

Lothian's Joint Learning Disability Strategy

Executive Summary

October 2008



Joint Lothian Learning Disability Strategy Review

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1. Introduction

NHS Lothian and the 4 Local Authority partners, City of Edinburgh, East, Mid and West Lothian Councils, aspire to provide people with learning disabilities, ASD (ASD) and/or AS(AS) with supports and services that will enable them to participate as fully involved and active members of their local communities.

People with learning disabilities, ASD and AS want to:

- Live healthy, productive and independent lives
- Be individuals, decide everyday issues and lifestyle choices for themselves
- Be engaged in all decision making which affects their lives
- Live their lives within their communities
- Maintain friendships, social and family ties
- Be able to access general services and specialist services when these are required.

In 1988, the Griffith's Report¹ began the social movement towards community care. This, and the subsequent National Health Service and Community Care Act 1990 informed the previous strategy for Lothian throughout the 1990's, which focussed on the closure of the long stay hospitals. This was successfully concluded in summer 1999 with the resettlement of some 300 plus people into various models of supported accommodation in their local communities.

In order to achieve the resettlement all partners invested significant resources into the service infrastructure which was necessary to provide the support required by people with learning disabilities to adapt to life in the community. This included the development of Community Learning Disability teams, the development of the assessment and treatment units on the Royal Edinburgh

¹ The Griffiths Report "Community Care: An Agenda for Action" A report to the Secretary of State for Social Services 1988 HMSO

Hospital campus, day, respite and residential services provided by local authorities and the voluntary sectors.

1.1 Why did we have a Strategic Review?

In the intervening decade since the conclusion of the last strategy, there has been a ground swell of legislative and policy change, accompanied by an ever stronger social movement which continues to raise the profile of people with learning disabilities, ASD and AS, emphasising their human rights and the requirement of statutory service providers to be at the forefront, alongside people with learning disabilities, in supporting individuals to exercise these rights.

Accompanying these changing and increasing expectations of people with learning disabilities ASD and AS, and their carers, has been the recognition nationally of changing demographics. People with learning disabilities now have longer life expectancy, both in term of surviving into adulthood whilst experiencing ever more complex disabilities, and surviving into old age, with some of the challenging health issues that this can bring. Whilst these are both undoubtedly success stories, they do present challenges to services in how to respond appropriately to this increasing level of need. We are therefore faced with an increasing number of people with learning disabilities seeking services, and the complex support needs of these individuals being greater than had previously presented.

In response to these changing circumstances and in recognition of the fact that many existing services were no longer fit for purpose, and no longer the type of service that people with learning disabilities and their carers want, the Lothian partners agreed to commission a full strategic review of services to people with learning disabilities, ASD and AS.

The agreed remit for this strategic review included:

- To focus primarily on Lothian level requirements i.e. issues that impacted on all partners, planning and services, whilst taking account

of the Partnership in Practice (PIP) Agreement work at local levels. The PIP's are joint documents, across Local Authorities and NHS Services, which describe the local interpretation of strategic service development and states the actions to be taken locally to achieve the implementation of the recommendations from "The Same as You?"².

- Focus primarily on services to adults, and transition from children's to adult services
- Build on recent developments of joint working and service developments such as those aimed at reducing delays in discharge from hospital.

2. Service User, Carer and Wider Stakeholder Involvement

We tried to conduct the review in ways that encouraged and supported the fullest possible involvement of service users, family carers and groups representing their interests. These people, along with health and social care professionals from all sectors, are best placed to know what could and should be available.

From the outset, service users were supported to be engaged with the work of the strategy, as equal members of the Strategic Board, and as representatives on many of the working groups. A Communications Group – chaired by People 1st, advised the Strategic Board about all communications, management of meetings and presentation of papers, to ensure accessibility of the information to as wide an audience as possible. Mid way through the strategy review, Carers indicated that they felt excluded from the process, and they requested we revisited our methods of engagement.

To address this, a Carers Scrutiny panel was established. A series of workshops were held on each of the main themes of the work of the strategy, and this group then adopted the roll of consultancy, feeding in comments via

² "The Same as You?"² Review of Services to people with Learning Disabilities, Scottish Executive, 2000.

their representatives to the Strategy Board

Following the conclusions of the working groups, a Strategic Report went out to public consultation for a 3 month period. This generated a significant amount of responses from many different groups and individuals. 370 comments were received in response to this public consultation. In the main these responses endorsed the strategic direction suggested by the strategy report. Where responses were not in full agreement with the proposals made by the strategy, they tended to be expressions of concern, particularly from carers who are worried that they will continue to have to struggle for access to services and compete against other groups of people with learning disabilities. It is the intention of this strategy that options such as self directed care and more equitable service offers will address these concerns.

3. A Resume of the Strategic Report.

3.1 The full Strategy Report

The full Joint Learning Disability Strategy Review Report contains much more detail on the findings and recommendations of all the strategy working groups, including the evidence and research supporting the recommendations. An electronic copy of the full report is available from: The Library and Resource Centre, Deaconess House, 148 Pleasance, Edinburgh, EH8 9RS or view the strategy document at www.lothianlearningdisabilityreview.info

This Executive Summary aims to capture the main points of the full joint strategy review report.

3.2 Core values

The core principles of "The Same as You?" endorsed by this strategy review are that people with learning disabilities, ASD and AS should be:

- Valued, encouraged to contribute to their community and not be picked on or treated differently from others
- Treated as individuals
- Asked about the services they need and involved in making choices
- Helped and supported to do all they are able to
- Able to use the same local services as everyone else, where possible
- Able to benefit from specialist social, health and educational services
- Able to access services which take account of their age, abilities and other needs.

3.3 Citizenship

People with learning disabilities ASD and AS deserve to be treated positively as active and valued citizens. In keeping with government commitments set out in the Changing Lives³ report, the Joint Learning Disability Strategy seeks to ensure that they are treated with respect and as equals, can play a full role in society and have access to the same public services as anyone else.

In doing so it strives to meet their needs as students, employees, parents and householders, and to recognise their contribution to their local communities and to society. It also recognises the need to look beyond the more formal aspects of life and make sure they are treated as people with the same rights to go out, have fun, and be involved in sports, arts and leisure activities like everyone else.

4. Under-pining Principles and Themes

In recognition of the core values set out by the “Same as You?” and the wish of the Strategic Board to endorse these throughout our work and service development, the report singled out the important themes that need to underpin everything we do to support people with learning disabilities, ASD and AS. These underpinning Principles and Themes are:

- Person Centred Planning
- Health Needs and Inequalities
- Improving Services and Improving Quality of Life
- Dealing with Transitions
- Self Directed Care and Support
- Workforce Development and Planning

4.1 A person-centred approach

Person centered planning reflects the core values of empowerment and personalisation that are driving the government's health and social care policies. We also now have hard evidence from recent research by Emerson⁴ that person centered planning leads to improvements in the life experiences of people with learning disabilities.

This research tells us that it is unfortunately commonly the case that many of those who most need a plan are less likely to get one. Person centred planning is not available to enough people and we have little evidence of how well it is being done. There are no local or national standards on what a Personal Life Plan is and how it should be carried out. Such standards are now required – the creation of quality standards need not necessarily mean that the plans will be any less unique and individual.

An example of the application of person centred planning, or life planning, could be supporting people with learning disabilities, ASD and AS who live with their parents to undertake this process and consider planning for a time when parents may no longer be able to provide care.

Until recently there has been little evidence of information from person centred planning being used by planners and commissioners to guide the shape of

³ “Changing Lives” Report of the 21st Century Social Work Review, Scottish Government 2006

⁴ Robertson J, Emerson, E et al “The Impact of Person Centred Planning on the Life Experiences of People with Learning Disabilities”, Institute for Health Research, Lancaster University, UK 2005

future services. Shaping the Future Together ⁵ is a tool which may help us to change this. It helps pull information together from individual plans to shape strategic commissioning and service development.

Strategy Recommendation	Timescale	Outcomes
A sample group in East and Midlothian will be supported to develop self directed support and to inform strategic planning by using person centred planning “Shaping the Future Together” and “In Control”.	This process started in August 2008.	Data from the person centred plans of all participants is being entered into the Shaping the Future data base – to begin to inform service planning which will respond to the preferences of the individuals. The project will be evaluated in 2009/10, with the potential to be adopted on a wider scale.
The partnership should agree a set of standards for person centred planning to be applied across Lothian	Start Date: December 2008, to be concluded by October 2009.	A clear set of standards that will inform all Users and Carers of the process, and final product that they can expect from a person centred plan from any statutory agency in Lothian.

⁵ “Shaping the Future Together: A Strategic Planning Tool for Services Supporting People with Learning Disabilities” The Foundation for People with Learning Disabilities, 2005

<p>A person centred training strategy should be developed across Lothian, ensuring users and carers are involved in the training and delivery</p>	<p>Start Date: February 2009; to be concluded by October 2009. Implementation of the training strategy will be undertaken in Phase 2 of the Implementation Plan</p>	<p>An agreed set of skills and package to deliver the required training, to include the training required to support people with Autism and/or AS engage in this process.</p>
<p>We need to extend the availability of person centred planning to people with Autism and/or Aspergers Syndrome.</p>	<p>With immediate effect. Local authorities to seek to expand availability of person centred planning through Local Area Coordinator Teams.</p>	<p>People with Autism and AS will have equitable access to the opportunity to undertake a person centred plan.</p>

Work Already Begun:

East and Midlothian Councils have jointly appointed a Project Coordinator to work with a sample group of service users, and which uses person centred planning, the Shaping the Future Together tool, and aspects of In Control, to help them develop self directed support options.

4.2 Health Needs and Inequalities

NHS Lothian and the 4 local authority partners adhere to the principle that all people with learning disability should have the good health necessary for a fulfilling life and a normal life expectancy. As with all members of the public, people with learning disability, ASD or AS should have their healthcare needs met at home or in local communities as far as possible.

One of the major challenges of our time is to guarantee high quality services for all - as locally as possible and as specialist as necessary. We know from national work that people with learning disabilities are more likely to suffer from particular illnesses, and to die earlier. As the number of people with

learning disability and/or ASD and AS grows, the demand for health care and other services will also increase. We need to make sure that health services improve their ability in meeting the particular needs of this population. In primary care, this might include personal health plans and annual health checks.

In acute services NHS Lothian's Learning Disability Nurse Liaison Service has led the way for Scotland through support to colleagues, patients and carers to plan admissions to hospital which take cognisance of the needs of the patient with learning disabilities beyond the immediate physical health need. Specialist health services are also needed to meet the complex needs of some people with learning disabilities ASD and AS.

What works in improving the health of the general population does not necessarily meet the health needs of many people with learning disabilities. If it is to be effective, Health Promotion work needs to be done in partnership with people with learning disabilities, ASD and AS.

Throughout late 2007/2008 there have been a number of reports, e.g. Healthcare for All ⁶ and Equally Well ⁷ which focus on this subject. Many similar issues have been highlighted in the most recent FAI ⁸ and subsequent determinations flowing from this. Although these reports could not inform the work of the strategy, it was agreed it would be inappropriate to omit the findings from our proposed actions. This was also the reasoning applied to the learning outcomes from the NHS QIS Peer Review undertaken in October 2008 in NHS Lothian, with support from our partners in Local Authorities. The following recommendations therefore are inclusive of NHS Lothian's response to these findings.

⁶ "Report of the Independent Enquiry into Access to Healthcare for People with Learning Disabilities" Sir Jonathan Mitchell, 2008; commissioned by the Department of Health

⁷ "Equally Well" Report of the Ministerial Task Force on Health Inequalities, Scottish Government 2008

Strategy Recommendation	Timescale	Outcome
To support staff in development of skills in supporting people with learning disabilities/ autism and Aspergers syndrome, through the availability of e-module training materials via NHS Lothian Intranet.	To begin within the current financial year.	The Learning Disability Quality Improvement Team will work with the Partnership Board to establish a guide to generic staff. The LD QIT to reflect this in their work plan and define a timescale for delivery.
Disability Discrimination Act Training and Awareness sessions revised to reinforce the Disability Equality Duty and the right of people with Learning Disabilities to access required healthcare services	Phase 1 – within the current year 2008/09 for roll out in 2009	Generic training and awareness sessions to staff across NHS Lothian will reinforce the Disability Equality Duty, the rights of people with learning disabilities and the expectations of NHS Lothian that staff will fully implement the values of “The Lothian Way.”
Promotion of Healthy Lifestyles: NHS Lothian to invest in the expansion of Local Area Coordination Teams across the 4 local authority areas; to develop the uptake to	To be initiated April 2009. This is funded via investment from SGHD for a 3 year period.	In line with “The Same As You?” recommendation, develop the Local Area Coordinator teams to support the health and wellbeing of people with learning disabilities,

⁸ Inquiry under the Fatal Accidents and Sudden Deaths Inquiry (Scotland) Act 1976, Donnet Fatal Accident Inquiry, Sheriffdom of Tayside Central and Fife at Dundee.

<p>healthy lifestyles, which would inform the input into person centred plans.</p>		<p>autism and Aspergers. People will be supported to engage with healthy eating, physical exercise and smoking cessation.</p>
<p>NHS Lothian should build on the population identification within Primary Care to undertake health needs assessments.</p>	<p>April 2009. The next phase of the Scottish Enhanced Services Contract with GP Practices will support the implementation and availability of health checks for people with learning disabilities.</p>	<p>The availability of health checks to support the appropriate targeting of healthcare to people with learning disabilities.</p>
<p>NHS Lothian to implement a Primary Care Facilitation Project to support the awareness training and implementation of health checks to people with learning disabilities.</p>	<p>April 2008 This is funded by the DES SGHD funding for 2009/2010</p>	<p>Skills enhancement and implementation of the NHS QIS Best Practice Statement across all GP Practices and Acute settings in Lothian via monthly multi disciplinary seminars.</p>
<p>NHS Lothian should develop specific initiatives which support and monitor arrangements to target health improvements and reduce health inequalities for people with learning disabilities.</p>	<p>This recommendation links directly with the NHS Lothian FAI Action Plan. There is a group established to monitor the implementation of this plan. This group has already convened and implementation is underway. Progress will</p>	<p>There are a number of outcomes which will be delivered including, e-systems which support the tracking of patients through the Healthcare journey; delivery of educational packages across generic staff groups and defined</p>

	be reported on a 6 monthly basis to both the Partnership Board and NHS Lothian	systems which support people with learning disability when they access healthcare on an unscheduled or emergency basis.
NHS Lothian will recruit a Project Manager for a 3 year period to focus exclusively on Health Inequalities for people with learning disabilities	Post to be recruited to in 2008/09. Funding secured from SGHD for a 3 year period to support this initiative.	Through a variety of methods, deliver improved and equitable access to general healthcare in Primary and Acute settings.
In partnership with FE Colleges, Local Authority partners, Users and Carers, NHS Lothian will work to apply the long term conditions self management model for use by people with learning disabilities and support the development of health awareness modules to students with learning disabilities at the 3 FE sites.	To begin April 09. This is funded by investment from SGHD for a 3 year period.	An adaptation of the Long Term Conditions Self Management model – accessible to people with learning disabilities. The delivery of a “Health Awareness” module through FE partners to students with learning disabilities to improve lifestyle choices and awareness of one’s own health.
NHS Lothian will support a 1 year project of “Health Diaries” to identify the real life patient experiences of	To be commissioned April 2009, funded via investment from SGHD.	NHS Lothian will receive a report on actual practice and patient experience, both good and bad, which will

<p>people with learning disabilities accessing healthcare across both Primary and Acute Care sites.</p>		<p>directly inform target areas to continue to build on provision of equitable healthcare for people with learning disabilities.</p>
<p>NHS Lothian will commission an organisation to “translate” general healthcare information leaflets into easily accessible, pictorial information leaflets that will maximize the opportunities for people with learning disabilities to become active participants in their own healthcare.</p>	<p>To be commissioned in 2009, for a three year period.</p>	<p>Public healthcare information, across the range of services, A&E, Acute, Out patients etc. that is accessible to people with learning disabilities and communication problems, maximizing their opportunities to be active and informed about their own healthcare</p>
<p>NHS Lothian should ensure the Information and Translation Service, public consultation plans/ newsletters and publicity materials are fully accessible in an effort to provide people with the information they require about their health services, in a manner that is accessible to them.</p>	<p>Within 2009/2010</p>	<p>Fully DDA compliant public information and consultation services, mainstreaming the accessible communication agenda.</p>

<p>NHS Lothian to consider the implications of the national audit of Learning Disability Liaison Nurse service – and seek to increase the capacity of the service to support people accessing healthcare on an unscheduled or emergency basis.</p>	<p>To begin in April 2009, funded via £90,000 investment secured from SGHD.</p>	<p>A confident professional response to patients with learning disabilities accessing healthcare on an unscheduled or emergency basis, with specialist support available to the generic staff teams out of hours.</p>
<p>In partnership with Liaison Nurses, CLD Teams, Primary Care, Local Authorities and Voluntary Organisations, develop health passports that will support the Patient and Carer to appropriately inform both Primary and Acute care of their health and support needs, in order to maximize the health benefits gained from the healthcare experience.</p>	<p>Beginning April 2009, with the intention to begin implementation of passports within the year.</p>	<p>An approved, recognised system which supports people with learning disabilities and their carers in sharing required information with health professionals which enhances the experiences and makes best use of the professional's intervention.</p>
<p>NHS Lothian should support an early focus on developing activities to address obesity amongst people with learning disabilities</p>	<p>Linking this to the investment in Local Area Coordinator teams, plus development of education across staff disciplines, we expect</p>	<p>People with learning disabilities, ASD or AS and their carers, paid or unpaid, will be supported in regard to food, fluid and nutrition,</p>

<p>through increased physical activity, improved diet and smoking cessation.</p>	<p>support to be made available to people with learning disabilities in 2009 with a focus on healthy lifestyle choices.</p>	<p>exercise and supported to engage with smoking cessation support groups or similar. Health Promotion campaigns will encompass the needs of people with learning disabilities and be accessible by them.</p>
<p>Development of use of special notes with LUCS and NHS 24 to support practitioners to have appropriate information regarding patients with learning disabilities.</p>	<p>Already begun – to be rolled out over 2009 as the GP Practices more accurately identify patients with learning disabilities.</p>	<p>As identified in the Donnet FAI, there is a requirement to track the patient journey for patients with learning disabilities. Use of LUCS notes will begin the information sharing process to support delivery of appropriate healthcare.</p>
<p>The MCN – Learning Disabilities, supported by developments in NHS Lothian, will progress a full review of current education and practice based development, identify gaps and develop education and career pathways for people working to support</p>	<p>To begin in 2009/2010 – through recruitment of an Education Coordinator position, funded by SGHD for 3 years.</p>	<p>Clear developmental academic and practice based pathways which deliver excellence in the skilled support of people with learning disabilities across the health and social care system.</p>

people with learning disabilities.		
Host a “Health Equalities” seminar at the end of the 3 year period to publicise and celebrate achievements, plus re-energize and refocus people in areas still be targeted.	Phase 2 - 2011	Building on activity, raise general awareness of work and achievements across NHS Lothian in relation to the increased equity of access people with learning disabilities are now experiencing. Launch the next phase of work.

4.3 Improving Services and Improving Quality of Life

People with learning disability, ASD and Aspergers, from across Lothian told the Strategy that they need services to:

- Ask the service users, about all changes that may impact on them
- Listen to them when they offer an opinion
- Act on their suggestions
- Make information accessible using a variety of formats
- Support from workers needs to be more readily available

The Strategy recommends that – in order to work towards these wishes, we need to find ways that measure how people’s lives are improving and check that the services they get support them to have good quality lives, to be supported to be valued members of their communities, be included, have friendships and be full citizens.

The Strategy aims to investigate the Quality of Life standards and, in negotiation with stakeholders and users, find ways to incorporate these into regulatory frameworks. Specifically the Strategy recommends:

Strategy Recommendation	Timescale	Outcomes
<p>The Respect Test Statements should be made available on small cards and distributed to all staff of each partner organisation, and all users of services.</p>	<p>Cards to be published and circulated within 09/10</p>	<p>Provision of wallet sized cards reminding staff of their duty to respond to people with learning disabilities with respect, and offer a high quality service at all times. The cards will also provide the service user with the option to use the card at any time when they feel they are not being responded to in an appropriate manner.</p>
<p>Partners should investigate the use of Quality of Life indicators as a means of evaluating service provision.</p>	<p>To begin in January 2009.</p>	<p>Quality of Life indicators/ standards will be agreed with all stakeholders and implemented into outcome based commissioning, becoming a key deliverable by service providers.</p>
<p>People with learning disabilities should be included in each Community Safety Forum.</p>	<p>To be achieved with 2009/2010</p>	<p>Local Joint Planning groups will have a direct relationship with their Community Safety Forum, and the needs and rights of people with</p>

		learning disabilities will be encompassed in all Community Safety Actions.
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4.4 Supporting Transitions

The changes that take place as people move from youth to adulthood should offer exciting opportunities for an independent and fulfilled life. However, it can be a confusing time for any young person and the situation can be far more difficult for those with learning disabilities, ASD and AS.

In the Lothian's there is a need to do more to inform, empower and enable young people to make informed plans and decisions on vital issues like education, housing, employment and travel.

There are many examples of excellent practice in the region to be celebrated and built on. One way ahead would be to ensure that each young person has a key worker who is in regular touch with him or her and their families during that time of life.

Where possible the aim should be to provide young people with the information to make informed, supported choices about their future, both immediate and in the longer term. Those from minority ethnic backgrounds must be confident that their cultures will be respected and that their planned transition fully takes their personal beliefs and preferences fully into account.

There are other transitions in life, such as the one to old age, where work is also required to ensure people are well informed and involved in making their own decisions about changes to their lifestyles and support services..

Strategy Recommendation	Timescale	Outcome
Each service user should have a named professional and, if requested, an advocate, to support them before, during and after transition from children to adult services.	Begin in current year. Lothian Independent Advocacy Plan states the access to advocacy for people with learning disabilities is a priority – and will be addressed in 09/10.	Young adults in transition from children's to adult services will have the opportunity to have an advocate to support them through service change and choices.
A Lothian wide group, incorporating Children and Adult services should be set up to achieve alignment of service eligibility criteria to inform priority for transitional support.	This will be informed directly by the current negotiations on Continuing Healthcare. This will also be informed by the work of the LD Strategy Partnership with the Joint Improvement Team which aims to reach an agreed spectrum of complex care as applied to people with learning disabilities, ASD and/or Aspergers.	Agreed criteria for complex care and associated Continuing Healthcare will directly inform care pathways, including those that support an individual in transition from Children's to Adult services.
NHS Lothian to develop a formal strategic link between the Children's and Adult services.	Short Life working group to be established in 2009/10 to identify areas where there is a lack of strategic fit	A Strategic journey which actively supports an individual in their passage from Children's into Adult healthcare

	<p>between the two areas.</p> <p>Phase 2 – 2010 onwards – to implement the identified actions to address the mismatch.</p>	<p>services.</p>
<p>A pilot scheme to inform young people approaching transition of the possibilities of Direct Payments/ Self Directed Care should be established.</p>	<p>City of Edinburgh Council to begin implementation of this within the current financial year 2008/09</p>	<p>Young people with learning disabilities and or ASD or AS will be supported to consider self directed care options for their post school service.</p>
<p>A sample group in East and Midlothian will be supported to develop self directed support ad to inform strategic planning by using person centred planning, “Shaping the Future Together” and In Control tools.</p>	<p>This pilot began in August 2008 – and will continue for 2 years.</p>	<p>The partner organisations will gain invaluable information about methods to support increasing the capacity to offer self directed support options to users of social care services.</p>
<p>The Lothian Partners will evaluate the above pilot schemes in order to identify and apply lessons about providing funds to better meet people’s individual support needs.</p>	<p>This will be undertaken toward the conclusion of the pilot’s, in October 2009 to inform next stages of service developments and the models of care for new service options.</p>	<p>The Lothian partners will be able to apply learning to current service delivery and commissioned models to expand opportunities for self directed care and support.</p>

4.5 Self Directed Care and Support

The Scottish Government is keen to see statutory agencies deliver support in a more flexible, imaginative manner that empowers the individual user and their carer, and supports them to be in control of the manner in which their services are arranged. As discussed in Section 4.1 “Work already begun” East and Midlothian Councils are working jointly with a sample group to explore the practical applications of this.

City of Edinburgh is working with young people in transition from school to offer them opportunities for direct payments and self directed support options e.g. involving them in designing their own support service, and is keen to roll this out across other groups of services users within the year.

NHS Lothian, supported by the Scottish Government Health Department is establishing a project with Further Education partners and local authorities to establish leadership capacity to take forward the personalisation agenda jointly across the statutory agencies.

Strategy Recommendation	Timescale	Outcomes
We will review the way in which support services are currently commissioned. We will develop quality mechanisms to ensure that people with learning disabilities and their families are included in the commissioning process.	October 2008 – begin to develop quality standards. Given the pilot being undertaken by East and Midlothian Councils, it is recommended that East Lothian Joint Planning Group	Service commissioning will be outcomes based to ensure that positive impacts on the quality of life of the service users are measureable,
NHS Lothian in	In Phase 1 2009/10	The growth of shared

partnership with Local Authorities, Academic Institutions Users and Carers will develop leadership capacity to support service providers to positively respond with models of service that offer control to the service user.	NHS Lothian to lead on the establishment of a partnership with respective agencies to develop a programme supportive of academic and developmental progression, embracing the principles of self directed care	understanding and skills in supporting and delivering change in the delivery of care, from block commissioning to self directed care and support.
Develop Leadership Capacity in the delivery of Self Directed Care	January 2009 – recruit a Project Manager to lead on the development of objectives related to self directed care, funded by SGHD for 3 years.	A dedicated resource, based in NHS Lothian, to develop the capacity of the partnership to deliver self directed care to people with learning disabilities.
In partnership with Local Authorities and Voluntary partners, develop staff development packages to raise awareness and understanding of their role in delivery of the self directed care and personalisation agenda.	Begin April 2009, led by the Project Manager	Along with the recommendations and outcomes above, this action will support NHS Lothian and partners develop a centre of excellence in the delivery of services to people with learning disabilities.

4.6 Workforce Planning and Development

Service Users and Carers need to know that those delivering service have the necessary knowledge and skills to meet their needs. They also need to know that providers are committed to helping staff in their day to day roles by

supporting their learning and development. Most staff working with people with learning disabilities are employed out with the public sector and the majority of these people are not registered with any professional body. Scottish Social Services Council plans to roll out registration to Housing Support Workers in 2009 to provide a framework which offers support and opportunities for professional development to the workers, whilst providing a regulatory framework which offers protection to those receiving support.

Service Managers in all areas highlight a range of common challenges including demographic change, funding issues, recruitment and retention difficulties, the low status of the workforce and a lack of recognised accredited training qualifications.

The Learning Disability Managed Care Network, which includes all the Lothian partners as members, has included the need to undertake and conclude a workforce analysis exercise in their 2008 – 2011 work plan.

The Lothian partners will fully engage with this process to inform the NHS Lothian and equivalent Local Authority Workforce Development plans.

Strategy Recommendation	Timescale	Outcome
A joint agency group should be established to carry out research on workforce demand projections over the next 5 – 10 years. This will inform the NHS Lothian workforce development plan.	To begin in 2009, in partnership with the MCN – Learning Disabilities and SEAT Workforce Planning.	Identification of skill requirements, career pathways and role diversification, from the SD Care projects and the Joint Improvement Team work with the partnership, will directly inform workforce planning.
A Joint training needs	To begin in 2009, again,	Identify the

analysis and implementation plan should be completed.	in partnership with the MCN – Learning Disabilities and particularly the Professional Education Group.	requirements of current and future workforces across the service providers and agencies, and deliver these in partnership with learning and development colleagues.
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5. What the working groups said

A series of working groups were formed to look at key issues and their suggestions formed the basis for the Recommendations made by the Strategy.

5.1 Older people with learning disability

Older adults with a learning disability must be considered separately from other groups, because of their particular needs.

There is a debate as to the age at which the “older adult” is defined in work with people with learning disabilities. One group of individuals with a learning disability, those with Down’s Syndrome, are particularly prone to developing Alzheimer type dementia and at a much earlier age than the general population.

It is estimated that between 1000 and 1500 individuals with learning disability in Lothian are currently over the age of 50 and of these around half are over 60. Of particular note, around 300 individuals will move into the over 60 range within the next 5 years.

There is little specialist provision available for this group of individuals. Family carers themselves will be going through the ageing process and, added to Carer responsibilities, it is recognised that this often takes its toll on their physical and mental health thus limiting their capacity to continue in a caring role.

Strategy Recommendation	Timescale	Outcome
A managed care network should be established to facilitate effective planning and provide a consultation and training resource to all stakeholders, for older people with learning disabilities.	To be taken forward by the LD MCN in 2009.	A collective, regional consideration of the needs of older people with learning disabilities and collective use of available skills and services.
Development of adequate services, both in health and social care, for older people with learning disabilities, including palliative care, should be established.	Phase 2 – 2010 onwards, directly informed by the outcomes of the partnership work being supported by the Joint Improvement Team	Identification of priority developments, disinvestment and reinvestment required across services to deliver for older people with learning disabilities.
Development of a multi agency programme aimed at identifying and treating health needs and promoting good physical and mental health and well being in older adults with learning disabilities, including service user education, preparation for change, support to maintain friendships and activities, and to	To begin within the current year, driven by the FAI Action Plan.	<p>Clarification and appropriate support throughout the patient pathway.</p> <p>Health assessments will be delivered to people with learning disabilities via the SES Contract across all Lothian GP Practices.</p> <p>Outcomes from the partnership work with</p>

<p>overcome barriers to accessing inclusive settings.</p>		<p>the Joint Improvement Team will inform any specific service developments discrete to older people with learning disabilities.</p>
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5.2 People with additional mental health issues or behaviour that challenges services.

Recent studies suggest that between 12 and 17% of people with a learning disability will display behaviour that is challenging to services. We also know from research that there are higher levels of mental health problems among people with learning disabilities than the general population, with most studies pointing to prevalence rate of somewhere between 30 and 50%.

Primary healthcare and/or social care staff do not always have the necessary training and experience in recognising and managing these conditions hence the need for specialist services.

NHS Lothian and the four local authorities, along with people who use services, agree that some of our current services for people with learning disabilities are not able to fully meet the needs of the Learning Disabled population in Lothian. Some services designed and built as part of the last Joint Lothian Learning Disability Strategy were fit for purpose in 1995, but have not been able to respond to the changes in demand since that time.

At the same time people who have finished their treatment and rehabilitation have not been able to move on from NHS accommodation, primarily because there are no appropriate social care services in Lothian. This is having an impact as there is a lack of availability of assessment and treatment beds for those who require admission for short periods

NHS Lothian and the four local authorities have agreed that we need to re-design the existing in-patient services, and consider developing new services that span the traditional boundary between NHS and social care. Progress is already being made through Edinburgh's new joint support service, which means the city council and NHS work as one. This is a model to be built on for the future.

Strategy Recommendation	Timescale	Outcome
NHS Lothian will redesign the layout of the assessment and treatment units to provide more appropriate and safer environments for people whilst they are in-patients. This will include female only provision.	Dependent upon response to capital bid being led by East and Mid Lothian CHP.	Appropriate physical environments that are therapeutically appropriate; and are provided in fit for purpose, gender specific environments.
NHS Lothian with partners should consider developing a Community Support and Treatment Service, i.e. Outreach/ In reach Nurse Liaison Posts and Intensive day service provision.	This work will be informed by the outcomes of the partnership work with the Joint Improvement Team – with the intention to implement in Phase 2; 2010.	The availability of a specialist team to provide onsite direct support across service providers to support people with learning disability who are requiring additional robust service responses, whilst preventing unnecessary

		admission to hospital.
NHS Lothian to seek to develop robust day hospital services in community settings, in partnership with local authority colleagues.	Phase 2 – 2010.	Day hospital therapy and treatments will be offered from community sites in partnership with local authority services.
Partners should look to develop robust residential services, to prevent unnecessary admission and support people in their own communities	Phase 2 – 2010. This work will be informed by the outcome of the partnership work with the Joint Improvement Team.	Robust models of care to support people with learning disabilities who require this level of service will be developed by the partners.

5.3 People with learning disabilities who commit offences

Across Scotland there is a lack of community provision for offenders with learning disabilities ASD and AS. There is a need to develop these services by working in partnership with provider organisations, social work services, the criminal justice system, housing, employment services and the NHS.

Local services must develop in line with national and regional ones, including developments at the State Hospital and the NHS secure provision being created in Fife. These developments are solely for male service users. There is now an identified need for NHS Lothian to give consideration to the specialist needs of women with learning disabilities who commit offences. NHS Lothian is actively seeking opportunities to develop services for this group of individuals.

New housing and community support models are required and need to focus on the need to protect people with learning disabilities whose behaviours

require ongoing support and close supervision. This will have the effect of limiting the potential for re-offending and ensuring public safety. Careful consideration will be required in identifying partner providers to develop support services for this group of people.

Planning for this small group, and any decisions to restrict individuals' liberty, must be based on robust risk assessments. Common practices and protocols must be agreed between relevant agencies. The strategy recommends the implementation of a Significant Risk Advisory Group to oversee the development and agree implementation of care, treatment and support arrangements which are then put in place for these individuals.

Strategy Recommendation	Timescale	Outcome
A Lothian Significant Risk Advisory Group should be established.	Phase 2 - 2010	A multi agency group, with developed pathways relating to the MAPPA arrangements and Adult Support and Protection, will make treatment and support recommendations, managing risk and allocating resources for individuals with learning disabilities with forensic behaviours.
Residential accommodation for people with forensic support requirements should be established, supported by a Forensic Learning Disability	Phase 2 – 2010. This will be directly informed by the outcomes of the development work with the Joint Improvement Team, informing models of care.	Clear, agreed, jointly delivered models of care that appropriately support people with learning disabilities with the more complex support needs/

Team.		requirements.
NHS Lothian to establish a Specialist Forensic Team to begin to build capacity within the system to support the implementation of the developed integrated care pathway for patients with learning disability with forensic needs.	Phase 1; 2009/2010. Investment and recruitment to be initiated in phase 1, to support the development of the SEAT Low Secure Unit and the emerging community based forensic services in Lothian	The availability of a robust infrastructure to support the risk management and skills development of community based forensic services for people with learning disabilities.
NHS Lothian to contribute to the development of the SEAT Low Secure Forensic Unit for men with learning disabilities	Phase 1 2009/2010	The availability of a regional service providing appropriate, fit for purpose, support and treatment services in a low secure setting for men with learning disabilities who have forensic behaviours.
Consideration should be given to making special provision for women with a learning disability who offend.	Phase 2 – 2010 Application to proceed on a regional or national basis being progressed throughout Phase 1.	Appropriate services within Scotland for women with learning disabilities who offend.

5.4 People with learning disabilities who are homeless or who are involved in substance abuse

This is a complex and hard-to-reach group. Little is known about their numbers, though there is a clear need for help. Difficult home lives, and many

other problems, can lead to homelessness. Homelessness in turn can bring vulnerability to substance abuse.

More people with learning disabilities, ASD and AS are now able to live, work and socialise in the community, and as such they are vulnerable to the same triggers as the general population. These include a desire to fit in with others or to try to escape stress.

Research suggests that services available to people who are homeless, or substance abusers, are often poorly suited to the needs of those with learning disabilities. Housing staff, who are often the first point of contact, need help identifying people with a learning disability so they can be appropriately placed and other services alerted. Where this does not happen and housing or other services are unsuitable the person can find themselves in increasingly difficult circumstances. This puts the person back to square one and wastes time and resources that could have been better used.

Strategy Recommendation	Timescale	Outcome
Appropriate safe accommodation for those who are homeless should be identified as a priority.	Phase 2. Levels of service and models of care will be informed by the outcome of the work with the Joint Improvement Team.	Delivery of services and accommodation appropriate to the needs of people with learning disabilities who are experiencing homelessness
Early involvement with people who are homeless will allow people to tell services what they need and want and for support to be offered at the earliest opportunity.	Phase 1 – 2009/2010	Housing Officers/ Housing Support services, supported by Learning Disability services provide appropriate early intervention and support to people with learning

		disabilities who are homeless.
Joint working and training should be developed to ensure better co-ordination across staff groups and an increased understanding of the needs of people with learning disabilities who are experiencing homelessness.	Phase 2 This recommendation is linked to the delivery of outcomes at recommendations 10 (i) and 23, analysis and delivery of training.	A shared understanding of the needs of individuals with learning disabilities, availability of appropriate support and knowledge of how/where to access specialist support as required.

5.5 People with profound and multiple learning disabilities

Both nationally and locally there has been a limited focus on people with profound and multiple learning disabilities compared to other people with learning disabilities. Improvements in medical technology are leading to significant increases in the number of adults with profound and multiple learning disabilities now and in the future therefore it is imperative that we plan and prepare services in order to be able to appropriately respond to the needs of this group.

People with profound and multiple learning disability experience a range of significant health needs that bring them in to frequent contact with healthcare services. The range and complexity of health needs experienced by this group increases with the severity of learning disability.

Some challenges facing us include the possibility of young people with profound and multiple learning disabilities remaining isolated from their peers as they grow into adulthood.

Lothian has many examples of good practice, e.g. Murraypark, a nursing home for young adults with multiple disabilities. However as the numbers of people experiencing profound and multiple disabilities increases, we need to develop alternative models and capacity in response.

A significant development elsewhere in Scotland has been PAMIS (Promoting a More Inclusive Society) which supports the interests of people with profound and multiple learning disabilities. PAMIS is not yet active in Lothian but could bring a level of expertise to the region, and be a focus for the development of services and training in this area.

Strategy Recommendation	Timescale	Outcome
The care management of people with profound and multiple disabilities must include appropriate health coordination.	Phase 1.	Through the Single Shared Assessment process, and the GP Enhanced services, people with profound and multiple learning disabilities will be supported to obtain appropriate healthcare assessment and treatment.
People with profound and multiple disabilities should have the choice of residential, home based short breaks or holiday respite services.	Phase 2.	People will be supported to consider self directed care/ direct payments as an alternative to traditional respite services.
NHS Lothian, on conclusion of the partnership work with	Phase 2 - 2010	Services, including respite, residential and day/evening support will

the Joint Improvement Team will redesign services for people with profound and multiple disabilities.		be available to people with profound and multiple disabilities.
NHS Lothian and their partners should consider funding a Lothian wide PAMIS Coordinator.	Phase 2 – 2010.	A PAMIS Coordinator will be considered as part of the redesign and delivery of services to people with profound and multiple disabilities.

5.6 People with Autism Spectrum Disorder and/or Aspergers Syndrome

The “Same as You?” explicitly stated that it expected statutory agencies to apply the recommendations to people with learning disabilities and people with ASD.

Council, health and other mainstream services should be sensitive to the needs of people with ASD and Aspergers Syndrome.

Needs are not matched by resources and the number of people identified with ASD and Asperger Syndrome with and without a learning disability is growing. Many fall through the gaps between services, which can mean they lack the support to lead independent lives.

Some children with ASD and Aspergers Syndrome go on to do well in later life but there are risks of depression, alcohol and substance misuse problems and suicide in adolescence.

Diagnosis is vital, and the earlier the better. The South East Scotland specialist service offers diagnosis and many other services but it needs to be developed as currently there is only one full time post with all other professional input delivered via professional interest sessions, i.e. it is an

unfunded service, which, although extremely valuable, cannot meet the demand. There is also Number 6, a one-stop-shop used by some 350 adults from across Lothian's with AS and high functioning autism, which is highly valued for services including Counselling and support into employment and provides one example of a model of provision for the future.

People with ASD and AS who attended the Autism Forum consultative event raised a series of issues that informed the working group's findings. These ranged from worries about what happens after their parents can no longer offer full emotional support, to the desire for a dating agency.

Strategy Recommendation	Timescale	Outcome
NHS Lothian and the 4 Local Authorities should consider funding a dedicated resource for people with High Functioning Autism and/or Aspergers Syndrome	Phase 1 ; 2009/2010	People with high functioning autism and/or AS are able to access specialist support on an as required basis, supporting their mental health and wellbeing.
50% of staff in all mainstream services, including the Police will undertake specific awareness training. The training should include Users and Parents/ Carers.	Phase 1	Mainstream public services have an effective awareness of the particular requirements of people with ASD/ Aspergers, and have built in capacity to be able to respond appropriately to the needs of this section of the public.
Each mainstream	Phase 2 – following	Staff within public

organisation involved in the above recommendation should identify 1 member of staff to act as a point of contact, supporter and adviser to other staff.	analysis of impact of the above recommendation.	organisations are aware of and have access to colleagues with more in depth knowledge of the needs of individuals with ASD/ Aspergers.
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5.7 People with learning disabilities from black and minority ethnic communities

People with learning disabilities from minority ethnic communities experience disadvantage in relation to both race and impairment. Negative stereotypes and the attitudes of service professionals can contribute to their disadvantage.

Service information must be more readily available and provided in minority languages. The Disability Rights Commission provides guidance and recommendations on meeting the information needs of Black and Minority Ethnic people. The Commission has also observed that there are often low levels of funding, and consequent poor performance, in specialist services to Black and Minority Ethnic disabled people.

There is a lack of clarity about the population of people from black and minority ethnic communities across Lothian. In the first instance the strategy recommends undertaking the audit endorsed by Valuing People Team – the English equivalent of the “Same as You?” , to help us identify populations and their use of and requirement for services.

Strategy Recommendation	Timescale	Outcome
An adapted version of the Valuing People	Phase 1 2009 /2010	Public agencies will be informed about, and

<p>Ethnicity Tool should be used to enable the partners to estimate the demand we should expect for services from the black and ethnic communities.</p>		<p>able to design services accordingly, people with learning disabilities from black and ethnic minority communities.</p>
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5.8 Parents with learning disabilities

People First (Scotland) has set up a group for parents with learning disabilities in Lothian. The group thinks that the community should accept that parents with learning difficulties may need ongoing and, where necessary, one-to-one support. However, the need for support should not, by itself, be seen as an indicator that their children are at risk.

Guidelines on supporting parents with learning difficulties are being developed by the Scottish Consortium for Learning Disabilities, supported by People 1st.

The Strategic Board needs to ensure an ongoing link with the work of this group in order that guidance can be considered and adopted as it becomes available.

Strategy Recommendation	Timescale	Outcome
<p>All information from Maternity, Children and Families and Education Services should be jargon free and available in accessible formats.</p>	<p>Phase 1 2009/2010</p>	<p>People with learning disabilities who are parents are more able to engage and make informed decisions through the provision of information in accessible formats</p>

NHS Lothian to commission an organisation to “translate” healthcare information into accessible formats, on behalf of NHS Lothian.	Phase 1 2009/2010, funded via investment from SGHD	Public healthcare information will be available to people with learning disabilities in formats that enables informed decisions.
A demonstration project in line with “Finding the Right Support” providing support to parents with learning disabilities should be set up.	Phase 1 – being taken forward by ADSW in 2009/2010	The Partnership Board will receive a report and learning from ADSW relating to how best to provide support to parents who have a learning disability.
All support staff working with parents with learning disabilities should have training on the needs of parents with learning disabilities. This should involve Service Users as trainers.	Phase 2	In partnership with the Scottish Consortium for Learning Disabilities, training sessions will be delivered to support staff.

5.9 Service redesign

"The Same as You?" said that no-one with a learning disability will live in hospital in Scotland. However, some people have stayed in NHS in-patient units in Lothian for many years now. The polarization of and categorization of people as either health or social care is unhelpful and creates rather than dissolves divisions and barriers for the service user.

Access to specialist support for complex behaviour or mental health should be available as close to a person's home as possible. Moving people out of their homes to receive treatment whether behavioural, psychiatric or for medical reasons, should be no more common for people with learning disabilities, ASD or AS than it is for the general population.

The services provided by the NHS and local authorities in Lothian have to be redesigned to meet changing needs. We need to make sure that sustainable community based services which negate the need for admission and/or enable earlier discharge home from hospital for others are available. A crucial task is to enable those who no longer need to be in hospital to live in the community, and to make NHS beds available to those who need them.

The Lothian partners, supported by the Joint Improvement Team, have agreed a work programme of work to be executed over the next 12 months, which supports a joint way forward to support new models of care for people with complex support requirements to enable them to live in their local community where-ever possible.

These new models of care will be informed by the developing Tele-care and Tele-health agendas, and the enhancement these technologies can bring to packages of care.

The Learning Disability Managed Care Network is also looking at regional joint commissioning for the very specialist services and the Lothian partners will be active parties in any developments.

Strategy Recommendation	Timescale	Outcome
A seminar should be held in each area, engaging all	Phase 1 2009/2010	The local joint planning groups will host a seminar to inform local

stakeholders, to address the planning for housing and support for people with learning disabilities, to ensure these processes are sufficiently robust.		housing strategies and development plans.
We will commission the Joint Improvement Team to assist all partners in undertaking a formal assessment of need of people with Learning Disabilities in Lothian.	Phase 1 – to be concluded by October 2009.	The partnership, with the Joint Improvement Team, will develop a full understanding of the population of people with learning disabilities, particularly those with complex needs.
Housing representatives should be actively involved in the implementation of the strategy and specifically in relation to the Joint Improvement Team Capacity Planning Exercise.	Phase 1	Housing representatives will support the above process with the Joint Improvement Team.
All partners need to implement the E-SAY database in line with Scottish Government requirements.	Phase 1 2009/2010	Data collection and analysis to inform redesign, and to link with partners in SGHD and Local Authorities will support further intelligence.
NHS Lothian to establish compatibility of	Phase 1 2009/2010	NHS will be able to support Local Authority

PIMS with the requirements of E-SAY data targets.		partners in the delivery of data in regard to the population and service use of people with learning disabilities, as required by SGHD.
CLD Teams to undertake an audit of all patients known to the teams, and identify those who require a review of service using the SSA model. Information from review to inform E-SAY data collection processes.	Phase 1	People known to the CLDT's will receive appropriate review and assessment, and data held will be accurate.
The Joint Improvement Team's "Capacity for Change" exercise should be used to inform the proposals for re-designed and/or new services.	Phase 1 – to be concluded by October 2009.	Extracts from the JIT workbook will be used to inform the needs assessment on people with learning disabilities with complex support needs.

6. Using our resources well: funding and supporting change

Voluntary Sector

As elsewhere in Scotland, the voluntary sector provides the majority of services to people with learning disabilities, ASD and Aspergers syndrome. These organisations have been and continue to be full partners in the strategy. The continued engagement is valuable for many reasons including: They have "lifetime relationships with service users and carers

They pioneer new service models

They reflect changes in what service users need and want

The voluntary sector acts as a reservoir of volunteer commitment

It employs half the workforce engaged in supporting people with learning disabilities and therefore needs to be a key partner in the workforce strategy.

Local authorities

The four local authorities in Lothian provide many services for people with learning disabilities. These include day centres, education, housing, respite care, training, and advocacy. They also commission substantial services from the independent sector providers.

The health service

The NHS provides a range of specialist services geared to the needs of people with learning disabilities. There are inpatient and day hospital services for acute assessment and treatment, and longer-term treatment and rehabilitation. NSH Lothian also provides eight multi-disciplinary community teams.

Among the most recent developments is a service – jointly managed with the City of Edinburgh Council – that provides robust social care for those who have come, or are at risk of coming, into contact with the criminal justice system.

There are also a variety of specialist community services offering assessment and treatment across Lothian. These include specialist services for autism, epilepsy and behaviour that challenge services.

The Managed Care Network

A major achievement has been the creation of a learning disability Managed Care Network, which serves Lothian and much of south east Scotland. It brings together the NHS, local authorities, service users and carers. The

network enables sharing of ideas on best practice, improved training opportunities, as well as potentially attaining the best use of resources by providing some highly specialist services locally, and others regionally

Current Financial Costs

The NHS and four local authorities spent £109 million in 2007/2008 on services specifically for people with learning disabilities. Please see Annex 1 for a detailed breakdown of the allocation of the financial commitment. There are an estimated 21600 people with learning disability in Lothian of whom 4,000 people, both adults and children, are known to the learning disabilities services. These figures do not include people on the Autism spectrum who do not have a learning disability

People are beginning to make use of services in a more individualised manner. For example, in 2007 there were more than 1,400 adults attending day time support services. Nearly 700 people with learning disabilities held their own tenancies and around 1,330 were in further education, training, voluntary work or employment programmes.

Funding and supporting change

The NHS and local authorities have limited amounts of money and resources that need to go a long way. Demand is increasing all the time because people are living longer as a result of advances in medicine and care. Service users and carers also – quite rightly – have ever-higher expectations.

To meet these challenges we need to redesign services so organisations work together more closely to provide more efficient, fit for purpose high quality services. This might include making better use of inpatient beds and deployment of available budgets. We also need to identify services that are no longer desired by people with learning disabilities, or fit for purpose, and disinvest from these services. One challenge will be the consideration of how to appropriately respond to the inequality in the distribution of services/resources, which is not related to assessed levels of support needs.

Redistribution of resources on a more equitable basis may enable statutory agencies to reinvest in new or different models of service provision, including self directed support.

Additional funding will also need to be provided if we are to improve the quality of life for service users in the way they, and we, wish. We need to address the lack of capacity within current service availability, as not doing so would increase the risk that many vulnerable adults and their carers struggle to maintain a decent standard of living, or become at serious risk due to stress and ill health.

But there will always be the need to prioritise. In the Strategy Report the partners seek to ensure that priorities are decided in the best possible way by giving more say to users and carers. This is being reflected at local levels through the Partnership in Practice Agreements and it is the intention of the Strategy Board that we establish an ongoing Partnership Board, with active user and carer representation, to assist us in identifying and agreeing a process and criteria which will enable us to decide on priorities at a Lothian wide level.

Strategy Recommendation	Timescale	Outcome
NHS Lothian and the 4 partner authorities will establish a Partnership Board to oversee the implementation of this strategy.	Phase 1	A Partnership Board, representative of all stakeholders, will be in place by January 2009.
All partners should use the People 1 st guidelines on inclusion and accessibility.	Phase 1 – with immediate effect.	All partners will ensure that continued engagement of service users in the design and

		service commissioning process is fully supported by inclusive engagement processes.
We should make sure that those who have greater communication difficulties are consulted in a way that is meaningful to them.	Phase 1 – with immediate effect.	Through the extended provision of advocacy, and training programmes to build staff skills, people with communication difficulties will be supported to make best use of opportunities to inform planning processes.
NHS Lothian and its partners will seek additional funding to enhance advocacy provision for people with learning disabilities.	Phase 1	Strategy investment will be used to enhance the availability of advocacy to people with learning disabilities across Lothian.

7. Next Steps

The Lothian partners have translated the recommendations of the strategy into a phased implementation plan. This full plan is attached in Annex 4.

Phase 1 has already begun, and is intended to be completed by October 2009. One of the key actions over the forthcoming 12 months is the conclusion of the work being undertaken with the Joint Improvement Team, discussed in 5.9, which will assist us in the definition of new models of care and service responses for people with the most complex needs.

Individuals have needs which are the responsibility of different agencies and have to be met through a coordinated response. This requires joint planning, commissioning and/or provision of service. With the support of the Joint Improvement Team, NHS Lothian and the 4 Local Authorities intend to reach agreement as to how to take this forward locally. The outcomes of this work will inform the content and priorities of Phase 2 of this plan, and the level of investment for service model redesign sought by the statutory partners.

Also included in this work will be the consideration of the support needs and services required by people with learning disabilities, ASD and AS who are currently accommodated out with the local area. Unless service users choose differently the assumption should always be that the person wants to be supported to remain in their local community.

8. Conclusion

NHS Lothian and the 4 local authorities, supported by people with learning disabilities from across Lothian, have set themselves a challenging programme for the coming years, to deliver appropriate, equitable and fit for future services across health and social care.

As noted in the recommendations and the section addressing service redesign, the work that the partnership will undertake, supported by the Scottish Government Joint Improvement Team, will directly inform stage 2 of the implementation plan.

We look forward to the next stage of this strategy, and, with the support of all partners and the development of the Partnership Board, look forward to the continued partnership with Users and Carers to support us with the implementation of our hopes and ambitions.

Annex 1

CEC LD Strategy

CEC LD Strategy

PROVIDER	2007/08 Outturn					Budget 2008/09				
	Net Outturn	Resource Transfer	Gross Outturn	Overhead	Total	Net Budget	Resource Transfer	Gross Budget	Overhead	Total
	£	£	£	£	£	£	£	£	£	£
RESIDENTIAL ACCOMODATION										
Health Council			0		0			0		0
Independent sector	1,217,274		1,217,274	53,864	1,271,138	1,128,676		1,128,676		1,128,676
	5,934,164	5,607,884	11,542,048	510,727	12,052,775	6,990,148	5,605,758	12,595,906		12,595,906
	7,151,438	5,607,884	12,759,322	564,591	13,323,913	8,118,824	5,605,758	13,724,582	0	13,724,582
CARE & SUPPORT AT HOME										
Health Council			0		0			0		
Independent sector	6,468,813	82,140	6,550,953	289,875	6,840,828	4,695,831	82,109	4,777,940		4,777,940
	10,335,937		10,335,937	457,358	10,793,295	9,207,157		9,207,157		9,207,157
	16,804,750	82,140	16,886,890	747,233	17,634,123	13,902,988	82,109	13,985,097	0	13,985,097
RESPIRE SERVICES										
Health Council			0		0			0		
Independent sector	1,612,009	60,089	1,672,098	73,989	1,746,087	1,725,571	60,044	1,785,615		1,785,615
			0	0	0			0		0
	1,612,009	60,089	1,672,098	73,989	1,746,087	1,725,571	60,044	1,785,615	0	1,785,615
DAY CARE SERVICES										
Health Council			0		0			0		
Independent sector	6,285,033	198,432	6,483,465	286,889	6,770,354	6,245,683	198,357	6,444,040		6,444,040
	3,139,994	845,221	3,985,215	176,343	4,161,558	2,880,995	844,905	3,725,900		3,725,900
	9,425,027	1,043,653	10,468,680	463,232	10,931,912	9,126,678	1,043,262	10,169,940	0	10,169,940
ASSESSMENT & CARE MANAGEMENT										
Health Council			0		0			0		
Independent sector	1,211,676	17,068	1,228,744	54,371	1,283,115	1,192,188	17,061	1,209,249		1,209,249
			0	0	0			0		0
	1,211,676	17,068	1,228,744	54,371	1,283,115	1,192,188	17,061	1,209,249	0	1,209,249
DIRECT PAYMENTS										
Health Council			0		0			0		
Independent sector			0	0	0			0		0
	348,559		348,559	15,423	363,982	241,970		241,970		241,970
	348,559	0	348,559	15,423	363,982	241,970	0	241,970	0	241,970

EMPLOYMENT SERVICES										
Health Council Independent sector	614,741	17,783	632,524	27,989	660,513	671,492	17,776	689,268		689,268
	614,741	17,783	632,524	27,989	660,513	671,492	17,776	689,268	0	689,268
ADULT PLACEMENT SERVICES										
Health Council Independent sector	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
LOCAL AREA COORDINATION										
Health Council Independent sector	218,524		218,524	9,670	228,194	273,975		273,975		273,975
	218,524	0	218,524	9,670	228,194	273,975	0	273,975	0	273,975
IN PATIENT SERVICES										
Health Council Independent sector	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
COMMUNITY HEALTH SERVICES										
Health Council Independent sector	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
DAY HOSPITALS										
Health Council Independent sector	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
HOSPITAL LIAISON										
Health Council Independent sector	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
MANAGED CLINICAL NETWORK										
Health Council Independent sector	0	0	0	0	0	0	0	0	0	0
	0	0	0	0	0	0	0	0	0	0
ADVOCACY										
Health			0		0			0		

Council			0	0	0			0		0
Independent sector	113,410		113,410	5,018	118,428	105,505		105,505		105,505
	113,410	0	113,410	5,018	118,428	105,505	0	105,505	0	105,505
CARERS' SUPPORT										
Health			0		0			0		
Council			0	0	0			0		0
Independent sector	25,000		25,000	1,106	26,106	25,000		25,000		25,000
	25,000	0	25,000	1,106	26,106	25,000	0	25,000	0	25,000
VOLUNTARY ORGANISATIONS - OTHER										
Health			0		0			0		
Council			0	0	0			0		0
Independent sector	157,859	72,513	230,372	10,194	240,566	157,859	72,513	230,372		230,372
	157,859	72,513	230,372	10,194	240,566	157,859	72,513	230,372	0	230,372
TOTAL	37,682,993	6,901,130	44,584,123	1,972,816	46,556,939	35,542,050	6,898,523	42,440,573	0	42,440,573

Finance Estimated Out-turn 2007-08

Midlothian Council

MIDLOTHIAN COUNCIL

PROVIDER	Gross Budget (Revised)	Resource Transfer	2007/08		Projected Over/(Under)spend 2007/08
			Net Budget (Revised)	Projected Outturn at Period 9	
	£	£	£	£	£
RESIDENTIAL ACCOMODATION					
Health			0		0
Council	49,518		49,518	63,069	13,551
Independent sector	3,614,896	1,975,531	1,639,364	2,430,525	791,161
	3,664,414	1,975,531	1,688,882	2,493,595	804,712
CARE & SUPPORT AT HOME					
Health			0		0
Council	49,736		49,736	49,736	0
Independent sector	3,128,216		3,128,216	3,080,984	-47,232
	3,177,952	0	3,177,952	3,130,720	-47,232
RESPIRE SERVICES					
Health			0		0
Council			0		0
Independent sector	100,685		100,685	214,982	114,297
	100,685	0	100,685	214,982	114,297
DAY CARE SERVICES					
Health			0		0
Council	1,367,668	-19,812	1,347,856	1,221,759	-126,097
Independent sector	678,030		678,030	853,848	175,818
	2,045,698	-19,812	2,025,886	2,075,607	49,721
ASSESSMENT & CARE MANAGEMENT					
Health			0		0
Council	397,722		397,722	410,598	12,876
Independent sector			0		0
	397,722	0	397,722	410,598	12,876
DIRECT PAYMENTS					
Health			0		0
INDIVIDUALS	1,420		1,420	35,103	33,683
Independent sector			0		0
	1,420	0	1,420	35,103	33,683
EMPLOYMENT SERVICES					
Health			0		0
Council			0		0
Independent sector			0		0
	0	0	0	0	0
ADULT PLACEMENT SERVICES					
Health			0		0
Council	18,693		18,693	18,693	0
Independent sector			0		0
	18,693	0	18,693	18,693	0
LOCAL AREA COORDINATION					
Health			0		0
Council			0		0

	Independent sector	110,399		110,399	110,399	0
		110,399	0	110,399	110,399	0
IN PATIENT SERVICES						
	Health			0		0
	Council			0		0
	Independent sector			0		0
		0	0	0	0	0
COMMUNITY HEALTH SERVICES						
	Health			0		0
	Council			0		0
	Independent sector			0		0
		0	0	0	0	0
DAY HOSPITALS						
	Health			0		0
	Council			0		0
	Independent sector			0		0
		0	0	0	0	0
HOSPITAL LIAISON						
	Health			0		0
	Council			0		0
	Independent sector			0		0
		0	0	0	0	0
MANAGED CLINICAL NETWORK						
	Health			0		0
	Council			0		0
	Independent sector			0		0
		0	0	0	0	0
ADVOCACY						
	Health			0		0
	Council			0		0
	Independent sector	40,831		40,831	40,831	0
		40,831	0	40,831	40,831	0
CARERS' SUPPORT						
	Health			0		0
	Council			0		0
	Independent sector			0		0
		0	0	0	0	0
VOLUNTARY ORGANISATIONS - OTHER						
	Health			0		0
	Council			0		0
	Independent sector	27,160		27,160	29,085	1,926
		27,160	0	27,160	29,085	1,926
OTHER - MISCELLANEOUS						
	Health			0		0
	Council	65,305		65,305	3,948	-61,358
	Independent sector			0		0
		65,305	0	65,305	3,948	-61,358
TOTAL		9,650,280	1,995,344	7,654,936	8,563,561	908,625

Source of information –

Period 9 Monitoring - all Learning Disability (73**) codes - non-horizontal budgets
Plus an apportionment of non 73** codes relating to Learning Disabilities in line with PIP
information (outturn = budget).

East Lothian Council

EAST LOTHIAN COUNCIL

PROVIDER	<----- 2006/07 Baseline Budget ----->					2007/08		
	Net Budget	Resource Transfer	Gross Budget	Overhead	Total	Net Budget	Gross Budget	Net Outturn over/(under)
	£	£	£	£	£		£	£
RESIDENTIAL ACCOMODATION								
Health			0		0			0
Council			0		0			0
Independent sector	1,172,969	0	1,172,969	47,587	1,220,556	1,530,811	1,530,811	216,000
	1,172,969	0	1,172,969	47,587	1,220,556	1,530,811	1,530,811	216,000
CARE & SUPPORT AT HOME								
Health			0		0			0
Council	366,847		366,847	14,883	381,730	537,857	537,857	0
Independent sector	5,267,386	1,618,625	6,886,011	279,365	7,165,376	5,052,990	6,671,534	287,000
	5,634,233	1,618,625	7,252,858	294,248	7,547,106	5,590,847	7,209,391	287,000
RESPIRE SERVICES								
Health			0		0			0
Council			0		0			0
Independent sector	258,757		258,757	10,498	269,255	294,676	294,676	-24,000
	258,757	0	258,757	10,498	269,255	294,676	294,676	-24,000
DAY CARE SERVICES								
Health			0		0			0
Council	1,803,535	0	1,803,535	73,169	1,876,704	1,621,303	1,621,303	-54,000
Independent sector	552,684	6,759	559,443	22,697	582,140	521,894	528,732	32,000
	2,356,219	6,759	2,362,978	95,866	2,458,844	2,143,197	2,150,035	-22,000
ASSESSMENT & CARE MANAGEMENT								
Health			0		0			0
Council	153,525		153,525	6,229	159,754	156,018	156,018	4,000
Independent sector			0		0			0
	153,525	0	153,525	6,229	159,754	156,018	156,018	4,000
DIRECT PAYMENTS								
Individuals	62,278		62,278	2,527	64,805	219,035	219,035	26,000
	62,278	0	62,278	2,527	64,805	219,035	219,035	26,000
EMPLOYMENT SERVICES								
Health			0		0			0
Council			0		0			0
Independent sector	410,284		410,284	16,645	426,929	354,663	354,663	0
	410,284	0	410,284	16,645	426,929	354,663	354,663	0
ADULT PLACEMENT SERVICES								
Health			0		0			0
Council	72,473		72,473	2,940	75,413	74,513	74,513	-6,000
Independent sector			0		0			0
	72,473	0	72,473	2,940	75,413	74,513	74,513	-6,000
LOCAL AREA COORDINATION								
Health			0		0			0
Council			0		0			0
Independent sector	65,000		65,000	2,637	67,637	86,000	86,000	0
	65,000	0	65,000	2,637	67,637	86,000	86,000	0
IN PATIENT SERVICES								
Health			0		0			0
Council			0		0			0

Independent sector			0		0			0
	0	0	0	0	0	0	0	0
COMMUNITY HEALTH SERVICES								
Health			0		0			0
Council			0		0			0
Independent sector			0		0			0
	0	0	0	0	0	0	0	0
DAY HOSPITALS								
Health			0		0			0
Council			0		0			0
Independent sector			0		0			0
	0	0	0	0	0	0	0	0
HOSPITAL LIAISON								
Health			0		0			0
Council			0		0			0
Independent sector			0		0			0
	0	0	0	0	0	0	0	0
MANAGED CLINICAL NETWORK								
Health			0		0			0
Council			0		0			0
Independent sector			0		0			0
	0	0	0	0	0	0	0	0
ADVOCACY								
Health			0		0			0
Council			0		0			0
Independent sector	35,000		35,000	1,420	36,420	35,000	35,000	0
	35,000	0	35,000	1,420	36,420	35,000	35,000	0
CARERS' SUPPORT								
Health			0		0			0
Council			0		0			0
Independent sector	57,799		57,799	2,345	60,144	63,322	63,322	0
	57,799	0	57,799	2,345	60,144	63,322	63,322	0
VOLUNTARY ORGANISATIONS - OTHER								
Health			0		0			0
Council			0		0			0
Independent sector			0		0			0
	0	0	0	0	0	0	0	0
TOTAL	10,278,536	1,625,384	11,903,920	482,941	12,386,861	10,548,082	12,173,464	481,000

Note - The 2007/08 figures do not include overheads, net outturn based on 31st January projections

West Lothian Council

WEST LOTHIAN COUNCIL

PROVIDER	<----- 2006/07 Baseline Budget ----->					2007/08			
	Net Budget	Resource Transfer	Gross Budget	Overhead	Total	Net Budget	Resource Transfer	Gross Budget	Net Outturn over/(under)
	£	£	£	£	£		£		
RESIDENTIAL ACCOMODATION									
Health			0		0				
Council	506,401		506,401	19,853	526,254	513,941		513,941	50,000
Independent sector	1,975,523	1,531,208	3,506,731	137,479	3,644,210	2,105,754	1,531,208	3,636,962	460,000
	2,481,924	1,531,208	4,013,132	157,332	4,170,464	2,619,695	1,531,208	4,150,903	510,000
CARE & SUPPORT AT HOME									
Health			0		0				
Council	854,155		854,155	29,293	883,448	703,741		878,575	-17,000
Independent sector	1,677,558	63,688	1,741,247	59,715	1,800,962	1,693,675	63,688	1,757,364	209,000
	2,531,713	63,688	2,595,402	89,008	2,684,410	2,397,417	63,688	2,635,939	192,000
RESPIRE SERVICES									
Health			0		0				
Council	37,275	5,585	42,860	5,644	48,504	30,541	5,586	36,127	12,000
Independent sector	350,277		350,277	46,122	396,399	344,779		359,779	-30,000
	387,552	5,585	393,137	51,766	444,903	375,320	5,586	395,906	-18,000
DAY CARE SERVICES									
Health			0		0				
Council	2,563,810		2,563,810	87,925	2,651,735	3,140,317		3,292,757	-18,000
Independent sector	441,168	396,298	837,466	28,720	866,187	470,875	396,298	470,875	-35,000
	3,004,978	396,298	3,401,277	116,645	3,517,922	3,611,192	396,298	3,763,632	-53,000
ASSESSMENT & CARE MANAGEMENT									
Health			0		0				
Council	253,475	0	253,475	8,693	262,168	263,117		263,117	-45,000
Independent sector			0		0				
	253,475	0	253,475	8,693	262,168	263,117		263,117	-45,000
DIRECT PAYMENTS									
Health			0		0				
INDIVIDUALS	152,962	0	152,962	5,246	158,208	213,562		213,562	24,000
Independent sector			0		0				
	152,962	0	152,962	5,246	158,208	213,562		213,562	24,000
EMPLOYMENT SERVICES									
Health			0		0				
Council		0	0		0	0		0	0
Independent sector	23,063		23,063	791	23,853	23,639		23,639	0
	23,063	0	23,063	791	23,853	23,639		23,639	0
ADULT PLACEMENT SERVICES									
Health			0		0				
Council	354,924	0	354,924	16,858	371,782	367,002		367,002	-21,000
Independent sector			0		0				
	354,924	0	354,924	16,858	371,782	367,002		367,002	-21,000
LOCAL AREA COORDINATION									
Health			0		0				
Council	103,864	0	103,864	3,562	107,426	104,118		104,118	-33,000

Independent sector			0		0			
	103,864	0	103,864	3,562	107,426	104,118	104,118	-33,000
IN PATIENT SERVICES								
Health			0		0			
Council			0		0	0	0	0
Independent sector			0		0			
	0	0	0	0	0	0	0	0
COMMUNITY HEALTH SERVICES								
Health			0		0			
Council			0		0	0	0	0
Independent sector			0		0			
	0	0	0	0	0	0	0	0
DAY HOSPITALS								
Health			0		0			
Council			0		0	0	0	0
Independent sector			0		0			
	0	0	0	0	0	0	0	0
HOSPITAL LIAISON								
Health			0		0			
Council			0		0	0	0	0
Independent sector			0		0			
	0	0	0	0	0	0	0	0
MANAGED CLINICAL NETWORK								
Health			0		0			
Council			0		0	0	0	0
Independent sector			0		0			
	0	0	0	0	0	0	0	0
ADVOCACY								
Health			0		0			
Council		0	0		0	0	0	0
Independent sector	51,250		51,250	1,758	53,008	52,531	52,531	0
	51,250	0	51,250	1,758	53,008	52,531	52,531	0
CARERS' SUPPORT								
Health			0		0			
Council			0		0	0	0	0
Independent sector			0		0			
	0	0	0	0	0	0	0	0
VOLUNTARY ORGANISATIONS - OTHER								
Health			0		0			
Council			0		0	0	0	0
Independent sector	13,666		13,666		13,666	14,007	14,007	0
	13,666	0	13,666	0	13,666	14,007	14,007	0
TOTAL	9,359,371	1,996,780	11,356,151	451,658	11,807,809	10,041,600	11,984,356	556,000

NHS Lothian

NHS Lothian

PROVIDER	Net Budget	----- 2007/08 Baseline Budget ----->			Total	2007/08 Net Outturn over/(under)
		Resource Transfer	Gross Budget	Overhead		
	£	£	£	£	£	£
RESIDENTIAL ACCOMODATION						
Health	3,801,451		3,801,451	423,397	4,224,848	438,788
Council			0		0	
Independent sector			0		0	
	3,801,451	0	3,801,451	423,397	4,224,848	438,788
CARE & SUPPORT AT HOME						
Health			0		0	
Council			0		0	
Independent sector			0		0	
	0	0	0	0	0	0
RESPIRE SERVICES						
Health	53,773		53,773	6,083	59,856	
Council			0		0	
Independent sector			0		0	
	53,773	0	53,773	6,083	59,856	0
DAY CARE SERVICES						
Health			0		0	
Council			0		0	
Independent sector			0		0	
	0	0	0	0	0	0
ASSESSMENT & CARE MANAGEMENT						
Health			0		0	
Council			0		0	
Independent sector			0		0	
	0	0	0	0	0	0
DIRECT PAYMENTS						
Health			0		0	
Council			0		0	
Independent sector			0		0	
	0	0	0	0	0	0
EMPLOYMENT SERVICES						
Health			0		0	
Council			0		0	
Independent sector			0		0	
	0	0	0	0	0	0
ADULT PLACEMENT SERVICES						
Health			0		0	
Council			0		0	
Independent sector			0		0	
	0	0	0	0	0	0
LOCAL AREA COORDINATION						
Health			0		0	
Council			0		0	
Independent sector			0		0	
	0	0	0	0	0	0
IN PATIENT SERVICES						

	Health	3,002,378		3,002,378	361,467	3,363,845	47,881
	Council			0		0	
	Independent sector	395,000		395,000		395,000	-1,362
		3,397,378	0	3,397,378	361,467	3,758,845	46,519
COMMUNITY HEALTH SERVICES							
	Health	3,790,932		3,790,932	273,810	4,064,742	-121,832
	Council			0		0	
	Independent sector			0		0	
		3,790,932	0	3,790,932	273,810	4,064,742	-121,832
DAY HOSPITALS							
	Health	597,377		597,377	67,241	664,618	9,527
	Council			0		0	
	Independent sector			0		0	
		597,377	0	597,377	67,241	664,618	9,527
HOSPITAL LIAISON							
	Health	73,727		73,727	7,763	81,490	1,175
	Council			0		0	
	Independent sector			0		0	
		73,727	0	73,727	7,763	81,490	1,175
MANAGED CLINICAL NETWORK							
	Health			0		0	
	Council			0		0	
	Independent sector			0		0	
		0	0	0	0	0	0
ADVOCACY							
	Health			0		0	
	Council			0		0	
	Independent sector			0		0	
		0	0	0	0	0	0
CARERS' SUPPORT							
	Health			0		0	
	Council			0		0	
	Independent sector			0		0	
		0	0	0	0	0	0
VOLUNTARY ORGANISATIONS - OTHER							
	Health			0		0	
	Council			0		0	
	Independent sector	96,596		96,596		96,596	
		96,596	0	96,596	0	96,596	0
TOTAL		11,811,234	0	11,811,234	1,139,761	12,950,995	374,177

Annex 2

Labels and Definitions – A Note on Language

During the course of the Strategy Review there has been a lot of discussion and debate about what language and labels we should use to describe people. Strong views were expressed by the members of People First and others on the Strategy Review Board in favour of using the term “people with learning difficulties” instead of “people with learning disabilities”. On the other hand some Board members expressed concern about such a change, mainly because “learning disabilities” and “learning disability” are the terms most used in our legislation.

We could find no simple solution to this dilemma. We were however in agreement that whatever words we ultimately decided to use, there would still be problems. People were concerned that they sometimes needed to acquire certain labels as a passport to specialist services, and yet at the same time they wanted to avoid those same labels in order to have a chance of being treated in the same way as everyone else.

A change in language on its own is not enough to create change, but it is the linchpin through which action for change is formulated and evaluated. It needs to keep moving forward as part of a process of reflection and action.

In order to avoid delaying the progress of the Strategy, those people who had argued in favour of a change, were able to agree to compromise and accept the use of the terms “learning disability” and “learning disabilities” in this Report.

The Strategy Board has formally written to the Scottish Government to raise their awareness of this dilemma and move the discussion to a national level.

