Children with Complex Difficulties and Disabilities: Who are the child/student population?

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Who are these children, and what are their numbers? McClusky and McNamara (2005) state that the latest Government figures indicate that there are as many as 700,000 disabled children in Great Britain, and that 'there are more than 100,000 severely disabled children in the UK and their numbers are known to be rising as a result of medical advances' (p.151). This latter statement directly relates to children whose disabilities, often profound, multiple and complex, are due to prematurity of birth. The EPICure UK study (Marlow et al., 2005) reports that 80% of children born at less than 26 weeks gestation now survive. A comparable New Zealand study (Woodward et al., 2004) suggests a 90% survival rate for pre-term infants weighing less than 1,500 grams at birth, with a 63% disability factor.

The need for intensive, very early intervention with these children is crucial (Carpenter and Egerton, 2005), but, again, do we actually have the intervention strategies that will truly maximise the learning of these vulnerable infants and minimise the impact of their traumatic birth and subsequent fragile health status? Champion (2005) details the brain development of these very-low-birth-weight, pre-term infants and the neurological compromise they face. Many will have complex health needs, requiring invasive procedures such as supported nutrition, assisted ventilation, rescue medication for complex epilepsy (Brown, 2009).

Where these children have severe and complex disabilities (and the EPICure study (Marlow et al., 2005) suggests this is so far well in excess of 50% of surviving infants), their patterns of learning may be different to those we have previously known in children with learning difficulties. For example, the sensory approaches many teachers have found effective for delivering a relevant curriculum may not engage children whose severe/profound and multiple learning disabilities (S/PMLD) emanate from pre-term birth.

Sensory pathways may not only be damaged, but also incomplete and compromised (Champion, 2005).

Another group of children causing major concerns are those with Foetal Alcohol Spectrum Disorder (FASD). International estimates suggest that the prevalence could be as many as 1:100 children (Autti-Ramo, 2002; British Medical Association, 2007; May and Gossage, 2001; Sampson et al., 1997), and the disabling effects range across the learning difficulty spectrum from mild to profound (www.fasaware.co.uk). Their emotional well-being is particularly fragile, leading to high rates of suicide in later life. (Again, the need for teachers to have a deeper understanding of mental health needs, and how to embed emotional well-being into their everyday teaching, is accentuated by this group of children and others; e.g. those with Autistic Spectrum Disorders (ASD)).

Whilst organisations such as the National Organisation for Foetal Alcohol Syndrome UK (www.nofas-uk.org) produce some excellent materials explaining the condition and warning of the perils of alcohol consumption during pregnancy, the need for a pedagogy specifically designed to embrace these children is vital. Take, for example, the fact that in children 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 Mathematics curriculum, if that part of the brain is compromised just how do we teach Mathematics to the child with FASD? A current TDA-funded project, through NOFAS-UK, is beginning to address this issue (info@ fasdeducation.org.uk), but much more needs to be done.

With recent research (O'Malley, 2007) suggesting that attention deficit hyperactivity disorder (ADHD) is a neurological disorder evidenced by a smaller frontal cerebellum, the information that can be gained from neuroscience (Souza, 2007) could significantly influence how we develop future pedagogy. This in turn could raise the attainment of these vulnerable children as our teaching becomes better matched to their learning styles. Whilst there has been much invaluable work around Personalised Learning (led for the Specialist Schools and Academies Trust (SSAT) by Professor David Hargreaves), when you interface this with neuroscience and the implications for mind and brain, the empirical work of Professor Susan Greenfield clearly indicates the exciting, next-level challenge in this debate, for she states (2008):

The mind is the personalisation of the brain through unique dynamic configurations of neuronal connections, driven by unique experiences.

Children with Complex Needs are certainly a unique group of learners, and their experiences formulate a unique and, at times, challenging perspective of this world.

We need to remind ourselves that parents, as the child's first educator, will be trail blazing approaches which support and engage their child. This is never more pronounced than in the area of chromosomal abnormality. Every day, children are born in this country with genetic abnormalities that are rare. Even if there is a diagnosis, they could be one of only a handful of children in this country, maybe even worldwide. One in every 200 babies is born with a rare chromosome disorder (www.rarechromo.org). Families search for information, often at great personal expense (Harrison, Henderson and Leonard, 2007), and become the 'expert' on their children's rare conditions. The need for teachers to be well-trained in family-centred approaches in order to establish a meaningful dialogue, and to work closely and collaboratively with parents in evolving pertinent approaches to education is paramount (Jones, 2007). Fragile X syndrome is now the most commonly inherited genetic cause of learning disability in the UK, and here, again, there are teaching approaches which are not widely communicated or understood by the teaching profession (Saunders, 2001). 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.

ASD also gives rise to severe, profound and complex learning difficulties in some children. The Medical Research Council estimate prevalence of ASD in the UK at 1 in 166 children. More recently, Professor Gillian Baird and her colleagues have calculated that children with some form of ASD constitute 1% of the UK's child population (a ratio of 1 in 86 children; Baird et al., 2006). Many of these children present with severe and complex learning needs. Often adolescence compounds these 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).

Whilst we know much about educating children with ASD (e.g. that they are predominantly visual learners), there are lessons emerging from neuroscience (Carpenter and Egerton,

2007; Ramachandran and Lindsay, 2006) that demand detailed consideration. The challenge for teachers is how to translate this information into classroom practices.

The examples of the children cited above demand that we remodel our pedagogy and, furthermore, that we generate teaching strategies which will embrace these children as learners. The debate around personalised learning, fuelled by the SSAT (www.specialistschools.org.uk), is surely an ideal opportunity to implement this for all children. If teaching is an evidence-based profession, then special education is its enquiry-based arm.

Effective teaching of children with complex special educational needs can happen in a variety of settings. What we need are 'pedagogies for inclusion' (Lewis and Norwich, 2005) that enable all children to be active participants in our school system and receive their entitlement to education. A 'one size fits all' approach to special educational needs (SEN) is naïve. We are working with children in that spectrum of learning difficulty associated with unique learning profiles, often linked to the nature of their disorder (e.g. Down's syndrome, ASD), who require specific and specialised teaching approaches. Even where outstanding teaching of children with S/PMLD exists, there is an ever-increasing group of children with Complex Needs who do not fit the current range of learning environments, curriculum models, or teaching and learning approaches, and who are challenging our most skilled teachers.

Which children am I referring to? Why are our practitioners, skilled in the art of curriculum adaptation, modification and differentiation, unable to address the learning needs of these pupils? It is because there is a 'new breed' of children with complex learning needs. The causal base of the difficulties in learning presented by these children is different from that we have traditionally known, and, because we do not have a hotbed of dynamic training courses spread across the country, enabling teachers to think, create and evolve the 'new pedagogy' – the teaching strategies and approaches that will touch these children at their point of learning need. Even our most experienced practitioners in mainstream and special schools, and SEN advisory services, find themselves challenged by the needs of these children. In truth, we are failing to offer high-quality education to these children who become disenfranchised from the school system. On a daily basis, skilled teachers know that they have not made a difference to a child through their teaching, but it is not their fault.

Defining Complex Needs

As a first step towards focussing our collective energies on resolving unmet need, both in our children, and in our SEN teaching workforce, we need to shape a definition of Complex Needs. This term has become widely used in education, and is the current focus of initiatives by major Government agencies such as the Training and Development Agency for Schools (TDA; www.tda.gov.uk) and Ofsted (Visser, 2009). Generally, it is used to refer to that group of 'new learners' in our schools, but it is loose, unfocused, all-embracing and a 'catch all'. A helpful starting point is the words of Porter and Ashdown (2002):

> *This is 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.*

A less accessible, but nevertheless indicative, definition of Complex Needs is that of Dee et al. (2002):

> *...a complex aggregation of difficulties in more than one area of [their] lives.*

There are a range of words in the literature, all of which indicate that when describing children with Complex Needs, we mean those children in whom two or more disabling conditions 'co-exist' (Visser, 2009), 'overlap' (Dittrich and Tutt, 2008) or 'co-occur' (Rose et al., 2009). The medical field would use the term, 'co-morbidity' to describe this phenomenon. In practice, this could mean children with Down's syndrome and mental health needs, with Noonan's syndrome and physical disability, with cerebral palsy and visual/hearing impairments (due to premature birth) or with ASD and ADHD.

The latter combination is an ideal example of a further dilemma facing teachers. Where two (or more) conditions do co-exist in one child, the styles of teaching intervention recommended to support the pupil's learning may not always be totally compatible. Have we truly thought through the resolution of the pedagogical demands of, say, ASD and ADHD when working with the child? There is a powerful literature base and clear guidance on how to educate a child with either of these disabilities, but how does that look when the conditions co-exist? What is the pedagogical interface? Are there tensions? Which aspects

of which approach take precedence? What are the criteria to inform our professional judgements in resolving such issues?

What is clear, particularly in relation to the group of learners we describe as having 'Complex Needs', is that 'we must seek to build an inclusive curriculum...around adaptation, modification and design...that will be relevant to all learners' (Carpenter, Ashdown and Bovair, 2002).

The Specialist Schools and Academies Trust invites you to contribute to the on-line debate around '**Children with Complex Learning Difficulties and Disabilities**':

- What are your thoughts?
- How would you, informed by your practice, describe Complex Needs?
- Do the issues and dilemmas articulated above resonate for you? If so, in what ways?
- Do you have specific examples of pupils you teach whom you think illustrate a child with Complex Needs?
- Are there particular words and terms mentioned above, or others you know of, which you think push us towards a definition of Complex Needs?

This online debate is open until 18 December 2009. We would welcome your views and contributions.

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