

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 x and No x !

Please provide any comments, evidence and/or examples here

- The evaluation itself clearly does reflect the views of the people sampled and this is very important as it reflects their lived experiences and ultimately this is what the strategy was about.

However,

- We note that the sample size is relatively small, only relates to four council areas and due to it being representative of the population of people with a learning disability as a whole inevitably has very small representation from people who have complex needs
- As much of the work of NHS psychology departments is focussed on people with very complex needs our response to this consultation will particularly consider the implications for this population.
- We were particularly disappointed to note the lack of any detailed consideration/evaluation of the services provided by community learning disability teams (whether uni- or multi- agency), NHS Assessment and Treatment units and residential services for people with complex needs.
- We feel that the exclusion up until now of consultation with service providers (in all sectors) has meant that some key issues currently facing services have not been given the prominence in the consultation document that they might have had there been a wider consultation. These issues will be seen in our response to the questions below.
- We would also wish to note that our current experience of direct payments and the independent living fund locally does not yet reflect the benefits reported in the consultation document. It may be that we see a skewed sample because of the nature of our clinical referrals but we have been involved in a number of cases where there have been serious concerns about how these methods of funding have been applied in practice.
- These concerns have included reports of clients who do not have capacity to manage these funds being manipulated by others, and concerns about how this is being used by family members in relation to their care. There have also been concerns that on some occasions specific recommendations from health professionals regarding appropriate services to meet care needs have not been implemented.
- Whilst it is recognised that the ASD strategy will be the primary driver for people on the autistic spectrum many people appropriately receive services in the context of specialist learning disability services and we would have hoped for a more explicit consideration of this group within the consultation process. A number of areas in Scotland have developed significant resources for people with ASD

within learning disability services such as multi-disciplinary assessment teams. This does not appear to have been recognised.

- A very significant gap is the lack of detailed consideration of services for people with very challenging behaviour. This population by definition provides a significant challenge to service providers and the resources (financial, structural, personnel and emotional) that are associated with this population have a huge impact on the availability of such resources for the wider population of people with a learning disability. The cost for care packages for individuals can be extremely expensive and the current position in Scotland means that many such individuals are placed far away from their own localities. The SEAT MCN Models of Care Project starkly highlights this.
- The information on dementia in the consultation document and associated reports also fails to take into account the developments that have taken place in a number of areas in line with the recommendations from the British Psychological Society and Royal College of Psychiatry good practice guidelines for dementia. It was disappointing that this guidance was not recognised in the consultation document.
- The documents are very limited in the extent to which they consider mental illness and wider mental health provision for people with learning disabilities.
- They are also limited in relation to the extent to which forensic issues are considered and there have been very significant developments in services and legislation relating to this population in the past 10 years.
- Services for people with profound and multiple disabilities and for people with substance misuse should also have been subject to greater scrutiny in the consultation documentation.

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*?

Please provide any comments and/or examples here

- The greatest success of *The same as you* has been ensuring the closure of the large hospitals (however, the continuation of what are effectively long-stay beds, of various designations, in NHS Assessment and Treatment Units, private hospitals and Nursing Homes does mean that a significant number of individuals can not yet be considered to be "Home at Last").
- In many areas integrated, or joint, community learning disability teams are working well.
- There have been a number of positive developments in care of people with dementia around the country that are not reflected in the consultation document.
- The increasing focus on physical health care needs of people with a learning disability in acute and primary care settings has led to improvement (but still has some way to go – see NHS QIS Tackling Indifference reports).
- NHS Assessment and Treatment units in some areas have been able

to provide a good assessment and treatment service within small units

- There has been a massive improvement in joint working between agencies as typified by the interagency work that goes on between health, social work and police services in relation to adult support and protection work (albeit that further improvement can be made).
- Collaborative approaches such as the development and evolution of the Managed Care Network in south-east Scotland have led to joint services, training and sharing of expertise.
- The use of the Care Programme Approach with people with a learning disability have provided a structured approach to supporting individuals with complex needs
- The changes in legislation, particularly the Adults with Incapacity Act, Mental Health (Care and Treatment)(Scotland) Act and the Adult Support and Protection Act have had a significant impact on support arrangements which have been very beneficial in many cases (although have had significant resource implications for psychologists and other health professionals with a knock on effect on other aspects of service provision).
- The principles governing these Acts have largely become embedded in practice.
- However, there is a concern that sometimes the implementation of this legislation is resulting in a culture that is risk averse rather than enabling.
- The development and maturation of advocacy services has been very beneficial to service users.

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

- Appropriate Adult services have continued to develop around the country but at varying rates and with very variable levels of resourcing. The recommendations of Lord Carloway's report that Appropriate Adults should become a statutory requirement should be accepted.
- The lack of services for people with Aspergers Syndrome in terms of early assessment and post diagnostic support – current arrangements are very disjointed and in many areas there are no clear pathways for people with Aspergers creating continuing pressure on specialist learning disability services.
- There needs to be significant development in the workforce across a wide range of services in relation to working effectively with people with complex needs. This includes a range of training and development opportunities that include skills-based and relational elements. This is particularly the case for people with severe challenging behaviour so that more local services can be developed. This should include the development of training and practice in relation to positive behavioural support and the availability of appropriate supervision and governance arrangements.

- Consideration needs to be given to how the most capable staff can be attracted to work in such services and be retained.
- Despite years of initiatives in relation to transition from child to adult services, in many areas this remains a significant challenge. Particular difficulties arise in relation to transition having to happen across multiple agencies and these can happen at different times in a young persons life.
- The development of SAY2 should include the development of a research to practice strategy that utilises the skills available around the country in a research to practice programme that reflects the national strategy and workforce development needs linked to a national implementation strategy for identified best practice. This should be developed explicitly rather than appearing to operate in the somewhat ad hoc fashion of recent years.
- There is a clear need, as part of the arrangements for integration of health and social care (or even before) for the development of joint commissioning arrangements for people with the most complex needs. As a priority this needs to include consideration of those individuals who are continuing to reside in hospitals or nursing homes inappropriately. Many of the individuals in hospital settings are effectively delayed discharge patients but are not recognised as such in ISD figures (see recent study by Perera et al.). There should be explicit reporting of these figures in Government statistics.
- The integration arrangements should also include consideration of reviewing the efficiency and effectiveness of extremely high cost care packages and whether acceptable alternative provision can be developed in a manner that allows more equitable use of resources.
- Consideration should be given to the development of a greater risk enabling culture within services, but with the development of clear structures of governance and quality assurance in place.
- Consideration needs to be given to how some specialist services can be provided on a more equitable basis across the country – for example there is a great deal of variation in the range of specialist forensic services.
- The needs of people with a learning disability in the criminal justice system require further development.
- The impact of the new legislation on the limited resource of clinical psychologists (and other specialist learning disability healthcare staff) should be recognised in any future funding arrangements to support the development of services in relation to these Acts.
- There is a significant issue for adult learning disability services in relation to eligibility criteria for specialist service provision. The policy and philosophy of lack of formal cognitive assessment in education means that a number of children at transition are being inappropriately referred to adult learning disability services and are subsequently assessed as not having a learning disability and therefore not eligible for specialist adult services. At times such assessments pick up patterns of cognitive deficit that do not appear to have been recognised within education services.
- There is a need for consistency and integration of IT systems across health and social work services (with appropriate permissions and firewalls etc in place to allow confidentiality to be maintained at the appropriate level).

- Improved IT systems and recording arrangements on a national and local basis would make a significant difference in relation to planning services.
- There are significant gaps in specialist health service provision for children and adolescents who have a learning disability in many areas of the country. Improvements in these services, particularly for children with complex care needs, could have long term benefits for both the children themselves and the required level of support in the longer term.
- Person centred planning for individuals in many areas has not been developed to the extent that many people would like (often due to competing demands and pressures forcing specialist services into a reactive rather than proactive approach to support).
- Improvements in the quality and consistency of models of risk assessment, risk management and risk enablement could have a significant impact on service design and outcomes for individuals.
- The loss of regular scrutiny of health services for people with a learning disability from NHS Health Improvement Scotland (and previously NHS QIS) means that there is a risk that NHS Boards will fail to give sufficient scrutiny to the health needs of people with a learning disability (primary care, acute and specialist services). At the very least there should be national standards against which NHS Boards should have to self-assess.
- There is likely to be benefit in revisiting the possibility of “light touch” multi-agency inspection of services to promote best practice (provided this can be developed in a manner that is not too time-consuming and does not detract from a focus on ongoing service provision).
- There is increasing concern about the availability of appropriate support services for people with a learning disability who are parents. Parents with a learning disability are often referred to specialist health services for assessment. It often appears that their needs as parents have not been well supported.
- There are continuing challenges in relation to the Adults with Incapacity Act. There is a need for greater clarity on pathways for assessment of capacity and when this does, or does not, require specialist multi-disciplinary assessment. There are still issues with some GP’s not being willing to complete Section 47 certificates. We are aware that the BPS response has highlighted the concern about clinical psychologists not being one of the professions that can sign Section 47 certificates for their own treatment interventions, and would concur with this view. We find this situation somewhat ironic given that it is clinical psychology that is usually asked to provide an assessment where issues of capacity are complex.

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

- Memory Multi-Disciplinary Team – this is an assessment and diagnostic service for people with learning disabilities and possible dementia which operates across Forth Valley. This team has developed a care pathway which is embedded in the NHS Forth Valley ICP for dementia and is consistent with “Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia” published in 2009 by the British Psychological Society and Royal College of Psychiatry.
- ASD Assessment and Diagnostic Team – this is a multi-disciplinary assessment and diagnostic service for people with a learning disability and ASD which has developed an area wide service based on adaptation of the SIGN guidelines “Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders” and is currently considering the recommendations of the recent NICE guidelines “Autism: recognition, referral, diagnosis and management of adults on the autism spectrum”.
- Multi-agency forensic learning disability group – As there is no dedicated forensic learning disability service in NHS Forth Valley we have established a group of interested professionals from CLDT’s (health & social work), Criminal Justice social work, Police and Procurator Fiscal services who meet to consider how to make best use of existing resources and promote appropriate service development. This has included a range of issues from individual case discussion to organisation of conferences.
- We have supported the work of nursing colleagues in relation to the Anticipatory Care project from Equally Well funding and in relation to the development of the role of the liaison nurse in acute care. We view these as very important developments in supporting access to healthcare for people with a learning disability.
- The psychology service has had a significant role in the development of Adult Support and Protection arrangements at both an individual and service level and see the benefits that this approach can bring (albeit that it results in a large demand on our limited resources).
- We have had significant involvement in the development and growth of the SEAT MCN and see that this has been of great benefit in professional and cross-boundary cooperation. The development of the low secure MCN forensic unit, range of training courses and Models of Care Project have been particularly important.
- We were pleased to be heavily involved in the development and implementation of the NHS NES Positive Behavioural Support pilot project (albeit disappointed that the recommendations from this were not implemented by NES).

Good Practice - Individuals

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

Please provide any comments and/or examples here

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?

Please provide any comments and/or examples here

- The NHS QIS Report "Tackling Indifference" highlights that there is still significant variation around the country regarding NHS Boards taking positive steps to ensure that people with a learning disability have appropriate access to all healthcare services. We would hope that there continues to be pressure on Boards to take the necessary steps (under The Equality Act if necessary) to ensure that improvements in access to services continues.
- We would support the development of further work from nursing colleagues in anticipatory care and acute liaison services as we see this as having been a very effective use of resources.
- The range of complex needs highlighted above needs to be considered a core part of the healthcare needs of people with a learning disability. There is a concern that the 'health' paper which was produced to inform the consultation did not give sufficient weight to the healthcare issues, and health service role, for these populations.
- We need to try to shift the balance in healthcare from a reactive response when there are problems to having people with a learning disability considered in all aspects of healthcare, particularly in relation to public health campaigns.
- Whilst making generic services accessible to people with a learning disability must be a core element of healthcare strategy there should be a continuing recognition of the benefits of specialist health professionals in supporting the needs of those with the most complex needs.
- There should be further investment in, and development of, psychological therapies for people with a learning disability with a greater emphasis on a stepped care model. This would include improving the accessibility of mental well-being materials and the development of a range of practitioners who can provide psychological therapy in accordance with the NES Matrix of Psychological Therapies. This includes interventions for challenging behaviour, mental well-being and mental illness. There should be clear governance structures relating to such developments.
- There needs to be a greater focus on a strategy to ensure that the existing evidence base for service provision and treatment is applied in practice and support for the development and evaluation of innovative approaches.
- There should be greater equity of specialist health staffing across NHS Boards.
- There is still a lot of room for improvement in the confidence and

practice of some GP's and hospital doctors in the application of the AWI Act and associated assessments.

- Work needs to continue on appropriate access to healthcare, particularly in relation to the full range of psychological therapies for people with a learning disability in prisons.

Future Priorities - Education

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

Please provide any comments and/or examples here

- Less use should be made of "out of area" educational placements. This is important both in terms of local connection for families and in relation to improving transition into adult services.
- There is need for the development of much greater choice in relation to adult education opportunities.
- We would like to see a stronger emphasis in providing education to individuals on ways to keep themselves safe (as a means of empowerment). This is due to significant pressures on our caseload relating to young people who are placing themselves in risky situations (with a particular concern about vulnerability in on-line activity).
- We would like to see stronger links between education and potential employment opportunities.
- Adult education services should provide more opportunities for vocational training in collaboration with potential employers.

Future Priorities – Independent Living

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

Please provide any comments and/or examples here

- There should be explicit recognition of the benefits that multi-agency specialist learning disability teams bring to supporting people with complex needs in community settings and there should be equity of provision across the country.
- This should include the development of robust support arrangements that allow people with severely challenging behaviour to be supported in community settings by staff who are sufficiently trained and skilled to provide positive community support (rather than just containment).
- There should be improved monitoring of care packages to ensure efficiency to free up resources.
- There should be investment in the use of telecare and associated

technology to ensure the most efficient and effective use is made of resources and to promote independence.

- There is a clear need to target services where there are still large groups of individuals living in aggregated care home settings to determine if this is the most appropriate arrangement.
- There should be a clear and explicit process of service review across services to ensure that there is good governance and best value in the specialist support services provided. The learning from this should be shared across the country.
- There should be a specific focus on service provision at transition with clear service standards which target support models that promote independent living arrangements as far as possible with a focus on building true community integration.
- There should be a multi-agency strategy to consider approaches to reducing risk for people with a learning disability resulting from use of the internet.
- Models of service should be developed that allow greater flexibility in the levels of support provided to individuals depending on their need at a particular time - this could include combinations of social work, health and third sector staff.
- There should be a greater emphasis on early intervention to prevent deterioration in situations including easy and speedy access to additional support at times of need – this can be a particular challenge in relation to eligibility criteria focusing on those at greatest need/crisis.
- Where independent living is not possible for an individual services should be required to show how they providing a person centred service specific to that individual.
- There should be a greater focus on services working to support individuals to build relationships within their communities and to reduce the risk of staff and families being their only significant relationships.
- Further work needs to be done in relation to supporting people with learning disabilities to have opportunities to develop meaningful relationships, including sexual relationships.

Future Priorities – Employment

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

Please provide any comments and/or examples here

- The services which are designed to support people with learning disabilities into employment need to be realistic about future employment opportunities (particularly in the current climate).
- There should be explicit links between employment training initiatives and organisations/companies that will be willing to employ people with a learning disability (perhaps as part of a work-sharing arrangement). Currently there is a significant degree of frustration for people who have been on employment training for years but do not have the pathways available to move into employment.
- There is a need for more creative solutions such as the development of social enterprise companies?
- The challenge of people and/or their families being reluctant to work due to the potential impact on benefits needs to be recognised and explicit arrangements put in place to ensure that people with a learning disability are not financially disadvantaged in the short or longer term by entering employment.

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)

Please provide any comments and/or examples here

- Significant improvement in the availability of specialist learning disability services for children and adolescents with complex needs across the country to allow early intervention thus reducing the potential need for out of area educational placements and the subsequent impact on adult services.
- There should be a workstream focussing on the development of appropriate and economically viable services for people with severe challenging behaviour in community settings. This should include further consideration of service design, staff training, additional supports, evidence-based intervention and quality/governance standards.
- Transition between child and adult services needs continuing improvement and learning from best practice to be shared across the country.
- Careful consideration needs to be given to how people with complex needs can make best use of self directed support arrangements without compromising quality of care.
- The new strategy should include explicit standards/outcomes that services can measure themselves against. This should be available in a manner that allows some form of light touch external scrutiny on

a multi-agency basis.

- The development of an explicit research strategy which focuses on the application of the existing evidence base into practice, service quality (particularly from a user and carer perspective, including outcomes) and innovative approaches to service delivery.
- There should be a greater focus on parents who have a learning disability.
- In collaboration with the Autism strategy there should be greater clarity regarding the interface between learning disability services and services for people with Aspergers.
- The development of personal safety and awareness programmes for people with a learning disability (including on-line safety issues).
- Improvement in arrangements for people with a learning disability from ethnic minority groups (such as liaison workers).
- The existing work in relation to people with a learning disability in the criminal justice system should continue (and the proposal for Appropriate Adult services to become a statutory requirement should be supported).