FIGURE 8
CONSULTANCY SERVICES LTD

2015

LEARNING DISABILITY AND AUTISM NEEDS ASSESSMENT

Executive Summary prepared for West Lothian Community Health Care Partnership

EVIDENCE INTO PRACTICE

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EXECUTIVE SUMMARY

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.

The full Needs Assessment report presents an overview and analysis of the health and social care needs for adults and young people with learning disabilities and/or autism across West Lothian; and provides an important and independent component to inform future support planning and provision.

Purpose and Objectives

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;

- 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.

The specific objectives of this project are to:

- Provide a comprehensive assessment and mapping of specialist and non-specialist services and support for those with a learning disability and/or autism;

- Conduct an assessment of local need for such services and support;

- Identify gaps and areas of unmet need in current provision;

- Examine the current use of services, both community and inpatient;

- Examine the accessibility, appropriateness and location of current services;

- Identify any areas with over-provision;

- Provide evidence based recommendations as to how services could be extended or adapted to meet need including relationship and any overlap between agencies; and

- Suggest locality pathways for intervention/support for those with a learning disability and/or autism.

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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).[1]

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 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.

Diagram of health needs assessment

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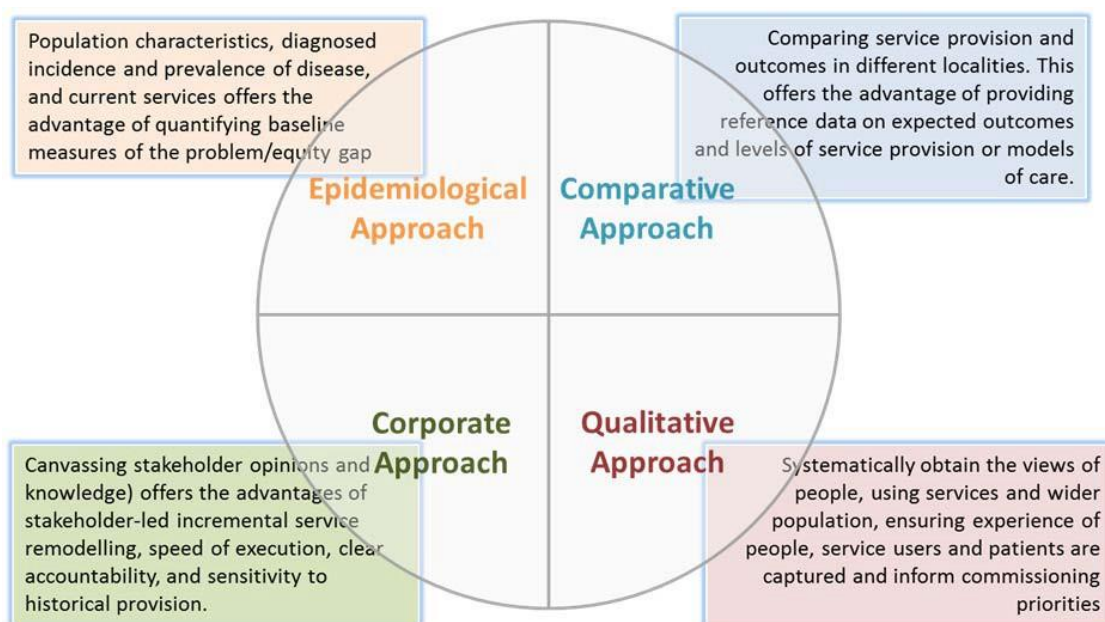
[1] Andersen, T.F. & Mooney, G. (Eds) (1990) *The challenges of medical practice variations.* MacMillan Press: London.

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Summary of Study Methods

The study methods used in this health needs assessment were designed to capture each of the four different approaches/perspectives above.

The study was conducted in five 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 the table below. All questionnaires and interview schedules were approved by commissioners prior to use. Copies of these are available upon request.

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)

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	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)

Key Findings and Recommendations

The limited published evidence base and research in this field 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:

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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)

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.

Ambition, Strategy and Communication (recommendations 1 -3)

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.[2]

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[2] Available at:
http://www.autismstrategyscotland.org.uk/index.php?option=com_docman&Itemid=&gid=361&lang=en&task=doc_download

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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;

- 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/*

<u>Integrated Autism Strategy</u>

RECOMMENDATION 2: An Integrated Health and Social Care Autism Implementation/Action Plan should be developed, in order to fully operationalise the existing 2015 Strategy[3].

The current West Lothian Council Autism Strategy sits with Young People's 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.

The Implementation/Action Plan needs to be linked and cross-referenced to current Scottish Government Autism priorities and strategic outcomes (2015-2017)[4] 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.

<u>Communication</u>

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

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[3] Available at:
http://www.autismstrategyscotland.org.uk/index.php?option=com_docman&Itemid=&gid=361&lang=en&task=doc_download

[4] 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].

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.

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 References

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*

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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 an 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.

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.

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 thought from commissioners. Provisions within the Children and Young People (Scotland) Act 2014[5] extend the age group which the Children and Families department, as well as the Education department, have

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[5] Available at: http://www.legislation.gov.uk/asp/2014/8/pdfs/asp_20140008_en.pdf [Accessed on 23 November 2015].

responsibility for; and this, along with named persons, must underpin the consideration for any remodelled pathways.

Good Practice References

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:

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

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 both 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

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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); 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.

<u>Housing strategy</u>

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.

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

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*

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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

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 mind-set 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.

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.

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

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.

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.

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.

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/

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[6] details clearly the view of people using services in terms of participation and involvement.

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*

Workforce Development (recommendation 17)

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.

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[6] Available at: http://arcuk.org.uk/scotland/files/2011/09/ARC-final-charter-297mmx297mm-12.12.14.pdf

EVIDENCE INTO PRACTICE

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*

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 main 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.

EVIDENCE INTO PRACTICE