

The Action on Hearing Loss report 'Hearing Matters (Scotland Supplement)'[2] states that in 2011, hearing loss affected more than 850,000 people in Scotland (one in six of the population). By 2031, it is estimated that this figure will have risen to 1.2 million. The World Health Organisation predicts that by 2030, adult onset hearing loss will be in the top 10 disease burdens in the UK and other high and middle income countries, above cataracts and diabetes.

There are four different levels of hearing loss defined as:

- **Mild hearing loss** – can sometimes make following speech difficult, particularly in noisy situations;
- **Moderate hearing loss** – may have difficulty following speech without hearing aids;
- **Severe hearing loss** – usually need to lip-read or use sign language, even with hearing aids;
- **Profound deafness** – usually need to lip-read or use sign language.

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[1] Scottish Government. 2014. *See Hear. A strategic framework for meeting the needs of people with a sensory impairment in Scotland.* Available at: http://www.gov.scot/Publications/2014/04/7863/0 [Accessed 10 June 2015].

[2] Action on Hearing Loss (2011). *Hearing Matters (Scotland Supplement)*. Available at:

The World Health Assembly views blindness as a public health issue directly linked with lifestyle and demographic factors. Currently, almost 2 million people in the UK are living with some degree of sight loss and this number is rapidly increasing. This figure includes around 360,000 people registered as blind or partially sighted, who have severe and irreversible sight loss[3]. By 2050, it is predicted that four million people will have sight loss. The UK population is ageing, and it is projected to continue to age over the next few decades, with the fastest population increases in the numbers of those aged 85 and over. This is the age group more at risk of eye disorders causing vision impairment[4].

When it comes to the term of *'deafblindness'*, there is no agreed definition, however, a commonly used definition is: '*Persons are regarded as deafblind if they have a severe degree of combined visual and auditory impairment resulting in problems of communication, information and mobility*.'[5]

'Acquired Deafblindness' is a term used to describe those who have become dual sensory impaired in later life and Deafblind Scotland suggest those with acquired deafblindness fall into three categories:[6]

- People who are born deaf and later lose their sight. This may be as a result of Usher Syndrome, which is a major cause of deafblindness.
- People who are born blind and later lose their hearing.
- People who lose both sight and hearing in later life.

1.2.3 Acquired Brain Injury

An Acquired Brain Injury is any sudden damage to the brain. Headway, the brain injury association, define an Acquired Brain Injury as: '*A non-progressive acquired injury to the brain with sudden onset*.'[7]

1.2.4 Wellbeing

This report examines not just physical disability, sensory impairment and acquired brain injury, but also considers what promotes and supports mental and emotional wellbeing. The concept of 'wellbeing' has gained a wider public airing following the decision to embark on a national measurement programme developed by the Office for National Statistics (ONS), introduced in 2011. At a personal level wellbeing is "a positive physical, social and mental state" at a population, or national level, a range of indicators are being included, individual wellbeing but also the quality of

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[3] Access Economics Pty Ltd (2009). *Future Sight Loss UK. The economic impact of partial sight and blindness in the UK adult population.*

[4] UK Vision Strategy 2013-18

[5] Deafblind Scotland. 2015. *Deafblindness*. Available at: http://www.deafblindscotland.org.uk/deafblindness/ [Accessed 22 June 2015].

[6] Deafblind Scotland. 2015. *Deafblindness*. Available at: http://www.deafblindscotland.org.uk/deafblindness/ [Accessed 22 June 2015].

[7] Headway. 2011. *What is an acquired brain injury?* Available at: http://www.headway.ie/download/pdf/what_is_abi.pdf [Accessed 1 July 2015].

the environment, equality, sustainability and the economy. Research indicates that 'wellbeing' comprises two main elements: feeling good and functioning well. Feelings of happiness, contentment, enjoyment, curiosity, and engagement are characteristic of someone who has a positive experience of their life. Equally important for wellbeing is our functioning in the world. Experiencing positive relationships, having some control over one's life and having a sense of purpose are all important attributes of wellbeing.[8]

In a review of the evidence on how individuals can improve wellbeing, the New Economics Foundation (nef)[9] identified five actions to improve wellbeing that individuals could be encouraged to build into their lives:

1. Connect … With the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community. Think of these as the cornerstones of your life and invest time in developing them. Building these connections will support and enrich you every day.
2. Be active … Go for a walk or run. Step outside, cycle, play a game, garden, or dance. Exercising makes you feel good. Most importantly, discover a physical activity you enjoy and that suits your level of mobility and fitness.
3. Take notice … Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you.
4. Keep learning … Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Set a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun.
5. Give … Do something nice for a friend, or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out, as well as in. Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you.

Aked et al (2009) contend that it is vital to combine consideration of the structural factors affecting the circumstances of individual's lives, together with the psychological and social aspects of their wellbeing. Only by taking this 'twin track' approach is it possible to account for the dynamic nature of wellbeing, where positive experiences ('feeling good') and outcomes ('doing well') arise through

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[8] Huppert F (2008) *Psychological well-being: evidence regarding its causes and its consequences* (London: Foresight Mental Capital and Wellbeing Project 2008).

[9] Aked, J. and Thompson, S. (2011). *Five ways to wellbeing – new applications, new ways of thinking*. New Economics Foundation: London.

the interplay between external circumstances, inner resources, and capabilities and interactions with the surrounding world.[10]

1.3 Risks and resilience - factors impacting the mental health and well-being of those with physical disabilities, sensory impairments and/or acquired brain injuries

The mental health of those with a physical disability, sensory impairment and/or acquired brain injury is not just a function of an individual's characteristics or attributes, it is also affected by a wide range of social, economic and environmental factors. These have been summarised in the table below.

- At an individual level people may be affected by biological or genetic factors or may have specific difficulties, for example communication difficulties, increasing vulnerability to mental health problems, by affecting their ability to engage, participate or understand aspects of daily living.
- There are numerous socio-economic circumstances which impact mental health and wellbeing; The Marmot Review[11] highlighted the issue of employment and education; but specific events can also affect mental wellbeing including bereavement, family or relationship breakdown and exposure to violence or abuse. When considering a life course, people may be more exposed to risks at different ages; for example older people are more likely to experience bereavement of partners/friends and may become more socially isolated whereas younger adults may be more at risk of homelessness and unemployment.
- It is recognised that experience in childhood is important and resilience in adulthood may relate to the experiences and skills developed in childhood.
- At a higher level wider factors such as basic access to services, economic recession or exposure to widespread violence or insecurity also impact mental health; these factors can be considered as the prevailing environment or conditions in which people live.

Table 1.1: Risk factors and resilience

LEVEL	ADVERSE FACTORS		PROTECTIVE FACTORS
Individual attributes	**Low self-esteem**	⇔	**Self-esteem, confidence**
	Cognitive/emotional immaturity	⇔	**Ability to solve problems & manage stress or adversity**
	Difficulties in communicating	⇔	**Communication skills**
	Medical illness, substance use	⇔	**Physical health, fitness**

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[10] Aked, J., Steuer, N., Lawlor, E. and Spratt, S., (2009), *Backing the Future*. See also Foresight Mental Capital and Wellbeing Project (2008), *Final Project report – Executive summary*, London: The Government Office for Science; and Thompson S, & Marks N (2008) *Measuring well-being in policy: Issues and applications*, New Economics Foundation: London.

[11] The Marmot Review (2010). *Fair Society, Healthy Lives*. Available at: http://www.ucl.ac.uk/whitehallII/pdf/FairSocietyHealthyLives.pdf [Accessed on 5th November 2014].

Social Circumstances	**Loneliness, bereavement**	⇔	**Social support of family & friends**
	Neglect, family conflict	⇔	**Good parenting / family interaction**
	Exposure to violence/abuse	⇔	**Physical security and safety**
	Low income and poverty	⇔	**Economic security**
	Difficulties or failure at school	⇔	**Scholastic achievement**
	Work stress, unemployment	⇔	**Satisfaction and success at work**
Environmental Factors	**Poor access to basic services**	⇔	**Equality of access to basic services**
	Injustice and discrimination	⇔	**Social justice, tolerance, integration**
	Social and gender inequalities	⇔	**Social and gender equality**
	Exposure to war or disaster	⇔	**Physical security and safety**

(Taken from Risks to Mental Health: An Overview of Vulnerabilities and Risk Factors WHO 2012)

1.4 Purpose

The purpose of this project is to assist West Lothian CHCP in:

- Identifying and profiling service users with physical disabilities, sensory impairments and/or acquired brain injuries in West Lothian;
- Assessing and describing the current strengths, gaps and inequities in such service provision;
- Identifying and describing the prevalence of people with physical disabilities, sensory impairments and/or acquired brain injuries in West Lothian;
- Profiling current service delivery to people with physical disabilities, sensory impairments and/or acquired brain injuries;
- Improving the number, quality, consistency, accessibility and integration of services appropriate for the needs of people with physical disabilities, sensory impairments and/or acquired brain injuries;
- Promoting a broader understanding of their needs and their right to effective services;
- Promoting equitable care through the promotion of positive values and attitudes;
- Reducing the inequalities experienced by people with physical disabilities, sensory impairments and/or acquired brain injuries.

1.5 Objectives

The specific objectives of this project are as follows:

- To provide a comprehensive assessment and mapping of specialist and non-specialist services and support for those with physical disabilities, sensory impairments and/or acquired brain injuries;

- To conduct an assessment of local need for such services and support;
- To identify gaps and areas of unmet need in current provision;
- To examine the current use of services, both community and inpatient;
- To examine the accessibility, appropriateness and location of current services;
- To identify any areas with over-provision;
- To provide evidence based recommendations as to how services could be extended or adapted to meet need including relationship and any overlap between agencies; and
- To suggest locality pathways for intervention and support for those with physical disabilities, sensory impairments and/or acquired brain injuries.

1.6 Scope

This document presents the findings of the needs assessment and reports on the future requirements for physical disability, sensory impairments and acquired brain injury services across West Lothian. Evidence from the Needs Assessment will assist:

- In providing evidence on the extent to which current services and support are meeting demand;
- In the commissioning of new services and support;
- In identifying gaps in existing service provision and support;
- In identifying areas of over provision;
- In providing evidence on the extent to which services and available support are accessible and in the right location; and
- In suggesting ways as to how West Lothian CHCP and its partners could extend/adapt services and support to meet need.

Conducting needs assessments in such a complex environment requires a great deal of understanding and flexibility on the part of the project team, and it is essential to engage as broad a range of interests as possible in the assessment process. To this end, the research team sought the views of a wide range of different physical disability, sensory impairment, acquired brain injury and mainstream services, people who use services, families and carers; advocates and other stakeholders. The qualitative element of the study in particular aimed to consult with staff from specialist physical disability, sensory impairment, acquired brain injury services, together with a sample of the following groups which support people with a physical disability, sensory impairment and/or acquired brain injury:

- Those who have a physical disability, sensory impairment and/or acquired brain injury, and who currently use West Lothian learning disability and/or autism specialist services;

- Those not currently using specialist physical disability, sensory impairment and/or acquired brain injury services, but who may benefit from doing so;
- Advocates;
- Families and Carers;
- Strategic Planners;
- GP's and Public Health Consultants;
- Mental Health Services;
- Criminal Justice and Youth Justice;
- Police Scotland;
- Health and Social Care Practice Teams;
- Third Sector and Independent Sector providers; and
- Mainstream services such as:
- Primary healthcare (inc. A&E);
- Older People's services;
- Adult education/training;
- Employability/Careers service;
- Housing/Homelessness Services; and
- Leisure and recreation.

Discussions with the project steering group and key strategic planners took place at several points during the fieldwork, and this acted as a helpful 'sounding board' for the emerging findings of the study.

1.7 Data Sources

The needs assessment incorporates data from a wide variety of sources, detailed throughout this report as footnotes; and includes evidence collated from an extensive consultation process with services users, local organisations and professionals. A note of data sources used for the Literature Review and the Epidemiology sections are provided at **section 2.4** and **section 3.2.2**. A full bibliography of data sources used is provided in Appendix **XX** and full details of those consulted as part of the study is provided in Appendix **XX**.

1.8 The Health Needs Assessment Process

In broad terms, health needs assessment (HNA) is the systematic approach to ensuring that the health service uses its resources to improve the health of the population in the most efficient way. It involves methods to describe the health problems of a population, identify inequalities in health and access to services, and determine the priorities for the most effective use of resources.

Health needs assessment has become important as the costs of health care are rising and resources for health care are, at the same time, limited. In addition, there is a large variation in availability and use of health care by geographical area and point of provision (Andersen and Mooney, 1990).[12]

Another force of change is consumerism. The expectations of members of the public have led to greater concerns about the quality of the services they receive, from access and equity to appropriateness and effectiveness.

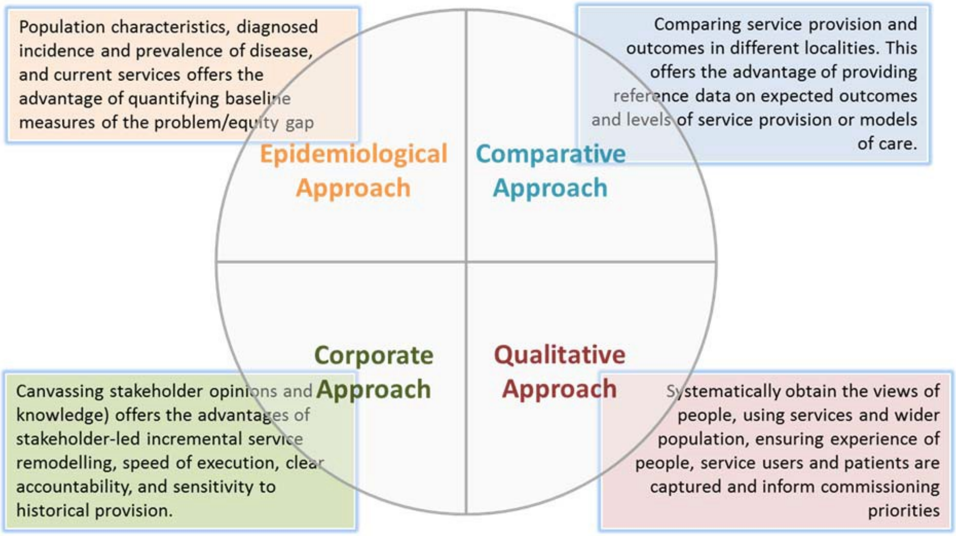
The health needs assessment (HNA) process has been defined, in guidance from the National Institute of Clinical Excellence (NICE), as:

> *"A systematic method for reviewing the health issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities."*[13]

The assessment process involves identifying need from four different perspectives (see Figure 1.5):

- **Epidemiological needs** – the use of health information based on the population, including demographic trends, health status and risk, as well as evidence of clinical effectiveness of services and interventions.
- **Felt and expressed needs (Qualitative)** – the views of the public, from surveys, focus groups and the like, often using participatory appraisal methods.
- **Normative or expert needs (Corporate)** – as identified by professionals or experts.
- **Comparative needs** – the scope and nature of services available to the population and how these compare with services elsewhere.

Figure 1.2 Diagram of health needs assessment



Population characteristics, diagnosed incidence and prevalence of disease, and current services offers the advantage of quantifying baseline measures of the problem/equity gap

Comparing service provision and outcomes in different localities. This offers the advantage of providing reference data on expected outcomes and levels of service provision or models of care.

Canvassing stakeholder opinions and knowledge) offers the advantages of stakeholder-led incremental service remodelling, speed of execution, clear accountability, and sensitivity to historical provision.

Systematically obtain the views of people, using services and wider population, ensuring experience of people, service users and patients are captured and inform commissioning priorities

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[12] Andersen, T.F. & Mooney, G. (Eds) (1990) *The challenges of medical practice variations.* MacMillan Press: London.

[13] Cavanagh S and Chadwick K (2005), "Health needs assessment: A practical guide". London: NICE. Available at: http://www.nice.org.uk/

The study methods used in this health needs assessment (outlined in section 1.9 below) were designed to capture each of these four different approaches/perspectives and are identified in Table 1.6 below.

1.9 Summary of Study Methods

The study was conducted in four stages. Each stage was tailored to the needs of the study, requiring a mix of data collection methods and sample populations. These are set out in the table below. All questionnaires and interview schedules were approved by commissioners prior to use. Copies of these are available upon request.

Table 1.3: Summary of Data Collection Methods

Stage 1	**Method**		**Link to approaches / perspectives on need**
Review of Existing Literature/Datasets	Desk-based review of national and local literature and datasets and any local specialist service data available.		• Epidemiological • Comparative
Stage 2	**Method**	**Sample**	
Quantitative Survey	Online Surveys	• Managers of all specialist PD, Sensory Impairment and ABI services • Staff in all specialist PD, Sensory Impairment and ABI services.	• Normative/Expert (Corporate) • Comparative
Stage 3	**Method**	**Sample**	
Quantitative Surveys	Online and paper-based surveys	• Service users • Non (potential) service users • Carers, family members, advocates	• Felt and Expressed (Qualitative)
Stage 4	**Method**	**Sample**	
Existing Service Review	Case Studies	• Those with Physical Disabilities, Sensory Impairments and/or Acquired Brain Injuries	• Felt and Expressed (Qualitative)
Stage 5	**Method**	**Sample**	
Stakeholder Event / Working Group /	Stakeholder Event	All key stakeholders invited to a half-day event in relation to Physical Disabilities, Sensory Impairments and Acquired Brain Injuries	• Normative/Expert (Corporate) • Felt and Expressed (Qualitative)

Qualitative Interviews / Focus Groups	Working Group	Sample of key stakeholders recruited via approaches from the Research Steering Group, and via the stakeholder event above. The working group to meet twice to explore Learning Disability, Sensory Impairment and Acquired Brian Injury issues.	• Normative/Expert (Corporate) • Felt and Expressed (Qualitative)
	Semi-structured interviews	• All specialist services • A range of non-specialist services • Other relevant stakeholders	• Normative/Expert (Corporate)
	Focus Groups	• Service users • Non (potential) service users • Carers, family members, advocates	• Felt and Expressed (Qualitative)

1.10 Considerations and limitations

There are a number of factors which should be taken into account when reading this report. These are:

- The views of those interviewed and surveyed were taken and reported in good faith and are their own, not necessarily those of Figure 8 Consultancy Services Ltd. or the organisations they represent. It cannot be assumed that the views of the participants in interviews or surveys are representative of all similar stakeholders.
- Making comparisons with other areas of similar population and/or geography, as well as prevalence of physical disabilities, sensory impairments and/or acquired brain injuries, allows for a degree of 'benchmarking' to observe the relative position of West Lothian. It should be noted that there may be variations between areas in the way in which this data is collected.
- The views of service users are drawn from those currently engaged with the services. This "self-selecting" group are more likely to be positively disposed towards the service, its staff and the interventions that they provide.
- In health care, need is commonly defined as 'the capacity to benefit'. If health needs are to be identified then an effective intervention should be available to meet these needs and improve health. There will be no benefit from an intervention that is not effective or if there are no resources available (Wright, Williams & Wilkinson, 1998).14 The definition of need used in this study is 'the number of individuals in the general population with mental health problems who could benefit from intervention'. There are several challenges in estimating the

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[14] Wright, J., Williams, R., & Wilkinson, J.R. (1998). Development and Importance of Health Needs Assessment. *British Medical Journal,* 316; 1310-1313.

prevalence of learning disabilities and autism in the general population involving the definition of ‘problems’ and the methods used to obtain the estimate.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The aim of this section is to present and summarise relevant, existing literature in relation to physical disability, sensory loss and/or acquired brain injury. This will provide a backdrop for the later sections of the Needs Assessment whilst situating the current project into the wider context.

2.2 Considerations and limitations

- The abbreviation of PD is used throughout this document. PD is used to describe a physical disability.
- At times the term disability is used as this was the term used in the article, rather than a specific physical disability.
- The literature at times uses specific categories such as 'deafblindness', whereas at other times the term disability is used to categorise a wide range of different impairments.
- The available literature is weighted towards learning disabilities.
- There is no national strategy for physical disabilities

2.3 Method of data collection

A literature review was conducted which included local, national and international databases. The articles included mixed-methods, quantitative and also qualitative designs. To obtain a focused, comprehensive overview and to identify all the available, relevant literature, a search of 'grey' literature was also conducted.

2.4 Data sources

The various data sources utilised in this report include:

- Centre for Disability Research http://www.lancaster.ac.uk/fhm/research/centre-for-disability-research/
- Centre for Welfare Reform http://www.centreforwelfarereform.org/
- DeafBlind Scotland http://www.deafblindscotland.org.uk/
- Department of Health https://www.gov.uk/government/organisations/department-of-health
- Equality and Human Rights Commission http://www.equalityhumanrights.com/
- Google Scholar http://scholar.google.co.uk/
- Headway https://www.headway.org.uk/home.aspx

- Independent Living in Scotland http://www.ilis.co.uk/
- Information Services Division Scotland http://www.isdscotland.org/
- National Records for Scotland http://nationalrecordsofscotland.gov.uk/
- National Skills Forum http://pol1-003-old.live.atomicant.co.uk/nsfapsg
- NHS Health Scotland http://www.healthscotland.com/
- Office for National Statistics http://www.ons.gov.uk/ons/index.html
- Public Health England https://www.improvinghealthandlives.org.uk/
- Scope About Disability http://www.scope.org.uk/
- Scottish Government http://www.gov.scot/
- Social Care Institute for Excellence http://www.scie.org.uk/
- ProQuest Central
- SAGE Journals
- Web of Science (Core Collection)
- Wiley Online Library

2.5 Context

There are two accepted models of disability within the literature on PD; the medical model and the social model. Within the medical model the medical disabilities are the root cause of a person's disability therefore this model emphasises the specific medical disabilities an individual has. The social model of disability, which is underpinned by the concept of independent living, suggests the disability arises due to the structural, physical and attitudinal barriers an individual with a PD faces in society, rather than any specific medical impairment.

Within this model, if the structural and attitudinal barriers are removed an individual with a PD can have an equal part in society, with more choice and control over their day to day activities.[15]

2.6 Definitions

According to the Equality Act (2010) "*a person has a disability if s/he has a physical or mental impairment which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities.*"

According to the Scottish Government's See Hear Strategy a sensory impairment includes individuals with a variety if impairments such as hearing loss, sight loss, and loss of both these senses combined.

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[15] Scope About Disability. *The social model of disability. What is it and why is it important to us?* Available at: http://www.scope.org.uk/about-us/our-brand/social-model-of-disability [Accessed 6 June 2015].

Sensory loss can be present from an individual's birth, however, for most, a sensory loss happens later in life.[16]

Action on Hearing Loss state there are four different levels of hearing loss which are defined by the quietest sound a person is able to hear, measured in decibels:

- **Mild** (quietest sound 25-39 decibels): A person can sometimes find following speech difficult, particularly in noisy situations.
- **Moderate** (quietest sound: 40-69 decibels): A person may have difficulty following speech without hearing aids.
- **Severe** (quietest sound: 70-94 decibels): A person usually needs to lip-read or use sign language, even with hearing aids.
- **Profound** deafness (quietest sound 95 decibels plus): A person will usually need to use sign language or lip-read.[17]

When it comes to the term of deafblindness, there is no agreed definition, however, a commonly used definition is: '*Persons are regarded as deafblind if they have a severe degree of combined visual and auditory impairment resulting in problems of communication, information and mobility.*'[18]

Acquired Deafblindness is a term used to describe those who have become dual sensory impaired in later life and Deafblind Scotland suggest those with acquired deafblindness fall into three categories:[19]

- People who are born deaf and later lose their sight. This may be as a result of Usher Syndrome, which is a major cause of deafblindness.
- People who are born blind and later lose their hearing.
- People who lose both sight and hearing in later life.

An Acquired Brain Injury is any sudden damage to the brain. Headway, the brain injury association, define an Acquired Brain Injury as "*A non-progressive acquired injury to the brain with sudden onset*."[20]

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[16] Scottish Government. 2014. *See Hear. A strategic framework for meeting the needs of people with a sensory impairment in Scotland.* Available at: http://www.gov.scot/Publications/2014/04/7863/0 [Accessed 10 June 2015].

[17] Action on Hearing Loss. 2015. *Levels of hearing loss.* Available at: http://www.actiononhearingloss.org.uk/your-hearing/about-deafness-and-hearing-loss/glossary/levels-of-hearing-loss.aspx [Accessed 22 August 2015].

[18] Deafblind Scotland. 2015. *Deafblindness*. Available at: http://www.deafblindscotland.org.uk/deafblindness/ [Accessed 22 June 2015].

[19] Deafblind Scotland. 2015. *Deafblindness*. Available at: http://www.deafblindscotland.org.uk/deafblindness/ [Accessed 22 June 2015].

[20] Headway. 2011. *What is an acquired brain injury?* Available at: http://www.headway.ie/download/pdf/what_is_abi.pdf [Accessed 1 July 2015].

2.7 Policy context

In contrast to learning disability there is no overarching national strategy for physical disability. The main national strategy in this area is the '*See Hear*' strategy which is the framework for meeting the needs of those with a sensory impairment. The Scottish Government's *'See Hear'* Strategy suggests three groupings should be considered:

- Individuals with a recognised sensory impairment;
- Individuals at risk of sensory loss due to a range of factors;
- Individuals who are likely to be living with a 'hidden and untreated' sensory loss, e.g. people who have had a stroke, have a learning disability or dementia.

The strategy has clear aims which are:

- The seamless provision of assessment, care and support to children and adults with a sensory impairment;
- Children and adults with a sensory impairment should expect the same access to education, employment, healthcare, social care and leisure as everyone else;
- People who have or develop a sensory loss understand what this loss will mean for them;
- People who have or develop a sensory loss are able to access information and be supported to take the maximum possible control over living as independently as possible, while also getting direct assistance when needed: appropriate communication is critical to this; and
- Children and young people with a sensory impairment should expect appropriate and timely intervention in the early years and for as long as is required.

2.8 Self-directed Support

There have been major developments in Scotland's social care landscape in recent years with the introduction of Self-directed Support (hereinafter referred to as 'SDS') legislation, an approach first introduced by the Scottish Government with their Self-Directed Support National Strategy (2010).[21] This 10 year strategy aims to improve social care outcomes and gives people greater choice and control when deciding how the social care support they are entitled to is provided. The approach is further cemented with the introduction of the Social Care (Self-directed Support) (Scotland) Act 2013 which came into force in April 2014. This new legislation is underpinned by all Councils altering their current delivery of social care services so that they offer clients, for example those with a PD, more choice and control over the support services they are entitled to.[22]

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[21] Scottish Government. 2010. *Self-Directed Support: A National Strategy for Scotland.* Available from: http://www.scotland.gov.uk/Resource/Doc/329971/0106962.pdf [Accessed 1 June 2015].

[22] Scottish Government. 2014. *Statutory guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013.* Available at: http://www.scotland.gov.uk/Resource/0044/00446933.pdf [Accessed 29 May 2015].

2.8.1 Social Care (Self-directed Support) Scotland Act 2013

The *Social Care (Self-directed Support) Scotland Act 2013* cements SDS into statute. The Act provides a new legal framework to which all Councils must adhere; guaranteeing that adults, children, young carers and adult carers assessed as requiring social care provision, will receive the support which is personal to *them*. Previously, the long-established approach involved the Local Authority arranging services (Option 3); whereas now an individual can now choose from four options when deciding on how their support package is managed. People with a PD, who are entitled to SDS can: have a Direct Payment and arrange their own support; direct the Local Authority in how they wish their allocated budget to be utilised (an Individual Service Fund); have the Local Authority arrange any support needs; or a combination of the above.

2.8.2 Direct Payment value per client group (aged 18-64)

Current statistics demonstrate disparity between service user groups and uptake of option 1, Direct Payments. The table below illustrates the value of direct payments for those with PD and those with a PD and a learning disability aged 18-64.

Table 2.1: Number of Clients Aged 18 to 64 and Value of Direct Payments, by Client Group, 2013[23]

Client Group	Number of Clients	Expenditure (£ thousands)	Average £ per client
Physical Disability Only	1,312	£20,325	£15,492
Learning Disability AND Physical Disability	182	£2,672	£14,680

2.8.3 SDS value per client group (aged 65+)

The table below illustrates the value of direct payments for those with a PD and a learning disability aged 65 and over.

Table 2.2: Number of Clients Aged 65 and over, and Value of Direct Payments, by Client Group, 2013[24]

Client Group	Number of Clients	Expenditure (£ thousands)	Average £ per client
Physical Disability Only	481	£4,756	£9,888
Learning Disability AND Physical Disability	5	£85	£17,061

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[23] Scottish Government. 2013. *Social Care Services, Scotland, 2013.* Available at: http://www.scotland.gov.uk/Publications/2013/11/8713/downloads#res-1 [Accessed 28 August 2014].

[24] Scottish Government. 2013. *Social Care Services, Scotland, 2013.* Available at: http://www.scotland.gov.uk/Publications/2013/11/8713/downloads#res-1 [Accessed 28 June 2105].

2.9 Barriers to independent living

Independent living means '*disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community…it means rights to practical assistance and support to participate in society and live an ordinary life.*'[25] A review of the literature shows that when compared to the general population adults with a PD experience significant physical, personal, social, economic and health-related barriers to independent living which are detailed below.

2.9.1 Day to day living

Studies suggest that people with a physical disability face many barriers which effect their ability to carry out day to day activities which non-disabled people take for granted. The literature reveals that those with a PD can have difficulties using facilities associated with bank accounts, such as ATMs and chip-and-pin, whereas individuals who are blind or partially sighted are less likely to use ATMs, and of those who use them, this process is difficult.[26] That said, in recent years there has been an increase in technologies designed for people with a visual impairment which has the potential to include those with an impairment take part in daily life the same way as the general population.[27] Research also reveals that during the general election of 2010, 67% of polling stations had one of more significant barriers to disabled voters, resulting in some not being able to vote.[28]

2.9.2 Home

The home is a fundamental setting for independent living for disabled and non-disabled alike, and it appears that housing quality significantly impacts the living experience and overall wellbeing of those with a disability.[29] Housing is an area, however, where disabled people face many disadvantages. For example there appears to be a lack of accessible and appropriate housing, and also housing to fit wheelchair-accessible standards, whereas more funding is required to develop adaptions for people within the home. Adaptions such as lower surfaces, or a shower instead of a bath can help disabled people to live independently and reduce the risks of accident, however it appears that adaptions are being removed when a disabled person leaves a home.[30] The literature

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[25] Independent Living in Scotland. *An essential guide to independent living in Scotland.* Available at: http://www.ilis.co.uk/uploaded_files/ilis_guide.pdf [Accessed 1 July 2015].

[26] Equality and Human Rights Commission. 2011. *How fair is Britain? Equality, human rights and good relations in 2010*. Available at: http://www.equalityhumanrights.com/sites/default/files/documents/triennial_review/how_fair_is_britain_-_complete_report.pdf {accessed 20 June 2015].

[27] Daniels, M 2015. *Computer vision and mobile phone technology could help blind people 'see'*. Available at: http://www.lincoln.ac.uk/news/2015/06/1110.asp [Accessed 15 August 2015].

[28] *Scope. 2010. Polls Apart 2010: opening elections to disabled people.* Available at: http://www.scope.org.uk/Scope/media/Documents/Publication%20Directory/Polls-apart-2010.pdf?ext=.pdf. [Accessed 11 June 2015].

[29] Hemingway, L. 2011. *Disabled people and housing: choices, opportunities and barriers*. Bristol: Policy Press.

[30] Independent Living in Scotland. *An essential guide to independent living in Scotland.* Available at: http://www.ilis.co.uk/uploaded_files/ilis_guide.pdf [Accessed 1 July 2015].

also reveals that those who have a PD facing physical, attitudinal, financial and communicational barriers when it comes to home ownership.[31]

2.9.3 Education

Correlations exist between the amount of education an individual has and improvements in physical health and wellbeing.[32] It appears, however, that disabled students face many physical barriers to higher education compared to the general student population, such as barriers to suitable student accommodation provided by the university[33], funding and social life experiences.[34]

2.9.4 Physical spaces

Many physical spaces and structures in mainstream society have been shaped without taking into account the needs of those with a disability, resulting in many spaces and structures preventing independent living.[35]

2.9.5 Transport

If those with a PD are to be truly independent, it is important that transport is accessible, affordable and available. The literature reveals, however, that access to travel and public transport is a significant barrier for many with a PD, with travel on public transport particularly difficult[36], especially for those with cognitive impairments, for example after a stroke.[37]

2.9.6 Employment

People with a PD face many barriers to independent living, with barriers to employment a key issue. Being employed can have many positive benefits to those with a PD as well as the general population in term of increased self-esteem and social inclusion. One of the Scottish Government's National Outcomes is 'We realise our full economic potential with more and better employment opportunities

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[31] Hemingway, L. 2006. *A risky business, a study of access to home ownership for disabled people.* Available at: http://disability-studies.leeds.ac.uk/library/author/hemingway.laura [Accessed 1 July 2015].

[32] Brennan, J., Durazzi, N., and Sene, T. 2013. *Things we know and don't know about the Wider Benefits of Higher Education: A review of the recent literature.* Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/251011/bis-13-1244-things-we-know-and-dont-know-about-the-wider-benefits-of-higher-education.pdf [Accessed 25 June 2015].

[33] Hemingway, L. 2011. *Disabled people and housing: choices, opportunities and barriers*. Bristol: Policy Press.

[34] Soorenian, A. 2013. Housing and Transport: Access Issues for Disabled International Students in British Universities. *Disability & Society,* 28(8): 1118-1131.

[35] Soorenian, A. 2013. Housing and Transport: Access Issues for Disabled International Students in British Universities. *Disability & Society,* 28(8): 1118-1131.

[36] Asplund, K., Wallin, S., & Jonsson, F. 2012. Use of public transport by stroke survivors with persistent disability. *Scandinavian Journal of Disability Research*, 14(4): 1–11.

[37] Wendel, K., Ståhl, A., Risberg, J., Pessah-Rasmussen, H., & Iwarsson, S. 2010. Post-stroke functional limitations and changes in use of mode of transport. *Scandinavian Journal of Occupational Therapy*, 17(2): 162-174.

for our people'.[38] However, those with a PD are more likely to be exposed to social determinants of poor health, one of which is unemployment, with the literature revealing that just under half (48.1 per cent) of disabled people in Scotland are in work, compared to around 75 per cent of the general population.[39] Of those who are in work many barriers and obstacles are faced such as physical barriers, low pay, being promoted, discrimination and social exclusion. Research focusing on supported employment, which promotes participation and integration for people with a learning disability into wider society, suggests it enhances the quality of life of people and has a positive effects on well-being for those with a learning disability[40], which could be of benefit to those with a PD. Those with sight loss are also less likely than those with no impairment to be in employment, and of those in work, they are limited in the work they are able to do. Those with a sight loss are more likely to be on a low income compared to those who are not. They also have difficulty accessing benefit services, with phone contact, lack of accessible information and unhelpful staff acting as barriers. People with a disability are more likely than those without to experience unfair discrimination within the workplace, such as with recruitment and promotion, and disabled women four times more likely to experience bullying.[41]

2.10 Health issues

People with sight loss experience inequality across life domains and face many challenges in day to day living. Recent evidence form the RNIB reveals many areas of disadvantage for those with sight impairments or loss.[42] For example, people with sight loss are more than three times as likely to report feeling depressed compared with those with no impairment. Furthermore, people with sight loss are more likely to report bad general health compared to those with no impairment. People with a sensory loss are also more likely to report difficulty in accessing health services, with using the telephone, transport, lack of help with communication and lack of confidence reported as barriers to accessing these services. There are many positive associated outcomes linked to participation in sports such as improved quality of life, improved social inclusion, increased confidence and self-esteem and increased social networks.[43] Furthermore, there is the potential for sports to reduce

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[38] Scottish Government. 2007. *National Outcomes.* Available at: http://www.gov.scot/About/Performance/scotPerforms/outcomes [Accessed 29 June 2015].

[39] Manthorpe, J., Hindes, J., Matineau, S., Cornes, M., Ridley, J., Spandler, H., Rosengard, A., Hunter, S., Little, S. and Gray, B. 2011. *Self-Directed Support: A Review of the Barriers and Facilitators*. Scottish Government Social Research. Available at: available online at http://www.gov.scot/Publications/2011/03/30091835/0 [Accessed 25 June 2015].

[40] Cramm, J.M., Kuijsten, R., Finkenflügel, H., and van Exel, N. J. A. 2009. How employment support and social integration programs are viewed by the intellectually disabled. *Journal of Intellectual Disabilities Research*, 53(6): 512–520.

[41] Equality and Human Rights Commission. 2011. *How fair is Britain? Equality, human rights and good relations in 2010*. Available at: http://www.equalityhumanrights.com/sites/default/files/documents/triennial_review/how_fair_is_britain_-_complete_report.pdf {accessed 20 June 2015].

[42] Royal National Institute for the Blind. 2015. *Living with sight loss: Updating the national picture*. Available at: http://www.rnib.org.uk/sites/default/files/Living%20with%20Sight%20Loss.pdf [Accessed 21 June 2015].

[43] Eime, R. M., Young, J. A., Harvey, J. T., Charity, M. J., and Payne, W. R. 2013. A systematic review of the psychological and social benefits of participation in sport for children and adolescents: informing development of a conceptual model of health through sport. *International Journal of Behavioural Nutrition and Physical Activity,* 10(98). doi:10.1186/1479-5868-10-98.

adverse health outcomes such as heart disease, type II diabetes, and obesity. The literature reveals, however, that people with a PD are less likely to participate in sports compared to those without a disability, with environmental barriers such as accessibility and transport preventing participation.[44] A recent systematic review of unintentional injuries in adults with disabilities found a significantly higher risk of unintentional injuries in adults with disabilities compared to those without, with physical disabilities having the highest odds ratio.[45] Obesity is now a serious issue amongst people with a PD with epidemiologic studies revealing that obesity prevalence is higher amongst people with physical disabilities compared to those who are not disabled. Furthermore, evidence suggests that those with a PD are at greater risk of diabetes and coronary heart disease. This is further exacerbated as obesity can put difficulties on getting in and out of wheelchairs and walking with the aid of devices, such as walking sticks increasingly difficult.[46]

2.11 Key findings

- Compared to the general population adults with a physical disability sensory impairment and/or acquired brain injury face significant physical, personal, social, economic and health-related barriers to independent living.
- People with a PD face many barriers to independent living
- There appears to be a lack of accessible and appropriate housing for those with a PD.
- Disabled students face many physical barriers to higher education compared to the general student population such as barriers to suitable student accommodation provided by the university, funding and social life experiences.
- Many physical spaces and structures in mainstream society have been shaped without taking into account the needs of those with a disability, resulting in many spaces and structures preventing independent living.
- Access to travel and public transport appears to be a significant barrier for many with a PD, with being able to travel on public transport particularly difficult.
- People with a PD are more likely to be exposed to social determinants of poor health, one of which is unemployment and of those who are in work many barriers and obstacles are faced.
- People with a PD are less likely than those with no impairment to be in employment, and of those in work they are limited in the work they are able to do.

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[44] Jaarsma, E. A., Dijkstra, P. U., Geertzen, J. H., and Dekker, R. 2014. Barriers to and facilitators of sports participation for people with physical disabilities: A systematic review. *Adapted Physical Activity Quarterly*, 31(3): 240-264.

[45] Shi, X., Wheeler, K. K., Shi, J., Stallones, L., Ameratunga, S., Shakespeare, T., and Xiang, H. 2015. Increased risk of unintentional injuries in adults with disabilities: A systematic review and meta-analysis. Disability and Health Journal, 8(2015): 153-164.

[46] Liou, T. H., Pi-Sunyer, F. X., and Laferrere, B. 2005. Physical disability and obesity. *Nutrition reviews*, 63(10): 321-331.

- People with a PD are more likely to be on a low income compared to those who are not. They also have difficulty accessing benefit services, with phone contact, lack of accessible information and unhelpful staff acting as barriers.
- People with a disability are more likely than those without to experience unfair discrimination within the workplace, with recruitment, promotion with disabled women more likely to experience bullying.
- People with a PD are more than three times as likely to report feeling depressed compared with those with no impairment and are more to report bad general health compared to those with no impairment, and are more likely to report difficulty in accessing health services.
- People with a PD are less likely to participate in sports compared to those without disabilities, with environmental barriers such as accessibility and transport preventing this.
- There appears to be a higher risk of unintentional injuries in adults with disabilities compared to those without.
- Obesity is now a serious issue amongst people with a PD with epidemiologic studies revealing that obesity prevalence is higher amongst people with physical disabilities compared to those who are not disabled.
- People with a PD are at greater risk of diabetes and coronary heart disease. This is further exacerbated as obesity can put difficulties on getting in and out of wheelchairs and walking with the aid of devices such as walking sticks increasingly difficult.

CHAPTER 3: EPIDEMIOLOGY

3.1 Introduction and Aims

After considering first the overall demographic make-up of West Lothian, this section is broken into a number of sub-sections. Under each of these, it examines the general research on physical disability, sensory impairment and acquired brain injury, then at the national statistics, and then the local figures where they are available.

3.2 Data Collection

3.2.1 Method of data collection

Information was identified and drawn together from a range of local and national sources on prevalence and trends in the patterns of physical disability, sensory impairment and acquired brain injury in Scotland over the past ten years. In order to provide comparative analysis on a range of health and social indicators three local authority areas were identified from similar socioeconomic deprivation backgrounds as West Lothian[47], as well as using information from the Local Government Benchmark Framework (LGBF).[48] The LGBF considers the many differences between local authorities that contribute to variations in performance, including: population; geography; social and economic factors; and the needs and priorities of local communities.

Falkirk, Renfrewshire and South Lanarkshire were chosen as comparators as they have similar characteristics as West Lothian (such as the size, density and composition of the population, unemployment, housing, ethnic diversity and wealth).

3.2.2 Data sources

The various data sources utilised in this report include:

- Audit Scotland http://www.audit-scotland.gov.uk/
- Centre for Disability Research http://www.lancaster.ac.uk/fhm/research/centre-for-disability-research/
- Google Scholar http://scholar.google.co.uk/
- Information Services Division Scotland http://www.isdscotland.org/
- National Records for Scotland http://nationalrecordsofscotland.gov.uk/

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[47] Scottish Government. 2013. *Deprivation- Scottish index of multiple deprivation.* Available at: http://www.scotland.gov.uk/Topics/Statistics/Browse/Social-Welfare/TrendSIMD [Accessed 21 July 2015].

[48] http://www.scotborders.gov.uk/info/691/council_performance/1352/local_government_benchmarking_framework

- NHS Health Scotland http://www.healthscotland.com/
- Office for National Statistics http://www.ons.gov.uk/ons/index.html
- Public Health England https://www.improvinghealthandlives.org.uk/
- Scottish Government http://www.gov.scot/
- Scottish Index for Multiple Deprivation http://www.gov.scot/Topics/Statistics/SIMD
- Scottish Public Health Observatory http://www.scotpho.org.uk/
- Social Care Online http://www.scie-socialcareonline.org.uk/
- West Lothian Council http://www.westlothian.gov.uk/
- World Health Organisation http://www.who.int/en/

3.2.3 Data issues

Data relating specifically to people with a physical disability, sensory impairment and acquired brain injury can be difficult to find and often there are problems with the data which mean that it does not give a completely accurate picture. This said the data which is available is still useful in providing information regarding the needs of this population as long as it is interpreted with certain caveats in mind.

In all data sets relating to people with a physical disability, sensory impairment and acquired brain injury it is likely that a significant number of people will be missed due to the fact that their disability is not recorded. This is most likely to affect those with **milder** physical disability, sensory impairment and acquired brain injury who are less likely to need specialist health or social care services and who live independently. This is also likely to be a problem in data sets where the focus of the information is not on physical disability, sensory impairment and acquired brain injury specifically, such as hospital episodes statistics. In this case only conditions which impact directly on the primary reason for admission to hospital are recorded, meaning that the presence of a physical disability, sensory impairment and acquired brain injury is likely to be recorded inconsistently and are again less likely to be recorded if the disability is mild. This is also the case in recording on death certificates, where only conditions relating directly to the cause of death will be recorded.

There are a variety of national sources of data relating to the number of adults with physical disabilities, and these are listed below. There are some known issues with the majority of these data sets.

- Office for Disability Issues/Department for Work and Pensions – Disability Facts and Figures for Great Britain 2014;
- ‘Disability in the United Kingdom 2014: Facts and Figures’ report (Papworth Trust)
- The Family Resources Survey UK, Department for Work and Pensions
- Scottish Annual Population Survey

- Scottish Household Survey
- Scottish Health Survey
- Small Business Survey Scotland
- ‘Dimensions of Diversity’ 2010 report
- ‘Variations in the Experiences of Inpatients in Scotland’ 2011 report
- Adult Social Care Data (SWIFT)
    - Only the primary social care need is recorded meaning that people with a physical disability, sensory impairment and/or acquired brain injury, who have another more prominent need may be missed from the data set.

3.3 Demography of West Lothian

Present and future need for services and assets to address physical disability, sensory impairment and acquired brain injury across West Lothian depends in part on the demography of the county. In this section basic population data is therefore briefly assessed.

3.3.1 Area Profile

West Lothian is an area of 165 square miles (428 square km) situated in the east of Scotland, positioned between Glasgow and Edinburgh, and surrounded by the council areas of Edinburgh, Falkirk, North Lanarkshire and the Scottish Borders. Livingston, Bathgate and Linlithgow are the main centres of population in this local authority.

Figure 3.1: Map of West Lothian [49]

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[49] West Lothian Map, Google Map 2015. Available at: https://www.google.co.uk/maps/place/West+Lothian/@55.8546737,-3.7929644,10z/data=!4m2!3m1!1s0x4887c514c305f6ff:0x9f54bb6a8afceff3. [Accessed on: 17 June 2015].

According to National Records of Scotland, the 2014 population for West Lothian was 177,150[50]; this is an increase of the whole population figures reported in 2011 Census (175,118). In relation to the comparison areas, the table below shows West Lothian has a higher population than Falkirk (157,640) and Renfrewshire (174,230), and lower than South Lanarkshire (315,360). Scotland's overall population is also shown (5,347,600).

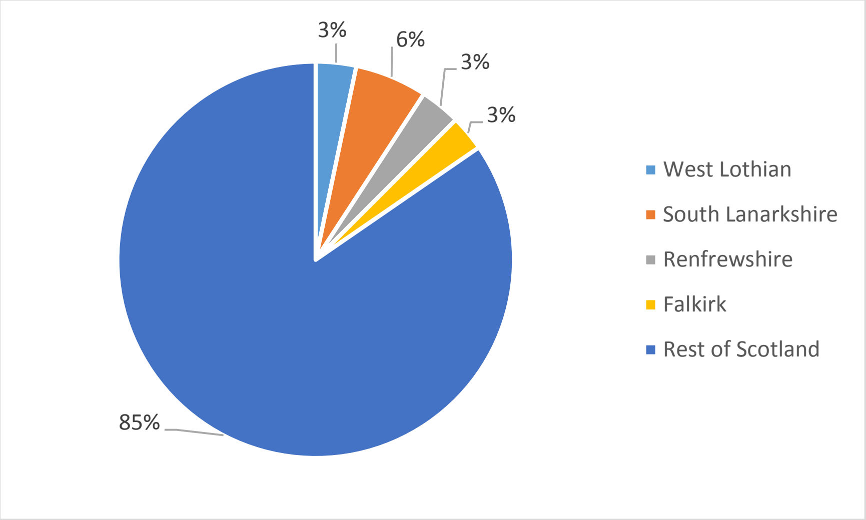
Table 3.2: Whole Population Figures for West Lothian, Scotland and Comparison Areas.[51]

	West Lothian	South Lanarkshire	Renfrewshire	Falkirk	Scotland
2014 Mid-Yr Estimate	**177,150**	315,360	174,230	157,640	5,347,600

*NRS = National Records of Scotland

Further analysis of these figures is demonstrated below which shows population percentages of West Lothian, South Lanarkshire, Renfrewshire and Falkirk compared with the rest of Scotland. The figure reveals that West Lothian, Renfrewshire and Falkirk have a similar population percentages (3%), with South Lanarkshire double this (6%). The rest of Scotland accounts for 85% of the population.

Figure 3.3: Population Breakdown of West Lothian, Comparison Areas and Rest of Scotland.[52]



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[50] National Records of Scotland.2015. *West Lothian Council Area- Demographic Factsheet. Available at:* http://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/west-lothian-factsheet.pdf. *Accessed on: 17th June 2015.*

[51] National Records of Scotland, 2015. *Council area profiles*. Available at: http://www.nrscotland.gov.uk/statistics-and-data/statistics/stats-at-a-glance/council-area-profiles [Accessed 17 June 2015].

[52] National Records of Scotland, 2015. *Council area profiles*. Available at: http://www.nrscotland.gov.uk/statistics-and-data/statistics/stats-at-a-glance/council-area-profiles [Accessed 22 June 2015].

3.3.2 Population: Sex

There are more females than males in West Lothian (90, 394 compared to 86, 756). As can be seen in the table below there are similarities between West Lothian figures, Scottish figures and comparison areas when male and female statistics are put in percentages.

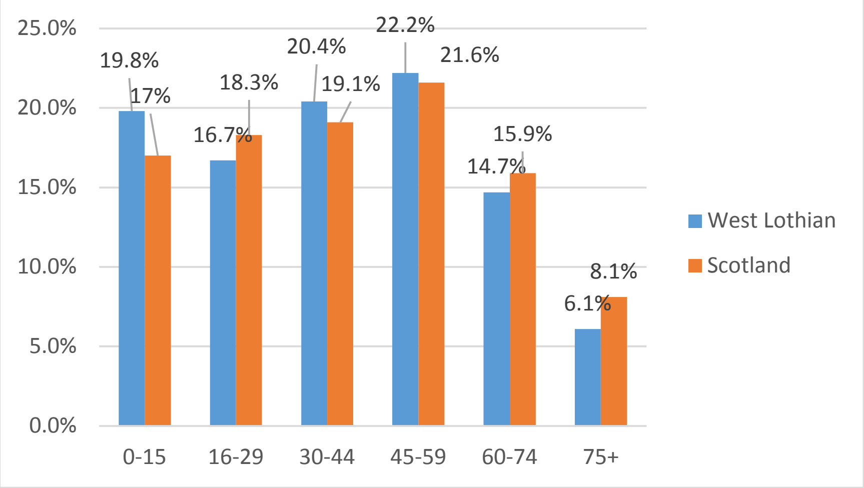
Table 3.4: Breakdown of population by Gender (for West Lothian, Scotland and Comparison Areas)[53]

	West Lothian	South Lanarkshire	Renfrewshire	Falkirk	Scotland
Male	**48.9%**	48.1%	48.1%	48.8%	48.5%
Female	**51.1%**	51.9%	51.9%	51.2%	51.5%

3.3.3 Population: Age

The population of the West Lothian is largely aged between the age brackets of 30-44 and 45-59 years of age, with 20.4% and 22.2% of people in West Lothian belonging to these age categories. This is more than the Scottish averages for these age categories (19.1% and 21.6% respectively). The graph below shows comparisons of age categories in West Lothian compared to the Scottish average.

Figure 3.5: West Lothian Population Breakdown by Age, Compared to the Scottish Average.[54]



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[53] National Records of Scotland, 2011 *Census*. Available at: http://www.scotlandscensus.gov.uk/ods-web/area.html. [Accessed 16 June 2015].

[54] National Records of Scotland. 2015. *West Lothian Council Area- Demographic Factsheet.* Available at: http://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/west-lothian-factsheet.pdf [Accessed 1 July 2015].

3.3.4 Population: Projected Population

Current projections for West Lothian are estimating an overall population increase of 11.7 % by 2037 (n=196,664). From the table below it can be seen that the projected population of West Lothian until 2037.

Table 3.6: Projected Population in West Lothian- 2017, 2022, 2027, 2032, 2037.[55]

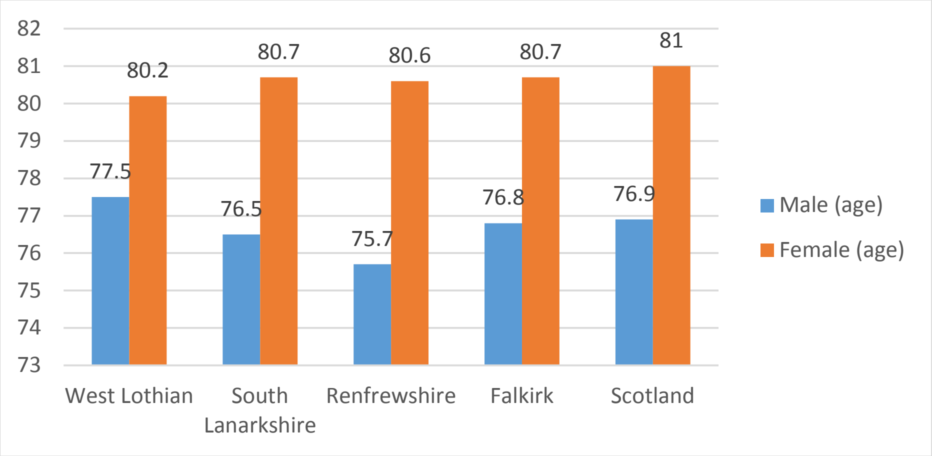
Projected years	2017	2022	2027	2032	2037
Projected population	180, 252	184,774	189, 208	193,254	196,664

3.3.5 Population: Life expectancy

Female life expectancy at birth (80.2 years) is greater than male life expectancy (77.5 years) in West Lothian, with male life expectancy higher than the Scottish average (77.5 years compared to 76.9 years) and female life expectancy lower (80.2 years compared to 81 years). Male life expectancy at birth in West Lothian is improving more rapidly than female life expectancy.

Further analysis is revealed in the graph below and it can be seen that life expectancy at birth for males in West Lothian is higher than all other areas (South Lanarkshire 76.5 years, Renfrewshire 75.7 years Falkirk 76.8 years). Life expectance at birth for females is slightly lower than all other areas (South Lanarkshire 80.7 years, Renfrewshire 80.6 years Falkirk 80.7 years).

Figure 3.7: West Lothian Life Expectancy at Birth by Sex, Comparison Areas and Scotland, 2010-2012.[56]



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[55] Ibid.

[56] National Records of Scotland, 2015. *Council area profiles*. Available at: http://www.nrscotland.gov.uk/statistics-and-data/statistics/stats-at-a-glance/council-area-profiles [Accessed 22 June 2015].

3.3.6 Population: Ethnicity

The 2011 Census reveals 97.5% of the people in West Lothian consider their ethnic group to be 'white' which is higher than national figures (96.1%). Further analysis of these figures demonstrates that 87.8% of people within West Lothian consider their ethnic group to be 'White Scottish', which, again, is higher than the national average (84%), but lower than all comparison areas (South Lanarkshire 91.6%, Renfrewshire and Falkirk both 91.3%). The table below demonstrates further analysis of 2011 census data on ethnicity.*

Table 3.8: Ethnicity Breakdown for West Lothian, Comparison Areas and Scotland.[57]

	West Lothian	South Lanarkshire	Renfrewshire	Falkirk	Scotland
White- Scottish	87.8%	91.6%	91.3%	91.3%	84%
White- Other British	5.8%	3.8%	3.3%	4.5%	7.9%
White- Irish	0.7%	1%	0.9%	0.6%	1%
White-Gypsy/Traveller	-	0.1%	-	0.1%	0.1%
White-Polish	1.9%	0.4%	0.7%	0.7%	1.2%
White- Other	1.3%	0.8%	0.9%	0.9%	1.9%
Asian, Asian Scottish or Asian British	1.7%	1.6%	1.8%	1.3%	2.7%
Mixed or multiple ethnic groups	0.3%	0.2%	0.2%	0.2%	0.4%
African	0.3%	0.2%	0.5%	0.1%	0.6%
Caribbean or Black	0.1%	0.1%	0.1%	0.1%	0.1%
Other Ethnic group	0.1%	0.1%	0.2%	0.1%	0.3%

3.4 Deprivation

It is documented that individuals from deprived areas have lower overall mental well-being compared to those from more affluent areas, with national and international research demonstrating that those in deprived areas are more likely to have higher rates of hospital admissions, increased

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[57] National Records for Scotland. 2013. *2011 Census: Key Results on Population, Ethnicity, Identity, Language, Religion, Health, Housing and Accommodation in Scotland - Release 2A. Available at:* http://www.scotlandscensus.gov.uk/documents/censusresults/release2a/StatsBulletin2A.pdf [Accessed 22 July 2015].

risk of premature death[58], are twice as likely to have anxiety problems than those in the least deprived areas, and also have higher rates of suicide.[59]

The Scottish Index of Multiple Deprivation (SIMD herein) is a Scottish Government tool which includes different aspects of deprivation to combine them into a single index. Specifically, the index incorporates seven domains to measure the multiple aspects of deprivation and the overall index is a weighted sum of the seven domain scores as follows: income (28%), employment (28%), health (14%), education (14%), geographic access (9%), crime (5%) and housing (2%). There are a total of 6,506 datazones (small areas) within Scotland to which the SIMD offers a relative ranking for each datazone from 1 (most deprived) to 6,506 (least deprived). The datazones contain approximately 350 households/ 800 people. Current SIMD (2012) figures for Scotland show that 742,200 people live in the 15% most deprived areas of Scotland. Figures also shows that multiple deprivation has become less clustered over time with 2004 figures highlighting approximately half of all datasets in the most deprived 10% across Scotland were in Glasgow City, whereas 2012 figures highlights that this has fallen to 35.8%. Currently Ferguslie Park, Paisley, is the most deprived area in Scotland, whereas the least deprived datazone is the Craiglockhart area of Edinburgh.[60]

3.4.1 Deprivation within West Lothian

Within West Lothian there are 211 datazones. The SIMD 2012 reveals that 13 (6.2%) of West Lothian's 211 datazones were found in the 15% most deprived datazones in Scotland, compared to 19 (9%) in 2009, 14 (6.6%) in 2006 and 9 (4.3%) in 2004. The most deprived datazone in West Lothian in the overall SIMD 2012 is S01006416, which is found in Bathgate East. It has a rank of 440, meaning that it is amongst the 10% most deprived areas in Scotland. The figure below shows the national quintiles for West Lothian.

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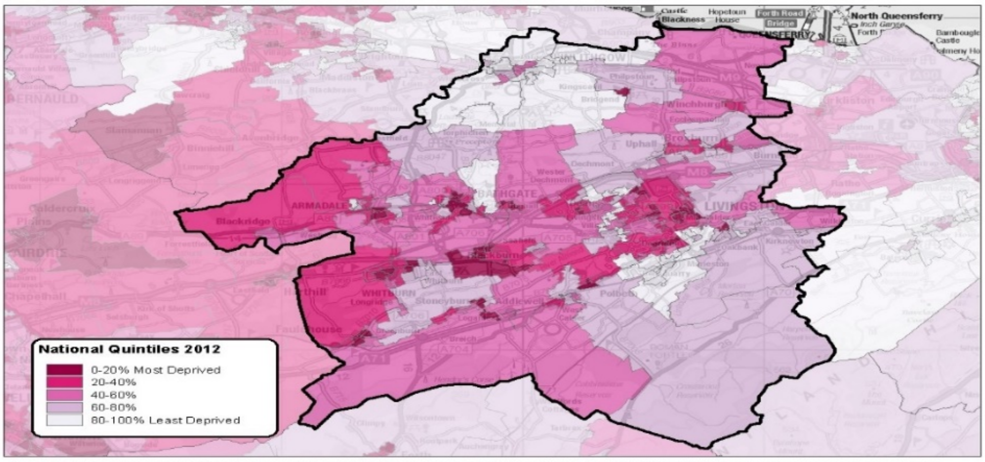
[58] Office of the Deputy Prime Minister. 2004. *Mental health and social exclusion: Social Exclusion Unit report.* Available at: http://www.socialfirmsuk.co.uk/resources/library/mental-health-and-social-exclusion-social-exclusion-unit-report[Accessed 22 July 2015].

[59] Audit Scotland. 2012. *Health inequalities in Scotland.* Available at: http://www.audit-scotland.gov.uk/docs/health/2012/nr_121213_health_inequalities.pdf [Accessed 22 July 2015].

[60] Scottish Government. 2012. *SIMD 2012 Results.* Available at: http://simd.scotland.gov.uk/publication-2012/simd-2012-results/ [Accessed 22 July 2015].

Figure 3.9: Levels of Deprivation in West Lothian in SIMD 2012 by quintile.[61]



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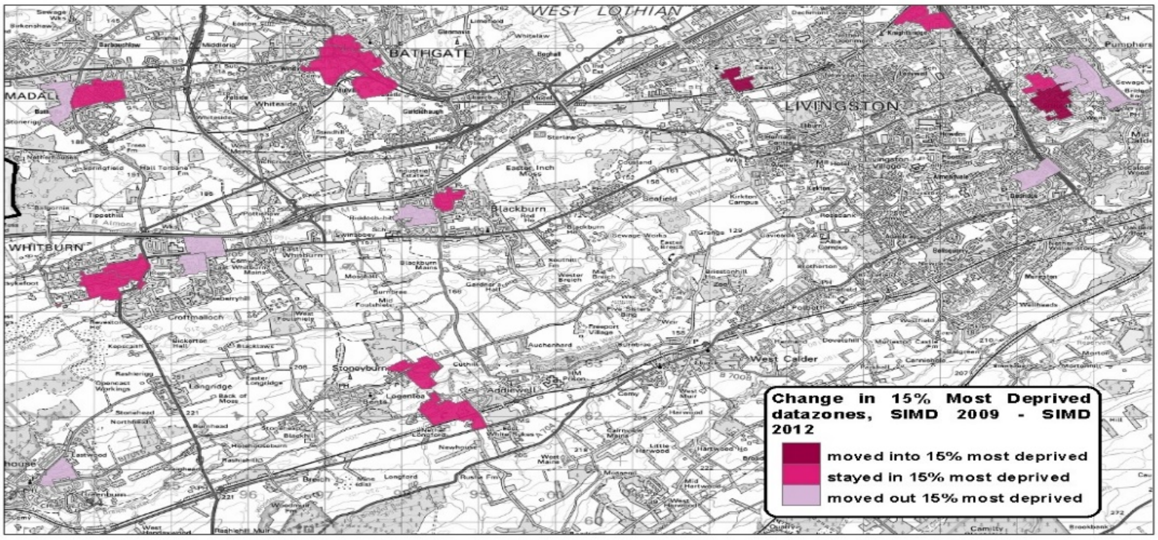
The figure below shows changes in deprivation within West Lothian with areas which have moved into the 15% most deprived, areas which have stayed in the 15% most deprived and areas which have moved out the 15% most deprived areas between SIMD 2009 and SIMD 2012.

Figure 3.10: Datazones in West Lothian Which Have Stayed in or Moved Out of the 15% Most Deprived in Scotland.[62]



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SIMD mages courtesy of the Scottish Government

Further analysis of the SIMD (2012) figures is presented in the table below which shows West Lothian as having 6.2% of the 211 datazones in the 15% most deprived datazones in Scotland. This figure is lower than South Lanarkshire (13.3%), Renfrewshire (22.4) and also Falkirk (9.1%).

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[61] Ibid.

[62] Scottish Government. 2012. *SIMD 2012 Results.* Available at: http://simd.scotland.gov.uk/publication-2012/simd-2012-results/ [Accessed 22 July 2015].

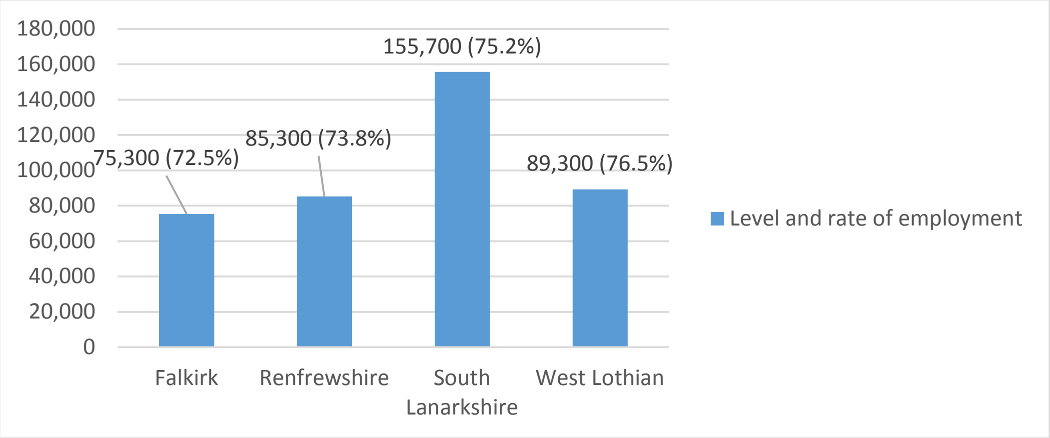
Table 3.11: Percentage of Most Deprived Zones in West Lothian and Comparison Areas According to SIMD 2012.[63]

West Lothian	South Lanarkshire	Renfrewshire	Falkirk
6.2% (13 out of 211)	13.3% (53 out of 398)	22.4% (48 out of 214)	9.1% (18 out of 197)

3.5 Employment (Working age)

Current figures show that there are approximately 89,000 people employed within West Lothian. The figure below shows employment rates and levels in West Lothian and comparison areas from April 2014- March 2015. It can be seen in the figure that employment rates in West Lothian, as an overall percentage, are higher than all three comparison areas (Falkirk 72.5%; Renfrewshire 73.8%; South Lanarkshire 75.2%).

Table 3.12: Employment Rates and Levels in West Lothian and Comparison Areas, April 2014 - March 2015.[64]



In further detail, the figure below shows employment rates and levels in West Lothian, comparison areas and Scotland in years 2012-2013, 2013-2014, and 2014-2015. The figure reveals that employment rates in West Lothian have increased in the three years with current figures for the year April 2014- March 2015 (76.5%) higher than South Lanarkshire (75.2%), Renfrewshire (73.8%), Falkirk (72.5%) and Scotland (72.9%).

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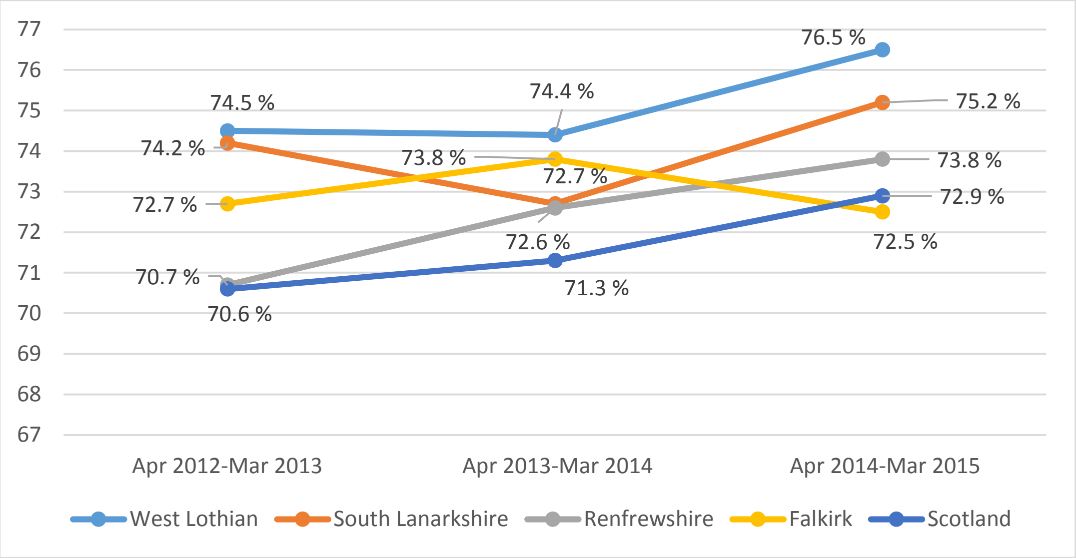
[63] Ibid.

[64] Scottish Government. 2015. *Annual population survey, results for year to March 2015- summary tables.* Available at: http://www.gov.scot/Topics/Statistics/Browse/Labour-Market/Publications/APSAMTables [Accessed 20 July 2015].

Figure 3.13: Percentages of Employment Rates in West Lothian, Comparison Areas and Scotland, 2012-2013, 2013-2014, 2014-2015. [65]



3.6 Unemployment

Overall unemployment figures include people who are out of work and not only those claiming unemployment benefits. From the table below it can be seen that the unemployment figures in West Lothian are lower than the Scottish average (5.6% compared to 6.2%). Furthermore, West Lothian has lower unemployment figures than South Lanarkshire (5.9%), Renfrewshire (6.4%) and Falkirk (6.4%).

Table 3.14: Unemployment Figures for West Lothian, South Lanarkshire, Renfrewshire and Falkirk Compared to Scotland, April 2014-March 2015.[66]

West Lothian numbers	%	Scotland
5,300	5.6 %	6.2%
South Lanarkshire numbers	**%**	
9,900	5.9%	6.2%
Renfrewshire numbers	**%**	
5,8000	6.4%	6.2%
Falkirk numbers	**%**	
5,200	6.4%	6.2%

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[65] Scottish Government. 2015, op. cit.

[66] Office for National Statistics. 2015. *Local authority profile.* Available at: http://www.nomisweb.co.uk/reports/lmp/la/contents.aspx [Accessed 25 July 2015].

Recent labour market profile figures show the breakdown of key benefit claimants who are of working age within West Lothian and from the table it can be seen that there were a total of 16,140 working age clients claiming key benefits from April 2014-March 2015.

Table 3.15: Working-age Client Group - Key Benefit Claimants in West Lothian, April 2014-March 2015.[67]

	West Lothian numbers	(%)	Scotland %
Total claimants	16, 140	14	14.3
Job seekers	1,980	1.7	2.2
ESA and incapacity benefits	9,030	7.9	7.8
Lone parents	1,290	1.1	1
Carers	1,690	1.5	1.5
Others on income related benefits	350	0.3	0.3
Disabled	1,530	1.3	1.2
Bereaved	280	0.2	0.2
Main Out-of-Work Benefits	12,650	11	11.4

*Main out-of-work benefits includes the groups: job seekers, ESA and incapacity benefits, lone parents and others on income related benefits

3.7 Welfare Sanctions

With the introduction of the new Welfare Reform Act in 2012, a new system of sanctions was implemented which has resulted in the number of unfavourable sanctions increasing for jobseekers. However, such sanctions can have negative outcomes for claimants.[68] The graph below highlights sanctions under the old regime and the higher level of sanctions since the new regime was implemented in 2012.

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[67] Office for National Statistics. 2015. *Local authority profile.* Available at: http://www.nomisweb.co.uk/reports/lmp/la/contents.aspx [Accessed 25 July 2015].

[68] Scottish Government. 2014. *Welfare Reform (Further Provision) (Scotland) Act 2012 Annual Report – 2014.* Available at: http://www.scotland.gov.uk/Resource/0045/00454504.pdf [Accessed 29 July 2015].

Figure 3.16: Annual Number of Adverse JSA Sanction Decisions in Scotland, 2001-2013[69]

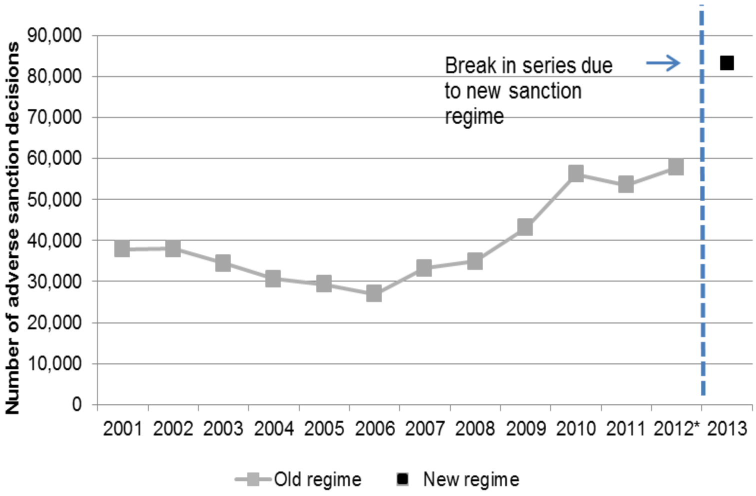

Image courtesy of the Scottish Government. 2014. Welfare Reform (Further Provision) (Scotland) Act 2012 Annual Report – 2014.

3.8 Homelessness

Evidence about physical, sensory, intellectual or brain injury amongst the homeless population is primarily drawn from ad hoc research. This shows that in many cases at the point of seeking help less 'obvious' disabilities are unlikely to be identified and sometimes are undeclared. People may also have more than one disability but these may not be identified until after a person has used a service for an extended period of time. Staff in homelessness services, are often not specifically trained to identify disabilities or health conditions, despite early identification being of enormous assistance to clients with a disability. The available evidence suggests that mental health problems are high amongst the homeless population. Incidences of acquired brain injury are similarly thought to be substantial but there is not a reliable evidence base to establish the frequency or impact of this disability. Traumatic brain injury is an issue of concern because it is often acquired before a person becomes homeless i.e. through violence. Alcohol induced brain injury is also a major concern. This is regarded as a cause of homelessness by some researchers because it diminishes a person's ability to retain their home and function independently. Using data from Canada, Hwang et al (2008) found that approximately 70 per cent of cases of acquired brain injury occurred before the onset of homelessness.[70]

Efforts to prevent homelessness require an understanding of the underlying causes and early indicators of risk. Evidence highlights that childhood physical disabilities are over-represented among homeless adults with complex comorbidities and predict a range of poor health outcomes in adulthood; including mood and anxiety disorders, suicidal ideation, early and severe substance use

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[69] Scottish Government. 2014, op. cit.

[70] Hwang et al (2008)

and physical health problems.[71,72,73] Poor health is both a cause and consequence of homelessness, with high levels of disability amongst homeless people and a shockingly low average age of death at just 47 (30 years below the national average of 77 years).[74]

The childhoods of homeless adults are disproportionately characterised by persistent poverty, residential mobility, school problems and other stressful and/or traumatic experiences[75,76] particularly among homeless individuals with severe mental illness.[77]

From a public health perspective, early interventions in childhood might change or moderate the cycle of homelessness across generations because early risk factors are often longstanding and drive a trajectory of cumulative risk, potentially leading to severe psychopathology and social exclusion. Physical and learning disabilities may contribute to challenges with obtaining and maintaining housing and employment and a wide range of daily living skills.[78]

From the table below it can be seen that in the year to March 2015 there were 1,331 applications made under the Homeless Persons Legislation in West Lothian, which was a 3.2% increase from 2013-14 figures (1,290) but a 5.7% decrease from 2012-13 (1,412). This is in contrast to the 10.7% decrease in homeless applications made in Scotland from 2012-13 (40,051) until 2014-15 (35,764).

Figure 3.17: Number of Applications under the Homeless Persons legislation by Local Authority 2010-11 to 2014-15[79]

	2012-13	2013-14	2014-15
West Lothian	1,412	1,290	1,331
Falkirk	1,087	1,046	1,206
Renfrewshire	1,103	975	825
South Lanarkshire	2,101	2,129	1,904
Scotland	40,051	37,234	35,764

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[71] Shinn M (2007). *International homelessness: policy, socio-cultural, and individual perspectives.* J Soc Issues 2007;63:657–77.

[72] Sullivan G, Burnam A, Koegel P (2000). Pathways to homelessness among the mentally ill. Soc Psychiatry Epidemiol 2000;35:444–50.

[73] Rees, S. 2009. *Mental ill health in the adult single homeless population: A review of the literature.* Available at: http://www.crisis.org.uk/data/files/publications/Mental%20health%20literature%20review.pdf [Accessed 29 July 2015].

[74] http://www.disabilitynow.org.uk/article/homelessness-disabled-peoples-support-needs-neglect

[75] Herman D, Susser ES, Struening EL, *et al* (1997). *Adverse childhood experiences: are they risk factors for adult homelessness?* Am J Public Health 1997;87:249–55.

[76] Koegel P, Malamid E, Burnam MA (1995). Childhood risk factors for homelessness among homeless adults. Am J Public Health 1995;85:1642–9.

[77] Sullivan, op. cit.

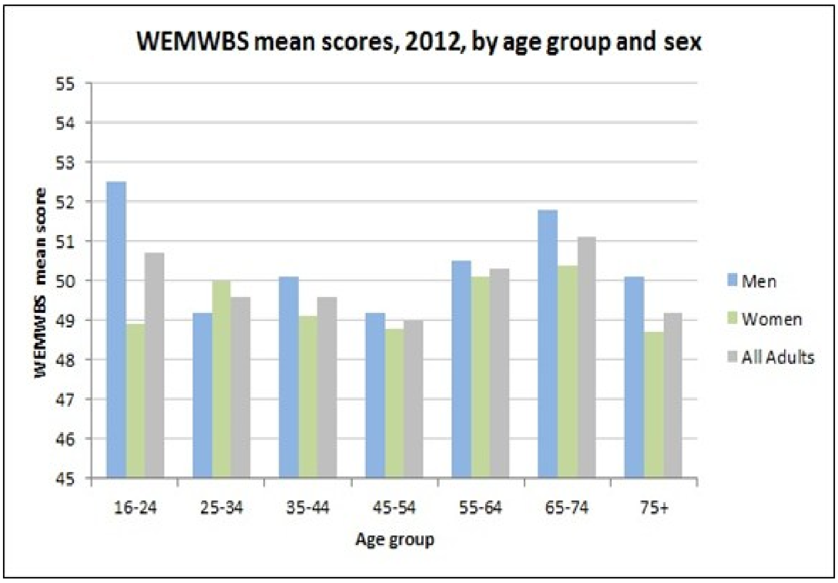
[78] Patterson, M.L. et al (2012). *Missed opportunities: childhood learning disabilities as early indicators of risk among homeless adults with mental illness in Vancouver, British Columbia.* BMJ Open 2012;2:e001586 doi:10.1136/bmjopen-2012-001586.

[79] Office for National Statistics. 2015. *Operation of the homeless person's legislation in Scotland: 2014-15. Available* at: http://www.gov.scot/Resource/0048/00480524.pdf [Accessed 9 August 2015].

3.9 Wellbeing

Mental wellbeing is an essential part of a person's capacity to lead a satisfying life which includes the capacity to make informed choices, study, pursue leisure interests, as well the ability to form relationships with others.[80] The nation's mental health is a key priority for Scottish government policy. In Scotland, mental health is measured within the Scottish Health Survey which adopts the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS). This scale is made up of 14 separate statements regarding mental health and wellbeing to which respondents answer. A score is then created to determine the person's state of mental wellbeing. The maximum score is 70 and the minimum score is 14, with the higher the score the better level of mental wellbeing.[81] At present there are no results for each local authority, with results available at a national level only. That withstanding, from the figure below it can be seen that for all adults, the age bracket of 65-74 had the greater level of wellbeing. Updated Scottish Health Survey results for 2013 will be released in December 2014.

Figure 3.18: Warwick Edinburgh Mental Wellbeing Scale Mean Scores (2012) by age group and sex[82]



Wellbeing results for each local authority are available from data in the UK Annual Population Survey.[83] To asses personal well-being in the UK the survey uses responses from approximately 165,000 people across the UK, and the publication includes the four following key questions to measure well-being which are answered on a scale from 0 to 10 with 0 the lowest and 10 highest.

The questions are as follows:

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[80] World Health Organisation. 2012. *Risks to mental health: An overview of vulnerabilities and risk factors.* Available at: http://www.who.int/mental_health/mhgap/risks_to_mental_health_EN_27_08_12.pdf [Accessed 31 July 2015].

[81] Scottish Government. 2012. *The Scottish health survey.* Available at: http://www.scotland.gov.uk/resource/0043/00434590.pdf *[Accessed 25 July 2015].*

[82] Scottish Government. 2012, op. cit.

[83] Office for National Statistics. 2014. *Personal well-being in the UK, 2013/14.* Available at: http://www.ons.gov.uk/ons/dcp171778_377460.pdf [Accessed 09 August 2015].

- *Overall, how satisfied are you with your life nowadays?*
- *Overall, to what extent do you feel the things you do in your life are worthwhile?*
- *Overall, how happy did you feel yesterday?*
- *Overall, how anxious did you feel yesterday?*

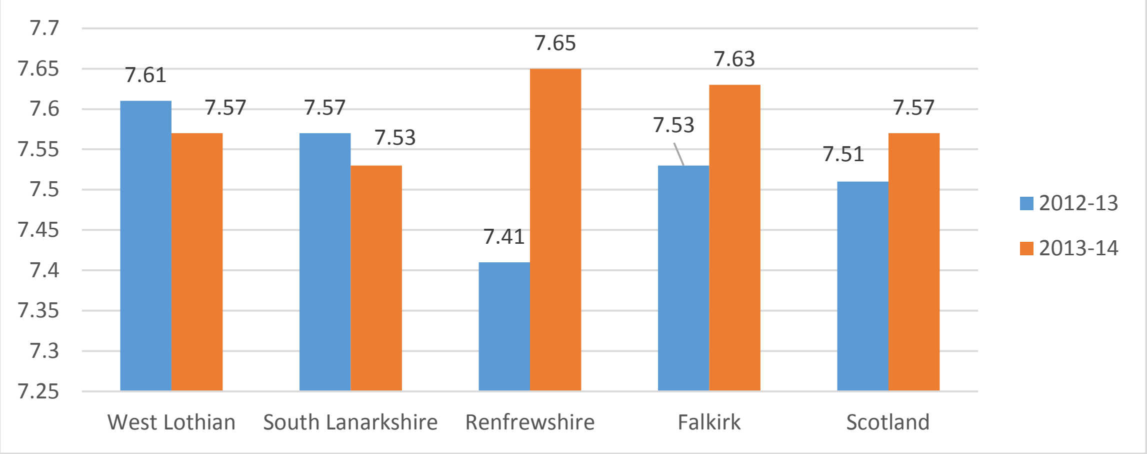
An overview of the well-being estimates is that there have been year on year improvements in reported average personal well-being ratings in the UK across each of the four measures of well-being, with the greatest gain being in the reduced anxiety levels. It should be noted that the survey should be interpreted as giving an estimate of well-being in the UK, rather than an exact measure.

There are mixed results for personal well-being in West Lothian with estimated average figures showing a slight decrease from 2012/13 to 2013/14 in reportings of life satisfaction (2012/13=7.61; 2013/14=7.57) and worthwhile (2012/13=7.83; 2013/14=7.81). Reportings on happiness measures have slightly increased (2012/13=7.46; 2013/14=7.49), whereas overall levels of anxiety have seen a reduction (2012/13=3.15; 2013/14=2.71). Further analyses of personal well-being ratings are presented below.

3.9.1 Life satisfaction

How satisfied a person is with their life is an important aspect of their overall well-being and from the figure below it can be seen that estimates of life satisfaction from 2012-13 to 2013/14 have increased in the Renfrewshire, Falkirk and Scotland, whereas ratings in West Lothian and South Lanarkshire have decreased.

Figure 3.19: Estimates of Life Satisfaction From the Annual Population Survey (APS) Personal Well-being 2012/13 and 2013/14[84]



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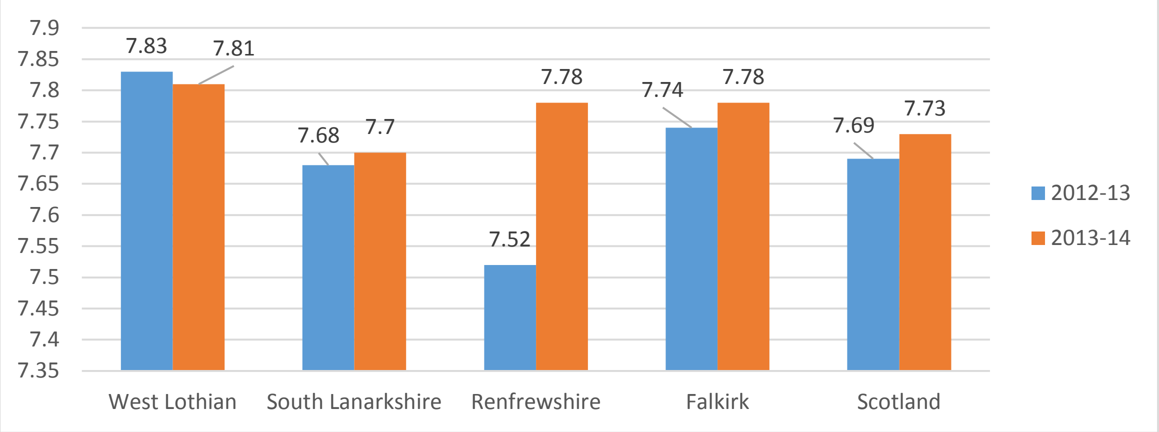
[84] Office for National Statistics. 2013. *Measuring National Well-being, Personal Well-being Across the UK, 2012/13*. Available at: http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-327124 [Accessed 10 August 2015].

3.9.2 Worthwhile

With regards to the worthwhile question, it can be seen from the figure below that ratings from 2012-13 to 2013/14 have increased in South Lanarkshire, Renfrewshire, Falkirk, and Scotland, whereas ratings have decreased in West Lothian.

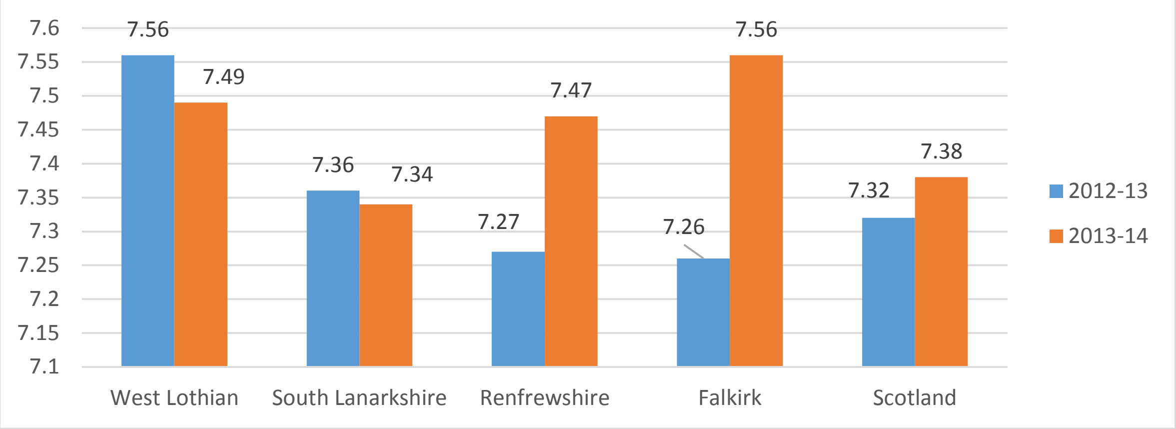
Figure 3.20: Estimates of Worthwhile From the Annual Population Survey (APS) Personal Well-being 2012/13 and 2013/14[85]



3.9.3 Happiness

With regards to happiness ratings there has been an increase from 2012/13-2103/14 in Renfrewshire, Falkirk and Scotland, whereas ratings for West Lothian and South Lanarkshire have decreased.

Figure 3.21: Estimates of Happiness From the Annual Population Survey (APS) Personal Well-being 2012/13 and 2013/14[86]



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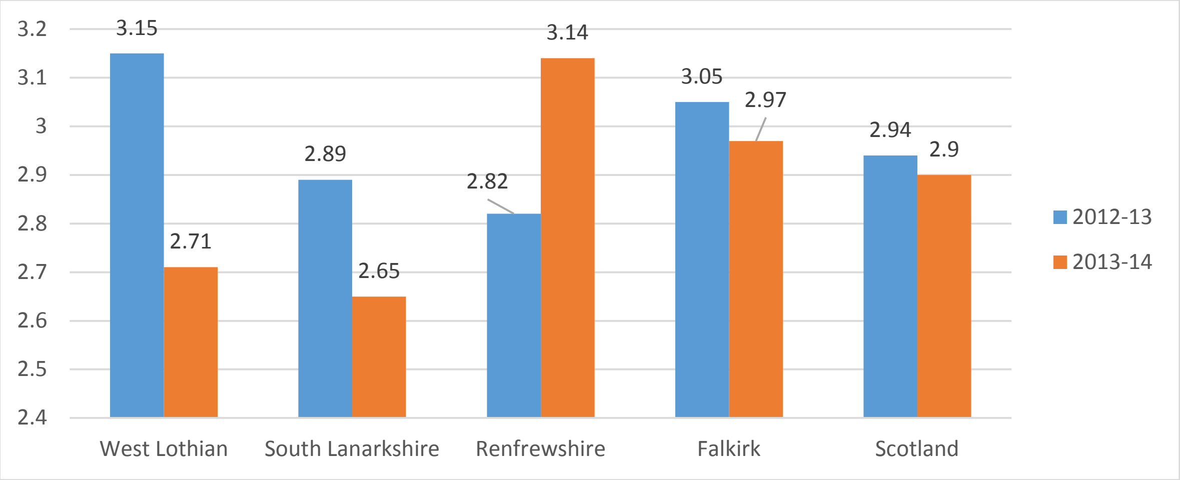
[85] Ibid.

[86] Ibid.

3.9.4 Anxiety

With regards to anxiety ratings there have been reductions in West Lothian, South Lanarkshire, Falkirk, and Scotland, whereas there has been an increase in anxiety ratings in Renfrewshire.

Figure 3.22: Estimates of Anxiety From the Annual Population Survey (APS) Personal Well-being 2012/13 and 2013/14[87]



3.10 Prevalence of physical disability

Current estimates suggest that there are over 12 million disabled people in the UK, almost 1 in 5 people; a figure which has stayed relatively constant in recent years (12.2 million in 2012/13). [88] Data from the Scottish Household Survey (2013)[89], which provides subjective responses on disability, amongst other things, reveals around one third of households in Scotland (34 per cent) contained at least one person with a 'long-standing illness, health problem or disability'. The survey asks participants if anyone in their household, including children, has: "*Any long-standing illness, health problem or disability that limits your/their daily activity or the kind of work that you/they can do? By disability as opposed to ill-health, I mean a physical or mental impairment, which has a substantial and long-term adverse effect on their ability to carry out normal day to day activities*." Further analysis of the survey data is revealed in the graph below which shows percentages of the age and gender profile of those with a long-standing illness, health problem or disability in Scotland. Although not primarily focussing on a physical disability, it can be seen that there are more females than males with a long-standing illness, health problem or disability (20% compared to 18%). The graph also demonstrates that rates of a long-standing illness, health problem or disability in Scotland increase with age.

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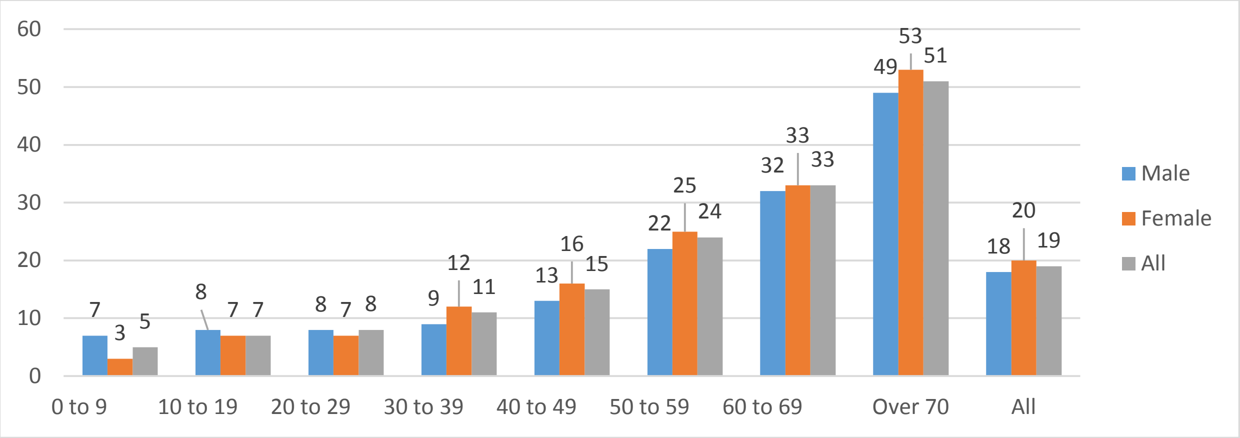
[87] Ibid.

[88] *Papworth Trust. 2015. Disability in the United Kingdom 2014: Facts and figures. Available at:* *http://www.papworthtrust.org.uk/sites/default/files/UK%20Disability%20facts%20and%20figures%20report%202014.pdf [Accessed 10 August 2015].*

[89] Scottish Government. 2014. *Annual Report: Results from 2013 Scottish Household Survey.* Available at: http://www.gov.scot/Resource/0045/00457570.pdf [Accessed 14 August 2015].

Figure 3.23: Percentage of Household Members with a Long-standing Limiting Illness, Health Problem or Disability by Age and Gender, Scotland, 2013[90]



3.11 Prevalence of hearing loss

In 2012, the World Health Organisation (WHO) suggested that there are 360 million people in the world with a hearing loss, which equates to 5.3% of the world's population.[91] The WHO further predicts that adult onset of hearing loss will be one of the top ten disease burdens in the UK.[92] Estimates by Action for Hearing Loss[93] suggest that over 10 million people in the UK have a hearing loss, one in six of the population, and suggest the figure for Scotland is at approximately 850,000. Action for Hearing loss suggest this figure is set to rise by the year 2031 to more than 14.5 million in the UK with 1.2 million of these people being in the Scottish population. A recent report to the Scottish Parliament puts the number of young people in education with a hearing impairment as 2241.[94] Applying a prevalence rate of 1 in 6 suggested by Action on Hearing would indicate there are likely to be approximately 29,525 individuals with some form of hearing loss in West Lothian based on the mid-2014 population estimates. The table below shows a breakdown of these estimations based on figures provided by Action on Hearing.

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[90] Scottish Government. 2014. *Annual Report: Results from 2013 Scottish Household Survey.* Available at: http://www.gov.scot/Resource/0045/00457570.pdf [Accessed 14 August 2015].

[91] World Health Organisation. 2012. *WHO global estimates on prevalence of hearing loss.* Available at: http://www.who.int/pbd/deafness/WHO_GE_HL.pdf [Accessed 4 August 2015].

[92] Action for Hearing Loss. 2011. *Hearing matters: Action on hearing loss.* Available at: http://www.actiononhearingloss.org.uk/ [Accessed 4 August 2015].

[93] Action for Hearing Loss. 2011. *Hearing matters: Action on hearing loss.* Available at: http://www.actiononhearingloss.org.uk/ [Accessed 4 August 2015].

[94] Scottish Government. 2014. *The Implementation of The Education (Additional Support for Learning) (Scotland) Act 2004 (as amended): Report to Parliament 2013.* Available at: http://www.gov.scot/Publications/2014/04/3050 [Accessed 4 August 2015].

Table 3.24: Prevalence Estimation of Individuals with a Hearing Loss in West Lothian

West Lothian	**Population**	**% of hearing loss**	**No. prevalence of hearing loss**
Population	177,150	1 in 6	29,525

Source: applying assumptions suggested by Action on Hearing to GROS 2014 Mid-Year Estimates.

3.12 Prevalence of sight loss

Data from the Royal National Institute for Blind People suggests that there are almost 2 million people in the UK living with a form of sight loss, with 360,000 registered as blind or partially sighted. Getting registered as blind or partially sighted with a local authority involves three processes and to be registered a person must be certified by an ophthalmologist (eye specialist). The processes are:

1. Getting referred to an eye specialist
2. Determination of certification by an ophthalmologist. In Scotland this certificate is called a BP1 and this will state whether a person qualifies as:
    - severely sight impaired (blind)
    - sight impaired (partially sighted)
3. Registration with your local social services[95]

People of all ages are affected by sight loss, but more so in older people, with 1 in 5 people in Scotland aged 75, and 1 in 2 aged 90 and over living with a sight loss.[96] Recent figures[97] show that 2.04 million eye examinations were carried out in Scotland between 2013-14 with 1.66 million of these primary care examinations[98] and 374,000 supplementary examinations.[99] Currently, there are approximately 34,500 people formally registered in Scotland, however as registration is voluntary as few as 23-28% of entitled people may be currently registered. It is suggested that 188,000 people live with significant sight loss in Scotland, with estimates suggesting this will double over the next two decades to approximately 400,000 people if the required action to prevent this is not implemented.[100] Based on mid 2014 population estimates this is equivalent to approximately 1 in 29

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[95] Royal National Institute of Blind People. 2015. *Registering your sight loss.* Available at: http://www.rnib.org.uk/eye-health/registering-your-sight-loss [Accessed 14 August 2015].

[96] Scottish Vision Strategy Advisory Group. 2012. *Success in Sight? Interim review.* Available at: www.alliance-scotland.org.uk/download/library/lib_4fa266b3f2134 [Accessed 16 August 2015].

[97] Information Services Division Scotland. 2015. *General Ophthalmic Services Statistics Updates of existing pages as at 31 March 2014.* Available at: http://www.isdscotland.org/Health-Topics/Eye-Care/ [Accessed 15 August 2015].

[98] An initial, routine, eye examination is carried out by an eye care professional, usually an Optometrist or ophthalmic medical practitioner, where the patient will have a comprehensive assessment of their eye health.

[99] If a second eye examination following the primary eye examination is required the patient will, usually, be referred to an ophthalmic hospital, to the patient's GP, or to another Optometrist or ophthalmic medical practitioner.

[100] Scottish Vision Strategy Advisory Group. 2013. Scottish vision strategy (2013-18). Available at: https://www.rnib.org.uk/sites/default/files/Scot_Vision_Strategy_refresh.pdf [Accessed 16 August 2015].

of the population. For West Lothian this would equate to 6,108 people having a significant sight loss as demonstrated in the table below.

Table 3.25: Prevalence Estimation of Individuals with a Sight Loss in West Lothian

West Lothian	Population	% of sight loss	No. prevalence of significant sight loss
Population	177,150	1 in 29	6,108

Source: applying assumptions suggested by Scottish Government to GROS 2014 Mid-Year Estimates.

3.13 Prevalence of dual sensory loss/deafblind

Current estimates from Deafblind Scotland suggest there are 5,000 people who have significant hearing and sight loss, with most of those people being over 60 and having become dual sensory impaired as part of the ageing process. Scottish Government (2010) figures show 1,473 people registered as deafblind in Scotland and a further 1,003 people registered as partially sighted and deaf.[101]

A recent study by Robertson and Emerson estimates that the number of people with a dual sensory loss in the UK today is between 151,000 and 394,000, with these figures set to rise by 50% by the year 2030. Robertson and Emerson[102] provide prevalence estimates for both children and adults. The authors use data from national data sources[103] where estimates of the age and gender-specific prevalence of co-occurring vision and hearing impairments could be derived from. Applying these prevalence estimates in West Lothian, the tables below reveal prevalence estimates across the lifespan, based on mid-2014 population figures.

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[101] Scottish Government. 2010. *Registered Blind and Partially Sighted Persons, November 2010.* Available at: http://www.gov.scot/Publications/2010/10/26094945/11 [Accessed 5 August 2015].

[102] Robertson, J., and Emerson, E. 2010. *Estimating the Number of People with Co-Occurring Vision and Hearing Impairments in the UK.* The Centre for Disability Research (CeDR). Available at: https://www.sense.org.uk/sites/default/files/CEDR_Research_Full_Report_PDF.pdf [Accessed 14 August 2015].

[103] Health Survey for England, Scottish Health Survey, General Household Survey, Disability Follow-Up of the Family Resources Survey, Annual Population Survey, English Longitudinal Study of Aging, Families and Children Study, Family Resources Survey, Living In Wales, Scottish Household Survey, Millennium Cohort Survey, DCSF Spring 2008 School Census.

Table 3.26a: Estimated Prevalence of Impairments of Both Hearing and Vision for Males in West Lothian

Age	Male	Upper estimate	Prevalence	Lower estimate	Prevalence
0-9	11,524	0.334%	38	0.052%	6
10-19	10,913	0.110%	12	0.016%	2
20-29	10,453	0.063%	7	0.036%	4
30-39	11,073	0.066%	7	0.009%	1
40-49	13,673	0.128%	18	0.02%	3
50-59	12,164	0.498%	61	0.053%	6
60-69	9198	1.253%	115	0.499%	46
70-79	5,565	1.064%	59	0.413%	23
80-89	1,966	4.029%	79	1.77%	35
90+	227	12.623%	29	12.757%	29

Source: applying assumption from Robertson & Emerson (2010) to WL Mid-Year 2014 Estimates (accessed via www.nomisweb.co.uk).

Table 3.26b: Estimated Prevalence of Impairments of Both Hearing and Vision for Females in West Lothian

Age	Female	Upper estimate	Prevalence	Lower estimate	Prevalence
0-9	10,897	0.085%	9	0.02%	2
10-19	10,438	0.047%	5	0.029%	3
20-29	10,501	0.034%	4	0.124%	13
30-39	11,553	0.056%	6	0.013%	2
40-49	14,597	0.223%	33	0.029%	4
50-59	12,470	0.316%	39	0.043%	5
60-69	9,939	0.471%	47	0.073%	7
70-79	6,479	1.445%	94	0.628%	41
80-89	2,898	4.419%	128	1.305%	39
90+	622	13.405%	83	5.571%	35

Source: applying assumption from Robertson & Emerson (2010) to WL Mid-Year 2014 Estimates (accessed via www.nomisweb.co.uk).

3.14 Prevalence of Brain injury

Current figures provided by Headway, a UK-wide charity which works to improve life after brain injury, shows there were 348,934 UK admissions to hospital with acquired brain injury (ABI) in 2013-14, 566 admissions per 100,000 of the population. ABI admissions in the UK have increased by 10% since 2005-6, with men 1.6 times more likely than women to be admitted for head injury; however, female head injury admissions have risen 24% since 2005-6. Applying a prevalence rate of 566 per 100,000 suggested by Headway, this would indicate there are likely to be approximately 1,003 individuals with some form of ABI injury across West Lothian based on the mid-2014 population estimates.

Table 3.27: Prevalence Estimation of Individuals with an Acquired Brain Injury in West Lothian

West Lothian	**Population**	**% of ABI**	**No. prevalence of ABI**
Population	177,150	566 per 100,000	1,003

Source: applying assumption from Headway to West Lothian Mid-Year 2014 Estimates (accessed via www.nomisweb.co.uk)

Headway figures also show there were 130,551 UK admissions for stroke in 2013/14, an increase of 9% since 2005-6, equating to 1 stroke every 4 minutes.[104] In Scotland, 21,217 people were admitted to hospital for head injuries and strokes. [105] Prevalence data for strokes provided by General Practitioners suggest an estimated Scottish prevalence of stroke/ TIA[106] of 2.2 per 100 patients 2013/ 2014.[107]

Cerebrovascular disease (CVD) develops as a result of problems with the blood vessels supplying the brain, which includes strokes and TAI's. Strokes are one of the common types of CVD, and there is a high prevalence of the risk factors associated with CVD in Scotland, with smoking, poor diet, high blood pressure, lack of exercise and drinking alcohol above the recommended limit, factors in this. The current incidence rate of CVD in Scotland is 257.4 per 100,000 for 2013/14, a 21.8% reduction from 2004/5 figures (328.9 per 100,000). Frequency rates for CVD are steadily higher in males than females. Findings from the Scottish Health Survey 2013, were 3.2% of men and 2.7% of women reported that they had experienced a stroke.[108]

Applying the current incidence rate of CVD in Scotland to mid-year 2014 population estimates in West Lothian would indicate approximately 456 individuals in West Lothian are likely to experience a CVD. The table below shows this estimate based on 2014 mid-year population estimates.

Table 3.28: Estimated Prevalence of Cerebrovascular Disease Occurrences in West Lothian

West Lothian	**Population**	**Incidence rate**	**No. of CVD occurrences**
Population	177,150	257.4 per 100,000	456

Source: applying current rate of CVD in Scotland to West Lothian Mid-Year 2014 Estimates (accessed via www.nomisweb.co.uk).

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[104] Headway. 2015. *Brain injury statistics.* Available at: https://www.headway.org.uk/brain-injury-statistics.aspx [Accessed 30 July 2015].

[105] Headway. 2015. *Brain injury statistics.* Available at: https://www.headway.org.uk/brain-injury-statistics.aspx [Accessed 30 July 2015].

[106] Transient ischaemic attack (TIA) – a temporary form of stroke, sometimes referred to as a 'mini-stroke'

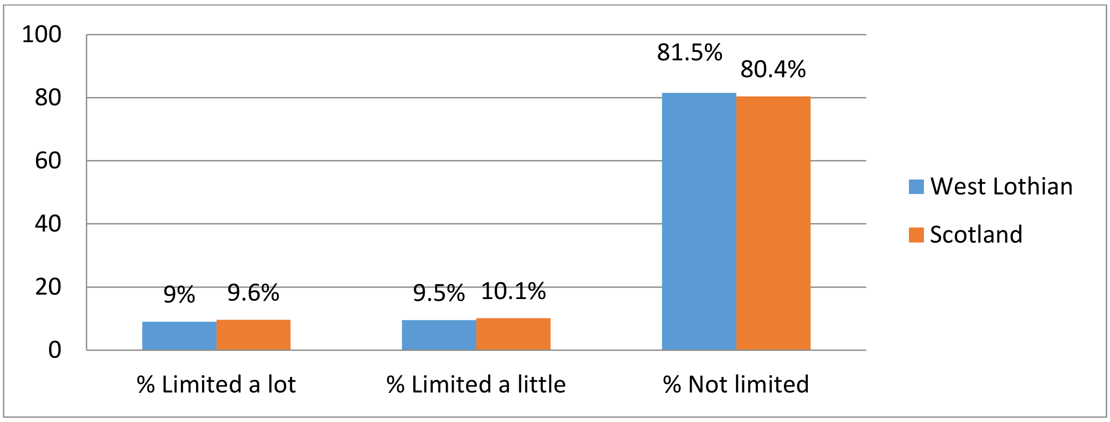
[107] Information Services Division Scotland. 2015. *Stroke statistics update.* http://www.isdscotland.org/Health-Topics/Stroke/ [Accessed 4 August 2015].

[108] Information Services Division Scotland. 2015. *Stroke statistics update.* http://www.isdscotland.org/Health-Topics/Stroke/ [Accessed 4 August 2015].

3.15 Adults known with a physical disability in West Lothian

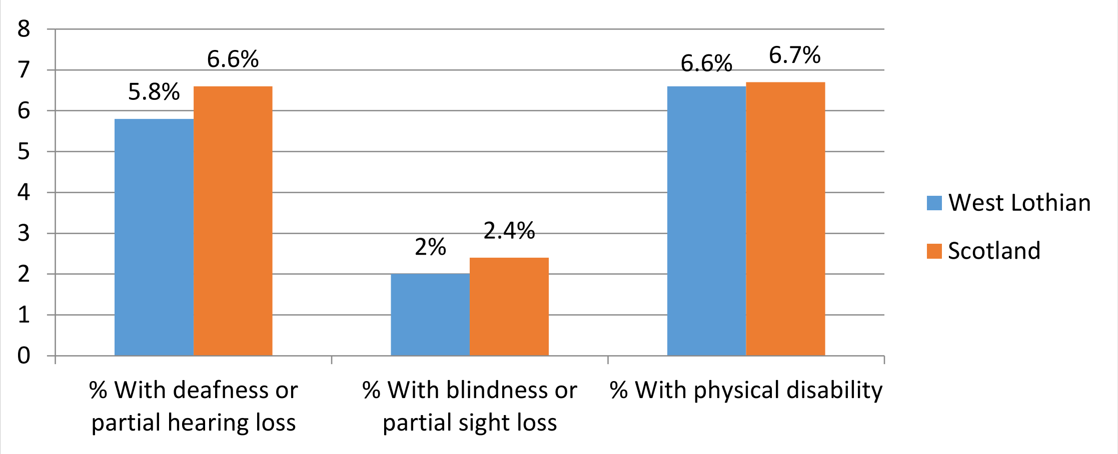
Data regarding those known to have a physical disability is provided by several national data sources. According to the 2011 census the proportion of people in West Lothian with a long-term activity-limiting health problem or disability was 19.5%, with 9% limited a lot and 9.5% limited a little. The figure below shows West Lothian figures for those with a long-term activity-limiting health problem or disability compared with Scotland.

Figure 3.29: Percentage of Individuals with a Long-term Health Problem or Disability in West Lothian and Scotland, 2011[109]



The 2011 census also reveals data relating to specific impairments for those with a long-term activity-limiting health problem or disability in West Lothian which are demonstrated in the figure below, again compared to Scotland.

Figure 3.30: Percentage of Individuals with a Hearing, Sight or Physical Impairment in West Lothian and Scotland, 2011[110]



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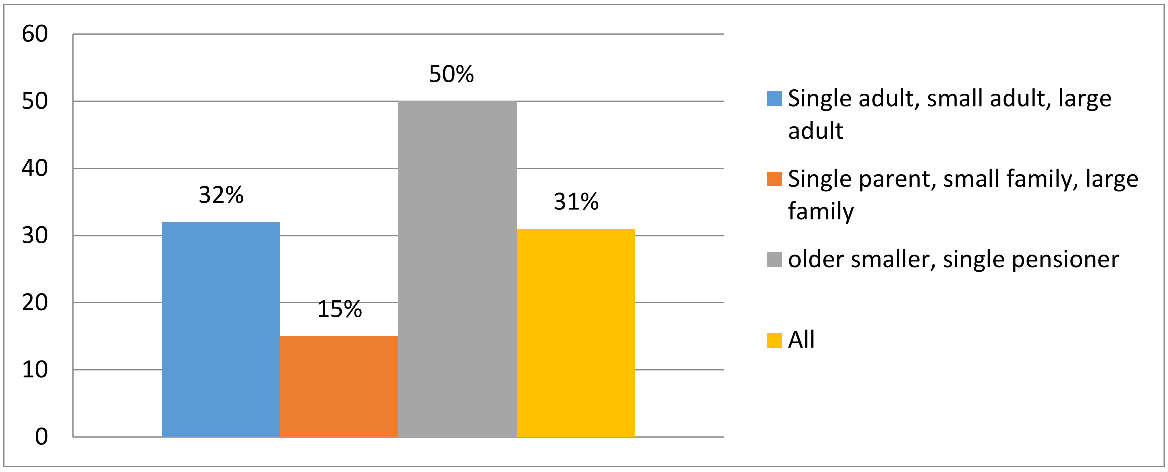
[109] National Records of Scotland, 2011 *Census*. Available at: http://www.scotlandscensus.gov.uk/ods-web/area.html. [Accessed 16 June 2015].

[110] National Records of Scotland, 2011 *Census*. Available at: http://www.scotlandscensus.gov.uk/ods-web/area.html. [Accessed 16 June 2015].

Data from the Scottish Household Survey (2013)[111] reveals approximately one third (31%) of households in West Lothian contained at least one person with a 'long-standing illness, health problem or disability'. The figure below shows the percentage of households in West Lothian where someone in the household has a long-standing illness, health problem or disability by the household type.

Figure 3.31: Percentage of Households in West Lothian where someone in the Household has a long-standing Illness, Health Problem or Disability - by Household Type[112]



A recent report to the Scottish Parliament on the number of children and young people who have having additional support needs shows there were 350 children in West Lothian with additional supports needs relating to physical disability. The principal factors giving rise to the additional support needs are detailed in the table below.

Table 3.32: Number of Pupils with the Additional Support Needs- Deafblind, Visual, Hearing and Motor Impairments in West Lothian, 2013[113]

Type of impairment	Deafblind	Visual	Hearing	Motor
Total	o	90	46	214

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[111] Scottish Government. 2014. *Annual Report: Results from 2013 Scottish Household Survey.* Available at: http://www.gov.scot/Resource/0045/00457570.pdf [Accessed 14 August 2015].

[112] Scottish Government. 2013. *Scottish Household Survey: Local authority tables West Lothian.* Available at: http://www.gov.scot/Resource/0046/00469326.pdf [Accessed 18 August 2015].

[113] Scottish Government. 2014. *The Implementation of The Education (Additional Support for Learning) (Scotland) Act 2004 (as amended): Report to Parliament 2013.* Available at: http://www.gov.scot/Publications/2014/04/3050 [Accessed 4 August 2015].

3.16 Key findings

- 2014 mid-year population estimates for West Lothian is 177,150. Current projections for West Lothian are estimating an overall population increase of 11.7 % by 2037 (n=196,664).
- Female life expectancy at birth (80.2 years) is greater than male life expectancy (77.5 years) in West Lothian.
- 97.5% of the people in West Lothian consider their ethnic group to be 'white' which is higher than national figures (96.1%).
- 13 (6.2%) of West Lothian's 211 datazones are found in the 15% most deprived datazones in Scotland. The most deprived datazone in West Lothian in the overall SIMD 2012 is S01006416, which is found in Bathgate East. It has a rank of 440, meaning that it is amongst the 10% most deprived areas in Scotland.
- Approximately 89,000 people are employed within West Lothian. Unemployment figures in West Lothian are lower than the Scottish average (5.6% compared to 6.2%).
- In the year to March 2015 there were 1,331 applications made under the Homeless Persons Legislation in West Lothian, a 3.2% increase from 2013-14 figures (1,290) but a 5.7% decrease from 2012-13 (1,412).
- Reports on personal wellbeing in West Lothian are mixed with estimated average figures showing a slight decrease from 2012/13 to 2013/14 in reportings of life satisfaction (2012/13=7.61; 2013/14=7.57) and worthwhile (2012/13=7.83; 2013/14=7.81). Reportings on happiness measures have slightly increased (2012/13=7.46; 2013/14=7.49), whereas overall levels of anxiety have seen a reduction (2012/13=3.15; 2013/14=2.71).
- Approximately 5.3% of the world's population (360 million) has some form of a hearing loss,
- There are estimated to be over 10 million people in the UK have a hearing loss, 1 in 6 of the population, with approximately 850,000 of these in Scotland.
- There are likely to be approximately 29,525 individuals with some form of hearing loss in West Lothian based on the mid-2014 population estimates.
- There are almost 2 million people in the UK living with sight loss, with 360,000 registered as blind or partially sighted.
- People of all ages are affected by sight loss, but more so in older people, with 1 in 5 people in Scotland aged 75 and 1 in 2 aged 90 and over living with a sight loss.
- There are currently around 34,500 people formally registered with a sight loss in Scotland, however as registration is voluntary as few as 23-28% of entitled people may be currently registered.
- There are approximately 188,000 people with significant sight loss in Scotland, with estimates suggesting this will double over the next two decades to approximately 400,000.

- There are approximately 5,000 people in Scotland who have significant hearing and sight loss, with most of those people being over 60 and having become dual sensory impaired as part of the ageing process.
- 2010 figures from the Scottish Government reveal 1,473 people were registered as deafblind in Scotland and a further 1,003 people registered as partially sighted and deaf.
- In the UK there were 348,934 UK admissions to hospital with an acquired brain injury in 2013-14, 566 admissions per 100,000 of the population.
- Acquired Brain Injury admissions in the UK have increased by 10% since 2005-6.
- Men are 1.6 times more likely than women to be admitted for head injury; however, female head injury admissions have risen 24% since 2005-6.
- Prevalence data provided by General Practitioners suggest an estimated Scottish prevalence of stroke/ Mini-stroke of 2.2 per 100 patients in 2013/ 2014.
- According to the 2011 census the proportion of people in West Lothian with a long-term activity-limiting health problem or disability was 19.5%, with 9% limited a lot and 9.5% limited a little.
- The Scottish Household Survey (2013) reveals approximately one third (31%) of households in West Lothian contained at least one person with a ‘long-standing illness, health problem or disability’.
- In 2013 there were 350 children in West Lothian with additional supports needs relating to a physical disability.

CHAPTER 4: PROFILE OF CURRENT SERVICE PROVISION

4.1 Introduction

This chapter sets out information on current service provision and is drawn from a variety of sources including data supplied from West Lothian Council, NHS Lothian [subject to Caldicott Guardian approval] and information provided by managers of physical disability, sensory impairment and acquired brain injury services in West Lothian. An online questionnaire was sent to all specialist physical disability, sensory impairment and acquired brain injury service managers in May 2015.

4.2 Current physical disability, sensory impairment and acquired brain injury service provision in West Lothian

Responses to the online questionnaire were received from 11 individuals and correspond to the following organisations:

- Ability Centre Support Service;
- Capability Scotland (West Lothian Advice, Information, Support and Peer Counselling Service);
- Community Store;
- Cornerstone (Forest Walk Care Home);
- Corporate Services;
- Deaf Action;
- Deafblind Scotland (Guide/Communicator Service);
- New Directions West Lothian;
- Occupational Therapy and Technology;
- Physical Disability Assessment Team; and
- Royal National Institute for the Blind (RNIB) Scotland.

The table below provides a breakdown of the statutory and commissioned services provided by organisations across West Lothian. Responses to the online survey were from the managers of these services.

Table 4.1: Breakdown of specialist physical disability, sensory impairment and acquired brain injury services across West Lothian

West Lothian CHCP Services (West Lothian Council and NHS Lothian)
Ability Centre Support Service (ACSS)
Care at Home – General
Community Equipment Store
CRABIS (Community Rehabilitation and Brain Injury Service)
Crisis Care
Home Safety Service (HSS)
Occupational Therapy (OT) Services
Sensory Support Service
Social Work Assessment Team
Supported Discharge and Re-enablement Team (REABLEMENT)
NON-STATUTORY (COMMISSIONED) PROVIDERS/SERVICES
Capability Scotland
Care and Repair Service
Cornerstone
Deaf Action
Deafblind Scotland
MECOPP
New Directions West Lothian
RNIB
Support for Carers (Carers of West Lothian)
The Thistle Foundation

4.3 Response Rate

There was a total of 12 responses. One response was deleted as the respondent only completed the personal information section.

4.4 Service Profile

This section of the report provides factual data on specialist physical disability, sensory impairment and acquired brain injury services currently commissioned in West Lothian.

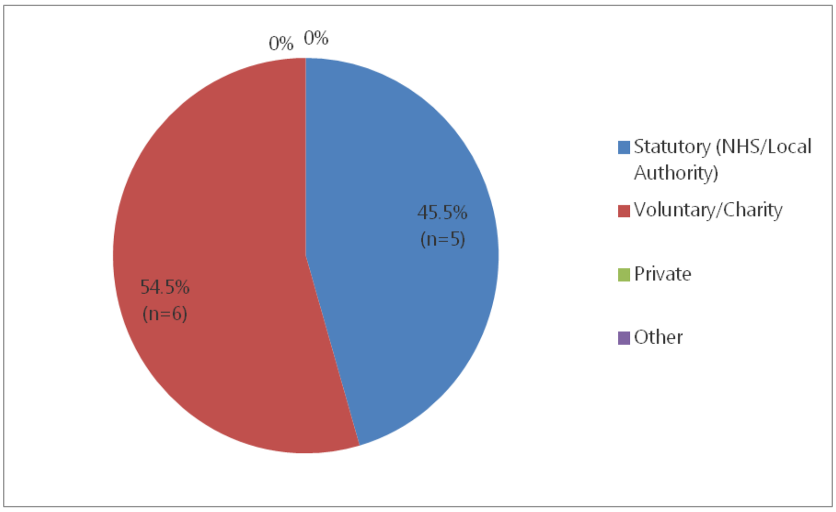
4.4.1 Locality of Services

All (100%; n=11) respondents indicated that their service covers the whole of West Lothian.

4.4.2 Type of Service

The majority (54.5%; n=6) of managers were in charge of a voluntary/charity organisation and 45.5% (n=5) were managers of statutory services.

Figure 4.2: Type of service



4.4.3 Description of Service

Managers were asked to provide a brief summary on what their service provides. Their descriptions are presented in the table below:

Table 4.3: Brief Description of Each Service [114]

Service	Service description
Ability Centre Support Service	*"The service provides day support to adults with physical disabilities both in the Centre and in various community based outreach locations."*
Capability Scotland	*"The service focuses on the provision of advice, information, support and peer counselling to disabled people."*
Community Store	*"We deliver and install equipment to enable people to remain independent, and to be nursed within, their homes. We also supply a range of incontinence pads and urology products."*
Cornerstone	*"We provide support for 4 residents, we also provide 2 respite places and 2 day respite places Monday to Friday. The people we support have physical and or learning disabilities."*
Corporate Services	*"Equality/ discrimination law and advice to councillors, senior management, line managers, council employees and community groups and organizations."*
Deaf Action	*"Provision of services to deaf, hard of hearing, deafened and deaf blind people, and those who use British Sign Language. They require access to services and professionals who understand the impact their deafness has on their lives, and whom are able to communicate directly and effectively with them. They are often unable or unwilling to access mainstream services due to barriers and lack of understanding."*
Deafblind Scotland	*"The guide/communicator service is provided to adults who have a dual sensory impairment, The service focuses on equal access to information and services through communication support, mobility support and providing access to information in a vast range of settings."*
New Directions West Lothian	*"We are registered as a support service without care at home for people aged between 16 and 65 years old. We deliver support through 2 different services: 1. Vision Community Support - for people with a learning disability, physical disability, mental health conditions, and acquired brain injury. This is a skills development service teaching independent living skills, self-travel skills and group work."*
Occupational Therapy and Technology	*"Provide occupational therapy assessment to residents of West Lothian and provide appropriate resources/education in line with West Lothian Council OT criteria."*
Physical Disability Assessment Team	*"Assessment and Care Management service meeting statutory social work, adult protection, SDS requirements etc."*

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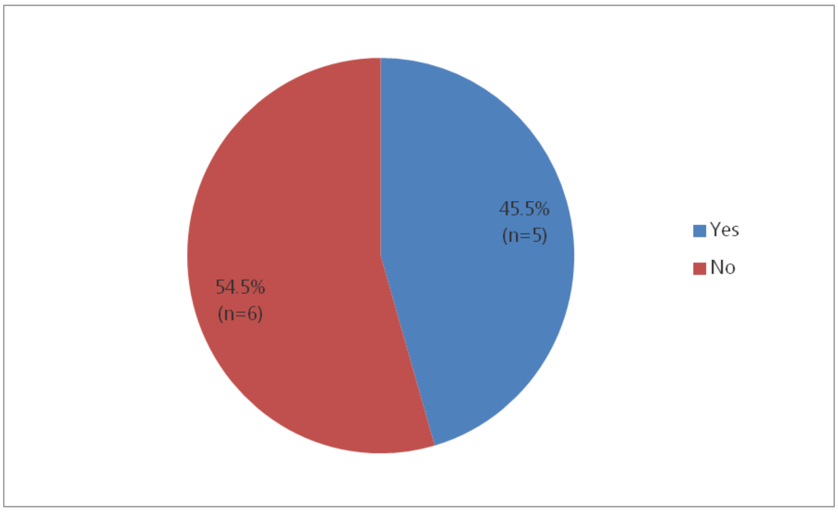
[114] Source: Management survey conducted by Figure 8.

RNIB Scotland	*"Providing a rehabilitation and mobility training service to the residents in West Lothian who have a visual impairment. Also provide awareness training to staff groups as requested."*

4.4.4 Formal partnerships with other organisations

Six respondents (54.5 %) stated that their service did not have any formal partnerships with other organisations. The remaining respondents (45.5; n=5) indicated that their services did have formal partnerships with other organisations.

Figure 4.4: Formal partnerships with other organisations



Respondents who specified that they did have a formal partnership with another organisation were asked to provide further details. Respondent's answers are presented below:

> *'West Lothian Council.'* (Cornerstone)
>
> *'Community Health and Care Partnership or more recently the Integrated Joint Board.'* (Occupational Therapy and Technology)
>
> *'West Lothian Council's partner is NHS Lothian West Lothian Division.'* (Community Store)
>
> *'Health primarily but informal partnerships with voluntary sector.'* (Physical Disability Assessment Team)
>
> *'Service Level Agreement'* (RNIB Scotland)

One respondent who stated that they did not have any formal partnership provided commentary, it is presented below:

> *'There are 4 other services operating out of the same building but the relationships are informal.'* (Ability Centre Support Service)

4.4.5 Sources of funding

Respondents were asked to specify the funding source(s) of their service. Respondents (100%; n=9) all stated that the main source of their funding come from the local authority. Two respondents did not provide an answer to this question.

4.4.6 Service user charging

Respondents were asked to specify whether their service currently charges its service users. The majority (82.8%; n=9) of respondents stated that there is no service charge for service users. Two (18.2%) respondents indicated that service users are charged for the service.

4.4.7 Referral Pathways into Services and Services referred to

Figure 4.5: Referral pathways and services referred to

Service	Referral Pathways and Service referred to
Autism Assessment Team	*'Referral pathway is: first contact and referral is made via the Contact and Referral Team, which then gets passed to the Adults Duty Screener, which then gets passed to myself to screen and place on the Autism Team waiting list, if appropriate. Organisations who refer to the team are: Community Learning Disability Team Autism Initiatives Education department West Lothian College No.6 One Stop Shop for Autism Signpost Community Adolescent Mental Health Service Community Education GP's Parents and carers.'*
Autism Initiatives	*'99% of referrals come through social work, we sometimes get referrals from health and from families with own budgets.'*
Ark Housing	*'Social Work Health Board / N.H.S. Self-Directed Support Self-Referral.'*
Barony Housing Association	*'Via West Lothian Council, although we would accept self-referrals from individuals, or their representatives, who have opted to manage their own SDS budget.'*
Community Inclusion Team	*'All referrals are as a result of Community Care Assessments carried out by Social Work Team. We have no self-referral system or drop in type service.'*
Community Integrated Care (Lismore)	*'When vacancy arises, social work dept. are aware and they match up person requiring support to the service and people currently being supported.'*
Eliburn Support Service	*'Referrals can be made via Social Work and in conjunction usually with health or education.'*

Enable	*'Referrals come from social work or through ENABLE direct which receives direct referrals from people requesting a service.'*
Employment Service	*'Self-referrals can been made to the service however it is more common that a referral is made from a support worker or other organisation. Initial contact can be made in person, by post, email and telephone. An information pack is then sent to the person and if they wish to proceed, they will return an application form. The majority of referrals are currently made from social policy staff members.'*
Housing Support Service	No comment provided.
Key Community Supports	*'KEY will accept referrals for direct support through any pathway – WLCHCP, direct referrals via Individual Budgets (SDS or referrals from individuals with direct payments. We are also registered to support people with disabilities under the age of 16 years. KEY provides highly personalised, flexible services therefore would design a service around the needs and wishes of the person and the information provided by their other key stakeholders.'*
Learning Disability Service	*'Referrals are made via: contact and referral team (social work) by letter.'*
Leonard Cheshire Disability	*'Referrals come from West Lothian Council.'*
Livingston Homereach Ltd	*'Notify vacancy to WLC Social Policy.'*
Local Area Coordination Service	*'All referrals are received through the Social Policy Contact and referral team and screened by team managers.'*
Mears Group Ltd	*'Social Work referrals.'*
New Directions West Lothian	*'VCS - Referral is made through social work.* *A2S - Referral is made through social work, through individuals who under SDS have opted for own control over their budget and also through a private arrangement.'*
Pathways	*'All referrals to Pathways are made through West Lothian Councils Social Policy Community Care Assessment Team. Any informal enquiries made by Parents/Carers to Pathways are directed to the Assessment Team.'*
Penumbra Supported Living Service	*'All referrals come to us through Social Work department at the present time.'*
Real Life Options	*'Local Authority Referral.'*

The Action Group	*'Most of our business in West Lothian is from the Social Work Department. We also have service users who come us directly with ILF, DP, and trust funds.'*
The Richmond Fellowship	*'Referrals received are from Social Workers, Community teams, individuals, families and SDS.'*
West Lothian Befriending Scheme	*'Users can self-refer but 99% are referred through the social work department.'*

4.5 Service User Profile

Data was sought from all commissioned services (period April 2014 – March 2015), in relation to:

- Referral activity;
- Numbers engaged with the service;
- Number of 'Did Not Attends'; and
- Discharge activity.

Local Authority and NHS services were unable to provide the data in the format requested. Local Authority data is kept on the SWIFT database. The Social Policy Team, who maintain the SWIFT database, were able to provide a series of reports, which have been used in the following sections and previously, in Chapter 3 (Epidemiology). At the time of writing, the authors are still awaiting permission from the NHS Lothian Caldicott Guardian to access local NHS data.

The data received from the commissioned services is presented in the table below:

Table 4.6: Referral, Engagement, DNA and Discharge Activity – by commissioned service

	Ability Centre Support Service	**Capability Scotland**	**Cornerstone**	**Deaf Action**	**Deafblind Scotland**	**New Directions WL**	**RNIB Scotland**
1a. Total number of referrals	38	N/A	12	180	0	47	
1b. Of which how many were appropriate referrals?	35		12	180	N/A	50	100%
1c. How many were self-referrals?	5		0	100	N/A	0	
1d. How many were 'returning' contacts?	2		0	65	N/A	9	
2. Total number of individuals engaged with the service?	166		32	200	6	58	
3. Total number of DNA's?	1328		0	Not recorded	0	3	0
4a. Number of planned discharges from the service?	'ALL'		0		0	7	0
4b. Number of unplanned discharges from the service?	5		0	7	0	5	0

4.6 Service Provision

4.6.1 The main presenting issues and needs of service users

Responses are summarised below in bullet form:

- Service providers have limited resources to provide the required variety and flexibility of services needed by service users.
- Services do not offer enough purposeful activities.
- Increased flexibility and responsiveness is required by service providers.
- Times of support groups/activities do not meet times suitable for service users.
- Occupational health assessment and input needs to be delivered more quickly.
- There is a need for speedier reaction to equipment or continence needs, in particular around hospital discharge and avoiding hospital admission.

- Service users are unable to access their own information and therefore unable to make informed choices about their lives and the things that are important to them.
- Service users are often unable to leave their homes unsupported; or if they can, communication with others can be difficult.
- People who are blind or severe visual impairment require better advice, equipment and support to aid mobility and their day-to-day living experience.
- Every person is an individual but generally people with physical disabilities experience issues of social Isolation, lack of information, a need for carer support, issues of low confidence and resulting mental health problems.

4.6.2 How service user outcomes are measured

Responses are summarised below in bullet form:

- Through assessment, care management and review processes (including multi-disciplinary/agency case conferences) which focus on:
- Identification of agreed goals;
- Progress against agreed goals;
- The effectiveness of support for the supported person in terms of advancements and life skills achieved;
- Whether support directly leads to a reduction in the amount of support hours required;
- Planned discharge/case closure from the service due to agreed needs being fully or partially but sufficiently met; and
- An outcome questionnaire is completed at the conclusion of all cases.
- Qualitative and quantitative feedback using tools such as questionnaires and surveys; some of which focus on satisfaction ratings of service users;
- Through the contract management framework for commissioned services which sets out a wide range of measures, directly aligned to service specifications;
- Reviewing progress against service user's personal outcomes, based on specific outcomes frameworks such as the Joint Improvement Team's systems Talking Points Personal Outcomes Approach;
- West Lothian Council has 10 corporate equality outcomes, linked to KPIs which are monitored and managed within appropriate services;
- Organisational outcomes frameworks are utilized; for example, Cornerstone;
- Through annual returns to OSCR for registered charities and West Lothian Council for commissioned services, as part of the contract management framework;
- Via service user and carer case studies;

- Via Care Inspectorate inspections and subsequent reports;
- Through internal and external evaluations;
- Through service user engagement; for example, specific consultations and fora such as meetings, working groups, seminars and conferences;
- Through the use of validated outcomes tools such as Outcomes Star; and
- Through learning sets and other types of training and development.

4.6.3 Key priorities for service improvement

Responses are summarised below in bullet form:

- Introducing or developing more purposeful activities in line with service user hopes and aspirations for the future, which are meaningful to the development of life skills and better inclusion in communities;
- Reintroducing a physical disability forum to provide opportunities for people with physical disability or sensory impairment to have their say; and for their say to be heard and acted up;
- Supporting staff to manage changes in assessment and recording processes that will impact positively on waiting times for clients; thus enabling staff to provide a proactive approach to meeting client needs;
- Supporting beneficiaries with self-management of conditions;
- Reducing the scale of crisis management;
- Improving hospital discharge rates and with improved service delivery pathways;
- Enhancing the role of the Community Equipment Store to help deliver individually tailored and holistic support packages;
- Improving the nature, scale and impact of service user engagement;
- Improving the nature, scale and impact of carer engagement;
- Reducing paperwork and making SDS processes more assessor and service user friendly;
- Encouraging more flexible and responsive services to be in place;
- Developing service user disability fora including developing relations with existing for a;
- Increasing funding to employ more staff and volunteers to offer an earlier intervention service for people with a physical disability;
- Reducing waiting times;
- Lower staff attrition rates;
- Increasing joint training opportunities; and

- Focusing greater emphasis as well as resources on linked challenges, in particular employability (B4 Work and On2 Work), housing options and transport.

CHAPTER 5: CORPORATE APPROACH (NORMATIVE OR EXPERT)

5.1 Introduction

The purpose of this element of the research was to seek the views from key professional staff and other non-service user or carer stakeholders on the current provision of specialist physical disability and sensory impairment services across West Lothian. Specifically, study informants were asked to provide their views on the quality of services, key issues, gaps and areas for improvements.

Findings in the first part (**5.2-5.14**) of this chapter derive from quantitative surveys which were distributed to physical disability and sensory impairment service staff across West Lothian during June 2015; with the aid of physical disability and sensory impairment service providers. There were two identical versions of the survey used; namely an online version and a hard copy version.

Findings in the second part of this chapter (**5.15-5.18**) derive from the following qualitative elements of the study:

- A stakeholder event held on 20 May 2015, involving 13 professional staff;
- Two working group meetings held on 27 May 2015 and 5 June 2015, involving 16 professional staff;
- 10 interviews held between 26 May 2015 and 10 June 2015, one of which was a joint interview; involving 11 professional staff; and
- A meeting held on 8 June 215, involving a professional staff member.

A summary of key findings from chapter 5 is outlined in section **5.19**.

A standalone report encapsulating views of people with and affected by a sensory impairment, together with professional staff accompanies this final report.

5.2 Response rate

There were 32 responses to staff survey, of which two were discarded as respondents completed less than 25% of the survey. The overall total of responses used for analysis was therefore 30, broken down as follows:

- 11 out of 30 (36.67%) responses were deemed 'complete', as 100% of questions were answered by respondents.
- 19 out of 30 (63.3%) responses were considered 'incomplete', as:
    - 13 of 30 respondents completed 50%-99% of the survey;
    - Six of 30 respondents completed 25%-49% of the survey.

5.3 Limitations

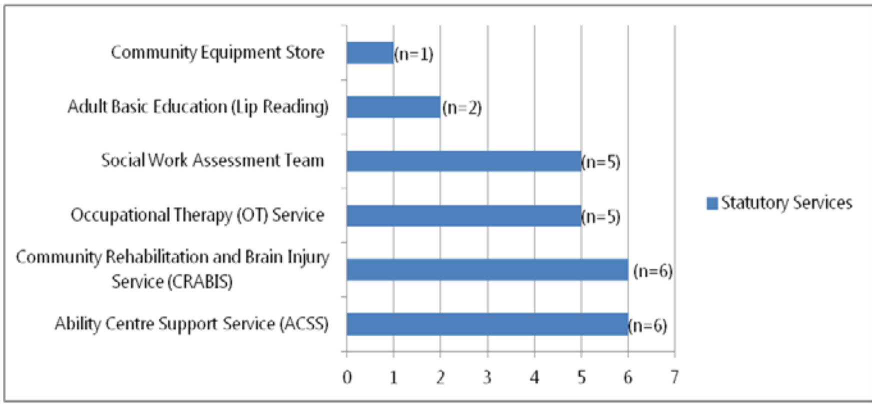
- All the services listed in the previous Chapter (Table 4.1, Section 4.2) were sent the link to the online staff survey and invited to participate. Varying levels of responses were received as shown in Figures 5.1 and 5.2 below.
- The services completing the survey represent a broad range of organisations (statutory and non-statutory), type of service (community based and residential) and size of service (from small to large), so results need to be read with these variances in mind.
- Care needs to be taken when interpreting findings as there were a number of questions which had varying levels of response rates.

5.4 Service Information

5.4.1 Statutory services

Respondents were asked to indicate what statutory services they were employed by. The majority of respondents were employed by the Community Rehabilitation and Brain Injury Service (CRABIS) (n=6) and the Ability Centre Support Services (ACSS) (n=6).

Figure 5.1: Breakdown of respondents by employment in Statutory Services



There were no respondents who worked in the following services:

- Care Home – General
- Supported Discharge and Re-enablement Team
- Home Safety Service (HSS)
- Respite and Short Breaks from Caring
- Care at Home – Independent Living, Specialist and Housing Support
- Crisis Care
- Housing Support

5.4.2 Commissioned services

Respondents were asked to indicate what commissioned services they were employed by. Responses are presented in the table below:

Table 5.2: Breakdown of respondents by employment in Commissioned Services

Commissioned Service Name	**No. of respondents:**
Cornerstone	n=1
Deafblind Scotland	n=1
Freespace	n=2

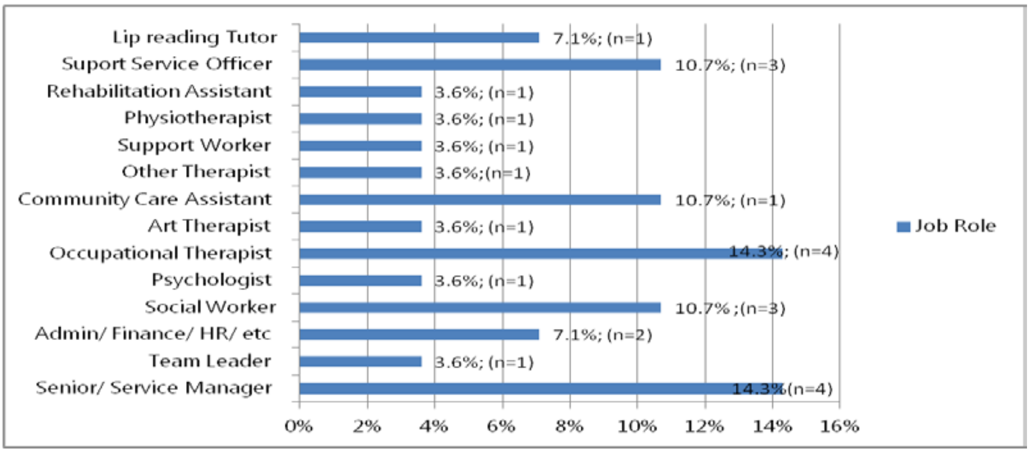
There were no responses from the following commissioned services:

- Support for Carers (Carers of West Lothian)
- Royal National Institute for the Blind (RNIB)
- Deaf Action
- MECOPP
- Rotary Residential and Care Centres
- Share Scotland
- The Thistle Foundation
- Care and Repair Services

5.4.3 Job Role

Respondents were asked to indicate what their job role was in the service which they work for. The majority of respondents either ‘Occupational Therapist’ (n=4) or ‘Senior/Service Manager(s) (n=4).

Figure 5.3: Breakdown of respondents by job role



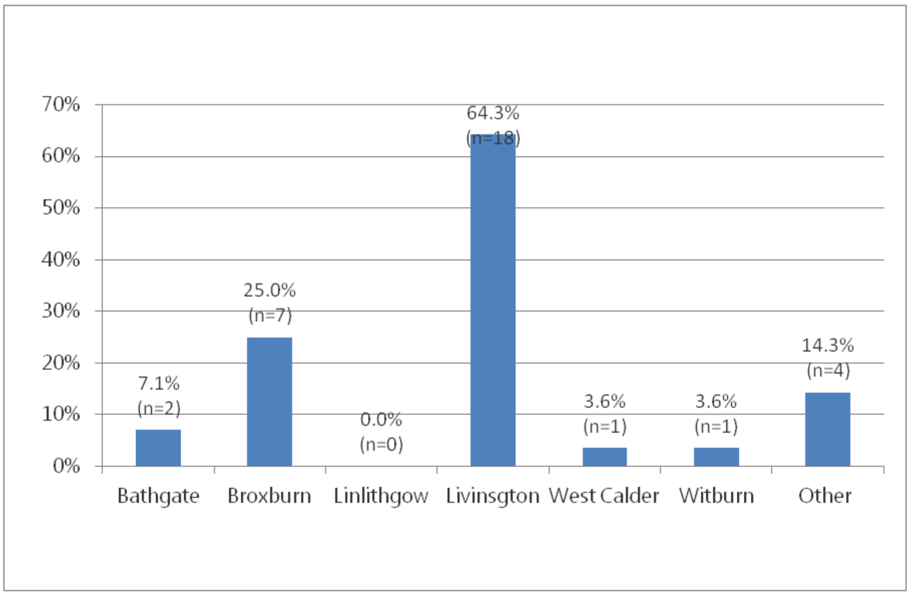
There were no respondents who indicated that they were in the following job roles:

- Nurse/Clinician
- Counsellor
- Case Worker/ Therapist
- Speech and Language Therapist
- Occupational Therapist Assistant
- Music Therapist
- Other Therapist

5.5 Service locality

Most of the services for physical disabilities, sensory impairment and/or acquired brain injury are located in Livingston (64.3%, n=18), this was followed by Broxburn, with 25.0% (n=7) of respondents indicating that their services are in this locality. There were no respondents that indicated that their service was based in Linlithgow (n=0). Respondents were able to choose more than one option.

Figure 5.4: Services by locality in West Lothian



Of the four respondents that, that indicated that their service locality was in another area:

- Two respondents indicated that their service was located in Edinburgh.
- One respondent indicated that their service was located in Uphall.
- One respondent stated West Lothian.

5.6 Rating of statements

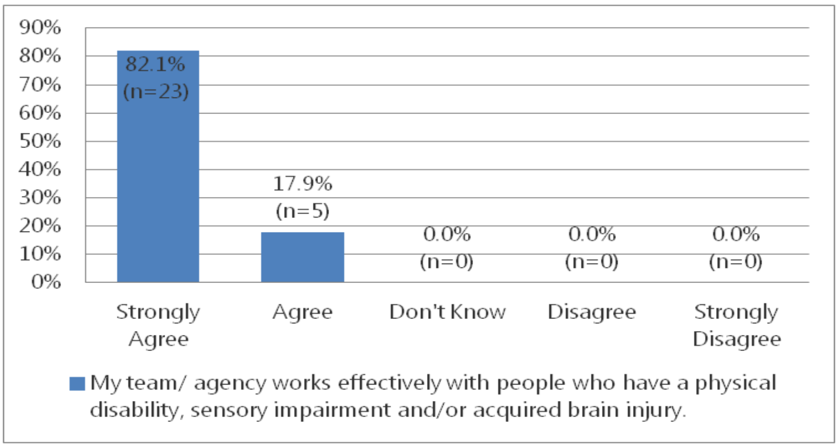
Respondents were asked to specify how much they agreed or disagree with a set of 13 statements. A breakdown of respondent's agreement/disagreement is presented in the figures below:

Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency works effectively with people who have a physical disability, sensory impairment and/or acquired brain injury.'*

The majority of respondents 'Strongly Agree (d)' (82.1%; n=23) or 'Agree(d)' (17.9%; n=5) with this statement.

Figure 5.5: Statement 1

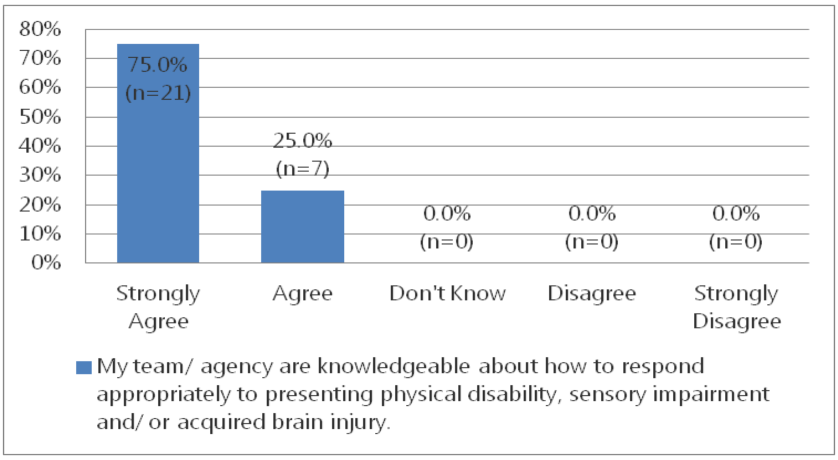


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency are knowledgeable about how to respond appropriately to presenting physical disability, sensory impairment and/or acquired brain injury'.*

The majority of respondents 'Strongly Agree (d)' (75.0%; n=21) or 'Agree (d)' (25.0%; n=7) with this statement.

Figure 5.6: Statement 2

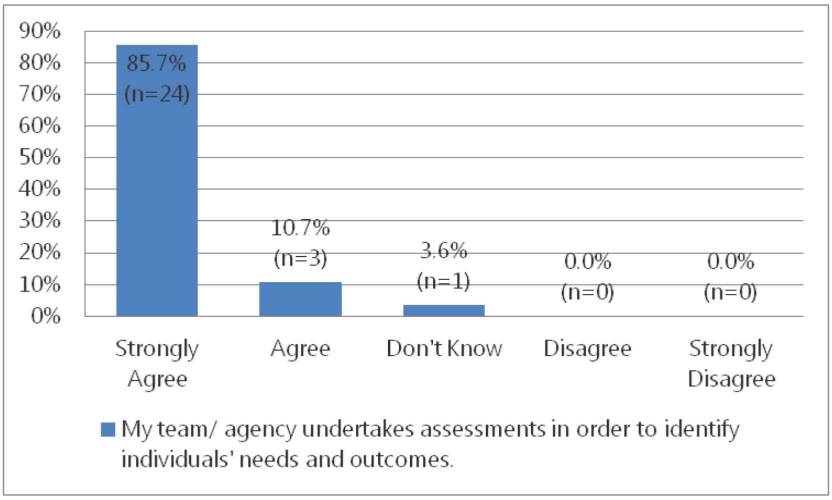


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency undertakes assessments in order to identify individuals' needs and outcomes.'*

The majority of respondents 'Strongly Agree (d)' (85.7%; n=24) or 'Agree (d)' (10.7%; n=3) with this statement. One respondent (3.6%) responded 'Don't Know'.

Figure 5.7: Statement 3

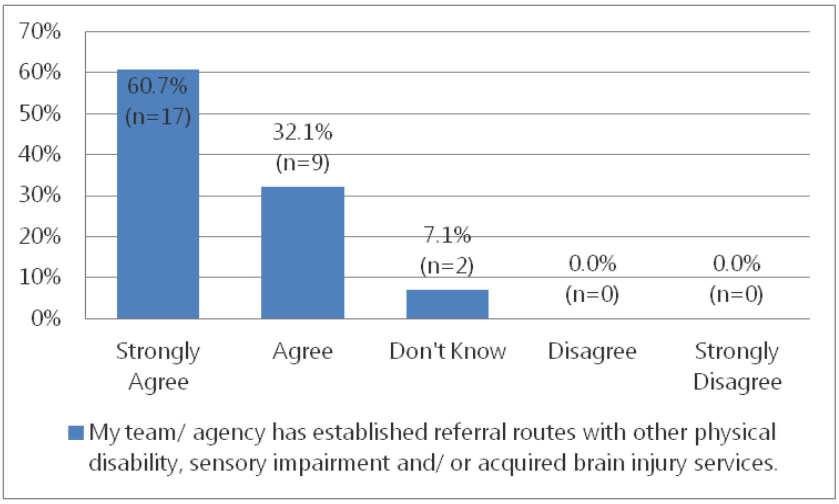


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency has established referral routes with other physical disability, sensory impairment and/or acquired brain injury services.'*

The majority of respondents 'Strongly Agree (d)' (60.7%; n=17) or 'Agree (d)' (32.1%; n=9) with this statement. Two respondents (7.1%) responded 'Don't Know'.

Figure 5.8: Statement 4

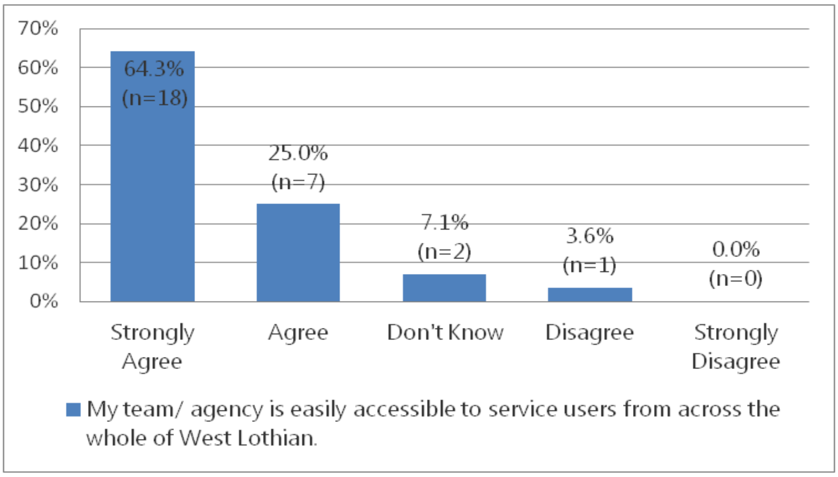


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency is easily accessible to service users from across the whole West Lothian.'*

The majority of respondents 'Strongly Agree (d)' (64.3%; n=18) or 'Agree (d)' (25.0%; n=7) with this statement. Two respondents (7.1%) responded 'Don't Know' and one (3.6%) respondent 'Disagree(d)' with this statement.

Figure 5.9: Statement 5

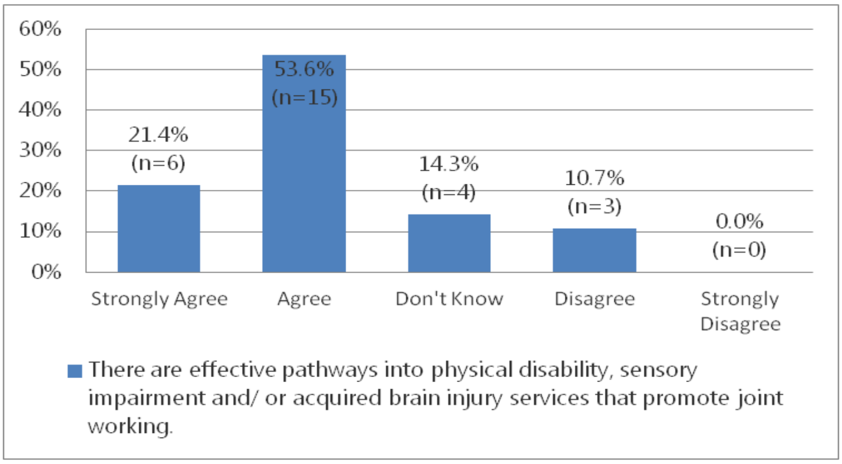


Respondents were asked how much they agreed or disagreed with the statement:

> *'There are effective pathways into physical disability, sensory impairment and/ or acquired brain injury services to promote joint working'.*

The majority of respondents 'Agree (d)' (53.6%; n=15) with this statement, though from the responses there seems to be some disparity in respondents answers. Six (21.4%) respondents 'Strongly Agree (d)' with this statement, four (14.3%) respondents stated they 'Don't Know' about this statement and three (10.7%) respondents 'Disagree (d)' with this statement.

Figure 5.10: Statement 6

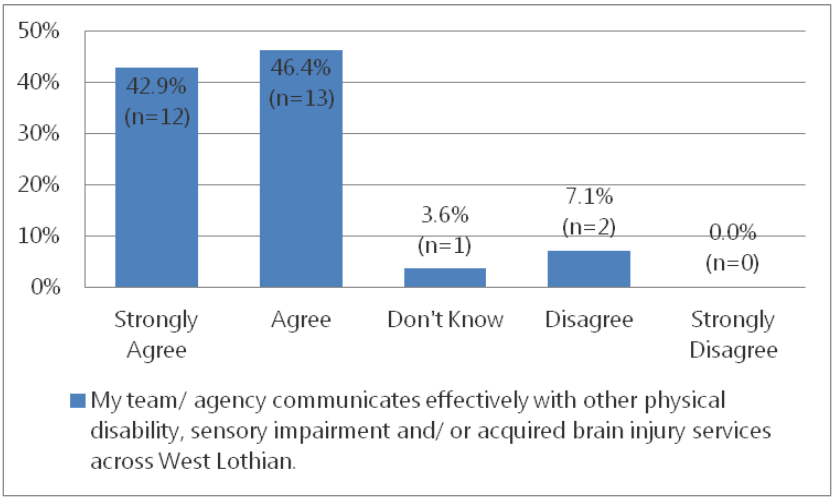


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/ agency communicated effectively with other physical disability, sensory impairment and/ or acquired brain injury services across West Lothian.'*

The majority of respondents 'Agree (d)' (46.4%; n=13) or 'Strongly Agree (d)' (42.9%; n=12) with this statement. Two respondents (7.1%) 'Disagree(d)' with this statement.

Figure 5.11: Statement 7

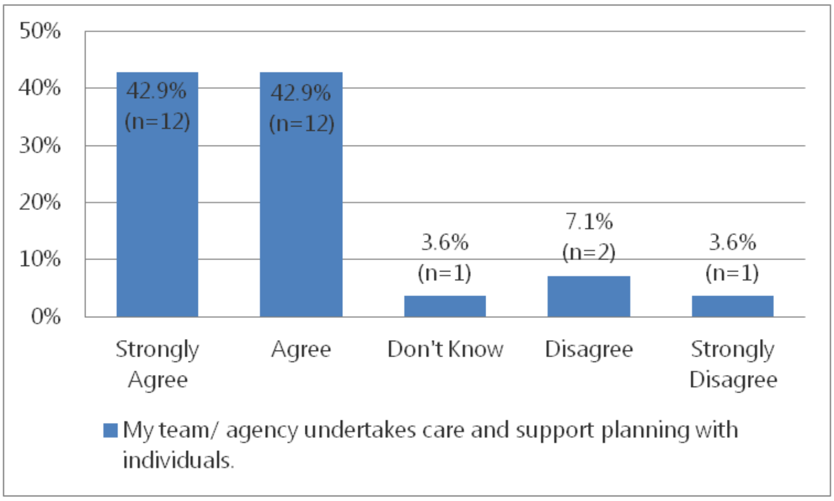


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency undertake care and support planning with individuals.'*

Most respondents 'Strongly Agree(d)' (42.9%; n=12) or Agree(d) (42.9%; n= 12) with this statement.

Figure 5.12: Statement 8

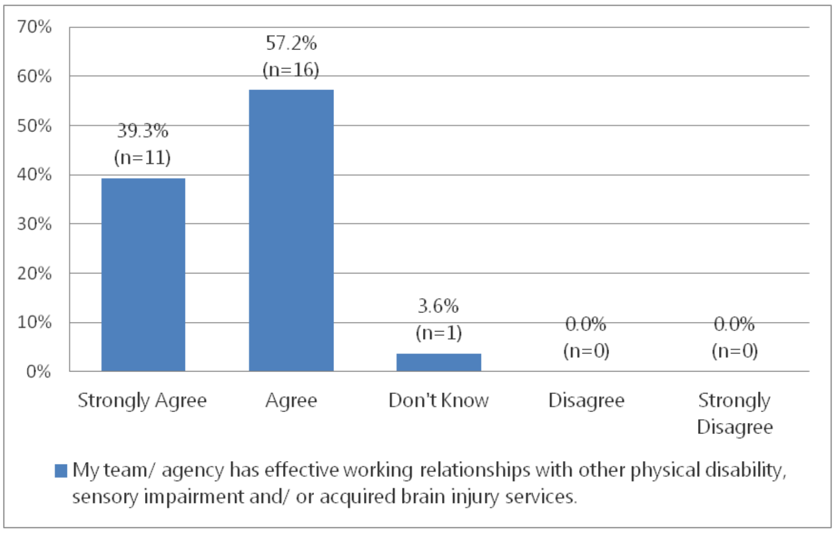


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency has effective working relationships with other physical disability, sensory impairment and/ or acquired brain injury services.'*

The majority of respondents 'Agree (d)' (57.2%; n=16) with this statement, this was followed closely by respondents 'Strongly Agree(ing)' with this statement.

Figure 5.13: Statement 9

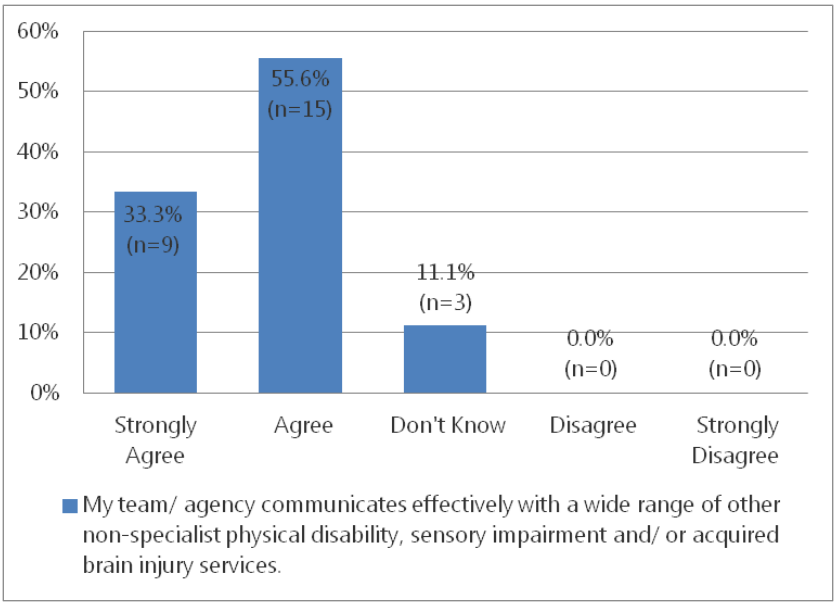


Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency communicates effectively with a wide range of other non-specialist physical disability, sensory impairment and/ or acquired brain injury services.'*

Just over half (55.6%; (n=15) of respondents 'Agree(d) with this statement.

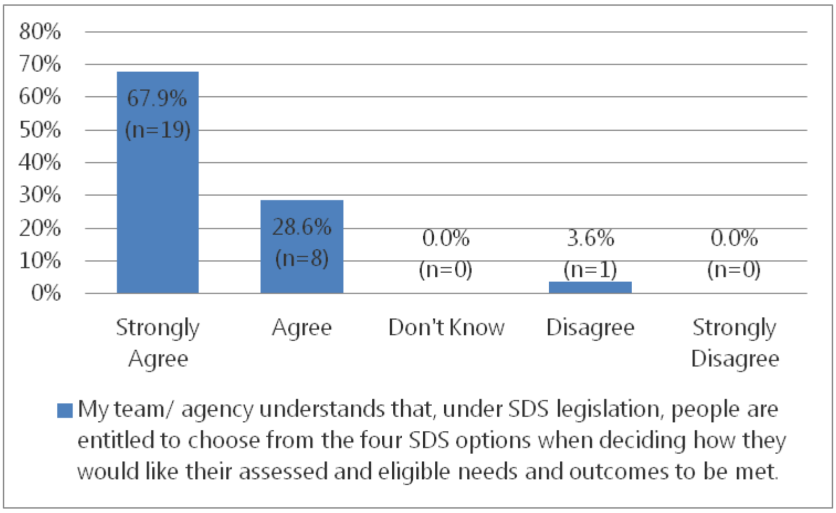
Figure 5.14: Statement 10



Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency understands that, under SDS legislation, people are entitled to choose from the four SDS options when deciding how they would like their assessed and eligible needs and outcomes met. '*

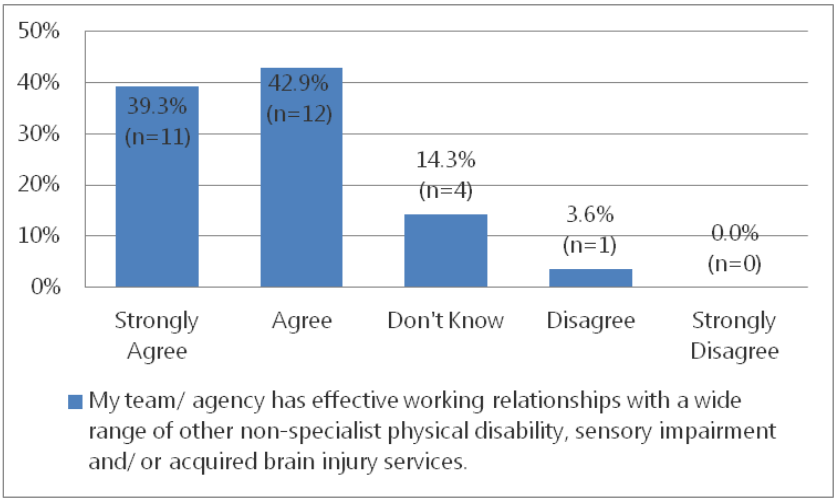
Figure 5.15: Statement 11



Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency has effective working relationships with a wide range of other non-specialist physical disability, sensory impairment and/ or acquired brain injury services.*
> *'*

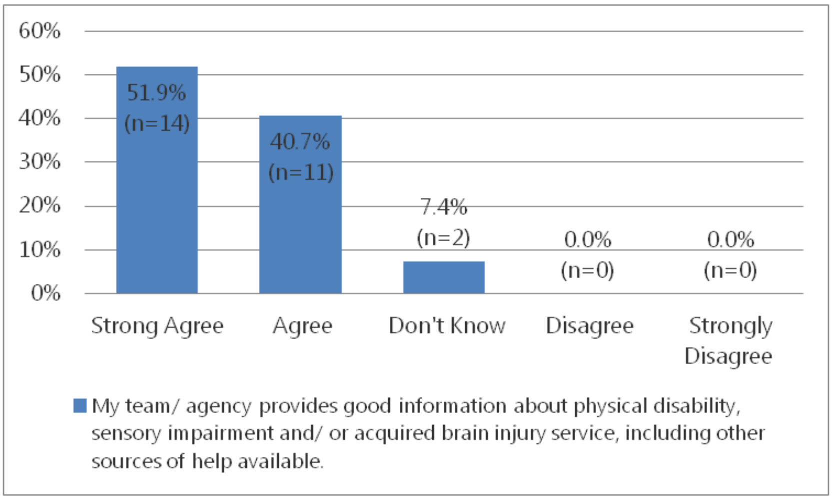
Figure 5.16: Statement 12



Respondents were asked how much they agreed or disagreed with the statement:

> *'My team/agency provides good information about physical disability, sensory impairment and/or acquired brain injury service, including other sources of help available.'*

Figure 5.17: Statement 13



5.7 What services excel at

Respondents were asked what they thought their team/agency did particular well. There were 24 responses and responses are broken down by the services respondents were employed by:

Figure 5.18: What respondents felt their service excelled at

Service Name:	Comments:
Ability Centre Support Service	*'My staff team has all different strengths which as a staff team can bounce of one another for different ideas and run an assortment of different groups for people with physical disabilities. Also with having these different strengths can help each other in certain circumstances.'* *'Communicates well with Service Users and other Service Providers to promote the best outcome for the Service User.'* *'Effective communication.'* *'I feel that the staff at the Ability Centre, communicate well both formally and informally, to maximise service success for the clients. There is a genuine concern and care for client wellbeing.'* *'Support people with Physical Disabilities to achieve their goals and realise their potential. Reduce social isolation by offering day care service both in Livingston and in people's local community. Liaising with other service/agencies to ensure correct support is offered for service users. Supporting service users to access other opportunities e.g. college, community groups and Employment.'* *'Dealing with a wide range of different disabilities and providing activities and social interaction on various levels.'*

Adult Basic Education	*'Communicating with people who have hearing loss as that is the prime objective of the lip-reading small team. We are part of a larger team in Adult Basic Education which deals with people who have learning disabilities as well as educational needs.'* *'Helping people to lip-read better; to improve their confidence; inform them about other organisations; provide a welcoming atmosphere where people can share with each other.'*
Community Rehabilitation and Brain Injury Service (CRABIS)	*'Provide a rehabilitation service to clients with a neurological disability.'* *'Tailored multi-disciplinary goal setting with individuals to help devise an appropriate community rehab programme specific to their needs.'* *'Multi-disciplinary assessment and intervention, responsive to the changing needs of the client.'* *'Rehabilitation of complex cases.'* *'Works hard to try and help clients achieve realistic goals.'*
Cornerstone	*'We provide good care /support to all residential /Respite users, involving all family members with information that is appropriate to the person we support.'*
Deafblind	*'Support and promote the needs of adults with dual sensory loss to maintain and regain independent lives, integrating them into their communities, families and local activities. We focus on developing and maintaining communication skills with people who are losing or have lost both their sight and hearing.'*
Freespace	*'Tailors support to meet individual's needs. Involves individuals, their families, reps in all planning.'* *'We work hand in hand with disabled adults ensuring that their needs are met and they are meeting their outcomes.'*
Occupational Therapy (OT) Service	*'Works with other agencies; coordinates client services; taking a long term view.'* *Teamwork. Takes opportunities to hear about other services that we can use.* *'Very proactive, outcome focused, client-centred. Work well as a team who are all very supportive and share knowledge as well as problem solve with colleagues in difficult situations.'* *'Able to signpost effectively should we not be able to provide a service.'*
Social Work Assessment Team	*'Accurately assesses need.'* *'Good joint team working relationship.'* *'Good relationship with clients to support them to think about how their needs can best be met.'*

5.8 Services/support needed in West Lothian

Respondents were asked to provide details about any services or support they thought were needed for those with a physical disability, sensory impairment and/or acquired brain injury and not currently provided in West Lothian. There were 19 responses. There were a number of key themes which emerged from respondents answers. They were:

- Four respondents felt that a befriending service was needed:

> 'Service Users often say how lonely they feel at times. Befriending opportunities would be of benefit to some.'
>
> 'Befriending services for client's with physical disabilities.'
>
> 'More befriending opportunities available.'
>
> 'Befriender.'

- There were 4 respondents that indicated that there were not enough support available in West Lothian:

> 'Not enough support services available i.e. golden years' project, support workers, volunteer drivers.'
>
> 'No support groups in West Lothian for people with a diagnosis of ABI or FND.'
>
> 'Could be more service providers.'
>
> 'There are very few service which specifically cater for people who have sensory impairments so this is an area which could be developed.'

- Three respondents did not know about any services or support that was needed in West Lothian for those with a physical disability, sensory impairment and/or acquired brain injury.
- Two respondents specified the need for more awareness of services in West Lothian:

> 'I think there are a lot of services in West Lothian but could be publicised a lot better. The people who are referred to the service are normally only referred by a professional worker. There are probably a lot more people out there who would benefit from our service.'
>
> 'I am not sure what services are offered to people with a sensory impairment in West Lothian apart from other UK and Scottish specialist organisations and charities for people with a hearing difficulty such as Lothian Deaf Counselling Service, Deaf Action, etc.'

- There were six responses that didn't fit into any particular theme. Respondents comments are presented below:

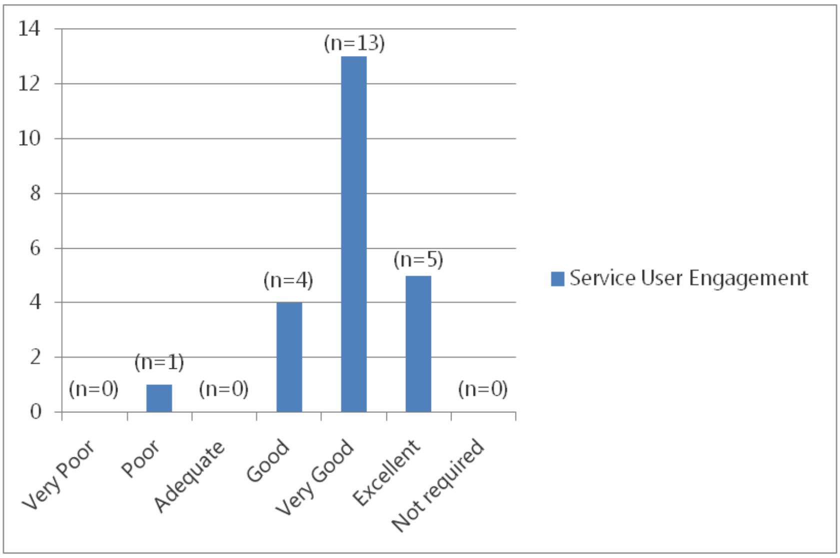
> 'Social/interactive places to go to be part of the community.'
>
> 'Assistance to manage SDS funding and explore other services not so well known.'

> ‘Sensory services a bit disjointed and equipment provision different for hearing than for sight loss- bit confusing!’
>
> ‘I feel that the area of Physical Disabilities does not have as high a profile as other areas. Whilst West Lothian does well, I would like us to look and learn from other countries that may do things differently, but more importantly from the individuals themselves. We have to be receptive to needs and never complacent.’
>
> ‘I feel that the biggest obstacle in West Lothian is transport.’
>
> ‘From the correspondence regarding the focus groups held recently it is obvious that the Council needs to brush up its knowledge regarding people who have sensory loss. For instance they provide loops in various public buildings but the staff do not know how they work. Hearing loss is as devastating as sight or physical loss.’

5.9 Service user engagement

Respondents were asked to rate the level of service user engagement within their service. Service user engagement was defined as ‘the active participation of those with a physical disability, sensory impairment and/or acquired brain injury in shaping their own needs and outcomes’.

Figure 5.19: Extent of service user engagement in services



5.10 Groups that are not well catered for

Respondents were asked if there are any particular groups that they felt were not well catered for in terms of those with a physical disability, sensory impairment and/or acquired brain injury and the reason why respondents thought these groups were not well catered for. Respondent’s answers are presented below:

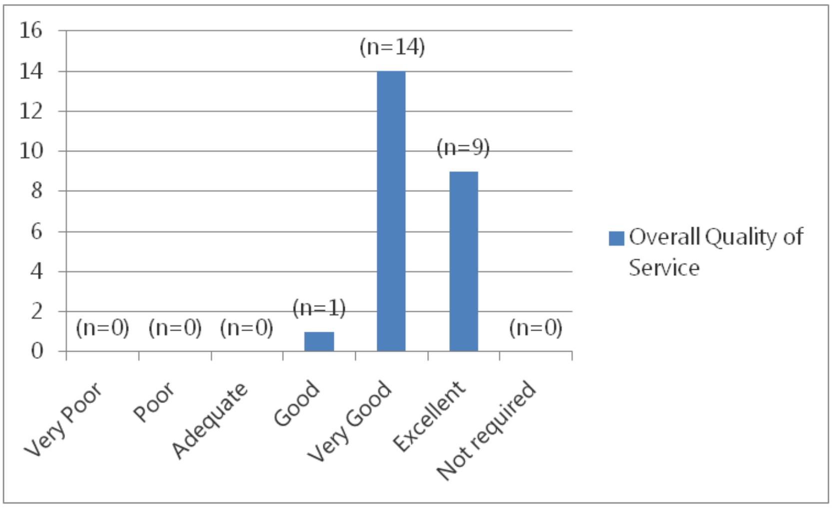
Figure 5.20: Groups that are not well catered for and the reasons why respondent think groups are not well catered for

Groups that are not well catered for:	Why they thought this group was not well catered for:
Two respondents 'did not know' whether there are any particular groups that are not well catered for.	
Three respondents thought that older people were groups that are not well catered for.	*'Funding not available.'* *'Funding gap - less finance available to older people.'* *'I believe when people reach a certain age they are not considered for individual support in housing and always end up in care homes.'*
'Young adults.'	*'Resources, time.'*
'Clients with mental health issues.'	*'Reduced staffing/ services in psychology.'*
'People for whom English is not their first language.'	*'This can create barriers to effective assessment and intervention - both because of the practicality of translation and lack of peer support available (e.g. clients unable to participate in/with predominantly English-speaking groups/supports).'*
'Under 65's with dementia.'	*'Lack of resources and overall percentage of people within W.L with this type of diagnosis.'*
'Adults in any category seem under-catered for.'	*'Service provision geared towards elderly and children. Perhaps a higher percentage of adult population does not have these health problems so are a minority.'*
'People within the ethnic minority communities living with dual sensory loss are not catered for in West Lothian that I am aware of.'	*'A lack of awareness and understanding of sensory impairment across ethnic minorities and sensory impairment sectors.'*
'Working people with a hearing difficulty. All lip-reading classes are day time ones. The number of younger people with a hearing difficulty is growing.'	*'West Lothian Council does not realise the above and think hearing difficulty is an 'older person thing'.*

5.11 Overall quality of service

Respondents were asked to rate the overall quality of their service. The majority of respondents indicated that the overall quality of their service as 'Very Good' (n=14) and nine respondents stated that the overall quality of the service was 'Excellent'.

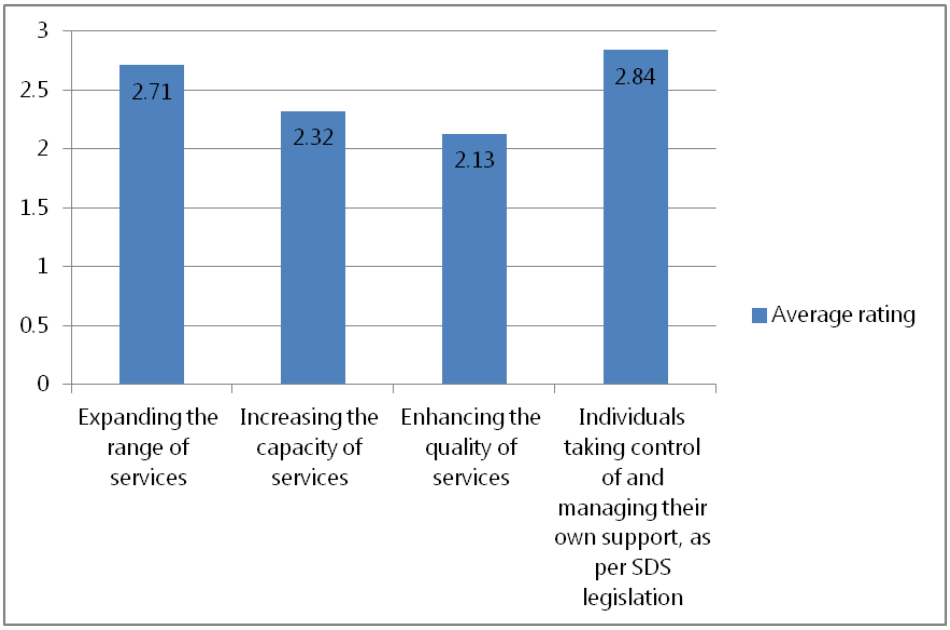
Figure 5.21: Rating the overall quality of the service



5.12 Future Investment

Respondents were asked to put four statements in order of importance with the rating of 1 indicating the most importance and rating of 4 indicating the statement as being least important. The statements were in regards to where respondents would like future investment to go. Respondents rated the statement *'Individuals taking control of and managing their own support, as per SDS legislation'*, with this statement receiving the highest average rating (n=2.84) from respondents. The statement that received the lowest average rating was '*Enhancing the quality of services' with* the average rating being 2.13.

Figure 5.22: Average rating of statement in regards to future investments in services



5.13 Other assets, resources, groups, individuals and opportunities

Respondents were asked what other assets, resources, groups, individuals, and opportunities are available across West Lothian to support mainstream services in meeting the needs of those with a physical disability, sensory impairment and/or acquired brain injury. Respondents gave more than one asset, groups, individuals and opportunities. The key assets, resources, groups, individuals and opportunities identified were:

- Ability Centre Support Service
- Capability Scotland
- Carers of West Lothian
- Deaf Action
- Golden Years- Crossroads
- Mood group
- B4 & On2
- West Lothian College
- Xcite
- Sensory Support Service
- Royal National Institute of Blind
- Places for People
- Physical Disabilities Team
- Medical professions (e.g. GP’s, CPA’s etc.)

5.14 Final comments

Respondents were asked if there were anything else they would like to add. Respondent’s answers are presented below:

> *‘Empty transport buses (i.e.) for Eliburn, Ability Transport, could be used for outings etc. at weekends instead of lying empty from Friday afternoon till Monday morning.’*
>
> *‘Introduction of befriending services for all age groups would greatly improve quality of outcomes and allow some individuals to engage with mainstream services e.g. attend gym/yoga class/computer group.’*
>
> *‘An overall directory of all Services available would be helpful for both service users and professionals thus enabling professionals to refer to appropriate services and hopefully making better use of all Services available (that they may currently be unaware of).’*
>
> *‘Improvements to accessible transport or more "Handicab" type service.’*

> *'Limited knowledge of West Lothian services available so unable to offer further comment.'*
>
> *'Access to information in alternative formats and specialist communication supports is vital to ensuring people living with dual sensory loss can participate in a meaningful and positive way.'*
>
> *'More knowledge of meeting the needs of those with hearing loss.'*
>
> *'Lip-reading classes should be advertised more widely though this would maybe mean more classes are needed.'*

5.15 Background to corporate approach

In this context, the term 'corporate approach' refers to professional staff and wider stakeholders who are not service users, non-service users or carers. Essentially the authors are referring to paid or voluntary staff employed by an agency/service provider, associated with an agency or provider; or people with a current, former or potential future stake or interest in the physical disability and sensory impairment sector. To this end, the authors primarily targeted professional staff from the local authority, NHS, specialist service providers (statutory and commissioned) and generic agencies.

Thirteen (13) professional staff participated in a stakeholder event; broken down, as follows:

- 8 West Lothian Council staff
- 2 NHS staff
- 1 Deaf Action staff
- 1 RNIB staff
- 1 Carers of West Lothian staff

Sixteen (16) professional staff participated in two working group meeting; broken down, as follows:

- 6 West Lothian Council staff
- 2 NHS staff
- 2 Carers of West Lothian staff
- 2 Capability Scotland staff
- 2 Disability West Lothian staff
- 1 Signpost staff
- 1 Deaf Action staff

Eleven (11) professional staff participated in interviews, 9 of which were conducted on a face to face basis. This is broken down, as follows:

- 4 West Lothian Council staff
- 2 NHS Lothian staff

- 2 Capability Scotland staff (joint interview)
- 1 RNIB staff
- 1 MECOPP staff
- 1 Cornerstone staff

An additional meeting took place with another West Lothian Council staff member, although a formal interview was not conducted.

In total, 33 professional staff participated in the qualitative elements of the study. The full interview scheduled is outlined at **Appendix XX.**

5.16 Purpose of corporate approach

The purpose of interviews was to find out:

- Views on current provision of treatment services;
- Gaps in current provision;
- Views in relation to the nature and extent of future requirements; and
- Assets (groups, networks, individuals, etc.) across West Lothian.

5.17 Limitations of corporate approach

In respect of the initial stakeholder event, a challenge was a lower (n=16) attendance figure, compared with the number (n=24) targeted. However, this appears to have had little, if any adverse impact upon the validity and quality of discussions. Another slight issue concerning that event was the breakdown of participants. Thirteen (13) out of 16 informants were professional staff. Furthermore, 8 of this group were from West Lothian Council which suggests a level of dis-proportionality, both in terms of the level of local authority involvement; and the balance among professional stakeholders, service users (n=2) and carers (n=1). Furthermore, some key specialist disability service providers were not represented at the stakeholder event.

In respect of the working groups, the 16 professional staff participants were inadequately balanced with only one carer and no service users involved. It is important to mention that carer and service user led organisations were represented at working groups. Furthermore, a service user and a carer who registered to attend both working groups did not show up to either meeting. It is also important to highlight that working group membership was targeted at 12 people in total. The majority of these informants were targeted at professional staff due to the study's wider and sufficiently robust methodology which included focusing specifically on service users and carers. Carer perspectives were directly and actively fed into working groups. In the view of the authors, service user perspectives were indirectly yet adequately fed into discussions, particularly via a service user led provider informant, but also more widely by several other working group members.

In respect of 1-1 interviews, these were dominated by professional staff, in line with the study's design. Due to design limitations and challenges concerning the entire needs assessment; and following liaison with the study commissioner, the authors focused on interviewing senior managers from West Lothian Council, NHS Lothian and selected commissioned service providers. Whilst acknowledging the success of the approach adopted, much of the feedback was unsurprisingly (and importantly) of a strategic nature; and not necessarily accurately representative of the views of practitioner and junior to senior managerial level staff; or indeed service users and carers. In highlighting this assertion, it should also be noted that a service user and a carer were also interviewed which facilitated improved balance. However, despite considered planning and decision making, the proportionality of interviews actually conducted may be seen by certain stakeholders as imbalanced, system heavy; and top heavy, in terms of senior management.

Whilst acknowledging that the research team has autonomy of decision making in terms of participant selection; indeed, the team and commissioners worked cohesively to identify and agree the interview schedule; the project's budget effectively constrained the number of stakeholders targeted for particular elements of this study. This resulted in the need to target certain role holders and specific service provider representatives which clearly influenced some of the qualitative methods adopted.

The timescales for scheduling and completing the qualitative fieldwork was also extremely tight (7 weeks effectively), which was further compounded by gaps in information regarding key contacts and services from the outset.

5.18 Corporate approach key findings

Findings in **5.11** derive from the views expressed by a total of 33 study informants. The authors have identified sixteen themes, namely:

- What works well;
- Knowledge of current physical disability and sensory impairment and linked services in West Lothian;
- Current management of people with physical disability and sensory impairment in West Lothian;
- Ethos of services and types of interventions currently used;
- Capacity of services and interventions to meet presenting needs;
- Interventions or services identified as needed, but not currently provided;
- Resourcing of services for people with physical disability and sensory impairment;
- Groups not well catered for;
- Accessibility of physical disability and sensory impairment services;
- Integration of physical disability and sensory impairment services;

- Asset mapping: other assets, resources, groups, individuals and opportunities to support people affected by physical disability and sensory impairment;
- Physical disability and sensory impairment; and independence;
- Service user involvement;
- Carer involvement;
- Client outcomes and customer satisfaction ratings; and
- Gaps and wider issues linked to change, service improvement and future basing.

5.18.1 What works well?

According to some informants, West Lothian is 'ahead of the game' in terms of integration of health and social care; and Self-directed Support, although this view is not universally shared among all consultees. A positive example cited is Eliburn Day Centre which supports people with co-occurring physical disability, sensory impairment and learning disability. Another example is the Ability Centre which supports people with a physical disability and sensory impairment, primarily through a statutory in-house team (West Lothian Council); and a multi-use/service building which also houses Capability Scotland's advice and support service.

Another positive centres on relationships at all levels which are generally good. Examples include relationships between service users and service providers, carers and service providers, service providers and service contract managers/commissioners; among specialist physical disability and sensory impairment service providers; and between specialist physical disability and sensory impairment service providers and linked generic services. From the evidence provided, relationships within the Community Health and Care Partnership (CHCP) are also very good, despite the known challenges of integration at both strategic and operational levels.

The role of Service Development Officer (SDO) (Physical Disability) is seen as helpful and crucial by social policy/planning CHCP colleagues and service providers alike. Work streams and relationships try to focus on genuine and successful partnership working, solutions, client outcomes, learning, quality, continuous improvement, value and accountability.

According to professional staff, the level of customer satisfaction, in terms of service users and carers is high. Whilst recognising that this is largely true for service users, this assertion does not accurately reflect service user feedback; and certainly not feedback from carers. In a similar vein, several staff perceive that service user involvement in West Lothian is reasonably good (or better), this is definitely not a view shared by many other staff, service users and carers.

5.18.2 Knowledge of current physical disability, sensory impairment and linked services in West Lothian

The level of knowledge of; and information concerning current physical disability and sensory impairment services in West Lothian is poor and inadequate. This is arguably the single biggest issue that emerged from the study’s qualitative fieldwork. The knowledge gap extends to all relevant stakeholder groups including but not limited to commissioners, specialist physical disability and sensory impairment service providers, generic services, service users and carers.

Whilst acknowledging the customary and valid challenges associated with developing, maintaining and disseminating accurate and up to date information, the general shortcoming concerning information and knowledge extends to Capability Scotland’s Ability Centre based Advice and Support service. This service was previously operated by Disability West Lothian with the transition occurring in April 2015 following competitive tendering. There is a hasty need for this fundamental service to coordinate information for all disability services in West Lothian.

‘Word of mouth’ among service users; and to a lesser extent, carers, is commonly used as a means of finding out about services, what they offer, how to contact them, etc. This is particularly prominent for people with sensory impairment, especially those who are not born with such impairments.

5.18.3 Current management of people with physical disability and sensory impairment in West Lothian

Current management of people with physical disability and sensory impairment in West Lothian is underpinned by SDS assessment and case management by an integrated health and social care (disability) team of professional staff from West Lothian Council and NHS Lothian, in partnership with wider NHS and council services including housing, the independent sector, service users and carers.

There has been vast investment in SDS infrastructure in line with legislation, national policy and local planning. Moving forward, SDS will continue to play an increasingly prominent role on the planning, delivery and coordination of care and support for people with physical disability and sensory impairment. Council services are delivered in partnership with health colleagues in the West Lothian Community Health and Care Partnership,

West Lothian Council provides a range of services for adults with disabilities aimed at promoting and maximising independence. These include assessment and care management, day opportunities, respite and short breaks from caring, care at home, supported living and occupational therapy. The option of a direct payment (under SDS) allows individuals to arrange and self-manage their own care and support. Some of these services are provided directly by the council; whilst others are purchased from voluntary and private sectors.

Services are provided for people with:

- Physical disability;
- Sensory loss;
- Head injury;
- Long term conditions and chronic illness; and
- Aids/HIV.

People who are deaf, deafened, hard of hearing, deafblind (experiencing dual sensory loss), blind or partially sighted can contact the Sensory Support Service based at St. John's hospital in Livingston for information, advice, support and access to specialist workers who provide assessment, technical support and equipment. The service is delivered by social work staff from both West Lothian Council and Deaf Action. The Deaf Action worker is a BSL (British Sign Language) user. The service can visit people in their own homes and assist with obtaining support based on an assessment of need. The service can also refer to specialist services for assessment and provision of equipment or mobility training. There is a weekly drop-in facility for BSL users.

The Lothian Joint Physical and Complex Disability Strategy, *Our Lives Our Way*[115] (2007), outlines the needs of disabled people in Lothian and the vision for the future delivery of services and support. There is a very broad spectrum of conditions and problems which people can experience and; as a result, support services have to meet an extremely diverse range of health and social care needs. Lothian Health and the four Lothian Local Authorities, including West Lothian, are working in partnership with service users, carers and relevant third sector organisations to implement the strategy.

West Lothian Council Strategic Service Statement for physical disability aims to set out how services will be developed and delivered over the 3-10 years to meet the current and potential needs of adults experiencing physical and complex disability living in West Lothian. The Strategic Statement has been developed within the context of national and local policy direction taking into account the key principles and values which underpin the planning, commissioning and provision of services to disabled people; and has been informed by consultation with key partners, service users and carers.

The aim of service planning, development and delivery is to promote, enable and sustain independence, social inclusion and quality of life for service users and carers within a framework offering flexibility and choice underpinned by SDS. The on-going challenge is to provide services that are personalised, of high quality and which can most effectively meet the needs from within finite resources. The Strategic Statement seeks to set out how West Lothian Council proposes to meet this aim and challenge in the future.

The Physical Disability Assessment Team provides an assessment and care management service to adults aged between 16 and 65 years with a physical disability. Based on assessed needs, the team can arrange care in a supported person's own home, community based support or residential care. The service offers people with a disability the option of arranging and managing their own care and support through SDS which includes a *Direct Payments* option. Carers who provide regular and substantial care to someone with a disability can also request a *Carer's Assessment*.

Commissioned services are monitored by West Lothian CHCP using a contract management framework, aligned to a Joint Commissioning Plan and Social Policy Management Plan, supported by inspection of certain services such as the Ability Centre by the Care Inspectorate. Fora include the Equality Disability Forum, Acquired Brain Injury Forum, Learning Disability Managers Meeting and

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[115] *Our Lives Our Way*, The Lothian Joint Physical and Complex Disability Strategy, NHS Lothian, City of Edinburgh Council, East Lothian Council, Midlothian Council, West Lothian Council, 3/07.

Lothian Physical and Complex Disability Programme Board. Service user consultations is also a feature of the physical disability, sensory impairment and acquired brain injury overall system in West Lothian, albeit one that conveys improvement opportunity.

5.18.4 Ethos of services and types of interventions currently used

The ethos of service provision for people with a physical disability and sensory impairment focuses on a number of key principles including:

- Person-centredness/individualism;
- Options and choice;
- Control;
- Self-management;
- Holistic/wraparound;
- Assessment based;
- Needs led;
- Outcome focused;
- Promotes independence;
- Integration and partnership working; and
- Value based.

Specialist statutory services include:

- West Lothian Council’s Ability Centre in Livingston which provides a structured day service for people with a physical disability and sensory impairment;
- West Lothian Council’s Ability Centre in Livingston which provides an outreach service for people with a physical disability and sensory impairment;
- West Lothian CHCP’s Community Rehabilitation and Brain Injury Service (CRABIS) which provides multi-disciplinary assessment and rehabilitation within the home or community setting to individuals over the age of 16 who live in West Lothian and who have a physical disability and/or acquired brain injury. The service also provides follow up and early intervention as required to individuals who have suffered a mild head injury. The service's core aim is to improve the individual's independence, level of function, participation and quality of life. CRABIS is funded by NHS Lothian and West Lothian Council and the service is delivered by an experienced, multi-disciplinary team, including:
- Occupational Therapists
- Physiotherapists
- Clinical Psychologists

- Speech and Language Therapists
- Rehabilitation Assistants
- Joint West Lothian Council/Deaf Action's Sensory Support Service People based in St. John's hospital in Livingston which provides information, advice and access to specialist workers, technical support for people with sensory impairment;
- West Lothian CHCP's Community Equipment Store (CES) provides a range of equipment, issued on loan, following an assessment of need by professional health and social work staff. Equipment is issued to a wide variety of people who require assistance in order to remain independent in the community including people with physical disability, frailty or following surgery to remain at home longer. Equipment ranges from simple feeding, dressing and toileting aids, including a range of continence products, to more specialised beds and hoists. The CES is a jointly funded service between West Lothian Council and NHS Lothian. The service arranges the delivery, uplift and maintenance of equipment to support Capability Scotland's advice and support service for disabled people which includes peer counselling; and
- West Lothian Council's Physical Disability Assessment Team which provides an assessment and care management service to adults aged between 16 and 65 years with a physical disability.

Other commissioned specialist physical disability and sensory impairment services provided by:

- Cornerstone's Uphall care home which provides residential care, residential respite care and respite day care;
- New Directions West Lothian which supports young people and adults experiencing disability, acquired brain injury and severe vulnerability to towards achieving full community life;
- Deaf Action;
- DeafBlind Scotland; and
- Royal National Institute for the Blind (RNIB).

Other non-commissioned specialist physical disability and sensory impairment services including:

- Disability West Lothian;
- Action for Blind People; and
- Royal National Institute for the Deaf.

Commissioned non-specialist physical disability and sensory impairment services including:

- Carers of West Lothian which supports carers including those who support a person with a physical disability and sensory impairment;
- MECOPP Carers Centre which supports minority ethnic carers including those who support a person with a physical disability and sensory impairment;

- Lothian Centre for Inclusive Living (LCiL) is a user controlled organisation which supports disabled people, people with long-term conditions and older people to live independently in their communities. LciL helps with all aspects of SDS and enables people to have more choice and control;
- Service user led mutual aid/self-help support groups such as the Vision Support Group and Sensory Support Group which operate independently;
- Carer led mutual aid/self-help support groups such as Carer's of West Lothian Carers Support Group which operates in affiliation with the service provider;
- Home care;
- Hospital treatment; and
- Adaptations carried out in conjunction with occupational therapy services; and sometimes linked to the equipment service.

The Ability Centre is Livingston is essentially the central hub of activity for people with a physical disability. The structured day service also supports people with a sensory impairment, either as a discrete impairment or as part of co-occurring physical disability.

5.18.5 Capacity of services and interventions to meet presenting needs

The following services were reported as being over capacity (demand currently outweighs availability):

- Social Work Disability team (high caseloads, administrative burden, IT compatibility challenges with integration agenda, bureaucracy/inefficiency of system whereby service users re-entering the system are processed as new clients which is more time consumer and not customer friendly);
- Ability Centre structured day service (waiting lists/times; time-limited discharge policy);
- Ability Centre outreach service [mixed views] (sometimes offered as an alternative to structured day service, awaiting entry to structured day service; or associated with service user dependency on service when discharge is recommended or required by the service;
- RNIB service (waiting times/lists; limited resource and high demand);
- SDS assessment and review (long waiting times are evident, especially for reviews – problem compounded by length of assessment tool, variants of tool; and an additional meeting, compared with previous custom);
- Non-emergency community occupational therapy services (increasing demand for service, primarily due to people living longer and an evolving shift away from building based towards more home and local community based service provision);

- Specialist residential care homes for people with severe and complex physical disability elated problems (placements taken up by people with co-occurring learning disability and physical disability/severe and complex problems);
- Supported housing for relevant people with physical disability and sensory impairment, as part of a wider housing options issue.

Several professionals also commented on a lack of communication support for people with sensory impairment.

The following services were generally reported as having under capacity to varying levels:

- Capability Scotland's Advice and Support service [mixed views] (information shortcomings have been previously highlighted in this report; and several stakeholders mentioned the need to roll out the peer counselling service);
- Carers of West Lothian in terms of attendance at their carer support groups;
- MECOPP Carers Centre in terms of lack of demand for service, coupled with logistical/practical challenges of actually providing the service;
- Respite day care at Cornerstone's Uphall Care home; and
- Eliburn Day Centre for people with co-occurring learning disability and physical disability;

Several study informants also raised transport issues in terms of the cost, inefficiencies and lack of competitive tendering for the council's in-house service which may yield improvements as well as financial savings.

5.18.6 Interventions or services identified as needed, but not currently provided

In a similar vein to issues highlighted by service users and carers, several staff informants raised the importance of adding social type purposeful activities as part of service delivery. This is currently lacking.

Befriending services was another area which professional stakeholders would like to see expanded throughout West Lothian.

As mentioned previously in this report; and again consistent with the views expressed by several staff also highlighted the lack of peer support, peer led networks and mutual aid/self-help groups. Peer ambassadors/champions were suggested as a way forward, although there is likely to be funding required to develop this type of initiative which is more commonplace in other health and social care sectors such as mental health recovery and alcohol/drug recovery.

There is a need to provide more and better prevention and early intervention services and activities for people with physical disability and sensory impairment; and their carers.

There is a further need to improve transitions between children and young people services and adult services; and adult services and older people services.

There can be improved use of new media.

5.18.7 Resourcing of services for people with physical disability and sensory impairment

Most service providers expressed the view that additional monies could or essentially would address capacity issues, where applicable; and support service expansion, quality improve, outcomes for people with physical disability and sensory impairment; and their carers. However, senior managers consulted in particular were more pragmatic in their outlook. Commonly expressed solutions by seniority centred on the following key themes:

- Making efficiency savings through multiple linked endeavours including:
- Lean management;
- Integration including Lothian wide;
- Co-location;
- IT migration/compatibility;
- realism in terms of number, range and scope of services;
- Efficient practice, whilst maintaining quality and consistency; and
- Efficient business practice concerning sharing information, joint training, eradicating hospitality and sharing offices
- Lower reliance on building based services;
- Ending Increased emphasis on lower threshold services, where appropriate; including prevention and early intervention;
- Evaluation of services to determine effectiveness, cost effectiveness and wider impact;
- Rationalisation or mothballing of services that are ineffectual, consistently operate with voids/are under capacity or simply no longer affordable;
- Reviewing and addressing transport challenges including cost of in-house transport service which ferries service users to structured day services such as the Ability Centre and Eliburn services;
- Better linkage with the wider system and strategy including housing options and employability;
- Improved performance and accountability.

Professional stakeholders at all levels highlighted the benefits including perceived cost-effectiveness of the following key themes:

- Promoting and helping facilitate independence;
- Promoting self-responsibility and management;
- Ending the culture of dependency on services, where appropriate;
- Addressing the imbalance between statutory led services and contracted out services – in due course, some current in-house services or part therein should be competitively tendered;

- Embedding service user involvement in all aspects of the system including service re-design, delivery, development and evaluation;
- Expanding user/peer led networks and initiatives; and mutual aid/self-help support groups, firmly embedded within integrated service provision/practice;
- Expanding carer user involvement in all aspects of the system including service re-design, delivery, development and evaluation;
- Passing responsibility for carer assessments to Carers of West Lothian which will be cheaper to administer;
- Developing and executing a fit for purpose and fair commissioning plan based on evidence, assessed needs, quality and value; and
- Jointly creating a new vision, underpinned by thinking out the box and doing things differently but better.

5.18.8 Groups not well catered for

The following groups were identified by professional stakeholders as not well catered for:

- Young adults with physical disability and sensory impairment in transition from children and family services to adult services due to reduced levels and types of support, implemented quickly;
- People with physical disability and co-occurring mental health and/or substance misuse problems;
- People with sensory impairment (mixed views);
- People with an acquired brain injury;
- People with severe and complex problems who require long term residential care.
- Carers who are elderly and fragile/infirm/unwell, suffer from a physical disability/sensory impairment or long term condition such as dementia and who are no longer sufficiently able to cope with the demands of caring;
- Supported people who lose lifelong/long term carers through ill health, hospitalisation, entry to a care/nursing home or bereavement and struggle to cope with the resultant trauma of such a transition;
- People with physical disability requiring re-housing due to lack of suitability of current home – the issue is compounded by a lack of suitable alterative house and a finite and pre-determined constrained budget; and
- Prisoners in custody with severe and complex problems [outwith scope of needs assessment, but relevant to mention].

5.18.9 Accessibility of physical disability and sensory impairment services

Contributors highlighted a series of issues concerning accessibility of services, many of which are covered in earlier parts of this chapter. These include, but are not limited to:

- Lack of information about services for people with physical disability and sensory impairment; and their carers;
- A 9-5, Monday to Friday culture which is service driven; and not based upon the assessed needs, aspirations and assets of service users and potential service users;
- Services are willing to be more flexible, if customer demand backs up the need to change; however, consultations, trials/pilots and former practices have been tried and tested; and found to not work that well;
- The need for greater service user and carer involvement at all system levels (from practice to social policy/planning); and
- The fundamental transport challenges and huge financial costs associated with escorting many people with physical disability to the Ability Centre and Eliburn day services on a daily basis (Monday-Friday).

On a more positive note, several stakeholders felt that services are accessible, welcoming, vibrant, flexible, person centred and invaluable in supporting independence and life gratification. One particular informant summed this up nicely:

> *'If the Ability Centre did not exist, it is not only vulnerable people who need ongoing and possible indefinite support that will die; the system itself will collapse like a pack of cards.'*

Several other staff member spoke positively about:

- Professionalism of staff;
- Dedication/commitment and enthusiasm of staff;
- Importance, relevancy and usefulness of staff training and qualifications;
- Competency of staff;
- Practice cultures of learning, continuous improvement, change/adaption
- Improved regulation of social care/health;
- Integration;
- Partnership working;
- Client/person-centredness; and
- Outcome focus.

5.18.10 Integration of physical disability and sensory impairment services

The vast majority of staff members consulted as part of the needs assessment have knowledge of the integration agenda in West Lothian to some extent. This knowledge includes the overarching integration of health and social care in line with legislation, national social policy and local planning, as well as how specialist physical disability and sensory impairment services inter-connect and link with generic services. Whilst recognising that all professional stakeholders expressed the view that they personally embrace integration, study informants highlighted a range of challenges associated with high level and ground level integration. A few selected examples are:

- Whether there is a real appetite for integration in West Lothian – the system and Scottish Government require health and social care integration; however, is the agenda 100% embraced and fully committed to by all partners;
- There are cultural and philosophical differences, issues and sometimes problems and disputes within large public bodies like local authorities and NHS Boards which can hinder integration – in earnest, there is a legacy of directorate/departmental bias, vested interest, self-sufficiency/satisfactoriness, superiority and even egotism at play which needs to be overcome;
- The types of cultural and philosophical differences aforementioned are more apparent when the two main statutory bodies (West Lothian Council and NHS Lothian) attempt to combine resources in terms of money and people, in this order; as well as services - through a process of coming together, uniting; and ultimately trying to 'stay together and work happily ever after';
- There are integration challenges within the third sector itself:
- Some of this comes down to an organisation's vision and aspirations concerning diversification, expansion and growth;
- Some of this centres on competition and the management of such;
- Other challenges centre on a growing trend of large national providers with robust infrastructures 'eating up' smaller, local providers;
- Whilst other factors include perspectives of and relations between the private and voluntary sector.

There is no doubt that there is a need for better joint working, but these initiatives and structures have to be set against the scale of the challenges. According to Hudson[116] (2014), these are the 6 six 'big ones':

- Moving from horizontal to vertical integration;
- Moving from institution-centred to community-centred relationships;

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[116] Bob Hudson, *The six challenges of joint working*. Guardian Professional, 2/14.

- Moving from an economic to a quality focus;
- Moving from an organisational to a user-centred perspective;
- Moving from structural change to cultural change; and
- Moving from statutory to inter-sectoral partnerships.

A developing solution for West Lothian to consider in respect of physical disability and sensory impairment integration might be a Public Social Partnership (PSP). A PSP is a strategic arrangement which embeds the third sector; and thereby the needs and assets of people and communities in all stages of the design and delivery of public services. A PSP involves public and third sector bodies co-designing services or interventions to deliver agreed social outcomes. This approach encourages effective partnership working across sectors, places the third sector at the heart of service design and delivery, and explicitly emphasises outcomes rather than activity.

The third sector has known for a long time that it makes sense to include people in the design and delivery of the services they use. The whole service user-led movement is based on that understanding. Prompted by some of the learning from England (*Total Place pilots*); and spurred on by the thinking within the Christie Commission[117] on the future delivery of public services, the public sector increasingly recognises the long-term benefits of engaging meaningfully with people and communities in the design and delivery of services they use.

The Scottish Government, too, is keen to encourage a range of approaches which enable people and communities to have greater agency and voice. A PSP is one way for public sector planners and commissioners to engage earlier and more deeply with third sector agencies acting in the interests of the people they serve. This approach puts people at the heart of service design and delivery. Once designed and trialled, such services can then be commissioned for the longer term through a competitive tendering process.

It is pertinent to illustrate a couple of examples of PSPs.

In collaboration with NHS Lothian, Edinburgh Council, Queen Margaret University and the third sector, the *Royal Edinburgh Hospital campus redevelopment programme PSP* (2012) has been identified as a major opportunity to redesign services through the collaborative application of the PSP model. With support and guidance from Ready for Business, two work streams of activity are underway and beginning to reshape the way that health services are delivered.

The *Life I Want PSP* was initiated in 2013 and committed to the modernisation of day services in Glasgow for adults with learning disability. This commitment is not only a response to SDS legislation, which is designed to enable service users to exercise choice and control over their care and support arrangements, including choice of provider; but also because it was clear to partner organisations that services needed to change to meet the aspirations and needs of the people who use them.

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[117] Dr Campbell Christie CBE. *Commission on the Future Delivery of Public Services*, Scottish Government. 6/11.

5.18.11 Asset mapping: other assets, resources, groups, individuals and opportunities to support people affected by physical disability and sensory impairment

The term 'asset mapping' is not well understood among study informants including professional stakeholders. However, the authors explained asset mapping in the context of community based assets, resources, groups, individuals and opportunities to support physical disability and sensory impairment and independence.

All staff consulted endorse SDS and personalisation and the aspiration of independence for people. Staff also support helping approaches related to self-management, peer support (helping others/providing service through 'giving is gain'), service user engagement, carer engagement, disability networks, purposeful activities, forging and sustaining friendships/alliances, etc. However, in West Lothian there is sporadic service user involvement, limited structured peer support, a lack of mutual aid/self-help support activity and no coordinated user network for disabled people.

People with a physical disability and sensory impairment are still faces the nature and level of challenges as they have experienced in recent years. The voices of disabled people are still there but are possibly being inhibited slightly by the system. For example, the Disability Equality Forum which evolved from the previous Disability Forum last met in January 2015 which is unacceptable, given that this is the main forum for service users to provide feedback on issues facing disabled people; and how to combat these in a successful and sustainable way.

On a brighter note, a fine example of a community asset is the Vision Support Group which, despite being self-funded for the most part (NB: a small grant of approximately £750 was made to the group in 2013 to develop and publish marketing literature), has big ambitions including examining the feasibility of setting up a social enterprise. On a simpler level, group members iterated the importance of social activities including discovering the treasures of West Lothian's countryside, towns and villages. Numerous study consultees, staff, service users and carers alike; have iterated the importance of social integration as part of a support plan. However, it seems that these conventional types of activities are becomingly increasingly obsolete. One particular manager remarked:

> *'Before we know it, we will be banning giving clients a cup of tea on the grounds of health and safety; or because it is deemed as hospitality or unaffordable – that's independence for you, alright!'*

5.18.12 Physical disability and sensory impairment; and independence

All staff declared that services and the wider system practice and promote a philosophy of independence, in line with SDS and integration priorities. However, this changing and developing culture is difficult to grasp for many service users and carers, as well as some staff; especially at practitioner level. As an important digression (or perhaps this is not the case), there is a lack of understanding among 'all' groups of study informants (professional stakeholders, service users, non-service users and carers) regarding the definition or meaning of 'independence'. In fact, definitions are so widely encompassing that it is difficult to argue the case for any single, accepted and valid definition of the term.

Dictionary.com (http://dictionary.reference.com/browse/independence) defines independence in one of 3 ways:

- The state or quality of being independent;
- Freedom from the control, influence, support, aid, or the like, of others; and
- A competency.

These meanings are, of course, all germane to the context of health and social care for people with physical disability and sensory impairment in West Lothian. However, these meanings are not only diverse, but very different.

5.18.13 Service user involvement

As previously highlighted throughout this chapter, service user involvement in respect of physical disability and sensory support is currently sporadic in West Lothian. Whilst recognising positive examples of service user involvement within the operating practices and cultures of specialist service providers such as Disability West Lothian and Capability Scotland, there is ample room for improvement at a system wide level. A particular issue concerns lost momentum of the Quality Disability Forum which last met in January 2015. This forum is an important vehicle for service users and carers of disabled people making their voices heard regarding issues affecting them and others; and associated potential solutions.

Moving forward; and taking account of national priorities and drivers including those concerning SDS and personalisation, the scope and level of service user involvement in West Lothian should be given the utmost priority in physical disability and sensory impairment system delivery and development. Service user involvement should be a key feature of any future West Lothian disability strategy; and which this needs assessment report should support. More importantly, service user involvement should be the cornerstone and fully embedded in physical disability and sensory impairment commissioning and service/practice culture in West Lothian due to the benefits for service users, their carers, service providers and commissioners.

This section should also be read in conjunction with **6.21.13** and **6.25.14** which sheds light on the views of service users and carers regarding service user involvement.

5.18.14 Carer involvement

Carers are fairly well embedded in the West Lothian health and social care system for people with physical disability and sensory impairment; however, there is room to further consolidate this baseline. In terms of practice, some carers highlighted the requirement to ‘bang down doors’ to enable then to fully participate in decision making about the supported person’s care; and when there are disagreements or disputes regarding the level of support and associated budget allocated by the social work led SDS related team.

Carers assessments seem to be lacking, primarily due to these being carried out by social work, as opposed to another provider such as Carers of West Lothian. It is commonplace in many Scottish regions for the local carer centre/organisation to carry out this function which may increase the number of carer assessments conducted, better support carers and be a more cost effective solution during a long term period of austerity.

Based on the evidence gathered, Carers of West Lothian are a dynamic, inspired, credible, integrated and important partner in the physical disability and sensory impairment system in West Lothian. However, despite their creative endeavours, the uptake at carer support groups and other organised events is sporadic and would benefit from greater participation by carers, despite some practical challenges for single carers, who sometimes suffer from ill health and disability themselves.

In a similar vein, the MECOPP service which supports minority ethnic carers needs to become better know and more integrated in the system; and support what is often a hidden population. There could also be improved relationships between carer organisations, as well as local advocacy service providers.

5.18.15 Client outcomes and customer satisfaction ratings

Perceptions in terms of client outcomes and customer satisfaction ratings among the professional workforce consulted in the qualitative fieldwork of the needs assessment are diverse. Some staff reported client outcomes and customer satisfaction ratings as overwhelmingly positive based on their involvement in helping to deliver or manage support packages for people with physical disability. Other staff reported the exact opposite which highlights polarisation of expressed views.

Several staff spoke of the need to develop robust recording systems at service, organisational and commissioner levels to ensure accurate and consistent collation, analysis and reporting of outcomes for supported people and their carers. The need for a fair playing field was also advocated; which the authors interpret as relating measurables identically to statutory and third sector service providers. The need to align local outcomes and other measures to National Outcomes and National Indicators was also reinforced.

Finally, perusers (and examiners) will see the self-reported results of service users and carers in respect of this fundamental theme as they read through **6.12.14** and **6.12.15**. Responses to the follow questions posed are interesting, gripping and perhaps persuasive:

- Q1) The extent to which needs are being met/have been met; and
- Q2) The level of customer satisfaction.

5.18.16 Gaps and wider issues linked to change, service improvement and future basing

Professional stakeholders identified numerous gaps and other key issues that, if successfully prioritised and tackled, should lead to change and service improvement. Most of the gaps and wider issues in this section have already been explored in earlier parts of this chapter. Common themes in terms of gaps, issues and solutions (improvement areas) are outlined in bullet below:

- There is benefit in developing a West Lothian physical disability and sensory impairment plan with emphasis on the total system, as well as outcomes;
- There is an elementary need to adhere to the principles of SDS and personalisation;
- There is a lack of funding for certain commissioned services which results in capacity issues, long waiting times and a risk of diluting the quality of services;
- There is a lack of information and knowledge about specialist physical disability and sensory impairment services;
- There is an imbalance of provision among service providers which is not the ethos of a partnership model in the making – the public bodies, West Lothian Council and NHS have a disproportionately high number of services and share nearly all of the budget pot – the third sector have more to offer, if given the chance;
- Collaboration and co-production is key;
- There is a lack of services and choice for people with a physical disability and sensory impairment – if you take away the Ability Centre, there is little else left - retention of structured day services is fundamental [mixed views];
- Day care services are well established, although there may be too many of them across combined physical and learning disability services – these services are largely building based, inflexible and need to rationalised according to some [mixed views];
- Flexible service options are required, taking account of constrained budgets, service user, carer and staff perspectives;
- There is an ongoing shift towards personalised care (which may or may not include day care);
- There are limited prevention, early intervention and lower threshold services for people with a physical disability and sensory impairment;
- There are limited services for people with severe and complex needs;
- Some services are under capacity, whilst others are above capacity;
- Social activities are lacking, despite high levels of demand;
- There is a necessity to eradicate the 9-5/Monday-Friday syndrome to improve accessibility of services;
- The entire disability workforce, including statutory and non-statutory appears largely immobile, with little cross-fertilisation between physical disability and learning disability;
- There are long waiting lists for SDS assessment and review;
- Service integration is not too bad and improving - providers are generally working collaboratively and it seems West Lothian is 'ahead of the game';

- Improving transitions between children and family, adult and older people services is a key priority;
- Improving the interface between specialist physical disability/sensory impairment and hospital based services is another main concern;
- There is a lack of physical disability and sensory impairment peer led network/movement;
- Service user involvement can be improved, as can carer involvement and advocacy involvement – resurrect Equality Disability Forum;
- Recruiting more volunteers including people with physical disability and sensory impairment would add mutual value;
- Improve linkage with generic services, especially housing and employability;
- Improve IT compatibility, especially between health and social care (West Lothian Council and NHS Lothian);
- Client outcomes need to be better collated, analysed and reported upon;
- Evaluate services to establish their effectiveness and value; and help inform future commissioning of services;
- Commissioning needs to be based on accurate and up to date evidence and research - joint commissioning is already reasonably well established in West Lothian; however, no service user or carer was involved in redesigning and commissioning the West Lothian Disability Advice and Support service;
- Review cost-effectiveness of transport arrangements; and
- Continually learn and improve, adopting a genuine and successful partnership approach to service design, delivery and development.

5.19 Key findings

This section summarises specific key findings from the sixteen themes outlined in **5.18**:

- Relationships at all levels are generally good (**5.18.1**);
- The role of Service Development Officer (Physical Disability) is seen as important and effective (**5.18.1**);
- The level of knowledge of; and information concerning current physical disability and sensory impairment services in West Lothian is poor, inadequate and unacceptable. (**5.18.2**);
- Capability Scotland’s Advice and Support Service is best placed to coordinate information for all disability services in West Lothian (**5.18.2**);

- The Lothian Joint Physical and Complex Disability Strategy, *Our Lives Our Way*[118] (2007), outlines the needs of disabled people in Lothian and the vision for the future delivery of services and support (**5.18.3**);
- West Lothian Council Strategic Service Statement for physical disability aims to set out how services will be developed and delivered over the next 3-10 years to meet the current and potential needs of adults experiencing physical and complex disability (**5.18.3**);
- Current management of people with physical disability and sensory impairment in West Lothian is underpinned by SDS assessment and case management by an integrated health and social care (disability) team **(5.18.3)**;
- The Physical Disability Assessment Team provides an assessment and care management service to adults aged between 16 and 65 years with a physical disability - the team can arrange care in a supported person's own home, community based support or residential care **(5.18.3)**;
- Carers who provide regular and substantial care to someone with a disability can also request a Carer's Assessment **(5.18.3)**;
- The ethos of service provision for people with a physical disability and sensory impairment focuses on a number of key principles (**5.18.4**);
- The Ability Centre is Livingston is essentially the central hub of activity for people with a physical disability (**5.18.4**);
- A number of services appear over capacity (demand currently outweighs availability), whilst others are under capacity (**5.18.5**);
- There appears a lack of communication support for people with sensory impairment (**5.18.5**);
- Transport is a particular challenge in terms of cost, inefficiencies and lack of competitive tendering (**5.18.5**);
- Supported housing options are limited for people with physical disability and sensory impairment(**5.18.5**);
- A number of interventions and services identified as needed, are currently not or under provided including social type purposeful activities, befriending services, peer support and peer led networks and mutual aid/self-help groups (**5.18.6**);
- There is a lack of prevention and early intervention services and activities for people with physical disability and sensory impairment; and their carers (**5.18.6**);
- There is a need to improve transitions between children and young people services and adult services; and adult services and older people services (**5.18.6**);

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[118] *Our Lives Our Way*, The Lothian Joint Physical and Complex Disability Strategy, NHS Lothian, City of Edinburgh Council, East Lothian Council, Midlothian Council, West Lothian Council, 3/07.

- It is generally viewed that additional monies would address capacity issues, where applicable; and support service expansion, quality improve, outcomes for people with physical disability and sensory impairment; and their carers (**5.18.7**);
- A set of identified specific key themes (n=10) are seen as beneficial and cost-effectiveness (**5.18.7**);
- Specific groups (n=9) are currently well catered for (**5.18.8**);
- There are mixed views concerning the accessibility of services (**5.18.9**);
- There are also mixed views concerning the current and emerging status of integration, although all stakeholders embrace integration; whilst acknowledging known challenges (**5.18.10**);
- There are developing models of integration such as Public Social Partnerships which West Lothian CHCP can examine/consider (**5.18.10**);
- The term ‘asset mapping’ is not well understood among study informants (**5.18.11**);
- West Lothian services and the wider system practice and promote a philosophy of independence, in line with SDS and integration priorities (**5.18.12**);
- The scope of definition of independence is diverse in nature (**5.18.12**);
- There is a general lack of service use involvement in West Lothian (**5.18.13**);
- Career involvement in West Lothian is improving, a trend that should continue (**5.18.14**);
- Perceptions in terms of client outcomes and customer satisfaction ratings among the professional workforce are diverse (**5.18.15**);
- There is a need to better and consistently collate, analyse and disseminate information and data, particularly related to client outcomes; aligned to National Outcomes and National Indicators (**5.18.15**); and
- A set of gaps and other key issues (n=30) have been identified and considered as solutions if successfully prioritised and tackled; leading to change and service improvement. (**5.18.16**).

CHAPTER 6: QUALITATIVE APPROACH (FELT AND EXPRESSED)

6.1 Introduction

The purpose of this element of the research was to seek the views from service users and carers on the current provision of specialist physical disability and sensory impairment services across West Lothian. Specifically, service users and carers were asked to provide their views on the quality of services, key issues, gaps and areas for improvements.

Findings in the first part (**6.2-6.9**) of this chapter derive from quantitative surveys which were distributed to service users across West Lothian during June 2015; with the aid of physical disability and sensory impairment service providers. There were two identical versions of the survey used; namely an online version and a hard copy version.

Findings in the second part (**6.10-6.17**) of this chapter derive from quantitative surveys which were distributed to families and carers across West Lothian during June 2015; with the aid of carer and physical disability and sensory impairment service providers. There were two identical versions of the survey used; namely an online version and a hard copy version.

Findings in the third part of this chapter (**6.18-6.21**) derive from four service user led[119] focus groups held in June 2015; and a carer focus groups held in June 2015.

Findings in the final part of this chapter (**6.22-6.25**) derive from the views of service users and carers expressed through a stakeholder event on 20 May 2015, two working group meetings held on 27 May 2015 and 6 June 2015; and two interviews held on 3 June 2015 and 8 June 2015.

A summary of key findings from chapter 6 is outlined in section **6.26**.

A standalone report encapsulating views of people with and affected by a sensory impairment, together with professional staff accompanies this final report.

6.2 Service user survey - response rates

There were **92** responses to the service user survey and therefore the overall total of responses used for analysis was **92**, and are broken down as follows:

- 44 out of 92 (47.8%) responses were deemed ‘complete’, as 100% of questions were answered by respondents.
- 48 out of 92 (52.2%) responses were considered ‘incomplete’, as:
- 46 of 48 respondents completed 50%-99% of the survey;
- 2 of 48 respondents completed 25%-49% of the survey.

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[119] Carers attended all 4 focus groups, although these were primarily user led by design and practice.

6.3 Limitations

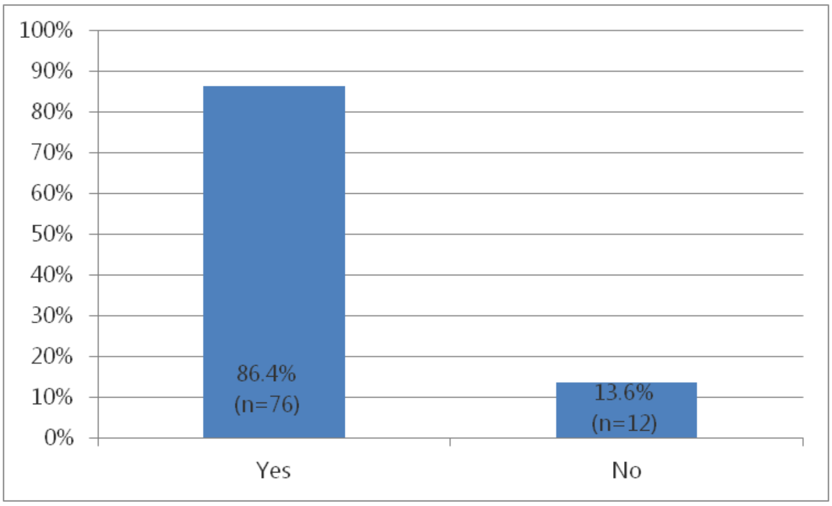
- One limitation is in respect of the varied quality and depth of responses given
- Another limitation is that 52.2% of surveys were only partially completed; therefore some care should be taken when interpreting these findings.
- Although, the survey was an important element of the study, the above limitations mean that the strength of the evidence gained through the survey is restricted. In light of this, the evidence gathered from service users through the varied qualitative elements of the study is deemed to be stronger and has been given greater consideration when forming the conclusions and recommendations of the study.

6.4 Demographics

6.4.1 Diagnosis

The majority (86.4%; n=76) of respondents indicated that had a physical disability, mobility loss or long-term condition which had a significant and lasting (i.e. has a lasted or is expected to last at least 12 months) impact on their ability to carry out day to day activities.

Figure 6.1: Breakdown of respondents who have physical disability, mobility loss or long term conditions



Respondents were asked to provide more details if they indicated that they had a physical disability, mobility loss or long term conditions. There were a number of key themes that emerged. Respondent's comments sometimes reflected multiple problems and each one is treated separately in this analysis. The different 'diagnosis'/problems identified were:

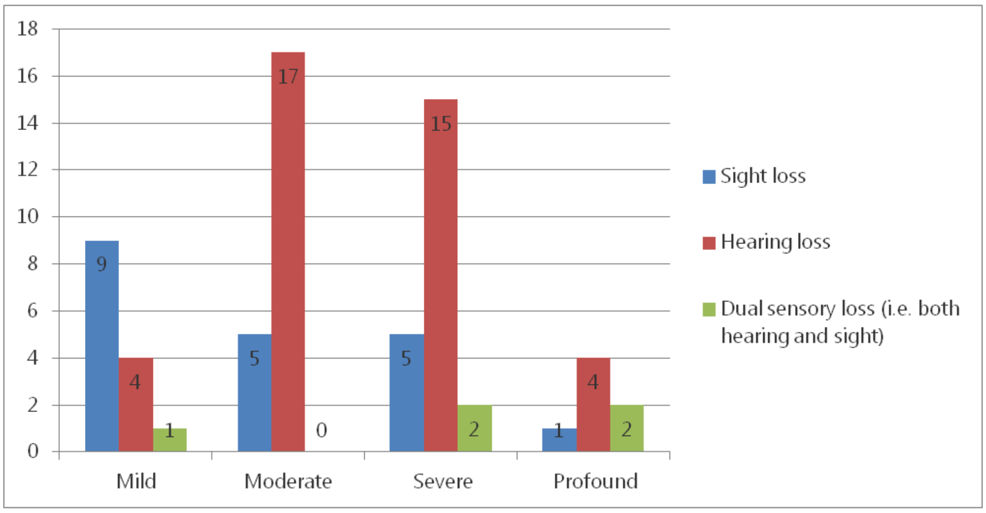
- 19 respondents stated that they had hearing loss
- 11 respondents had experienced a stroke

- 10 respondents had a diagnosis of Arthritis
- 9 respondents had Cerebral Palsy
- 8 respondents stated that they had mobility problems
- 5 respondents had sight loss
- 4 respondents had both sight and hearing loss
- 2 respondents had Spina Bifida
- 2 respondents had a diagnosis of Parkinson’s
- 2 respondents had muscular dystrophy

Other conditions/mobility problems/physical disabilities mentioned by respondents were:

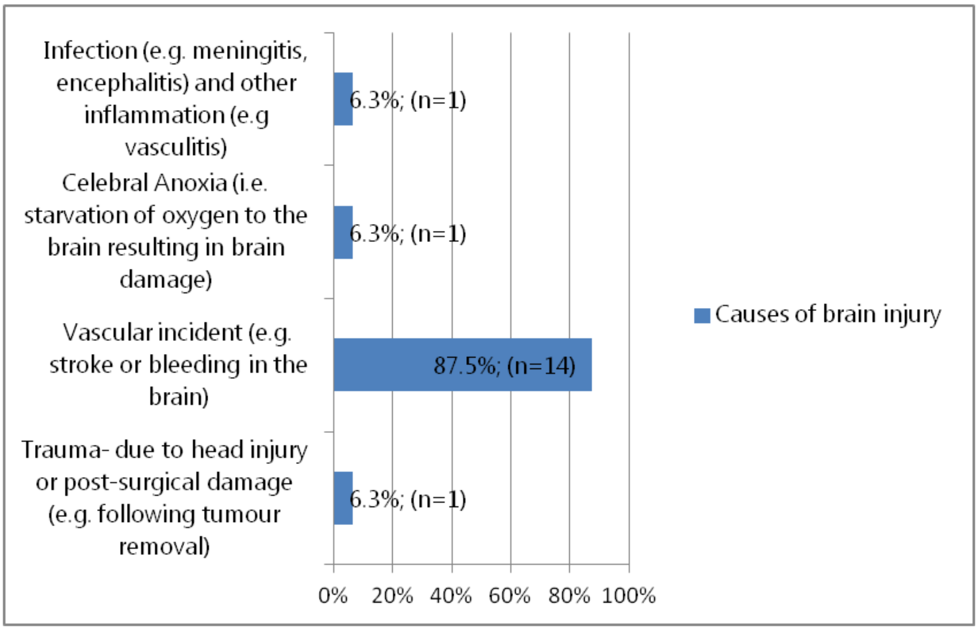
- Osteoporosis (n=1); Huntington disease (n=1); Korsakoffs (n=1); Tuberculosis (n=1); Severe back pains (n=1); Brain haemorrhage (n=1); Orthopaedic problems (n=1)
- 17 respondents stated that that they experienced moderate hearing loss, this was followed by 15 respondents indicating that they experienced severe hearing loss. Nine respondents had ‘mild’ sight loss.

Figure 6.2: Breakdown of respondents by a type of sensory loss



Respondents were asked if they had been diagnosed with a brain injury, to specify what caused the brain injury they had experienced. 87.5% (n=14) of respondents had experienced a vascular incident (e.g. stroke or bleeding in the brain).

Figure 6.3: Breakdown of respondents by cause of brain injury experienced

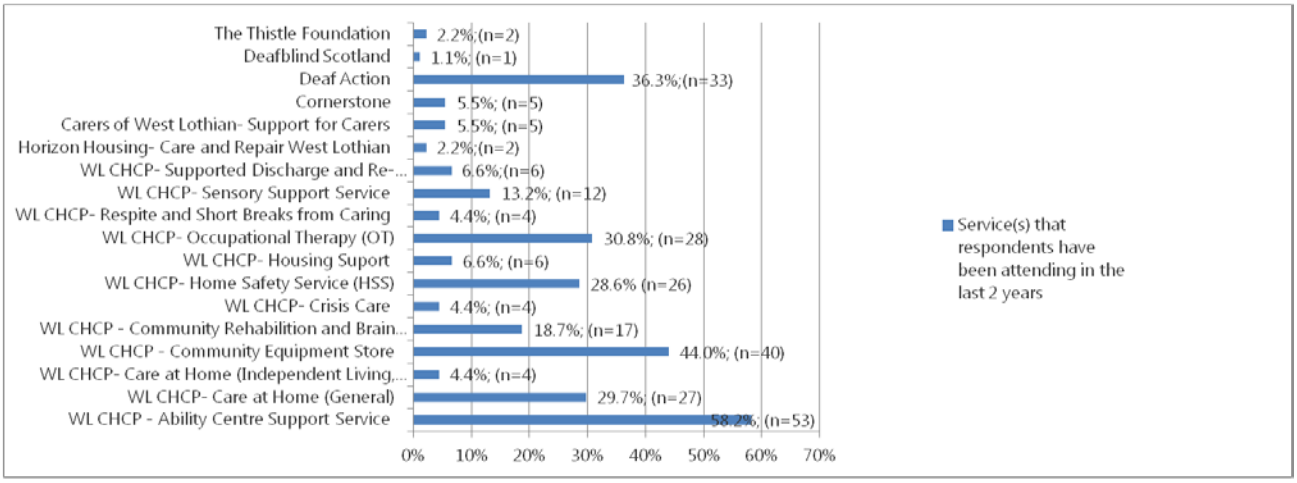


6.5 Services

6.5.1 Services recently attended (within the last 2 years) or currently attending

Respondents were asked to specify what services they have attended within the last two years. Respondents were able to choose more than one service. The majority of respondents indicated that they had attended the WL CHCP Ability Centre Support Service (58.2%; n=53); this was followed by the WL CHCP Community Equipment Store. Only one respondent had attended Deafblind Scotland and two respondents had attended the Thistle Foundation.

Figure 6.4: Services that were attended by respondents in the last two years



*WL CHCP = West Lothian Community Health and Care Partnership

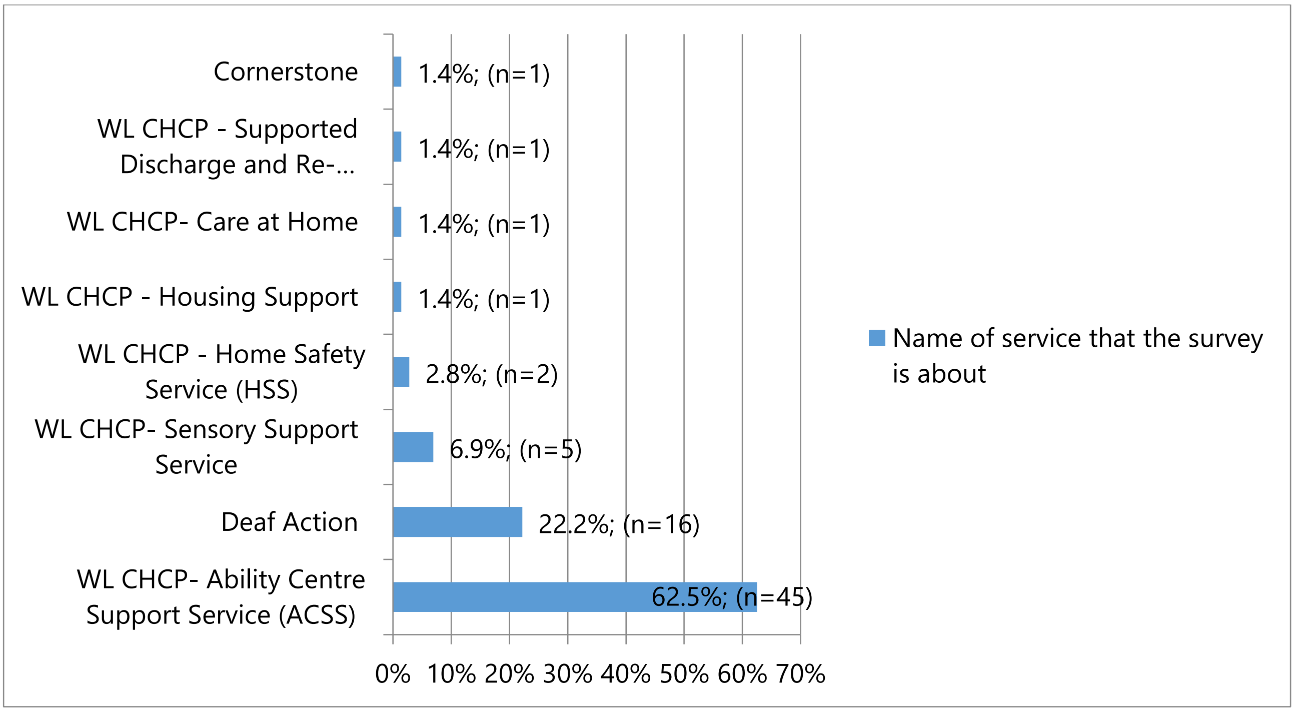
There were no respondents indicating attendance at the following services within the last two years:

- Freespace Scotland
- MECOPP
- Royal National Institute for the Blind (RNIB)
- Rotary Residential and Care Centres
- Share Scotland

6.5.2 Service which survey response is in relation to

Respondents were asked to specify the service which they were answering the remainder of the survey questions about. The majority of respondents were answering the survey about the Ability Centre Support Service (ACSS) (62.5 %; n=45).

Figure 6.5: Services that respondents were answering the survey about



Respondents were able to provide the name of other services which they were answering the survey about. The following service names were provided:

- 14 respondents didn’t state what service they were referring to
- Lip Reading Classes (n=4)
- Deaf Aid (n=2)

- Ear, nose and throat department- St John’s Hospital (n=1)
- Careline (n=1)
- Heatherfield Care (n=1)
- Physiotherapy (n=1)

There were no respondents who answered the survey about the following services:

- WL CHCP – Care at Home (Independent Living, Specialist & Housing Support)
- WL CHCP- Community Equipment Store
- WL CHCP- Community Rehabilitation and Brain Injury Service (CRABIS)
- WL CHCP- Crisis Care
- WL CHCP – Occupational Therapy (OT) Service
- WL CHCP Respite and Short Breaks from Caring
- Horizon Housing – Care and Repair West Lothian
- Carers of West Lothian
- Deafblind Scotland
- Freespace Scotland
- MECOPP
- Royal Institute for the Blind (RNIB)
- Rotary Residential and Care Centres
- Share Scotland
- The Thistle Foundation

6.5.3 Extent that respondent agreed/disagreed with statements about service(s)

Survey respondents were asked indicate whether they agree or disagree with a number of statements about the service which they are answering the survey about by using the following rating scale:

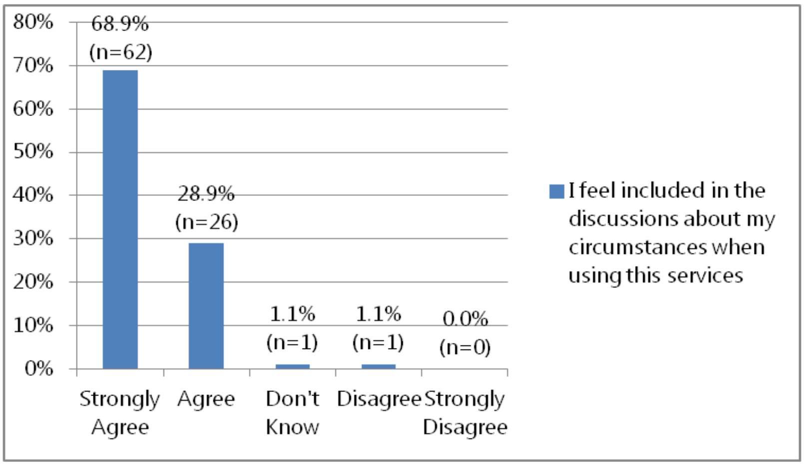
- Strong Agree
- Agree
- Don’t Know
- Disagree
- Strongly Disagree

The following figures provide breakdowns of the extent that respondents agreed or disagreed with the following statements:

- ‘I feel included in the discussions about my circumstances when using the service.’
- ‘The staff treat me with care and concern.’
- ‘I have confidence and trust in the staff of this service.’
- ‘I feel safe using this service.’
- ‘Overall, I feel that my experience of using this service is good.’

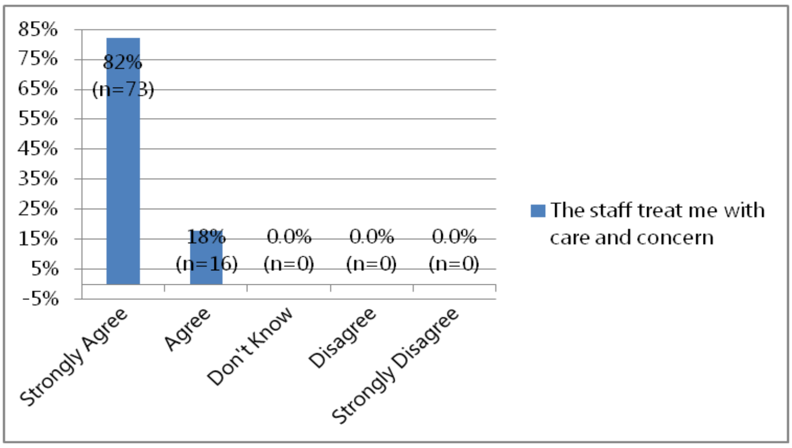
Almost 70% (68.9%; n=62) of services users agreed that they felt included in discussions about their circumstances using the service. One respondent (1.1%) disagreed with this statement and one (1.1%) respondent said they didn’t know.

Figure 6.6: Extent that respondents agreed with the statement ‘I feel included in the discussions about my circumstances when this service’



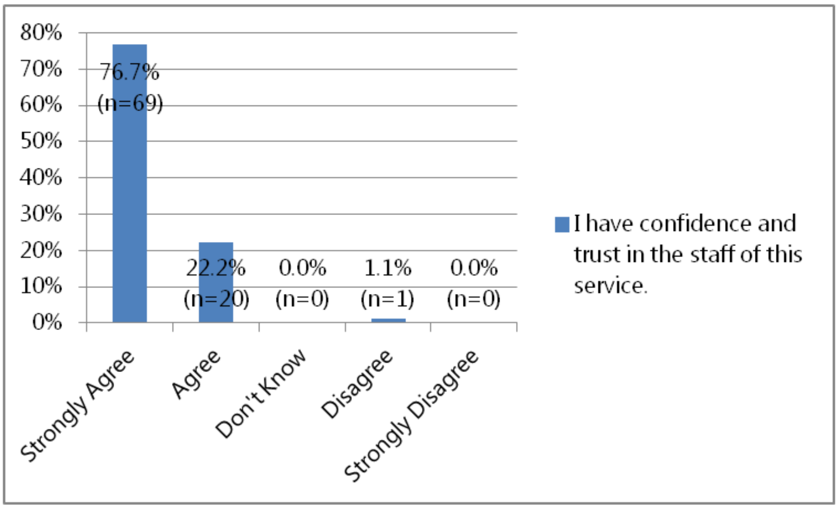
Respondents were mostly in agreement with the statement that staff treat them with care and concern, with 82% (n=73) strongly agreeing at 18% of respondent agreeing with this statement.

Figure 6.7: Extent that respondents agreed with the statement ‘The staff treat me with care and concern’



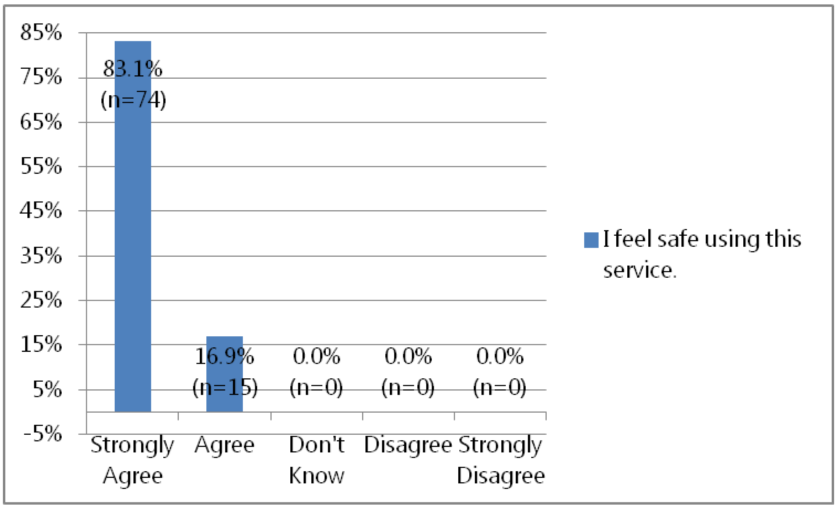
Just over three quarters of respondents (76.7%; n=69) strongly agreed that they have confidence and trust in the staff of the service they are attending and 22.2% (n=20) of respondents agreed with this service. Only one respondent (1.1%; n=1) disagreed with this statement.

Figure 6.8: Extent that respondents agreed with the statement 'I have confidence and trust in the staff of this service'



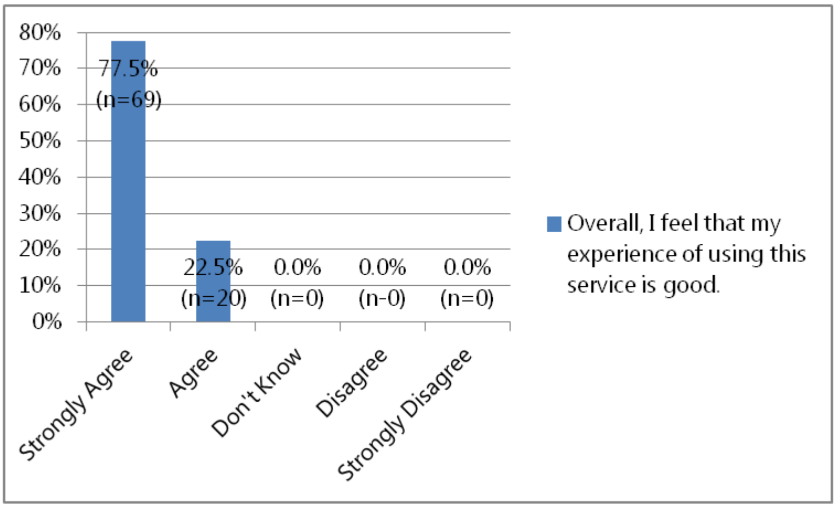
83.1% (n=74) of respondents strongly agreed with the statement "I feel safe using this service", and 16.9% (n=15) agreed with this statement.

Figure 6.9: Extent that respondents agreed with the statement 'I feel safe using this service'



The majority of respondent felt that overall experience of using the service they were attending were good, with 77.5% strongly agreeing with the statement 'Overall, I feel that my experience of using this service is good.' No respondents were in showed disagreement with this statement.

Figure 6.10: Extent that respondents agreed with the statement 'Overall, I feel that my experience of using this service is good'



6.6 Quality of Services

6.6.1 What respondents like about services

Respondents were asked to specify what it was they liked about the service they are attending. There were a number of key finding that emerged. They were:

- A number (n=16) of respondents comments are in regards to the staff. Some of the commentary provided in relation to this theme is presented below:

> *'Great service, very helpful in identifying equipment to make my life easier and free of charge. Very nice staff. Had equipment on the day. They came to my home which was very easy for me.'*
>
> *'The team were very patient and kind and explained everything very well. They were really nice people whose company we enjoyed.'*
>
> *'Pleasant staff.'*
>
> *'The help and encouragement from staff.'*
>
> *'Friendliness of staff. They never get upset when I do things wrong (and cause extra work).Excellent support.'*
>
> *'I feel the staff are warm and welcoming towards me and I look forward to coming to the ability centre. I enjoy the activities that I am able to participate in.'*
>
> *'The staff are very nice and very helpful.'*
>
> *'Staff all very good.'*
>
> *'I like the staff they are all friendly, gets me out the house, learned new skills.'*

'All staff are very supportive and encouraged to be independent.'

'Words cannot express what this service has done for me, from then to present time. The staff are all fabulous, understanding, caring, skills, knowledge of their job, helpful. Not to forgot the restaurant staff. The volunteer workers + more. Importantly the people who they care for. To meet friends from all walks of life with different 'disabilities'. I'll never forget them.'

- A (n=4) few respondent comments reflect the efficiency of the service:

'Good and fast response.'

'Services was prompt, careful, detailed.'

'I was impressed by the installation team that fitted my loop system, they conferred well the F1 wheel change teams! They no sooner started installing the system which by the way has worked perfectly every day since, then they were leaving my home, an impressive team. I thank you for the help! Cheers.'

'When phoned about a problem, they are prompt and always endeavour to fix the problem.'

- Respondents (n=17) also liked the service due to the activities and social aspect offered by the service:

'Everything- the people- service users, staff - very, very nice. Activities.'

'I like the company at the centre and I like the relaxation classes.'

'Everything, socialising, doing activities and learning new skills.'

'This service provides me with an outlook on life as this has been relatively new to me. It has helped me to socially function within a different environment and the staff at the day centre has helped me in helping develop more in the functions that I can do and use without the day centre I would have been sitting in my house feeling depressed and cut off from the outside world.'

'I like getting out the house and meeting other people. I feel lonely at home.'

'Best things that's happened". Isolated at home and now look forward to my day out of the house.'

'Meeting people and trying new things.'

'I meet and talk to people in a friendly environment and get involved using skills.'

'It gets me out the house once a week to meet people and have conversation. It's the only time I get out of the house, it's an outlet for me.'

'The activities and the people.'

'Good to get out the house and mix with other people in a safe environment.'

'Day out the house and social aspect.'

'Because I like socialising and meeting new people. It makes me feel safe. It gives my mum some time to herself.'

'Meeting new people and making friends.'

'Going trips, quizzes, communication.'

'Variety of outing and activities.'

'To have the opportunity to get out of the house and meet other people. I really enjoy having the change to go on outings.'

- Other (n=16) comments provided by service users were:

'It is very helpful support group as well as good training lip-reading.'

'Helpful, understanding and listen.'

'Careline service check on me regularly through the box to make sure I'm okay, if there is something wrong they phone my daughter in law.'

'This service offers comfort and peace of mind to my whole family.'

'Courteous and helpful and very understanding of any problems or concerns that anyone may have.'

'Satisfying, genuine and kindness and get on with other clients. The service makes feel more genuine.'

'I like everything that is provided at this service.'

'I enjoy all aspects of coming to the centre.'

'Great to come here on a Monday. Made to feel welcome and part of the family.'

'Feelings of equality with client and support worker.'

'I know when I came in here I'm safe and get support with any problems. ("Leave my problems at front door").'

'It helps me to retrain my independence through support and interaction through activities.'

'Without help of making phone calls, writing letters and communication support, it would be very difficult to get things done.'

'Personal attention by tutor to all members of class.'

'Lip reading- Very friendly, good to share our experiences.'

'As I attend lip reading group I am kept up to date about what is happening. If I was not goodness knows where I would be. Sitting at home probably thinking my problems were only peculiar to me.'

'The teaching environment and method. The ability to try new technology. The attendees act like a support group.'

'Welcoming and very helpful attitude - no sense of being different.'

6.6.2 What respondents dislike about services

Respondents were asked to specify what it was they disliked about the service they are attending. Their responses are present below:

- 25 respondents stated that there was nothing they disliked about the service which they attend.
- Other (n=13) responses were:

'Not enough staff.'

'Occasionally not enough staff to help out.'

'Long waiting list.'

'Not enough staff.'

'Occasionally not enough staff to help out.'

'Any time I have tried to access help, it seems to take ages but that is only because one has urgent needs.'

'More bus outing offered.'

'Food could be improved, shorter journeys.'

'The entrance (Outreach community centre building).'

'They have no transport for respite users to be taken on day trips or outings.'

'Rather inflexible in attendance requirements.'

'Lack of communication.'

'Lack of publicity about the existence of this service. I have been attending audiology services and practitioners for more than five years before I found out about the Sensory Centre.'

'Sometimes things that are promised to happen get forgotten in the mists of time. Sometimes they need reminded and not everyone in our service likes to keep phoning to remind them!'

6.7 Carer survey - response rates

There were only 5 responses to the service user survey.

No quantitative analysis was possible due to lack of returns; however, a number of qualitative responses were made which have been incorporated into the following section of the report.

6.8 Limitations

One limitation concerning analysis of the service user survey element of the Needs Assessment centres on the partial completion of surveys by 78.3% of respondents; therefore some care should be taken when interpreting these findings.

6.9 Background to service user and carer focus groups

A total of five service user and carer focus groups were held in West Lothian in June 2015. The original intention was to jointly cater for both service users[120] and carers at each focus group. However, a carer specific focus group was held following a request from a carer organisation. Carers were represented in three of the four service user led focus groups.

A total of **30** service users and **13** carers participated in the five focus groups; broken down, as follows:

- Physical disability focus group, Ability Centre, Livingston, 28/5/15 (**n=17**):
    - 15 service users; and
    - *2 staff.*
- Vision support (sensory impairment) focus group, Ability Centre, Livingston, 3/6/15 (**n=11**):
    - 9 service users; and
    - 2 carers.
- Deaf & blind (sensory impairment) focus group, Sensory Support Service, Livingston, 8/6/15 (**n=12**):
    - 5 service users;
    - 1 carer;
    - *2 staff; and*
    - *4 communications support.*
- Deaf blind (sensory impairment) & physical disability focus group, Sensory Support Service, Livingston, 8/6/15 (**n=7**):
    - 1 service user;
    - 1 carer;
    - *1 staff; and*
    - *4 communications support.*

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[120] Service users in this context includes people who currently use services or have formerly used services – no known 'non service users', that is people who are eligible to use services and/or would benefit from using services, participated in the study's qualitative fieldwork.

- Carer focus group, Carers of West Lothian, Livingston, 10/6/15 (**n=10**):
  - 9 carers; and
  - *1 staff.*

6.10 Purpose of focus groups

The purpose of carer and service user focus groups was to find out:

- Views on current provision of services;
- Gaps in current provision;
- Views in relation to the nature and extent of future requirements; and
- Assets (groups, networks, individuals, etc.) across West Lothian.

6.11 Limitations of focus groups

The scope of the study, in terms of its qualitative methods, restricts the number of focus groups targeted (n=4) and delivered (**n=5**); together with the number of service users targeted (n=28) and delivered (**n=30**) and carers targeted (n=12) and delivered (**n=13**). However, the design limitation is offset by the study's additional methods including:

- Service user case study (n=2);
- Carer case study (n=1);
- Service user engagement at stakeholder event (n=2);
- Carer engagement at stakeholder event (n=1);
- Carer engagement at working group meetings x 2 (n=1):
- Interview with service user (n=1);
- Interview with carer (n=1);
- Service user survey; and
- Carer survey.

6.12 Focus group key findings

Findings in **6.21** derive from the views expressed by a total of 43 study informants (30 service users, 13 carers). The authors have identified sixteen themes, namely:

- What works well;
- Knowledge of current physical disability and sensory impairment and linked services in West Lothian;

- Current management of people with physical disability and sensory impairment in West Lothian;
- Ethos of services and types of interventions currently used;
- Capacity of services and interventions to meet presenting needs;
- Interventions or services identified as needed, but not currently provided;
- Resourcing of services for people with physical disability and sensory impairment;
- Groups not well catered for;
- Accessibility of physical disability and sensory impairment services;
- Integration of physical disability and sensory impairment services;
- Asset mapping: other assets, resources, groups, individuals and opportunities to support people affected by physical disability and sensory impairment;
- Physical disability and sensory impairment; and independence;
- Service user involvement;
- Carer involvement;
- Client outcomes and customer satisfaction ratings; and
- Gaps and wider issues linked to change, service improvement and future basing.

6.12.1 What works well?

This sub-section should be read in conjunction with **6.12.15** which elaborates on the themes of client outcomes and customer satisfaction.

Service users and carers explained what works well in relation to services that support people with and affected by physical disability and sensory impairment in West Lothian. Statistics outlined in **6.12.15** show that 57% (n=17) of service users self-report their needs are being/have been 'fully met'; and a further 20% (n=6) of service users self-report their needs are being/have been 'partially met'. The statistics further show that 54% (n=16) of service users expressed full satisfaction with the service they receive; and 33% (n=10) of service users expressed partial satisfaction with the service they receive. Satisfaction ratings are higher among service users of the structured day service (Ability Centre).

Carer ratings in respect of outcome measurables (extent to which needs of both the carer and supported person are being/have been met; satisfaction ratings) are also outlined in **6.12.15**. Ratings for carers are not as high as ratings for service users, based on self-reports from these distinct groups of study informants.

Approximately two thirds (n=19) of service users spoke highly of their named worker, as well as the wider service team; and the general service/s they access or have previously engaged with. Service users and carers reported a few cases of changes to designated workers due to lack of compatibility. Poor worker attitude was the main reason cited.

Several service users and carers spoke positively about partnership working between/among services; although for the most part, they see partnership working as inconsistent. In a similar vein, knowledgeable service users and carers embrace the integration of physical disability and sensory impairment services at all levels, including between health and social care; and involving the third sector.

Service users and carers welcomed the West Lothian Needs Assessment study which they hope will:

- Inform change and improvement;
- Improve outcomes for themselves and others;
- Reduce ignorance and stigma concerning physical disability and sensory impairment;
- Promote and celebrate independence;
- Improve the accessibility, capability, quality and consistency of service delivery; and
- Support greater service user, carer and public involvement in the physical disability and sensory impairment system.

6.12.2 Knowledge of current physical disability, sensory impairment and linked services in West Lothian

Most service users and carers know something about some statutory and commissioned, services in West Lothian. However, knowledge is mainly limited to the actual service/s currently or formerly used, rather than the wider or full range of services and support on offer. To this end, knowledge of specialist and generic services is largely lacking among service users and carers alike.

Study informants explain this in three main ways. Firstly, a lack of accurate, up to date information in the form of published literature and website information which is universally seen as the responsibility of all service providers first and foremost. Secondly, the perceived combined lack of a single agency to coordinate information, together with the creation and maintenance of a single West Lothian wide Directory of physical disability and sensory impairment services in both electronic and print formats. In this regard, it is interesting to note the diversity of views concerning the scope of Capability Scotland's West Lothian Advice and Support service. Following scrutiny by the research team, it is apparent that Capability Scotland's West Lothian service is responsible for coordinating disability information across West Lothian. Thirdly, a perception that the system itself is deliberately designed and managed in a way to restrict information and control access to services, some of which are already beyond capacity. In essence, a financial correlation is perceived which is further elaborated upon in **6.12.3** under the auspice of Self-directed Support.

As mentioned in **6.12.1**, although some service users and carers are aware of integration initiatives, the majority are unaware of this agenda; and very few study participants have been involved at all in the integration process, despite a certain service user consultation element. Interestingly, most carers and service users are unaware of the expected or potential benefits that an integrated model can support. Furthermore, most service users view each physical disability and sensory impairment service as a discrete service; and it will take significant levels of information, awareness raising and time to try to transform this cultural norm towards an integrated, understood and embraced physical disability and sensory impairment service.

6.12.3 Current management of people with physical disability and sensory impairment in West Lothian

Service users and carers are generally aware of the main routes (GPs, Social Workers, Occupational Therapy, and St. John's Hospital) into statutory and commissioned physical disability and sensory impairment services. However, other referral routes such as from self, carer/family, advocate, peer support group, others (police/criminal justice service, clergy, generic service, etc.) are less known about. Service users are generally knowledgeable about assessment and care/support planning and delivery, although many service users consulted do not appear to have sufficient experience or knowledge of carer and advocate opportunities. This issue also extends to some carers consulted.

There is a consistent lack of knowledge and understanding among service users and carers concerning Self-directed Support (SDS). This is despite the apparent endeavour by West Lothian Community Health and Care Partnership and a wide range of providers and agencies to promote SDS. Service users and carers reported considerable delays in carrying out SDS reviews for people currently receiving a care package. There are also reports that the onus has shifted to the supported person now having to ask for a review, compared to the previous custom of getting a review at regular intervals of say 6 or 12 months. There is also concern with the time new SDS assessments are taking to complete. This is at least partly explained through the length and level of detail contained within the updated SDS assessment tool, the lack of capacity of the assessment team (the team is too small), the need for a further meeting due to the budget element of the assessment process, adopting a more holistic approach which takes more time to set out support options; and the time necessary to try to explain the complexity of SDS itself.

Most service users consulted generally believe that the West Lothian health and social care system is not only helping themselves, but many others; notwithstanding identified improvement areas. This view is shared by most carers consulted. Service users also generally believe that the system does not require major overhaul to make it more fit for purpose. Priorities identified by service users include the interface between GPs and physical disability and sensory impairment services which requires greater consistency across the region; the interface between hospital and day/home services; the interface between physical disability and sensory impairment services and housing options, the interface between physical disability and sensory impairment services and employability including paid and voluntary work; the need to embrace SDS principles in terms of choice, control, personalisation and supporting independence; greater levels of service user and care involvement across the entire system; improved flexibility and variety of services including expanded delivery outwith the central hub of Livingston; more focus on self-help/mutual aid groups; a shift away from short termism; increased responsibility for self-management among individuals and service users; and improved information, as previously highlighted.

The Ability Centre is consensually viewed as integral and vital; not just as a physical disability and sensory impairment service option, but the main hub of service activity in West Lothian. However, whilst the majority of service users and carers consulted view the service as fundamental and a service that simply must be sustained, a number of considerations were suggested. These include increased flexibility in terms of limited evening and weekend opening times, increased person-centredness amidst some views that care packages are service driven and not needs led/person centred; greater variety of purposeful activities including social excursions/events; satellite service delivery in other hubs/premises outwith the Ability Centre in Livingston; wider input/delivery from other providers/stakeholders; and greater service user involvement in the delivery, development, monitoring and evaluation of the service.

6.12.4 Ethos of services and types of interventions currently used

Physical disability and sensory impairment services generally promote ethos's of wellbeing and independence. A range of treatment and interventions including psychological, peer counselling, structured day service, group work, 1-1 key working, residential and respite (day care and residential) are provided through a range of service types. Peer support/mutual aid, self-help/management; and to a lesser extent, social activities exist, although these are primarily delivered through disabled peers themselves.

Multi-disciplinary reviews occur when a service user's case is care managed by a Social Worker. Occupational therapy services are also commonplace for many disabled people. In patient treatment occurs, where necessary. Communication support for people with sensory impairment is available, albeit generally on a limited basis which can cause issue and disquiet among service users and carers. Carer/family involvement in service planning, delivery and monitoring is very limited. Carer reviews appear sporadic and are undertaken by social work, rather than a carer organisation which is now common practice in other Scottish regions; for example, the Borders. Support for carers themselves takes the form of support groups, information and training covering a range of issues.

6.12.5 Capacity of services and interventions to meet presenting needs

Several service users and carers reported service capacity and related issues. This is counter-balanced to some extent by positive feedback concerning system and service ethos, professionalism of staff and integrated working. However, the main issues highlighted are:

- Lack of funding, at both a personal and system level;
- Lack of long term investment (including funding);
- A short term outlook;
- Lack of service choice;

- Lack of capacity of certain services such as the social work disability team, occupational therapy service, Ability Centre structured day service, Ability Centre outreach service, RNIB service, residential service, residential respite service and supported accommodation services;
- Perceived long waiting times and lists for certain services and interventions such as the Ability Centre, SDS assessment, SDS review, RNIB service, occupational health service
- The size of the physical disability and sensory impairment social work team is inadequate/too small to cope with client demand
- Lack of service planned and funded social activities;
- Lack of transport and cost of transport;
- Over reliance on building based services;
- Over reliance on Livingston based services;
- Lack of specific minority ethnic, gender and older people services;
- Disproportionate configuration of physical disability and sensory impairment services in West Lothian, which some service users and carers see as overly weighted towards West Lothian CHCP (West Lothian Council and NHS Lothian)/statutory service providers; and
- Perceived fewer physical disability services, compared to services available in West Lothian for people with a learning disability.

It was reported that the Uphall Care Home was designed as a residential service for young people with a severe/complex physical disability; however, 3 out of the 4 placements were allocated to young people with co-occurring physical disability and learning disability. Whilst recognising the needs of these residents; service users and carers alike (as well as some staff) expressed concern that eligible physically disabled people cannot access this specialist service and some have been placed in similar out of area services at even greater financial cost to the taxpayer.

Carers and service users also highlighted the need for sharing resources through joint service delivery, training, learning networks; as well as a need for greater levels of service user and carer involvement in service redesign.

6.12.6 Interventions or services identified as needed, but not currently provided

Standalone, peer led mutual aid/self-help networks and activities in West Lothian are limited; notwithstanding the existence of a few organisational led/driven support groups, as well as peer led support groups. Capability Scotland also provides a peer counselling service. However, there is not a coordinated physical disability support network as such which could complement, support and enhance the current system. Furthermore, the disability forum has lost momentum in recent months and is now amalgamated within a wider equality framework which some service users are carers see as a backward step as specific disability issues do not appear to carry as much weight as in the past.

There is no specific funding to help develop peer led networks for people with a disability in West Lothian.

Other key issues centred on lack of social activities due to funding policies and budget constraints. One particular service user suggested that a social enterprise such as a community cafe should be developed to raise the profile of disability issues and to support employability opportunities for disabled people.

On the face of it, funding to promote greater carer involvement and additional support for carers does not appear to have yielded targeted levels of success to date in terms of carer uptake, despite the ongoing endeavour of Carers of West Lothian.

6.12.7 Resourcing of services for people with physical disability and sensory impairment

This section is linked to 6.25.5 (capacity of services). Service users and carers expressed concern regarding a number of resourcing-related issues. These include:

- Disproportionate configuration of statutory and certain commissioned physical disability and sensory impairment health services – views expressed ranged from too much statutory provision to too less statutory provision;
- Lack of funding for commissioned services;
- Lack of service options and ultimately choice;
- SDS being used for rationalisation intention, rather than its stated policy purpose; and
- Lack of communication support for people with sensory impairment

6.12.8 Groups not well catered for

Service users urged greater involvement of carers in the overall system, a view reinforced by carers themselves. Whilst progress has been made regarding this local endeavour and national policy drive, it is noticeable that there is still room for development, particularly around service contact. There may also be scope to allow Carers of West Lothian to carry out carer assessments, either in addition to or in replacement of the current arrangement undertaken by social work.

The other groups of people identified by service users and carers as 'not well catered for' are:

- People with co-occurring mental health and/or substance misuse problems;
- People with sensory impairment; and
- People with an acquired brain injury.

Another group not well catered are young adults in transition from children and family services to adult services. Several service users and carers highlighted a fundamental reduction in the nature and level of support or people in transition, compounded by inadequate handover arrangements.

Another group not well catered for are older and infirm carers who struggle to care for their disabled loved ones due to their own ill health, often associated with old age. Dementia and mental ill health are other features of the range of challenges experienced by older carers in particular.

The general consensus is that people with co-occurring physical disability and learning disability are normally well catered for, primarily due to an extensive range of learning disability services and learning disability led services such as Eliburn Day Centre.

6.12.9 Accessibility of physical disability and sensory impairment services

Based on service user and carer feedback, physical disability and sensory impairment services in West Lothian, for the most part, appear generally accessible to people with and affected by physical disability and sensory impairment. Some service users and carers mentioned long waiting times to access certain services and interventions. However, the main issues concerning accessibility centre on:

- The lack of opening times which affects a number of services, particularly the Ability Centre;
- A service led approach, as opposed to a needs led support package caused by issues concerning culture/custom and practice, service capacity, building limitations; and not listening and acting upon expressed user and carer voices;
- A limited number of sessions per week; and
- A limited time with the service, such as 6 months.

Several service users and carers expressed inadequate levels of knowledge of SDS; and where applicable, their understanding was generally limited. Among study informants who have a clearer understanding of SDS, SDS as a principle is fully embraced; however, a number of accessibility and other (including funding) related issues were reported. Issues mainly concerned lack of reviews, delays in conducting reviews, the time to undertake initial assessment and what is regarded as a non-simplistic, complex and over onerous reviews and waiting times.

No charging policy related policy/practice issues were reported for accessing services which is a positive position. In other Scottish regions, charging practice is largely seen by service users, carers (and many staff) as unnecessary, immoral, bureaucratic, costly to administer/non cost-effective) and inhibiting to service engagement and positive client outcomes..

6.12.10 Integration of physical disability and sensory impairment services

As highlighted in **6.12.2**, most service users and carers consulted know nothing at all or very little about the ongoing integration of physical disability and sensory impairment services and wider health and social care in West Lothian. Several informants have a basic awareness; however, very few have been involved to date in the integration process. This situation appears surprising given the longstanding history of the physical disability and sensory impairment and wider disability integration endeavour and practice in West Lothian, its current high profile, the link with the national and local SDS agenda, the link with the national and local health and social care integration agenda.

6.12.11 Asset mapping: other assets, resources, groups, individuals and opportunities to support people affected by physical disability and sensory impairment

When discussing 'asset mapping' with carers and service users in focus groups, it is apparent that this term is not well understood. Nor does the term appear user friendly. However, when asset mapping is explained in the context of community based assets, resources, groups, individuals and opportunities to support physical disability and sensory impairment and independence; interest and attraction immediately grew amongst informants.

Most service users and carers consulted fully embrace, promote and practice concepts of self-management, peer support (helping others/providing service through 'giving is gain'), service user engagement, carer engagement, disability networks, structured and inclusive activities, forging and sustaining alliances, etc. However, in reality in West Lothian there is very little service user involvement at any level, limited structured peer support, a lack of mutual aid/self-help support activity and no coordinated user network for disabled people.

Furthermore, the Disability Equality Forum which evolved from the previous Disability Forum last met in January 2015 which is an issue according to service users and carers (as well as staff). On a more positive note, a good example of a community asset is the Vision Support Group which meets monthly in the Ability Centre, monthly in public place and organises 3-4 social excursions per annum; thus conveying social, practical and therapeutic benefits.

6.12.12 Physical disability and sensory impairment; and independence

Whilst the definition or interpretation of 'independence' is unique for each individual with a physical disability and sensory impairment, there are a number of accepted and important features/characteristics including:

- Hope, optimism and strength;
- More than coping with disability;
- Control, choice and inclusion;
- Self-management;
- Finding meaning and purpose; and
- Relationships.

Service users were asked, *"What needs to be done to maximise opportunities for independence for people with a physical disability and sensory impairment in West Lothian"*. Key responses include:

- Work together in a genuine and involving manner;

- Empower and involve service users, families, carers, advocates more;
- Hold joint information awareness sessions;
- Hold joint training sessions;
- Respect bottom up approaches and the role and impact of service users and carers;
- Produce information and publish, market and coordinate this effectively - information should outline support options including specialist physical disability and sensory impairment services and peer led/self-help/mutual aid support groups;
- Learn from other disciplines, models and areas;
- Focus on outcomes, measure and report accordingly;
- Develop an aspirational culture within the physical disability and sensory impairment network, services, the wider system; involving the public, as far as is practical;
- Support the development of physical disability and sensory impairment networks, aligned to community assets and relevant policy and strategy;
- Improve understanding of SDS and adhere to SDS principles in practice;
- Provide greater focus on prevention and early intervention services;
- Adequately fund services and related activities/initiatives; and
- Eradicate short termism and do things differently.

Participants were also asked, *"What do service users need to do in order to maximise opportunities for independence for people with a physical disability and sensory impairment in West Lothian?"* Key responses include:

- Get involved in shaping the future and improving lives and society;
- Stay positive and encourage others to become or remain upbeat;
- Increase the baseline of expectation and aspiration by promoting independence; and
- Develop community based and peer led networks and assets, such as peer support groups and social (enterprise) cafes.

6.12.13 Service user involvement

A key feature of service user involvement is the active participation of people who, because they have used services, can bring their knowledge and experience to contribute to the design, planning, delivery and evaluation of services at a local, regional and national level. This includes all those affected by a physical disability and sensory impairment, such as the individual user; and their family, carer and friends.

As is documented in other sections of this chapter including **6.12.11** and **6.12.12**, the level of service user involvement in West Lothian can be improved. This assertion is not intended in any way to demean the importance and benefit of ongoing service user involvement enterprise. It is important to acknowledge that West Lothian Council and NHS Lothian have used service users, former service users and disability champions on a range of business activities including governance recruitment. However, in reality, such opportunities appear limited at best.

6.12.14 Carer involvement

Some service users and carers highlighted a lack of carer involvement in West Lothian, although acknowledged that carers are increasingly becoming part of the local physical disability and sensory impairment system, supported by the ongoing endeavours of Carers of West Lothian and other providers. However, there is a long way to go to fully embed carers in the culture and day to day practice. A number of carers explained that they are both carers and service users which can cause issue with some service professionals who view these people primarily as patients/clients. The general consensus among those consulted is that carer involvement will, in almost every case, act as a key component of the solution; operating harmoniously with self-management and person centred support.

Carer assessments are carried out by social work, a task that could be carried out by Carers of West Lothian. Carers also highlighted a range of carer specific information events, training events, a consultation and an ongoing support groups provided by Carers of West Lothian which they have been involved with. Attendance among informants at these events has been sporadic and could be improved. Carers are being encouraged to get involved in these initiatives which have benefit for carers as well as supported people.

6.12.15 Client outcomes and customer satisfaction ratings

It is important to highlight that this sub-section focuses solely on analysing the views expressed by service users and carers in focus groups; rather than the other qualitative methods deployed (stakeholder event, working group meetings, 1-1 interviews), or the quantitative analysis of provided service data or survey data/information. It is also important to highlight common perceptive issues expressed by service users and carers concerning the robustness of client outcome measures and collation/reporting systems.

Nonetheless, it is equally worthy to at least attempt to gauge a snapshot of service user and carer perspectives concerning client outcomes , using two main measurables: firstly, the extent to which needs are being met/have been met; and secondly, the level of customer satisfaction.

To this end, the authors identify the following ratings in response to the first question:

- 17 out of 30 (57%) service users self-reported their needs are being/have been fully met;
- 6 out of 30 (20%) service users self-reported their needs are being/have been partially met; and
- 7 out of 30 (23%) service users self-reported their needs are not being/have not been met

- 3 out of 13 (23%) carers self-reported the needs of the supported person are being/have been fully met;
- 6 out of 13 (46%) carers self-reported the needs of the supported person are being/have been partially met; and
- 4 out of 13 (31%) carers self-reported the needs of the supported person are not being/have not been met.
- 2 out of 13 (15%) carers self-reported their own needs are being/have been fully met;
- 7 out of 13 (54%) carers self-reported their own needs are being/have been partially met; and
- 4 out of 13 (31%) carers self-reported their own needs are not being/have not been fully met.

The authors identify the following ratings in response to the second question:

- 16 out of 30 (54%) service users expressed full satisfaction with the service they receive/have received;
- 10 out of 30 (33%) service users expressed partial satisfaction with the service they receive/have received; and
- 4 out of 30 (13%) service users expressed no satisfaction with the service they receive/have received.
- 3 out of 13 (23%) carers expressed full satisfaction with the service provided to the supported person;
- 6 out of 13 (46%) carers users expressed partial satisfaction with the service provided to the supported person; and
- 4 out of 13 (31%) carers expressed no satisfaction with the service provided to the supported person.
- 2 out of 13 (15%) carers expressed full satisfaction with the service provided to themselves;
- 8 out of 13 (62%) carers users expressed partial satisfaction with the service provided to themselves; and
- 3 out of 13 (23%) carers expressed no satisfaction with the service provided to themselves.

The above statistics show that 57% (n=17) of service users self-report their needs are being/have been 'fully met'; and a further 20% (n=6) of service users self-report their needs are being/have been 'partially met'. The statistics further show that 54% (n=16) of service users expressed 'full satisfaction' with the service they receive; and 33% (n=10) of service users expressed 'partial satisfaction' with the service they receive.

The above statistics show that 23% (n=3) of carers self-report their needs are being/have been 'fully met'; and a further 54% (n=7) of carers self-report their needs are being/have been 'partially met'. The statistics further show that 15% (n=2) of carers expressed 'full satisfaction' with the service provided to themselves; and 62% (n=8) of carers expressed 'partial satisfaction' with the service provided to themselves.

A summary of these statistics are also outlined at **6.12.1** to highlight 'what is working well'. Section **6.16.14** also outlines relevant ratings-related information derived from other qualitative methods adopted.

6.12.16 Gaps and wider issues linked to change, service improvement and future basing

Service users and carers identified a number and range of gaps and other key issues that should be addressed through change, service improvement and priorities for future investment. Most of the gaps and wider issues in this section have already been explored in earlier parts of this chapter. Common themes in terms of gaps, issues and solutions (improvement areas) are outlined in summary (bullet) form **6.16.15**. Selected examples include:

Gaps and wider issues

- Lack of services and choice for people with a physical disability and sensory impairment;
- Limited early intervention services for people with a physical disability and sensory impairment;
- Duplication as well as under capacity of certain services;
- Lack of effective service integration of services;
- Inconsistent practice;
- Insufficient accessibility including opening times of services;
- Lack of physical disability and sensory impairment support network;
- Lack of service user involvement;
- Lack of carer involvement;
- Lack of advocacy involvement;
- Poor transportation;
- Limited supported housing and other housing options; and
- Perceived lack of funding for certain commissioned services.

6.13 Background to stakeholder event, working groups and 1-1 interviews

Findings in the final part of this chapter (**6.16**) derive from the views of service users and carers expressed through a stakeholder event held on 20 May 2015; working group meetings held on 27 May 2015 and 5 June 2015; and two interviews held on 3 June 2015 and 8 June 2015. Salient points have been outlined in bullet form only, as similar themes expressed in focus groups are explained in more detail in **6.12**.

There was an intention to involve service users in the working group meetings; however a registered person did not attend either meeting.

A total of **3** service users and **3** carers participated in the stakeholder event, working group meetings and interviews; broken down, as follows:

- Stakeholder event, Howden Park Centre, Livingston, 20/5/15 (**n=16**):
    - 2 service users
    - 1 carer
    - *13 staff*
- Working group (meeting 1), Pathway Cafe, Livingston, 27/5/15 (**n=13**):
    - 1 carer
    - *12 staff*
- Working group (meeting 2), Pathway Cafe, Livingston, 5/6/15 (**n=7**):
    - 1 carer [NB Same carer participated in both working group meetings]
    - *6 staff*
- 1-1 interviews, Uphall Care Home, 3/6/15 & Premier Inn, Livingston, 8/6/15 (**n=2**):
    - 1 service user
    - 1 carer

6.14 Purpose of stakeholder event, working group and 1-1 interviews

The purpose of the stakeholder event was to find out:

- Views on needs of people with and affected by physical disability and sensory impairment in West Lothian
- How needs are currently being met
- What is currently going well
- What is not going so well and how can this be improved

The purpose of the working group and 1-1 interviews was to find out:

- Current provision of treatment services;
- Gaps in current provision;
- Views in relation to the nature and extent of future requirements; and
- Assets (groups, networks, individuals, etc.) across West Lothian.

6.15 Limitations of stakeholder event, working groups and 1-1 interviews

The scope of the study, in terms of its qualitative methods, restricts the number of working group meetings, together with its membership. Accordingly, two working group meetings were planned and delivered, targeting 12 members including 2 service users and two carers. However, the attrition rate of service users and carers meant that only one carer participated in working groups. This prompted the authors to arrange 1-1 interviews with a service user and a carer. The study's design limitation is offset by the additional methods highlighted at section **6.11**.

Key findings outlined in 6.25 derive from the views of 6 study informants (3 service users, 3 carers). As a principle, caution would normally be exercised when analysing findings from such as low cohort size. However, key points expressed by these 6 contributors accurately reflect the views expressed by other service users (n=30) and carers (n=13) in focus groups.

6.16 Stakeholder event and working groups and 1-1 interviews - key findings

The authors have identified fifteen themes, namely:

- What works well?
- Knowledge of current physical disability and sensory impairment and linked services in West Lothian
- Current management of people with physical disability and sensory impairment in West Lothian
- Ethos of services and types of interventions currently used
- Capacity of services and interventions to meet presenting needs
- Interventions or services identified as needed, but not currently provided
- Resourcing of services for people with physical disability and sensory impairment
- Groups not well catered for
- Accessibility of physical disability and sensory impairment services
- Integration of physical disability and sensory impairment services
- Asset mapping: other assets, resources, groups, individuals and opportunities to support people affected by physical disability and sensory impairment
- Service user involvement
- Carer involvement
- Client outcomes and customer satisfaction ratings
- Gaps and wider issues linked to change, service improvement and future basing

An additional theme, *physical disability and sensory impairment; and independence* emerged from focus group discussions and is explained in **6.12.12**.

6.16.1 What works well?

- Carrying out the needs assessment – seeking to improve services and outcomes;
- Relationships at all levels are generally good – no service user or carer raised an issue concerning the process or outcome of the recently re-commissioned Advice and Support service (an issue was raised by a single professional stakeholder)
- The role of Disability Development Officers are important to identifying, influencing and driving system change
- Staff are generally professional and caring;
- Some service user involvement;
- Some carer involvement; and
- Services promote independence and support life gratification.

6.16.2 Knowledge of current physical disability and sensory impairment services; and linked services in West Lothian

- Social work disability team;
- Occupational therapy;
- Community nursing team;
- The Ability Centre (main hub);
- Eliburn Day Centre;
- Uphall Care Home;
- Capability Scotland's advice & support service (formerly provided by Disability West Lothian);
- Deaf Action;
- Deafblind Scotland;
- RNIB;
- Sensory Support Service;
- Carers of West Lothian;
- MECOPP (Minority Ethnic Carers);
- Edinburgh Advocacy Representation Service (EARS); and
- The Advice Shop.

6.16.3 Current management of people with a physical disability and sensory impairment in West Lothian

- Via SDS assessment and personal plan;
- Via other/non SDS route;
- Peer support/mutual aid/self-help;
- Hospital/outpatient treatment;
- Occupational therapy;
- Carer involvement including carer assessment (social work conducted); and
- Transitions: from children & family to adult; and adult to older people

6.16.4 Ethos of services and types of interventions currently used

- Structured day service;
- Residential service;
- Respite service;
- Information and advice;
- 1-1;
- Group work;
- Peer counselling;
- Physiological interventions (limited);
- Social activities (limited);
- Peer support/mutual aid; and
- Self-management/help (limited);
- Adaptations, aids and equipment;
- Communication support; and
- Other; e.g. taxi vouchers.

6.16.5 Capacity of services and interventions to meet presenting needs

Most services at or beyond capacity; for example:

- SDS assessment team;
- Social work disability team;
- Ability Centre;

- RNIB;
- Limited respite services (which are very expensive); and
- Scope to attract more carers to support meetings and training events.

6.16.6 Interventions or services identified as needed, but not currently provided

- Family therapy;
- Peer support is generally limited/lacking;
- Telephone counselling;
- Social excursions/activities; and
- Social enterprise.

6.16.8 Groups not well catered for

- People in transition from children and family to adult services;
- People with co-occurring physical disability/sensory impairment and mental ill health;
- People with co-occurring physical disability/sensory impairment and alcohol/drug problems;
- Minority ethnic service users and carers;
- People with severe and complex physical disability;
- People who experience loneliness and who would benefit from a befriending type service; and
- Carers who are old and fragile themselves experiencing physical disability/sensory impairment/poor physical health, mental ill health and dementia; and no longer able to support loved ones to customary standards.

6.16.9 Accessibility of physical disability and sensory impairment services

- Mixed views regarding accessibility – some services are accessible and others are not;
- Opening times can be expanded;
- Waiting times and waiting lists are long, especially for certain services such as SDS assessment and review, social work disability team, occupational therapy (non-urgent) and RNIB;
- Services need to be more person centred and needs led – currently some service are predominantly service led
- Transport links are limited and costs are high – West Lothian Council's transport service do a good job transporting people with a disability to a service,

6.16.10 Integration of physical disability and sensory impairment services

- Mixed views (positive): Physical disability and sensory impairment services are integrated, which will be further consolidated with the integration of health and social care;
- Mixed views (positive): Physical disability and sensory impairment services are fairly well integrated but require better linkage with generic services, especially employability, housing and money advice;
- Mixed views (negative): Physical disability and sensory impairment services are not really integrated, but rather standalone, with providers focusing on themselves, their team and their service;
- Mixed views (negative): Physical disability and sensory impairment services are not effectively integrated – particular issues include hospital discharge and transitions (children and family to adult services; and
- SDS is supposed to support integration, but opportunities are not being maximised.

6.16.11 Asset mapping: other assets, resources, groups, individuals and opportunities to support people with physical disability and sensory impairment

- Vision Support Group – meet monthly in Ability Centre, meet monthly in public place and arrange 3-4 social excursions per annum; and
- Disability Equality Forum – last met in January 2015

6.16.12 Service user involvement

- Service user involvement is largely tokenistic – there have been consultations for specific reasons and initiatives, such as integration; however, there has been no feedback on the impact of expressed views at a system or service level;
- Service users used to far more prominent in fora, working groups, seminars, conferences; however, momentum has been lost; possibly due to the temporary suspension of the disability form;
- Service users need to be involved at strategic as well as operational levels; and
- There are some positive examples of service user involvement in services including Disability West Lothian, Capability Scotland and the Ability Centre.

6.16.13 Carer involvement

- Carers are becoming increasingly involved in all aspects of the system including the planning, delivery and co-ordination of care for the supported person;
- Carer assessments are carried out by social work

- Carer assessments could be carried out by Carers of West Lothian; and
- Attendance at carer specific training, consultation/information events and support groups can be improved.

6.16.14 Client outcomes and customer satisfaction

- The perception from service users and carers is that client outcomes do not appear to be recorded and measured in a robust manner; and this is an area that requires further examination and development, dependent upon scrutiny findings;

In line with the approach adopted and the statistics outlined in **6.12.15**, there was a simple attempt by the authors to gauge the views of service users (n=3) and carers (n=3) concerning client outcomes, using two main measurables: firstly, the extent to which needs are being met/have been met; and secondly, the level of customer satisfaction.

The following ratings in response to the first question:

- 3 out of 3 (100%) service users self-reported their needs are being/have been fully met.
- 2 out of 3 (67%) carers self-reported the needs of the supported person are being/have been fully met; and
- 1 out of 3 (33%) carers self-reported the needs of the supported person are being/have been partially met.
- 2 out of 3 (67%) carers self-reported their own needs are being/have been fully met; and
- 1 out of 3 (33%) carers self-reported their own needs are being/have been partially met.

The authors identify the following ratings in response to the second question:

- 3 out of 3 (100%) service users expressed full satisfaction with the service they receive/have received.
- 2 out of 3 (67%) carers expressed full satisfaction with the service provided to the supported person; and
- 1 out of 3 (33%) carers expressed partial satisfaction with the service provided to the supported person.
- 2 out of 3 (67%) carers expressed full satisfaction with the service provided to themselves; and
- 1 out of 3 (67%) carers expressed partial satisfaction with the service provided to themselves.

6.16.15 Gaps and wider issues linked to change, service improvement and future basing

- A Physical disability and sensory impairment plan/strategy would be a helpful starting point;
- The level of aspiration needs to increase;

- Stop focusing on short-termism, but adopt and successfully execute a long term vision;
- Providers need to work in real partnership, underpinned by a Partnership Agreement;
- Improve information and communication, including developing a single coordination information resource;
- Improve IT compatibility, especially between health and social care (West Lothian Council and NHS Lothian);
- Fully adhere to the principles of SDS and personalisation, whilst addressing SDS assessment and review capacity issues and inconsistent practice;
- There needs to be more prevention and early intervention services;
- Review the balance of statutory and non-statutory services; or at least start delivering services jointly and explore co-habitation opportunities;
- Address over capacity issues in relevant services;
- Improve accessibility of services including shifting away from a traditional but now largely obsolete 9-5/Monday-Friday culture of opening times;
- Retention of structured day services is fundamental, although integration must be improved, involving providers over and above West Lothian Council and NHS Lothian; together with improved options for service delivery in respect of purposeful activities;
- Provide satellite services across West Lothian – there is too much emphasis on service delivery in Livingston;
- Services have never been evaluated which would be good practice, complement the needs assessment and help inform future commissioning of services;
- Commissioning needs to be based on available evidence, which should be accurate, up to date and reflective of best known practice;
- Improve level of service user engagement; and act upon valid suggestions;
- Measure and report outcomes;
- Develop physical disability and sensory impairment peer networks;
- Review terms of reference for West Lothian Disability Equality Forum to establish whether an additional forum is required;
- Review cost-effectiveness of transport arrangements;
- Celebrate achievement more;
- Fully embed carers (as well as service users) in physical disability and sensory impairment system improvement;
- Continually learn and improve, adopting a genuine and successful partnership approach to service delivery.

6.17 Summary of specific key findings

This section summarises specific key findings from the 16 themes outlined in **6.12** and the 15 themes outlined in **6.16**. There is considerable similarity between findings in **6.12** and **6.16**, therefore, findings have largely been amalgamated (as indicated). The main exception relates to **6.16.14** and **6.16.15** which are outlined discretely.

- Service users and carers embrace the integration of physical disability and sensory impairment services at all levels (**6.12.1**);
- Service users and carers welcome the West Lothian Needs Assessment study (**6.12.1**);
- Knowledge of specialist and generic services is largely lacking among service users and carers (**6.12.2**);
- Most carers and service users are unaware of the expected or potential benefits that an integrated model can support (**6.12.2**);
- Many service users and carers lack knowledge of carer and advocate opportunities (**6.12.3**);
- There is a lack of knowledge and understanding among service users and carers concerning Self-directed Support (SDS) (**6.12.3**);
- Most service users and carers believe that the West Lothian health and social care system is not only helping themselves, but many others; notwithstanding identified improvement areas (**6.12.3**);
- Service users generally believe that the system does not require major overhaul to make it more fit for purpose (**6.12.3**);
- The Ability Centre is consensually viewed as integral and vital; not just as a physical disability and sensory impairment service option, but the main hub of service activity in West Lothian (**6.12.3**);
- Physical disability and sensory impairment services generally promote ethos's of wellbeing and independence (**6.12.4**);
- A range of treatment and interventions including psychological, peer counselling, structured day service, group work, 1-1 key working, residential and respite (day care and residential) are provided through a range of service types (**6.12.4**);
- Carer reviews appear sporadic and are undertaken by social work, rather than a carer organisation (**6.12.4**);
- There are service under capacity issues which are influenced by Many factors (**6.12.5**);
- There is a need to share resources through joint service delivery, training, learning networks; as well as a need for greater levels of service user and carer involvement (**6.12.5**);
- There is a lack of a coordinated physical disability support network which could complement, support and enhance the current system (**6.12.6**);

- There is no specific funding to help develop peer led networks for people with a disability in West Lothian (**6.12.6**);
- The disability forum has lost momentum and is now amalgamated within a wider equality framework which some service users are carers see as a backward step (**6.12.6**);
- There is potential scope to develop or improve employability opportunities for disabled people, including social enterprise (**6.12.6**);
- There is a lack of desired social activities (**6.12.6**);
- There are a number of resource-related issues including (**6.12.7**):
    - Disproportionate configuration of statutory and certain commissioned services;
    - Lack of funding for commissioned services;
    - Lack of service options and ultimately choice;
    - SDS being used for rationalisation intention, rather than its stated policy purpose;
    - Lack of communication support for people with sensory impairment;
- Groups of people identified as 'not well catered for' include (**6.12.8)**:
    - People with co-occurring mental health and/or substance misuse problems;
    - People with sensory impairment;
    - People with acquired brain injury;
    - Young adults in transition from children and family services to adult services;
    - Older and infirm carers;
- There are some service accessibility issues relating to waiting periods, opening times, service models/programmes and transport (**6.12.9**);
- There are a lack of case reviews, which is compounded further by the SDS agenda (**6.12.9**);
- Service user and carer knowledge of; and involvement with, the ongoing integration of physical disability and sensory impairment services; and wider health and social care in West Lothian, is very limited (**6.12.10**);
- The term 'asset mapping' is not well understood among with carers and service users (**6.12.11**);
- There are a number of identified characteristics of 'independence' including (**6.12.12**):
- Hope, optimism and strength;
    - More than coping with disability;
    - Control, choice and inclusion;
    - Self-management;

  - Finding meaning and purpose;
  - Relationships;
- Service user responses to the question, "What needs to be done to maximise opportunities for independence?" include (**6.12.12**):
  - Work together in a genuine and involving manner;
  - Empower and involve service users, families, carers, advocates more;
  - Respect bottom up approaches and the role and impact of service users and carers;
  - Produce better information and publish, market and coordinate this effectively;
  - Develop an aspirational culture;
  - Development peer led networks;
  - Improve understanding of SDS and adhere to its principles in practice;
  - Provide greater focus on prevention and early intervention services;
  - Adequately fund services and related activities/initiatives;
  - Eradicate short termism and do things differently;
- Service user responses to the question, "What do service users need to do in order to maximise opportunities for independence?" (**6.12.12**):
  - Get involved in shaping the future and improving lives and society;
  - Stay positive and encourage others to become or remain upbeat;
  - Increase the baseline of expectation and aspiration by promoting independence;
  - Develop community based and peer led networks and assets, such as peer support groups and social (enterprise) cafes;
- As previously highlighted, there is a general lack of service user involvement in West Lothian (**6.12.13**);
- Carers are increasingly becoming part of the local physical disability and sensory impairment system, supported by the ongoing endeavours of Carers of West Lothian and other providers. (**6.2.14**);
- Fifty seven percent (57%) n=17) of service users self-report their needs are being/have been 'fully met'; and a further 20% (n=6) 'partially met' – additionally, (54%) (n=16) of service users express 'full satisfaction' with the service they receive; and 33% (n=10) 'partial satisfaction' (**6.12.15**);
- Twenty three percent (23%) (n=3) of carers self-report their needs are being/have been 'fully met'; and a further 54% (n=7) 'partially met' – additionally, 15% (n=2) of carers express 'full satisfaction' with the service provided to themselves; and 62% (n=8) 'partial satisfaction' (**6.12.15**); and

- Gaps and wider issues summarily identified by service users and carers include (**6.12.16**):
    - Lack of services and choice for people with a physical disability and sensory impairment;
    - Limited early intervention services for people with a physical disability and sensory impairment;
    - Duplication as well as under capacity of certain services;
    - Lack of effective service integration of services;
    - Inconsistent practice;
    - Insufficient accessibility including opening times of services;
    - Limited transportation and housing options
    - Lack of physical disability and sensory impairment support network;
    - Lack of service user involvement;
    - Lack of carer involvement;
    - Lack of advocacy involvement; and
    - Lack of funding for certain commissioned services.
- One hundred percent (100%) (n=3) of service users self-reported their needs are being/have been fully met (**6.12.14**);
- Sixty seven percent (67%) (n=2) of carers self-reported their own needs are being/have been fully met (**6.12.14**);
- One hundred percent (100%) (n=3) of service users expressed 'full satisfaction' with the service they receive/have received (**6.12.14**);
- Sixty seven percent (67%) (n=2) of carers expressed 'full satisfaction' with the service provided to the supported person (**6.12.14**);
- Sixty seven percent (67%) (n=2) of carers expressed full satisfaction with the service provided to themselves (**6.12.14**);
- Gaps and wider issues summarily identified by service users and carers include (**6.12.15**):
- A Physical disability and sensory impairment plan/strategy would be a helpful starting point;
- The level of aspiration needs to increase;
- Stop focusing on short-termism, but adopt and successfully execute a long term vision;
- Providers need to work in real partnership, underpinned by a Partnership Agreement;
- Improve information and communication, including developing a single coordination information resource;

- Improve IT compatibility, especially between health and social care (West Lothian Council and NHS Lothian);
- Fully adhere to the principles of SDS and personalisation, whilst addressing SDS assessment and review capacity issues and inconsistent practice;
- There needs to be more prevention and early intervention services;
- Review the balance of statutory and non-statutory services; or at least start delivering services jointly and explore co-habitation opportunities;
- Address over capacity issues in relevant services;
- Improve accessibility of services including shifting away from a traditional but now largely obsolete 9-5/Monday-Friday culture of opening times;
- Retention of structured day services is fundamental, although integration must be improved, involving providers over and above West Lothian Council and NHS Lothian; together with improved options for service delivery in respect of purposeful activities;
- Provide satellite services across West Lothian – there is too much emphasis on service delivery in Livingston;
- Services have never been evaluated which would be good practice, complement the needs assessment and help inform future commissioning of services;
- Commissioning needs to be based on available evidence, which should be accurate, up to date and reflective of best known practice;
- Improve level of service user engagement; and act upon valid suggestions;
- Measure and report outcomes;
- Develop physical disability and sensory impairment peer networks;
- Review terms of reference for West Lothian Disability Equality Forum to establish whether an additional forum is required;
- Review cost-effectiveness of transport arrangements;
- Celebrate achievement more;
- Fully embed carers (as well as service users) in physical disability and sensory impairment system improvement;
- Continually learn and improve, adopting a genuine and successful partnership approach to service delivery.

CHAPTER 7: KEY FINDINGS AND RECOMMENDATIONS – WHAT THIS MEANS FOR WEST LOTHIAN

7.1 Introduction

Removal of barriers that marginalise disabled people is the key to empowering disabled people, and giving them the opportunity to exercise their responsibilities as citizens – in the home, in the community and in the workplace.

We need a step change in the way we view disability. Demographic trends will mean that increasingly we will all experience disability either as individuals or through our family and friends; and often in caring roles. An understanding of this should drive a change in attitudes and increased commitment to inclusion and accessibility.

The key messages for local commissioners and service planners are to learn from the latest national surveys and research based on the social model of disability. Look at the interactions of societal barriers and impairments locally, understand who and why people have benefited from any improvements and where more progress needs to be made; giving disabled people across West Lothian opportunities to fulfil their potential and play a full role in society; resulting in improved health outcomes, participation, wellbeing and quality of life.

This section sets out a summary of the key findings from all elements of the study, along with a series of recommendations. There are 18 recommendations in total for deliberation by West Lothian Community Health and Care Partnership and their partners. Recommendations are derived from evidence gathered and analysed from the review of literature, surveys and fieldwork, including study informants; and have been grouped under the following five key themes:

- Ambition, Change and Strategy (recommendations 1-3)
- Commissioning, Monitoring and Evaluation (recommendations 4-7)
- Integrated Practice (recommendations 8-15)
- Workforce Development (recommendation 16)
- Empowerment, Independence and Achievement (recommendations 17-18)

7.2 Key findings and recommendations

The overall environment in West Lothian is generally regarded as positive, with a varied landscape, strong heritage and diverse cultural and leisure opportunities contributing to a high quality of life for many residents. From the outset of this research contract being commissioned, the research team has been highly impressed with the commitment and desire of the majority of stakeholders to strive for significant improvements to both service provision and commissioning of services for those with physical disability and sensory impairment. The following ambitious set of recommendations has been developed to match the level of commitment and desire demonstrated. The research team believe that a genuine focus on these recommendations will lead to a comprehensive programme of change and improvement over the next 5-10 years; and improved outcomes for people with physical disability, sensory impairment and/or acquired brain injury; as well as West Lothian communities.

7.3 Ambition, Change and Strategy

Ambition, Change and Strategy (recommendations 1 -3)

7.3.1 Integrated Physical Disability, Sensory Impairment and Acquired Brain Injury Strategy

RECOMMENDATION 1: An Integrated Health & Social Care Physical Disability, Sensory Impairment and Acquired Brain Injury Strategy should be developed with a broad range of stakeholders, considering and agreeing a set of joint principles for action to be addressed through the lifetime of the strategy.

There are a number of challenges and opportunities which drive the need for developing a robust overarching, integrated strategy for physical disability and sensory impairment in West Lothian:

- The growing needs and demands of an ageing population generally including those with a physical disability and sensory impairment; and the implications for health and social care services.
- Residents on the whole enjoy good health, but there are also variations across the region which must be reduced. Deprivation has a strong direct association with poorer health as well as other aspects of life that influence health and wellbeing, such as employability.
- The longstanding delicate state of the economy nationally makes an ambition for better health and wellbeing even more pressing. The climate of austerity and the need for public services to make efficiency savings and remove duplication could widen health inequalities without a coordinated response. Collective action in developing models and public services which deliver effective and sustainable solutions is vital.
- Improving the quality of services, whilst ensuring value for money.
- Making the right connections with residents, customers and communities.

- Supporting people towards and in their independence, promoting capability to make personal choices about their health and social care for longer.

There is challenging work to be done to successfully address the collective needs of West Lothian citizens, particularly in regard to health inequalities. The proposed new strategy should seek to tackle health and wellbeing in the broadest sense and should recognise that there are a number of related strategies already in place.

Priorities in all strategies and commissioning plans must be informed by the voices of service users, families, carers and residents; and supported by all outcome frameworks. By using the collective influence gained through the development of a joint strategy, it will also be possible to achieve improved outcomes through other factors that impact on the health and wellbeing of communities such as housing, education, employment and the environment.

The new strategy should incorporate learning primarily derived from the content but also the enablers and processes that led to the publication of relevant strategies in other Scottish regions. A good example is: '*Opportunity and Independence: East Lothian's Joint Strategy for Physical Disability or Hearing or Sight Loss 2013-2020*, (10/13)'.[121]

By embedding an agreed set of joint principles it will be possible to avoid duplication or simply reinventing ways of tackling existing challenges. All relevant commissioners should be asked to consider how they will contribute to these priorities. The priorities agreed should be used to judge and challenge future commissioning plans and we would encourage commissioners to use them as an integral part of developing their plans.

The broad set of priorities listed below are suggested as a starting point for discussion. Any agreed set of priorities should be based on lifestyle and risk factors that impact on the wellbeing of people with a physical disability, sensory impairment and/or acquired brain injury in West Lothian; and that might limit their choice, control and independence.

The suggested list of joint principles for action are:

- Demonstrating engagement with service users, families and carers and their participation in the design of services;
- Identifying not only financial and resource constraints but also assets and strengths;
- Being clear on improved outcomes;
- Demonstrating improved collaboration and integration (between health and social care commissioning);
- Identifying contributions to reduce health inequalities, increased service user access, choice and control and more seamless care and support pathways;

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[121] *East Lothian's Joint Strategy for Physical Disability or Hearing or Sight Loss 2013-2020*, East Lothian Physical Disability and Sensory Impairment Joint Planning Group (10/13).

- Being transformational and innovative where necessary;
- Providing local opportunities and services wherever possible
- Removing barriers to change that would have an early impact;
- Shifting the focus towards all aspects of early assessment and prevention;
- Identifying the potential interaction with other services such as housing, transport, community planning and education; and
- Promoting full involvement of all stakeholders, modelling practice on the new national Charter for Involvement for people and creating real opportunities for third and Independent Sector services to be in practice 'equal' partners.

Final agreed priorities should fit well with both national and local policy directions and be directly linked to the Scottish Government National Outcomes[122], particularly the following eight:

- We live longer, healthier lives;
- We have tackled the significant inequalities in Scottish society;
- We have improved the life chances for children, young people and families at risk.
- Our people are able to maintain their independence as they get older and are able to access appropriate support when they need it;
- Our public services are high quality, continually improving, efficient and responsive to local people's needs;
- We realise our full economic potential with more and better employment opportunities for our people;
- We have strong, resilient and supportive communities where people take responsibility for their own actions and how they affect others; and
- We take pride in a strong, fair and inclusive national identity.

Good Practice Reference

'The Voluntary Sector is key to Health & Social Care integration, not an optional extra' Community Care June 2014.

Check out: ***http://thirdsectordumgal.org.uk/integration/***

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[122] Information about each of the National Outcomes can be found at: http://www.scotland.gov.uk/About/Performance/scotPerforms/outcome

7.3.2 Resource a disability 'change agent'

RECOMMENDATION 2: In order to involve all relevant stakeholders as equal partners in developing an overarching strategy, underpinned by a set of joint principles for action (Recommendation 1), it is recommended that commissioners consider resourcing a disability 'change agent'. A primary function of the 'change agent' would be to ensure a full communication strategy is developed and engaged with across all services and stakeholders.

Cultural and organisational change is required to drive the system forward across West Lothian, especially during the intensive period of change being experienced across the statutory sector due to health and social care integration. A suitably experienced and influential person is required to supplement existing physical disability, sensory impairment and acquired brain injury resources, particularly the Service Development Officer (Physical Disability); and to lead from the front as a champion of change. As an additional benefit, consideration should be given to this change agent working across other areas (for example, learning disability or autism), to bring positive change to a wider set of issues experienced by those with a physical disability, sensory impairment and/or acquired brain injury.

The appointed person should give consideration to developing a long-term plan of cross-cutting themes and priorities for all services. The vision would be to tackle and promote 3-4 key themes per year over the next five years, aligned to the developing/published strategy, to allow concerted effort and staged change and improvement to service provision and outcomes for people. Cross-cutting themes and priorities may include:

- Independence and holistic care;
- Assessment and review (Self-directed Support)
- Information and communication;
- Accessibility of services;
- Service integration and connectedness across a wider range of services;
- Prevention and early intervention;
- Transitions;
- Service user involvement;
- Carer involvement; and
- Combating stigma and discrimination.

A programme of events, seminars, workshops could be arranged with all services and stakeholder representatives. Opportunities for cross-fertilisation with other sectors and regions should be sought around this health, wellbeing and independence agenda.

Responses and comments from the West Lothian workforce across the partnerships reflect a significant lack of knowledge about local communities and their resources. This is indeed a surprising result. Investment in a 'change agent' should be focused on embedding a culture of community, through developing a knowledgeable and confident staff group. This, in turn, would contribute to streamlining and improving the care pathway for people with a physical disability, sensory impairment and/or acquired brain injury.

Good Practice Reference

STAKEHOLDER EVENTS:

Consultation – on new Scottish Legislation related to Disability:

http://www.lothiancil.org.uk/wp-content/uploads/2015/08/New-Powers-workshops-Inclusion-Scotland.pdf

7.3.3 Inspiring innovative and creative opportunities

RECOMMENDATION 4: Commissioners need to work with providers, service users, carers and other stakeholders to consider how innovation and creativity can be further developed within the physical disability, sensory impairment and acquired brain injury sector.

There is a need for greater aspiration and inspiration at all levels. A number of helping approaches, some of which have evolved from the mental health sector, promote simple, straightforward but potentially impactful messages.

Good Practice Reference

An example is promoting the 'Five Ways to Wellbeing', developed by the New Economics Foundation (NEF).[123] In a review of the evidence on how individuals can improve wellbeing, the NEF identified five actions which individuals can build into their lives:

1. Connect ... With the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community. Think of these as the cornerstones of your life and invest time in developing them. Building these connections will support and enrich you every day.

2. Be active ... Go for a walk or run. Step outside, cycle, play a game, garden, or dance. Exercising makes you feel good. Most importantly, discover a physical activity you enjoy and that suits your level of mobility and fitness.

3. Take notice ... Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be

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[123] Aked and Thomson (2011) op.cit.

aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you.

4. Keep learning ... Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Set a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun.

5. Give ... Do something nice for a friend, or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out, as well as in. Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you.

Since these actions apply to everyone, regardless of circumstance; the potential innovation here is to encourage people with physical disability and sensory impairment to build these five actions into their own lives and lead by example, rather than focusing on traditional methods of service provision.

http://www.neweconomics.org/projects/entry/five-ways-to-well-being

Living well with multiple conditions - Listening to the experience and ideas of people who's our services offers valuable insight, advice and support to help improve these services. This Action Plan was developed with people who live with multiple conditions. It describes actions we must take in each GP practice, in all community teams and in every community in Scotland to improve the lives of people with multiple conditions.

http://www.alliance-scotland.org.uk/download/library/lib_5469c0678579e/

7.4 Commissioning, Monitoring and Evaluation

Commissioning, Monitoring and Evaluation (recommendation 4-7)

Based on the strength of findings in this study, a crucial element which should be taken into account in all future commissioning, monitoring and evaluation planning, is the issue of transport and the significant challenges it poses to services and individuals/families across West Lothian. It would be prudent to consider the issue of transport when planning on how to address each of the four recommendations in this section. For example, are there any examples of good practice regarding how services have considered the importance of transport links in improving accessibility (when planning a new service or enhancing an existing service), which could be promoted across all services and local communities?

Good Practice Reference

“Sustrans makes smarter travel choices possible, desirable and inevitable. We’re a leading UK charity enabling people to travel by foot, bike or public transport for more of the journeys we make every day. We work with families, communities, policy-makers and partner organisations so that people are able to choose healthier, cleaner and cheaper journeys, with better places and spaces to move through and live in. It’s time we all began making smarter travel choices.” ***www.sustrans.org.uk***

7.4.1 Formulate a detailed West Lothian commissioning strategy

RECOMMENDATION 4: In order to maximise opportunities in respect of client outcomes, a detailed West Lothian commissioning strategy for physical disability, sensory impairment and acquired brain injury services should be formulated. The strategy should be aimed at developing transparent, high quality, needs-led and integrated services, available to all those who require them across West Lothian.

Commissioning transparent, high quality, needs-led and integrated services is of paramount importance to everyone. Such endeavour and achievement will promote coordinated health and social care; effective partnership working and communication; and maximise opportunities in respect of positive, sustainable outcomes for people with a physical disability, sensory impairment and/or acquired brain injury in West Lothian.

The commissioning strategy should be transparent about the levels of resourcing for physical disability, sensory support and acquired brain injury services in West Lothian. Where under-resourcing is identified, an action plan should be developed to address this.

In September 2012, West Lothian CHCP developed a draft *Physical Disability including Sensory Loss and Acquired Brain Injury Commissioning Plan 2012 – 2015*. The plan was never published but aims to set out how services will be developed, commissioned and delivered over the next three years to meet current and potential needs of people living in West Lothian aged 18 to 65 experiencing physical and complex disability, sensory loss and acquired brain injury. The plan was partially informed by the 2009 SWIA Self-Evaluation Guide to Strategic Commissioning[124] which offered the following definition of strategic commissioning:

‘Strategic commissioning is the term used for all the activities involved in assessing and forecasting needs, agreeing desired outcomes, considering options, planning the nature, range and quality of future services and working in partnership to put these in place’.

These features remain relevant and useful; however, can also be reviewed in the context of more recent national and local policy initiative developments such as Self-directed Support.

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[124] *SWIA Self-Evaluation Guide to Strategic Commissioning,* Social Work Inspection Agency, 2009.

In October 2013, West Lothian CHCP published a Contract Monitoring Framework for the Provision of Quality Care and Support Services.[125] This framework aims to ensure that service users receive the highest quality of service, which demonstrates value for money, meets contractual standards and is continuously improved.

The framework is applied to 'external' care and support services commissioned by West Lothian CHCP. This aim is aligned with West Lothian Council's Corporate Plan, which sets out the council's strategic direction for 2013 - 2017 to improve quality of life for people in West Lothian. The plan sets out the 8 priorities. The key priorities which contracted provision of care and support can positively influence are outlined as:

- Delivering positive outcomes and early interventions for early years;
- Improving attainment and positive destinations for school children;
- Improving the quality of life for older people;
- Minimising poverty, the cycle of deprivation and promoting equality; and
- Delivering positive outcomes on health.

The framework also highlights key principles in respect of contract monitoring. Best practise guidance relating to contract monitoring for care and support services identifies the need to minimise duplication with other regulatory bodies such as the Care Inspectorate and ensure that contract monitoring is proportionate to identified risks. There is also an emphasis on provider's responsibilities to ensure compliance with contract terms and conditions and to maintain quality assurance systems. The principles can be summarised as:

- Proportionate, seeking more detailed information only where required;
- Avoids duplication, making use of information from all available sources;
- Equitable in approach for all providers; and
- Transparent and outlines reasons for decisions.

Again, this framework remains as relevant as important, beneficial and today as it did in 2013; and its consistent application can only be mutually rewarding.

7.4.2 Recognition of good practice

RECOMMENDATION 5: Commissioners are encouraged to consider how they routinely identify, affirm and encourage good practice.

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[125] *Contract Monitoring Framework for the Provision of Quality Care and Support Services*, West Lothian Community Health and Care Partnership, 2013

Commissioners need to further encourage, identify, affirm and recognise good services and practice. Apart from the Service development Officer (Physical Disability), many study informants expressed disconnect between the needs and desires of service users and their carers, services provided and the roles and actions of senior management from West Lothian CHCP's social policy directorate. Proposed solutions include:

- Visit services and engage with staff, service users and carers;
- Learn about what makes services and staff perform better than others;
- Inspire, motivate and affirm staff and volunteers; and
- Ensure good services and practice is reported, known about and recognised.

7.4.3 Evaluation of Physical Disability, Sensory Impairment and Acquired Brain Injury Services

RECOMMENDATION 6: Consideration needs to be given to conducting ongoing, consistent and equitable evaluation of all physical disability, sensory impairment and acquired brain injury services across West Lothian.

West Lothian CHCP should develop and execute a programme which facilitates ongoing, consistent and equitable evaluation of all physical disability and sensory support services across West Lothian. The evaluation should include in-house services; not just contracted services.

7.4.4 Ensuring commissioners in West Lothian make robust commissioning decisions based on good quality evidence

RECOMMENDATION 7: Undertake regular needs assessment and specific, targeted research to address areas of unmet need and inequality.

Physical (and learning) disability commissioners in West Lothian are commended for contracting this needs assessment study. However, there is a need to continue a programme of regular needs assessments; as well as specific, targeted research such as young people, transitions, hidden populations and mutual aid/self-help networks.

7.5 Integrated Practice

Integrated Practice (Recomendations 8-15)

7.5.1 A coordinated, single point of information

RECOMMENDATION 8: Produce, maintain and coordinate West Lothian wide disability information from a single, central source, in order to ensure ready availability and accuracy.

It is logical to designate responsibility for coordinating all disability information in West Lothian to Capability Scotland's Advice and Support service. Consideration should be given regarding how best to provide this fundamental service, including satellite extension from the Ability Centre to Eliburn and Pathways centres. The consideration to have a single, central information resource in no way negates the need for all services and service providers to effectively feed into a coordinated information system, in addition to maintaining their own organisational information systems. Provision, dissemination and explanation of key information products such as Integrated Care Pathways will help to improve promote understanding and support integration and joint working.

7.5.2 Information sharing protocol

RECOMMENDATION 9: Design an information sharing protocol for use across all physical disability, sensory impairment and acquired brain injury services.

The current lack of an information sharing protocol is seen by stakeholders as problematic and an easily achievable improvement area. The development of this protocol should involve the main physical disability, sensory impairment and acquired brain injury specialist service providers, as well as GP's and other relevant stakeholder agencies, including carers and families.

7.5.3 Integrated working across all partner agencies and stakeholders

RECOMMENDATION 10: Construct an integrated working guide involving physical disability, sensory impairment and acquired brain injury specialist services, learning disability services, housing, employability, GPs, other relevant services (e.g. criminal justice and alcohol/drug) and peer led networks.

This study has highlighted inconsistencies in integrated working within, between and across specialist physical disability, sensory impairment and acquired brain injury services; and other crucial linked services, including learning disability services. In the longer-term, there would be great benefit in developing and agreeing an integrated working guide involving all relevant stakeholders.

Good Practice Reference

King Fund article on achieving Health and Social Care Integration:
http://www.kingsfund.org.uk/publications/quest-integrated-health-and-social-care?gclid=CI3U5vCksMcCFZHHtAoduRUFew

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7.5.4 Reduce physical disability and sensory impairment across West Lothian

RECOMMENDATION 11: Develop clear strategic approaches to reducing; and where possible, preventing physical disability and sensory impairment.

There is a case to focus resources at earlier stages of intervention to prevent deterioration of physical disability and sensory impairment, where possible. This approach should be aligned to the promotion of independence which may extend to addressing dependency on specialist services under certain circumstances.

7.5.5 Responsive and proactive services

RECOMMENDATION 12: Services need to be developed to be more responsive including ensuring that waiting time targets are consistently met, having clear access criteria, being available for longer hours and also ensuring that staff understand what services are available and how to appropriately refer.

There is a need for services to be more person centred, responsive, accessible, joined up/coordinated and effective to meet assessed needs; and changing needs. This will require a review of inclusion and exclusion criteria, access routes, opening times, programmes/interventions/activities, discharge, throughcare and re-entry arrangements; viewed primarily from the perspectives of service users and their carers. Peer led mutual aid/self-help networks must be a key feature of new practice culture.

Good Practice Reference

Visibility Early Intervention project

www.visibility.org.uk (Valerie Breck, Operational Director).

Provide assessment for people who are recently diagnosed with a severe visual impairment where Glasgow City Council is unable to do so and so prevent long waiting lists.

7.5.6 The role of IT in mental health support

RECOMMENDATION 13: Commissioners need to work with providers to look at how IT can be more effectively used to enhance appropriate support.

Examples include:

- Web-based advice;
- Information and support including email referral and communication systems; and
- Integrated records.

7.5.7 Strengthening the Third Sector and peer support across West Lothian

RECOMMENDATION 14: Enhance the role and availability of the third sector and peer support services and networks to support integrated care and outcomes for people.

The third sector is 'business critical' as a fundamental element of any solution concerning the health and wellbeing challenge in West Lothian. However, some third sector organisations have expressed issue type sentiments such as being under funded, utilised and valued. It is evident that the third sector can continue to make a vast impact on results at an individual, family, local community and wider societal basis.

Working together with commissioners with commonly identified and agreed goals, third sector organisations must better demonstrate their effectiveness; particularly in terms of outcomes for people and their carers. However, statutory physical disability and sensory specialist support services must also demonstrate their results and be held accountable for performance. In-house services are not monitored under the Contract Monitoring Framework for the Provision of Quality Care and Support Services (see **7.4.1**) which is a model which commissioners may seek to review in the future.

Currently, peer support networks, activities and initiatives in West Lothian are lacking; notwithstanding the endeavours of a few third sector organisations. However, there needs to be heavier investment including financial backing to developing peer support/mutual aid models and practices to complement more conventional services.

Good Practice Reference

Moving out of Home - The Lothian Centre for Inclusive Living (LCiL) hosts a peer support group for parents and carers of disabled children and children with additional support needs. A recent meeting focused on 'Moving out of home' with input from Housing Options Scotland on the pathway for a young disabled person moving out of home. ***http://www.lothiancil.org.uk***

VOCAL - The Lothian Centre for Inclusive Living (LCiL) and VOCAL Midlothian Carer Centre are hosting a two-part workshop for parents and carers of disabled children/young people and children with additional support needs living in Midlothian. ***https://www.carerstraining.co.uk/***

Home from Hospital – Voluntary Action East Renfrewshire – An initiative led by the Third Sector interface uses a co-production and asset-based approach to supporting people. ***Anne.Kidd@va-er.org.uk*** [0141 876 9555].

Opportunity and Independence: East Lothian's Joint Strategy for Physical Disability or Hearing or Sight Loss Good practice reference

East Lothian's Joint Strategy for Physical Disability or Hearing or Sight Loss 2013-2020

7.5.8 Increasing the profile of Service Users and their Families/Carers

RECOMMENDATION 15: Consideration should be given to developing a clear framework for how service users and their families/carers could and should be involved in the commissioning, delivery, development, monitoring and evaluation of specialist physical disability, sensory impairment and acquired brain injury services, and the wider system.

The evolution, planning and development of community assets, services, and commissioning processes should be built around the ambitions of service users and their families/carers within an independence-orientated system of care. Developing services in this way will not only provide benefits to people who use services, but will also help develop community based mutual aid and peer support networks, thereby enhancing the ability for people to move on from services. The first step should be to develop a meaningful West Lothian-wide consultation system which would enable service users and families/carers to work in collaboration with commissioners and services to develop a long-term inclusion and involvement strategy.

Service users and carers must also be instrumental in developing an overarching, integrated West Lothian strategy for disability and sensory impairment. Several service users, as well as some carers and service provider staff across different roles and grades, have largely described service user involvement using terms such as infrequent, tokenistic, and piecemeal; and affiliated to specific tasks or consultations, rather than an ongoing feature of continuous learning and development.

7.6 Workforce Development

Workforce Development (recommendation 16)

Integration represents a seismic change for services, in terms of operations, governance and workforce development. It demands a change of mindset and a maximisation of use of resources in an efficient and effective way. Services and individual professionals working closely together will bring about improvement and better outcomes for each person. This cultural journey needs to start now at all levels of services. Engagement by the workforce with this agenda is paramount and support from West Lothian Organisational development resources within NHS and West Lothian Council may be a source of support to physical disability, sensory impairment and acquired brain injury services alike.

7.6.1 Developing an experienced, flexible, responsive and hopeful workforce

RECOMMENDATION 16: Devise a long-term programme of workforce development opportunities.

The transition to outcomes-focused working and the development of new leadership structures has opened up demand for new skills, competencies and scope of service delivery in the workforce.

Consideration should be given to undertaking a training needs analysis and development of a training schedule for specialist and generic staff and other stakeholders (including carers/families) who support people with physical disability and sensory impairment.

Good Practice Reference

Midlothian Voluntary Action Training plan and newsletter: ***http://mvacvs.org/index.php/our-services/training***

Mindspace Recovery College covering Perth & Kinross – information available at: ***http://www.mindspacepk.com/recovery-college/***

7.7 Empowerment, Independence and Achievement

Empowerment, Independence and Achievement (recommendations 17-18)

7.7.1 Visibility of achievement is critical to demonstrate the power and possibility of empowerment and personal independence

RECOMMENDATION 17: Promote empowerment and personal independence; and celebrate achievement.

People with physical disability and sensory impairment can and do achieve optimal independence and associated life gratification. There is a greater need in West Lothian to promote empowerment and independence; and also to celebrate achievement. Currently, the level and nature of such endeavour is sporadic and limited. The term, 'independence' is not routinely used in West Lothian and there are many interpretations of what 'independence' means. In certain circumstances, particularly for people with severe and enduring conditions; concepts of full empowerment and independence are lacking which may mitigate aspirations being identified and achieved.

7.7.2 Furthering the personal independence agenda

RECOMMENDATION 18: Learn from experience and emerging evidence; and forge alliances to support networks and communities.

Throughout West Lothian, there has been limited momentum gained in respect of ground level and bottom up peer led communities; for example, the Vision Support Group and Sensory Impairment Group provides mutual self-help to people with a range of emotional, practical, social and other needs. There is opportunity to learn from the experience of this network; and to forge alliances to support the future development of support networks and communities, for which there is a demonstrable need.

7.8 In summary

In summary, this study has a number of limitations in common with other health and social care needs assessments. However, the assumptions and limitations have been clearly described in the body of the report, and due caution should be exercised in interpreting the findings. It will be for future research to address the limitations of the current study.

WEST LOTHIAN STRATEGIC PLANNING GROUP

Date: 7 April 2016	
Agenda Item: 7	

LOCALITIES GROUPS – TERMS OF REFERENCE

REPORT BY DIRECTOR

A PURPOSE OF REPORT

To provide for the consideration of the members of the Strategic Planning Group (SPG) proposed terms of reference including membership of two Locality Groups as required within West Lothian IJB Integration Scheme and Strategic Plan.

B RECOMMENDATION

1. To agree terms of reference including membership of two Locality Groups as required within West Lothian IJB Integration Scheme and Strategic Plan be finalised and submitted for approval by the IJB.
2. To agree to deliver a development event for locality group members in June 2016.

C TERMS OF REPORT

In accordance with the Public Bodies (Joint Working) (Scotland) Act 2014 West Lothian Council and NHS Lothian prepared an integration scheme for West Lothian. The scheme was approved on 16 June 2015. The legislation requires that the Strategic Plan includes arrangements for the area of West Lothian to be divided into at least two localities, to be determined by the IJB, and for the Plan to include measures for strategic aspects of services to be delivered to those different localities.

The IJB approved its Strategic Plan on 31 March 2016. The plan defined two localities across which our health and care services will be planned. The Strategic Plan notes that the way health and social care services are delivered locally can have a significant impact on addressing the main health and wellbeing challenges. To ensure the quality of localities' involvement in strategic planning, Locality Groups will be formed with the direct involvement and leadership of:

- Health and social care professionals involved in the care of people who use services
- Representatives of the housing sector
- Representatives of the third and independent sectors
- Carers and patients' representatives
- People managing services

Appendix 1 provides draft terms of reference for the Locality Groups. The Strategic Planning Group is invited to consider this draft. The intention is to present a report to the IJB seeking approval for the establishment of the Locality Groups within approved terms of reference.

It is also recommended that a development event be hosted in June 2016 for identified members of both locality groups for the purpose of providing background context for the work of the locality groups and of developing workplan priorities for 2016-17for each group.

D CONSULTATION

- Relevant council and health board officers

E REFERENCES/BACKGROUND

- Public Bodies (Joint Working) (Scotland) Act 2014, and related statutory instruments and guidance
- Scottish Government Guidance and Advice - http://www.gov.scot/Topics/Health/Policy/Adult-Health-SocialCare-Integration/Implementation/ImplementationGuidance
- West Lothian IJB Strategic Plan 2016-2026

F APPENDICES

1. Locality Group terms of reference draft

G SUMMARY OF IMPLICATIONS

Equality/Health	This report has been assessed as having little or no relevance with regard to equality or the Public Sector Equality Duty. As a result, an equality impact assessment has not been conducted.
National Health and Wellbeing Outcomes	None
Strategic Plan Outcomes	None
Single Outcome Agreement	None
Impact on other Lothian IJBs	None
Resource/finance	None

Policy/Legal	Public Bodies (Joint Working) (Scotland) Act 2014 and statutory regulations and guidance
Risk	None

H CONTACT

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7 April 2016

West Lothian Health & Social Care Partnership | NHS Lothian | West Lothian Council

[Area] Locality Group

Terms of Reference and Membership

A. Remit of Locality Group

The West Lothian Integration Joint Board (IJB) has established two localities within West Lothian in accordance with the requirements of the Public Bodies (Joint Working) (Scotland) Act 2014.

The localities have been built up from 2011 datazones to support data capture for planning purposes and aligned as best fit to General Practice (GP) populations and multi-member wards to support development of integrated models around GP Practice clusters as well as localities. The geographies of the localities are laid out in section G.

The *[Area]* Locality Group is to provide an organisational mechanism for local leadership of service planning, to be fed upwards into the IJB Strategic Commissioning Plan and to influence how resources are utilised in their area.

The purpose of the *[Area]* Locality Group is to:

- Support the principles that underpin collaborative working to ensure a strong vision for service delivery.
- Support GPs to play a central role in providing and coordinating care to local communities and by working more closely with others – including wider primary care team, secondary care, social care colleagues and third sector providers - to help improve outcomes for local people.
- Support a proactive approach to capacity building in communities and better integrated working between primary and secondary care.
- Provide a consultative function to the Integration Joint Board when a decision is to be made that is likely to significantly affect service provision in a locality.

The *[Area]* Locality Group will develop a locality plan which will take account of community plans and local regeneration plans within the localities. It is anticipated that the locality plan will build on the insights, experiences and resources in localities to support improvements in local networks, enable development of robust and productive professional relationships and improve health and wellbeing outcomes.

The locality plan will include

- A list of all services under the management of the IJB of which the locality is a part
- A note of the priorities for each locality under each of the service headings
- Planned expenditure for each service heading, using the locality budget as

determined taking account of population need and any factors relating to provision of services in the area.

The locality plan will be consistent with appropriate commitments within the following related high level strategies: West Lothian IJB Strategic Plan, care group Commissioning Plans, West Lothian Health and Social Care Partnership (HSCP) Engagement Framework, West Lothian Single Outcome Agreement, NHS Lothian Local Delivery Plan, NHS Lothian Clinical Strategy, West Lothian Housing Strategy, and West Lothian Council Corporate Plan.

B. Frequency

The group will meet quarterly.

C1. Lead Officer

The group will be chaired by [Head of Service].

C2. Contact

The Lead Officer will be supported by support officer/s from within West Lothian HSCP.

D. Reporting

The group will report to the West Lothian Integration Strategic Planning Group in accordance with the IJB Strategic Plan.

E1. Membership Profile

Participants are chosen in line with the Health and Social Care Localities Guidance, July 2015 to provide the relevant knowledge and expertise to fulfil the remit of the group.

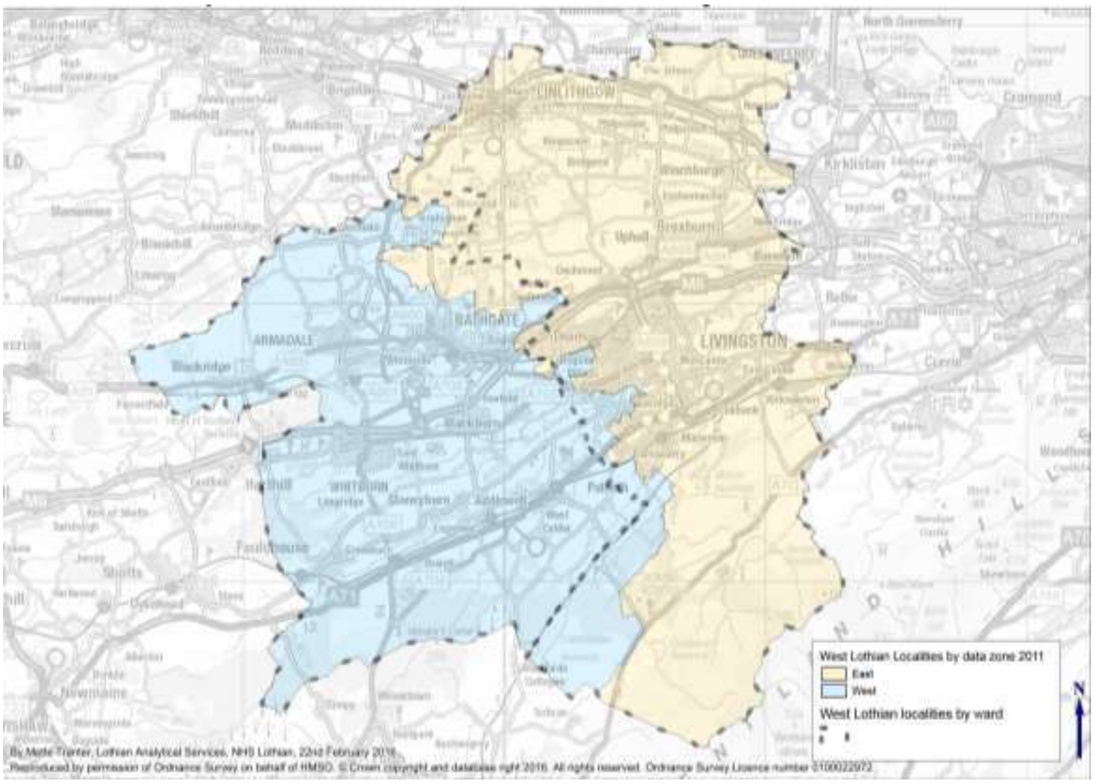
E2. Membership

Member	Role
	Lead Officer
	GP representative
	Health Care representatives
	Housing representative
	Social Care representatives
	Third sector provider representative/s
	Independent sector representative/s
	Service user representative/s
	Carer representative/s
	Do you want to include anyone from CPP regneration team?

F. Review

The terms of reference will be reviewed on an annual basis.

G. Locality areas



WEST LOTHIAN STRATEGIC PLANNING GROUP

Date: 7/04/2016	
Agenda Item: 8	

PARTICIPATION AND ENGAGEMENT STRATEGY

REPORT BY DIRECTOR

A PURPOSE OF REPORT

The purpose of this report is to update members of the Strategic Planning Group (SPG) on progress in preparing the West Lothian Health and Social Care Participation and Engagement Strategy (attached as appendix 1)

B RECOMMENDATION

It is recommended that the SPG:

1. notes the draft Participation and Engagement Strategy;
2. provides guidance on finalisation of the strategy; and
3. notes the intention to submit the finalised strategy for approval by the Integration Joint Board (IJB) on 31 May 2016

C TERMS OF REPORT

C.1 West Lothian Integration Scheme

The approved Integration Scheme commits NHS Lothian and the council to developing a Participation and Engagement Strategy which will ensure significant engagement with, and participation by, members of the public, representation groups and other organisations in relation to decisions about the carrying out of delegated functions. This will include using existing forums, networks and stakeholder groups with an interest in health and social care. The strategy is to be approved by the IJB within one year of the establishment of the IJB and must be reviewed regularly by the IJB.

C.2 IJB Stategic Plan

The draft West Lothian IJB Strategic Plan 2016-26 recognises that “communities are the engine house for delivering transformation and, in order to realise our vision, the planning and delivery of services must take account of needs at the local level”

The Strategic Plan commits to bringing together NHS and council Social Policy engagement activity in a Participation and Engagement Strategy to deliver a "single, unified, systematic approach which will improve standards of engagement and involvement across all services and staff groups, with the goal of improving outcomes for patients and service users".

C.3 Draft Strategy

Taking into account the requirements of the Integration Scheme and the above commitment in the Strategic Plan, officers have prepared a first draft of the Participation and Engagement Strategy for comments by the SPG.

The draft plan comprises three sections:

1. Overview

2. Community Participation and Engagement

3. Communication

Section 1 of the draft sets the context for the strategy within relevant legislation and national policy drivers, the Single Outcome Agreement 2013-33 and Strategic Plan, commits to the principles set out in the National Standards for Community Engagement 2005 and the Participation Strategy for the NHS in Scotland 2010 and provided an undertaking to building on the Investment in People Standard, with which both organisations are accredited.

Section 2 sets out five key objectives for the strategy, as follows:

1. Develop and roll-out effective engagement with staff, customers and the wider public.

2. Co-ordinate the consultation and engagement activity of services.

3. Provide opportunities for communities and individuals to get involved in decisions that affect their lives.

4. Provide opportunities for staff to influence decisions that affect their working lives and the service experience of their customer groups.

5. Measure the success of engagement activity.

Section 2 also outlines potential methods of engagement, including within localities, commit to sharing and learning from best practice and identifies the challenges in bringing together the approaches of the NHS Lothian and West Lothian Council.

Section 3 explains the role and objectives of the Health and Social Care Partnership communications team.

C.4 Next Steps

Officers will finalise the draft strategy over the next month in consultation with key stakeholders with a view to presenting a finalised strategy to the IJB for approval at its meeting on 31 May 2016.

In particular, it is proposed to develop an action plan which will identify specific activities to be undertaken in the coming year.

The SPG is invited to provide guidance on the work required to fund the plan. Alternatively, officers will be happy to arrange individual discussions over the next few weeks.

D CONSULTATION

Consultation has taken place with relevant council and health board officers and stakeholders and this work will continue as the plan is finalised.

E REFERENCES/BACKGROUND

Public Bodies (Joint Working) (Scotland) Act 2014 and related statutory instruments and guidance.

Draft West Lothian IJB Strategic Plan 2016-26.

F APPENDICES

1. Draft West Lothian Health and Social Care Partnership Participation and Engagement Strategy

G SUMMARY OF IMPLICATIONS

Equality/Health	The draft strategy will be assessed to determine if an equality impact assessment is required.
National Health and Wellbeing Outcomes	The draft strategy is consistent with national health and well-being outcomes.
Strategic Plan Outcomes	The draft strategy delivers the Strategic Plan undertaking to prepare a participation and engagement strategy.
Single Outcome Agreement	The draft strategy is consistent with the Single Outcome Agreement.
Impact on other Lothian IJBs	Opportunity to share best practice.
Resource/finance	The strategy will be implemented from existing resources.
Policy/Legal	Public Bodies (Joint Working) (Scotland) Act 2014 and statutory regulations and guidance.
Risk	None.

H CONTACT

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7 April 2016

Data Label: PUBLIC

West Lothian Health and Social Care Partnership

Participation and Engagement Strategy

2016 - 2026

1 Overview

1.1 Background

The West Lothian Health and Social Care Partnership engages with a range of stakeholders (customers/patients, staff and the public) in the delivery of a substantial range of NHS and council services including: community care, personal care, residential care, continuing care, health improvement, mental health, general practitioner, dental, pharmacist, district nursing, health visiting, allied health professions, community-based children's services, learning disabilities, physical disabilities, Tobacco, Alcohol and Drug Partnership (TADP) and criminal justice.[1]

Priority outcomes for the West Lothian Health and Social Care Partnership, as included in the West Lothian Community Planning Partnership Single Outcome Agreement 2013-23 and the West Lothian Health and Social Care Partnership Strategic Plan 2015-XX, are informed by national and local strategy and include:

- Our children have the best start in life and are ready to succeed
- Older people are able to live independently in the community with an improved quality of life
- We live longer, healthier lives and have reduced health inequalities
- People most at risk are protected and supported to achieve improved life chances (delivered in conjunction with the Community Safety Board).

Key elements in the approach of the West Lothian Health and Social Care Partnership to reduce the health inequalities gap and improve wellbeing include:

- Early intervention, prevention, anticipatory care
- Managed care pathways around the person
- Integrated teams and systems
- Seamless frontline services.

The West Lothian Health and Social Care Partnership Participation and Engagement Strategy 2016-26 will provide a structured approach to the engagement of stakeholders in the development and delivery of West Lothian Health and Social Care Partnership services,

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[1] The West Lothian Integrated Joint Board has governance for some but not all of these services. The majority of Children and Families services, and Criminal and Youth Justice services are not within the integration scheme and are therefore subject to the governance of the parent organisation. However, all these services are operationally managed through the West Lothian Health and Social Care Partnership.

and is applicable to existing partnership services, plus hosted services and those that will be amalgamated into the partnership following integration.

1.2 Vision and Context

The West Lothian Health and Social Care Partnership Participation and Engagement Strategy relates closely to the Community Planning Partnership Community Engagement Plan (as required for the West Lothian Single Outcome Agreement) and the Scottish Government commissioned report: Future Requirements and Possibilities for Public Involvement in Health and Social Care, (Scottish Health Council, June 2013); and is in line with the National Standards for Community Engagement, Scottish Health Council Participation Standard, the Customer Service Excellence Standard, the Commission on the Future Delivery of Public Services (Christie Commission report), the Public Sector Improvement Framework, and the United Nations Convention on the Rights of the Child (UNCRC).

The West Lothian Health and Social Care Partnership Participation and Engagement Strategy has the aim to draw together NHS and council Social Policy engagement activity within a single unified systematic approach which will improve standards of engagement and involvement across all services and staff groups, with the goal of improving outcomes for patients and service users.

In 2013, the Scottish Health Council[2] noted that there were noticeable differences in how NHS and local authorities approached engagement across Scotland that reflect their different models of practice (i.e. medical and social models), there was inconsistent application of engagement across services, and crucially that engagement activity did not consistently result in improvements to services.

As cited in the Scottish Health Council research, West Lothian Health and Social Care Partnership (previously the West Lothian Community Health and Care Partnership) enters into this strategy with already well-established mechanisms for engagement[3]. However, the following new developments and national drivers compel and motivate us to improve on our existing good practice:

- Public Bodies (Joint Working)(Scotland) Act 2014

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[2] Scottish Health Council (2013) Future Requirements and Possibilities for Public Involvement in Health and Social Care, June 2013,

[3] pp78-84

- Children and Young People (Scotland) Act 2014
- Public Sector Equality Duty
- Social Care (Self-directed Support) (Scotland) Act 2013
- Getting It Right For Every Child
- Reshaping Care for Older People
- Caring Together: The Carers Strategy for Scotland 2010 – 2015
- Getting it Right for Young Carers: The Young Carers Strategy for Scotland 2010-2015

The West Lothian Health and Social Care Partnership Participation and Engagement Strategy is intended to unite and improve practice across customer engagement, workforce engagement and public communication.

1.3 Overarching Principles of Engagement

The strategy draws together engagement activity aligned to two complementary standards of engagement: The National Standards for Community Engagement[4], launched in 2005 and developed for use within Community Planning Partnerships; and the Participation Standard for the NHS in Scotland[5], which was developed by the Scottish Health Council in 2010 to enable NHS Boards to deliver their participation responsibilities.

The following principles, taken from the National Standards for Community Engagement[6], underpin the West Lothian Health and Social Care Partnership Participation and Engagement Strategy:

- Fairness, equality and inclusion must underpin all aspects of community engagement, and should be reflected in both community engagement policies and the way that everyone involved participates.
- Community engagement should have clear and agreed purposes, and methods that achieve these purposes.
- Improving the quality of community engagement requires commitment to learning from experience.

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[4] Communities Scotland (2005) National Standards for Community Engagement;

[5] Scottish Health Council (2010) A Participation Standard for the NHS in Scotland;

[6] p5

- Skill must be exercised in order to build communities, to ensure practise of equalities principles, to share ownership of the agenda, and to enable all viewpoints to be reflected.
- As all parties to community engagement possess knowledge based on study, experience, observation and reflection, effective engagement processes will share and use that knowledge.
- All participants should be given the opportunity to build on their knowledge and skills.
- Accurate, timely information is crucial for effective engagement.

Within the strategy, engagement methodology should be based on evidence of good practice, appropriate for use with the relevant stakeholder groups and proportionate to the purpose of engagement.

So that engagement results in improvements, it is recommended that a tool such as VOiCE[7] (Visioning Outcomes in Community Engagement) is used to plan, implement and review the effectiveness of the engagement, with feedback to stakeholders being a key element of the engagement process.

With regard to staff engagement, the West Lothian Health and Social Care Partnership Participation and Engagement Strategy builds on the Investors in People (IIP) standard with which both NHS Lothian and West Lothian Council are separately accredited.

The Investor in People framework enables organisations to improve their performance through the workforce, by developing effective strategies for business, learning and development, leadership and management; managing the workforce effectively, recognising and valuing their contribution, involving the workforce in decision-making and measuring the impact of workforce engagement activity.

Four key enablers to engagement were identified in the MacLeod Review[8] :

- *Leadership* expressing the purpose and vision of the organisation and how individuals' work contributes to the organisation's purpose. Organisational culture should be characterised by "stretch, discipline, trust and support".
- *Engaging managers* to facilitate and empower staff; to treat staff with appreciation and respect; to show commitment to developing, increasing and rewarding the capabilities of staff.

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[7] http://www.voicescotland.org.uk/

[8] MacLeod, D & Clarke, N (2009) Engaging for success: enhancing performance through employee engagement: A report to Government, Dept of Business, Innovation and Skills

- *Voice*: employees' views are sought, listened to and responded to; staff should be able to speak out and challenge when appropriate
- *Integrity*: Behaviour throughout the organisation is consistent with the organisation's values and leads to trust and integrity.

The MacLeod Review recommends an embedded approach to engagement where "employees are at the heart of strategy development and delivery" and where their insights and ideas are regularly sought, and put into action.

2 Community Participation and Engagement

2.1 Objectives

In line with the West Lothian Community Planning Partnership Community Engagement Plan, the West Lothian Health and Social Care Partnership Participation and Engagement Strategy has the following objectives:

Table 1

Objective	**Related outcomes**
1. All service areas within the WL H&SCP will develop and roll out effective engagement with its staff, customers and wider public	Develop an agreed understanding of community engagement and its desired outcomes across all service areas of the WL H&SCP
	Build the capacity of staff and stakeholders to engage effectively with customers and public
	Build the capacity of managers to engage effectively with staff
	Contribute to the CPP database of good practice in engagement, and utilise this in engagement activities
2. Coordinate the consultation and engagement activity of services	Develop structures to share information re planned engagement activity
	Develop structures to share findings of engagement activity within the WL H&SCP and with other partners as relevant
3. Provide opportunities for communities and individuals to get involved in decisions that affect their lives	Develop clear processes for agreeing who needs to be engaged with, at what level, for specific issues
	Develop clear processes which consider the most appropriate ways to involve and engage customers and

	communities
4. Provide opportunities for staff to influence decisions that affect their working lives, and the service experiences of their customer groups	Develop clear processes for agreeing which staff groups should be engaged with, at what level, for specific issues
	Develop clear processes which consider the most appropriate ways to involve and engage staff groups
5. Measure the success of engagement activity	Develop clear processes which consider the most appropriate ways to involve and engage customers and communities, and staff groups

The West Lothian Health and Social Care Partnership Participation and Engagement Strategy:

- supports the outcomes of the West Lothian Health and Social Care Partnership's major workstreams: Reshaping Care for Children, Reshaping Care for Older People, and Reducing Reoffending;
- supports delivery of the 10-year Single Outcome Agreement for West Lothian – Achieving Positive Outcomes
- reflects best practice in the engagement of marginalised customer populations;
- develops further existing good community engagement practice across Social Policy and NHS,
- embeds customer engagement systemically and as routine across the West Lothian Health and Social Care Partnership,
- embeds staff engagement systemically and as routine, linking to the Organisational Development Plan, and
- in particular ensures that engagement results in improvements in service delivery.

2.2 Types of Engagement and Methods

Community and customer engagement is carried out for different purposes, and methods of engagement should be appropriate to the purpose, acceptable to the participants and suitable for their needs and circumstances.

West Lothian Health and Social Care Partnership service users include people with learning disabilities, physical disability and sensory loss and the method of engagement used should always be acceptable and suitable for their needs. The language and cultural needs of people from minority ethnic communities should also be considered when identifying methods of engagement.

Methods should identify, involve and support excluded groups and should be chosen to enable diverse views to be expressed. Methods should be evaluated and adapted in response to feedback.

Table 2

Example of good practice for different service user groups		
Methods/ *Purpose*	***Methods of participation and engagement for Children and Young People***	***Methods of participation and engagement for Adults and Older People***
Strategic planning	Having Your Say	*Senior Forum*
Service improvement	Investing in Children	Safe and Sound Adult Protection Forum
Care planning	Single Child's Plan Viewpoint	Single Shared Assessment (SSA)

A variety of methods should be used, the deployment of which will depend on the objective, timescale and nature of the engagement / event.   Methods will include forums, advocacy, engagement events, face to face interaction, surveys / questionnaires, pre and post-course evaluations, participatory appraisal tools.

2.3 Levels of participation and engagement

The Guide to Participation, developed in 1994 by David Wilcox [9], offers a simple and effective way to manage engagement. Wilcox's framework has five levels which offer increased stakeholder control, the top three offering a desired 'substantial' level of participation.

Table 3

Level	**Description**
Supporting Independent Stakeholder Initiatives	Helping others do what they want
Acting Together	Deciding together and forming a partnership to implement change

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[9] Wilcox (1994) The Guide to Effective Participation, Joseph Rowntree Trust

Deciding Together	Encourage others to provide additional ideas and options, and join in deciding the best way forward
Consultation	Offer options and listen to the feedback
Information	Telling people what is planned

In order to engage in the process of participation, Wilcox outlines four phases:

Table 4

Phase	**Description**
Initiation	Something triggers the need to involve people and you start to think what that involves
Preparation	Thinking through the process, identify all the stakeholders and agree an approach
Participation	Using appropriate participation methods
Continuation	Depends on the level of participation – might involve feedback on consultation or setting up partnership

Wilcox[10] says that the following issues should determine the method used:

- different levels of participation are appropriate for different situations
- there isn't one 'community' but many interests and stakeholders to consider
- participation takes time
- we should be clear about our role in the engagement activity

Wilcox offers a grid of options for participation which provides a useful orientation and method of categorising the various engagement activities across the West Lothian Health and Social Care Partnership (appendix 1).

2.4 Engagement Activity

The West Lothian Health and Social Care Partnership is a statutory community planning partner, and as such subject to duties placed on Community Planning Partnerships by the Community Empowerment (Scotland) Act.

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[10] p8

Within the community planning arrangements, the West Lothian Health and Social Care Partnership has significant engagement with key delivery partners including Health, Education, Police Scotland, SCRA, Scottish Government, Scottish Prison Service, Victim Support, private providers, the voluntary sector, ethnic minority groups and religious / interfaith and belief groups.

Localities Guidance requires integrated bodies to agree geographical localities within its boundaries with the objective of engagement with key stakeholders. The guidance states:

> "*localities exist to help ensure that the benefits of better integration reach all the way into communities and people's lives, and that the contribution of individuals and communities reaches all the way into, and informs, service redesign and improvement*"[11]

Across localities, participation and engagement activities should support the direct participation of GPs and the range of professionals involved in the direct care of patients/service users in acute and community service sectors; representatives of the housing sector, third and independent sectors, care and patient representatives, and people managing services within the area.

Information from local and national sources, health profiles and Scottish Index of Multiple Deprivation (SIMD) data can be used to identify and target engagement activities.

The West Lothian Health and Social Care Partnership is committed to taking an inclusive approach to the involvement of service users, their carers and key stakeholders in strategic and service planning processes. We should identify and involve those people and organisations who have an interest in engaging and identify and overcome any barriers to participation. The principles of personalisation and choice are embedded within our strategic approach to the commissioning of social care services and should ensure that we enable individuals alone, or in groups, to find the right solutions for them and to participate in the delivery of service.

An increasing requirement for outcomes-focused strategic commissioning and delivery has further reinforced the need for effective and meaningful engagement with our service users and their families and carers in the planning of services.

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[11] p6 Health and Social Care Integration, Public Bodies (Joint Working)(Scotland) Act 2014 Localities Guidance, Draft 23 March 2015

Many of our services operate by receiving referrals from other specialist partners / enforcement agencies. In the case of enforcement agencies much of our consultation activity is defined by statutory guidance.

Engagement can be evidenced through a range of reports including survey results, evaluation of engagement events / training courses, reviews of statutory orders, reviews of care plans, participatory appraisal (PA) tools, minute of joint meetings, case notes.

Table 5

Examples of good practice using participation and engagement methods	**Level of Participation (from table 3)**
Health Issues in the Community	Supporting
A training programme aimed at increasing community capacity, increasing community participation, and establishing/ consolidating community development approaches to tackling inequalities in health.	
Having Your Say Forum	Supporting
A youth forum for Looked After young people in West Lothian. It brings together a cross section of Looked After children and young people and provides a platform to raise and explore issues pertinent to them. The Having Your Say forum is one mechanism by which young people can influence decisions that affect their lives and play a part in shaping the services they receive.	
Delivering Better Outcomes public consultation	Consultation
The Delivering Better Outcomes consultation sought the views of council staff, community groups and the public about the council's priorities for a 5-year period and how services could be delivered in a better way to achieve a balanced budget. The consultation had 2,953 submissions and 17,738 comments and suggestions.	

2.4 Performance and Improvement Measures

As a learning organisation, West Lothian Health and Social Care Partnership should act on the findings of community engagement to improve service delivery and outcomes. Organisers of community engagement activities should undertake to feedback to all those affected the options that have been considered and the decision and actions that have been agreed.

Many of our services are delivered in a shared manner either with our internal West Lothian Health and Social Care Partnership partners or with one or more of the many agencies which we have external partnership arrangements. Where appropriate and relevant, information should be shared routinely to evaluate and improve service delivery / design. This can be via written reports, newsletters, You Said We Did, forums, support groups.

Information should be shared in a variety of formats and media channels to reflect the wide and varied needs of our service users and enable people to have as full a part as possible in the process. Information should be routinely provided in Plain English and should take consideration of language and ethnicity requirements. Activities should be subject to Equality Impact Assessment to ensure we do not unintentionally discriminate against groups of service users when developing and implementing plans.

Information should include details about opportunities for future involvement and encourages positive contributions from groups and individuals in the community.

So that the engagement approach can be systemically and consistently applied across the West Lothian Health and Social Care Partnership, engagement champions will be identified to work with each locality area.

A Community Engagement Practitioners Network has been set up with representatives from across the Community Planning Partnership to quality assure and develop the SOA Community Engagement Plan. Consideration will be given to incorporating the engagement champions into the Practitioners Network or otherwise linking engagement champions with the Practitioners Network.

The West Lothian Health and Social Care Partnership Engagement Champions will:

- Develop and oversee the implementation of an annual action plan
- Coordinate engagement activity across locality/service areas
- Disseminate and champion good practice
- Monitor the quality of engagement activity
- Monitor the impact of engagement on equality groups
- Monitor the outcome of engagement activity

2.5 Challenges and Practical Action

Engagement, when effectively implemented, can be resource intensive, although benefits can be great. There should be an audit of current engagement activity, which should recommend where existing resources can be redesigned and reused, and consider what additional resources may be required.

There are practical challenges such as engaging minority populations, people with learning disabilities, cognitive impairments, physical disabilities and sensory impairment. The West Lothian Health and Social Care Partnership Participation and Engagement Strategy should be subject to an early Equalities Impact Assessment that engages with groups with protected characteristics.

Both parent organisations, West Lothian Council and NHS Lothian hold separate Investors in People (IIP) awards. Whilst the IIP approach is familiar to both organisations, the implementation of workforce engagement activities have historically been different in each organisation.

The approach to consultation and engagement with the trades unions is markedly different in NHS and in local authority. There are significant challenges to the development and implementation of a consistent approach across the West Lothian Health and Social Care Partnership.

Employee engagement should be an ongoing process embedded in the organisation’s structure, with significant effort required to embed cultural integrity. This is a particular challenge though periods of organisational change.

3 Communication

3.1 Activities

NHS Lothian and West Lothian Council Corporate Communications Services have jointly established a framework to enable the West Lothian Health and Social Care Partnership to communicate efficiently and effectively with all key audiences, acknowledging the importance of having a co-ordinated approach to internal and external communications (including media relations) with common values and common messages.

A West Lothian Health and Social Care Partnership communications team is made up of representatives from the West Lothian Health and Social Care Partnership, West Lothian

Council Corporate Communications Team, and NHS Lothian Corporate Communications Team.

The function of the communications team is to:

- Share ideas and best practice in order to develop the profile of the West Lothian Health and Social Care Partnership
- Raise the profile of the West Lothian Health and Social Care Partnership to internal and external audiences
- Assist with building an understanding of the West Lothian Health and Social Care Partnership among staff
- Help promote and publicise West Lothian Health and Social Care Partnership services to improve access to local people
- Support the communications officers in the delivery of communications strategy and plan
- Ensure an integrated approach to all communications activities

The objectives of internal communications are:

- To promote the West Lothian Health and Social Care Partnership identity internally to the partnership
- To ensure staff understand the West Lothian Health and Social Care Partnership and represent it in a consistent way, with awareness of all shared goals and key messages
- To provide communications support and advice to West Lothian Health and Social Care Partnership staff
- To communicate in an open and honest manner
- To release and exchange information in a timely two-way process
- To provide open and transparent opportunities to consult with staff - getting their views, and offer ideas and suggestions
- To keep staff informed about organisational developments within the West Lothian Health and Social Care Partnership

The objectives of external communications are:

- Externally, to raise awareness of the West Lothian Health and Social Care Partnership in West Lothian
- To promote the West Lothian Health and Social Care Partnership structure as a excellent model of health and social care, in which we provide the best possible services for local communities
- To inform target audiences on developments, service changes etc
- To promote the West Lothian Health and Social Care Partnership in the wider public forum

- To publicise events
- To encourage feedback from local people and use the feedback to improve services
- To develop relationships with key media

The communications team works together to produce a Communication Plan that utilises evidence based methods of communication and public engagement. The Communication Plan is updated as required and reviewed regularly by the communication team. A wider variety of communication methods is used, including printed literature, email, Website, Social media, press and media.

The key messages of the communications strategy are:

- The West Lothian Health and Social Care Partnership is a partnership between NHS Lothian and West Lothian Council,
- The West Lothian Health and Social Care Partnership provides a wide range of community based health and social care services delivered in the community, homes, health centres and clinics,
- The West Lothian Health and Social Care Partnership is committed to continuously improvement, developing high quality local health and social care services to meet your needs.

Table 6

Examples of good practice using communication media	**Level of Participation (from table 3)**
West Lothian Health and Social Care Partnership website *The website provides a one-stop access point for information on all services within the West Lothian Health and Social Care Partnership and by giving local people up-to-date accurate information when they need it, will improve their access to health and social care services in West Lothian.*	Information
Twitter and Facebook *It is important to ensure that all media channels are used in order to reach our wide-ranging target audiences. NHS Lothian's corporate communications team and West Lothian Council each has a Twitter account and Facebook page which will be used to promote positive messages on campaigns, initiatives and services.*	Information/ Consultation
Community Newsletters *The Bulletin is a West Lothian Council newsletter delivered to every home and business in West Lothian four times each year.*	Information

Health Link is an NHS Lothian newsletter aimed at the public and is produced four times each year.	
Staff Newsletters	Information
West Life highlights news, projects, and initiatives to West Lothian Health and Social Care Partnership staff three times yearly.	
Inside St John's is a monthly newsletter highlighting health service developments at St John's Hospital and in the community. This is circulated to staff and a wide range of stakeholders within the local community.	
Foster carer recruitment drive	Information
Campaign required to recruit foster carers and promote foster caring	
Project LISA	Information
Promote the LISA project and promote a strong message against violence against women	

3.2 Performance and Improvement Measures

The communications team monitors media reporting of council related information and compiles statistical information which is reported on Covalent. The West Lothian Health and Social Care Partnership has access to well-developed social media with popular Facebook pages, Twitter and weekly council eBulletin.

Staff are periodically consulted on their views on the communications they receive, what they like and where they would like improvements to be made. This has resulted in Connections newsletter being emailed to staff; a monthly team brief sent to managers to cascade to staff; intranet and website use monitored by the number of hits to each page; media coverage monitored and reported via the Lothian Digest.

3.3 Challenges and Practical Action

Locality planning will incorporate the development of local communication plans, tailored to the needs of the locality, enabling services, providers, carers and patients and service users to feel well-informed and connected across the locality.

Communication plans will be responsive to the demands of stakeholders and provide informative and engaging material suitable to a wide audience, including those with specific communication needs.

APPENDIX 1: Wilcox's Participation Framework (from 'A Guide to Effective Participation')

LEVEL *STANCE*	**Information**	**Consultation**	**Deciding together**	**Acting together**	**Supporting**
Typical process	Presentation and promotion	Communication and feedback	Consensus building	Partnership building	Community development
Typical methods	Leaflets, media, video	Surveys, meetings	Workshops, planning tools	Partnership bodies	Advice, support, funding
Initiator stance	"Here's what we are going to do…"	"Here's our opinion…what do you think?"	"We want to develop options and decide actions together"	"We want to carry out joint decisions together"	"We can help you achieve what you want within these guidelines"
Initiator benefits	Apparently least effort	Improve chances of getting it right	New ideas and commitment from others	Brings in additional resources	Develops capacity in the community and may reduce call on service
Issues for initiator	Will people accept no consultation?	Are the options realistic? Are there other options?	Do we have similar ways of deciding? Do we know and trust each other?	Where will the balance of control lie? Can we work together?	Will our aims be met as well as those of other interests?
Needed to start…	Clear vision, identified audience, common language	Realistic options, ability to deal with responses	Readiness to accept new ideas and follow them through	Willingness to learn new ways of working	Commitment to continue support

APPENDIX 2: Resources

The National Standards for Community Engagement	http://www.scotland.gov.uk/Resource/Doc/94257/0084550.pdf
A Participation Standard for the NHS in Scotland	http://www.scottishhealthcouncil.org/patient__public_participation/participation_standard/participation_standard.aspx
Visioning Outcomes in Community Engagement (VOiCE)	http://www.voicescotland.org.uk/media/resources/VOiCE_folder/standards_and_sitemap.pdf
A Guide to Effective Participation	http://www.partnerships.org.uk/guide/
Investing in Children	http://www.iic-uk.org/
Investors In People	http://www.investorsinpeople.co.uk/Home/index.html

West Lothian Health and Social Care Partnership

Participation and Engagement Strategy 2016-2026

Jim Forrest
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April 2016

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West Lothian Civic Centre
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Date: 7/04/2016

Agenda Item: 9

Schedule for Progress of Integration Strategic Planning Group Meetings 2016/17

SPG AGENDA SETTING MEETING	**SOCIAL POLICY SMT MEETING DATE**	**AGENDA/REPORTS TO COMMITTEE SERVICES (noon)**	**SPG MEETING DATES THURSDAY at 2.00 pm**
TBC	21 July 2016	4 August 2016	**11 August 2016**
TBC	15 September 2016	29 September 2016	**6 October 2016**
TBC	27 October 2016	10 November 2016	**17 November 2016**
TBC	TBC	12 January 2017	**19 January 2017**
TBC	TBC	23 February 2017	**2 March 2017**
TBC	TBC	13 April 2017	**20 April 2017**
TBC	TBC	3 June 2017	**15 June 2017**
All meetings will be held in meeting rooms 2 & 3 at Strathbrock Partnership Centre, Broxburn unless otherwise advised			

Date: 7/04/2016

Agenda Item: 10

WORKPLAN FOR WEST LOTHIAN STRATEGIC PLANNING GROUP 2016

Date of SPG meeting	Meeting to set agenda	Title of Report	Lead Officer	Action
30 June	9 June			
		Health Inequalities	Margaret Douglas	
		NHS Lothian Oral Health Strategy	Robert Naysmith	Work on the Oral Health Strategy is being led by the South East and Tayside (SEAT) Dental Public Health Network. RN will advise if paper will be available for this meeting.
		Updates on Learning Disabilities and Physical Disabilities Commissioning Groups	Alan Bell	
		Localities Update	Jane Kellock / Marion Barton	
		Planning Cycle	Carol Bebbington	
11 August				
6 October				
17 November				
