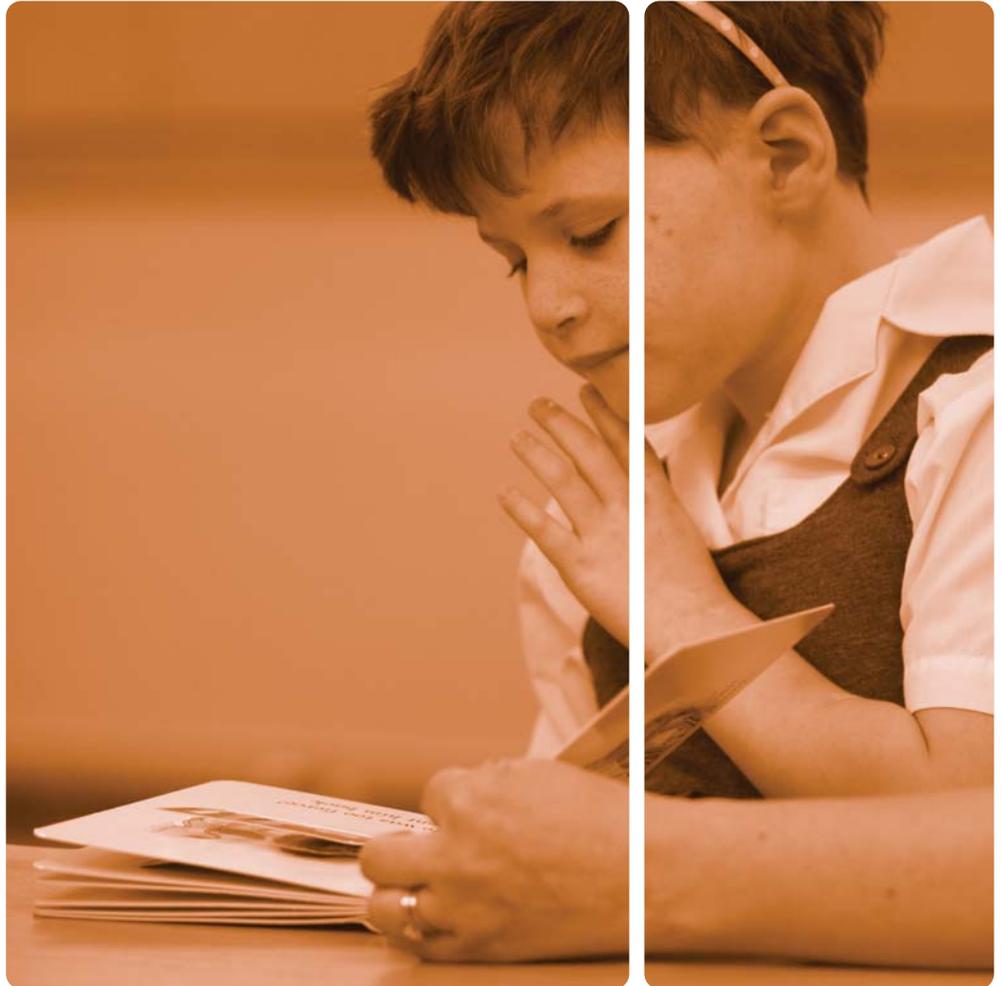


## The family context, community and society

Barry Carpenter

COMPLEX NEEDS SERIES

No.6



# New generation families

Over the last decade, we have seen a significant shift in the profile of childhood disability. It has been part of the changing landscape in early childhood intervention in the UK (Carpenter and Campbell, 2008). In the last five years, there has been a massive increase in the numbers of children with disabilities. The most recent figures from a study by Blackburn et al (2010) show that the number of families recognised as having a child with disabilities has risen from 700,000 to 950,000 since 2004, which is a 36% increase. The authors believe this new figure to be a 250,000 underestimate (Ramesh, 2010). This would equate to a total increase of 71%.

The new wave of children with complex learning difficulties and disabilities (CLDD) entering schools in the UK has brought with it new challenges to the families that are far beyond those experienced by families of children with more traditional disabilities.

While there are many societal and ethical considerations to debate, at the heart of this situation are the families themselves, and their needs must be paramount.

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## Case study: a mother's experience 1

My son was born at 24 weeks. He is five years old, and commenced a mainstream primary school this September. He has a statement of special educational needs. He has been diagnosed with global learning delay and has difficulty with his behaviour and attention.

I would like to say how pleased I am that at last professionals are understanding that children like my son have very different needs, and research is desperately needed. I would like to be able to say that my son has 'additional needs of extreme prematurity', but that condition does not exist in the medical or teaching world.

I often dread picking my son up from school to be informed of his antics. I will dutifully go through the motions of discussing his behaviour with him and the teacher, but really I feel very sad for him because it is not all his fault. The teachers do not understand that sometimes he just cannot help his behaviour. He is definitely wired differently to his peers!

*(Ricks, 2010)*

# The birth of a child with CLDD

At the birth of a child with CLDD, families have, overnight, a life changing situation (Carpenter, 2010a). As Thistlethwaite (2010) writes:

**With no warning, they step into unknown territory, more often with complete strangers as their first point of contact for this new journey.**

The Early Support Programme ([www.earlysupport.org.uk](http://www.earlysupport.org.uk)), alongside other UK early childhood intervention initiatives, offers excellent guidance (Carpenter and Russell, 2005). Its parent information sheets are helpful, and the Family Support Plan is a model of family focussed practice. Contact a Family too is an important information source ([www.cafamily.org.uk](http://www.cafamily.org.uk)).

However, there is currently a mismatch between our education system and the needs of families. Services have been unprepared for the tsunami of children with CLDD, and the significant alterations in service delivery style, organisation, curriculum and pedagogy needed. As schools re-align themselves along the needs-led approach required by children with CLDD, this will change.

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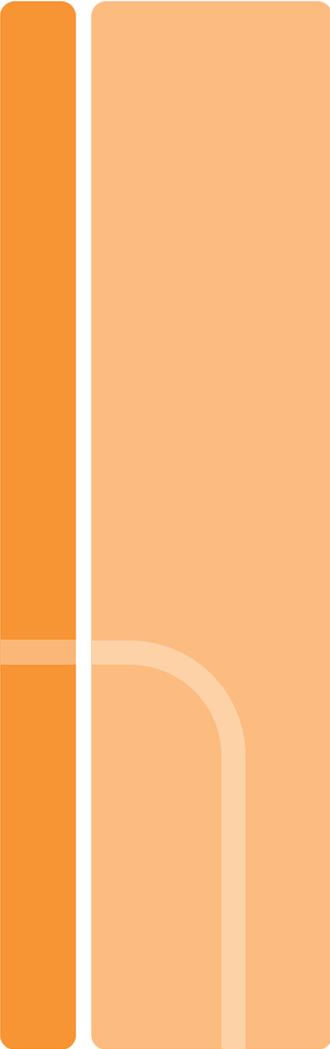
## Case study: a mother's experience 2

I once evaluated why looking after a child with complex needs gives rise to such high levels of stress, anxiety, frustration and exhaustion for the family – in particular the main care giver. The love that I have for my child totally negates the complexity of his life and the consequences that has for the family both physically and emotionally.

The stress, anxiety, frustration and exhaustion that I have experienced is categorically initiated from the extended world – namely, the service providers and educators. Central policies and initiatives are very reassuring, but the cruel reality is that they are to little effect as service providers and educators continue to operate within their comfort zones. I will readily refer to my family situation as the new generation of disability, and the brutality of it is that you learn to survive on your own. (Godden, 2010)

## Parenting beyond capacity

The family, through its love, nurture and support, breaks new ground in its parenting and care giving.



The parents and carers of children with CLDD are truly pioneers, charting new pathways in raising their child. They will have created their own care support, therapeutic interventions and educational approaches, based on their deep and rich understanding of their child, long before any school-based professional ever comes into contact with them.

The demands on parents mean that they have been required, as one teacher said, to 'parent beyond their capacity'. What we are seeing are children of whom even the most experienced professional has little or no experience.

Children born prematurely are presenting with configurations of development that have previously not been seen. Children with rare syndromes, who only two decades ago would have died in infancy, now, through skilled medical interventions, survive into childhood and enter our school system. All of the time the family, through its love, nurture and support, breaks new ground in its parenting and care giving – day after day, week after week, year after year.

Sadly, for some of the new generation of children with CLDD, a loving family is not the reality. Children born as a result of maternal substance or alcohol abuse are likely to find themselves in care at some point in their early childhood. A northern county council recently advertised for an adoptive family for Mikey. The advertisement read:

*Mikey is a sociable, loving five year old. Mikey's mother misused alcohol during pregnancy, and this has led to some developmental delays. Mikey attends mainstream school, but has a statement of special educational needs.*

Mikey is facing life without his birth family, and seeking a new family; potentially commensurate attachment issues may follow. Sue Mier, of the National Organisation on Fetal Alcohol Syndrome (Australia), reports that children with foetal alcohol spectrum disorder (FASD) form the largest percentage group going into fostering and adoption. The London-based fostering and adoption agency, The Adolescent and Children's Trust (TACT), has now a major focus on children with FASD.

# Partnership with families

These children with CLDD are 21st century children born to 21st century families. Families nowadays are increasingly diverse and complex in their composition.

**Families are big, small, extended, nuclear, multi-generational, with one parent, two parents and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage or from a desire for mutual support. A family is a culture unto itself, with different values and unique ways of realising its dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighbourhoods, communities, states and nations. (Carpenter, 2002)**

Demographics and social change mean that many families, even when blood-related, do not necessarily live close to each other. Grandparenting, for example, can be conducted across continents on a regular basis by mobile phone, text messaging, email, webcam or social networking websites.

Schools may find themselves interacting with non-traditional, but valued, self-defined family members: a grandparent who brings the child to school every day; an older sibling who collects them after school; or a family friend acting as a child minder. Many schools and professionals have established excellent working relationships with parents nurtured over many years (Beveridge, 2005). These can form the basis of the new partnerships that schools now need to forge with families. Communication through familiar channels (eg home–school diaries, newsletters, parents’ meetings and reviews) may no longer be solely with the mother and/or father. Our audience has broadened – has our thinking and practice as schools broadened also?

‘Partnership with families’ is a far more inclusive term than ‘partnership with parents’. It values the contribution of key family members, whether related by blood or social ties, and matches practice with reality. There is a whole family pathway to be charted if we are to achieve a truly engaged partnership that is relevant and responsive to the daily context the family finds themselves in.

Although mothers still tend to adopt the main liaison role, many fathers are seeking more ways to be proactive in the life of their disabled child. Fatherhood needs to be offered status and equality, and the fathers of children with disabilities warrant respect and support (Carpenter and Towers, 2008). The Recognising Fathers Project (Towers, 2009) has contributed to our understanding particularly in relation to a child with CLDD.

Grandparents too need recognition. They are increasingly shouldering large amounts of responsibility, and offering direct assistance to families through child minding, practical and financial support.

As a result of Don Meyer's pioneering work in the USA ([www.siblingsupport.org](http://www.siblingsupport.org)), there is now sound guidance to help practitioners fully understand the concerns of siblings and how they can best be supported (Strohm, 2004). Some siblings may share with professionals their deep knowledge of their brother or sister's likes and dislikes, or of how to calm or motivate them.

A family's non-blood relatives – friends, neighbours, work colleagues – may find themselves included as essential and valued members of the family network. Their involvement reduces the family's isolation and offers a lifeline of support.

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### **Case study: family reality**

Whilst the family network is incredibly dynamic and admirable, the reality is that it is not a sustainable format in its entirety. As the child grows older, the enormity of the long term situation emerges, the siblings leave home and the grandparents pass away, the danger is that the formidable family network becomes vulnerable. My child is eight years old; his siblings are four years and two years old; my parents are now deservedly enjoying their retirement; and I am beginning to see signs of a decline in the strength of this network.

A new and emerging challenge for my family is to manage the impact on the siblings. I have always viewed them as fortunate – being younger siblings and born into this situation rather than having their lives disrupted. However, having started school and nursery, they are becoming aware of the differences in our lifestyle and the lack of spontaneity: 'Mummy, do you have to use the hoist? It takes too long,' 'Next time, can we choose a brother without cerebral palsy?' and 'Who will be here when I wake up in the morning?'

The strength of the family network, the duration of that strength and the impact on the siblings, is yet to be fully tested. (*Godden, 2010*)

# Supporting new generation families

Society will need to recontextualise its traditional views of how it supports families of children with disabilities. We are not talking small numbers of children. Alongside the figures published by Blackburn mentioned earlier, between 2004 and 2009 there has been a 29.7% increase in children with profound and multiple learning disabilities (PMLD) (DCSF, 2010).

The Coalition Government (2010) has recognised the importance of the caring role, and the welfare of carers, stating:

**...supporting physical and mental wellbeing of carers through the provision of breaks can help carers carry out their caring role safely and effectively and can keep families together in their own homes – where they want to be – for longer.**

Their policy statement continues, 'supporting vulnerable children is a priority for the Government'. Certainly vulnerability is the thread that unifies this rapidly emerging group of children and young people with CLDD, whether the source of that is disability, deprivation, disadvantage or a combination of any of these 'three Ds' (Carpenter, 2010b).

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## Case study: the poverty trap

John and Carrie worked hard to buy their first home. They were overjoyed at Carrie's much longed for pregnancy, but Joshua was born 15 weeks premature, weighing only 900g. To his anxious parents, looking into his incubator, there seemed to be more tubes than baby.

Joshua was a fighter. After five months and three operations, he left hospital with oxygen to aid his breathing, and special food for his nasogastric tube. He thrived at home, although his developmental delay became quickly apparent, and every milestone was hard won. By 18 months, his profound physical disability meant he needed a side lying board to aid positioning and postural drainage. Where, in the modern semi, do you store oxygen cylinders, cases of special food and side lying boards?

John and Carrie's mortgage for their home was based on two salaries, but Joshua's care needs and frequent epilepsy meant Carrie could not return to work. Mortgage repayments became a nightmare. After five years of struggling, John and Carrie lost their home when it was repossessed.

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## Booklets in the complex needs series

- 1 A vision for the 21st century special school
- 2 Children with complex learning difficulties and disabilities – who are they and how do we teach them?
- 3 Curriculum reconciliation and children with complex learning difficulties and disabilities
- 4 Mental health and emotional well-being
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