



Down's Syndrome Scotland

helping people realise their potential

Education and Culture Committee
Room T3.40
The Scottish Parliament
Edinburgh
EH99 1SP

Friday 26th July 2013

Dear Convener,

Call for Written Evidence - Children and Young People (Scotland) Bill

Down's Syndrome Scotland welcome the opportunity to respond to this call for evidence from the Education and Culture Committee of the Scottish Parliament. As a charity, we work to improve the quality of life for everyone in Scotland with Down's syndrome and their families. Therefore we have a particular interest in the proposed changes outlined in the Children and Young People (Scotland) Bill which has the potential to improve the lives of children with Down's syndrome by ensuring that their rights are being taken seriously.

Ideally Scotland should be a place where the needs of children and young people with Down's syndrome would be systematically encompassed in any new legislation and its ensuing practice. But the reality is that their interests still need to be supported and promoted by organisations like Down's Syndrome Scotland so that their voices can be heard by politicians across the country and practitioners reminded that children and young people with Down's syndrome are included in the legislation.

1. Firstly, Down's Syndrome Scotland welcome the Bill's Policy Memorandum to put children and young people at the heart of planning and delivery of services and to ensure their rights are respected. We also support the duty on the Scottish Ministers and public authorities to promote awareness of the rights of children. Nevertheless we are of the view that the United Nations Convention on the Rights of the Child (UNCRC) should be fully incorporated into Scots law to guarantee the protection of children's rights throughout the country.





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2. To ensure Scotland is the best place for children to grow up in, their rights should be respected and protected across the entire public sector. Whilst we recognise the duties imposed by the Bill on certain public bodies (as presented in Schedule 1 of the Bill) to promote awareness of the rights of children, we are of the view that the Bill should lay stronger emphasis on the requirement for all service providers/public authorities to effectively demonstrate that they have considered the UNCRC and responded to it by adapting support and services accordingly.
3. Then, we fully support the Bill's provision to increase the powers of Scotland's Commissioner for Children and Young People (SCCYP) and we note the financial implications for these proposals as presented in the Financial Memorandum. However, a clear remit of this role is still needed which clearly outlines the work and new powers of the SCCYP in relation to other legal institutions (like the courts) in Scotland. Furthermore, we would seek clarification on the way the Scottish Government intends to present and promote the SCCYP's new role to children and young people, specifically to children and young people with Down's syndrome, and the associated costs. We would also suggest that this issue could be partially addressed by working in partnership with organisations whose constituencies include children and young people with learning disabilities.
4. As far as the Child's Plan is concerned, we welcome the single planning approach proposed for children with additional support needs but the Bill does not outline how to actually make it work in practice. This is a concern given that at present the quality of services available to children with Down's syndrome and their families considerably varies across Scotland. On one hand, as noted in the *Analysis of Responses to the Children and Young People Bill Consultation*¹, one should be aware that the provision of more services may result in services of poorer quality and it is crucial to ensure that this does not happen. On the other, we are currently dealing with significant issues with regard to the great disparity in the range of services provided by local authorities. As an example, a single mother of five children, two of whom have Down's syndrome, is receiving 4 hours of support weekly in one local authority, while another mother with one child with Down's syndrome is being offered 15 hours of support per week in another local authority. Furthermore, members of our Family Support Team have seen some examples of excellent practice within Education, but they are also raising serious concerns about the

¹ See <http://www.scotland.gov.uk/Resource/0040/00409290.pdf>





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implementation of Coordinated Support Plans (CSPs) and Individual Educational Plans (IEPs) and the amount of support offered to children with Down's syndrome in mainstream schools. In one local authority, parents have been told that there are not enough support workers to help a child with Down's syndrome going into a big class (a class of 25 which is permissible in P1). Further, even if there is support available, they will not know that until the child begins school in August. This is a very difficult and upsetting situation for parents. In another area, there is no support at all in some cases, while in a fifth local authority composite classes of P1/P2/P3 make the situation of children with Down's syndrome extremely difficult.

In relation to secondary school education, while we do not have information from across the country, we are aware that transition between primary and secondary remains difficult for schools to implement because of other pressures. In fact, one of our Family Support Officers was informed by the principal teacher of support in one local authority that secondary teachers are too busy to make the child a priority because they are under stress with implementing the Curriculum for Excellence! Clearly this is a worrying and stressful time for children and their parents when they should be receiving the support they need wherever they live in Scotland.

5. It is also important to note that cooperation and coordinated services are critical during transition periods for children with Down's syndrome (e.g when a child is starting or leaving school). As already outlined by Susan Deacon in her report *Joining the Dots*² (<http://www.scotland.gov.uk/Resource/Doc/343337/0114216.pdf>, from page 9), there is strong evidence available showing that investing in early years and early intervention is essential for a child's development. Two years after the publication of this report, serious problems still persist with regard to early years support and we believe that legislation is now urgently needed to ensure that transitions are planned properly. In fact, transparency and accountability are key in strengthening the provision of early years support and childcare, even more so for children with Down's syndrome. Monitoring the implementation of the proposed change will thus be crucial. Whilst we recognise the duties imposed by the Bill on local authorities and health boards to publish reports on progress on children's services plans every year and the possibility for Scottish Ministers to act if local authorities and/or public bodies fail to carry out these duties, we feel that more provisions should be included

² See <http://www.scotland.gov.uk/Resource/Doc/343337/0114216.pdf> (from page 9).





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in the Bill about the monitoring of new policies and services. We strongly believe that the views of children, parents and carers with lived-experience must be collected and assessed in order to comprehensively evaluate the work of local authorities and public bodies, and the services children and their carers are entitled to receive.

6. Then, the concept of the 'named-person' outlined in the Bill remains unclear and more guidance is needed on this issue. In particular, we believe that more consideration should be given as to what this role will precisely entail in relation to the Child's Plan and whether appropriate resources will be made available for it. As a charity supporting the interests of individuals with Down's syndrome, we are particularly concerned about the fact that a named-person could be a head teacher within a school. Being a named-person as well as a teacher would not only increase teachers' workload but we would also question the resources available to them as a named-person for what may be large numbers of pupils. For example, we are not convinced that teachers would have time to deal with the care coordination programme appropriately. In our opinion, problems are also likely to arise during school holidays, especially over the summer, when teachers and pupils are away from school over an extensive period of time. With regard to this point, it is also worth mentioning that education is not always a positive experience for children with Down's syndrome and we would question what alternatives would then be offered to families in need of support if their child is not going to school. Lastly, if this concept is implemented, we would suggest that a 'named-person' should be appointed until the age of 25 years for individuals with Down's syndrome. Local authorities should then be made accountable for providing such a service systematically for young people with Down's syndrome; this would ensure that individuals do not have to go through what might be a lengthy process (potentially leading to a temporary suspension of the service provided) of requesting the service to be continued after they turn 18.
7. Finally, we warmly welcome the proposed changes to offer more support to kinship carers.





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We trust these comments assist the Committee with its enquiry. Please do not hesitate to contact our office on 0131313 4225 or by email at sarahvp@dsscotland.org.uk should you have any question.

Yours sincerely,

Pandora Summerfield

Pandora Summerfield
Chief Executive
Down's Syndrome Scotland

