‘Navigators of Learning’

The global challenge of educating students with profound and complex learning needs

By Professor Barry Carpenter

The iNet ‘Charter for leaders in an Era of Transformation and Innovation’ is committed to raising the quality of leaning opportunities for all children in this 21st Century. Indeed, it goes deeper in seeking to ensure that every child is a learner.

Often such exhortations fail to include those children whose educational opportunities may be limited or disadvantaged due to a disability which gives rise to difficulties in learning. Thus it is refreshing to read in the Charter that it seeks assurance from all school leaders that their work will reflect an ‘unrelenting commitment to ensuring success for all students in all settings, including and especially for children with profound and complex learning needs who have equal rights as global citizens’. This equality of educational opportunity, based on a child’s rights as a citizen in their Society, is a fundamental principle if we are to fulfil their entitlement to the kind of education described in the Charter: one that is rich with personalisation, choice, diversity and technological opportunity.

As ever, the Specialist Schools and Academies Trust is at the forefront of recognising that significant innovation is crucial if the aspirations of the Charter are to become a reality and we are to transform our educational system globally to meet the needs of 21st-Century students. The Charter goes on to exhort us ‘to challenge traditional ways of doing things – to determine new “default settings” – building confidence in new ways.’ Nothing could be more appropriate when reflecting on the challenge of how to educate an ever-growing population of children with complex learning needs, the prevalence of whom is impacting on countries throughout the world.

As such, I have borrowed a phrase from the Charter for the title of this paper – ‘Navigators of Learning’ – for this expresses the journey into uncharted waters that educators in all settings – special and inclusive, early years, primary, secondary and tertiary – are involved in. In the 21st Century, children with complex disabilities are presenting new profiles of learning need, which we, as a teaching profession, have not yet resolved how to meet through our teaching styles or

curriculum frameworks. We need to be honest about this – for the sake of our professional practice, and, even more so, for the sake of the children. As it stands we are, what I have recently termed, 'pedagogically bereft' (Carpenter, 2009 – in press). This is not through professional negligence, but rather that, as Society has changed both in its medical skill and moral code, a by-product has been a 'new breed' of children with complex disabilities, whose brain functioning is configured differently to that previously known to educators of children with disabilities (Goswami, 2008a).

This is a phenomenon facing many countries – it is a global challenge. For and with the children, we must navigate their routes to learning. Armed with the tools of personalisation (so powerfully articulated by Professor David Hargreaves in his series of publications for SSAT), we must innovate a responsive pedagogy, one that will transform the life chances of children who otherwise will become disenfranchised from the universal education system, and will be ill-equipped to enjoy active citizenship in 21st Century Society.

The Global Challenge

> *Worldwide, 780 million young children are affected by biological, environmental and psychosocial conditions that can limit their cognitive development.* (Guralnick, 2005)

This quotation, from Dr Michael Guralnick, President of the International Society on Early Intervention, paints the scale of the challenge. All phases of the education system need to listen to colleagues working with young children in Early Childhood Education. They are the first to identify changes in the child population and can alert other sectors to prepare themselves for the necessary changes in curriculum and pedagogy.

Children with Complex Needs are a global challenge requiring global resolution. In fact, I would go so far as to say that it is only through an international sharing of our global wisdom, knowledge and understanding that we have any chance of evolving a framework of education that is meaningful and relevant, and which can truly address the profound learning needs of these children. If I were seeking the very best of current research and practice in relation to various 'new' and emerging complex disabilities, I would turn to different countries for information. On pre-term infants, I would look at the work of New Zealand colleagues (e.g. Champion, 2005; Woodward et al., 2004), and on the medical management/education delivery

interface of these children to Scotland (Brown , 2009). On the burgeoning mental health problems plaguing adolescents in many developed countries (e.g. Australia, UK, Japan), I would turn to work in Austria (Pretis and Dimova, 2007) and Ireland (Coughlan, 2007). On chromosomal abnormalities such as Fragile-X Syndrome, the empirical research of Dr Don Bailey in the USA (e.g. Bailey and Skinner, 2007; Bailey et al., 2000, 2008). For the dramatic immediate and long-term effects of alcohol, and other drugs, on the learning brain, the work of Professor Elizabeth Elliot (O'Leary et al., 2007; Peadon et al., 2008) in Australia or the system of educational provision developed in British Colombia, Canada, around children with Foetal Alcohol Spectrum Disorders (FASD) (Conry, 1996).

There is, of course, the ongoing and almost intangible challenge of poverty. In itself, it can so limit a child's life chances that it impairs their developmental progress to the extent that they find themselves 'disabled'. This is a perpetual challenge that we, as a Global Community of educators, must seek to fight. Let us not forget the liberation from the shackles of poverty that education can bring. For whilst we must acknowledge the devastating impact of poverty, we must work in the hope that we can, through education, deliver some children from the bleakness of that existence.

The World Health Organisation is reported to have said:

> *Poverty, violence and stress will condemn an increasing number of children and young people to life with a troubled mind.* (Northern, 2004)

For almost 40 years in the United States, the Head Start programme has served disadvantaged children in low-income families throughout the nation, with the overt goal of increasing children's readiness for school. The programme has been critically examined over those 40 years. Despite mixed reviews, often dependent on the political and economic climate, the latest longitudinal analysis by Barnett and Hustedt (2005) indicates generally positive evidence regarding Head Start's long-term benefits. Every 1$ spent on children in the early years saved the state $7 later by reducing the intervention necessary on crime, welfare, mental health and job prospects.

The Head Start programme in the USA was the inspiration for our Sure Start programme in the UK. Similar universal childcare programmes helped the Nordic nations abolish child poverty by

catching potential problems early. Within the Head Start Programme, Webster-Stratton and Reid (2004) recently reported their work into early childhood conduct disorders. They stated:

> *This sample of socio-economically disadvantaged preschoolers is at higher risk of developing oppositional behaviour disorders and attentional hyperactivity disorders, as well as experiencing language and learning delays (Webster-Stratton and Reid, 2004).*

Their programme has developed a range of interventions targeted at training teachers and parents to enhance children's social competence, reduce aggression and strengthen early literacy. In so doing, they aim to prevent some of the secondary risk factors such as school failure, peer rejection and conduct disorders. There is a particular emphasis on 'emotional literacy' and helping children to learn words to express their feelings and understand other people's feelings. Such skills as effective problem-solving, anger management, making and keeping friends, and communicating with others are taught during 'circle time' using child-sized puppets.

What is the potential for culturally sensitive, universal application of such programmes? This is just one example of how, as a global educational community, we could pool our resources for the common good.

Vulnerable children

Later in this paper, I will move towards a definition of Complex Needs, but these children are not a homogenous group. In reflecting on this child/student population, comparing them to teaching approaches and curriculum concepts I have employed earlier in my career (Carpenter, Ashdown and Bovair, 2002), I am struck that the over-riding, unifying factor across these children is 'vulnerability'. I have sought to conceptualise the triggers to this vulnerability, which subsequently manifests itself in complex learning patterns, extreme behaviour patterns, and a range of socio-medical needs which are new and unfamiliar to many schools.

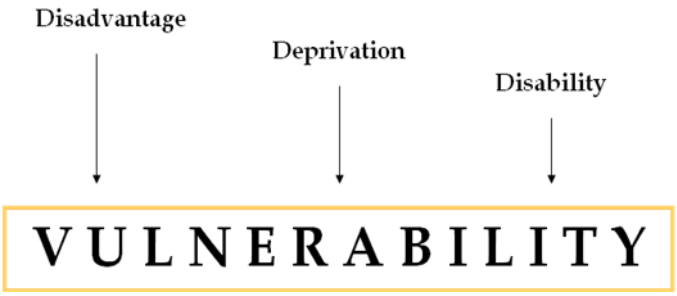

Figure 1. The continuum of vulnerability

Children can fall anywhere on the continuum of vulnerability due to disadvantage, economic or social deprivation or disability. Indeed, some children will find themselves disabled, living in situations of extreme social deprivation, and thus hugely disadvantaged compared to their peers in their own, or other countries. Poverty can increase the risk of a child having an impairment, indeed can create a life of risk for the child whereby they face on a daily basis physical illness, abuse, malnourishment or emotional starvation. It is a sad fact that in the developing world, iodine deficiency is the greatest cause of intellectual disability (Fujiura, 2004). Thus 'the challenge to our *global* society is to loosen and break the stranglehold of poverty on the development of our children' (Mittler, 2000) [my italics].

Whilst education may not be able to overturn poverty in our societies, it can build resilient children: 'resilience factors are those processes which buffer or minimise the effects of adverse stimuli on a person'. (Pretis and Dimova, 2007). Many international studies (Mittler, 1995) have shown that where a child experienced educational success, their self-esteem was raised, enabling them to develop a level of emotional resilience which, in turn, raised their opportunities in life. This, I feel, is at the heart of educational transformation; the capacity to transform a child's life for the better.

Who are the children with Complex Learning Needs?

Largely, there are children in our 21st Century Society, whose causal base of complex learning disability emanates from some new medical or social phenomena – for example: assisted conception or premature birth; maternal drug or alcohol abuse during pregnancy; or medical advances. A UK project looking at mental capacity and wellbeing for children with learning difficulties/disabilities found that:

> *Scientific advances in genetics and neuroimaging offer a potential opportunity within the next 20 years to identify children with learning difficulties in infancy. Cognitive neuroscience is already uncovering neural markers or biomarkers for detecting the different learning difficulties measurable in infancy. Such advances will eventually enable environmental interventions from infancy which would alter developmental learning trajectories for these children with consequent benefits throughout the life course.'*
> (Goswami, 2008b)

Certainly, there is a strong argument for strengthening the interface between neuroscience and education. In the field of Autism alone, where, internationally, work in the USA (Mesibov, Shea, Schopler, 2006), Holland (Peeters, 1999) and UK (Jordan and Powell, 1995), neuroscientific research has generated revolutionary ideas about how to educate this rapidly expanding group of children effectively by mapping the connections between brain states and learning patterns for practitioners. As Frith (2007) states (in relation to people with autistic spectrum disorders):

> *Evidence from MRI studies showed reduced brain activity in self-reflection and attribution of emotional states to 'self'.*

Such insights can greatly aid the process of what I would term 'pedagogical reconciliation', where we seek, through practitioner-led, evidence-based approaches, new and innovative approaches to teaching that generate personalised curriculum pathways, and touch the child with complex need at their point of learning need. They would empower our schools to (in the words of the Charter) 'provide the strongest possible guidance, counselling and other forms of support for all students as they navigate increasingly complex pathways of learning, especially for students who fall behind or are not experiencing success'.

To achieve this, we must find ways of implementing structured opportunities for the professional development of school staff to ensure that what the Charter terms 'new professional capacities' are supported. We have to acquire new professional skills, and more creative and responsive styles of teaching, if we are to meet the challenge of engagement for children with Complex Needs. If we do not, many children will be lost in, and to, our school system; cognitively disenfranchised, socially dysfunctional and emotionally disengaged. Again, research will show that not only are biomedical and psychological factors giving rise to complex needs, but also the

interwoven experiences of poverty, educational disadvantage (Hirsch, 2007) and low educational achievement (Cassen and Kingdom, 2007).

Towards defining 'Complex Needs'

As a first step towards focussing our collective energies on resolving unmet need, both in our children, and in our special educational needs 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 UK 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 Contribution of the International School Community

Such is the complicated challenge of resolving the many issues surrounding children with complex needs, I believe that no country can 'go it alone'. The joint contributions of all countries, through the platform for collaboration and co-operation offered by iNet, will bring us closer to a deep and enriched understanding of how we resolve unmet need in this group of children.
In considering who these children are and what their numbers are, we can already chart a pattern of international contribution that can be maximised throughout the strong and growing network of schools belonging to the SSAT.

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 (as documented by a trans-European study, Soriano, 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. A Scottish study has shown that 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. Ongoing research in New Zealand has shown that 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.nofas-uk.org). For some countries, such as South Africa, prevalence rates of Foetal Alcohol Syndrome (FAS) are very high, with rates of 40+ children per 1,000 in certain South African wine-producing communities (Molteno, 2008; Rendall-Mkosi et al., 2008). An American researcher has shown that their emotional well-being is particularly fragile, and leads to high rates of suicide in later life (Streissguth, 1997). (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? In the UK, a current project funded by the Training and Development Agency for Schools (TDA), through NOFAS-UK, is beginning to address this issue (info@ fasdeducation.org.uk), but much more needs to be done. Indeed, extensive practitioner-led, classroom-based research in Canada has led to the creation of specific curricular designed to address the unique learning needs of children with FASD (Alton, 2006).

With recent research from Canada and Ireland (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 (Sousa, 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 around the world with genetic abnormalities that are rare. Even if there is a diagnosis, they could be one of only a handful of children in their 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, USA, and many European countries and here, again, there are teaching approaches which are not widely communicated or understood by the teaching profession (Saunders, 2001). Research in Ireland (Barr and Millar, 2003) has shown that 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. As well as the educational needs of the child with Fragile X, the reverberations of the genetically inherited condition across families has to be carefully thought through, as recent American research has demonstrated (Bailey and Skinner, 2007). Similarly, the learning spotlight has been shone by groundbreaking Japanese brain research looking at language functioning and impairment in the brains of children with Fragile X Syndrome (Hayashi and Tonegawa, 2007). These insights provide new platforms for teachers to plan creative and innovative learning pathways for children with these complex conditions.

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 international professional learning community

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 children with profound and complex needs is naïve. We are

working with children in that spectrum of learning difficulty/disability associated with unique learning profiles, often linked to the nature of their disorder (e.g. FASD, Fragile X Syndrome, ASD), who require specific and specialised teaching approaches. Even where outstanding teaching of children with mild, moderate or severe learning disabilities 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.

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 world, enabling teachers to think, create and evolve the 'new pedagogy', then the in-roads of progress into this issue are limited. 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 alienated as learners 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.

Hopefully this paper has outlined not only the challenge of children with complex needs, but also given examples of what complex needs may actually look like in the classroom. In essence, not only are 'new'; disabling conditions emerging that present pedagogical challenges previously unknown to teachers, but more children are being diagnosed with co-morbid, co-existing conditions which overlap, merge and intermingle, presenting profiles of learning previously not seen. These may be, for example, ASD and ADHD: which is the dominant learning disability? We know much about how to teach either group of children, but do those teaching approaches fit together when the two disabilities influence learning within one child? It is a process which I will term, 'pedagogical reconciliation'. Obvious as it may seem, that two or more conditions which co-exist in a child need to be reconciled to each other, it is not a practice I observe in our schools.

There is much that the international schools community can do to resolve these issues for teachers, for children, if we marshal our resources, pool our knowledge, and come together in a

spirit of openness and sharing. We need to create a professional Learning Community committed to applying the ethos and principles of the Charter to all children, but especially to those with profound and complex learning needs. Only then will we innovate new, dynamic and personalised learning for children with complex needs, enabling a transformation in their lives, and for our Society(ies) to meet its responsibilities to its most vulnerable children. This is a journey of discovery: there will be times when we are lost, and times when we discover new places of learning. We are all navigators of learning, and for every discovery we make another child, or group of children, becomes engaged as an effective learner. Journey on!

Professor Barry Carpenter
Associate Director (Special Educational Needs)
Specialist Schools and Academies Trust
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