

## Children with complex learning difficulties and disabilities

Who are they and how do we teach them? Barry Carpenter



# These children [with complex learning difficulties and disabilities] are the next frontier of education.

Professor Daphne Thomas, University of South Florida (2010)



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Children with complex learning difficulties and disabilities (CLDD) are challenging our most skilled teachers, but this is not a reflection on their quality of teaching. These new children do not fit our current range of learning environments, curriculum models or teaching and learning approaches.

The disabilities of this new breed of children have previously rare causal bases — from assisted conception or premature birth, from maternal drug or alcohol abuse during pregnancy, or from medical advances, for example.

Over the last five years, there has been a massive increase in the numbers of children with disabilities in the UK. 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. In 2005, McClusky and McNamara calculated that there were more than 100,000 children with severe learning disabilities (SLD), and observed that their numbers were known to be rising as a result of medical advances. Between 2004 and 2009, the total number of children with SLD increased by 5.1%, and the total number of those with PMLD rose by an average of 29.7% (Department for Children, Schools and Families, 2009).

The increasingly complex difficulties and disabilities of children in our schools are noted by Ofsted inspectors in their reports, and the headteacher of a Cumbrian special school observes:

...we are seeing a regular increase in pupils with profound difficulties, some with complex needs, many with ASD, some with genetic conditions and some as the result of acute infections and diseases (eg cytomegalovirus, leukaemia and meningitis). (Cartwright, 2010)

### CLDD-towards a definition

As a first step towards resolving unmet need, both in our children and in our special education teaching workforce, we need to shape a definition of CLDD. Porter and Ashdown (2002) provide a useful starting point, describing children with complex needs as:

...a wide and varied group of learners. They include pupils who do not simply require a differentiated curriculum or teaching at a slower pace, but who, at times, require further adaptation to teaching if they are to make progress.

As part of the Department for Educationsupported CLDD Research Project (September 2009–March 2011), the schools, learning disability charities and other professional groups consulted have voiced agreement that children and young people with CLDD may:

• be working at any level of the national curriculum including P scales, and communicating using a range of strategies, including augmentative approaches and assistive technologies, signed or spoken language

- have conditions that co-exist (Visser, 2009) with one or more special educational needs that overlap (Dittrich and Tutt, 2008) and interlock, creating a complex profile of learning need
- show inconsistent attainment, presenting an atypical or uneven profile, due to the co-occurring (Rose et al, 2009) and compounding nature of complex learning difficulties
- have a range of issues and combination of layered needs — eg mental health, social, behavioural, physical, medical, sensory, communication and cognitive. These needs may require informed, specific support and strategies to allow children to engage effectively in the learning process and to participate actively in classroom activities and the wider community. These may include multidisciplinary or transdisciplinary support
- require personalised learning pathways that recognise their unique and possibly changing learning patterns.

Without transformative education, [these children] will become ill-equipped to enjoy active citizenship in a 21st century society.

Children with CLDD are an infinitely diverse group, but what they have in common is vulnerability in multiple areas of their lives. Without transformative education, they will become disenfranchised and ill-equipped to enjoy active citizenship in a 21st century society.

#### **Coexisting conditions**

What are the pedagogical resolutions for children with co-existing conditions — for children who have Down's syndrome and mental health needs; Noonan's syndrome and physical disability; visual impairment (VI) and autism? In VI and autism, for example, despite a powerful literature base and clear educational guidance on the individual disabilities, the teaching styles are not totally compatible (VI and Autism Project, 2009). Which aspects

of which approaches take precedence? What are the criteria which inform our professional judgements?

#### Premature birth

From the UK EPICure study, Marlow et al (2005) reported that 80% of children born at less than 26 weeks gestation survive, and that over 50% of these have severe and complex disabilities. Many have

neurological compromise and complex health needs, requiring supported nutrition, assisted ventilation, rescue medication for complex epilepsy, etc (Brown, 2009). Traditional sensory curriculum approaches may not engage children whose severe/profound and multiple learning disabilities (S/PMLD) stem from preterm birth. Their sensory pathways may not only be damaged, but also incomplete and compromised (Champion, 2005). What strategies will help them to learn?

#### Fetal alcohol spectrum disorder

Children with foetal alcohol spectrum disorder (FASD) are newly acknowledged in the UK as a group of learners needing specialised intervention (Blackburn, forthcoming). They may account for as many as one in 100 children (British Medical Association, 2007), ranging across the learning disability spectrum from mild to profound. Neuroscience shows that, with FASD, the brain's parietal lobe can be significantly reduced (Goswami, 2004). This area controls numeracy and mathematical computation. However skilled a teacher may be in differentiating the maths curriculum, if that part of the brain is compromised just how do we teach maths to this child?

#### Chromosome abnormality

One in every 200 babies is born with a rare chromosome disorder (www.rarechromo.org). Even if there is a diagnosis, they could be one of only a handful of children in this country, maybe even worldwide. Teaching approaches are not widely communicated or understood by the teaching profession. Parents and professionals will need access to comprehensible information about genetics in general, and specific disorders in particular, if we are to improve the life chances of this group of children with chromosomal disorders.

#### Mental health needs

Adolescence compounds difficulties as mental health needs emerge — young people with learning disabilities are six times more likely to have a mental health problem than other children in the UK (Emerson and Hatton, 2007). Teachers need a deeper understanding of mental health needs. How do we embed emotional well-being into everyday teaching for young people with autism or FASD, for example?

#### CLDD case profile (Carolyn Blackburn, 2010)

Diagnoses for children with FAS are typically complex - as an example, alongside FAS, one child is also diagnosed with ASD, oppositional defiance disorder, attention deficit hyperactivity disorder (ADHD), reactive attachment disorder and sensory integration disorder. Their complex needs arise not only from overlapping diagnoses and compounding factors, but from their extreme vulnerability. As well as following an asynchronous developmental pathway, these children present with impaired social communication skills - particularly in the area of understanding. Their poor receptive language skills are often masked by strong verbal skills. Extreme impulsivity, hyperactivity and a lack of sense of danger present a challenge to parents and others in keeping the child safe. Children with FASD will often approach strangers and irritate peers with their 'in your face' need for social interaction and friendship. For schools, to offer a 12-year-old student with the impulsivity of a four-year-old the opportunity to access practical curriculum sessions (eg science) relies on a high adult to child ratio.

Shared goals and priority targets mean that intervention becomes focused, cumulative and achievable for all.

Children with CLDD are certainly a unique group of learners, and their experiences formulate a unique and, at times, challenging perspective. Their needs demand that we remodel our pedagogy and that we generate teaching strategies to embrace them as learners. In our journey towards evolving a new generation pedagogy for this new generation of children, differentiation-the process of adjusting teaching to meet individual needs - points us in the right direction. However, it is not in itself sufficient. Children with CLDD require something more (Porter and Ashdown, 2002).

#### **Engagement for learning**

For students with disabilities, engagement (participation of the child in learning) is the single best predictor of successful learning (eg Bulgren and Carta, 1993; lovannone et al, 2003). Without it, there is no deep learning, effective teaching, meaningful outcome, real attainment or quality progress. As teachers, we must penetrate the mask of disengagement generated by many children with CLDD. As ever, we must see beyond the disturbed and disturbing behaviour, beyond the tubes and medical equipment, beyond the physical apparatus to the child as a learner. Our work must be to transform these children into active learners by releasing their motivation, unlocking their curiosity and increasing their participation. Key to this are relationship processes — warmth, sensitivity and responsiveness. From there the child becomes engaged, and their personalised learning journey begins. Their engagement will be the benchmark for assessing whether we have achieved this goal.

#### Personalising learning

What does personalised learning look like for a child with CLDD? David Hargreaves (2006) writes:

Personalising learning demands that schools transform their responses to the learner from the largely standardised to the profoundly personalised.... If students are to engage in deeper learning, they will need new forms of enriched support.

It is a process which will enable us to mould the learning experience directly around the child with CLDD. To do this we have to map the learning needs and pathways of that child. As Corinna Cartwright (2010) observes:

This is on a range of levels — caring for their social and mental health needs and their educational needs. Sometimes this means we need to decide what is of overriding importance at any given time (ie deciding what their most important need is, and wrapping the curriculum around that need).

#### Teaching and learning partnerships

Often we do not yet know the learning needs and pathways for children with CLDD. We need to reach across professional boundaries to illuminate our existing knowledge, and achieve pedagogical reconciliation. Collaborative relationships-with families, with professionals from other disciplines such as health, psychology, speech and language therapy, occupational therapy - provide huge benefits for the child. 'Person Centred Planning' (Department of Health, 2001) and the 'Team Around the Child' (Limbrick, 2005) are excellent models. Shared goals and priority targets mean that intervention

becomes focused, cumulative and achievable for all.

Families are the first educators of their children with CLDD. They are often deeply knowledgeable about their children's conditions and abilities. Schools have access to specialist approaches, knowledge and resources which are valuable to parents in supporting their child. Shared information allows effective planning which ensures the best services and support for the child (Cartwright, 2010).

The information that can be gained from neuroscience (Sousa, 2007) can significantly influence how we develop future pedagogy. This could raise the attainment of these vulnerable children as our teaching becomes better matched to their learning styles. Through ongoing interdisciplinary conversations, we can learn about the implications for and effects of educational practice on the developing brain-for example, how 'imitation' affects mirror neurons in children with ASD (Carpenter, 2007; Ramachandran and Lindsay, 2006) and the effect of the reduced parietal lobe on the maths abilities of children with FASD

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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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