

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

Whilst services for people with learning disabilities have evolved over the last 10 years there is still work to be done.

Health inequalities and barriers to health care need to be tackled.

An increase in more easily accessed meaningful activities for people with learning disabilities be that employment, education or leisure is also essential.

Specialist services for young people with learning disabilities remain patchy. More thought needs to be given to support around transitions.

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?*

Closure of long stay hospitals with increase in care and services in the community.

Increase in advocacy for people with learning disabilities.

Increased opportunities in leisure, education and employment.

Successes following the emphasis on health needs for people with learning disabilities have led to a number of health screening initiatives.

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

Services for young people.

Health inequalities and access to health care.

Use of Adults with Incapacity Act within primary care.

Care and treatment locally for those who have the most challenging behaviour, many of whom are cared for away from their local area due to lack of suitable care provision locally.

Stigma continues to need to be tackled.

Improved access for those from minority communities.

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?

Following the raising of awareness with regards of health needs and health inequalities for people with learning disabilities there have been a number of initiatives trying to address these issues through for example the development of specific health screening clinics.

Concerns about the support for children and adolescents with learning disability has led to a number of appointments of psychiatrists with training in the psychiatry of learning disability or special interest providing services to children and adolescents with learning disability.

The Royal College of Psychiatrists continues work with other professionals in an attempt to support, educate and combat stigma and to ensure access to appropriate health and social care.

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?

Improved access to primary and secondary health care, along with training on the communication support needs of people with learning disabilities and how to meet these needs.

Ensuring that the Adults with Incapacity Act is used where appropriate to ensure the same health care as those without a learning disability.

Improving attitudes towards people with a learning disability and ensuring that their value as citizens is appreciated.

Improved knowledge of condition specific health needs (for example in Downs syndrome or tuberous sclerosis).

Future Priorities - Education

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

Ensure appropriate educational opportunities at all ages to maximise people's potential.

Ensure access to meaningful further education courses.

Improve estate of and transport to educational establishments.

Future Priorities - Independent Living

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

We have to ensure that people with learning disabilities are adequately supported whilst living in the community. There are times when support offered is not adequate to meet the individual's needs and as psychiatrists we have to continue to act as advocates for our patients and their families to try to procure the best possible support.

Future Priorities - Employment

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

Increase access to supported employment schemes.

Education of potential employers about the benefits of employing someone with a learning disability as well as what support they may need (reduce stigma)

Change expectations and attitudes within the community about the ability of people with learning disabilities to undertake 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)**

Health inequalities and removing barriers to appropriate health care.

Increase the opportunity for meaningful activity

Increase support for carers

Address the changing needs of people with learning disability (ageing population and development of cognitive impairment)

In terms of priority themes and actions, dementia and children are highlighted,

but otherwise there are no recommendations regarding mental health services for PWLD. Given that this population group experiences a greater incidence of mental illness than the non learning disabled population this should be looked at.

As a Faculty we are also concerned about the fact that, in some areas, we struggle to provide "assessment and treatment" in patient facilities for people with learning disabilities (PWLD). The National prospective study identifies that there is a new "long stay" population. These individuals are, by and large, within assessment and treatment beds. From the 2012 census data (Perera, Simpson, Douds) there were 318 LD patients in hospital. 28% were identified as delayed discharges. Worryingly, 78 of the 318 patients had been admitted to these wards directly from long stay hospitals. The delayed discharge figure for the forensic LD population was 32%. We are concerned that delayed discharges are not consistently identified and reported across the country and that the overall figure of 28% is an under-estimate.

The SAY report does not comment on or allude to the above issue. Another very significant, over-lapping, issue is only briefly referred to, namely that SCLD had previously identified 13 individuals receiving care within an independent hospital setting. Castlebeck care alone has 26 beds at Monroe house in Dundee.

We are, rightly, delighted that PWLD are no longer living in long stay NHS hospitals, but are very concerned about a creeping development of non-NHS long stay care. As well as Castlebeck, there are 2 other private hospitals providing care for PWLD, namely the Ayr clinic (Partnerships in care) and Surehaven in Drumchapel, Glasgow. The 2012 data almost certainly fails to capture all PWLD being cared for within private hospitals, the data suggests only 25 (Scottish patients) in Scotland and England. For completeness, faculty members know of at least another 9 patients being cared for by NHS England.

With regard to private sector care, another issue is, the number of PWLD managed within "residential homes". Castlebeck alone have 3 residential homes (with 40 beds), then there are a variety of other groups, e.g. Balhousie, Voyage care, Choices. We do not think that the proliferation of private residential homes is within the spirit of SAY and many of the concerns associated with long stay hospitals apply equally in these settings, not least dislocation from family, and concerns about governance and safety.

The financial outlay by both Health and Local Authorities for independent hospitals and private residential homes detracts from the ability of both to be able to deliver and develop appropriate services closer to home. There are numerous papers detailing this issue, particularly from England where the problem is proportionately greater.

The report briefly mentions specialist interventions for PWLD and complex/severe behavioural problems. The NES "positive behavioral support" (PBS) programme (2010) for LD nurses is described as an example of good practice, but sadly this did not get beyond pilot status and has never been rolled out.

With regard to PWLD within the criminal justice sector (as offenders), the report is vague stating "appropriate support" should be in place for PWLD leaving the CJS". Despite a high profile report ("No-one Knows" referenced within the report) there has been no action taken in Scotland to address the health/treatment needs of PWLD in prison. Prison healthcare is now the responsibility of the NHS, so hopefully this might change. Further studies of need in this area are not felt to be required and services now need to meet the challenge of providing care to this group.