JCHR legislative scrutiny priorities for 2012-13: call for evidence

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Introduction

Every Disabled Child Matters (EDCM) is the campaign for rights and resources for disabled children and their families. EDCM is a consortium campaign run by four of the leading organisations working with disabled children and their families: Contact a Family, the Council for Disabled Children, Mencap and the Special Educational Consortium. The campaign has over 35,000 supporters, the campaign partners represent over 770,000 disabled children and young people in the UK, and our Campaign Network is made up of 75 organisations from across the disabled children’s sector.


In September 2011, pathfinder activity got under way. 20 pathfinders started to test out the ideas in the Green Paper, including the single assessment and plan. Pathfinder activity is being supported and evaluated to inform the development of the Government’s proposals.

On 9 May 2012, the Queen’s Speech announced a Children and Families Bill. A draft Bill will be published for consultation in September 2012 and for pre-legislative scrutiny in autumn/winter 2012. It is expected that the Bill will be introduced to Parliament early in 2013 and is expected to be ‘carried over’ into the next Parliamentary session, receiving Royal Assent in early 2014.

On 15 May 2012, the Government published its *Next Steps* document, *Support and Aspiration: a new approach to special educational needs and disability: Progress and next steps*. The *Next Steps* document provides summaries of the responses to the Green Paper consultation; it sets out the progress made since the publication of the Green paper; it fleshes out aspects of the proposals that will be in the Children and Families Bill; and reports on the Government’s next steps in relation to other SEN reforms.

Disabled children and young people’s right to participate

Opportunities for children and young people to participate in decisions and issues that affect them have increased significantly. However, this is not the case for disabled children and young people, particularly those with complex needs and communication impairments, despite them being disproportionate users of support services in health, social care and education settings.
Disabled children and young people have the same rights as non-disabled children and young people to participate in decisions and issues that affect them. This is outlined in both Article 12 of the UN Convention on the Rights of the Child (UNCRC) and in Article 7 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Despite this, disabled children and young people continue to face significant barriers and challenges to participation.

The Children and Families Bill presents an opportunity to enhance the protection of these rights for disabled children and young people. However, EDCM is concerned that the ‘Support and aspiration’ policy proposals do not give sufficient importance to the voice of children and young people and their right to participate is not currently being respected in the process of shaping the Children and Families Bill. ‘Support and aspiration’ states that a Young People’s Advisory group will be established to help shape the next stages of reform and drive young people’s participation at a local level. However, there is no further reference to this group or how it is to be involved in the document and there has been no further information about its development. This raises concerns about the priority of the voice of children and young people in the current proposals.

**Opportunities in the Children and Families Bill to enhance protection of human rights**

EDCM believes that the views of children and young people with SEND should be taken into account in relation to their own single assessment process, Education, Health and Care Plan and should have a strategic role in determining what is available through the Local Offer. Local agencies should demonstrate the way in which disabled young people have been able to take ownership of their own Education, Health and Care Plan and, where relevant their personal budget.

EDCM welcomes the proposals to pilot claims and appeals being made to the Tribunal by children and young people themselves. This is an important proposal that has already been consulted upon. There may be helpful learning from the Scottish experience of children and young people making claims under the disability discrimination legislation. EDCM is pleased that there is now the potential for these proposals to become a practical reality.

**Human rights issues raised by the Children and Families Bill**

EDCM believes there are insufficient references to the importance of the voice of children and young people, and there is no focus on their wishes and aspirations in the proposed assessment and planning processes within the *Support and aspiration*
and Next Steps proposals. We are concerned that this undermines the Government’s aspiration to create a more personalised approach to service provision.

EDCM welcomes the government’s commitment to the principle of ‘no decision about me without me’ in health and social care. This principle should cover all public services and we expect government, in view of its duties under the Equality Act 2010, to be committed to implementing this with equal effect for disabled young people.

The ownership of their own Education, Health and Care Plan by disabled young people raises issues about the balance between the views of the child and those of their parent or carer. These are complex issues but have to be addressed to ensure that the child or young person is at the heart of the planning process and that the views of the parent are taken into account and valued.

EDCM is also concerned that unless the insights of children and young people are central to assessment and planning and making support and services more personalised, proposals to pilot children and young people making claims and lodging appeals in their own right may founder. If children and young people are not significantly included in the assessment and planning process from the start, it will be difficult for them to come in at the end with an appeal or a claim.

For further information please contact Peter Hardy, EDCM Campaign Assistant, at peter@edcm.org.uk or 020 7843 6082.