

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

Please provide any comments, evidence and/or examples here

Overall welcome the majority of the findings but some highlighted areas not given adequate prominence:

- There is a lack of clarity in the report between adult, lifespan and children's services.
- No children or young people under age 20 were interviewed.
- Mental health/challenging behaviour were not given adequate prominence. Experience of working with families with children/young people with moderate to severe learning disabilities and mental health difficulties is that these families are usually isolated and exhausted and unlikely to take part in consultations and studies. Concern that the views and experiences of such families may therefore not be represented in this consultation.
- Long stay hospital closures are welcomed and positive. However, there was an unacknowledged lack of planning around the mental health needs of children, who rightly moved out first. Please see LD CAMHS Framework document for more information. Unfortunately, with unaddressed mental health needs escalating due to lack of accessible services for this group, some children eventually end up in out of area residential schools or hospitals out of Scotland.
- Improvements in education are unfortunately not universal in some experiences. In some areas education for those with more severe LD & autism is not well-developed and schools can struggle to meet the needs of those with mental health difficulties and challenging behaviour. This is particularly where inclusion policies appear to be taken to the extreme and there is a lack of flexible thinking about the needs of individual children. Some experience of problem arising where children and young people with complex but very different needs are mixed together, such as those with profound and multiple learning and physical disabilities with those with severe autism and mental health and/or behavioural difficulties. This can lead to environments and interactions that are extremely stressful to both groups.
- People may be asked what they want more than in the past, but some experience of where this might conflict with the views of the local statutory services about models of service provision. For example, a local authority view and plan that adults with learning disability should not use day centres, and so this type of provision is therefore not

available. However without adequate alternatives those families and closely-involved professionals may believe it to be necessary to meet their needs. Similarly, the limited available overnight respite/short breaks providers in some authority areas for children/young people. If what is available is not appropriate for the young person concerned, or they or their parents/carers want to access a different service, experience suggests this is rarely possible, and can lead to long and distressing 'campaigns' by the parents. In turn leading to unnecessary breakdowns in trust between families and local services, as well as conflicts between agencies with differing opinions.

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

Has gone some way towards raising the profile of the needs of people with learning disabilities across all areas nationally; and giving a voice to those people and their families.

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

On page 12 re: need for close joint working and joint commissioning. Some experience of local council having set ideas about what services should be provided, which can appear to be based on a model of 'inclusion at all costs'. Conflicting with health professionals suggestions, based on detailed mental health and behavioural assessments, as to the type of environment required for an individual (which may include all environments they access, including respite or outreach care). This can cause some conflict in inter-agency working and some experience where suggestions have been rejected if it does not fit the LA ideology of what should happen. Unfortunately, inappropriate environments can lead to increases in anxiety and challenging behaviour leading to risks of family and placement breakdown and necessitating the use of medication which carries its own risks. Experience of some patients who have the highest levels of challenging behaviour and families at most need of respite have no respite for these reasons.

Lack of understanding in some LA's/ services/ plans that the aim for all people with learning disability to access the community in the same way and using the same resources actually restricts the access of some individuals. This is particularly true for some individuals with one or a combination of severe learning disability, autism, sensory processing difficulties and/or mental illness. Busy, noisy environments with a lack of structure, routine and appropriate communication can increase levels of

anxiety, distress and consequently challenging behaviour which then restrict their ability to access community facilities and have an improved quality of life.

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

A number of developments in some Health Boards of LD-CAMHS within existing CAMHS where no service or referral pathways existed previously. Ranging from full multi-disciplinary services existing and integrated into CAMHS, to developments of services at various stages. These developments provides mental health services specific to the needs of children and young people with learning disabilities ranging from supporting and capacity building in existing CAMHS to providing a specialist multi-disciplinary service by clinicians with specialist training and expertise in LD-CAMHS. This also supports good transition planning with adult LD services for some of the more complex (mental ill health and/or severe challenging behaviours) young people with learning disabilities.

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

A number of Learning Disability nurses employed in Health Boards in CAMHS to facilitate access to services through bringing LD skills and providing nursing in specialist LD-CAMHS teams. A small group of LD-CAMHS clinicians developed the Scotland LD-CAMHS Framework document on behalf of the CAMHS Stakeholders Group, MH Division, SG; and developed a Scotland LD-CAMHS Network of predominantly health professionals working in or interested in developing this area of practice.

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

Mental health difficulties and challenging behaviour are major barriers to children and young people with learning disability accessing community services. This underlines the need for access to mental health services that can meet the needs of this group. Access to mental health services for children and young people with learning disabilities as described in answer to other questions is increasing and further needs have been identified in the Scotland LD CAMHS Framework document and Mental Health Strategy.

A careful look at the impact of changes in the Community Paediatrics workforce on access to healthcare for children and young people with learning disabilities. The current reviews of Community Paediatrics/Child Health and the ongoing development of 2 year old health checks and follow up from these need to be linked into 'the same as you?' review. The role for Neurodisability Paediatricians should also be considered in all areas. As could the potential role for LD Nurses in paediatric settings.

The need for support in early years for challenging behaviours associated with learning disability/ neurological conditions. Current experience of some areas having lifespan CLDT services which meet this need; some areas having T3-4 LD-CAMHS but the need not addressed in T2 services; some areas this need is addressed in T2 paediatric services.

The work developing Liaison Learning Disability Nursing services for adults needs to be extended in all areas to children and young people. There is often an assumption that health needs of children are better met and co-ordinated, but this is often not the case. In some areas access to medical assessment and treatment is particularly a problem for those with severe challenging behaviour, particularly where communication difficulties prevent people from directly expressing their symptoms.

Ensuring adequate follow up from a medical and social care perspective when a child is identified at birth with a disability so that people do not get lost to the system and present in crisis.

Training of all healthcare professionals should address the needs of the population of people with learning disabilities e.g. training for hospital staff in making end of life decisions for people with LD as this is an aspect training that staff don't currently receive; all training should ask the question "and what if the person has a learning disability?" to focus awareness across all areas.

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

Better liaison and joint working between mental health services and education to reduce the impact of mental health difficulties and challenging behaviour on the children's access to education.

Having alternative forms of education available rather than a standard system for children with specific learning difficulties.

Transitions - not just post school but also primary to secondary need adequate planning and support.

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

Better early assessment and intervention (i.e. from early childhood) for those with 'challenging behaviour' and/or mental health problems would help prevent these becoming entrenched. These are major barriers to some people to independent living and access to community facilities.

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

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

Mental health services for children and young people with learning disabilities are included in the recently published Mental Health Strategy for Scotland as a priority area. This followed on from a document circulated by the Scottish Government last year giving advice on how the CAMHS Framework (2005) should be implemented to meet the needs of children and young people with learning disabilities. A study of service models and their outcomes is planned in collaboration with the Scotland LD CAMHS Network and Glasgow University. It is important that the need for appropriate access to mental health services for children and young people with learning disabilities are reflected in 'the same as you?' and that these 2 important elements of both strategies are linked. This could come under the priority area of 'children and young people' and/or the 'reduce health inequalities' priority area. It should be noted that interventions to meet mental health needs do not just come from health services.

Social and leisure opportunities for children and young people with learning disabilities, particularly for those with moderate to severe learning disabilities and mental health difficulties/challenging behaviour. A particular focus is required on better access for those with the most complex/challenging behaviour and mental health needs to short breaks which also provide respite for their families.

Better dialogue and joint planning between the various agencies involved in the lives of children and their families (at both local and national level).

Better clarity as to where nationally and locally the needs of children and young people with learning disability are considered and services planned for. They are included in 'the same as you?' in part, but it is not clear (where services for 'people with learning disability' in fact refer to services exclusively for adults). Particularly within health services, this can lead to confusion and even assumptions that services exist for children when, in fact they don't. An example of this is in the 'Assessment and treatment places' section on page 10 of the consultation report. This recommends a reduction in assessment/treatment places for people with learning disabilities. There are, in fact no Psychiatric assessment/treatment units accessible to young people aged 12-16 in Scotland with severe and profound learning disabilities and limited/patchy access for this group aged 16-18 or for those with moderate learning disability aged 12-18. More information is available regarding this in the LD CAMHS Framework document report (ref). Unfortunately, this is not due to good alternative intensive community services, which are only in their infancy in one or two Scottish Health Boards.

Within the priority area of 'children and young people', need to include much more of a focus on mental health in its broadest sense. Early years section should also include learning-disability and autism specific early advice/interventions, e.g. in the areas of parenting, sleep and behaviour management. There should be a focus on those with indicators of potential later severe difficulties, for example early repetitive behaviours, self injury and hyperkinesis. Positive reactions to the birth of children with disabilities needs to be matched by regular follow up and honest and realistic evaluations of their needs as they grow and appropriate interventions

offered.

The Scotland LD-CAMHS Framework document and a conference report (to be issued by SG soon) should be referred to for more detail on mental health needs and gaps in provision for children and young people with learning disabilities.

Priority: 'joint commissioning appropriate local support to improve outcomes for people with learning disabilities whose behaviour challenges services' – we would very much endorse this as a challenge, which should be a priority area. It is important that this is an area that applies to children's as well as adult services and should include early intervention/preventative services.

In some areas there appears to be a gap in knowledge in Children's Services regarding the Adults with Incapacity Act. This can lead to families not being informed in a timely manner about the need to consider Guardianship for those between the ages of 16 and 18. Health, Welfare and Financial decisions can therefore be made for some young people without informed consent and outside of the required legal framework. Experience of where it would be inappropriate for families to take on the responsibility of Guardianship, Local Authority Children's Services are often reluctant to take this on and leave decisions to adult services, with a 2 year gap with no legal Guardian.

Active promotion of the development of social and leisure activities for children and young people with disability but particularly learning disability as it has wide ranging effects not just on teenagers but middle childhood youngsters, especially as they become aware of and experience difference in access and availability of activities. Project based approaches are helpful but not sufficient –there is a need to have something more substantial, integrated into local authorities/ third sector.

Lack of emergency respite or crisis support is often a significant problem - not just planned respite.

Policy, planning and development of all healthcare should address the needs of the population of people with learning disabilities by asking the question "and what if the person has a learning disability?" to focus awareness across all areas.