

## **Consultation on a National Framework for Assessing Children and Young People's Continuing Care: Mencap's response**

Mencap is the leading charity working with children and adults with a learning disability, their parents and carers. We are fighting for a world where everyone with a learning disability has an equal right to choice, opportunity and respect, with the support they need.

Mencap is a member of the Council for Disabled Children (CDC) and has contributed to the CDC response to this consultation. Mencap endorses the CDC position that the framework should be statutory.

Mencap would go further as we believe that children with complex health need to have the protections of a statutory framework in order to realise their right to access healthcare. There are an estimated 12,567 children with profound and multiple learning disabilities (PMLD) under 18 in England.<sup>1</sup> A substantial (but unknown) proportion of these children with PMLD have complex health needs.<sup>2</sup> Mencap's research<sup>3</sup> highlights the lack of access to healthcare experienced by people with a learning disability.

In September 2008 the Department of Health (DH) introduced annual health checks for all adults with a learning disability known to their local council with GPs paid to carry out these checks. Mencap believes that children with a learning disability should have an equivalent health check. In addition, children with a learning disability and complex health needs should have a written healthcare plan that is reviewed annually on a statutory basis.

Mencap believes that the proposed Framework needs further development so that it does not rely on the Ps of the current draft (process, procedures and pathways). A revised Framework needs to be underpinned by the 3 Rs (rights, reviews and regulation). Mencap believes that Regulations will be needed to incorporate these changes.

As the CDC response makes clear there is an urgent need to be definite and clear about the population of children that the government intends will be covered by this framework. If the intention is to only cover children with complex health needs then this should be explicit in order to avoid confusion and falsely raising expectations. In developing a revised framework there is a need to achieve clarity about terminology. For example, there is need to be clear that the focus is on a healthcare plan. The current draft repeatedly uses the term 'care plan' which has a particular meaning within social care.

Children with PMLD and complex health needs are a neglected group of children who need to have the security of the clearest possible legal framework in order to have their healthcare needs met. This revised system

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<sup>1</sup> Emerson.E. and C.Hatton (2008) CeDR Research Report 2008:6

<sup>2</sup> Michael J. 2008 Healthcare for All

<sup>3</sup> Mencap 2004 Treat me Right

needs to be on a par with the system for looked after children (LAC). In 2002 the DCSF/DH introduced comprehensive health assessments for all LAC.<sup>4</sup> Care Matters in 2004 built on this by requiring that all LAC have a named health professional to ensure that their health needs are met. Although many children with PMLD will be known to a number of health professionals, this does not give the security of a named health professionals with specified responsibilities.

A new legal framework for healthcare will need to be aligned with the special educational needs (SEN) legal framework. The government announced in 2001<sup>5</sup> that Health Action Plans would be in place by 2005 for all people with a learning disability. However this requirement has still not been incorporated into the SEN framework.

Health needs should be included in a Statement of SEN in Part 5 and Part 6 should cover the way that these health needs will be met. However, although health authorities are required by law to provide (on request) written advice to the annual review of a Statement, there is no requirement to invite health professionals to the statutory annual review. This gap in the SEN legal framework is especially important for children with PMLD and complex health needs. This gap becomes even more problematic at the stage of transition to adult services. If annual health checks and health action plans were placed on a statutory footing and there was a requirement to update these during transition reviews, fewer children with complex health needs would fall through this gap.

Although the consultation draft includes the core value that 'regular reviews are built into the process' there is a need for much greater clarity about how different assessments and reviews are integrated. Mencap would expect all children with PMLD to have a Statement of SEN and an annual review of this Statement. Some children with PMLD will be living away from home in specialist services and should have LAC status and will have statutory reviews twice a year. There is an urgent need to integrate these reviews.

In conclusion, rather than a non-statutory framework for continuing care for children with complex health needs Mencap believes that the following components need to be in place:

- Annual health checks for children with a learning disability who have a Statement of SEN
- A named lead health professional with access to a budget to ensure that the health needs identified in annual health checks are being met
- Health Action Plans for children with a learning disability who have a Statement of SEN
- Named health professionals to be invited to annual reviews of Statements of SEN to ensure that Health Action Plans are updated
- The Framework for assessing children's continuing care needs to be placed on a statutory footing and integrated with other assessments

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<sup>4</sup> DCSF/DH 2002 Promoting the Health of Looked after Children

<sup>5</sup> Valuing People 2001 DH