

Joint Lothian Learning Disability Strategy Review
Any views you wish to convey should be directed to
Denis Rowley, Strategy Review Manager 07868 730520
or email him dr@denisrowley.fsworld.co.uk

Summary report for consultation

1: Why are we having a review?

2: The guiding vision

3: How we went about doing the review: who has been involved and who still needs to be involved?

4: Some common themes

- **Person centred approaches**
- **Supporting transitions**
- **Promoting good practice**

5: What the working groups said

- **Older people with learning disabilities**
- **People with additional mental health issues or behaviour that challenges services**
- **People with learning disabilities who commit offences**
- **People with learning disabilities who are homeless or who are involved in substance abuse**
- **People with profound and multiple learning disabilities**
- **People with autism spectrum disorders or asperger syndrome**
- **People with learning disabilities from black and minority ethnic communities**
- **Parents with learning disabilities**
- **Transitions**

- **Service re-design**

6: Using our resources well : funding and supporting change

7: Your views

8: Recommendations and consultation questions

1: Why are we having a review?

The health service, local authorities and others strive to provide people with learning disabilities, autism spectrum disorder and asperger syndrome with the services and support they need to enjoy the fullest possible lives.

People today expect to be able to make choices about many aspects of their lives and how they live them. People with learning disabilities and Autism Spectrum Disorder in Lothian, and their carers, are no exception to this expectation. They have responded enthusiastically to the invitation to play a full part in the review of services the NHS and councils have carried out.

This document sets out a range of exciting and challenging recommendations which have been worked up by the Strategy Review Board. In Lothian the community services for people with learning disabilities were built up in the late 1990s, and the long stay hospitals were all shut down. We believe that the time is ripe for another step change in the services and support for this group of people. Now we want to ask your views on what we should do to achieve this.

Right now the strategy is only a draft and no final decisions have been made. Before that happens we want the wider community to have its say, which is why we are holding a public consultation. This gives everyone living in the Lothians the chance to comment and put forward their ideas for the future of these important services. Once the final strategy is agreed, it will be the blueprint from which the partners will work for the next 10 years.

This document

The full Joint Learning Disability Strategy Review Report contains much more detail on the findings and recommendations of all the strategy working groups. You can get the full report from: Learning Disability Strategy, Deaconess House, 148 Pleasance, Edinburgh, EH8 9RS or view the strategy document at www.lothianlearningdisabilityreview.info

This summary document aims to capture the main points of the full joint strategy review document.

2: The guiding vision

The strategy aims to put into practice the visions and values set out in the Scottish Executive's report *The Same as You?*¹ which was published after a national review of learning disability policies in 2000.

Core values

The report's core principles, and those in this strategy review, are that people with learning disabilities, autism spectrum disorder and asperger syndrome 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.

Inclusion

There has been a high level of involvement of service users, family carers and others in the work that has gone into this review and it is hoped that this has laid a good foundation for people with learning disabilities and their families to have real power and influence over future developments.

Our aim is to keep making progress so that service users and carers continue to have a powerful voice in the planning and delivery of services and supports. To do this, we want to create a Partnership Board bringing together all those with an interest in learning disability services to have oversight of service planning at a Lothian level.

¹ Scottish Executive (2000) *The Same as You?* A review of services for people with learning disabilities. Edinburgh: The Stationery Office.

Citizenship

People with learning disabilities deserve to be treated positively as active and valued citizens. In keeping with government commitments set out in the *Changing Lives*² 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.

The strategy seeks to address the interests of people with learning difficulties as active members of the wider community. In doing so it strives to meet their needs as students, employees and householders, and to recognise their contribution. 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.

Health and well-being for all

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 grows, the demand for health care and other services will also increase. We need to make sure that health services do better at meeting the particular needs of this population. In primary care, this might include personal health plans and annual health checks.

In secondary care NHS Lothian's Liaison Service has led the way for Scotland and we should consider developing this further. Specialist health services are also needed to meet the complex needs of some people with learning disabilities Autism Spectrum Disorder and Asperger Syndrome.

It is also very important to get in early and prevent illness wherever possible.

² Scottish Executive (2006) *Changing Lives Report of the 21st Century Social Work Review*. Edinburgh: The Stationery Office.

What works in improving the health of the general population is inadequate at meeting 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 and autism spectrum disorder.

3: How we went about the review : who has been involved and who still needs to be involved?

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

A large number of individuals and organisations have already had their say and together they have come up with far-reaching ideas for change and improvement.

4: Some common themes

A person-centred approach

Person centred 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 research³ that person centred planning leads to improvements in the life experiences of people with learning disabilities.

It is commonly the case, however, that 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 knowledge about 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

³ Robertson, J Emerson, E et al (2005) The Impact of Person Centred Planning on the Life Experiences of People with Learning Disabilities, Institute for Health Research, Lancaster University, UK.

of quality standards need not necessarily mean that the plans will be any less unique and individual.

Life plans for people with learning disabilities, autism spectrum disorder and asperger syndrome who live with their parents should include plans 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 future services. Shaping the Future Together ⁴ 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.

Dealing with 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, autism spectrum disorder and asperger syndrome.

In the Lothians 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 opportunity for independent living and employment. Whether this is possible

⁴ The Foundation for People with Learning Disabilities (2005) Shaping The Future Together :A strategic planning tool for services supporting people with learning disabilities.

or not, all agencies should have a positive attitude to maximising the young person's opportunities.

Those from minority ethnic backgrounds must be confident that their cultures will be respected.

There are other transitions in life, such as the one to old age, where work is also required to ensure a smooth transition in which people are well informed and involved in making their own decisions.

5: What the working groups said

A series of working groups were formed to look at key issues. This is what they said. Their suggestions are the basis for many of the ideas in the Recommendations and Consultation Questions section.

Older people with learning disability

Older adults with a learning disability must be considered separately from other groups, because of their particular needs. They suffer from a greater degree and range of physical health problems than the general population and their mental health is affected by the same conditions that affect younger adults.

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. Further, around 300 individuals will move into the over 60 range within the next 5 years.

There is little specialist provision available. Accessing appropriate services including respite care can be difficult for some people and their carers. Family carers themselves will be going through the ageing process and this often take its toll on their physical and mental health too.

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 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, are in agreement that some of our existing services for people with learning disabilities are not able to fully meet the needs of the population in Lothian. The 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 not appropriate social care services in Lothian. Perhaps 45 of our 77 NHS in-patient beds are being used by people who no longer need to be there.

NHS Lothian and the four local authorities have agreed that we need to re-design the existing in-patient services, and also develop a new range of services that span the traditional boundary between NHS and social care. Progress is already being made through Edinburgh's new joint care service,

which means the city council and NHS work as one. This is a model to be built on for the future.

People with learning disabilities who commit offences

Across Scotland there is a lack of community provision for offenders with learning disabilities autism spectrum disorder and asperger syndrome and 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.

New housing and community support models must be developed and must focus on the need to protect persons with learning disabilities whose behaviours require ongoing support and close supervision. This will have the effect of limiting the potential for re-offending. Careful consideration will be required in identifying partner providers to develop specialist accommodation and 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.

Though some specialist NHS services exist in Lothian they need to be enhanced. Consideration should be given to the specialist needs of women.

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.

As more people with learning disabilities, autism spectrum disorder and asperger syndrome are able to live, work and socialise in the community, they are also 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 – 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 services are unsuitable they can fail. This puts the person back to square one and wastes time and resources that could have been better used.

People with profound and multiple learning disabilities

Both nationally and locally there has been a limited focus on people with profound and multiple learning disability compared to other people with learning disabilities. This needs to be addressed because improvements in medical technology are leading to a significant increase in the number of adults with profound and multiple learning disability now and in the future.

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.

Young people with profound and multiple learning disabilities may remain isolated from their peers as they grow into adulthood.

Lothian has many examples of good practice but there is a shortage of appropriate daytime facilities. New healthcare models need to be developed as the size of this group increases.

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 substantial benefits if it was.

People with Autism Spectrum Disorders and Asperger Syndrome

Autism Spectrum Disorder is a complex disability not adequately recognised by the statutory agencies responsible for providing services. Council, health and other mainstream services, should be sensitive to the needs of people with Autism Spectrum Disorder and Asperger Syndrome.

Needs are not matched by resources and the number of people identified with ASD and Asperger Syndrome is growing. Many fall through the gaps between services, which can mean they lack the support to lead independent lives.

Some children with Autism Spectrum Disorder and Asperger Syndrome go on to do well in later life but there are risks of depression, alcohol 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. There is also Number 6, a one-stop-shop used by some adults with Asperger and high functioning autism, which is highly valued and should be a model for the future.

People with Autism Spectrum Disorder and Asperger Syndrome 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.

If services and support are to be truly person-centred then their voices need to be heard.

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.

We will work to ensure that this consultation reaches black and minority ethnic people with learning disabilities, their families and their communities.

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 and the People First group believe that NHS Lothian and the local authorities should sign up to them. A local steering group to oversee work in this area would help and should include parents with learning difficulties.

Service redesign

The last strategy review of services for people with learning disabilities in Lothian took place 10 years ago. Much has changed since then, with growing numbers of people in need of services and new ways of providing support.

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 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 alternatives to admission are provided, to prevent the need for admission to hospital in some cases and to enable earlier discharge home from hospital in others. 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.

Any funds that can be released by reducing the number of NHS beds may not be sufficient to fund all desirable developments and it may be that extra money is required in the future. There is still work to do to get to the point of making clear recommendations about proposals to redesign our NHS inpatient services. This work will carry on over the summer of 2007.

6: Using our resources well: funding and supporting change

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 wide range of care geared to the needs of people with learning disabilities. There are inpatient and day hospital services for acute assessment and treatment, longer-term treatment and rehabilitation. There are eight multi-disciplinary teams working in the community.

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 challenges 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 centrally.

The budget

The NHS and four local authorities spend £109 million each year on services specifically for people with learning disabilities. There are an estimated 21600 people with learning disability in Lothian of whom 5,000 adults and children in the area who are known to the learning disabilities services. These figures do not include people with asperger syndrome.

In 2006 there were more than 1,400 adults attending day centres. 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. Existing facilities also have to be used more efficiently and effectively. This might include making better use of inpatient beds and agreeing which agency should pay for what.

However, extra money will also need to be found if we are to improve the quality of life for service users in the way they, and we, wish. But there will always be the need to prioritise. The strategy review wants to make sure that priorities are decided in the best possible way by giving more say to users and carers.

In Control

One way we want to offer more choice is by piloting the *In Control* approach to services. This gives users the chance to influence, or decide, how money is spent on meeting their needs.

Users, carers and professionals act as partners in providing for the present and planning for the future. It is a system that is transparent and encourages imagination, creativity and meaningful engagement with local communities.

7: Your views

We want to hear as many people's views as possible before making a decision on the future of learning disability services in Lothian. These services make a tremendous difference to the lives of many people, so it's important to be sure we're getting it right.

NHS, local authority and other public services are paid for by all of us, so we want to make sure that everyone can have their say. Please take the time to let us know whether or not you agree with the recommendations in this consultation paper. If you think some, or all, of what is suggested could be done differently or better, then this is your chance to make your voice heard. Feel free to respond to the specific questions in the *recommendations and consultation* section – or to comment on any specific or general issues you feel are important.

Every response will be looked at and recorded. The results of the consultation will be reported to the NHS Board and the four Lothian Local Authorities and will be considered before a final decision is reached. You can take part in the consultation in any of the following ways:

Write to: Denis Rowley, c/o Deaconess House, 148 Pleasance, Edinburgh, EH8 9RS

Email: Denis.Rowley@lpct.scot.nhs.uk

Phone: 0131 466 6820

Fax: 0131 536 9406

Send a CD/DVD or tape to: Denis Rowley, c/o Deaconess House, 148 Pleasance, Edinburgh, EH8 9RS

All responses must be delivered by 31/10/2007 to be included.

Copies of the full strategy review can be obtained from: Learning Disability Strategy, Deaconess House, 148 Pleasance, Edinburgh, EH8 9RS or view the strategy document at www.lothianlearningdisabilityreview.info

8: Recommendations and Consultation Questions

These recommendations and questions have been drawn up by the various working groups of the learning disability strategy.

It is important to note that the recommendations have not been put to the governing bodies as yet – rather they are intended to establish the views of a wider audience in order to inform the final Joint Lothian Learning Disability Strategy.

The recommendations may change because of what people say in the consultation. We will also be able to understand which ones are most important to people. The final Strategy will clearly indicate which recommendations have been accepted, and what the agencies have agreed to do over the next 5 years.

Scotland now has an Outcomes Framework for Community Care.⁵ This will help agencies to develop services so that they improve people's lives in four ways:

- improved health;
- improved wellbeing;
- improved social inclusion; and
- improved independence and responsibility.

We have taken some of the recommendations from the various Strategy Working Groups and grouped them under these four headings in Section A, Better Outcomes, below.

Some of the working groups' recommendations are about developing better processes and these are grouped under two further headings:

- Joint Planning and Commissioning

⁵ Information on the National Outcomes for Community Care can be found at www.scotland.gov.uk/Topics/Health/care/JointFutures/NationalOutcomes

- Joint Service Development and Re-design

These are listed in Section B, Better Processes, below.

BETTER OUTCOMES

Improving Health

Health Promotion Recommendations

Recommendation 1

- A multi-agency health promotion programme should be developed aimed at identifying and meeting health needs and promoting good physical and mental health and well being in adults with learning disability, autism spectrum disorder and aspergers syndrome. This should include service user education, preparation for change, support to maintain friendships and activities and support to overcome barriers to accessing inclusive settings.

Recommendation 2

- NHS Lothian should support an early focus on developing activities to address obesity amongst people with learning disability through increased physical activity, improved diet and smoking cessation to reduce coronary heart disease.

Health Promotion – Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

Improving Social Inclusion and Citizenship

Person Centred Approach Recommendations

Recommendation 3

- We should move from a resource led to a person centred and individualised approach in order to achieve better quality outcomes for individuals. To achieve this we should undertake a review of our approach to Care Management and Service provision. Specifically we propose conducting pilots as follows:
 - New group based approaches to Person Centred Planning like *The Big Plan* will be piloted and evaluated in Midlothian and East Lothian as part of the local Day Opportunities Change process
 - A person centred approach to strategic planning will be piloted and evaluated in Midlothian and East Lothian using the ‘Shaping the Future Together’ planning tool.

Recommendation 4

- Work should be done to create an agreed set of standards for Person Centred Plans and Personal Life Plans.

Recommendation 5

- We should review the way in which support and services, both specialist and non specialist, are currently commissioned and provided, and identify what we need to change in order to respond to what people and their families want. As part of this we should develop quality mechanisms for ensuring that people with Learning Disabilities and their families are included in the process. We will identify and record the areas where services cannot respond to the informed choices of individuals.

Recommendation 6

- Development of adequate and specialist in-patient (hospital as well as nursing home), day patient and terminal care services, as well as person-centred day services and respite for older adults with learning

disability, particularly those with dementia or illness including those over 65 years of age.

Person Centred Approach - Consultation Questions

- Have we got our priorities right, and do they fit in well with the recommendations of the 'Same As You?' review?
- What should the size of the pilot projects be and who, or which groups of people should we prioritise?
- How can we make sure that we make best use of the experience and skills of people who use services and their families and carers when delivering training?
- How can we ensure that we are targeting our resources to achieve person centred outcomes?

Transition Recommendations

Recommendation 7

- In keeping with statutory duties, a named professional (who might be a Key Worker, Social Worker, Local Area Coordinator, Careers Scotland Key Worker or Careers Adviser) who knows the person well should be available before, during and after the transition from children's to adult services, to ensure that the person is fully involved. If the young person or their family ask for one, an advocate should also be available throughout this time. The provision of independent advocacy for young people is one of the priorities being considered in the development of the Lothian Independent Advocacy Plan 2007-2010.

Recommendation 8

- A key to effective transitions is working in genuine partnership with young people and families. In order to empower young people and

their families throughout the process they should be provided with clear up to date accurate information, well in advance of the school leaving date, about all of the different options and service resources available. A pilot scheme to inform a group of school leavers of the individual budget available for their support (whether or not this is part of an In Control approach) should be established.

Recommendation 9

- A working group involving Children's Services, Adult Services and NHS Lothians should be set up to look at the problems caused by the different legal definitions and service eligibility criteria that are used to decide who gets priority for transition support. This group should try to reach some openly available common definitions and criteria to ensure that the young people have their needs assessed and receive suitable support.

Transition - Consultation Questions

- How can we make sure that we pay attention to all of a person's education, employment, personal or emotional support, health needs and suitability of transport when planning transition in their life?
- What skills and knowledge do transition key-workers need to have to be an effective support to young people experiencing transition in its various forms: for example, from school to employment or college, or in the move from family home to supported living?
- How do we ensure that initiatives which demonstrate good practice in empowering and building the capacity of young people and their families through transitions (for example, the transition passports used in some East Lothian schools) are available and used more widely?

- How can we make sure that a person gets good support through all the transitions in their life?

Inclusion Recommendations

Recommendation 10

- All the partners should use the People First guidelines on inclusion and accessibility. You can see these on the strategy review website at www.lothianlearningdisabilityreview.info

Recommendation 11

- We should make sure that those who have greater communication difficulties are consulted in a way that is meaningful to them. This could include supported use of symbol boards, one to one interviews, and using techniques such as talking mats or any other approach favoured by that individual

Recommendation 12

- As part of the implementation of this review the Respect Test statements should be made available on small cards and distributed to all staff in all services including transport, leisure and so on. (You can read more about these in the full strategy report or on the strategy review website on www.lothianlearningdisabilityreview.info) They should then also be distributed to anybody who uses services so that they can remember the things they are entitled to, and give them to anyone who they feel is not treating them with respect.

Recommendation 13

- We recommend the creation of a Learning Disability Partnership Board run according to the inclusion and accessibility guidelines proposed by People First. We recommend that half of the board consists of people

with learning disabilities, parents and family carers with the other half being professionals.

Recommendation 14

- An adapted version of the Valuing People Ethnicity Audit Tool should be used to enable the partners to estimate how many black and minority ethnic community people with learning disabilities we should expect to have in Lothians; the numbers using existing services; and to enable us to gauge how well we are doing in meeting the needs of this group.

You can see the Valuing People Ethnicity Audit Tool at www.valuingpeople.gov.uk/dynamic/valuingpeople87.jsp

Inclusion – Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

Communication Recommendations

Recommendation 15

- All the partners should use the People First guidelines on inclusion and accessibility. You can see these on the strategy review website at www.lothianlearningdisabilityreview.info

Recommendation 16

- We should make sure that those who have greater communication difficulties are consulted in a way that is meaningful to them. This could include supported use of symbol boards, one to one interviews, and using techniques such as talking mats or any other approach favoured by that individual

Recommendation 17

- All information and reports by children and families services, adult services, education, voluntary agencies and maternity services etc. should be jargon free, in large print and available on tape and CD/DVD. This should include letters and reports from schools and nurseries.

Communication – Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

Improving Wellbeing

Improving wellbeing Recommendations

Recommendation 18

People with learning disabilities, autism spectrum disorder or aspergers syndrome should be included (with support) in each community safety forum and should be consulted by each domestic abuse forum.

Recommendation 19

As we move in to the implementation phase of the strategy the partners should investigate the use of Quality of Life Indicators as a way of evaluating whether services are helping people to achieve better lives.

Improving wellbeing – Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

Improving Independence and responsibility

In Control/Personalisation Recommendations

Recommendation 20

- NHS Lothian and the four Lothian Local Authorities should work together with local provider organisations to develop a shared understanding of *In Control* and to learn from pilots of this way of providing support

Recommendation 21

- Where appropriate, NHS funds should be considered as part of the individualised budgets that will be made available to people using *In Control*.

Recommendation 22

- At least two *In Control* projects should be piloted and evaluated. One of these will be in Midlothian and will focus on people in transition. It is recommended that the other will include people who are currently delayed in NHS Lothian in-patient services.

In Control/Personalisation– Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

Homelessness and Substance Abuse Recommendations

Recommendation 23

- Early identification and intervention must be promoted to enable the appropriate services to be offered at the earliest possible time to

people with learning disabilities, autism spectrum disorder or aspergers syndrome who are homeless and those involved in substance abuse.

Homelessness and substance abuse – Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

Advocacy Recommendations

Recommendation 24

- In keeping with statutory duties, a named professional (who might be a Key Worker, Social Worker, Local Area Coordinator, Careers Scotland Key Worker or Careers Adviser) who knows the person well should be available before, during and after the transition, to ensure that the person is fully involved. If the young person or their family ask for one, an advocate should also be available throughout this time. The provision of independent advocacy for young people is one of the priorities being considered in the development of the Lothian Independent Advocacy Plan 2007-2010.

Recommendation 25

- Parents with learning difficulties should have access to independent advocacy.

Advocacy – Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

BETTER PROCESSES

Joint Planning and Commissioning

Needs Assessment Recommendations

Recommendation 26

- A more formal assessment of the number and needs of people with learning disability in Lothian should be undertaken, especially in relation to future needs that may arise from changes in the population. This should build on and develop the national work of population identification within primary health care services.

Recommendation 27

- The recommendation from *The same as you?* about establishing databases of people with learning disability, and recent clarification about using the e-Say database format developed by the Scottish Consortium for Learning Disabilities, need to be actioned as a matter of urgency.

Needs Assessment – Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

Capacity Planning Recommendations

Recommendation 28

- Housing representatives should be actively involved in the Joint Improvement Team Capacity Planning exercise which is currently being addressed by the four Local Authorities and NHS Lothian. This work will assist with the collection and collation of data to evidence need in the longer term.

Recommendation 29

- In the interim, it is recommended that a seminar is held in each of the Local Authorities, bringing together the key stakeholders to address whether the current systems for planning to meet the housing and support needs of people with learning difficulties are sufficiently robust, and if not, what improvements can be made in the short term. We envisage that relevant people from Registered Social Landlord development, Housing Investment, Care and Support Package Commissioners, Nominations Officers, Housing Assessment officers, and Voluntary sector support providers will be involved.

Capacity Planning – Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

Funding Recommendations

Recommendation 30

- The four Lothian local authorities and NHS Lothian should agree models of service, demographic projections, and any necessary changes to the guidance about who pays for services to meet continuing health care needs. Each of the five agencies should then identify any additional funds required to meet the needs of people with learning disabilities year on year throughout the life of the Joint Lothian Learning Disability Strategy. The amount of resource required will be calculated through development of one Lothian and four local implementation plans (Partnership in Practice agreements).

Recommendation 31

- NHS Lothian and the four local authorities will agree additional guidance to support officers in using the existing agreed *Policy and*

eligibility criteria for the provision of health services to meet continuing health care needs and this guidance will be incorporated into the final Learning Disability Strategy Documentation in Autumn 2007. Councils and NHS may need to adjust their processes and budgets to make sure that the criteria can be implemented quickly each time they are needed.

Funding – Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

Workforce Development and Planning Recommendations

Recommendation 32

- Linking to the Needs Assessment we will undertake, a joint agency group should be established to carry out research on workforce demand projections over the next five to ten years and this information should be used to develop plans for increasing the workforce supply.

Recommendation 33

- The NHS Lothian Workforce Development Plan should take account of the findings and recommendations of this Strategy Review.

Recommendation 34

- A joint training needs analysis and plan should be completed for the staff working in specialist and generic services offered to people with learning disabilities, linking to the population Needs Assessment we will carry out.

Recommendation 35

- The Person Centred Planning Training Strategy devised by the Person Centred Planning sub group should be adopted. You can read more

about this in the full strategy report or on the strategy review website at www.lothianlearningdisabilityreview.info) This is to include breadth and depth training and build upon a set of standards for Person Centred Plans. We will need to ensure Users of Services and Carers are part of the training team.

Recommendation 36

- Joint Working and Training should be developed to ensure that all relevant staff are working in a more co-ordinated way, with more knowledge of the needs of people with learning disabilities who are homeless and those involved in substance abuse

Recommendation 37

- Arrangements should be made to ensure that there is appropriate health co-ordination within care management for people with profound and multiple learning disability. This will require consideration to be given to ensuring that there are adequate specialist health care staff available and that health and social-care staff are able to benefit from a program of education and appropriate training in work with people with profound and multiple learning disability.

Recommendation 38

- People with Autism Spectrum Disorders or Asperger Syndrome are entitled to Autism Spectrum Disorder services and resources but this is not always happening. Part of the reason for this is that their needs are simply not recognised, or if they do the workers involved do not feel they have the expertise to respond, or believe that it is someone else's responsibility to do so. As a step towards reducing this fundamental barrier to people with Autism Spectrum Disorders or Asperger Syndrome having their needs met it is recommended that 50% of staff in all mainstream services, including the police, will undertake Autism Spectrum Disorders and Asperger Syndrome Awareness training by

2010, and to this end a specific allocation of training money should be made available to fund a specific contract.

Recommendation 39

- Each mainstream organisation, including the police, should identify a member of staff who will be given a higher level of awareness and training in autism spectrum disorder and asperger syndrome (for example, an Equality and Diversity Officer in the police; a Local Area Co-ordinator in social work; or a Practice Nurse in a GP surgery) who will act as a point of contact, supporter and adviser to other staff.

Recommendation 40

- All professionals working with parents with learning difficulties should receive training on the needs of parents with learning difficulties. Part of this training should be run by parents with learning difficulties.

Workforce Development and Planning – Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

Joint Commissioning Recommendations

Recommendation 41

- In order to enable people to remain in their community and to allow the discharge of patients no longer requiring hospital care, multi-agency community service development should proceed for people with learning disabilities and include provision of specialist residential accommodation with the use of specialist care providers, more robust community residential resources which could perhaps be jointly managed (NHS and social care), a Community Forensic Learning Disability Team and appropriate Day Hospital provision.

Recommendation 42

- The four local authorities and NHS Lothians should develop a joint commissioning approach for services for all people with learning disabilities with complex needs and behaviour that challenges services. This system, which would take some months to develop and implement would have a discrete budget and resources and would be closely linked to the commissioning systems of the four local authorities.

Recommendation 43

- Any *In Control* pilots we run in Lothian will provide valuable lessons in providing funds to meet people's needs. If the pilots are successful NHS Lothian and the four local councils should consider the establishment of Joint Budgets to support the *In Control* model of working.

Joint Commissioning – Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

Joint Service Re-design and Development

Service Re-design Recommendations

Recommendation 44

- NHS Lothian should re-configure the bed layout of existing acute assessment and treatment areas to provide smaller units (4 beds maximum) and to include a female only provision.

Recommendation 45

- NHS Lothian should consider with the council and voluntary /private sector partners the recommendations of the Lothian Learning Disability Service Redesign Project (2005) to “improve Community Learning

Disability service provision by developing the Community Support and Treatment Service and enhanced Day Hospital provision”.

Recommendation 46

- An inclusive working group should be constituted to draw up proposals for new or re-designed services at a Lothian-wide level to meet the needs of people with learning disability. This work should be reported for approval to the Joint Learning Disability Strategy Review Board, or the Lothian Learning Disability Partnership Board once that is set up. It will then need to be formally approved by the partner bodies.

Service Development Recommendations

Recommendation 47

- The Older Adults with learning disabilities working group recommends the Development of adequate and specialist in-patient (hospital as well as nursing home), day patient and terminal care services, as well as person-centred day services and respite for older adults with learning disability, particularly those with dementia or illness including those over 65 years of age.

Recommendation 48

- A Managed Clinical Network for Older Adults with a Learning Disability including a Lothian specialist team with representation from Health, Health and Social Care/Social Work, Housing, Community Education, Users and Carers, should be established to facilitate effective planning and provide a consultation and training resource to all stakeholders.

Recommendation 49

- Special provision should be made for women with a learning disability who offend.

Recommendation 50

- Appropriate safe accommodation for those who are homeless should be developed as a priority. This basic need has to be met before meaningful assessments, therapy or support can be implemented.

Recommendation 51

- New services including a home-based respite care service and increased residential respite care need to be developed and resourced to meet the future needs of people with profound and multiple learning disability.

Recommendation 52

- NHS Lothian and their partners should fund a Lothian-wide PAMIS co-ordinator post to promote and support the development of better services for people with profound and multiple learning disability

Recommendation 53

- The Autism Spectrum Disorder/Asperger Syndrome working group recommends that the four local authorities and NHS Lothians should core fund a dedicated resource based on the successful pilot at Number 6 enabling it to draw down a wide range of grants and other funds and thus to meet the relevant Health and Social care needs of this otherwise unsupported group.

Recommendation 54

- Parents with learning difficulties should be able to get ongoing, one to one flexible support with parenting as needed. There needs to be clear agreement across services as to who will provide this support. It should be co-ordinated by one person, not two different teams. Parents should be consulted fully about the support they need. We recommend that a demonstration project is set up to provide good, ongoing, flexible support to parents with learning disabilities .

Recommendation 55

- A post of Lothian Learning Disability Partnership Manager should be created and be given real responsibility for the main areas of service planning and delivery on a multi-agency basis.

Service re-design and development – consultation questions

- Do you support the above recommendations and agree that these are the priorities for improving services for people with learning disability, autism spectrum disorder or asperger syndrome?
- Are there other actions we should be taking?
- Are there people who do not need assessment and treatment but whose needs can only be met in an NHS setting? If so, what is it about their needs that can only be provided by the NHS?
- How can community supports for individuals be maintained, developed and funded during episodes of in-patient assessment and treatment?
- What mechanisms need to be put in place to ensure that the social and health care needs of young people with a learning disability, behaviour that challenges services and/or mental health issues and who are approaching the transition to adulthood are being properly addressed?
- What developments need to take place to effectively meet the health needs of people with profound and multiple learning disability across Lothian?
- What day support/services options should be made available for adults with profound and multiple learning disability?
- Should we consider creating a Lothian-wide complex physical healthcare team based within CHPs and is this the best model for providing and coordinating services for people with profound and multiple learning disability?
- Do you agree that funding a specialist coordinator post is the most effective way of promoting and supporting the development of better services for people with profound and multiple learning disability?

- Are there adequate specialist health care staff e.g. Speech and Language Therapists, Community Nurses, Dieticians and Physiotherapist available to improve the quality of life for people with profound and multiple learning disability?
- Is there adequate specialised respite care (home-based or residential) available for people with profound and multiple learning disability and their families?
- Is there a need to develop a specialist advanced nursing role to ensure that all those with profound and multiple learning disability are receiving regular health checks, health promotion support and education and support for carers?
- How can the NHS and the four local authorities influence the design and implementation of environmental changes which are going to improve the quality of life for people with profound and multiple learning disability - such as providing public toilets with adequate facilities.

Risk Management Recommendations

Recommendation 56

- A Lothian Significant Risk Advisory Group should be convened with a degree of urgency and should agree to adopt the use of the Care Programme Approach⁶ to manage the care of relevant individuals.

Risk Management – Consultation Questions

- Do you support the recommendations we have made?
- Are there other actions we should be taking?

⁶ The Care Programme Approach is defined in *The same as you?* as “a way of making sure that all those with serious mental health problems and **complex needs** have an assessment and care plan that all the different professionals agree on (for example, social workers and doctors). This is checked regularly to see how well the person is doing.”