

Children’s Heart Federation response to the consultation on the Green Paper: *Special Education Needs and Disability – Support and Aspiration*

Children’s Heart Federation (CHF), the leading UK charity and umbrella organisation for charities working to support children and young people with congenital and acquired heart disease (CHD) and their families welcomes the government’s impulse to improve the support for children with special educational needs (SEN) and disabilities. As a member of the *Health Conditions in Schools Alliance*, we support that consortium’s response to the broad issues raised by the Green Paper proposals.

We are also members of the Every Disabled Child Matters Campaign and support their response.

CHF’s individual consultation response picks up the issues that are particularly pressing for children with CHD, many of which are also applicable to children with other complex conditions. We look first at the profile of children and young people with CHD and the challenges they face in the context of education and then look at issues of planning raised by the Green Paper.

Examples of situations faced by children are expressed as:

- *Italicised bullet point*

CHF’s recommendations about how to support children with CHD and other health problems are

Childhood heart conditions are common

About 5000 babies a year (one in every 133) are born with a heart problem and a further 1000 children a year acquire a heart defect through infection or the side effects of another condition or treatment. These children are separate from those who have developed heart problems through obesity. Although some heart problems are very mild and resolve themselves without surgery or ongoing treatment, most schools will have one or more child with a heart condition that continues to have an impact on their daily life.

Heart conditions can create a wide range of challenges for children

Heart conditions and their treatments are wide ranging, and typical issues related to school may include the following physical challenges:

- *Need to take time off for treatment and/or tests;*
- *Fatigue and need to manage energy;*
- *Breathlessness;*
- *Feeling colder than other children;*
- *Need to take medication (e.g. warfarin, diuretics);*
- *Need to eat different food from other children (typically very high fat and high calorie diets);*
- *Some physical limitations for physically exerting activities (sport);*
- *Body-consciousness through scarring or smaller than average stature;*
- *Continence problems.*

In addition:

- *Seven out of ten children with CHD have a learning disability and/or developmental delay, which may be caused by the heart problem, the treatment itself or having to miss school. For some children, the impact of the learning disability may deepen as the child gets older, increasing the attainment gap between the child and his/her peers. In some conditions, such as DiGeorge Syndrome, these problems (in this case, a struggle with mathematics directly related to the syndrome), can be anticipated and planned for before they appear.*
- *Some children have complex physical co-morbidities (e.g. problems with lungs, kidneys, digestion and continence) which may be accompanied by a learning disability. Heart conditions can be part of other syndromes, such as Downs Syndrome.*

- *Children with CHD may have an intermittent disability. If they lose time at school, they can have few opportunities to catch up with school work, social contact and the development of life skills.*

CHD can be ‘invisible’ and poorly understood

Many families work very hard for the child to have as normal a life as possible, to overcome the debilitating and differentiating effects of CHD. In normal circumstances, unlike mobility problems, heart conditions are not directly physically obvious; this can work against children with CHD when they need additional support. It is common for parents, frustrated by being turned down for services the child legitimately needs to observe of gatekeeping professionals:

“They don’t think of our child as ill.”

So, children with CHD may have an unseen disability, which is a disability in itself.

As the impact of CHD can be poorly understood within the school environment, children’s needs can be ignored, denied or inadequately met. Here are some examples of school experiences for children and young people with CHD:

- *A girl was disciplined for keeping her coat on during a class on a cold day. She was trying to offset the effects of poor circulation but the teacher thought she was being cheeky.*
- *A boy got permission to use the school lift because he found it tiring to climb the stairs and walk long distances between lessons. In order to use the lift, he had to collect and return the key to the school office, which involved an extra walk.*
- *A boy with continence problems was given permission to use a toilet that was normally locked during class time but had to collect the key from the office. He would put off leaving the classroom and frequently did not reach the toilet in time. The school excluded him on the grounds that his personal care needs were too high.*
- *A girl whose diet included very high calorie items because her weight was low due to her heart problem was disciplined for eating unhealthily.*
- *A boy was disciplined for sitting during laboratory practical work. He had to use all his available energy for standing which left none for learning.*

Conversely, teachers may be so fearful of a child ‘having a heart attack’ that they dramatically over-estimate the risks of the condition and restrict the child’s participation in suitable activities.

- *Children with CHD are sometimes prevented from joining school trips;*
- *Some children with CHD are banned from PE lessons or regularly made to do an activity that is unnecessarily undemanding physically, such as scoring.*
- *A girl with CHD was unable to get a work experience placement, because the school had exaggerated the risks and local businesses were unwilling to take her on, the school was unwilling to help her find a placement so she had to find one herself or stay in school.*

Sometimes, lesson targets and activities need to be modified to include a child with a heart condition, but with flexibility and creativity, children can join in at their own level.

Poor understanding of the risks of supporting a child with a heart condition can mean that schools balk at the management of medicines.

- *Some teachers are unwilling or unable to support children on warfarin or diuretics.*
- *One school closed its doors to a child on oxygen because it deemed the oxygen tank posed too much of a risk.*

Broadening legal entitlement to support

CHF welcomes the move towards an integrated *Education, Health and Social Care Plan*. As children with CHD can have interrelated needs in all these areas, it should be beneficial to look holistically at the child's capabilities and needs.

As there is a close correlation for many of our children between physical and learning challenges, we would expect that the **presence of a health difficulty would trigger an assessment for a learning difficulty**. If a learning disability is not identified, a child will not receive help and support with learning which can delay his/her development even further.

Because CHD can cause peaks and troughs in the child's health and have an intermittently disruptive effect, the child's needs should be reassessed over period of time.

Not all children with CHD have a 'Statement' although they have support needs related to physical or learning challenges. As the current 'Statement' gives legal protection, in contrast to all other assessments which are advisory, **CHF calls for (words deleted) enforceable cover for medical and social needs, or a strengthening of the *Education, Health and Social Care Plan* to give it the same legal standing as a statement** to ensure that children with CHD are entitled to, and receive, the integrated care and support they need.

Accommodating the needs of children with CHD

Schools should make appropriate adaptations to enable (words deleted) to enable children who have a medical condition face meet physicality of the school environment by, for example, adjusting policies, practices, timetabling (words deleted) and medicines management

The rhetoric of inclusion needs to be backed by awareness raising / training for staff – so that they have sufficient understanding of hidden disability and are able to respond flexibly, appropriately and proportionately, with proper risk assessments rather than knee-jerk reactions.

In some cases, schools need to make reasonable adaptations to their facilities for children with disabilities due to health conditions, e.g. by providing lockers for children with extreme fatigue who have real difficulties carrying books and equipment or changing toilet doors that are too heavy for an exhausted child

With the creation of Academies and the reduction to the provider role of local authorities there must be clarification which body ensures the needs of children with health conditions are met by local schools. (re worked and words deleted).

Some children with CHD have frequent and/extended periods of time off school. **Provisions for children with health conditions need to cover hospital schools and home education which currently fall outside the 'mainstream v special schools' debate.**

Ensuring children with CHD are supported

We note with concern that the trend of policy-making is bringing about a situation in which schools will not have to support children with educational or physical needs, who will be more expensive to serve. **We seek reassurance that children with health conditions, including CHD, will have a right to high quality, appropriately-provided education.**

Need to clarify who is responsible

CHF shares *Every Disabled Child Matters*' concern that the current Health and Social Care Bill does not make it clear where responsibility will lie for disabled children within the health service, in terms of the National Commissioning Board and GP Consortia. To avoid agencies 'passing the buck', leaving parents having to fight for services, **we seek clarification on who will be making the offer of services and reassurance on the enforceability of the offer.**

Early support

We are disappointed that the structures for Early Support, including who is responsible and accountable are unclear. We note the reduction in budget in this area and ask for a **worked through explanation of how agencies are going to be accountable with a reduced budget and the plan and budgets for involving voluntary agencies in providing services and support.** In addition, **we would expect to see the principles of a Family Support Plan which were developed through Early Support as a key feature of the Education, Health and Care Plan.**

Key workers

We welcome the intentions around the involvement of key workers and are cautious because, on the ground at present training provided by SENCOs is often cursory. **We would urge new ways of working to include support for people who provide supervision to key workers, and want an opportunity to comment on detailed plans that cover the curriculum for training, how key workers will be identified, trained, accredited and supervised, how key worker schemes will be scrutinised and, crucially, in a climate of cost-cutting, funded.**

Transition into higher education

We note that the Green Paper has little detail about transition into higher education. At the time that many young people are making a transition to further education or on to higher education, many young people with CHD are also making a transition from children's heart services to adult cardiac care – so this can be a particularly stressful time of change.

Some young people with CHD and a learning disability have a slower learning rate than their peers, so education provision needs to be extended. **We would expect the link between health needs and learning needs to trigger planning for any extra transition support needs.**

Some young people find that working takes all their energy leaving them little capacity for truly independent living. **Careers counselling for young people with CHD needs to take account of any physical challenges and the broader picture of who will be providing support.**

Funding

We have not experienced a demand from parents for personal budgets; to date, they have wanted a statement of need and the provision their child needs to be provided, without having to fight for every piece of support. We note that managing staffing (which is what running a personal budget entails) may be a freedom and is an additional burden.

We would expect to see high quality brokerage and personal budget support services in place to enable parents to understand the range of services, service providers and methods of managing the personal budget to derive maximum benefit for their child. We would expect particular attention to be focused on support for economically deprived families. We suggest it would be appropriate to involve voluntary sector groups used to supporting parents of children with complex conditions in the design and delivery of brokerage and support services.

We note the high costs of equipment supply that are often passed on to parents and would press for funding and services to relieve this burden.

Short breaks

At present, having a cardiac condition does not automatically trigger a review of the need for short breaks in the way that a diagnosis of cancer, epilepsy or diabetes does. We believe that the provision of short breaks should be needs-based rather than condition based, but would **expect to see the health need triggering assessment of additional support, as described above.**

There is a particular need around end stage heart failure which is comparable to end stage cancer. We note that virtually all social service respite care has been removed even from the severest cases of children with a single cardiac issue – support is usually provided in cases of co-morbidity. We would expect **clear guidelines about the sources of funding and how funds are released for end of life care to enable families who need this support to receive it in a timely way, without having to push for it at a time of great stress.**

Listening to the voice of young people and parents

While the consultation document refers frequently to the including and empowering parents, it makes very little mention of asking and involving children. Many children who have a long-term condition have a maturity in relation to their needs and care pathway well beyond their years. **We would expect to see clear and appropriate engagement strategies for children and young people, developed in partnership with experts in this activity.** Working with its member groups, CHF is able to call on young people to take part in consultative activities to help shape policy and services.

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