

Children with complex learning difficulties and disabilities: developing meaningful pathways to personalised learning

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Introduction

Complex learning difficulties and disabilities (CLDD) have been described as a 21st Century frontier for education. Children with CLDD include those with co-existing conditions (eg autism and ADHD), or profound and multiple learning disabilities. However, they also include children who have newly begun to populate our schools – among them those with difficulties arising from premature birth; those who have survived infancy due to medical advances; those with disabilities arising from parental substance and alcohol abuse; and those with rare chromosomal disorders. Many may also be affected by compounding factors such as multisensory impairment or mental ill-health, or require invasive procedures, such as supported nutrition, assisted ventilation and rescue medication. However, their unifying factor can be described as ‘pedagogical vulnerability’ (Carpenter, 2010a), which may manifest in complex learning patterns, extreme behaviour or a range of socio-medical needs which are new and unfamiliar to many schools.

The population of children with CLDD in our schools is increasing. Over the last five years, there has been a massive increase in the numbers of children with disabilities in the UK. The most recent figures from Blackburn et al (2010) show that numbers of families recognised as having a disabled child have risen from 700,000 to 950,000 since 2004, and Blackburn observed that their numbers were known to be rising as a result of medical advances (Ramesh, 2010). The numbers of children with severe and complex needs in one local authority more than doubled between 1981 and 2001 (Emerson and Hatton, 2004). Between 2004 and 2009, the total number of children with SLD increased by 5.1 per cent

and the total number of those with PMLD rose by an average of 29.7 per cent (Department for Children, Schools and Families, 2010).

This trend is also noticed in schools. One head teacher writes:

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

Another comments:

‘Three years ago, we had up to seven children with gastrostomies – we now have 16. Just recently, we have enrolled two students with tracheotomies who need full time medical support.’ (Fergusson and Carpenter, 2010)

The learning patterns of children with CLDD are different to those we have previously known. We have spent the last 20 or more years focusing on the delivery of a curriculum. The resulting innovation in this time has genuinely broadened and enriched the learning framework for children with special educational needs. However, the time has come to refocus on learning and the learning context. We must strive to capture a pedagogy for this new group of learners, and to deepen our understanding of their learning styles and needs.

CLDD research project

Between September 2009 and March 2011, the Specialist Schools and Academies Trust (SSAT) are carrying out Department for Education-supported research into developing meaningful pathways to personalised learning for children with CLDD. The programme of

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research has brought together a multidisciplinary team of researchers and advisors with specialisms across education, health, psychology, therapies and neuroscience. In Phase 1 of the project, the research team worked together with 12 special schools and staff, 60 children, and their parents/carers, using an action research approach, to develop educational tools to enable practitioners to formulate an effective teaching and learning package for the children with CLDD in their classrooms. The project builds on and synthesises existing national and international expertise in the field, as well as drawing upon practitioner experience to develop and trial modified and new approaches for these children. The tools developed during Phase 1 are now being trialled in 50 further special schools in the UK and 15 internationally between September and December 2010. Following this phase, there will be a mainstream trial (January–March 2011).

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The outcome of the project will be a resource 'tool box' to support educators of children with complex needs, and will include:

- A series of information sheets on conditions which commonly co-exist in children with CLDD giving information on effective educational strategies
- A profiling and monitoring tool focusing on engagement
- A flexible educational practice framework, inclusive of multidisciplinary involvement and linked to the five outcomes of *Every Child Matters*
- Downloadable training materials.

Developing effective educational approaches

Four key tenets of effective educational approaches emerge from literature:

1. The dialogue with neuroscience

Research insights from neuroscience could shape teaching approaches that are better matched to learning styles of children with CLDD, thus raising their attainment, and resulting in lifelong benefits (Goswami, 2008). For example, what are the implications for teaching of the discovery of a relationship between mirror neurons and imitation in children with ASD (Carpenter, 2007; Ramachandran and Lindsay, 2006), and a reduced parietal lobe on the maths difficulties of children with FASD (Cohen Kadosh et al, 2007).

2. Transdisciplinary approaches

Often we do not yet know the learning needs and pathways for children with CLDD. We need to reach across professional boundaries to illuminate our existing knowledge, and achieve pedagogical reconciliation.

Collaborative relationships – with families, with professionals from other disciplines such as health, psychology, speech and language therapy, occupational therapy – provide huge benefits for the child. 'Person Centred Planning' (Department of Health, 2001) and the 'Team Around the Child' (Limbrick, 2009) are excellent models. Shared goals and priority targets mean that intervention becomes focused, cumulative and achievable for all.

3. Student engagement in the context of personalised learning

As Hargreaves (2006) suggests, schools need to:

'... transform their response to the learner from the largely standardised to the profoundly personalised.'

Children with CLDD need a curriculum which is wrapped around them in order to engage in learning (Cartwright, 2010). For students with disabilities, engagement (participation of the child in learning) is the single best predictor of successful learning (eg Iovannone et al, 2003).

4. Partnership with families

Families are key to our ability to achieve effective educational approaches for children with CLDD. Educating a child with CLDD is a collaborative venture. The parent is the child's first educator. By the time their child enters school, many parents will have researched, inquired, visited and discussed with everyone who can shed light on their child's condition and future development. Together, parent, teacher and other professionals can illuminate the learning pathway for the child, using a combination of acquired information, applied wisdom and previous experience.

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 three 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. Delivery of the curriculum to the child with CLDD needs to be sharp, focused, meaningful and purposeful, as well as balanced. 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.

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. We should not underestimate the magnitude of this challenge, which demands a significant shift in thinking and a more inquiry-based style of teaching rather than the curriculum driven styles of the last two decades.

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 of the learner with CLDD.

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).

The engagement approach

Engagement is the bridge between the student and their learning target (see *Figure 1*). 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,

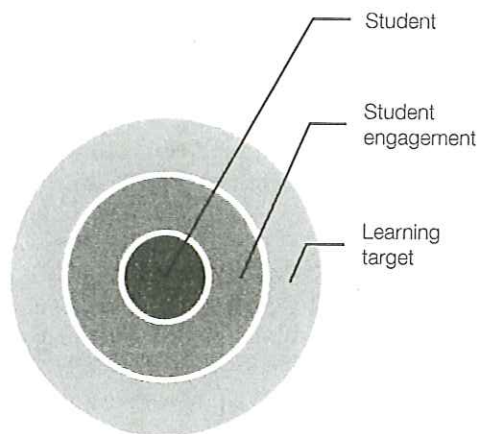


Figure 1: Relationship between engagement and learning

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.

The Engagement Profile and Scale¹ 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?' and '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.

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¹ The Engagement Profile and Scale is currently under development as part of the ongoing project and therefore cannot be illustrated as part of this article.

Schools and individual teachers may already use an engagement approach, 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, as described below.

Using the CLDD project's Engagement Profile and Scale

The following is a case study of a young girl involved in the CLDD research project. It describes an intervention, structured and monitored using the Engagement Profile and Scale, which resulted in her re-engagement with formal communication.

Introduction

Eva (not her real name) is a six year old girl with tuberous sclerosis (TS), epilepsy and global learning and communication delay, in addition to major social and communication difficulties and associated behavioural difficulties. She also has cardiac rhabdomyoma (a heart tumour associated with TS) which requires monitoring. She lives with her family, and is dependent on carers for all aspects of care in all environments, and requires access to trained staff for acute management of multiple daily seizures.

Eva attends a leading day special school which offers many specialisms. She currently has multidisciplinary support from a community nurse, family support worker, occupational therapist (to address sensory issues), a speech and language therapist, music therapist and numerous consultants, one being a neurologist. Eva's teacher supports an interdisciplinary approach, and makes it priority to communicate with these colleagues and Eva's parents.

Eva is currently working towards P1 (i) in all subjects, although her teacher and parents feel that she is functioning slightly above this level, which reflects Eva's behaviour difficulties during the assessment process. (Her attention skills and alertness vary depending on seizure activity and her interest in the task.)

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.

In structuring the intervention using the Engagement Profile and Scale, the school-based teacher researcher and the research assistant needed to establish Eva's priority learning need as a focus for the intervention, and identify her individual strengths, difficulties and motivators so that the activity could be personalised to increase Eva's engagement with it.

Completing the Engagement Profile

Using the Engagement Profile and Scale, a high-engagement profile was drawn up for Eva by observing her involved in water play – a favourite activity – and describing her actions against each of the seven engagement indicators. This allowed all teaching staff to recognise the level of engagement that Eva was capable of and the kind of behaviours they were aiming for in other activities. It helped them to develop high expectations for Eva.

Establishing a priority learning need

Eva's teacher identified communication needs, self-harming and lack of motivation as the three key factors preventing Eva from fulfilling her learning potential, and felt that the first two were linked. Eva's current three main strategies for communicating with adults were: reaching towards something she wanted to eat; backing herself on to an adult's lap to request a cuddle; and screaming and self-harming/biting to express frustration and to communicate what she did *and* didn't want. Consequently teaching staff were often confused about the cause of her distress.

Both Eva's teacher and her parents selected her priority learning need as establishing meaningful communication/choice-making based on the Picture Exchange Communication System (PECS). Due to Eva's regressive condition, many strategies that had been successful in the past were no longer working, and both staff and her parents were finding it difficult to come to terms with this. Observation showed that while she used to be able to understand symbols, they now appeared to have no meaning for her. This priority learning need accorded with a number of Eva's learning objectives and *Every Child Matters* outcomes:

SSEN learning objective: To develop communication skills

School focus: Student autonomy and self-advocacy

Long-term target: To initiate communication in a variety of situations to help relieve frustrations

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Every Child Matters outcomes

Be healthy: To choose appropriate healthy foods

Stay safe: To make choices, relieving frustration and hopefully leading to a decrease in self-harm

Enjoy and achieve: To enjoy making her own choices; to show achievement and success in choice-making

Make a contribution: To make a choice within a group; to turn take.

Economic well-being: *No current correspondence*

After discussion among staff and the research assistant about Eva's levels of understanding and functional communication, they replaced the symbols in her communication system with True Object Based Icons (TOBIs). The tactile quality of these thick, cut-out photographic images allowed Eva to focus on and understand the image.

Identifying a motivating context

Although Eva's interests are very limited, she is highly motivated by food. She can finger feed and drink from a spouted cup. Therefore snack times were chosen as an initial context for communication.

Prior to the intervention, at snack times Eva was seated at the table with peers either side of her. She needed close and constant staff support to prevent her self-harming, and reaching and grabbing at what she wanted. She made no attempt to use her PECS board when it was offered. When there was no more food on her plate, she would become distressed, then get up from the snack table and wander around the classroom. The total baseline Engagement Scale scores across all engagement indicators for Eva's engagement in communication during two snack sessions was 2 of a possible 28.

Identifying and addressing the barriers to engagement

From real-time observation and subsequent review of video and discussion by the teacher and teaching assistants, the following barriers to Eva's engagement were identified over a number of sessions.

- *Lack of understanding.* As Eva wasn't able to understand symbols, her choices weren't currently meaningful. She needed a personalised choice board which used TOBIs instead of symbols to indicate choice. Once choices were no longer available, they needed to be removed from the choice board. Eva also needed specific teaching in relation to

PECS to help her understand how to communicate using the system. The number of choices on the board needed to be reduced so she was not overwhelmed.

- *Using challenging behaviour to get her needs met.* Teaching staff minimised their response to Eva's behaviour, while using hand-over-hand, gentle physical prompt and/or gesture to direct her to use the TOBIs to exchange for snack items.
- *Raised anxiety levels.* Eva is auditory and tactile defensive. Sitting at the table with peers either side of her meant her space was invaded, and the noise levels were high. She was unable to focus on learning the new communication system. Therefore, Eva was temporarily moved away from the rest of the group, giving her a calm environment in which she was able to attend to the exchange of a TOBI for her chosen food item. When she had learned the system, she would be seated at the periphery of the group.
- *Auditory processing issues and processing time.* Eva finds it difficult to process spoken language, therefore verbal communication was minimised. Staff also gave her longer to process simplified speech/TOBIs and to make choices.
- *Self-harming.* Eva had to wait for longer than she was capable for her turn, resulting in episodes of self harming. Therefore, intervals between waiting for her turn needed to be reduced. Her raised anxiety levels were also causing her to self-harm, so it was decided to move her away from the group to calm.

During one-two sessions each week, the Engagement Scale was used to score her engagement level, and decisions were made about how the activity could be further personalised in the next session to increase her engagement still more. Whenever possible, video was reviewed as it gave a much fuller and more accurate record of events and allows time to notice things which would otherwise be missed.

Monitoring outcomes using the Engagement Scale

Eva's baseline engagement data (including two observation schedules) were taken during two snack time sessions both on the same date. This took place in within the classroom once with her peers at a busy table and one staff member, the second time on a one to one teaching table with two staff. The post-intervention scoring increased as changes

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Table 1: Engagement Scale data for Eva G.

BASELINE		
DATE	SCORE	OBSERVATION SUMMARY
30.3.10 (AM)	1	Eva showed distress, and lack of understanding of the communication system or staff verbal instructions. She indicated what she wanted by reaching towards it, and made repeated attempts to grab food from other students.
30.3.10 (AM)	1	
INTERVENTION		
DATE	SCORE	OBSERVATION SUMMARY
30.3.10 (PM)	13	TOBI choice board introduced and modelled hand-over-hand.
19.4.10	14	Eva remained focused on the TOBIs for the duration of the activity, and showed curiosity and investigation. Although she became cross and anxious when the food on the plate was nearly finished, however she remained sitting when normally she would lose interest in the snack activity and walk around.
21.4.10	15	
17.5.10	15	Eva showed anticipation by seating herself at her snack table as she saw the TOBI choice board being set up. Eva started to use eye pointing to the TOBIs to indicate a choice, so eye contact was reduced during snack time to encourage her to refocus on picture exchange. Eva stopped reaching out to grab food, although was still anxious when her plate was empty.
19.5.10	6	
20.5.10	10	
24.5.10	5	
25.5.10	10	
28.5.10	11	
9.6.10	15	Although a gentle physical prompt was still given at times for Eva to pick up the TOBI from the communication board, she became more independent in using it and less anxious when the food came to an end. On the 14.6.10, for the first time Eva vocalised at a TOBI, then laughed. She became more confident when using the TOBIs. Staff now gave her more processing time, and a clear start and finish for the snack.
10.6.10	13	
14.6.10	18	
17.6.10	16	
21.6.10	15	
28.6.10	22	
30.6.10	22	Although on 2.7.10, Eva was distressed all day, and could not focus on PECS, by 7.7.10, she showed sustained engagement throughout the snack activity.
1.7.10	2	
2.7.10	23	
5.7.10	24	
7.7.10	28	

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were made to the activity over subsequent sessions to personalise it further for Eva. Outcomes are shown in *Table 1* and *Figures 2a and 2b*.

Intervention postscript

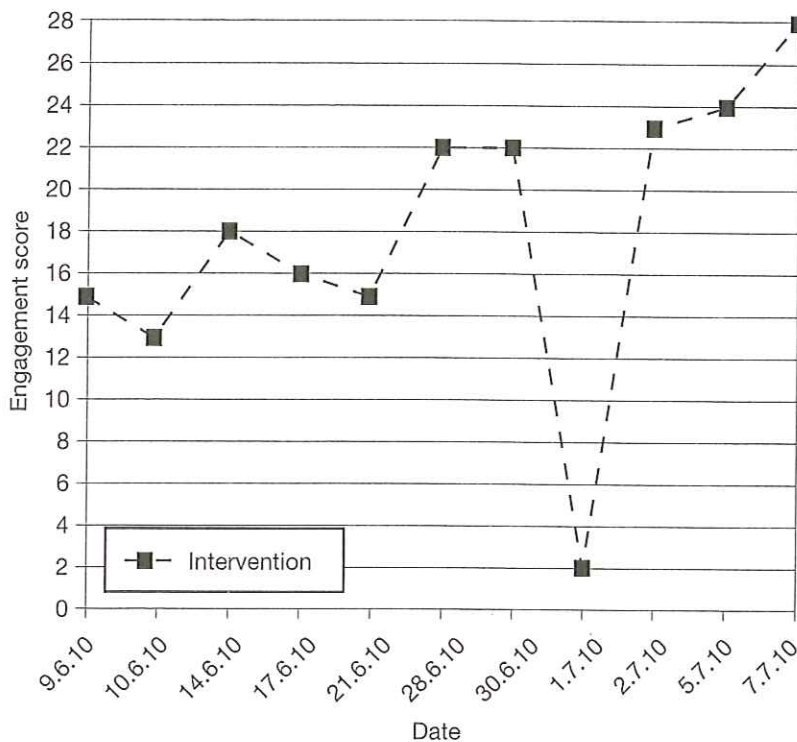
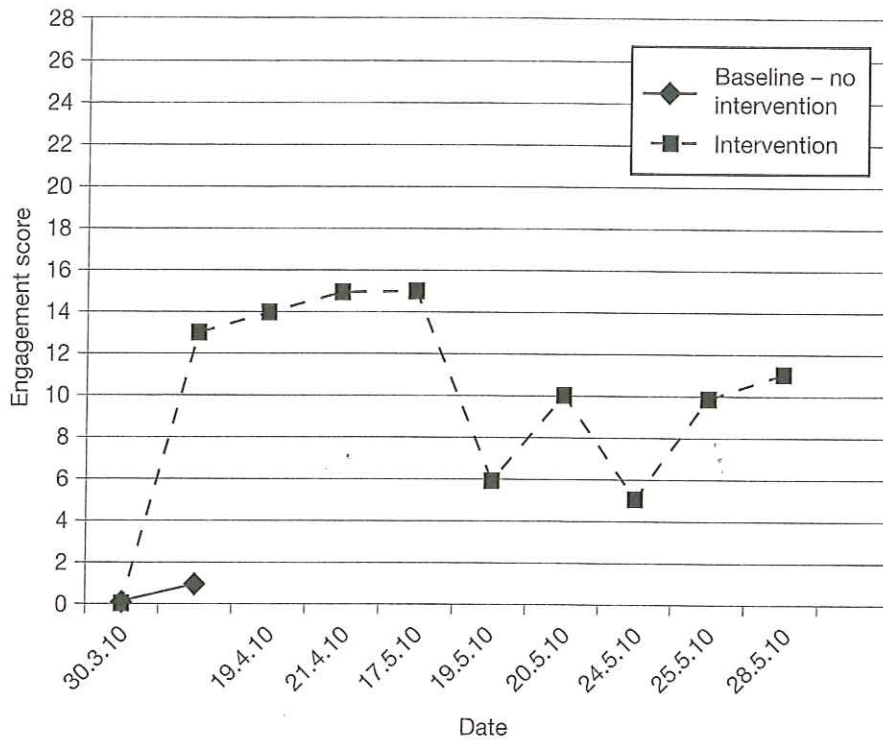
Using the Engagement Profile and Scale, Eva's teacher and the research assistant were able to increasingly personalise the activity to Eva so that she became able to engage and achieve communication and choice-making within the activity. The scoring across the seven indicators of engagement highlighted different areas that needed attention, which led to an overall increase in engagement scoring over a number of weeks. Eva's teacher was very pleased with how the Engagement Profile and Scale had helped her structure and monitor the intervention for Eva.

Eva's parents were also keen to use the choice system and TOBIs at home, so the school asked the CLDD research assistant to make a home visit to explain and demonstrate the choice and communication system to them.

The next step for staff teaching Eva is to begin to extend choice-making from food into other areas of learning.

Conclusion

Children with CLDD are certainly a unique group of learners, and their experiences formulate a unique and, at times, challenging perspective. Their needs demand that we remodel our pedagogy and that we generate teaching strategies to embrace them as learners. In our journey towards evolving a new generation pedagogy for this new generation of children, differentiation – the



Figures 2a and b: Engagement scale graph for Eva G.

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process of adjusting teaching to meet individual needs – points us in the right direction. However, it is not in itself sufficient. Children with CLDD require something more (Porter and Ashdown, 2002)

What are the teaching strategies that will enable us to engage children with CLDD as active participants in the dynamics of our lessons, programmes or learning environments? The overall goal of pedagogy is

'engagement for learning'. Our quest is to engage the learner with CLDD in their environment. Our challenge is how to achieve engagement. How do we recognise when a child is engaged? How do we measure engagement? How do we chart its outcomes? The teacher must remain committed to engagement for learning as a core tenet of curriculum experience for the child with CLDD. The permutations of special educational needs presented by some children

can send a teacher off at a pedagogical tangent or embroil them in a level of detail not helpful to the learning process. With engagement as a focus, the practitioner is armed to transcend these complexities.

The place of special schools in aiding society to meet the challenge of supporting children with CLDD is vitally important. They are uniquely placed to evolve a framework for teaching and learning for these children which is relevant and realistic. Special schools need to become pedagogical think-tanks – nurturing, shaping and framing approaches that are dynamic and innovative, and that transform these children into active participants in the process of learning. This demands inquiry-based reflection from school leaders who support investigation, aid the process of inquiry, do not know all the answers, and see their school as a research organisation.

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