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# CHAPTER 1: INTRODUCTION

## Introduction and background

Figure 8 Consultancy Services Ltd. was commissioned by West Lothian Community Health Care Partnership (CHCP) in April 2015 to carry out a comprehensive physical disability (including sensory loss and acquired brain injury) 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 with physical disability, sensory loss and/or acquired brain injury across West Lothian; and provides an important and independent component to inform future support planning and provision.

All references to 'physical disability' in this report will include sensory loss and/or acquired brain injury, as well as physical disability – unless otherwise stated.

## Purpose and objectives

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

- Identifying and profiling service users with physical disabilities in West Lothian;
- Identifying and describing the prevalence of people with physical disabilities in West Lothian;
- Profiling current service delivery to people with physical disabilities;
- Assessing and describing the current strengths, gaps and inequities in such service provision;
- Improving the number, quality, consistency, accessibility and integration of services appropriate for the needs of people with physical disabilities;
- 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.

The specific objectives of this project are to:

- Provide a comprehensive assessment and mapping of specialist and non-specialist services and support for people with a physical disability;
- 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 and support for people with a physical disability.

## The Needs Assessment Process

This needs assessment project uses a tried and tested model for health needs assessment (which is detailed below) and applies it to both the health and social care needs of people with a physical disability across West Lothian.

In broad terms, health needs assessment 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).<sup>1</sup>

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 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."*<sup>2</sup>

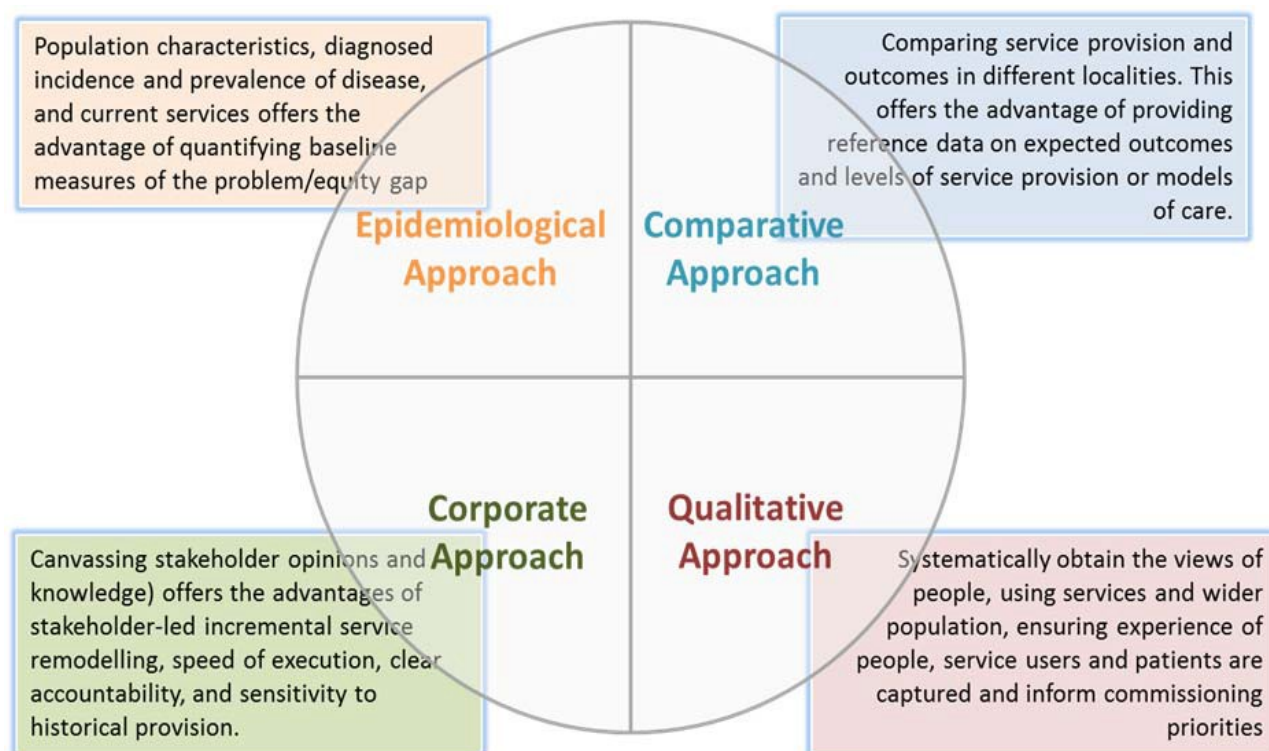
The assessment process involves identifying need from four different perspectives (see Figure 1.2):

- **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.

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

<sup>2</sup> Cavanagh S and Chadwick K (2005), "Health needs assessment: A practical guide". London: NICE. Available at: <http://www.nice.org.uk/>

Diagram of health needs assessment



## Summary of Study Methods

The study methods used in this 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 in 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
<b>Review of Existing Literature/Datasets</b>	Desk-based review of national and local literature and datasets and any local specialist service data available.		<ul style="list-style-type: none"> <li>Epidemiological</li> <li>Comparative</li> </ul>
Stage 2	Method	Sample	
<b>Quantitative Survey</b>	Online Surveys	<ul style="list-style-type: none"> <li>Managers of all specialist physical disability services</li> <li>Staff in all specialist physical disability services.</li> </ul>	<ul style="list-style-type: none"> <li>Normative/Expert (Corporate)</li> <li>Comparative</li> </ul>

Stage 3	Method	Sample	
<b>Quantitative Surveys</b>	Online and paper-based surveys	<ul style="list-style-type: none"> <li>• Service users</li> <li>• Non (potential) service users</li> <li>• Carers, family members, advocates</li> </ul>	<ul style="list-style-type: none"> <li>• Felt and Expressed (Qualitative)</li> </ul>
Stage 4	Method	Sample	
<b>Existing Service Review</b>	Case Studies	<ul style="list-style-type: none"> <li>• People with a physical disability</li> </ul>	<ul style="list-style-type: none"> <li>• Felt and Expressed (Qualitative)</li> </ul>
Stage 5	Method	Sample	
<b>Stakeholder Event / Working Group / Qualitative Interviews / Focus Groups</b>	Stakeholder Event	All key stakeholders invited to a half-day event in relation to physical disabilities	<ul style="list-style-type: none"> <li>• Normative/Expert (Corporate)</li> <li>• Felt and Expressed (Qualitative)</li> </ul>
	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 physical disability issues.	<ul style="list-style-type: none"> <li>• Normative/Expert (Corporate)</li> <li>• Felt and Expressed (Qualitative)</li> </ul>
	Semi-structured interviews	<ul style="list-style-type: none"> <li>• All specialist services</li> <li>• A range of non-specialist services</li> <li>• Other relevant stakeholders</li> </ul>	<ul style="list-style-type: none"> <li>• Normative/Expert (Corporate)</li> </ul>
	Focus Groups	<ul style="list-style-type: none"> <li>• Service users</li> <li>• Non (potential) service users</li> <li>• Carers, family members, advocates</li> </ul>	<ul style="list-style-type: none"> <li>• Felt and Expressed (Qualitative)</li> </ul>

## Key Findings and Recommendations

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 19 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:



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 people with a physical disability. 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.



Integrated Health and Social Care Physical Disability (including Sensory Loss and Acquired Brain Injury) Strategy

**RECOMMENDATION 1: An Integrated Health & Social Care Physical Disability (including Sensory Loss 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 in West Lothian:

- The growing needs and demands of an ageing population generally including those with a physical disability; 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)*'.<sup>3</sup>

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 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;
- 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<sup>4</sup>, particularly the following eight:

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<sup>3</sup> *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).

<sup>4</sup> Information about each of the National Outcomes can be found at:  
<http://www.scotland.gov.uk/About/Performance/scotPerforms/outcome>

- 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.

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### 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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### 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 resources, 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.

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.

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## Good Practice References

### 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>

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Inspiring innovative and creative opportunities

**RECOMMENDATION 3: 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 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.

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### Good Practice References

An example is promoting the 'Five Ways to Wellbeing', developed by the New Economics Foundation (NEF).<sup>5</sup> 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* ... 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.

Since these actions apply to everyone, regardless of circumstance; the potential innovation here is to encourage people with physical disability 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/](http://www.alliance-scotland.org.uk/download/library/lib_5469c0678579e/)

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<sup>5</sup> Aled and Thomson (2011) op.cit.

### Transport consultation and strategy

**RECOMMENDATION 4: The development of an inclusive strategy which needs to address accessibility of services within West Lothian; must include a conversation around transport provision to and from services, as well as access to community activity and work, for people with physical disabilities 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 physical disabilities in West Lothian:

- The growing demands of a physical 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 physical disability.
- 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 physical disability.

There is therefore work to be done in addressing the transport needs of West Lothian people with a physical disability, 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 physical disability; including access to services pertaining to housing, education and employment.

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## 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](http://www.sustrans.org.uk)

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### Commissioning, Monitoring and Evaluation (recommendations 5-8)

Formulate a detailed West Lothian commissioning strategy

**RECOMMENDATION 5: Create a West Lothian commissioning strategy for physical disability services; and commission and manage transparent, needs led, good quality and integrated services to maximise opportunities in respect of service user outcomes.**

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 in West Lothian.

The commissioning strategy should be transparent about the levels of resourcing for physical disability 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<sup>6</sup> 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’.*

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<sup>6</sup> SWIA Self-Evaluation Guide to Strategic Commissioning, Social Work Inspection Agency, 2009.

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.

In October 2013, West Lothian CHCP published a Contract Monitoring Framework for the Provision of Quality Care and Support Services.<sup>7</sup> 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.

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<sup>7</sup> *Contract Monitoring Framework for the Provision of Quality Care and Support Services*, West Lothian Community Health and Care Partnership, 2013



Recognise good practice and promote effective customer relations between commissioners and services

**RECOMMENDATION 6: Encourage, identify, affirm and recognise good practice through commissioner engagement.**

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.

Evaluation of physical disability services

**RECOMMENDATION 7: Consideration needs to be given to conducting ongoing, consistent and equitable evaluation of all physical disability services across West Lothian.**

West Lothian CHCP should develop and execute a programme which facilitates ongoing, consistent and equitable evaluation of all physical disability services across West Lothian. The evaluation should include in-house services; not just contracted services.

Ensuring commissioners in West Lothian make robust commissioning decisions based on good quality evidence

**RECOMMENDATION 8: Undertake regular needs assessment and specific, targeted research to address areas of unmet need and inequality.**

Physical 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.

### A coordinated, single point of information

**RECOMMENDATION 9: Produce, maintain and coordinate West Lothian wide disability information from a single, central source, in order to ensure ready availability and accuracy.**

The need for better communication highlights the importance of the service recently commissioned from Capability Scotland and the opportunity that exists 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 a local 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. 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.

### Information sharing protocol

**RECOMMENDATION 10: Implementation of an information sharing protocol for use across all physical disability services.**

The current lack of an implemented information sharing protocol is seen by stakeholders as problematic and an easily achievable improvement area. The implementation of existing protocols should involve the main physical disability specialist service providers, as well as GP's and other relevant stakeholder agencies, including carers and families.

### Integrated working across all partner agencies and stakeholders

**RECOMMENDATION 11: Construct an integrated working guide involving physical disability 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 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.

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## Good Practice References

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=C13U5vCksMcCFZHHtAoduRUFew>

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](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](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)

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Reduce physical disability across West Lothian

**RECOMMENDATION 12: Develop clear strategic approaches to reducing; and where possible, preventing dependency or deterioration of physical disabilities.**

There is a case to focus resources at earlier stages of intervention to prevent deterioration of physical disability where possible. This approach should be aligned to the promotion of independence which may extend to addressing dependency on specialist services under certain circumstances.

Responsive and proactive services

**RECOMMENDATION 13: 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.

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## Good Practice Reference

### Visibility Early Intervention project

[www.visibility.org.uk](http://www.visibility.org.uk) (Valerie Breck, Operational Director).

Provide assessment for people who are recently diagnosed with a severe visual loss where Glasgow City Council is unable to do so and so prevent long waiting lists.

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### The role of IT in support

**RECOMMENDATION 14: 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.

### Strengthening the Third Sector and peer support 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 physical disabilities; critically within the framework of Self Directed Support. However, statutory physical disability 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 **7.5.1**) 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.

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### Good Practice References

**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](mailto: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

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### 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 commissioning, delivery, development, and commissioning of specialist physical disability services, and the wider system.**

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<sup>202</sup> details clearly the view of people using services in terms of participation and involvement.

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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>

National Standards for Community Engagement - <http://www.scdc.org.uk/what/national-standards/> and <http://www.gov.scot/Topics/People/engage/NationalStandards>

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### Workforce Development (recommendation 17)

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 services.

Developing an experienced, flexible, responsive and hopeful workforce

**RECOMMENDATION 17: 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 disabilities.

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## 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/>

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Visibility of achievement is critical to demonstrate the power and possibility of empowerment and personal independence

**RECOMMENDATION 18: Promote empowerment and personal independence; and celebrate achievement.**

People with a physical disability 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.

Furthering the personal independence agenda

**RECOMMENDATION 19: 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 Loss 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.

**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.