

**The Family Journey: reflecting on the needs of families of children with Complex Learning Difficulties and Disabilities.***Professor Barry Carpenter, OBE, PhD**Director, Complex Learning Difficulties and Disabilities Research Project*

'I see parents parenting beyond their capacity'.

*A teacher  
CLDD Research Project School*

The new wave of children with Complex Learning Difficulties and Disabilities (CLDD) entering schools in the UK have brought with them new challenges to their families, far beyond those experienced by families of children with more traditional disabilities. These parents are truly pioneers, charting new pathways in raising their child with complex needs. They will have created their own core 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.

Families will hopefully have benefitted from some of the excellent advice and guidance offered by the Early Support Programme ([www.earlysupport.org.uk](http://www.earlysupport.org.uk)). The Parent Information sheets on 'Rare syndromes' or 'When my child has no diagnosis' are particularly welcome, and the Family Support Plan is a model of family focussed practice. The Early Support Programme, alongside other initiatives, is part of a raft of encouraging developments in early childhood intervention in the UK in the last decade (Carpenter and Russell, 2005).

However, as the opening quotation states, the demands on parents means that they have been required to 'parent beyond their capacity'. What we are seeing are children of whom even the most experienced professional has little or no experience. Our interventions and support are based on applied knowledge from practice with other children with special educational needs and disabilities. 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. And all of the time the family, through its love, nurture and support, breaks new ground in their parenting and care giving – day after day, week after week, year after year.

As Think Piece 2 in this series reported, 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). Indeed, in just the last five years, there has been a massive increase in the numbers of children with disabilities. The most recent figures from Blackburn et al. (2010) show that numbers of families with a disabled child have risen from 700,000 to 950,000 since 2004. This is a 36% increase, and the same study estimated their figures were a 250,000 underestimate (Ramesh, 2010). This would equate to a 71% increase.

There are many societal and ethical considerations to debate, but at the heart of this are the families themselves, and their needs must be over-riding and paramount.

## New generation families

'Families need services not labels, but families seek labels in order to find services.'

(Visser, 2009)

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

'...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.'

The Government's 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, 2010a).

### Family case study

John and Carrie had been together for five years. They had worked hard to get their first home together – a smart, modern semi-detached house.

Then the much-longed for pregnancy happened. They were overjoyed, until at 25 weeks into the pregnancy Carrie gave birth to Joshua. Their anticipated joy quickly turned to distress, wondering if their baby would survive. He weighed 900g, and was quickly placed in an incubator. To his anxious parents, there seemed to be more tubes than baby.

For Carrie, her biological wiring was completely interrupted. She had dreamt of the congratulations cards, flowers, balloons, the smiles of proud grandparents, the effusive greetings of friends. These dreams had gone and were replaced by guilt, fear, profound worry.

But Joshua was a fighter. He went home after five months in the hospital's special care baby unit. He had undergone surgery three times, and, when he left hospital, it was with oxygen to aid his breathing, and special food for his nasogastric tube. Where in the modern semi, do you store oxygen cylinders: and is the modern domestic refrigerator big enough to store the special food?

Joshua thrived at home, although his developmental delay became apparent very quickly. By 18 months, his profound physical disability led the physiotherapist to recommend a side lying board to aid positioning and postural drainage. Where in the lounge of your modern semi do you locate a side lying board?

Joshua continued to grow and develop, but slowly; every milestone a hard fought achievement. As the infant became a child, the Buggy had to be replaced with a Major Buggy. Have you tried to get a Major Buggy through the doorways in a modern semi?

John and Carrie had planned the mortgage for their home based on two salaries. Joshua's care and needs were such that no day nursery would enrol him. His frequent epilepsy worried his grandmother so much that she would never be left alone with him. Carrie's plans to return to work, even on a part-time basis, never materialised. The mortgage repayments became a monthly nightmare. After five years of struggling, and with a second child on the way, John and Carrie's smart, modern, semi-detached home was re-possessed.

The new generation of children with CLDD is creating 'new generation families'. However, at the moment there is a mismatch between the education system and the needs of these families. This is temporary, and has been caused by the tsunami of children with CLDD that have hit the school and service systems. Our services were not prepared for this volume of children, and it has necessitated some significant alterations in service delivery style, organisation, curriculum and pedagogy.

This will change rapidly in the coming years, I am sure, as schools re-align themselves along the needs-led approach required by children with CLDD, but at the moment the reality is best typified by the following extract from an email received by the CLDD Project on Christmas Eve, 2009.

'My son was born at 24 weeks: he is now five years old, and commenced a mainstream school in September 2009. He has been diagnosed with global learning delay and has difficulty with his behaviour and attention.

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

He is definitely wired differently to his peers!

*A mother (December 2009)*

### **And without a family...**

The child at the heart of the quotation above had a loving family to guide and nurture his development, to face challenges for and with him. Sadly, for some of the new generation of children, this is not the reality. Children born as a result of maternal abuse of alcohol during pregnancy, who have Foetal Alcohol Spectrum Disorder (FASD), may find themselves 'in care' at some point in their early childhood.

Sue Mieir, of NOFAS-Australia, reports that children with FASD form the largest percentage group going into fostering and adoption. The London-based fostering and adoption agency, 'Partnerships for Children', has now focussed its entire efforts on children with FASD.

Sir Ian Gilmore, President of the Royal College of Surgeons (and himself a liver specialist), reports (2010) that, as a result of Britain's binge drinking culture, young women in their mid- to late 20s are suffering from fatal liver disease. If medical interventions fail, and the mother dies, the child (who may already be displaying the challenging traits of FASD) may be left without a family. (If the child was conceived in a random encounter as a result of a drunken stupor, then the father may not be known.)

Only a few weeks ago a northern County Council 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.'

Society will need to recontextualise its traditional views of how it supports families of children with disabilities in the light of this 'avalanche of children with CLDD' (Thistlethwaite, 2010) entering our system. In the two examples cited above, you have a family charting new pathways to education, care and support as a result of their child's premature birth, contrasted with a child, already in the primary school system, facing life without its birth family, seeking a new family, with potentially all of the commensurate, attachment issues that may follow.

We are not talking small numbers of children either. Alongside the figures published by Blackburn mentioned earlier, the DfE are reporting a 29.7% increase in children with PMLD (most of whom will enter special schools); already secondary schools are noting new patterns of need in their students (Carpenter, Coughlan and Fotheringham, 2010).

### **Partnership with 21<sup>st</sup> century families**

The children discussed in this paper are 21<sup>st</sup> century children born to 21<sup>st</sup> 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, as was the case just a few decades ago. Grandparenting, for example, can be conducted across continents on a very regular basis by mobile phone, text messaging, email, web-cam or Facebook. This is the context into which 21<sup>st</sup> century children with CLDD are born, and, from that moment of birth these families are on a journey – as families, not just parents.

Many schools talk of ‘Partnership with parents’: it is not the reality. ‘Partnership with families’ is a far more inclusive term. It promotes a whole family approach, valuing the contribution of key family members, whether related by blood or family ties. Parents are a part of families, so this re-focussing of practice is not exclusive, but rather seeks to match it to the reality for the child.

Schools need to ‘think family’: to consider those approaches that encourage family life to flourish through a positive and dynamic relationship with their child’s school. They need to focus on family engagement. 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. 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, stepfather or stepmother who collects them after school; or a family friend acting as a child-minder. Therefore, although we continue to communicate with families through familiar channels (e.g. home-school diaries, newsletters, parents’ meetings and reviews), the recipients and attendees may no longer be solely the mother and/or father. Our audience has broadened – has our thinking and practice as schools broadened also?

Many schools and professionals have established excellent working relationships with parents, gently nurtured over many years (Beveridge, 2005). These form the basis of the new partnership of engagement that schools now need to forge with families.

## The challenge of the partnership with families

Previously, I have advocated an extended family support network (Figure 1) that values the 'self-defined' family (Carpenter, 2000). Looking at this model, various challenges arise for schools when they consider the 'how' of family involvement.

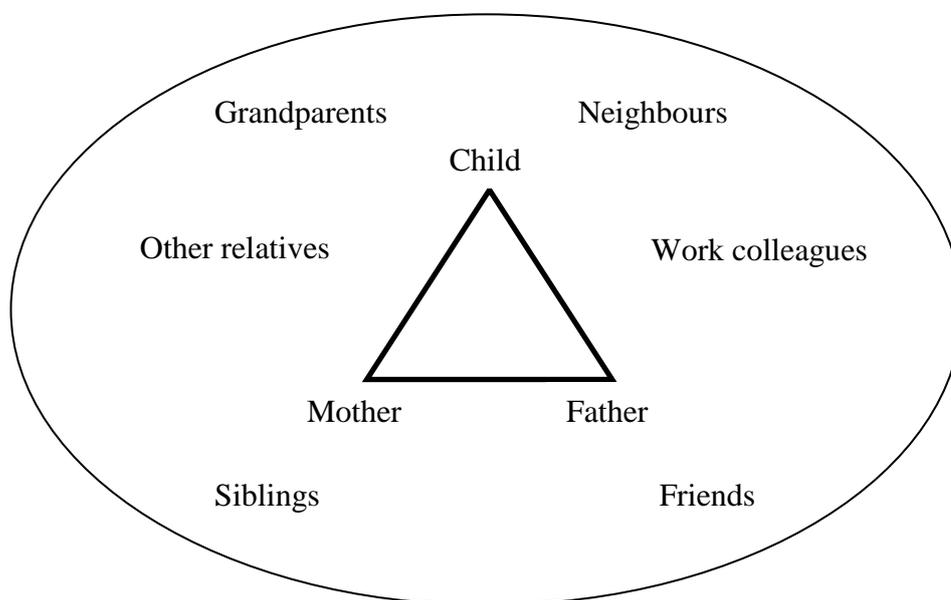


Figure 1. An extended family support network

The birth of a child with a disability, the identification in the early years of a child's special needs, brings about life-transforming experiences. In spite of major changes in family structures over the last two decades, mothers still tend to adopt the main liaison role, through their daily care giving, with a child's school (Kingston, 2007). Schools have established good communication strategies with mothers; this has not been so easy to achieve with fathers. Again there has been a shift in emphasis, and many fathers are seeking more ways in which to be proactive in the life of their disabled child. The 'Recognising fathers' (Foundation for People with Learning Disabilities, 2006) project has contributed to our understanding of fatherhood in 21<sup>st</sup> century, particularly in relation to a child with complex needs; 'Fatherhood needs to be offered status and equality, and the fathers of children with disabilities warrant respect and support' (Carpenter, 2007).

Grandparents are an under-used and under-recognised resource in many schools, yet, in the current climate, they are increasingly shouldering large amounts of responsibility, and offering direct assistance to families through child minding, practical and financial support.

The focus on the needs of siblings of disabled children has increased considerably in the last 10 years as a result of the pioneering work of Don Meyer in the USA ([www.thearc.org/siblingsupport](http://www.thearc.org/siblingsupport)). There is now sound guidance to help practitioners fully understand the concerns of siblings and how they can best be supported (Strohm, 2004). However, do schools seek to include them, and draw upon their deep knowledge of their brother or sister's likes and dislikes, of how to calm or motivate them?

Then there are the 'significant others', the non-blood relatives, who find themselves included as essential and valued members of families. These are friends, neighbours,

work colleagues, whose involvement reduces the family's isolation and offers a lifeline in terms of support. It is not uncommon to find an elderly neighbour who undertakes childminding for the child with CLDD while the lone parent works. In doing so, this neighbour is undertaking some of the functions that a grandmother may have undertaken three or four decades ago when we were a less mobile society.

### **Family-focussed future**

New generation children have given rise to new generation families. What is important for schools is that they recognise that these families do not always know the answers about the complex needs of their children. As those needs unfold, the phenomena may be as new to them as it is to us. This is uncharted territory for families, just as it is for schools and professionals.

A really positive shift that schools could make is to move to more family focussed (as opposed to parent-centred) models of partnership. This more inclusive, all embracing family-centred approach recognises the invaluable contribution each family member can make to the education, care and support of those vulnerable children with complex learning difficulties and disabilities.

### **Ponder points**

1. Is your school policy called 'Partnership with parents'? What tweaks and adjustments could you make to ensure that it becomes a 'Partnership with families' policy?
2. How would you need to restyle aspects of your practice to ensure it reflected this realignment of policy (e.g. newsletters addressed to families)?
3. If you have a 'Parents room' is that its label? Is that what you mean? Are siblings and grandparents allowed into this room? If so, does it need to be re-labelled 'Family centre'?
4. Have you ever held an event specifically for siblings or dads? If not, look up the factsheets with helpful suggestions on the Contact-a Family website – [www.cafamily.org.uk](http://www.cafamily.org.uk)

The CLDD Research Project would welcome your responses to this 'think piece' on its blog <http://blog.ssatrust.org.uk/thinkpiece/>

### **References**

Beveridge, S. (2005) *Children, Families and Schools: Developing partnerships for inclusive education*. London: Routledge/Falmer.

Blackburn, C.M., Spencer, N.J. and Read, J.M. (2010) 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey', *BMC Pediatrics*, 10, 21. [Online at: <http://www.biomedcentral.com/1471-2431/10/21>; accessed: 4.7.10]

Carpenter, B (2000) 'Sustaining the family: meeting the needs of families of children with disabilities,' *British Journal of Special Education*, 27 (3), 135–144.

- Carpenter, B. (2002) 'Enabling partnership: families and schools'. In: B. Carpenter, R. Ashdown, and Bovair, K. (eds) *Enabling Access: Effective teaching and learning for pupils with learning difficulties*. London: David Fulton Publishers.
- Carpenter, B. (2007) 'Fairer to fathers: the role of schools in nurturing positive fatherhood – a United Kingdom perspective', *Kairaranga*, 8 (1), 13–16.
- Carpenter, B. (2010a) 'Disadvantaged, deprived and disabled', *Special Children*, 193, 42–45.
- Carpenter, B. (2010b) 'Think piece 2: children with complex learning difficulties and disabilities'. [Online at: <http://blog.ssatrust.org.uk/thinkpiece/?p=16>; accessed: 4.7.10]
- Carpenter, B. and Campbell, L. (2008) 'The changing landscape of early childhood intervention in the UK: strategy, policy and practice', *Infants and Young Children*, 21 (2), 142–148.
- Carpenter, B. and Russell, P. (2005) 'Early intervention in the UK: current policy and practice'. In: M.J. Guralnick (ed.) *The Developmental Systems Approach to Early Intervention*. Baltimore, MD: Paul H. Brookes.
- Carpenter, B., Coughlan, B. and Fotheringham, J. (2010) *Mental Health and Emotional Well Being: The new dimension in the curriculum for children and young people with special educational needs*. London: Specialist Schools and Academies Trust.
- Foundation for People with Learning Disabilities (2006) *Recognising Fathers: Understanding the issues faced by fathers of children with learning disabilities*. London: Mental Health Foundation.
- Gilmore, I. (2009) Personal communication.
- HM Government (2010) *The Coalition: Our programme for government*. London: Cabinet Office.
- Kingston, A.K. (2007) *Mothering Special Needs: A different maternal journey*. London: Jessica Kingsley.
- Ramesh, R. (2010) 'Study shows links between poverty and disability are more pronounced', *Guardian* (19 April).
- Strohm, K. (2004) *Siblings: Stories of everyday life with children who are different*. London: David Fulton Publishers.
- Thistlethwaite, J. (2010) Personal communication.
- Visser, J. (2009) 'Policy in SEN in the UK'. Keynote presentation to the Australasian Special School Principals Conference. Wellington, New Zealand (September).