

## Summary

*"How can I get out with a baby and toddler who can't walk?"*

*"How can my son go abroad with us if he can't bear weight and we can't take wheelchairs on board an aeroplane?"*

*"We'd like to go camping with our family, but how is it possible?"*

*"We are fed up with strangers coming into our home to care for our son five nights of the week. We'd prefer to choose our own team."*

These are a few of the questions asked of us by families who have sons or daughters with complex health needs or who are dependent on medical technology. Finding solutions to problems like these enables families to enjoy ordinary activities the rest of us take for granted. Yet attention to such concerns is often absent from the ways we currently support these families. When a child has complex health needs the formal processes, such as the Common Assessment Framework (CAF) and other education or medical assessments, can sometimes focus on the health problems at the expense of parents' views about what would help ordinary family life. The numbers of children and young people with complex health needs are growing steadily and we need to ensure support is genuinely person-centred and family-centred. This briefing for practitioners, children's health and social care commissioners, schools and colleges aims to inform and raise awareness about the aspirations of this group of children and their families.

## Introduction

This briefing summarises findings about some of the current issues affecting children and young people with complex health needs (who may also be using medical technology) and their families. It is based on a development project funded by the Department of Health Voluntary Sector Investment Programme and carried out by the Foundation for People with Learning Disabilities. Nearly 40 children and families across England took part in the project. We heard from them about the barriers to achieving an ordinary family life and what things they were trying to overcome these; and we worked in five different areas with some families to help them try new approaches. Families described the difference that a suitable home, personal budgets (including the new personal health budgets) and person-centred approaches can make to their quality of life. They also discussed the support they need to achieve this.

## Who are we talking about?

By medical technology we mean the use of technology to keep a person alive. The most common forms of medical technology for children are: on-going or intermittent mechanical ventilation; tracheostomy and oxygen therapy; enteral and parenteral nutrition; intravenous drug therapies, and peritoneal dialysis and haemodialysis. The children and young people we met used a range of technologies, including mechanical ventilation, oxygen therapy, an intrathecal pump that releases medication into the sheath around the spinal cord, and gastrostomy; some relied on a combination of these. Although there is no accurate UK data on this group of children, Glendinning et al (2001) estimated there were around 6,000 children in this group. Kirk and Glendinning (2002) described the diversity within the group:

- the cause can be congenital, genetic, through an

- illness, accident or prematurity
- the age at onset can range from premature birth to adolescence
- the duration ranges from months to lifelong
- the prognosis and life expectancy vary, along with the incidence and severity of associated disabilities.

## What are the current issues facing this group of children and young people?

### Increase in numbers

Children who are technology-dependent or have complex health needs are growing in number and more are living into adulthood. Ludvisgen and Morrison (2003) reported a 77% increase in the number of children who are oxygen/ventilator dependent from 1997-2000 and Townsley and Robinson (2000) reported a 60% increase in the number of children who were tube-fed over a two-year period.

This is a positive development, but looking after a child who needs 24-hour care makes significant demands on their family, as well as on health and social care. We need to ensure that publicly funded services work as effectively and efficiently as possible to support the family and their own network.

### The right to an ordinary childhood

As well as their health issues, these children face multiple barriers in order to exercise of some basic childhood rights, including communication, independence, friendships, and leisure opportunities. This contravenes the 1989 UN Convention on the Rights of the Child, which includes Article 23 (Children with disabilities): Children who have any kind of disability have the right to special care and support, as well as all the rights in the Convention, so that they can live full and independent lives; and Article 31 (Leisure, play and culture): Children have the right to relax and play, and to join in a wide range of cultural, artistic and other recreational activities. Research by Townsley and Robinson (2000), and Townsley et al (2004) showed

that families had difficulties in finding and organising social activities for their child and 'the system' did not support their desire to do things as a whole family. These children are not only fighting to stay alive, but they also have to fight for the opportunities to do ordinary things that others take for granted.

### A loud voice

There are few charities or support groups that advocate especially for this group. We hope this paper will raise awareness of the aspirations of this group of children and their families and the opportunities to improve their lives.

### What makes an ordinary life?

When we asked families what would improve their quality of life, they often wanted support with really practical issues. The questions at the beginning of this briefing paper illustrate this. For example:

- A 15 year old wanted to find out about the travel systems used in aeroplanes, so that he could go abroad on holiday. We arranged for him to visit the Virgin Airlines International rig near Gatwick Airport to try out the options. Both the young man and his parents are delighted to know that it is possible for him to go on a plane in the future.
- A mother wanted a double buggy that could accommodate her new baby and her toddler with mobility problems. We gave her a list of charities that can lend or part-fund such equipment and she got a buggy on loan from the Newlife Foundation so she could take both children out at the same time.
- For the family who wanted to go camping we discovered that there are some adapted motor-homes that can be rented. This made it possible for the young woman and her mum to join the rest of the family at a campsite for their holiday.
- The parents who wanted more control over their son's package of care, so they could choose who comes in to care during the night, have been supported to have a personal health budget.

Many of the issues raised by the families we met may not feature during a CAF or other assessments, yet these were things that could make all the difference to family life. The sections below summarise the main issues highlighted by the project work as making a difference to the children, young people and their families.

### Keeping things joined up

Children with complex health needs are usually in contact with a whole range of professionals, yet it is very rare to find a family who say they have someone who can join all these up for them. Key workers can help to reduce this stress, help parents to navigate through the system and help them to plan and get the right support for their child. Recent research by the charity Kids (Boyd-Wallis, 2012) showed that key workers were valued by families of children with disabilities because:

- They offered a professional, friendly source of

information and support

- They helped people to secure support to which they were entitled from other agencies
- Their ability to arrange and chair meetings and enable communication between multiple agencies led to:
  - More suitable care packages
  - Less duplication of work
  - More consistency and continuity for family
- They enabled more peer support and networking of parents in similar situations by:
  - Signposting parents to support groups
  - Offering emotional support themselves
- They empowered parents to become more assertive with other professionals and in their communities.

The research showed that, whatever model of key working was used, it must work in partnership with families.

National policy has promoted approaches such as the use of key workers, navigators or the team around the child for over ten years and most councils claim to operate key working, yet today it appears that many families are still lacking such a joined up approach and some organisations that supported it are no longer funded (Limbrick, 2013). Implementation plans for the Children and Families Act 2014<sup>1</sup> include funding for Independent Supporters to offer liaison across agencies and support with personal budgets. If this programme delivers what is promised, at the level and with the continuity required by children with complex health needs, it will be welcomed by families.

### Having the right home

Most children with complex health needs and their families will spend more time than their non-disabled peers at home. There are a number of issues to consider when ensuring that the home meets the child's needs - it should for instance be warm and comfortable, it should have the appropriate aids and adaptations to keep the child at home and it needs space to accommodate the technology, equipment and supplies needed by the child. Families must also be informed about their rights to a range of benefits and about the organisations that can help them make the most of their home.

Some families have to move to find a home that will be more suitable as their child grows. This can cause considerable financial strain on the family and there can be considerable delays in getting adaptations made. These may include, for example, having a tracking hoist to take the child to the bathroom from their bedroom and/or lounge; transforming a room downstairs into a bedroom, or making the entrance wider to accommodate a wheelchair. Amongst most of the families involved in this project it was common to have a long wait for an adaptation: for example, one took over four years to come to fruition and the family felt they had no option but to keep their child off school so that the Education Welfare Officer would report it, in order to speed up the adaptation required for their child to get in

and out of their flat safely.

Some families reported lack of consideration about what would suit the individual circumstances. For example, one family were refused a porch to store a wheelchair. This resulted in the wheelchair having to be stored in a leaky garage, so on a wet day it needs to be dried before the child can get in it. One parent who shared a bedroom with her child was refused funding by the local authority to adapt an extension into a bedroom for herself, because the child's needs were being met. For divorced parents, it can often result in the child ceasing to visit one of the parental homes as they get older because Disability Facilities Grants are usually offered to one home only.

Families would like more opportunities to explore options on what is best for their child in their home, and more choice over the materials and how the work is done. For example, some families told us they were offered tiles that made the bathroom look like a hospital bathroom rather than a family home one (some people paid extra for more homely materials). Having a tracking hoist fitted can have a great emotional impact on the family, as it is a continual reminder that their child is disabled for life. Moore et al (2010) describe this as the family home being reconstructed around the child's needs, as equipment and adaptations intrude on the home. The family home can begin to feel like a hospital, which is what these families wish to avoid at all costs. Professionals need to be highly sensitive to this issue.

### Being part of the community

Getting out and about and being spontaneous in a choice of activities can be more difficult for this group of children, yet many parents spoke of their great desire for their children to have a connection with their community. Families need to be informed about the various ways that obstacles to full participation can be broken down. For example, they need to be made aware of:

- the Changing Places campaign (which highlights fully accessible toilets across the UK)
- the various models of wheelchairs and seating available, which can make going out less of a chore
- where they can go on holiday that will cater for the needs of the whole family.

The personal assistant role also has a part to play in supporting engagement with the local community. Whilst the focus of their support is usually to ensure the health and well-being of the child or young person, this should be extended: rather than merely helping children and young people to be present in the community, true engagement occurs when they are supported to take part in specific activities, by matching their skills, talents and interests with the range of activities going on and with others in their local community.

Having a personal assistant can also enable children to take part in family outings or activities that may be

difficult for a family to manage on their own.

### Information and knowledge

Parents need to be better informed about their rights and about the opportunities available to their children. It is common knowledge that parents often rely on information from other parents, but this can be partial and patchy. The Local Offer promised in the 2014 Children and Families Act is expected to improve information about a wide range of local services and supports.

The kinds of information and knowledge required by families include:

- their right to a carer's assessment and an assessment for short-term breaks, and what they can spend allocated funding on
- their financial rights and the allowances for which they can apply
- the assessment process and options around education
- the right for some children and young people to have a personal budget (including health funding, October 2014).

Families should also be informed about person-centred planning approaches and how they and their children can benefit from these, as well as being supported to think about their circles of support. This means that practitioners need to be familiar with these concepts and respectful of family leadership.

### Personalised support arrangements

The families we worked with received support from a variety of sources. Some children were supported by the local children's continuing care teams; in one area the team worked in a very personalised and flexible manner to accommodate the family's wishes (including sending nurses or support workers on holidays with the family). Other families were trying out personal budgets (including direct payments) and a few families were using the new personal health budgets.

This is a time of great change in policy for children with complex health needs in England. By the end of 2014 some children with special education needs or disabilities will be offered a combined Education Health and Care (EHC) plan, with funding committed from each of the responsible authorities. Children and young people assessed as needing an EHC plan or with an EHC plan will have the option of a personal budget from September 2014. The families of children receiving continuing care funding already have the right to request a personal health budget.

Personal budgets have the potential to give the child or young person and their family more control over the kind of support and care that is appropriate for them. The stories we heard from those who have already tried combined budgets are very positive. They showed it was possible to:

- improve links between home and school, especially if personal assistants can work between the two

- fund specific equipment or therapies, e.g. wheelchairs, postural care support, sleep systems
- give families greater say over who supports the child/family
- ease pressures at transition to adulthood if the family keep the same support team.

However, the process does take time and it will only be successful if the family are supported along the way with people who are passionate about personalised approaches to care and understand the different options for managing a personal budget. We must respect the fact that not all parents want a direct payment or to recruit and manage personal assistants, but too many people still equate a personal budget (whether for children or adults) with a direct payment. Families need to be equipped with the knowledge to make the right choices for them, and supported to make their choices work. (This includes the option of a personal budget and/or personal health budget for themselves, based on their carer's assessment).

To find out what difference a Personal Health Budget has made for a young person with complex health needs see [www.personalhealthbudgets.england.nhs.uk](http://www.personalhealthbudgets.england.nhs.uk).

### Personal budgets and the workforce

Whilst personal budgets may be the 'next big thing', one of the key areas of concern is having a skilled workforce available to care for these children and clear lines of clinical governance for workers who will be performing very specialist tasks. Some families with personal budgets have found it hard to recruit skilled staff, or have trained staff over months to work with their child only to find the person leaves for another job. Being a personal assistant to a child using medical technology can be very daunting, as it is necessary to learn how to use the technology as well as learning how to communicate effectively with the child and fitting in with a family unit. Those who have run a personal budget successfully (see [www.peoplehub.org.uk](http://www.peoplehub.org.uk)) can testify to the huge difference it can make to their lives, allowing for more flexibility and choice in how they are supported.

### Conclusions

Children with complex health needs require a wide range of support to ensure they have the same opportunities as their peers. No single professional or organisation can provide this range, which reinforces the need for families to have a named person whose role is to help them navigate through the system. These navigators need to be familiar with person-centred planning and able to connect families with local supports beyond traditional services. For most children and young people their families are their greatest allies: services need to recognise this and work positively with families, helping them to build their resources.

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### Additional resources

The following resources that were developed through the course of the project are available from [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk).

- An Ordinary Life booklet
- Children and Young People with Complex Health Needs – a one stop booklet for parents
- Factsheets on leisure, flying and financial benefits
- A Book About Me communication passport
- One page profile template
- An example of a completed one page profile
- My Health and Person Centred Plan

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