

Children in Scotland

every child - every childhood

Towards an autism strategy for Scotland

Response from Children in Scotland to Scottish Government consultation

Children in Scotland is pleased to respond to the above consultation. We recognise the difficulties faced by many people with autistic spectrum conditions, and the frequent lack of responsiveness they experience in accessing appropriate advice and support. We have, however, opposed the creation of any 'hierarchy' implying preferential status for certain conditions and disabilities, or 'ranking' of plans and intervention strategies which might result in some children and adults being deemed to have a lesser entitlement to appropriate help.

As far as children are concerned, we believe that the 2009 Additional Support for Learning Act, if fully implemented and properly resourced, has provision to ensure that children are diagnosed, assessed consistently with the principles of GIRFEC, and supported effectively. We are aware that too often the experience of children and families differs from this. Obtaining a diagnosis can be difficult and involve a long wait. Without a diagnosis, however, a child's access to appropriate assessment and support is frequently compromised. Even when a child has been diagnosed and assessed, there are often difficulties in making sure that they receive the support they need, as services across Scotland are patchy and inconsistent. Children in Scotland manages and operates *Enquire*, the national ASL help and advice service. These concerns are frequently raised by parents who contact the service.

There is, furthermore, a high correlation between autism and mental health problems in childhood. This, coupled with the stress placed on families coping with the condition, means both that outcomes for the individuals affected are often negative and the social cost of failing to support them high (for example because of the high percentage of adults with autism who are unable to access the labour market). For these reasons we support the introduction of a national strategic approach for adults. For children, we urge that the ASL Act, the Early Years Framework, and GIRFEC are fully resourced and implemented.

Diagnosis of an autistic spectrum disorder now frequently takes place in early childhood – before the age of two (around eighteen months would generally be the earliest point) in some cases, and usually by the age of three. The Scottish Government's Early Years Framework aims to deliver "a renewed focus on 0-3 as

the period of a child's development that shapes future outcomes". It is essential that the particular needs of children who need extra, and often specialised, help are effectively addressed during this critical period. All children are assessed by a Health Visitor between birth and six to eight weeks, at which point they are allocated to a Health Plan Indicator. The vast majority of families are allocated to the 'core' HPI, meaning that future contact with the Health Visitor will, by and large, be parent-initiated. Autistic spectrum conditions will, therefore, not be evident at the point the HPI allocation is made. As diagnosis is usually a prerequisite of receiving services under the ASL Act, as outlined above, this may compromise the ability of a family to access appropriate provision for their child at an early and critical stage in her/his development. The Strategy references the ASL Code of Practice (Page 6, Section 9) and notes the duty placed on NHS Boards to adhere to the Code. Current procedures limit their ability to do this, thereby making it difficult to ensure not only early support, but also appropriate preparation for the child's transition to nursery education and beyond. Proposals to improve waiting times and diagnostic methods are of great importance, but it must be noted that for some families the first step on the diagnostic pathway is missing. For this reason, we welcome the inclusion of primary care staff in the distribution of improved information, though if no primary care staff are in contact with the child their ability to use the information to deliver practical help is limited.

We note the many examples of good practice and positive parent and child experience cited in the document. This underlines that the problem is not a lack of knowledge of what works. Ensuring access to best and most responsive practice should underpin the development and implementation of the strategy. While this will include the support and further development of specialised services, it is also important that staff in mainstream health, education and childcare settings have sufficient knowledge and understanding to work in an inclusive way with children with ASD. Children in Scotland's recent 'Working for Inclusion' report highlighted the difference that can be made in terms of inclusion (<http://www.childreninscotland.org.uk/docs/WFIreport25Jan10.pdf>) by more effective service integration and pedagogical approaches.

Coherence with the Curriculum for Excellence is, of course, important, but only comes into effect from three years of age. As we have stated above, however, the birth to three period is critical to later development. It is therefore of some concern that the complementary 'Pre-Birth to Three' document, recently published by Learning and Teaching Scotland makes no mention of ASD. This does not reinforce the intention that GIRFEC, specifically referred to in the consultation document, will put in place the right provision for each child.

Children in Scotland broadly supports the recommendations contained in the document. We see their potential for contributing to improved diagnosis, increased user involvement and public awareness, enhanced access to and delivery of services and better outcomes. We urge, however, that the needs of

children, particularly pre-school children, with ASD are fully taken into account in the implementation of all of the recommendations. We are also concerned that they focus largely on inputs without any indication of the intended impact or outcomes.

Children in Scotland is Scotland's national agency for organisations and professionals working with and for children, young people and their families. It exists to identify and promote the interests of children and their families and to ensure that policies and services and other provisions are of the highest possible quality and are able to meet the needs of a diverse society. Children in Scotland represents more than 450 members, including 90% of Scottish Local Authorities, all major voluntary, statutory and private children's agencies, professional organisations, as well as many other smaller community groups and children's services. It is linked with similar agencies in other parts of the UK and Europe.

The work of Children in Scotland encompasses extensive information, policy, research and practice development programmes. The agency works closely with MSPs, the Scottish Government, local authorities and practitioners. It also services groups such as the Cross Party Parliamentary Group on Children and Young People (with YouthLink Scotland). In addition, Children in Scotland hosts Enquire - the national advice service for additional support for learning, and Resolve: ASL, Scotland's largest independent education mediation service.