

## CONSULTATION QUESTIONS

### Progress and Challenges

**Q.1 Do the findings of the evaluation broadly reflect your views about services for people with learning disabilities/carer?**

Yes  No

It was appropriate that the original national policy addressed service needs and lifestyle opportunities for the majority, however there is a need to ensure equity for all people with learning disability, particularly those with complex needs and/or challenging behaviour – which experience suggests excludes them from many normal community opportunities. Consideration of how to address the lifestyle opportunities for these individuals including those with profound and multiple disability whose needs require particular support, should be the focus of service and policy developments going forward. .

The principles and values of the original document remain wholly relevant. However the growing levels and combinations of intensive support needs is having an impact on service availability. It is a view that the range of existing community services is becoming increasingly inadequate, particularly for those with Autism. The ability to offer people the minimum of life quality opportunities such as a physically active lifestyle in order to sustain mental and physical health and wellbeing is not available to many people with learning disability. and needing fresh air and activity.

Whilst the large Hospital closure was a huge success for many people, something was lost in this process and, for those individuals requiring access to large external space and opportunity to remain separate from the majority of others on occasion, services have been struggling to find appropriate alternatives since.

It is the view of NHS Lothian that the range of care and support needs encompassed within the learning disabled population is vast and as the report currently stands this is not adequately reflected.

A general comment about the Consultation Process:

Feedback from some of NHS Lothian's service users indicated that, whilst the easy read symbolised version of the consultation document was appreciated it was still hard to understand. The experience of supporting service users to respond to this consultation suggests that the timescale was inadequate. The support required to gather meaningful opinion from service users with communication difficulties is significant, requires large amounts of preparation and consultation can only be undertaken in "bite sized" chunks. However, we wholly endorse the need for policy about and affecting people with learning disability should be directly informed by them.

**Q. 2 Can you give examples, either locally or nationally, of what you think has worked well over the last 10 years of *The same as you?***

Colleagues across NHS Lothian, from specialist Learning Disability services, acute and primary care services have suggested the following range of examples as areas where they have seen improvements in the choices, services and increased equity of opportunity for people with learning disability over the past decade.

- Enhance General Practice services for people with learning disabilities where this has been supported through the Scottish Enhanced Services Programme (SESP).
- Acute Hospital Liaison Nurses
- Closure of long stay Learning Disability hospitals and the subsequent development of community living/ independent living options.
- Local Area Co-ordinator services
- Continued growth in awareness that day centres are not the only day time service response for people with learning disability, that more diverse activities and flexible supports are possible, are available to some and need to be supported to continue to evolve to ensure more equity of provision/ choice to all.  
“I go to Artlink and Dancebase. They are good”.  
“I go to Tippereth it is OK. I would like to go swimming.”  
“You can make friends at places you go to”.
- Better awareness of ethnicity issues and easier to access translation services – however this response advocates that this is an area that continues to require a specific focus.
- Better legislative framework e.g Mental Health (Care and Treatment) (Scotland) Act, Adults with Incapacity (Scotland) Act, Adult Support and Protection (Scotland) Act, which individually and collectively have driven the improvement of citizenship, rights, care , support and, where necessary, protection of people with learning disability.
- Enhanced focus on Autism services.
- The creation and continued development of SCLD – although the profile of engagement/ collaboration is very different in the East and West of Scotland and perhaps some exploration of why this has evolved, and what could be done to address this could be considered.
- The development of accessible information, and the use of systems such as Talking Mats to support people with communication and engagement.
- Collaborative multi disciplinary and multi agency working – delivering service in a complimentary way that assists the individual in achieving the outcomes that they want/ need. For example, better links and communication between NHS, Social Care, Acute Care, Housing, Police and Education.
- The continuing development of person centred, individualised

treatment, and the ability to develop that in environments that feel more akin to a home rather than a hospital. Wherever people are placed, it is crucial that good leadership is recognised, valued and supported in organisations delivering care, support and treatment.

**Q. 3 Can you give examples of issues in current work and/or policies that still need to be addressed?**

Please provide any comments and/or examples here

In the opinion of NHS Lothian, Scotland would benefit from the development of a national strategy and associated targets to deliver continued investment in learning disability services for people with more specific needs, in order that this group of people are not disadvantaged by different local priorities set by their local authority or health board of residence. Ideally we want people to receive the support they require, be supported to maintain links with families and friends and have the opportunity to be engaged citizens, as far as they are able and desire. Along side this, Scotland would develop a workforce with the full range of specialist knowledge and skills and continue to be at the forefront of upholding the human rights of the vulnerable members of its population.

NHS Lothian would like to suggest that integration needs to provide an opportunity for the education and learning of the health and social care workforce. For example, expanding the availability and targeting of resources developed by NES to services across the Third Sector and Local Authority provision would support the development of uniformity and confidence in a robust baseline of skills and knowledge across the full workforce. Current segregation and lack of sharing of workforce development inputs etc. has resulted in large amounts of duplication, unnecessary use of scarce resources and a lack of uniformity of standards and baseline skill sets across the workforce.

NHS Lothian would also suggest consideration is given to ways in which there could be an investment in Speech and Language Therapy (SALT) for people with learning disability. The known levels of requirement for communication support for people with learning disability and additional complex care needs has been shown to be in the region of 80% of individuals. SALT therapeutic requirements associated with dysphagia etc, are also significant particularly within the population of people with profound and multiple disability, an area where research tells us we will see continued growth in numbers of individuals, and therefore associated service pressures in both health and social care.

Some comments from service users of NHS Lothian were:

- We need more suitable places to live that are in the right place.
- We need rules to make us feel safe.
- We need help with money.
- It is important to have your own key.

Other areas felt to be of continued importance for sustained focus and development include:

- Transition from child to adult services. There remains an issue that

many children/ young people with a learning disability do not receive a specific diagnosis and are supported through the “additional needs for learning” processes. This can result in people being denied supports and interventions that may be of importance to the individual and/or their family. There is also a concern that late identification of a learning disability is traumatic for families and carers as well as the individual themselves.

- Community Learning Disability services to provide services across the lifespan nationally. The current model within NHS Lothian enables Community LD Nurses to provide service across the lifespan, but this is not the case for Allied Health Professionals and other disciplines. It is suggested that the segregation of children’s and adult specialist learning disability services is not beneficial to the individual with learning disability or their families.
- Better understanding of the needs of people with learning disabilities in the criminal justice system, and adaptations made to the systems to ensure people can manage adequately and are not being disadvantaged as a result of their learning disability.
- Health inequalities – taking cognisance of a changing picture, for example weight management services for the general population are not routinely available to people with learning disabilities
- NHS Lothian would wish to see routine health checks offered to people with learning disabilities and delivered in primary care.
- Recognition of the ongoing dependency on family carers, NHS Lothian would advocate for continued growth in the investment and flexibility of respite and short breaks services.
- Continued development and availability of psychological therapies for people with LD.
- Workforce and Practice Development service modelling to reflect changing demographics. Population changes leading to an increased demand for services
- Increase awareness of Adults with Incapacity Act across social care and medical workforces.
- In patient services need to be improved in order that people who require this level of service have their full range of needs met, i.e. across the range of physical and mental health and wellbeing, not just receiving treatment for the issues that informed the need for an admission. Environments providing assessment and treatment should be small and homely. For people requiring longer term hospital placements, this is even more important.
- There is a continued need to recognise that children and adults with learning disability are some of the most disadvantaged people in our society, and that the issues they face are life long. Subsequently there is an ongoing requirements for the Scottish Government to continue to support these individuals in positive ways – through explicit inclusion in all policies for Scotland’s people.

It is the view of NHS Lothian that the potential negative impact of the current and ongoing Welfare Reform is of particular importance. As commented on above, people with learning disabilities have life long needs – and the majority of these needs do not decrease. The current Welfare Reform will significantly impede the life opportunities of many people with learning disabilities. It is recognised that the

prevalence of learning disability is significantly higher in areas of multiple deprivation. Policies to support people within these areas/catchment groups must include a specific focus and recognition of people with learning disability.

### **Good Practice – Organisations**

**Q. 4 Can you provide examples of what you have done over the last 10 years, within your organisation, to improve services and access to services within your local area?**

Please provide any comments and/or examples here:

Across Lothian the uptake of the Scottish Enhanced Service Programme by the vast majority of GP practices, and the subsequent collaborative work with the LD Service has seen particular health benefits delivered to people with learning disability.

Since 2007 contract requirements have built on the QOF requirements to develop and maintain an LD register within each practice, with incremental changes each year that have included:

- Annual joint reviews with the local Community Learning Disability Team for all patient on the practice case load
- Improved management and review of adults with learning disability with chronic disease by provision of easy read appointment letters and communication aides.
- Completion of practice profiles of co-morbidity under QOF area of all patients on the practice LD register.
- Annual health checks within primary care with IT based supporting material
- Training offered to all primary care staff about health and access needs of people with LD.
- Development and delivery of resource packs of accessible information sent to all Lothian practices.
- Employment of a Primary Care LD Liaison Nurse to support practice development in GP practices.

Some of these initiatives were mainstreamed across other service areas, for example, the 'Keep Well' service now use the easy read invitation letter as standard.

Other areas where NHS Lothian has seen the development of good practice includes the development and delivery of psychological therapies to people with learning disability.

NHS Lothian developed a specific Cognitive Behavioural Therapies (CBT) nursing post, which was given the specific remit to raise both the profile of, and access to CBT for people with learning disabilities and mental health issues.

During the past decade, CBT has developed as an effective

treatment framework for a variety of mental health issues and complex presentations.

The work has been disseminated through both conference presentations and published works. One of the most recent examples is provided below:

July 2008 "Simple or Elegant?: What are the creative ways in which clinicians adapt Cognitive Behavioural Therapy for people with a learning disability. British Association of Behavioural and Cognitive Psychotherapists, 36<sup>th</sup> Annual Conference, University of Edinburgh.

The service has promoted the application of routine self-report measures and specific mental health assessments. This is now standard practice throughout several community teams. The identified benefits to people with learning disabilities include a clarity of understanding distress, and a targeted treatment response.

The service also works with those who support people with a learning disability e.g. family members, carers and support teams. It is known that the effectiveness of support can be affected by stress. In response to this NHS Lothian has adapted Behavioural Family Therapy (BFT) for people with a learning disability, and their supporters.

NHS Lothian Learning Disability service now has 3 trainers and 43 clinicians from a variety of clinical backgrounds delivering this approach, plus conducting research on the continued development of the evidence base.

A brief overview of other areas of local initiatives which, in the opinion of NHS Lothian, continue to deliver best practice include:

- The continued increase in investment into the Learning Disability Acute Hospital Liaison service, which has seen capacity increased from 1 to 3 full time nurses, and ongoing evaluation and development of the role.
- Building on the Scottish Government's investment and development of "Number 6" for people on the Autism Spectrum, NHS Lothian continues to invest in and support the development of this service to people across Lothian.
- Collaborative work between NHS Lothian and the Family Advice and Information Resource (FAIR) service has resulted in the production of accessible Health information materials for people with learning disability, including specific materials for people with learning disability using cancer services.
- NHS Lothian investment in to Local Area Co-ordinators has resulted in the development of a clear health improvement and health education role within this service.
- The development of Adult Protection Interagency Referral Discussion reviews involving NHS Learning Disability staff.
- The support and development of the Learning Disability Managed Care Network – of particular success has been the improved access to training.

- A well developed Epilepsy Service. The Epilepsy service has, in particular developed flexibility in the provision of clinics to improve access. Local clinics are provided in 7 sites across Lothian, with further clinics held in local authority day centres. There is a specific, regular “Transitions” clinic supported by the Adult Epilepsy service in partnership with Paediatric services. The service also provides domiciliary visits on an “as required” basis. There is a telephone consultancy and advice service available to support people affected by epilepsy, their families, carers and involved professionals .

Further work within the NHS Lothian Epilepsy Service includes collaborative and multi-disciplinary approaches to Joint Clinics which have the support and engagement of Psychiatry, Epileptologists, Specialist Epilepsy Nurses and Neurology.

**NHS Lothian’ s own development of accessible information:**

There has been a raft of information developed over the past decade that aims to support people with Learning Disabilities and their carers/ families.

Examples given include:

Diabetes pictorial booklets

British Dietetic Association (BDA) Best Practice and Guidance for Care Homes

BDA Consensus statements on enteral feeding and obesity.

Other local initiatives to progress accessibility for staff groups as well as members of the public and people with learning disabilities includes the development of intranet ( internal systems) and internet based information and downloadable information on a range of subjects.

Joint working/collaboration across disciplines within healthcare has shown demonstrable improvement in outcomes for all concerned. For example Joint input from Speech and Language Therapy and Dietetics.

Opportunities for shared learning and developmental practice have also delivered improvements across the services: examples of which include: NHS Lothian Health inequalities work plan; Care Group for people with Profound and Multiple Disabilities – supported by the MCN.



## Good Practice – Individuals

### **Q.5 What have you done, as an individual, to make positive changes within your local area?**

There are a multitude of examples from the full range of professionals involved in delivering care support and healthcare to people with learning disability across Lothian.

Two specific examples received in response to this consultation are:

a) Cognitive Behavioural Therapy service - colleagues have worked in collaboration with colleagues from a variety of professions both in NHS Lothian and other health boards in developing psychological therapies for people with a learning disability.

This has included involved in the development of the “Matrix” and the delivery of psychological therapies for people with learning disabilities. We have focused on different levels of input from low intensity to high intensity therapy, and have concentrated this effort into two community learning disability teams, which have responded well to this system of care and support.

Within these systems clinicians now routinely use:

Mental health outcome measures

Psycho-educational frameworks

Bio-psycho-social formulation

Behavioural Family Therapy

Cognitive Behavioural Therapy for teams

Support and supervision of care providers to deliver psycho-education e.g. anger management

b) Colleagues within the Dietetics services have provided input to the British Dietetic Association’s Manual of Dietetic Practice and the updating of a chapter on issues affecting people with learning disabilities; up skilling generalist dietetic staff in regard to learning disability.

## Future Priorities – Healthcare

### **Q.6 What still needs to be done to ensure that people with learning disabilities have access to better and more appropriate healthcare?**

NHS Lothian has greatly appreciated the focus from the Scottish Government, building on the recommendations from Equally Well, and the experiences from 2 Fatal Accident Enquiries, and the targeted investment to address and improve the access to and outcomes from healthcare for people with learning disabilities.

Many of the examples of positive change identified in Question 4 have been possible as a direct result of Scottish Government investment, and from the shared learning that has been an outcome of the national Learning Disability Health Inequalities network.

However, the breadth of healthcare is significant and there remain areas where improvements could be made. Colleagues across NHS Lothian have identified the following examples as areas where, locally and nationally, policy could be a means of continuing to deliver improvements across the system for people with learning disabilities and their families.

- Recognition that a legitimate part of someone's care and support is the support to enable the person with learning disability to engage appropriately with healthcare appointments. Training input across social care staff would assist in establishing core principles about preparedness and appropriate input to ensure the best outcomes for the individual with learning disability.
- Continuing education and support for medical and clinical staff working in acute and primary care about learning disability and associated additional needs in healthcare settings/ to engage with their healthcare and wellbeing.
- Flexibility of funding. The support following the individual to allow support to continue, as appropriate to the individual's needs, if it is necessary to admit the person with LD to an acute hospital.
- Enhance end of life care for people with LD.
- If all people with learning disabilities are to be supported to live as independently as possible, care and support services need to be enabled to be able to appropriately support people with the full range of their care needs, including assisting them with medication and informed, supported engagement with their healthcare.
- Greater awareness in family carers and social care staff about health needs and different healthcare issues for people with LD in comparison with general population, in order that the individual with learning disabilities can be supported appropriately and early indications of particular ill health is recognised and acted upon by the carer/ support workers. Perhaps consideration could be given to the development and delivery of health promotion and educational campaigns to support and inform family and other carers.
- Support and management of people with learning disability and dementia, and other age associated illnesses. In recognition of the demographic changes that are facing the whole population, and that

this will be similarly reflected in the learning disabilities population, health and social care services need to be prepared to enhance support, and education of support staff to ensure age related needs are responded to as required.

- Continuation and expansion of the work to enhance opportunities of healthy lifestyle input to ensure the general health and wellbeing of people with learning disabilities, including nutritional education to all support staff; and support for the person with learning disability to ensure opportunities for a physically active lifestyle.
- Enhanced services to manage prevalence of obesity across the learning disabled population.
- Appropriate information, education and access to services to assist people with learning disability/ family carers manage diabetes.
- Building on the work initiated by the SESP with Primary Care services, NHS Lothian recommends the development of a National Enhanced Service for the delivery of annual health checks for adults with learning disability to ensure uniformity and high standards of care.
- NHS Lothian would also suggest mainstreaming the provision of a primary care LD liaison service as a point of specialist support.
- Current experience suggest that general screening programmes, e.g. for Bowel cancer are not particularly successful or proactive in engaging people with learning disabilities. NHS Lothian would like to see this addressed at a national level
- Considering the more specialist aspects of healthcare for people with learning disability, NHS Lothian recommends that there should be access to specialised and individualised assessment and treatment services. This should include appropriate and specialist care for those people with severe challenging behaviour associated with autism, for whom high staffing numbers of specially trained and skilled staff can be required. Access to exercise is essential as part of the treatment for example access to gyms, swimming pools. One family made positive comments about the excellent service provision provided to their son at a national NHS Service in the North of England. They felt that this level of specialism should be available in Scotland and should be a future Healthcare priority.
- In recognition that the Mental Health Strategy for Scotland 2012 – 2015, Commitment 10 , provides the beginnings of a national approach to these specialist services, we would urge that any forthcoming revised national policy for Learning Disability across Scotland takes cognisance of this, with regard to planning transition and in recognition that some services, e.g. Learning Disability Nurses already work across the full age spectrum. We would be very keen to support strategy the ambitions for specialist CAMHS services and the standards and quality of outcomes expected for children with learning disability who require assessment/ treatment and intensive services.
- QIS Standards for the Provision of Healthcare to People with Learning Disability would benefit from a revision and expansion of the ambition for a more profound impact from these standards across all healthcare.
- Application of the Patient Rights Act to people with learning disability should be monitored to ensure individual Health Boards are

proactively upholding and meeting the rights of people with LD across the system.

- Some examples gleaned from patients of NHS Lothian included:  
Going to the hospital, doctor or dentist can be embarrassing for some people.  
One person had been to the dentist, it was not nice but the staff were nice.  
The dentist might talk to the carer, not the person.  
One person said that they are happy with their appointments.

## Future Priorities – Education

### **Q.7 What still needs to be done to ensure that people with learning disabilities have access to better educational opportunities?**

NHS Lothian encompasses 4 local authority areas. Views were gathered from across the 4 areas as access to educational opportunities can differ from one area to another.

Colleagues from across the service provided suggestions of areas of service development which would improve the opportunities and life experiences for people with learning disabilities. These are offered below:

- There is a concern that courses locally have been cut. With the growing focus on vocational courses and the range of targets that FE institutions must meet, there is a growing perception that people with learning disabilities are, at minimum being disadvantaged, if not being explicitly excluded.
- We would encourage more liaison between agencies to support meaningful education opportunities. Education should not be viewed as a direct alternative to social care – and people should be supported to access both as appropriate to their needs and wishes. FE courses should be outcome based. Whilst it is recognised “Partnership Matters” provides a framework for local agreement for multi agency collaboration, there remains a debate over responsibility for provision of physical support to be able to manage within an FE environment on both a social and educational level, which become even more exaggerated where there are healthcare or medication issues.
- There is a perception that people with learning disability are encouraged to leave school at the earliest opportunity as opposed to being encouraged to maximise their education to reap the maximum benefits – and allow for a slower maturation.
- Training opportunities for employment : on the job training schools/ training academies which include adapted learning which is inclusive of the needs of people with learning disabilities should be maximised.
- Views received from some of NHS Lothian's patients suggest that people are not always managing to access further education.  
"I can't go to college now. You can only go to college for a short time."  
" There is no money for courses. Sometimes Tutors come to where you are; that is good."

## Future Priorities – Independent Living

### **Q.8 What still needs to be done to ensure that people with learning disabilities are able to live independently?**

NHS Lothian suggests that it is essential that access to a wide range of activities and appropriate employment is available as a way of improving health, reducing healthcare requirements and supporting greater independence. Through our strategic developments NHS Lothian is of the opinion that an increase in Core and Cluster living opportunities which recognise the need for intensive individualised support, balanced with provision of specialist services by a well trained and supported team, would be of great benefit in expanding the availability and opportunity for community based living opportunity for those people with learning disability with a range of needs, in a manner that provides a level of efficiency in maximising the utilisation and application of staff skills.

In recognition of individualised needs, and some of the difficulties that can be experienced by some people who are less comfortable with urban environments, it would be helpful to create more opportunities to live in the country, or certainly less urban environments if this is required.

Whilst families and services involved in supporting people with learning disabilities are already aware, NHS Lothian suggests that there would be a benefit from securing recognition that the needs of people with learning disabilities are life long, and are unlikely to decrease significantly throughout their life time. Therefore, whilst budgets can be reviewed to ensure maximum efficiency is being achieved, as the learning disability population grows, so will the pressure for appropriately trained support staff and the associated financial pressures to fund these services.

Although it is not perhaps particular to the support of people with learning disabilities, we would recommend that national policy seeks to influence future standards around the provision of housing stock and the benefits that could be secured through housing designs which reduce the impact of restricted mobility, negating the need for people to move home as they become older.

Forthcoming changes in legislation, and the organisation of health and social care services, such as the implementation of Self Directed Support, needs to be configured in such a way, and associated information prepared in such a way that those with additional needs such as learning disabilities and their families can access these choices and opportunities.

NHS Lothian would also support a drive for more local investment and expansion of local capacity to provide the full range of supported services to enable people with learning disabilities to have opportunities for community based living. As is already well understood, this will enable people to maintain close contact with family, friends and support networks. We need to ensure that the continued focus on independent living includes enough flexibility that those individuals who need more intense support are also

afforded the opportunity to have personalised individualised outcomes all be it that they may not be able to live successfully in more traditional models of independent living.

## **Future Priorities – Employment**

### **Q.9 What still needs to be done to ensure that people with learning disabilities have access to better employment opportunities?**

Whilst NHS Lothian is fully behind the ambition that people with learning disabilities should be afforded the same opportunities into employment as others in society, it is perhaps necessary to consider meaningful changes that are deliverable within the current climate, or need to be undertaken at a macro level to affect the level of change desired.

Other key points that we would wish to make are:

- There needs to be recognition that people with challenging behaviours, or more specific needs, will not gain access to the employment market unless there is a specific and funded drive to support employers to do so.
- More social enterprise opportunities would be appreciated – with recognition that support to move on to permanent employment opportunities is the most valued.
- Volunteering opportunities have become more limited because there is less capacity to support volunteers and there is competition from non disabled people trying to gain work experience. NHS Lothian would suggest that there needs to be some assistance to support non-statutory agencies in strengthening schemes to encourage opportunities for people with learning disability.
- Employment support agencies need to be strengthened and given explicit duties to support people with learning disabilities. If the perception remains that this requires “specialist services” for everyone with learning disabilities to experience a working environment then the mainstream employment support agencies and employers will not develop their knowledge or skill set, and thus mainstream opportunities will not expand in number or quality. . However – this needs to be developed in parallel with agencies which do solely focus on the development and provision of employment opportunities for people with learning disabilities as improvements in mainstream provision will take time, plus some people with learning disabilities will require this more intensive, focussed provision.



## Future Priorities

### **Q.10 What other future priorities do we need to focus on? (Please list these in order of importance with the most important first)**

In developing the response to this consultation, NHS Lothian sought the views of colleagues from a wide range of healthcare settings, both from within the specialist Learning Disability services and from other health care professionals and areas. Below is the range of areas that people wish to see considered for inclusion in future national policy for people with learning disability. We would also wish to draw attention to the response to question 3 where we identified issues in current work and/or policies that, in our opinion, still need to be addressed.

- Scottish Government Strategies, for example; the Parenting Strategy; Carers Information Strategies etc. need to explicitly include, make reference to and recommendations about care and support of families where there is a member with a learning disability. Experience would suggest that a reliance on the impact of the Equalities duties and Rapid Impact Assessment processes is not enough to secure full and appropriate consideration of the needs of people with learning disabilities. For example: the work associated with ensuring positive destinations for all school leavers was not consistently applied to school leavers with learning disability.
- Implications of increasing complexity of care needs to be addressed strategically at national level e.g. we have ageing population of people with learning disabilities as well as a growing number of people with profound and multiple disabilities.
- Support for Family cares – including the supported options and meaningful opportunity of opting out from being a life long carer. Where people choose to continue in the role of carer, they should be adequately supported through the provision of short breaks and respite in a shape and frequency required to support that caring relationship.
- Any re-design of mental health services needs to take account of the LD population.
- As described in the response to question 6, there are a range of continued initiatives required to build on the Equally Well agenda and remove the health inequalities experienced by people with learning disability.
- Greater support for parents who have a learning disability. For example we would like to see support being made available to parents with a learning disability throughout pregnancy, birth and early years. The expansion of the Family Nurse Partnership model specifically to support parents with learning disability would be ONE method of delivering the support required.

- Access to Advocacy when it is not an emergency – access is not equitable.
- In recognition that 3 years have passed since the publication of the report “Tackling Indifference” we would welcome a focus from Health Improvement Scotland to drive the necessary improvements and achieve the ambition as set out.
- A continued need to ensure that all staff associated with social and healthcare support of people with learning disabilities are competent and confident with the application of the full legislative framework of rights, support and protection, but particularly the powers within the AWIA
- Accessible information, including easy read information should be formally recognised as one of the requirements for all Public Bodies for ALL of their public facing information.
- Support for staff to have a ‘can do’ and enthusiastic culture with a commitment to developing and maintaining positive values and attitudes. An Increase in the recognition of the importance of the caring role by valuing staff, ensuring staff are properly trained and supported to fulfil their roles effectively would be essential in underpinning the development of a learning culture.
- Work across ethnic groups to ensure people with LD within these growing communities have equity of access and provision of services. Also, work within the gypsy travelling communities specifically targeted at supporting people with LD within these communities.
- There is a requirement to build on the embryonic work begun to support people with learning disabilities in the criminal justice system including: specific delivery of LD healthcare for prisoners with Learning Disability, particularly Speech and Language Therapy to ensure people with Learning Disability in both the criminal justice system and in prisons can understand and navigate within the respective systems. Appropriate Adult schemes need to be strengthened and become more readily available, understood and recognised throughout the system. Still within the Criminal Justice system, but from a different perspective, we would recommend that better use is made of vulnerable witness measures for victims of crime.

To conclude, whatever priorities are included in the final policy, we would urge that the outcomes and measures of success are clear and explicit to ensure we can demonstrate positive change and equity of services and opportunities nationally.