

## 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

**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*?**

What has worked well to enable all of the developments we have made is the more fundamental shift in attitudes amongst the general public, professionals and amongst people with learning disabilities and their families. The SAY work made people see those with learning disabilities as independent individuals, with their own needs, wants, talents and ambitions, rather than as a homogenous group many of whom were contained in long-stay wards. For a lot of people, it was the first time that they heard the voices of people with learning disabilities and understood the need for change.

The most obvious examples from Fife are the significant reduction in bed numbers at Lynebank Hospital, including closure of all long stay beds, the review of day time activities, the review of commissioning for those with complex needs and development of a joint strategy, as well as the development of a wider range of accommodation solutions and care providers with expertise in a variety of fields. For those people who have to go in to hospital for treatment of mental health or psychological problems new environments have been developed to improve quality and person centred care. The Joint Improvement Team made a significant contribution to the way on which services can understand and commission evidence based care.

Specific examples of things that work well in Fife include the choices people with learning disabilities can make over where and how they would like to live, including joint health and social care provision for those whose needs are extremely complex. We have developed a range of different options, from single tenancies to shared living, and we can meet almost all needs within Fife, by working closely with a range of independent service providers.

#### SCLD and South East Scotland LD Managed Clinical Network

Both of these organisations have made very useful contributions to the development of services, and to the involvement for people with a learning disability as well as learning from each other. The recent paper produced by LD MSN on Models of Care will be particularly useful for considering the needs of the most complex groups. It would be useful to encourage more

working together, to allow services right across the country, including the north, to benefit from work which has been learned and is being done. Additionally the national Forensic Network has achieved a great deal in terms of sharing good practice and the work of their LD work stream could be more explicitly shared and linked to these LD organisations.

The Health Needs Assessment Report for People with Learning Disabilities published in 2004 been extremely helpful in promoting a greater understanding of the health needs of this population and highlighting current service delivery gaps. This identifies the additional mental health needs as well as physical health needs.

In terms of improving health, NHS Fife has developed a strategy to address health inequalities, as well as a strategy for improving the availability and use of good quality accessible information. This has included training for primary care staff; development of specialist nurse roles (primary and acute care, epilepsy, child to adult transition and challenging behaviour); delivering one stop health screening for people with Downs syndrome; development of a pathway for assessing dementia and providing information, training and support for carers; regular training for care providers raising awareness and understanding of how learning disability impacts on communication, health and behaviours; and identifying and promoting quality standards for accessible information, launching an on-line database of quality assured accessible information and providing training in this area.

Development of a single point of access to the three multi-disciplinary community learning disability teams ensures efficient processing of referrals and quick allocation to appropriate health specialist. We now have some evidence that these approaches are identifying a greater number of health needs and offering support in more effective ways.

Specialist multi-agency forensic services have developed both for in-patients and to support and manage risks for those able to live in the community. A regional specialist low secure unit now provides a service across the south east region.

Fife took part in the NES pilot for training health staff in using Positive Behavioural Support and continues to develop services to people with severe challenging behaviour in the community delivered by specialist nurses and clinical psychologists.

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

Supported employment, training and further education opportunities for people with learning disabilities is challenging. Meaningful employment opportunities are crucial to help people live lives free of poverty and without the risk of social exclusion.

The SAY health review document highlights that Better Health Better Care

was committed to improving health through increasing efforts to improve lifestyle choices that impact on health. This emphasises the need for health to be everyone's business and the ongoing active participation of people with a learning disability or ASD in the day to day opportunities that the remainder of the population are afforded. This therefore is also about attitudes and values of the wider population.

The strategy for jointly commissioning services for those with complex needs should improve the delivery of care which is more individualised and effective using evidence based approaches. Clearly developments in the integration of health and social care will be significant in this respect. Service users and carers represented at the Learning Disability and ASD Strategic Implementation Group in Fife are very clear that integrated services (from assessment, to delivering care, to budgets) are the way ahead.

Such jointly commissioned services will need to ensure that care/support staff are well trained in not just generic care standards but the specific needs of people with learning disabilities and complex mental health, physical health and behavioural needs. Management of such services will need to be aware of best practice with specific groups of people building on work done by the Joint Improvement Team.

Specialist multi-agency forensic services at present are almost exclusively for male patients and at present there is no specific inpatient service for adult females with learning disability and forensic needs. Attempts to address this issue at a regional level in South East Scotland have recently commenced.

Specialist Services to be developed which support children and young people with a Learning Disability and Autism who have complex needs and challenge services.

### **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

Significant work has been done in Fife to improve services and access to services over the last ten years. However, although we have had a lot of successes in small and larger scale projects and developments, it is the underlying approach that has made the difference and improved our services. We have worked in partnership across Fife, via our Learning Disability / ASD Strategic Implementation Group, to ensure that we offer choice, quality and often ground-breaking services here.

A few examples of the things we have achieved via our partnership group include:

The provision of health and social care on a single site for people with complex needs in Dunfermline. This joint care facility allowed people to move out of long stay hospital with some of the most complex health and social care needs. This model is being further developed in relation to the very few long-term patients in Lynebank hospital to reflect lessons learned from the service described above.

We appointed an ASD Coordinator. The post was recently evaluated, showing that we have made some services more accessible to people with ASD, and that we have raised awareness of the needs of people with ASD with our staff and members of the public.

Through our own in-house provision, and through independent sector provision, we are able to provide a range of community living options, while partnership arrangements have allowed a network of community treatment, rehabilitation and care services to wrap around the individual.

We recently completed the development of a joint commissioning strategy for learning disability / ASD, focusing on how we can best commission services for people with complex needs. The strategy is currently being implemented and tested across Fife, and we will consider rolling out the successful aspects of this approach to other groups of people.

In terms of improving health, NHS Fife has developed a strategy to address health inequalities, as well as a strategy for ensuring accessible communication. This has included training for primary care staff; development of specialist nurse roles (primary and acute care); delivering one stop health screening for people with Downs syndrome; development of a pathway for assessing dementia and providing information, training and support for carers; regular training for care providers raising awareness and understanding of how learning disability impacts on communication, health and behaviours; accessible materials have been developed and introduced in a range of healthcare contexts including ante-natal care and parenting. Healthcare passports have also been developed to support people with a learning disability in acute settings. Development of a single point of access to the three multi-disciplinary community learning disability teams ensures efficient processing of referrals and quick allocation to appropriate health specialist. We now have some evidence that these approaches are identifying a greater number of health needs and offering support in more effective ways.

Specialist multi-agency forensic services have developed both for in-patients and to support and manage risks for those able to live in the community. A regional specialist low secure unit now provides a service across the south east region.

Fife took part in the NES pilot for training health staff in using Positive Behavioural Support and continues to develop services to people with severe challenging behaviour in the community delivered by specialist nurses and clinical psychologists.

The work of the SEAT LD MCN has allowed a greater sharing of good practice across the region as well as development of services and

efficiencies in their delivery e.g. psychiatry on call rota.

### **Good Practice - Individuals**

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

### **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?**

Health promotion messages are key. People with learning disabilities may need to hear the same message several times, and may need support to gain motivation, and to understand the implications for their own behaviour around health.

See examples of developments over the last ten years in Fife Q2 and 4 above.

Further developments such as the healthcare passport will refine the progress made to date.

People with learning disabilities need more support in healthcare settings, including in-patient settings – a recent project in Fife has developed the Healthcare Passport, a document which sets out the needs of a person with learning disabilities, and which can be shared with health service providers in any medical setting. It gives important information about how the person communicates, who their carer / contact is, what health needs, conditions and allergies etc they might have and other information aimed at supporting their communication with medical staff.

Improving Access to Psychological Interventions or Therapies has been a focus of the Government's Reshaping Care and Mental Health Division over the last few years. A matrix of evidence based interventions for people with a learning disability has been included. Services need to ensure that the improved standards in delivery of psychological interventions (in terms of waiting times, qualified therapists and supervision being assured) now anticipated for those in mainstream populations is also delivered to those with a learning disability, ensuring an equal standard of service, despite the more systemic context and challenges of delivering much of the work through carers in many cases.

The communication needs of people with LD need to be recognised and supported across all health care settings and accessible information should not only be available but staff should be skilled and confident in how to use this appropriately with people with LD's.

As important will be government support for continued research into all

aspects of physical and mental health care for this minority group as we know that their needs and effective interventions may be different from the mainstream. It is not easy to carry out robust research into small populations with diverse needs but they deserve evidence based health and social care.

Regarding children with a learning disability, decisions need to be made about how best they access the specialist services they require in terms of both health and social care. It is important that CAMHs teams and general practitioners feel skilled to work with these children and their families from the earliest stages. This includes availability of specific psychiatry provision across the country.

### **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

It would be very helpful if educational services would identify children with a learning disability at the earliest possible stage, in the context of Additional Support for Learning, providing appropriate information and advice to these children and their families at the earliest stage.

We know there is a more general link between education and employment success, including income levels. People with learning disabilities who are able to achieve qualifications will be better placed to find meaningful employment. It brings undoubted benefit in terms of day structure, personal growth and social opportunity. However consideration needs to be given to the role of tertiary education and ensure that people are supported at the correct level to improve personal development or employment prospects.

### **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

We would like to see investment in and development of new technology to support independence, whilst acknowledging the need for assessment of needs on an individual basis so that appropriate support and input is provided to each person.

Professionals could perhaps support people in positive risk taking to a greater extent than at present, through a culture of enablement (and in some cases, re-ablement).

People and their families need to be clear what level of support they can expect and about decision making processes about these levels of support

so they can plan their lives appropriately.

We need to maximise independence within the abilities of the person. Any risk assessment needs to take into account people's skills/potential but also needs to recognise their support needs. More emphasis on enablement and participation is required.

### **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

- Better training and education, targeted at employability.
- Supported employment
- Employers beyond the public sector could be supported to understand the value that people with learning disabilities could bring to their organisation.
- Multi-disciplinary and agency approaches to employment can contribute specific skills in ability assessment, job analysis and activity adjustment (for example occupational therapists). This can help address potential achievements as valued employees rather than focus on impairments.

### **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

Improved commissioning of services for people with learning disabilities

More consultation, more involvement and engagement with the wider community, e.g. community councils and community planning groups – people with learning disabilities can become much more visible within their communities, and have their voices heard.

Increased partnership working with the independent sector to meet a diverse range of need with tailored solutions.

Continued development of joint working between health and social services.

Research into demographic changes, and into how we achieve the best possible outcomes for a growing population of people with increasingly complex needs.

Ensuring people in prison with a learning disability are known about and

receive equal and accessible services for managing offending behaviour as well as health and social care.