



## Special Educational Needs and Disability Green Paper

HemiHelp welcomes many of the interesting ideas set out in the Government's Special Educational Needs (SEN) and Disability Green Paper, particularly proposals designed to give parents greater control in deciding the most appropriate support for their children's education.

Many of our members have found the current system challenging to navigate, and experience dramatic disparities and variations in the levels of support they receive across the often many services they use. HemiHelp therefore welcomes measures that would create a more joined-up approach ensuring greater consistency of provision, and provide more individually tailored support through the introduction of a single assessment and an 'Education, Health and Care Plan' for each child living with SEN or disability.

However, the Green Paper offers few practical suggestions as to how to tackle the issue of awareness in schools and ways to challenge negative perceptions of SEN and disability. Our members also often express concerns about stigmatisation and not wanting to feel different, and an understanding of this basic need must carry through and inform all discussion during the next round of consultation.

Our response has been informed by consultation with representative groups of HemiHelp's members. Below we outline in greater detail our reactions to a number of the ideas set out in the Green Paper:

- **Single Assessment and the 'Education, Health and Care Plan'**

It is our belief that the current system of assessment is chaotic and confusing, can often cause distress to both parents and children, and too often children fall through the net and are diagnosed late.

HemiHelp welcomes proposals to introduce a programme of single assessment and the introduction of a tailored 'Education, Health and Care Plan' for children living with SEN or disability. Such a system will help to ensure consistency of provision, and with greater input from parents develop the most appropriate support plans for each child.

However, in order for such proposals to be most effective it is vitally important that the concerns of parents are allayed through greater access to information about the support options available. Parents must be fully equipped with all the tools they need to make informed choices. All discussions that follow must recognise the specific challenges faced by parents of children with a range of SEN and disabilities, and variations in levels of confidence to decide the most appropriate support. A tailored

approach must also be adopted to help guide parents through the range of available options.

- **Personal Budgets**

A number of parents expressed concerns about the amount of time and effort that managing personal budgets would require. Many parents are fearful of making mistakes, apprehensive about their ability to perform as parents and have enough time to sufficiently select services for their child, whilst others believe that strains on their time would limit their capacity to work.

Furthermore, many parents did not believe that a sufficient number of key workers would be employed, or that key workers would be sufficiently qualified to properly advise parents. A number of parents also felt that the allocation of personal budgets may result in a “post code lottery”; whilst others felt that there would be a disproportionately low allocation of funds to mildly affected children.

The additional support needs of children with hemiplegia vary considerably. The visible physical effects of the condition – a weakness down one side of the body, which may be more or less severe – are easy enough for educators to understand and deal with, but over half of these children also have less visible difficulties that can affect their learning. These may be medical in nature, for example epilepsy or a visual impairment, or they may stem from other neurological factors, for example dyslexia, dyscalculia, visual spatial difficulties or attention deficits. As a result of this complexity, children with hemiplegia do not fit in an obvious box and their problems are often overlooked.

Despite this, many parents welcomed the idea of personal budgets, believing they would empower them. The impact of personal budgets will only be seen with implementation and HemiHelp strongly urges the Government to work to minimise the potentially large burden that personal budgets could have on parents. HemiHelp will continue to consult with the Government over plans to introduce personal budgets.

- **The right to express a preference for any state-funded school**

It is our belief that parents are best placed to choose a school for their child. HemiHelp supports the Government’s proposal to introduce legislation to remove the bias towards inclusion. Parents were supportive of this move.

- **The opportunity for all maintained special schools to become Academies**

HemiHelp supports the potential for increased investment, a wider curriculum, and higher attainment levels that academies often bring. However many parents did not like the involvement of the private sector, and were concerned about the continuity of education and funding, and the accountability of the academy to maintain levels of provision for SEN children. HemiHelp shares these concerns.

- **Free schools**

Proposals that make it easier for teachers, charities and parent groups to open new ‘free schools’ received a mixed response from our members. Many were positive about the idea, but others were concerned about their capacity to found a new school.

HemiHelp will continue to consult with our members and with Government and look forward to the recommendations set out in the White Paper.

- **Pupil Premium**

The pupil premium proved a particularly controversial point with HemiHelp's members, and was overwhelmingly unpopular. There was much confusion about the usefulness of providing the pupil premium only for children whose parents have an annual income of less than £16,000. Many parents expressed concerns that it was discriminatory, and that the allocation of funding to schools with children with SEN or disability should be based on need and not on income.

## **Appendix:**

### About HemiHelp

HemiHelp aims to promote the rights and well-being of children and young people with hemiplegia and to raise general awareness of the condition. Founded in 1990 by a small group of parents, HemiHelp now has a thriving membership of families and professionals in the UK and beyond. They provide information, support and events for children, their families and the professionals who work with them. HemiHelp believes that every child with hemiplegia deserves the chance to fulfil their potential.

### About Hemiplegia

Childhood hemiplegia (sometimes called hemiparesis) is a condition affecting one side of the body (Greek 'hemi'= half). We talk about a right or left hemiplegia, depending on the side affected. It is caused by damage to some part of the brain, which may happen before, during or soon after birth, when it is known as congenital hemiplegia, or later in childhood, in which case it is called acquired hemiplegia. Generally, injury to the left side of the brain will cause a right hemiplegia and injury to the right side a left hemiplegia. Childhood hemiplegia is a relatively common condition, affecting up to one child in 1,000 live births.

\*Based on the number of children living in the UK in the last census (2001) and the number of estimated 'live births' each year in the UK.