

***The same as you?* – Consultation**



The same as you? is the policy belonging to people with learning disabilities in Scotland. It was launched by the Scottish Executive in May 2000 and reviewed the services available at that time to people with learning disabilities and people on the autism spectrum. It contained 29 recommendations intended to drive a change programme which would improve services. The recommendations were underpinned by principles recognising the individuality and worth of every person with a learning disability in Scotland; their right to be included in, and contribute to, society and their right to have a voice, support and to live the life of their own choosing.

In 2010 the Scottish Government set up an Evaluation Team to find out how the lives of people with learning disabilities and/or on the autism spectrum and their families have changed since the launch of *The same as you?*

What improvements have there been and what challenges still remain?

The results of the evaluation will be used to inform priorities for further policy and service development.

The evaluation process highlighted a number of areas where further work was still required, for example:

- Healthcare
- Education
- Housing
- Employment

We would now like to hear your opinions on the outcome of the evaluation and how we can improve things in the future. This is important as your opinions, along with the outcomes of the evaluation, will be taken forward to inform, develop and produce a new policy document for people with learning disabilities.

A new national learning disability strategy group will be formed to work on this new policy during 2012.

The following questions ask about your opinions and experiences so we would appreciate it if you could take the time to respond as we only have a limited amount of funding to do this work so we need to make sure we are spending this on the right areas.



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

Thank you for the opportunity to provide comment on “The same as you?” Consultation.

While responding in the affirmative to this overarching question, we nonetheless do so with significant qualifications. As a consequence, in addition to responding to the individual questions 2 to 10 below, I have also provided more general comments under this item.

The report and the accompanying health scoping exercise and evidence scoping exercise provide a significant amount of information. However, there are some factual errors which, had the reviewers opted to speak to people and organisations who have access to relevant information, might have been avoided. For instance, contact does not appear to have been made with psychiatrists, social workers or mental health officers to ascertain their views, nor with organisations such as ourselves or the Care Inspectorate. A further matter of concern is that the conclusions from the evaluation have been drawn from such a limited interview base, amounting to only 0.18% of the number of people who are in touch with services. It is our view, therefore, that any conclusions have to be interpreted with extreme caution. The Commission would be happy to share relevant information and to be involved, as appropriate, in discussions regarding the future strategic direction following the review of all the responses.

The following items relate to the actual reports.

Page 5 - The statement “the overwhelming majority of adults with learning disabilities now live in the community” is misleading insofar as the overwhelming majority always did live in the community (only 25% of people with learning disability were in hospital based institutional care when at its “height”).

Page 9 - Where people live now:

There is no doubt that the closure of long stay hospitals and the increased provision of community resources to enable people to live more normal lives has been a success. However, the eSAY data that is reported does not discriminate between those people living in their own homes with no or minimal support and those who have a tenancy but have staff present at all times. This can lead to misunderstanding by people who are not aware of the wide variety of arrangements which are in place to support people and which facilitate “independent living”.

Page 10 - Assessment and treatment places:

The quote from Perera et al is incorrect. In their paper they state that there were 91 people in forensic beds, this does NOT equate to the number of

people with LD who are on statutory orders as reported in the consultation. The Mental Welfare Commission carries out a biennial census which reports on the number of people on statutory orders either through the Mental Health Act or the Criminal Procedures Act. We also report on the number of people subject to guardianship. In 2008 there were 272 people on either MHA or CPSA orders. This number has increased significantly in the subsequent years (to 338 in 2010). Our next census is due to be carried out in September 2012. There were also more than 2000 people with LD subject to guardianship.

It is also misleading to refer to people “still living in hospital”. Whilst there are clearly some individuals for whom a hospital place is a long term reality, there are many more who are admitted to hospital for short periods of time; in this context, for the assessment and treatment of additional mental illness or other mental disorder. Research carried out in 2005/6 in Lothian showed that the majority of people who were in assessment and treatment beds were in fact new to the service and were not people who had formerly been in long stay hospital care. (Lyall and Kelly 2007).

Page 18 - It is noted that the pattern of college attendance is different for people with learning disability. The need for FE colleges and other higher education institutions to ensure that they have enough funding often leads to a mismatch between the courses that they offer and what people would like to be available. Nevertheless, it is important that FE colleges are not seen merely as a replacement for appropriate day services which may be lacking and that courses that are available are meaningful for participants and enhance their skills and life experience.

Page 32 - It is regrettable that there is not a separate section on mental health issues given the statement that children and young people are at much higher risk of mental illness than the rest of the population. There is also an emerging issue with drug and alcohol abuse. Both this report and the health needs report appear to concentrate on aspects of physical health care for people with learning disability. This reinforces the status and perceptions of mental health services, and in particular mental health services for people with learning disability, as the poor relation within health services. Whilst the health report has a significant section on behaviours that challenge and positive support for this and a section on Child and Adolescent Mental Health Services (wrongly titled as Child and Mental Health Services in the report), there is very little on adult mental health. Given the actual figures quoted above regarding the number of people subject to compulsory treatment under the Mental Health Act this is a serious omission. Neither the Mental Welfare Commission nor psychiatrists working within the learning disability field appear to have been approached for their perspectives and input to the report.

Page 39 - Reference is made to 3 people “living under Community care and Treatment orders”- we assume that this should actually be Community Compulsory Treatment Orders.

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 hospital closure programme has been successful for most people involved and many have much better lives than before. The greater visibility of people with a learning disability within communities is helping to change attitudes. The increasing knowledge amongst professionals and others with regard to people with ASD is also helping to improve the delivery of appropriate care and support.

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

Although the provision of a greater degree of choice in day to day activities has been generally beneficial there are many people for whom the absence of a structured daily placement, which is equivalent to that for people in work, has resulted in an endless round of visits to coffee shops and garden centres with little or no apparent benefit. The appropriateness and availability of day activities should be more widely reviewed.

The move to self directed support should enable more people to have a real choice about what they do. However, the needs of those with limited or no capacity to make decisions in these areas have to be protected and appropriate safeguarded arrangements put in place so that the most vulnerable people are not put at even greater risk.

The individual tenancy which is very highly supported has the potential to be even more restrictive for the person concerned than a placement in a larger, congregate setting. The Commission have significant concerns about individuals' quality of life in these circumstances and the lack of access to peers. As such placements are often for people with very complex needs or behaviour that significantly challenges, consistency of staffing is a major problem and turnover is high. This adds further to the adverse psychological consequences for people with learning disability who are already known to have to deal with much more loss in their lives than most people. Consideration needs to be given to the sustainability and appropriateness of such models of care. This is potentially very important in the context of the proposed integration of health and social care where the very significant differences between care packages for older people and those for people with a learning disability may lead to a significant reduction of resources for people with learning disability. The consequences of this, for the provision of appropriate accommodation and care needs, may have a detrimental effect on a significant number of people. The specialist requirements of some people with severe difficulties as a result of ASD are of particular concern in this regard.

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

The Mental Welfare Commission is not a provider of services. Nevertheless our programme of visits to individuals with mental disorder, including those with a learning disability, in the community and in health and social care services allow us to ensure that people are enabled to access appropriate services. We make recommendations and follow up on individual issues with relevant people and organisations. We have carried out a number of investigations in to the care and treatment of people with a learning disability over the last 10 years. These can be found on our website and contain recommendations to local authorities, NHS Boards and to the Scottish Government. In addition, we produce relevant guidance and information leaflets in easy read or alternative communication formats such as DVDs. We have service user representation from people with a learning disability as part of our visits to services and they provide input to various other strands of our work programme. We have an ongoing programme of consultation and engagement with relevant self advocacy organisations.

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

As an organisation, the Commission has recognised the valuable input of service users to its work. We had a part time commissioner with a learning disability until the governance structure of the Commission changed in April 2011. We now have a number of Commission Visitors, one of whom has a learning disability and who provides a perspective on all relevant aspects of the Commission's work. We consult with self advocacy groups, in particular, People First, as we do with other relevant advocacy and professional groups, about our strategic plans.

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 specific health needs and vulnerabilities of people with a learning disability and ASD should be an integral part of training for all health professionals from the moment they start as students. This may require a major change in the way in which curricula, particularly the medical curricula, are put together. This is a UK wide issue and it is now the responsibility of the GMC to set standards for medical schools and the NMC for pre-registration nursing education. It would be useful for an evaluation of the effectiveness of health curricula in respect of people with learning disabilities to be undertaken.

At a more local level, the application of QOF targets for learning disability and the integration of explicit standards- where relevant, in relation to people with learning disability will assist in ensuring that the health needs of people with a learning disability are given greater prominence. The recent Dementia Standards, whilst not having one particularly related to people with learning disability and dementia, are clearly stated as being applicable to anyone who has the diagnosis.

In respect of treatment for additional mental illness or personality disorder as well as the assessment and management of behaviour that challenges, the Commission believes that the current number of assessment and treatment beds is probably about right. There are a significant number of delayed discharges across the system as a result of people who no longer require NHS care being unable to move on due to financial and staffing issues- often these people require specialist approaches to care and have complex needs such as those with an autism spectrum disorder and additional difficulties. This results in others being admitted inappropriately to adult mental health beds and in some cases to private hospital resources both here and in England. The cost to the NHS in Scotland for people who are placed in specialist resources in England and in independent facilities both here and in England is considerable. It is also important to remember that assessment and treatment beds are short term and not providing, nor intended to provide, lifelong care settings. Forensic beds for people who have been in contact with criminal justice are most likely to provide accommodation for lengthy periods of time and need to be considered separately from assessment and treatment.

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

This is not our area of expertise

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

Our visits to individuals with a learning disability give us an insight into how they are being supported. One area that is not particularly well addressed is the issue of risk assessment and management and we have seen people at both ends of the spectrum- where risk has not been assessed/managed and risky behaviour is accepted as someone's choice despite a clear lack of capacity to make informed decisions about the behaviour and others where service providers are so risk averse that the individual is never allowed to learn from experiences, even in a protected manner. Training and support for care staff with regard to this should be undertaken and issues about capacity and consent should be part of each individual's PLP and care plan.

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

This is an issue which affects a wide range of people in the current economic climate and is not confined to people with a learning disability. The importance of sheltered and supported employment places as a means of gaining skills and confidence should be recognised and not dismissed because they are not mainstream. For example, The Engine Shed, which provides sheltered employment and employment experience for young people with learning disability, has good track record in facilitating moves into mainstream employment. It is also a setting where people feel valued and make a significant social and economic impact on the surrounding area.

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

There is nothing in the list of priorities relating to accommodation and support. For those with complex or high support needs the availability of appropriately trained and experienced staff and the consistency of these staff requires a re-evaluation of the status of these jobs including the pay and conditions.

There should be a range of sustainable accommodation options which is not predicated on the assumption that everyone wishes to live alone- they do not. People with learning disability need to know that their accommodation is appropriate and secure for the long term, but also that there is flexibility in the system should they need or wish to move.

There are significant numbers of people with learning disability subject to Welfare Guardianship orders as noted in earlier comments. Although the number of indefinite orders granted has reduced a little this year, the Commission remains concerned about the lack of automatic periodic review

by judicial authority. This position is not compatible with ECHR and a proportionate response to this is necessary. It is likely that the numbers of people subject to welfare guardianship will continue to increase

Thank you for taking the time to read the consultation document and taking the time to respond to the question. Your continued input and support is vital in ensuring that we continue to close the inequality gap that people with a learning disability face daily.

All completed questionnaires should be returned to Sarah Grant either by e-mail or at the address below. The closing date for responses is 30th September 2012.

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