

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, progress has clearly been made in relation to societal and professional attitudes toward, and treatment of, children and young people with learning disabilities. However, this progress has been inconsistent/patchy in terms of implementation of policies/services/support and the lived experiences of the intended beneficiaries of them across Scotland. There continue to be differences along geographic, socioeconomic and situational (e.g. type of learning disability) lines. Some goals of *The same as you?* – while remaining as valid and important as ever – continue to be honoured more in rhetoric than in reality.

Still, the fact that there *are* clearly articulated, and officially endorsed and enacted, high aspirations and good intentions about children and young people with learning disabilities have had the positive effect of establishing a widely agreed direction of travel and a more robust, positive vision of what ‘success’ for the generation growing up in Scotland now than used to be the case.

Examples of the promising direction of travel can be found in the development (since *The same as you?* initiative was launched) of such landmark laws and policies in Scotland as the: Additional Support for Learning (ASL) Act in 2004 (as amended in 2009); the Getting it right for every child (GIRFEC) model/approach to integrated, holistic, child-centred planning and service delivery; inclusion and diversity priorities within Scotland’s Curriculum for Excellence; and, the Early Years Framework (and now, the Early Years Collaborative).

These, in turn, have generated a variety of excellent programmes, groups and activities that are becoming ever better vehicles for delivering the goals of *The same as you?* Even just within Children in Scotland, Enquire (the national information and advice service on ASL), Resolve: ASL (the nation’s largest education mediation service) and Access All Areas (a pupil consultation and inclusion project with the Scottish Borders Council) have all been launched in the aftermath of *The same as you?* We would be happy to provide detailed information about any of these activities benefitting children and young people with learning disabilities.

We also are optimistic about the potential impact of such new or forthcoming developments as the Scottish Government’s National Parenting Strategy, the Children and Young People Bill that will be introduced at the Scottish Parliament during 2013 and the implementation of recommendations from the Doran Review. All of these, as well as such bodies as the national Advisory Group of Additional Support for Learning (AGASL) and the possibilities inherent in such new groups as *for Scotland’s Disabled Children* (fSDC) bode well for improving the wellbeing and rights of children and young people with learning disabilities.

The continuing challenge is one bringing about the broader cultural and attitudinal changes needed across Scottish society. Progress has been made, but more is needed. From improving the initial education/socialisation of professionals who may end up working children and young people having learning disabilities, to promoting practical efforts to encourage greater empathy, sense of social justice and emotional literacy among children and young people, the cultural and attitudinal changes needed will result from action as well as patience.

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

Please see our answer to Q1.

In addition, we would like to note that numerous member organisations of Children in Scotland have been making a difference for the better for children and young people with learning disabilities – and many continue to go from strength to strength (despite difficult financial times). To cite just one of several possible examples, there has been a sea change since *The same as me?* was launched in 2000 in understanding, attitudes and practical assistance for children and young people with autistic spectrum disorder. While much remains to be done, it seems indisputable that the lives and life chances of these children and young people are much better now across Scotland.

One other powerful and relevant change during this period is the ascension of a children's rights ethos and infrastructure within Scottish society. From the creation of Scotland's Commissioner for Children and Young People (which has undertaken valuable work around the rights and wellbeing of disabled children and young people) to the maturation of such voluntary sector groups as the Children's Parliament and Together (formerly the Scottish Children's Rights Alliance), there is a strengthening network of groups who are making the United Nations Convention on the Rights of the Child (UNCRC) much more than a marginal talking point. This growing commitment to 'make rights real' has been both echoed and advanced by the policies and actions of the Scottish Government over these years. It is hoped that the forthcoming Children and Young People Bill to be introduced at the Scottish Parliament in Spring 2013 will both reinforce and propel this trend.

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

There is one issue that seem not to have received as much attention (and, therefore, not as high a priority) as it deserves in *The same as you?* documents. This is a reference to the meaning of the Scottish Parliament's and Scottish Government's new emphasis on 'preventative spending' in the context of, and as it applies to, children and young people with learning disabilities.

There are numerous examples of primary and secondary 'prevention' that still need to be addressed in Scotland. For instance, there continues to be little understanding of, or meaningful action, in Scotland around *preventing* fetal alcohol harm – which has been identified as the most common known cause of learning disabilities:

<http://www.childreninscotland.org.uk/docs/EYFbriefingsFetalAlcoholv5.pdf>

While potentially 100% preventable, it is not, in fact, being prevented in our nation. As a result, the conservative estimate is that approximately 10,000 children and young people (0-18) in Scotland are affected by this type of brain damage. And, because those affected are not as immediately identifiable as children and young people with, for example, Down's Syndrome, there is a continuing problem with misdiagnosis and inadequate management/support.

In terms of secondary prevention, there is not enough effective action being taken to reduce the frequency and severity of 'bullying' and other negative peer relationships between children and young people with learning disabilities and those without them. The diminution of bullying would prevent one set of challenges for people with learning disabilities from being exacerbated and turning into more, and sometimes more severe, physical, emotional and mental health problems that could have averted.

Children in Scotland also completed a research project for NHS Health Scotland in 2011/12 that is of relevance to this consultation (but not cited among the references). It was a study of the experiences, views and recommendations of three groups of marginalised parents of young children (young mothers, fathers and parents with literacy issues)[See: <http://www.childreninscotland.org.uk/docs/19013-RE001ExecSum.pdf>]. One of the points stressed by parents across all three groups was a strong (largely unmet) desire/need for information about parenting and child health that is personalised and delivered through strong relationships of mutual trust and respect between parents and professionals.

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

Again, please note our answer to Q1.

Children in Scotland hosts Enquire - the national advice service for additional support for learning, and Resolve: ASL, Scotland's largest independent education mediation service. We also have operated a relevant awareness raising and pupil consultation project in the Borders for the past decade (Access All Areas).

Enquire is for parents and carers of children and young people with additional support needs, children and young people themselves, as well as the professionals working with them. It offers advice and information through a helpline that can be contacted by telephone, email or via the Enquire websites. It also produces a range of publications. See <http://enquire.org.uk/>

RESOLVE: ASL is the largest education mediation provider in Scotland and assists local education authorities in meeting the mediation requirements in the Education (Additional Support for Learning) (Scotland) Act. Some of these cases involve children and young people with learning disabilities. Resolve: ASL also offers workplace mediation.
http://www.childreninscotland.org.uk/html/serv_res.htm

Since 2003, Scottish Borders has funded Children in Scotland to carry out Access All Areas – a children's rights and equalities project. Its aim has been to consult meaningfully with children and young people in order to:

- raise their awareness and understanding of 'accessibility' and 'additional support needs';
- find out how accessible and welcoming they think their schools are;
- explore what they think does and does not work in terms of making their school a friendlier and more inclusive place; and,
- . gather and share their views on what could and should be improved.

See: http://www.childreninscotland.org.uk/html/par_acc.htm

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

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

One answer is to safeguard the future of the laudable improvements that have been made over the past decade in improved healthcare for children and young people with learning disabilities. Many of these were highlighted in the research that informed the Scottish Government's three reports here. It is vital that these services, organisations and supports are strengthened and expanded as Scotland moves forward, rather than continually battling for sustainability and having to fend off attempts to shrink, weaken or eliminate them by pursuing false economies.

Another key is to deepen the appropriate kind support for the mothers/fathers/carers – and extended families -- of children and young people with learning disabilities (including young carers and kinship carers). A project conducted by Children in Scotland – and funded by the Esmee Fairbairn Foundation – revealed that many parents of babies and young children born with disabilities experienced two different realities. On the one hand, they received a great deal of welcome and useful professional support for their children from a wide variety of professionals (primarily within the health and allied health professions). On the other hand, many felt marginalised as parents by all this professional attention – and perceived themselves as having been reduced to the roles of 'chauffeur' and 'appointment scheduler' in relation to their own children. This is not the best that could and should be done.

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

There are four steps that would greatly increase the chances of these children and young people receiving, and benefitting from, better educational opportunities:

1. Full, consistent and appropriate implementation of the Additional Support for Learning Act throughout Scotland.
2. Full, consistent and appropriate implementation of Scotland's Curriculum for Excellence at the pre-school, primary school, secondary school and special school levels – especially the diversity, health and wellbeing and inclusion elements of CfE.
3. Better and earlier planning for, and implementation of, the transitions from: home to pre-school; pre-school to primary school; primary school to secondary school; and, secondary (or special) school to adulthood, adult services, further education and/or employment.
4. More robust implementation of children and young people's UNCRC rights, including the right to be heard and taken into account in the decision-making and implementation processes around their education and transitions.

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

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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