

## Complex needs and Children with FASD

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‘Complex’ is a word often used to describe children with FASD. What does it mean in the context of their learning? What are the implications for educating the child with FASD? What clues does it give us as we plan their individual education programme?

In the 21<sup>st</sup> Century, children with complex learning difficulties and disabilities (CLDD) are presenting new profiles of learning needs, which we, as a teaching profession, have not yet resolved how to meet through our teaching style of curriculum or 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. In relation to children with FASD, teachers can be described as ‘pedagogically bereft’ (Carpenter, 2011). This is not through professional negligence, but rather because, as society has changed in both 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).

### **The learning complexity of children and young people with FASD?**

Children with FASD are certainly a unique group of learners, and their experiences formulate a unique and, at times, challenging perspective of this world. There are a number of elements that come together to create their often highly complex learning profile:

- ***The breadth of learning difficulty***

FASD encompasses deficits in learning, attention, memory and judgement. It also involves difficulties with receptive and expressive language, and in processing communication from others. Individuals with FASD are often misdiagnosed due to assessment outcomes focusing on their behaviours, rather than the alcohol-caused brain damage (Streissguth, Barr, Kogan & Bookstein, 1996). Canadian research has shown that many children with FASD are initially misdiagnosed with autistic spectrum disorder (ASD), Asperger’s syndrome (AS), attention deficit/ hyperactivity disorder (ADHD) and obsessive compulsive disorder (OCD) (O’Malley, 2007).

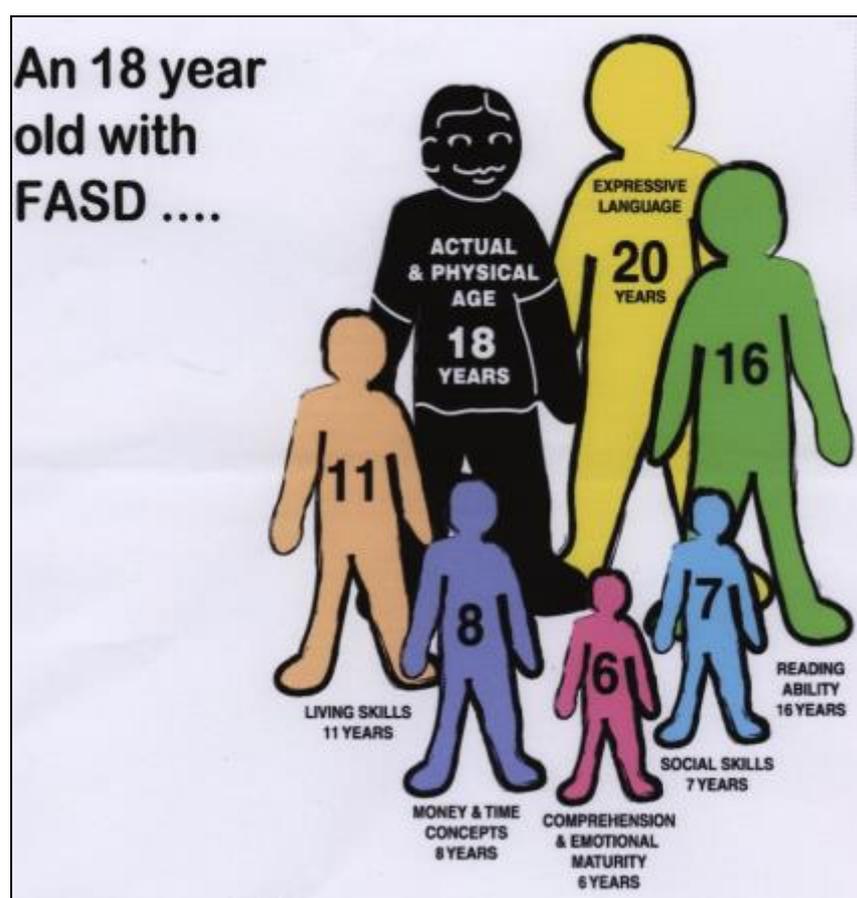
Carr-Brown and Halle, (2005) state that they believe ‘that a proportion of children who have ADHD may have developed it as a result of the mother’s drinking during pregnancy’. Their hypothesis is further extended by Kieran O’Malley (2007) (a Psychiatrist with extensive experience of working with children and young people with FASD), when he says, ‘Children with FASD are true clinical masquerades and ADHD is their most likely disguise’. Many UK school settings will not be aware that they have

children with FASD in their pupil population – they may be present, but with the alternative diagnoses described above.

- ***The unevenness and inconsistency of the learning difficulties***

The developmental profile of children with FASD is variable, and this means that children with FASD are difficult to accommodate within English National Curriculum key stages. Their expressive language may be in advance of their actual age, and their reading skills may be chronologically appropriate. However, in areas such as social skills and emotional maturity, they may be performing at half their developmental age. Mathematical and numerical concepts are particularly challenging for this group of children in that, for some, the parietal lobe, which controls numeracy and computational activity in the brain, may have significantly reduced functioning (Goswami, 2004; Kopera-Frye, Dehaene & Streissguth, 1996). However skilled a teacher may be in differentiating the Mathematics curriculum, if that part of the brain is not functioning effectively, just how do we teach Mathematics to the child with FASD?

The diagram below, from the FASD Trust, powerfully illustrates just how unique the learning profile of the student with FASD can be.



Not only is the learning profile of the student with FASD uneven, or 'spiky', but their ability to carry out activities may vary from day to day. On one day, they are able to

accomplish as task, but on the next, they cannot. This causes frustration to the student and their educators. Educators often feel, mistakenly, that this inability is due to lack of self-application on the part of the student, whereas it is a well recognised feature of the learning profile of a student with FASD.

- ***Secondary impact of difficulties***

It is estimated that as many as 85% of children with FASD end up in the foster care system. As these children grow, they often experience poor mental health and disrupted school experience. It is reported that many young people with FASD will have early entry into the criminal justice system – Kelly (2009) reported that, above age 11 years, 60% of young people with FASD were in trouble with the law, and 50% had experienced confinement. As adults, they may become homeless and chronically unemployed, and many do not complete compulsory education. Without intervention, they will become ‘revolving door prisoners’ (S. Meier, personal communication, 2008). Streissguth and colleagues (1996) found that 3% of 6–11-year-olds and 12% of 12–20-year-olds, and 23% of adults from a cohort of 415 subjects diagnosed with FAS or Foetal Alcohol Effects had attempted suicide. (The adult figure is five times the US national average.)

- ***Compounding factors***

It is clear that FASD is multifactorial (Autti-Ramo, 2002). In various studies, the women interviewed were not only consuming large amounts of alcohol, but were also smoking and using drugs. Research shows 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). Social circumstances were also a factor – women living in poverty were found to be more prone to binge drinking – and there were those women too whose genetic predisposition contributed to the impact of alcohol on the fetus (R. Gray, personal communication, November 2009).

Whatever the background of these children and young people with FASD, the challenge remains: how do we optimise learning for this pupil group? Even more so, we have to ask, how do we teach them? Often teachers, being unaware of this group of children, do not identify them or plan specifically to meet their learning needs.

In the UK, a recent project funded by the Training and Development Agency for Schools (TDA), through NOFAS-UK, has addressed this issue ([www.nofas-uk.org](http://www.nofas-uk.org); [info@fasdeducation.org.uk](mailto: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 curricula designed to address the unique learning needs of children with FASD (Alton and Evenson, 2006).

### **CLDD and Students with FASD**

In this 21<sup>st</sup> Century Society, for students with CLDD the causal base may emanate from some new medical or social phenomena – for example: assisted conception or premature birth, maternal drug or alcohol abuse pregnancy; or medical/genetic advances. Children with FASD form part of this wider group of children with Complex Learning Difficulties and Disabilities. Their learning profile corresponds with the definition of CLDD established

through the Complex Learning Difficulties and Disabilities Research Project supported by the Department for Education. The definition states:

**Definition of complex learning difficulties and disabilities**

Children and young people with Complex Learning Difficulties and Disabilities (CLDD) have conditions that co-exist. These conditions overlap and interlock creating a complex profile. The co-occurring and compounding nature of complex learning difficulties requires a personalised learning pathway that recognises children and young people's unique and changing learning patterns. Children and young people with CLDD present with a range of issues and combination of layered needs – e.g. mental health, relationships, behavioural, physical, medical, sensory, communication and cognitive. They need informed specific support and strategies which may include transdisciplinary input to engage effectively in the learning process and to participate actively in classroom activities and the wider community. Their attainments may be inconsistent, presenting an atypical or uneven profile. In the school setting, learners may be working at any educational level, including the National Curriculum and P scales. This definition could also be applicable to learners in Early Years and post-school settings.

***Conditions that coexist, overlap and interlock***

As described in the preceding chapter, there is an array of learning difficulties associated with FASD – cognitive, behavioural/emotional, social, physical and medical as well as learning difficulties. As well as a range of learning difficulties, young people may also have physical difficulties associated with the condition, including body organ and skeletal damage. For the young man described in the case study overview below, FASD is made more complex through associated attachment disorder, BESD and physical difficulties.

***Requiring a personalised learning pathway***

Educators need to respond to students with FASD in a way that is respectful and affirmatory, and work with them where they are now. Personalised learning pathways need to build on the student's strengths and interests at an appropriate developmental level with realistic expectations from both students and educators. However, they need to incorporate strategies which take account of the student's difficulties with attention, distraction, and memory and build bridges into learning for the student. Educational success for the student needs to be factored into any learning activity to allow them to achieve.

***Transdisciplinary support***

The key to educating children with FASD successfully is a team approach involving representatives of all of the main agencies working with the child and its family. The most successful practice in this area adopts a transdisciplinary approach, where professionals transcend the disciplinary boundaries that often lock them into particular style of single disciplinary practice. In working in the transdisciplinary style in the CLDD project, around the

engagement of children with CLDD, including those with FASD, Dr. Michael Brown, Nurse Consultant for NHS Scotland observed:

*This transdisciplinary interactive approach to Engagement is evolving a common shared language and understanding that is applicable to all disciplines.*

Combining professionals in a transdisciplinary team – around the child gives a powerful dynamic to the process of inquiry. Ultimately our goal for children with FASD is to penetrate that mask of complexity which often shrouds their true learning needs, to then unlock their curiosity, release their motivation and increase their participation.

### ***An inconsistent, atypical and uneven profile***

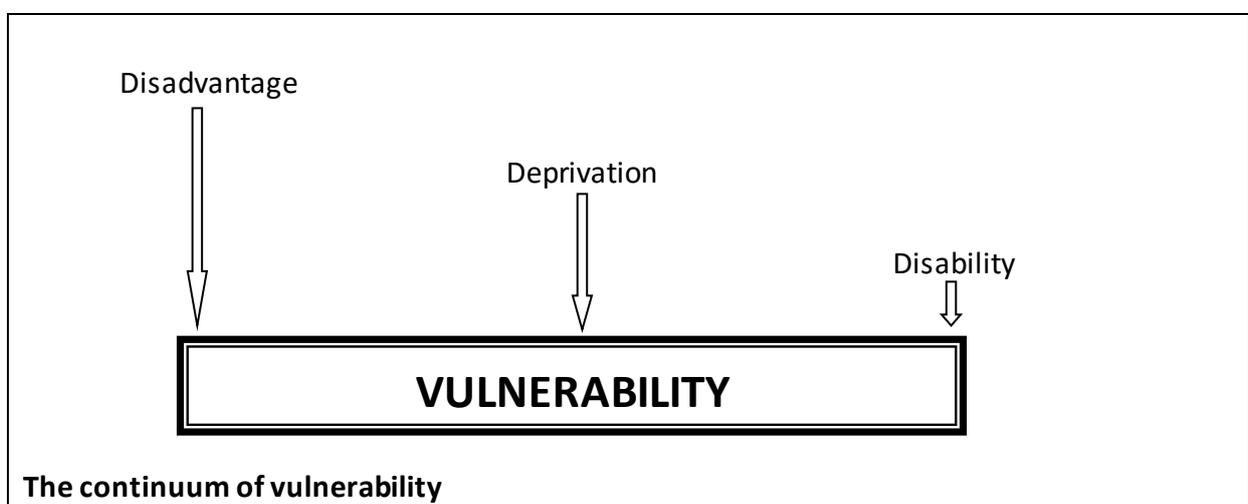
By definition, all children with learning difficulties and disabilities have an uneven profile of learning. What distinguishes those with CLDD are the series of peaks and troughs in their overarching profile. It is what teachers would call a 'spikey profile', represented for the student with FASD by the illustration above.

### ***Working at any educational level***

There are many students with FASD in mainstream schools. Again the picture above illustrates that an 11 year old with FASD could, in National Curriculum attainment terms, have Literacy skills at level 5, but Numeracy at p7. This is not uneven development, this is a spike!

### **Vulnerable children**

While these students with CLDD are not a homogenous group, their over-riding, unifying factor is 'vulnerability'. The diagram below conceptualises the triggers to this vulnerability, which manifests in complex learning patterns, extreme behaviour patterns, and a range of socio-medical needs which are new and unfamiliar to many schools.



Children with FASD can fall anywhere on the continuum of vulnerability due to disadvantage, economic or social deprivation or disability. Whilst education may not be able to overturn poverty in our society, 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, 2008)

Research and practice have shown (Pretis and Dimova, 2008) that where a child experiences educational successes, their self-esteem was raised, enabling them to develop a level of emotional resilience which, in turn, raised their opportunities in life. This is at the heart of educational transformation: the capacity to transform a child’s life for the better. Never was this aspiration more applicable than in the education we offer children with FASD.

### **New generation pedagogy**

To educate these 21st century children meaningfully, effectively and purposefully we must evolve new generation pedagogy. This pedagogy needs to be within the framework of practice that currently exists in schools. Our layers of pedagogy in the classroom therefore become: ‘for all’; ‘additional’; ‘new, innovative and personalised’. The components of new generation pedagogy are:

#### ***Curriculum calibration***

The often variable profile of need and attainment of the child with CLDD can easily result in a fragmented curriculum which lacks cohesion, congruence and continuity. In curriculum calibration, the child’s profile of need is critically reviewed, and their patterns of engagement profiled. A personalised curriculum experience is sought to match each strand of their learning need.

#### ***Pedagogical reconciliation***

This may require ‘pedagogical re-engineering’: adapting or adjusting an approach from our existing teaching repertoire. In this process, we carefully analyse the structure and components of other successful pedagogies in the field of special educational needs (Lewis and Norwich, 2005), and match them to a new generation of children with CLDD. This is a process of analysis, deduction and refinement, reconciling those pedagogies to the unique profile o

#### ***Creation of new and innovative teaching strategies***

Alongside pedagogical reconciliation is the need to create and innovate a new pedagogy that is responsive to the new profile of learning need presented by this evolving cohort of children with CLDD. What are the teaching strategies that will enable us to engage this child as an active participant in the dynamics of our lesson, programme or learning environment? We need specific interventions (Wolke, 2009).

### ***Personalising learning pathways***

Personalising learning enables us to mould the learning experience directly around the child with CLDD. To do this we have to discover the learning needs and pathways of these very diverse children, and establish their learning capacity and learning effectiveness. The child has to see relevance and to find themselves truly engaged in a dynamic and coherent process of learning that makes sense to them.

### **Finding ways to teach children with FASD**

There is a great educational vulnerability around these children with FASD, which means that the current style and structure of many classrooms is not conducive to engaging them as effective learners. Many of their behavioural traits militate against sustained learning with cumulative gains. As one mother, Julia Brown, the founder of the FASD Trust, stated:

*It's like living with someone who is drunk. They are clumsy, suffer memory loss, and display socially inappropriate behaviour. They think they are invincible: that they are Superman and can fly!*

In terms of classroom practice, there are profound implications for teaching students with FASD. As Porter and Ashdown (2002) point out with reference to complex needs:

*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 adaptations to teaching if they are to make progress.*

This seriously challenges our pedagogy and how we teach. What is more than differentiation, if differentiation is the process of adjusting teaching to meet individual needs?

### **Challenges and responses**

Teachers will ask what will these defining characteristics look like as 'learning' in my classroom? Based on recent research in UK classrooms (Blackburn, 2010; Carpenter, 2011), the following is a summary of some of the key 'Learning Challenges' for students with FASD.

Learning challenges for children with FASD:

1. Slower processing pace
2. Memory problems
3. Gaps and inconsistencies in understanding
4. Difficulty in processing and sequencing auditory information
5. Impulsivity and distractibility
6. Anxiety about change
7. Incomplete concept of self

8. Social interaction and peer group difficulties
9. Limited attention span
10. Hyperactivity and inattentiveness.

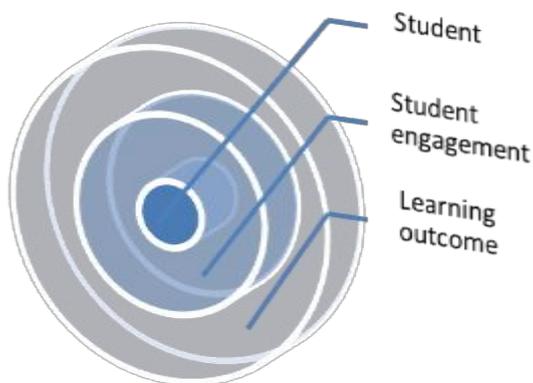
This is where we have to meet the complex needs of children with FASD, with fresh, creative pedagogy: 'We must seek to build an inclusive curriculum . . .around adaptation, modification and design . . .that will be relevant to all learners' (Carpenter, Ashdown and Bovair, 2002).

### **Finding ways to teach children with FASD**

#### ***Engaging students with FASD***

A key output from SSAT's Complex Needs Project (<http://complexld.ssatrust.org.uk>) has been that the new pedagogy required for this group of learners, including those with FASD, needs to be built on 'engagement':

*Sustainable learning can occur only when there is meaningful engagement. The process of engagement is a journey which connects a child and their environment (including people, ideas, materials and concepts) to enable learning and achievement.*



**Figure 1. Relationship between engagement and learning**

Literature has widely endorsed that 'for students with disabilities . . . engaged behaviour is the single best predictor of successful learning', (Iovannone, Dunlop, Huber and Kineveral, 2003; Brooks, 2010). It is the bridge between the student and their learning target.

Engagement not only enhances the process of differentiation it personalises it leading to what can be termed, 'Personalised Engagement'. This concept builds on, and refines for this pupil group, the process of personalising learning advocated by David Hargreaves:

*Personalising learning demands that schools transform their response 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...*

Engagement is a powerful vehicle for the student/learner voice as the child, either through voice or by implication, demonstrates their preferences for engagement style and the pathway by which, and through which, they will engage.

### **The CLDD Engagement for Learning approach**

The Engagement Profile and Scale<sup>1</sup> is a classroom tool developed through SSAT's research into effective teaching and learning for children with complex learning difficulties and disabilities. It allows teachers to focus on the child's engagement as a learner and create personalised learning pathways. It prompts student-centred reflection on how to increase the learner's engagement leading to deep learning.

Engagement is multi-dimensional, and encompasses awareness, curiosity, investigation, discovery, anticipation, persistence and initiation. By focusing on these seven indicators of engagement within the Engagement Profile and Scale, teachers can ask themselves questions such as: 'How can I change the learning activity to stimulate Robert's curiosity?' 'What can I change about this experience to encourage Shannon to persist?' The adaptations made and the effect on the student's level of engagement can be monitored and recorded, together with a score 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 student's levels of engagement. This can then be applied to other learning situations for the student.

Schools and individual teachers may already focus on engagement for their students, but often this valuable and time-consuming personalising of learning goes unrecorded and the outcomes unmonitored. The Engagement Profile and Scale offers a means of doing both.

### **Using the CLDD project's Engagement Profile and Scale**

Classroom accommodation, adaptation and amelioration are required to engage children with FASD as effective learners. The following is a case study of a young man with FASD who was involved in the CLDD Research Project. It describes an intervention devised by his class team, and structured and monitored using the Engagement Profile and Scale. The intervention resulted in his increased engagement and independence in learning, and was able to be generalised to other lessons.

### ***Introduction***

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<sup>1</sup> The Engagement Profile and Scale is currently under development as part of the on-going project and therefore cannot be illustrated as part of this article.

Naseem (not his real name) is a young man of 15 years, who has been diagnosed with FASD and moderate learning difficulties, made more complex by attachment disorder and behavioural emotional and social difficulties (BESD). He also has growth issues and talipes bilateral. His teacher had reviewed Naseem's learning, and concluded that one of his most important barriers to learning was his apparent inability to complete tasks and activities. This target was therefore established as a priority learning need for Naseem, and became the focus for the intervention.

### ***Using the Engagement Profile and Scale***

The Engagement Profile and Scale works on the principle of enabling a student's engagement through personalisation of an activity or learning task which enables students to attain their learning targets. It offers a way of recording the pathways and monitoring outcomes of personalising learning through an engagement score.

### ***Completing the Engagement Profile***

An Engagement Profile was drawn up for Naseem by observing him taking part in a favourite activity – and describing his actions against each of the seven engagement indicators. This allowed all educators to recognise the level of engagement that Naseem was capable of and the kind of behaviours they were aiming for in other activities. It helped them to develop high expectations for Naseem.

### ***Establishing a priority learning need***

His teacher and teaching assistants identified his individual strengths, difficulties and motivators so that the activity could be personalised to increase his engagement with it. His difficulties, in common with many students with FASD, were a high level of distractibility, and the need for continual reminders and prompts from the staff working with him to keep him on task.

Naseem's first target was to complete his class job of setting the table for snack. Keeping in mind the Naseem's barriers, the teacher used the following strategies – introduced over a number of sessions – to allow Naseem to achieve success:

1. She developed a series of visual photographic prompts for each part of Naseem's task to aid his memory retention. The photographs were initially sequenced in the right order as he found sequencing difficult, but in later sessions, to extend Naseem's independence, he was given the responsibility for sequencing the photos.
2. The teacher physically modelled and rehearsed with Naseem how to use them to build on his kinaesthetic learning strengths, rather than relying on auditory instruction which Naseem struggled to process and retain.
3. Students with FASD need repetition of facts or requests many times, as they have difficulties with retaining learning. Use of the visual prompts allowed a continuing

permanent reminder to Naseem of the task he was doing and the steps he needed to make to complete it. It is important to 'script' the task or activity so that the child can link fragments of knowledge and make a 'whole' response.

4. The teacher praised Naseem, increasing his self-esteem and self-confidence. It is also important to share a students' achievement with their family, so that they can further reinforce the successes.

In this way, the teacher supported Naseem to keep active as a learner and to experience success.

### ***Monitoring outcomes using the Engagement Scale***

Naseem's baseline engagement was documented using the Engagement Scale prior to the intervention taking place. This allowed the teacher to show Naseem's progress from his original level of engagement with the activity before the intervention to his post intervention level the intervention was in place.

The graph below shows the intervention engagement outcomes for Naseem over a two-month period.

The 'Pre' marker, shows Naseem's level of engagement before his teacher put the interventions in place.

The 'Post 1' line shows Naseem's progress in completing his classroom job. As Naseem increased in his ability to engage with the activity, the teacher added new elements to extend and expand his learning. These extensions broadly correspond to dips in his engagement as each unfamiliar element was included within his photographic task instructions, and then increasing engagement as his confidence grew. The extensions to the task were introduced as follows:

<b>Target 1:</b> To complete allocated class job (see graph below: Post 1)
Strategy 1: Visual Schedule - eight photographs in correct order to support completion of activity (Session 1)
Strategy 2: Eight photographs in incorrect order to support independence in completion of activity (Sessions 2–6)
Strategy 3: Peers instructed not to interact with Naseem (Session 6)
Strategy 4: Additional job: to make drinks to give him more responsibility (Session 7)
Strategy 5: Fewer photos (5) (Session 8)
Strategy 6: Additional job: putting cups out (Session 9)

Strategy 7: One additional photo introduced for additional element of task (Sessions 10–11)
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Strategy 8: Additional job: to pour drinks (Sessions 12–16)
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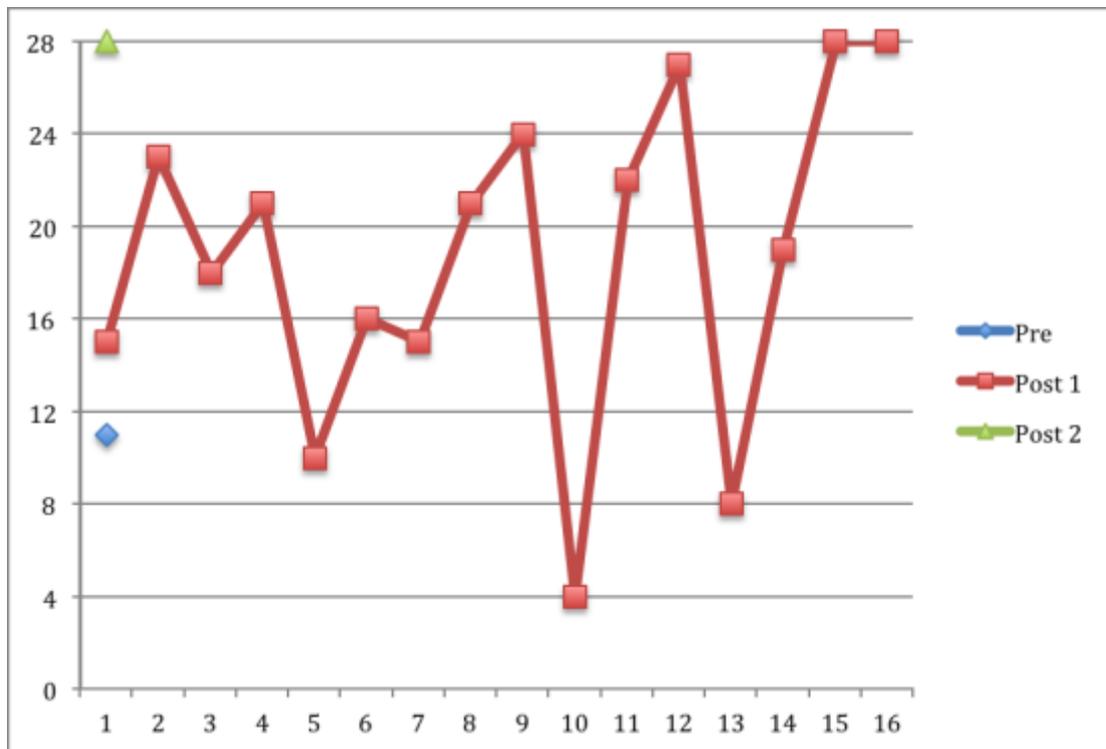
Following Naseem's success using the sequenced photo cues for completing his class task, the teacher decided to generalise this strategy to his Science lessons. Previously, Naseem had never been able to set up the equipment for his science experiments, so it was hoped that the photo cues strategy would be effective in this situation. His teacher created a set of photos showing each piece of science equipment needed for a practical and where in the classroom they were to be found, with a final photo of how the equipment should look when it was set up.

Naseem entered the Science room, set out his photos and collected the equipment. He got only one piece wrong, bringing a glass rod rather than a thermometer, but he was able to correct this when questioned what the photo was. He then set up the equipment perfectly apart from putting the thermometer in upside down.

The 'Post 2' marker on the graph below shows the success of this intervention. His teacher noted in the Engagement Scale comment boxes: 'Naseem went straight to where his photos kept, put them out in correct order and looked at them... He started task without being needed to be told... It was a massive improvement; he completed the whole task without the teacher needing to intervene and keep him on task.'

The teacher concluded of the intervention: 'It was an amazing success. I will now start to photograph all practicals to have a set of photo packages for all students to use.'

**Graph showing Naseem's Engagement for Learning outcomes monitored using the Engagement profile and scale [X-axis – session number over a two-month period; y-axis Engagement Scale Score]**



This case study overview shows the benefits for both student and educators of personalising learning for students using appropriate strategies (concrete visual cues; modelling; praise) to meet the acknowledged learning strengths (visual/kinaesthetic learning style) and needs (distractibility, difficulties with memory) of students with FASD, based on the concept of Engagement in Learning.

### **Conclusion**

Engagement is the bridge between the student and their learning target. Without engagement, there is no deep learning (Hargreaves, 2006), effective teaching, meaningful outcome, real attainment or quality progress (Carpenter, 2010a). Children with CLDD need to be taught in ways that match their individual learning styles by teachers who recognise their abilities and potential for engagement in learning. Our work must be to transform children with CLDD into active learners by releasing their motivation, unlocking their curiosity and increasing their participation. A focus on engagement can underpin a process of personalised inquiry through which the teacher can develop effective learning experiences. Using evidence-based knowledge of a child's successful learning pathways, strategies can be identified, high expectations set, and incremental progress recorded on their journey towards optimal engagement in learning.

These 'partnerships in learning', are vital if we are to unravel the complexity of the learning profile for the child with CLDD, for, as Rose (2010) says:

*If we are to move beyond the tokenistic we have to develop a commitment to engagement based upon mutual respect rather than seeing one part of such partnerships simply as a source of information.*

Through this process of creating a personalised pathway to learning, the teacher finds themselves involved in intricate inquiry – exploring, investigating and discovering. This was observed many times during the CLDD Research Project, with one Headteacher noting:

*You have to acknowledge that you don't have all the answers. Contexts and children have changed dramatically. We need a 'finding out culture' in schools.*

To achieve this, we must be find ways of implementing structured opportunities for the professional development of school staff to ensure that 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 FASD specifically and CLDD more widely.

Looking to the future, there is a strong argument for strengthening the interface between neuroscience and education. Information from neuroscience (Sousa, 2007) could significantly influence how we develop future pedagogy for students with FASD. Access to the anatomy and physiology of the developing brain will further contribute to the accuracy of diagnosis, and enable us to better understand how the child with FASD learns (Giedd and Rapoport, 2010). It could raise the attainment of these vulnerable children as our teaching becomes better matched to their learning styles. Goswami (2008b) writes:

*Scientific advances in genetics and neuroimaging offer a potential opportunity within the next 20 years to identify children with learning difficulties 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)*

For, and with children with FASD, we must navigate their routes to learning. Armed with the tools of personalisation (Hargreaves, 2005), we must innovate a responsive pedagogy, one that will transform the life chances of these children. If we do not, many children with FASD, will be lost in, and to, our school system: cognitively disenfranchised, socially dysfunctional and emotionally disengaged. As teachers we must acquire the knowledge, understanding and skills to equip them to enjoy active citizenship in 21<sup>st</sup> Century Society.