



The
Children's
Society

Consultation: A National Framework for Assessing Children and Young People's Continuing Care

The Children's Society's response

28th December 2008

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The Children's Society is a leading national charity, driven by the belief that every child deserves a good childhood. The Children's Society operates around 60 projects across England, working mainly with disabled children, children at risk on the streets, children in trouble with the law and young refugees. Much of its work is conducted in association with local authorities in line with the Government's *Every Child Matters* approach to the wellbeing of children and young people. As well as helping 50,000 children directly each year, the charity also campaigns for children's rights, publishes research and leads the debate on many children's issues.

The Children's Society welcomes the opportunity to respond to this consultation and has used evidence from our practice as well as from submissions to The Good Childhood ® Inquiry to shape our response.

1. A Mandatory National Framework

The Children's Society supports the development of a transparent national framework for continuing care. Most importantly, we are of the view that it should be mandatory.

A Mencap report [2004]¹ highlighted the lack of access to health care experienced by people with a learning disability. The Health Care Commission Report [2007]² found that 75% of trusts providing hospital care to children were poor or weak and needed to make improvements. The United Nations Committee on the Rights of the Child [2008]³ in their recent concluding observations noted that disabled children in the UK continue to face barriers in the enjoyment of their rights including their right to access health services.

Disabled children, including those who are assessed as requiring continuing care, require services from both universal and specialist health services. Despite their crucial importance, families using our services frequently report that universal health services are inaccessible. Families also experience a postcode lottery in accessing specialist health services. An investigation by the Disability Rights Commission⁴ revealed 'an inadequate response from the health service to the major physical health inequalities experienced by some of the most socially excluded citizens: those with learning disabilities and/or mental health problems.' This included disabled children and young people. The investigation found children and young people in particular experienced 'diagnostic overshadowing' – that is reports of physical ill health being viewed as part of the mental health problem or learning disability – and so not investigated or treated.

¹ Mencap [2004] Treat Me Right

² The Health Care Commission [2007] Improving Services for Children in Hospital

³ Committee on the Rights of the Child [2008] Concluding Observations UK and Northern Ireland. 49th Session

⁴ Equal Treatment: Closing the Gap A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems

In order that children with the most complex health care needs have their needs met in a holistic way **The Children's Society believes a greater focus on disabled children's right to access health care is now required.** The focus in the consultation document on procedures, processes and pathways will not in our view be enough to make the significant shift that is required and it is therefore essential for the continuing care framework to be statutory.

The document does not clarify who the group of children are that will be covered by the framework. An agreed definition will be essential to avoid confusion and unrealistic expectations.

In relation to Annex A the list of possible mandatory duties we have a number of specific points:

- Point 6 refers to PCT's taking reasonable steps to consult with social services authorities before making a decision. This must be a requirement if holistic assessments and packages of care are to be a reality.
- The involvement of both parents and children and young people in their own right should be additional mandatory duties
- A regular review of the child or young person's continuing needs should also be mandatory.

2. Assessments and Reviews

There is a need for much greater clarity about how different assessments and reviews will be integrated. Rather than the results of other assessments informing the continuing care assessment these should all be joined up into one holistic assessment of the child's needs. Similarly the reviewing process should be integrated in a similar way and linked to existing statutory reviews such as the transition review.

The framework will need to clearly dovetail with a number of other statutory frameworks including those, which relate to looked after children and children with special educational needs. Children who have complex health care needs and are living away from home receive little mention in the consultation document. Pinney [2005]⁵ estimated that some 13,300 disabled children are living in long-term residential placements in education, social care or health care settings. Many of these placements will be a long way from the child's home local area. Whilst it is not clear how many of these children would be included within the continuing care framework nevertheless it is essential that they are not forgotten. Linkages with the health related provisions in the Children and Young Person's Act 2008 and the implementation of Care Matters will be essential.

The diagram on page 54 is not helpful without greater explanation.

⁵ Pinney [2005] Disabled children in residential placements. Available online: <http://www.everychildmatters.gov.uk/resources-and-practice/RS00014/>

The assessment table offered on page 49, as an example of good practice is worrying as it offers an alternative to the common assessment framework rather than an integrated approach. In addition it leaves out many important elements of a holistic assessment such as:

- the child or young person's general health and fitness
- details of the child's friendships and other important people in their life
- emotional wellbeing
- reference to the use of direct payments

3. The involvement of children and young people

The active involvement of disabled children and young people needs to be reinforced throughout the consultation document. This is crucial given that progress on involving disabled children and young people in making choices about their care, support and treatment has been so limited. Again evidence from the Health Care Commission Report found that few trusts reported that staff had received any training on communicating with children. It is important that reference is made to the Aiming High for Disabled Children Core Offer however more detail as to how this will be implemented within the continuing care context is needed. For example many children with complex health care needs will also have communication support needs and should have the option of being supported through the assessment and review processes by someone who knows their means of communication such as an independent advocate. This is even more crucial in the context of any proposed changes to the health care plan and in relation to dispute resolution. We are of the view that no changes to the child or young persons health care plan should be made without first taking into account the views of child or young person.

Children and young people are unlikely to be accessing PALS services. Heaton and Sloper [2003]⁶ found that only 7% of PALS services had policies and service specifications that highlight the needs of children. Research conducted by The Children's Society⁷ found very limited provision of advocacy services for disabled children and most alarmingly the most vulnerable children were those least likely to receive a service. **The Children's Society believes independent advocacy should be offered for all children and young people with chronic and/or complex health needs to support their active involvement in their treatment and care.**

4. The Decision Support Tool

⁶ Heaton, J., and Sloper, P. (2003) 'Access to and use of Patient Advice and Liaison Services (PALS) by children, young people and parents – a national survey', *Research Works*, 2003–04, Social Policy Research Unit, University of York:York.

⁷ The Children's Society (2007) *When will we be heard? Advocacy provision for disabled children and young people in England*. Available from http://www.childrenssociety.org.uk/all_about_us/how_we_do_it/research/Research_Area_Disabled_Children_6313.html

The care domains selected have a poor fit with the lives of children and the levels of need do not seem appropriate, particularly in the context of the drive towards inclusion for all disabled children and young people . It is not clear why autistic spectrum conditions have been added to the column on seizures on page 55. The reference to sleep deprivation in the mobility section is not clear if this refers to the child or the parent. The management of safety and lifting and handling are missing.

5. Other Points

The document needs to reinforce the significance of the safeguarding of children with complex health care needs. This is particularly important given the Health Care Commission's ⁸ findings that child protection remains a major risk. They found that only 60% of nurses had relevant training in basic child protection and 58% of the services used by children did not meet the necessary training standards. This is in the context of what research tells us about why disabled children are more vulnerable to abuse. Factors particularly relevant to children with complex health care needs include indicators of abuse being mistakenly attributed to the child's impairment; children often lacking the assistance they need with communication; an impaired capacity to resist or avoid abuse; children receiving intimate personal care from a number of carers.

There is very **little reference in the document to the link with short break services including those provided by the voluntary and community sector.** The very continuation of short break support for a child or young person may be dependent on a combined package of support from health and social care such as training of short break carers and befrienders in continence care, behaviour which challenges and drug therapies and medicines etc.

In relation to **the timing of assessments** it is important to note that working mothers may also need appointments outside of normal working hours and children and young people may need appointments outside of school hours in order that they can be fully involved without disrupting their education.

⁸ The Health Care Commission [2007] Improving Services for Children in Hospital