

## 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  
The evaluation does reflect the issues for people with learning disabilities and their carers and to quote from page 58 "the principles and direction of travel established by 'The Same as You' remain fit for purpose." The major issues are identified with updated progress on what has been achieved and what still remains a problem. The evaluation also begins to set 'The Same as You' in the context of on-going Scottish Government strategy and policies such as Getting It Right for Every Child.

**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  
Taking a population perspective, over the past 10 years there has been a greater acceptance and inclusion of people with learning disability, although more remains to be done. The closure of long stay learning disability hospitals has brought more people with learning disability into communities and increasing provision of college and employment opportunities has raised their visibility. There has also been a move towards greater and more sympathetic portrayal of people with learning disability in the media, with para-sports also giving positive role models.

As the RCPCH is the representative body for Paediatricians this response will concentrate on the health care needs of children with learning disability and their families.

There has been increasing recognition of the importance of listening to the views of children (including those with learning difficulty) and their families in the designing and review of services. All Paediatricians in future will be required to provide information on patient opinion of their services.

Over the time period advances in diagnosis, particularly in the field of genetics, has made it more likely that families will be given an reason for their child's learning difficulties, whereas previously the cause was often unknown. The internet has made it easier for support groups to disseminate information and link up families with children with similar problems (although advice does need to be given on which are the most helpful sites and information from unofficial sites should be viewed with caution).

The strategic guidance from the Scottish Government has been strongly towards inclusion, joined up working and early intervention. The ethos of multiagency and multidisciplinary working in teams continues to be strengthened, with community children's nurses playing an increased role in

supporting these families. This can make services more flexible and responsive to the needs of families of children with learning difficulties.

Many children with learning difficulties are now in mainstream school placements and with support are doing well. Some parents are particularly pleased that their child is integrated within this environment, often in the same school as their siblings.

There has been a strong move in Scotland to strengthen care in Paediatric Specialties through National Managed Clinical Care Networks. The Network for Children with Exceptional Healthcare Needs has been very useful in collecting information, disseminating good practice and providing support to 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

Although the national strategy is for joined up working and this is preference for most of the professionals working with children with learning disability, the realities of a hard-pressed workforce with competing demands and limited resources often means that care can be increasingly fragmentary and multiagency working more difficult than previously.

The medical needs of majority of children with learning disability in Scotland are currently mainly provided by Community Paediatricians, many of whom also undertake a significant care-co-ordination role. This workforce is aging with three-quarters being over the age of 50 years. Few trainees are specifying an interest in Community Paediatrics and many vacant posts are unfilled. Although there is now a move to provide some Community Child Health training for all Paediatric trainees, many of the General Paediatricians currently in post have not had this experience. The Scottish Government commissioned a report 'Community Child Health for the 21<sup>st</sup> Century' to look at this, but its publication is awaited. It is possible with the imminent loss of a significant percentage of the workforce that medical services for children with learning disability and their families will deteriorate. A reconfiguration of services is required and many of the roles previously undertaken by doctors could be taken over by specialist nurses. This will, however, require the nurses to be adequately trained and supervised and this will have resource implications.

Although some children with learning difficulties thrive in mainstream school, others have greater difficulty. Schools may lack the resources to provide the additional support needed and some parents report greater difficulties in accessing therapies than in special school environments. A successful compromise in some cases appears to be for the child to attend special school but have some sessions in mainstream. Co-ordinated Support Plans can be useful, but the experience of some parents is that the process can be hindered and delayed because of competing demands of the professionals involved and workload pressures.

Transition is highlighted in the document as the major problem area and this

continues to be the case. Often parents are well supported until their child leaves school. In some cases, particularly in children with more severe difficulties, care is almost exclusively provided by paediatric services, with little input from Primary Care. Adult medical services are patchy for People with Learning Disability and tend to not provide the holistic approach of Paediatrics. When the child leaves paediatric services, parents often feel abandoned and the General Practitioner may be faced with a complex young person with multiple needs whom they have previously not cared for.

Many children with Learning Difficulties have problems with behaviour and this can be the biggest difficulty for families. This is recognised in the document but access to Learning Disability Child and Adolescent Mental Health Services is still patchy and families are left with limited support.

Respite is a life-line for some families with children with Learning Difficulties. Although much has been done in this area, adequate provision is still an ongoing issue. The document says relatively little about the needs of siblings of children with Learning Disability, some of whom adopt a young carer's role.

### **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 RCPCH continually reassesses and evaluates its training of future Paediatricians and it is now possible for doctors in training to competitively apply for Grid training in Neurodisability. The doctors completing this programme will have specific expertise in working with children with learning disability. Trainees now also have to explicitly demonstrate with evidence that they have the specific competencies to work at Consultant level. In addition, all Paediatric trainees now undertake a minimum of 6 months of work in community child health, which provides training in the assessment of children with learning disabilities and gives experience of the services available for these children. This will ensure that Paediatricians at all levels will have greater understanding and experience of children with learning difficulties.

The RCPCH has recently produced a Report from the Children and Young People's Health Outcomes Forum for the Department of Health. This recommends that the RCPCH work with the Royal College of Physicians to ensure that health outcomes and experience for transition are improved. In England, they also recommend that NICE produce a quality standard for age and developmentally appropriate care of teenagers and young adults including through transition.

The RCPCH has a youth advisory panel to garner the views of children and young people and provides a guide to the participation of children and young people in Health Services.

### 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

Many RCPCH members have instituted local initiatives. In my area, we have set up a specialist health visitor led multidisciplinary clinic for children with neurodisability (including more complex learning disabilities). The children remain with their General Paediatricians (who have varying amounts of formal training in neurodisability) but co-ordination of care is done through the multidisciplinary clinic. Reports are issued under GIRFEC headings and user opinion has been audited. Similarly, children with Down's Syndrome remain with individual Paediatricians but the Specialist Health Visitor has developed a pathway that co-ordinates screening and referral to other disciplines and agencies to ensure equity of care.

### 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

Improved training for staff in the needs of people with learning disability – in the example given in Q4, increased training of all paediatricians should improve the experience of families around diagnosis and in on-going care. Diagnosis should be given by a senior Paediatrician with appropriate communication skills and knowledge.

Review and re-organisation of Community Paediatric services to ensure that children with learning disability continue to be reviewed by professionals familiar with their issues and who are able to co-ordinate their care. Services should be equitable throughout Scotland.

Work at local and national level to strengthen and clarify the transition process from children's to adult services.

Continued development of a multidisciplinary team approach to these children and their families, with tasks being undertaken by the most appropriate professional. This needs sufficient resources to enable this approach and prevent it suffering under competing demands.

Provision of adequate and equitable Learning Disability Child and Adolescent Mental Health Services.

Provision of developmentally appropriate health care information.

### 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

**A review of the experience of families of children with Learning Difficulties to assess the optimum balance between mainstream education and special schooling provision.**

**The Doran review is being undertaken to look at provision for children with more complex needs.**

**Ensuring all young people with Learning Difficulties have the opportunity of further education after school leaving if they wish. Recent anecdotal reports suggest that some colleges may be limiting places under financial pressure.**

### 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

### 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

1. Provision of Community Paediatric services in Scotland – the imminent workforce crisis has the potential to cause deterioration in quality of service to children with learning disability and other disabilities.
2. Enabling multiagency and multidisciplinary working at a local level (which includes seeing this as a priority amongst competing demands and providing resource for this).
3. Respite care
4. Transitional care

5. More equitable provision of Learning Disability CAMHS services
6. Support of siblings