Engaging young children with complex learning difficulties and disabilities

by Dr Carolyn Blackburn and Professor Barry Carpenter

'The CLDD Project aimed to find ways to re-engage children with complex learning difficulties and disabilities through engagement and 'meaningful pathways to personalised learning'

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complex learning difficulties and disabilities found that engagement was critical to effective learning.

N THE 21st century, children with complex learning difficulties and disabilities (CLDD) are presenting new profiles of learning need, which educational professionals have not yet resolved how to meet (Carpenter, 2010). These children will have two or more conditions, that overlap or interlock, which means that their participation and inclusion in early years settings will require informed and reflective practitioners who are equipped with a range of observation and intervention tools to support their learning and development.

The term CLDD encompasses those children with co-existing conditions (for example, autism and ADHD), or profound and multiple learning disabilities. It also includes those who have difficulties arising from recent medical or social phenomena; for example, children born extremely prematurely who, have survived infancy due to medical advances, have disabilities arising from parental substance and alcohol abuse, and/or have rare chromosomal disorders (Carpenter et al, 2011).

Many children may also be affected by compounding factors, such as multi-sensory impairment or mental ill-health, or require invasive procedures, such as supported nutrition, assisted ventilation and rescue medication (ibid). The 218 children involved in the Complex Learning Difficulties and Disabilities Research Project (CLDD) (Carpenter et al, 2011) experienced a range of complex, overlapping, interlocking, co-existing and compounding conditions, ranging between one to 18 conditions per child.

For the four young children involved in the project being supported within the framework of the *Early Years Foundation Stage* (EYFS), these conditions included: Left Hemiplegia, Autistic Spectrum Disorder, Attachment Difficulties, Speech and Language Delay, Speech and Language Disorder, Fragile X Syndrome, Sensory Processing Difficulties, gross and fine motor delay, visual impairment, hearing impairment and social interaction difficulties.

Since child development takes place through a process of progressively more complex interaction between an active child and the persons, objects, and symbols in its immediate environment (Bronfenbrenner and Morris, 1988), the nature of these overlapping and interlocking conditions has implications for the progress these children make against the early learning goals, unless the children's workforce is equipped with the knowledge and tools to prepare the learning environment for their needs.

The CLDD Project aimed to find ways to re-engage children with CLDD through 'meaningful pathways to

personalised learning', using engagement for learning resources developed with educators, multi-disciplinary colleagues, families, project advisors (both UK and internationally-based) and a project steering board.

HOWDOES GOVERNMENT POLICY AFFECT IDENTIFICATION AND ASSESSMENT?

Government policy in England increasingly places importance on the assessment and diagnostic roles of practitioners (Mroz and Hall, 2003) in meeting the individual needs of young children in the foundation stage. The EYFS, the SEN Code of Practice (DfES, 2001), the Child Health Programme (Department of Health, 2008) and the Common Assessment Framework (CWDC, 2009) all emphasise the need for practitioners to work closely with multi-professional colleagues and families in order to identify and assess young children's individual needs at an early stage so that appropriate support can be tailored to specific needs.

The government's SEN Green Paper (DfE, 2011) urges high quality early identification and intervention for all children where they need it: 'Professionals from health services, such as health visitors, and from early years settings work with parents to assess the development of all children to clarify where they need additional support or a different approach.'

It has been reported that the population of children with CLDD is rising (Carpenter et al, 2011). In the last five years, there has been an increase in the numbers of children with disabilities. The most recent figures (Blackburn et al, 2010) show that the number of families recognised as having a disabled child has risen from 700,000 to 950,000 since 2004, and their numbers are thought to be rising (Ramesh, 2010).

Between 2004 and 2009, the total number of children with Severe Learning Difficulties (SLD) increased by 5.1 percent and the total number of those with Profound and Multiple Learning Difficulties (PMLD) rose by an average of 29.7 percent (DCSF, 2010). In 2005, McClusky and McNamara reported that government figures indicated that of the 700,000 disabled children in Great Britain, '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'.

Wolke (2011) attributes some of this rise to an increase in the survival rates of extremely and very preterm babies. Blackburn et al (2010) attribute the rise in part to 'intergenerational poverty and modern medical progress'.





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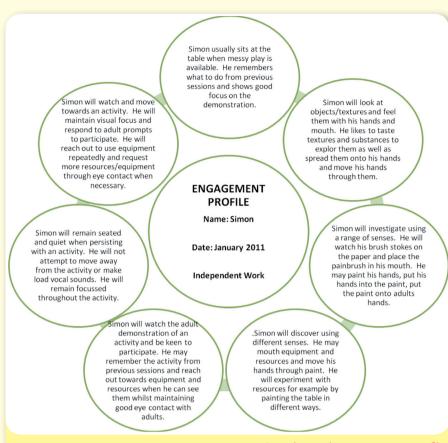


Figure 1: Completing the engagement profile

In order to fulfil the demands, mentioned above, of identification, assessment and support for children and families, therefore, practitioners may need a wider repertoire of tools than has previously been available to them. In addition, knowledge of an increasing range of diverse and complex needs may need to be embedded within the early years workforce.

The importance of 'fit' between the adults and environments supporting children with CLDD is high. The ability of practitioners to identify, assess and support the particular needs of this group of children, given the key role of early childhood intervention (see Allen, 2011; Guralnick, 2005) in improving long-term progress, is crucial.

Further, the early years are far and away the greatest period of growth in the human brain. The connections, or synapses, in a baby's brain grow 20-fold, from having 10 trillion at birth to 200 trillion at three-years-old (Allen, 2011). The importance of early development and learning, therefore, cannot be understated.

WHAT ROLE DOES ENGAGEMENT PLAY IN LEARNING AND DEVELOPMENT?

Child engagement can be defined as 'the amount of time children spend interacting with the environment (with adults, peers or materials) in a developmentally and contextually appropriate manner' (McWilliam and Bailey, 1995).

It could be argued that engagement is the single best predictor of successful learning for children with learning disabilities (Iovannone et al, 2003). It is thought that engagement is critical for learning (McWilliam and Baily, 1992). Further, without engagement, there is no deep learning (Hargreaves, 2006), effective teaching, meaningful outcome, real attainment or quality progress (Carpenter, 2010).

In terms of early childhood, engagement has been recognized as one of the goals of early intervention (Bailey and Wolvery, 1992) and has been the focus of considerable research in early childhood special education (ibid). Within the CLDD project, engagement has been used as an intervention tool with children across the age range, from early childhood to those making the transition to post-compulsory education in Australia, New Zealand, the United States, Ireland, Scotland and England, in a range of educational settings.

Complex learning difficulties and disabilities project

Engagement approaches in early years settings

The concept of engagement in learning underpins the development of all the resources in the CLDD research project's *Engagement for Learning Resource Framework*. The three engagement for learning resources resulting from the CLDD project represent the three facets of an engagement approach to teaching and learning.

The original research questions for the project asked:

- What are the conditions under which the specific child becomes/can become an effective, engaged learner with reference to environment, curriculum, staff support, resources, and so on? If the child is not yet learning, what can be done to get them there?
- In what ways can the quality of the child's experience as a learner be improved?
- What external elements (for example, multidisciplinary targets) need to be incorporated or accounted for within the child's learning experience

Research design: Materials and methodology

The CLDD project adopted a case study (Yin, 2009) approach to investigate the concept of complex learning difficulties and disabilities within a range of educational settings using a participatory action research cycle. Teacher-researchers from educational settings have worked alongside project-dedicated research assistants to develop and trial project resources. A recently developed Accessible Research Cycle (Jones, Whitehurst and Egerton, 2012), designed to easily embed into the routines and structure of everyday practice, was adopted.

Engagement resources were developed, trialled and modified in consultation with the project's development settings (March-July 2010), and trial settings (September-December 2010). All of these settings were special schools – the children involved ranged in age from four to 18-years-old. In January 2011, the tools were trialled in 12 mainstream settings

and two early years settings to ensure that a full evidence base of provision from birth to 19-years-old, and across the educational sector, was secured.

The learning resource framework

The CLDD *Engagement for Learning Resource Framework* resulting from the project comprises:

- Briefing packs on conditions commonly occurring among children with CLDD, from Fetal Alcohol Spectrum Disorders (FASD) to Fragile X Syndrome.
- An Engagement profile and scale.
- An Inquiry framework for learning.

The briefing packs identify the main learning needs and key teaching strategies associated with the needs that children with CLDD will experience, given the co-existing and overlapping conditions already mentioned.

The Engagement profile and scale enables educators at all levels to develop high expectations of children with CLDD around their engagement in learning through identifying the child's levels of engagement in activities, that are of high interest for them, measured against seven key indicators: Awareness; curiosity; investigation; discovery; anticipation; persistence and initiation. By reframing learning activities to address and monitor these indicators of engagement, educators can support the child to move towards deeper engagement in learning.

The *Engagement profile and scale* is a resource that enables practitioners to observe, record and chart the engagement in learning of a child with CLDD towards a personalised learning and development target, and to monitor their subsequent progress. It allows practitioners to focus on the child's engagement as a learner and to create personalised learning pathways. This encourages child-centred reflection, supporting practitioners to develop learning experiences and activities around child's strengths and interests.

Adaptations made through intervention and the effect of the intervention on the child's level of engagement can be recorded and scored on the engagement scale. Over time, it is possible to chart the success of interventions and adjustments, and the effect this has had on the child's levels of engagement play and learning, and subsequent development.

The *Inquiry framework for learning* indicates possible areas for further personalisation of children's learning, and supports an inquiry-focused approach to engaging children with CLDD in learning. The questions within the framework identify the starting points from which educators, in association with the child's family, and colleagues from their own and other disciplines, can explore focused learning issues for individual children, and to formulate potential routes to learning.

CASE STUDYENGAGEMENT TOOLS IN PRACTICE

The following case study of a young child attending a specialist early years setting highlights the engagement

and inquiry-based approach to re-engaging children in learning through use of the CLDD tools. The child's name has been changed to protect his identity and the setting has not been named.

Simon is aged four-years and two-months-old, and has a developmental age of 12-18 months, according to teacher assessment against the development goals of the EYFS. He has Fragile X Syndrome, and Global Developmental Delay. He needs particular support with communication, especially in relation to social interaction, expressive and receptive communication skills. He engages in sensory seeking/calming behaviour (inattention, hyperactivity, vocal outbursts, hand twisting, flapping, twirling).

At the time of the project, his teacher's main concern was regression in skills over a period of several months. For example, whereas previously he had shown some peer interaction, participating in circle time, joint attention sharing with adults, at the time of the setting's involvement in the project, he was spending the majority of his time pacing the room while vocalising, mouthing a variety of objects and other solitary activities. This was of particular concern to his teacher: 'I find it really hard, because I've never taught a child like this ever, not in mainstream settings, not here. We've tried everything. Nothing works consistently.'

Teacher interview, CLDD project

She was concerned that the amount of time he spent in sensory seeking/calming behaviours limited his engagement with the environment and activities, not to mention the adults and peers available to him — therefore, this limited his ability to learn and develop. She was eager to find a way to re-engage him in learning, play and interaction with others.

Step 1: completing the engagement profile

The engagement profile is completed on observation of an activity in which the child would normally be highly engaged (an activity of high interest). Thus, Simon's engagement profile was completed during his participation in a painting session.

During one painting session, his teacher observed that he demonstrated engagement in all seven of the indicators in the profile. This profile, once completed, is a document that can be shared with other practitioners, therapists and multi-disciplinary colleagues who support Simon, other settings he attends and Simon's family. It can be used to provide a picture of what an individual child may do, and therefore, what adults can look for when he/she is fully engaged in an activity of high interest.

Step 2: completing the engagement scale

The engagement scale is an instrument used to highlight learning and development targets, and when used with the other tools in the resource pack, to increase engagement in areas of learning where a child has become disengaged to the point where

This encourages child-centred reflection, supporting practitioners to develop learning experiences and activities around child's strengths and interests

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there is concern about progress and development. A baseline engagement scale is completed on observation of the child involved in an activity/area of learning or development that is causing concern. The child's engagement in each of the seven indicators is recorded, together with ideas for actions/interventions to improve engagement for the next session. Simon's baseline score totalled 2 out of a possible score of 28, highlighting the need to improve engagement.

Step 3: selecting a learning/development target

The data from the baseline engagement scale is used to provide a priority learning/development target. After discussion between the teacher, researcher and other professionals within the setting, it was decided that the most appropriate and meaningful target would be for Simon to engage in an early years play-based environment.

The strategies to support this target mainly focused on the reduction of the sensory seeking behaviours in order to free up his attention and concentration skills so that he could focus on interaction with his environment and peers. It was decided that a strategy using Chewlery (a chewable item specifically designed to satisfy the sensory-based need to mouth objects), which had been used successfully with another child involved in the project would be used to support Simon. While the teacher was waiting for delivery she found that the setting already had a Chewy Tube (a similar item, with a different shape). This proved to be more popular with Simon. Consequently, the tube was used throughout the intervention.

Step 4: using the briefing sheets and inquiry framework for learning

Simon's teacher used the briefing pack for Fragile X Syndrome and found it useful in understanding his condition and particular difficulties. The information helped her and her staff to understand aspects of his condition, such as a dislike of eye contact (which had implications for his communication style and strategies), inattention and hyperactivity, and dislike of certain types of physical touch: 'There are so many symptoms, which could be Fragile X, could be Autism or something else, but knowing that gaze aversion is to be expected helped. Also, the bit about hyper-arousal was useful, we had tried a lot of things like letting him run to see if he could run off the energy, a lot of times he could not calm himself down. If he went to the sensory room he would come back and not be able to calm himself down.

'Also the bit about touch, he won't hold hands, I didn't know about that aspect of his condition. So the sheets helped us to understand him better. We now don't insist on eye contact from him during circle time.'

Simon's teacher also accessed the *Inquiry framework* for learning. This resource highlights particular areas of teaching and learning and asks key questions that may help practitioners to reflect on child engagement

and barriers to effective engagement. It is not related to a curriculum or the EYFS, but is designed to be used with any area of SEND, including children with the most complex needs. Simon's teacher found this particularly useful for highlighting the areas of difficulty she had encountered in engaging Simon in learning. The questions for reflection under each heading are questions contained within the framework, which she found useful in considering strategies to support Simon's learning and development target:

- Engagement: What kind of activity does the child show engagement with? What conditions does the student need to help them focus on the activity?
- *Communication and interaction:* What motivates the child to communicate/interact positively?
- Sensory perception and processing: If the child's own means of getting strong sensory feedback is not appropriate for the learning environment, what other sensory opportunities may be offered to substitute? For example, manipulation toys, mouthing and chewing. What are the child's dominant learning styles tactile, gustatory, proprioceptive, vestibular? Before and during learning, what sensory input does the child need to help them to become ready to learn for example, touch.
- Behaviour for learning: What prior activities increase the child's readiness for learning?

Step 5: implementing, recording and progressing the engagement intervention

Using the engagement tools allowed Simon's teacher and her staff to personalise his learning and development opportunities. Developmentally appropriate (see Nutbrown and Clough, 2006; Wilson, 2003) child-initiated and teacher-directed strategies were used in order to support the learning/development target.

Each observation provided information on how activities could be tailored to suit his individual needs. Time was put aside for the staff team to focus on his progress against the learning target and to plan future strategies to increase engagement. Scoring against the seven indicators highlighted areas needing extra attention and gave staff a common language to talk about his progress and development: This led to an increase in Simon's engagement score from 2 to 18 over a period of eight weeks: see Figure 3. Simon's teacher was happy with the progress that he had made and although an engagement score of 28 had not been achieved, it was felt that the final score of 18 at the end of the eight-week project intervention was realistic given the regression in skills previously been recorded.

Simon's teacher experimented with the Chewy Tube to decide the best way of supporting him. This was given prior to activities, during activities when Simon mouthed or chewed particular objects, and sometimes in conjunction with other sensory stimuli, such as music to act as a calming tool.

Simon's teacher reflected that the Chewy Tube reduced noises and increased engagement in a play-

Figure 2: completing the engagement scale								
Engagement Indicators	Score (0-4)		What happened? What happened/what didn't happen and why?			Next actions What will I do next time and why? How will I make the activity more appealing (see Inquiry Framework)?		
Awareness	0	S picked up the kitchen play mats and a hanger. He moved around without focus making loud vocal sounds. S had no awareness of other toys or what to do with them except mouthing.						
Curiosity	1	hands and	S did not look at other play items. He explored the hanger with his hands and mouth. He did not use the play mat but liked the feel of it scrunched up.			Direct S to one of the activities and model simple play sequences.		
Investigation	1	S investiga	S investigated the hanger but showed no interest in anything else.			Provide Chewlery to give sensory input and maybe stop the vocal sounds so S can investigate the free play items.		
Discovery	0	S was only interested in mouthing, twirling or making vocal sounds.						
Anticipation	0		An adult directed S to other toys and removed the hanger but he showed no interest in these toys.			Show S photos of 2 or 3 items that he is interested in and give him a choice.		
Initiation	0	Repetitive behaviour displayed. No meaningful initiation with any activity.						
Persistence	0		l in his own movement, mouthing and shouting. No e in playing with the toys provided.					
Total score	Total score 2 NB: NOW CIRCLE TOTAL SCORE ON SCALE							
Key for scoring		O No focus	1 Low and minimal levels – emerging/fleeting	2 Partly	sustained	3 Mostly sustained	4 Fully sustained	

based environment. In addition, prior use of Chewy Tube had a cumulative effect (if Simon used the tube prior to participation in activity, he was more engaged during an activity). He learned to discard the tube when other sensory input was present in an activity, suggesting he had not become dependent on it to the point where it was needed constantly.

During the intervention, Simon's teacher also observed other areas of development for future intervention. For example she recorded in one observation that he prefers songs and rhymes with which he is familiar, his difficulty in associating and engaging with new songs/rhymes and the need for frequent repetition of songs/rhymes for Simon to develop an enjoyment of them and to join in.

She also noted that he responded well to being provided with props and visual cues, such as photographs and pictures to assist his participation in circle time activities.

HOWDID PRACTITIONERS PERCEIVE THE ENGAGEMENT APPROACH?

It could be argued that practitioner confidence has improved through use of the tools and, in particular, involvement in the project has been a positive experience for some practitioners.

Simon's teacher reflected at the end of the project that she had expected the project researcher assigned to her setting to solve the issues with Simon's lack of progress and regression, which suggests that she had lost confidence in her own ability to provide solutions: 'We had done everything we could think

of with this child and referred him to so many professionals for a second opinion because we were so worried about him. I thought that you were going to come in and wave a magic wand and say this is what you need to do. Then I realised it was down to us.'

Through using the CLDD engagement tools, alongside the EYFS, this teacher has re-engaged Simon in learning and involvement in his environment. She highlights the benefits of the engagement approach and tools as:

- Setting time aside for observations was useful.
- Using one strategy at a time means persistence with the target beyond the point where you may normally give up.
- The use of scoring helps focus.
- Sharing of ideas with parents and other settings is encouraged (Chewy Tube is now used both at home and the mainstream nursery setting where Simon attends).
- The briefing sheet helped staff to understand Simon's behaviour and to accept that the need for sensory stimuli and being over stimulated are a feature of his personality.

Conclusion

Practitioners involved in the CLDD project have reported that the tools and the engagement approach complement the EYFS and support the range of observations necessary to provide enhanced provision for children with complex needs. As one teacher noted: 'Our ethos is not to do things unto children but to discover what we can elicit from them... engagement is key to that.'

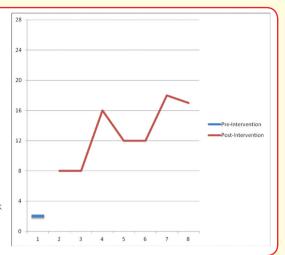
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FIGURE 3: Engagement for Learning outcomes monitored using the Engagement profile and scale

[X-axis – session number over a twomonth period; y-axis Engagement Scale Score].

The pre-intervention marker shows Simon's engagement score before the intervention took place. The post-intervention line shows Simon's engagement score during the 8 week intervention



The landscape of early childhood continues to change rapidly, and with it the profile of needs in young children have diversified and become more complex (Carpenter and Russell, 2005). The range of interventions must also diversify if we are to penetrate the mask of complexity presented by our young children with CLDD. As Champion (2005) astutely comments: 'We also know that interventions which begin early, and which prioritise an emotionally reciprocal and supportive caregiver-infant relationship together with targeted infant learning strategies, have the best chance of promoting optimal development, and therefore of preventing secondary disability in this vulnerable population.'

Certainly, the common thread that can be woven across all of the new generation children with CLDD is their vulnerability. Vulnerable children are fragile learners, and this research project has sought to evolve a range of supportive and informative approaches, which will enable educators to celebrate these children as effective learners. Key to this process is engagement, which we believe to be the antidote to pedagogical vulnerability. The outcome of the project is a *CLDD Engagement for Learning Resource Framework* to support educators of children with complex needs.

Useful resources

The key components are available to download online at http://complexld.ssatrust.org.uk.

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Key points

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