
Chapter 1

Children and Young People who have Complex and Continuing Health Needs

Developments in biomedicine, technology and supportive care mean that life-threatening conditions and events which were previously considered incompatible with life (such as extremely premature birth) can now be survived. At the same time, children who have progressive diseases (for example muscular dystrophy) often have increased life expectancy (Noyes 2006a).

This ability to save and sustain life means that there are an increasing number of children and young people who require medical or technical support for many years, sometimes for their entire life, to maintain or optimise their health. Many children and young people in this situation also need substantial and ongoing care to avert death or to prevent their disabilities from worsening (Nessa 2004). Such children and young people are sometimes described as having health needs that are complex and continuing (Department of Health 2004a). As children who have complex and continuing health needs are increasingly living into adulthood, a population of young people and adults who have this type of need is now also emerging (Condliffe 2006; Shribman 2007).

DEFINITIONS

The increasing number of children and young people who have complex and continuing health needs is often referred to, but there is no absolute consensus on what constitute 'complex and continuing health needs' (Stalker et al. 2003). The phrase 'children with complex needs' is often used to refer to this group. However, this can be confusing, as the term does not relate exclusively to those with complex and continuing health needs. It includes children and young people with a variety of complex needs: those who are the subject of child protection plans; looked after children; children who are leaving care

2 *Providing Support at Home*

settings; children for whom adoption is planned; children with complex educational needs; young offenders; children who have significant mental health problems; and children with complex disabilities or complex health needs (Department for Education and Skills and Department of Health 2006).

The term 'complex and continuing health needs' implies that a child or young person has complex health related needs, rather than the more general term 'children with complex needs'. It also means that their health needs are expected to be sustained and are continuing over some time, rather than an acute stage of an illness. However, precisely how a child or young person is assessed as having a complex and continuing health need is not always easy to articulate.

Many of the definitions related to children and young people having complex and continuing health needs have been developed in conjunction with eligibility criteria for services. The reasons for this may include enabling service providers to ascertain what services the child or young person is likely to require or be entitled to in a relatively straightforward manner, or to account for or anticipate the need for service provision (Shenkman and Wegener 2000; Boddy et al. 2006). Such definitions may use service use alone (for example, whether or not a child or young person requires the involvement of a certain service or number of services) or a combination of service use and whether the child or young person has specific impairments (Greco and Sloper 2004; Boddy et al. 2006; Stevens 2006). One problem with this approach is that the individual concerned must already be using, or have been assessed to require, services in order to be defined as having complex and continuing health needs. A self-perpetuating cycle may be set up in this way if a child or young person is not assessed as requiring services. Because of not requiring certain services, they may not be considered to have complex and continuing health needs, which may in turn mean that they are not deemed to require certain services. It may also exclude children and young people who are awaiting assessment, or whose needs do not neatly fit a particular type of service provision.

Another approach to defining whether or not a child or young person has complex and continuing health needs is to focus on medical or physical health issues, and base the definition on their diagnosis or diagnoses (Shenkman and Wegener 2000) or the complexity of their health related needs (Boddy et al. 2006). These definitions focus very clearly on whether or not a child or young person has complex health needs, rather than other types of complex need. However, they can mean that other important needs which they have are excluded from their assessment. For example, their social and emotional needs, any behavioural difficulties that they may have and organisational aspects of support may be missed, although these may be very important

to their quality of life. In addition, definitions that focus on diagnosis may exclude those children or young people who do not have, or do not yet have, a definite diagnosis and reduce their options for service provision despite having significant needs (Boddy et al. 2006).

The terms 'technology dependent' or 'dependent on technology' have also been used to describe some children and young people who have complex and continuing health needs (Noyes 2006b). These terms provide considerable clarity over the child or young person's needs and over what aspects and types of medical or technical assistance they require (for example, assisted ventilation, continuous positive airways pressure). Nonetheless, like the definitions that focus on the child or young person's physical or medical needs, they may mean that support becomes focused on medical or technical needs, rather than seeing the child or young person and their family holistically.

Another option is to base assessment on the child or young person's individual needs, and decide on a case-by-case basis whether they have health needs that are complex and continuing. This allows service providers the opportunity to place the person, not just their diagnosis, physical or medical needs, or service use, centrally (Boddy et al. 2006). However, whilst it fulfils the ideal of seeing the child or young person holistically and humanistically, it may be problematic in any situation in which numbers and predefined or standardised criteria are required to account for the use of resources.

The debate over the definition of a child or young person who has complex and continuing health needs illustrates the difficulty that can be experienced in seeing the child or young person and their family holistically, when service provision and decisions as to which service will fund aspects of support needs to be accounted for. One of the problems with attempting to define what constitutes a child or young person who has complex and continuing health needs is that this tends to categorise people in a way which can be unhelpful (Boddy et al. 2006). Whilst ostensibly creating a mechanism to provide children, young people and their families with support, it may predispose to that support being organised and delivered in a way that devalues people as individuals and focuses on tasks or discrete needs. A vital aspect of working with children and young people who have complex and continuing health needs and their families is to acknowledge, but see beyond, these needs to the person and people involved (Leonardi et al. 2006).

The complexity of defining whether or not a child or young person is defined as having complex and continuing health needs means that precisely how many children and young people have this type of need is difficult to determine (Glendinning and Kirk 2000). However, there are now estimated to be as many as 6000 children in the United Kingdom living at home, but dependent on technology to meet their health needs and sustain their lives (Shribman 2007).

4 *Providing Support at Home*

PROVIDING CARE AT HOME

There has, for many years, been a trend in The United Kingdom for health related care and support to be delivered in the home, rather than hospital or institutional settings, wherever possible (Department of Health 1990). There has also been a sustained move towards enabling all people who have long-term conditions to live at home, and to develop and improve the services that people receive when their health and social care needs are met in the community (Department of Health 2006).

As well as a general move towards providing community, rather than hospital based care, avoiding children being hospitalised unnecessarily has been on the British policy agenda since the late 1950s, with the Platt Report (Platt 1959) often cited as an early instrument of implementing this aim. Ongoing recommendations, such as the Court Report (Commission of Child Health Services 1976) and the Audit Commission (1993) report have continued to identify that children should only be cared for in hospital when this has a therapeutic advantage over home care. This approach has more recently been advocated in the National Service Framework for children, young people and maternity services (Department of Health 2004a).

The move away from children being hospitalised has been largely attributed to consideration of the child and family's well-being. It has been suggested that children's emotional, psychological, developmental, educational, and social needs are generally better met at home than in hospital (Balling and McCubbin 2001; Neufeld et al. 2001). There is also some evidence that the physical health of children who have complex health needs is improved when they are cared for at home compared with when they are cared for in hospital (Appierto et al. 2002).

The philosophy of enabling children to remain at home, rather than in hospital or institutional settings wherever possible applies equally to children and young people who have complex and continuing health needs. This nonetheless represents a significant change from the way in which their care was traditionally provided. Children and young people who have this type of need would once have spent prolonged periods of time in hospital, in some cases their entire lives (Kirk et al. 2005). Where they required assisted ventilation this would have included long periods of time being spent in an intensive care unit. However, it has been recognised for some time that intensive care units are not appropriate places for children and young people who require long-term assisted ventilation but are otherwise medically stable to be cared for (Department of Health 1998).

The intensive care environment is not conducive to a child or young person's development, because intensive care units are primarily designed for

sustaining life in acute situations. Children and young people who spend prolonged periods of time on an intensive care unit will usually be exposed to sights, sounds and disturbances to their day that are not developmentally or emotionally beneficial. Their daytime routines and sleep are likely to be disturbed, and the children around them will not normally be able to play and interact with them. Although parents are welcomed on paediatric intensive care units, they are usually unable to maintain the natural contact with their child that they would have in the family home and their privacy is very limited. The child's mobility is usually constrained by the environment if not by their physical needs, as they are not free to explore intensive care units as they would be their home environment. Their ability to access education, visit and be visited by family and friends is also likely to be limited by their location.

Where the competing demands on paediatric intensive care staff include carrying out life-saving and preserving interventions, providing a full range of developmental experiences for a child or young person who is medically stable is unlikely to always hold the highest priority. It is therefore almost inevitable that children who are cared for long term in an intensive care unit will be exposed to inappropriate levels of stimulation and will not enjoy the same developmental experiences enjoyed by other children or young people of their age (Boosfeld and O'Toole 2000).

An acute hospital setting is also an inappropriate place for children to grow up in. Although the other children and young people in hospital wards are not usually as acutely or critically ill as those on intensive care units, they are unlikely to provide the type of peer relationships that children and young people would usually experience. Children are also unlikely to have the same range of experiences or interactions with adults that they would encounter at home. The number of staff who care for children in hospital and their varied views on child rearing makes establishing consistent practices problematic. Although parents often provide for the majority of their child's day-to-day care on hospital wards, they effectively 'parent in public' and have very limited privacy, both for establishing and maintaining a relationship with their child and for conducting their own relationships.

Caring for their child whilst they are in hospital can place a much greater burden on parents than caring for their child at home. Travelling to and from hospital means that juggling the visiting and care of the child in hospital, with the rest of their lives is very difficult. If the family have other children, parents' contact with them and the child's contact with their siblings will be disrupted when one child is hospitalised long term. Similarly, relationships between parents and with other family members and friends may be affected and parents may have relatively little opportunity for social support. Friends

6 *Providing Support at Home*

and relatives may have to travel a greater distance than they otherwise would to visit the child, and restrictions on visiting can mean that the child and their parents cannot see groups of their family or friends together.

Taylor (2000) also suggests that children, young people and their families are generally provided with better information when their care is provided outside the hospital environment. It is also possible that parents will be in a more powerful position at home than they would be in hospital. In hospital, healthcare staff are often seen as holding more power than parents, and parents are visitors in an unfamiliar environment. This situation is somewhat reversed in the family home, as healthcare staff are the visitors and have a greater obligation to respect the family's rules, values, norms and ownership of their child (Farasat and Hewitt-Taylor 2007). As Chapter 5 discusses, this does not mean that parents will necessarily find having a child who has complex health needs living at home an empowering experience. However, it may be less disempowering than their child being in hospital long term.

Despite the general acceptance of the ideal of organising healthcare to enable children and young people to remain at home, it is also important to note that there is a relatively weak research base to support the move to home care. It is more likely that this has been popularised and developed because of its intuitive appeal to the public and professionals (Parker et al. 2006).

ECONOMIC ISSUES

Although the benefits that children, young people and their families can derive from home care are often cited, there are also a financial and organisational incentives for support to be provided to enable children and young people who have complex and continuing health needs to live at home. Appierto et al. (2002) suggest that care at home is the most cost effective option for children with complex and continuing health needs. Providing hospital based care for them has been described as an inappropriate use of resources, both in financial terms and in terms of use of acute care facilities (Boosfeld and O'Toole 2000). The increasing population of such children and young people is one which the availability of acute beds, particularly paediatric intensive care beds, and staffing cannot support. However, although it is generally suggested that home care is a cheaper option for service providers, Noyes et al. (2006) identify that this is mostly, but not always, the case when the child or young person requires long-term assisted ventilation. There are circumstances where hospital based care for some children or young people who require long-term technical intervention is less costly, particularly if they are housed outside an intensive care setting.

Another consideration with cost estimates is that whilst home care may be the most cost-effective option for the National Health Service, it may move some of the financial burden of caring for children with complex and continuing health needs from the National Health Service to the families concerned (O'Brien and Wegner 2002). Having a child who has complex and continuing health needs is often very costly, financially, for their families (O'Brien and Wegner 2002; Parker et al. 2006). Whilst the cost of home care (for example, funding for equipment, staffing and supplies) may be met by the NHS and Social Services, the family usually incur many incidental expenses. It is estimated that the cost of bringing up a disabled child is three times higher than bringing up a child who is not disabled (Department of Health 2004a). This cost is likely to be even greater where the child has complex and continuing health needs. The costs that parents incur may include: providing transport for their child; buying toys that their child can use (which are often more expensive than other toys); obtaining specialist furniture; providing electricity to power the devices which they use; and the numerous telephone calls which they have to make (Hewitt-Taylor 2007). Many parents' ability to remain in employment and the type of employment in which they can engage is adversely affected by having a child who has complex and continuing health needs (Hewitt-Taylor 2007). This often means that families have a lower income whilst their outgoing expenses are increased (Department of Health 2004a).

The expenses associated with a child being hospitalised long term have not been formally compared with the expenses incurred by families when a child is cared for at home. It is nonetheless clear that having a child who has complex and continuing health needs is expensive in comparison to a child who does not have this type of need. In addition, not all the costs incurred by parents as a result of their child's health needs are met by service providers or state benefits.

THE BEST OPTION FOR INDIVIDUALS

The assumption is generally that enabling children and young people to live at home is the most desirable option. However, this will not always be the case. As well as the financial cost that parents incur when they have a child who has complex health needs living at home, there is considerable responsibility and work placed on the whole family (Parker et al. 2006; Hewitt-Taylor 2007). Where a child has the type of needs that require daily, continuing and demanding care provision, the cost in physical, social and emotional terms for a family may be a burden which they are unable to bear, despite ideally wanting their child to be at home (Carnevale et al. 2006; Parker et al. 2006).

8 *Providing Support at Home*

When decisions are made regarding where and by whom a child with complex and continuing health needs is cared for and will live, the needs of the whole family should be taken into account, and who will benefit and whose benefit is the most important considered (Hewitt-Taylor 2007). These are potentially difficult and emotionally charged decisions, and include not only the child's quality of life but their parents' quality of life, the quality of life of any siblings, and how these will impact on one another. Although the child's well-being is paramount in all decisions concerning them (Department of Health 2004b), every child's well-being, including that of siblings, and how parents' well-being will impact on their children's well-being must be included in the decision making process.

Although home care is, in principle, the best option, what is best will not be the same for every child or family. For some children and families, caring for their child at home is not the best option. Where this decision is reached, the family should be offered support to help them to live with the difficult decisions that they have made, and to continue to have meaningful and rewarding input into their child's life (Parker et al. 2006). Where home care is the best option, support to enable children, young people and their families to achieve the best possible quality of life needs to be put in place.

ACHIEVING HOME CARE

When it is decided that a child or young person who has complex and continuing health needs will live at home, setting up the services which will enable them to be discharged from hospital can be a protracted process (Department of Health 2004a). In addition, whilst the initial setting up of the services required may be difficult to effect, equally important and potentially problematic is ensuring that the ongoing support which children and their families need is in place (Department of Health 2004a; Brazier 2006).

In order to facilitate the child or young persons' discharge from hospital, and to provide effective support for them and their families once they are at home, careful planning, co-ordination and co-operation between services is needed. This necessitates a comprehensive assessment of the child or young person's needs, including their medical, technical, social, emotional and educational needs and the needs of their family. Funding, responsibilities for various aspects of support, and governance frameworks must all be agreed. A range of health, social care and education providers and professionals at managerial and individual level are likely to be involved in establishing home care, and all need to work in a co-ordinated and co-operative manner if this is to be achieved smoothly and to a high standard.

Facilitating home care provision requires staff who are able to support children and their families during the discharge process, but also following their discharge home. When it becomes clear that a child will require long-term health related intervention and home care is the goal, a team of staff must often be provided who can assist the child and family on a day-to-day basis. This frequently includes needs or services that span both health and social care provision. From the healthcare perspective, an NHS or Primary Care Trust is often not in a position to have a bank of staff employed awaiting such a need to arise. This means that families must often wait whilst decisions are made as to how and by whom support will be provided, and in many cases whilst staff are recruited and trained to assist them. Recruiting and retaining staff to fulfil such roles is often difficult and significant delays in a child or young person who has complex health needs being discharged home often occur because of the need for staff to be recruited to support them (Hewitt-Taylor 2007).

In addition to staff having to be recruited and trained, parents often have to develop new skills and knowledge related to their child's requirements and need the opportunity to develop confidence in these before they take their child home (Boosfeld and O'Toole 2000; Department of Health 2004a). As well as developing practical skills and knowledge, parents need to be given the chance to consider, and be supported, in accommodating the emotional workload of caring for a child who has complex and continuing health needs. This includes having to perform tasks which contrast with their expected parenting role, and which are unpleasant and distressing for them and their children (Abbott et al. 2005; Kirk et al. 2005). This can again take some time and requires staff to be available to work with and support parents who are preparing to take their child home.

The aim of enabling children who have complex and continuing health needs to live at home should be to facilitate them and their families achieving as good a quality of life as possible. For this to happen, the staff who support them need to have some insight into their needs as people, not just knowledge and skills in the medical or technical aspects of their care.