



Overview of the Research Project: steps and impact

Professor Barry Carpenter, OBE, PhD. Former Director, Complex Learning Difficulties and Disabilities Research Project



<http://complexd.ssatrust.org.uk>

Photography by Andrew Hendry and Michelle Brookes



Specialist Schools
and Academies Trust
THE SCHOOLS NETWORK™

Department for
Education

‘We will commission work on developing special schools as leaders in teaching and learning practice for children with the most complex learning difficulties including Profound, Multiple Learning Disabilities.’

*DCSF (2009) Your Child, Your Schools, Our Future:
Building a 21st-century school system. London: TSO.*



The Specialist Schools and Academies Trust (SSAT), with support from the Department for Education, is taking forward a project involving staff in special schools working together with parents, other schools (mainstream and special), universities and local authorities, and health professionals to research, devise and test new approaches to teaching and learning for children with emerging complex learning difficulties and disabilities and share those widely. As the school system becomes more diverse the importance of this specialist role will increase’.

*Green Paper, March 2011
H.M. Coalition Government.*





The Project was:

- **School-based**
- **Practitioner-led**
- **Inquiry-based**





Support to schools through a Research Team:

- **Project Director**
- **Project Research Officer**
- **4 Research Assistants**





Advisory Group

- to reflect
- to critically review
- to actively participate
- to advise and support

Membership from:

- Education
- Higher Education
- Health
- Neuroscience
- Inspection
- Speech Therapy
- Clinical Psychology
- International Collaboration
- Learning Disability Nursing
- Educational Psychology
- Sensory Impairment





Phase 1

- 12 Development Schools
- Lead Teacher Researcher
- Attached Research Assistant

Phase 2

- 50 Trial Schools (England)
- 15 International Trial Schools





Phase 3

- Mainstream Trial Phase
- January – March 2011
- Primary Schools
- Secondary Schools,
including Academies
- Early Years Settings
- Transition Phase







A Research Spiral







~~Research~~

Inquiry





~~research~~

as a route to
Inquiry
research



- **Training of Lead Teacher Researchers**
- **Literature Review**
- **Regional road shows**
- **Interviews with Families**
- **Consultation with stakeholders**
- **Feedback days with schools**
- **Discuss with national organisations**
- **Advisor visits to schools**
- **Analysis of trends by Advisors and Board**
- **Quality Assurance Visits**
- **International collaboration**
- **Think pieces and online debate**



Landmarks in the Journey



“ The validity of this piece of qualitative research comes from multiple trails , by multiple teachers , in multiple classrooms.”

Jane Thistlethwaite

CLDD Project Advisor



Children with Complex Learning Difficulties and Disabilities - CLDD



Key Defining Words

- *Co-existing*
- *Overlapping*
- *Interlocking*
- *Compounding*
- *Co occurring*
- *Unique and
changing learning
pattern*
- *Inconsistent
attainments*



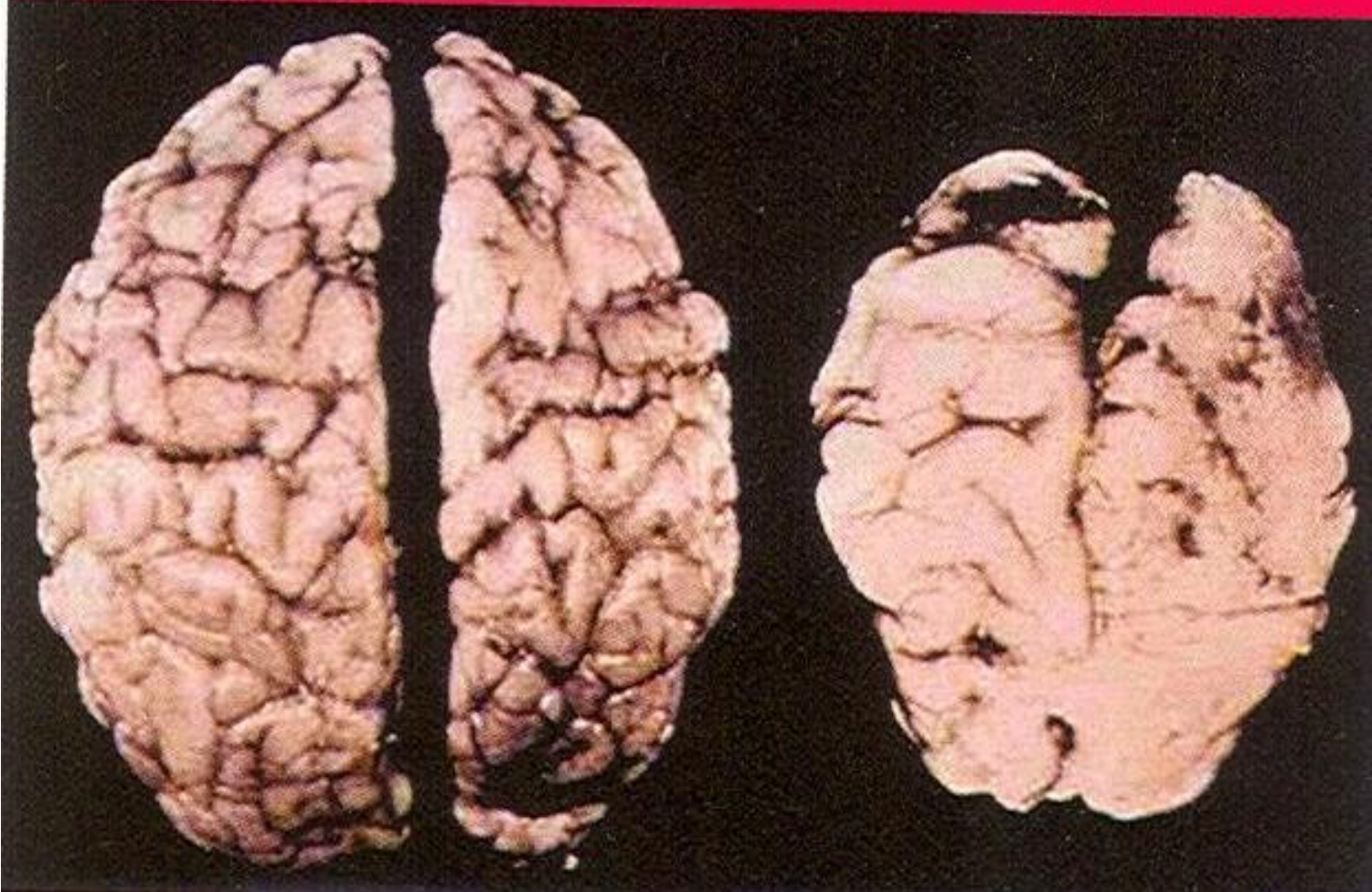
Children who are the New Phenomena

- @ **Autistic Spectrum Disorders**
- @ **Mental Health Needs**
- @ **Chromosomal disorders (e.g. Fragile X)**
- @ **Prematurely born children**
- @ **FASD**



Brain of normal baby

Brain of baby with FAS



Ways Forward

- **Rethink?**
- **Redesign?**
- **Restructure?**
- **Remain the same?**





‘These children (with complex learning difficulties and disabilities) are the next frontier of education’.

Professor Daphne Thomas (2010)

University of South Florida

*International Research Project Collaborator
Cited in ‘Children with Complex Learning
Difficulties and Disabilities’, Pamphlet 2*





Teacher-researchers in this Project were ‘Navigators of Learning’. They created new pathways to learning for a new generation of vulnerable children with complex disabilities.



Key Outputs

- Briefing sheets
- Engagement Profile and Scale
- Inquiry Framework for Learning



PURPOSE OF THE CLDD BRIEFING PACKS



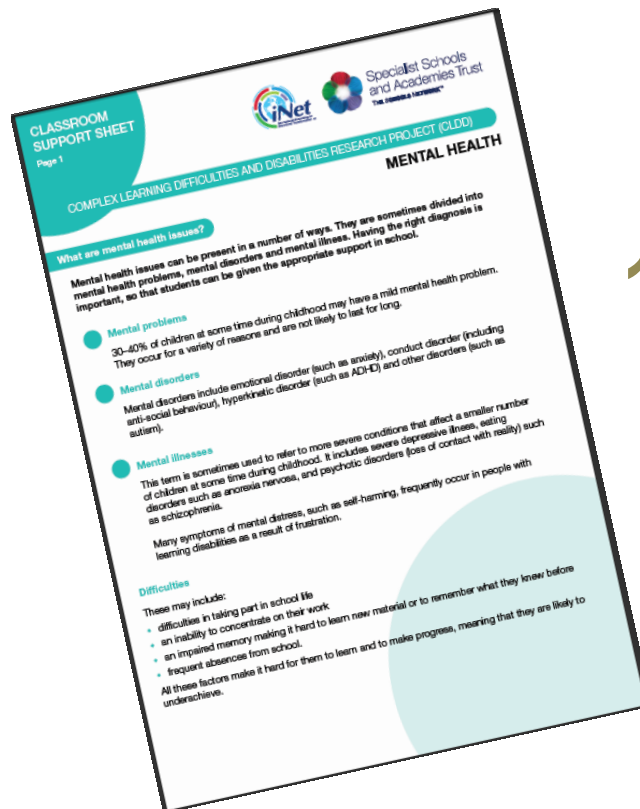
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Education

Objective: to raise awareness of learning barriers and teaching strategies relating to different CLDD conditions

10 packs

Commonly occurring co-existing CLDD conditions



BRIEFING SHEET
Page 1

COMPLEX LEARNING DIFFICULTIES AND DISABILITIES RESEARCH PROJECT (CLDD)

FOETAL ALCOHOL SPECTRUM DISORDERS

FOETAL ALCOHOL SPECTRUM DISORDER (FASD)?

What is foetal alcohol spectrum disorder (FASD)?

FASD is an umbrella term used to encompass the range of possible effects of prenatal exposure to alcohol (British Medical Association, 2007). The following diagnostic or educational terms are included in the spectrum:

- foetal alcohol syndrome (FAS) – the most easily recognisable condition due to characteristic facial features which are formed during the first trimester of pregnancy and disappear with age
- partial foetal alcohol syndrome (pFAS) – some but not all of the criteria for FAS are met (FAS-like, etc)
- foetal alcohol related neurodevelopmental disorder (FASD) – includes characteristics such as organ damage, attention deficit, etc
- alcohol related birth defects (ARBD) – includes characteristics such as organ damage, heart defects, sight/hearing problems
- alcohol related birth defects (ARBD) – can include attention deficits, behaviour problems, etc

A diagnosis of FAS is not an indication of the severity of the impairment, which varies considerably for each individual. Four criteria must be met:

- growth deficiency
- characteristic facial features
- central nervous system damage
- confirmed alcohol exposure.

The characteristics of students

The characteristics of FASD are individual to each student depending on timing and dosage of maternal alcohol consumption, and maternal well-being and health during pregnancy. Damage to the central nervous system results in changes to the structure of the brain that will persist throughout life. Permanent damage to organs and bones can occur at particular periods of pregnancy. Generally, however, the following characteristics may be observed in these pupils:

Possible strengths

Students may be:

- bright in some areas: highly verbal
- artistic, musical, athletic, have good practical skills
- friendly, helpful, affectionate and good with younger children
- determined and persistent.

CLASSROOM SUPPORT SHEET
Page 1

COMPLEX LEARNING DIFFICULTIES AND DISABILITIES RESEARCH PROJECT (CLDD)

FOETAL ALCOHOL SPECTRUM DISORDERS

What are foetal alcohol spectrum disorders (FASD)?

FASDs are the result of alcohol being drunk while pregnant. FASD includes foetal alcohol syndrome (FAS), which is the easiest to recognise, as the students have certain facial features. These can include a thin upper lip, short nose and slightly unusual ears. Although the behaviour of students with FASD can be difficult, they also have strengths.

Possible strengths are:

- strong verbal skills
- bright in some areas, such as being artistic, musical, athletic, or having practical skills
- friendly, affectionate, helpful and generous
- good with younger children
- determined and persistent.

Difficulties are:

- memory problems; difficulty storing and retrieving information
- poor performance (on and off days)
- easily distracted and disorganised
- difficulty following instructions, but not to put them into action
- difficulty understanding abstract concepts such as maths, money management and time
- poor attention span
- poor organisation; needing time to think
- difficulty understanding what is said to them, such as only taking in every third word
- poor understanding of the consequences of their actions
- poor understanding of the consequences of their actions

Students with FASD may be affected in different ways and to different degrees, depending on what stage of pregnancy the mother drank alcohol. This means that every student's pattern of difficulties will be different. For students who are slow to develop, these students may have particular difficulties in areas such as reading, writing and maths. These students may find it difficult to make learning some things extremely hard. Often, these students may be very bright in some areas.

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INFORMATION SHEET
Page 1

COMPLEX LEARNING DIFFICULTIES AND DISABILITIES RESEARCH PROJECT (CLDD)

FOETAL ALCOHOL SPECTRUM DISORDERS

What is foetal alcohol spectrum disorder?

The term foetal alcohol spectrum disorder (FASD) is an umbrella term used to encompass the range of possible effects of prenatal exposure to alcohol (British Medical Association, 2007), including foetal alcohol syndrome (FAS), partial foetal alcohol syndrome (pFAS), foetal alcohol effects (FAE), alcohol related neurodevelopmental disorder (ARND) and alcohol related birth defects (ARBD). Any amount of alcohol consumed by a mother during pregnancy crosses the placenta, and can result in birth defects for her child, including physical, mental, behavioural and learning disabilities, with life long implications. Full FAS is associated with characteristic physical effects including facial dysmorphism, but even where there are no observable effects, children are left with irreversible brain damage.

Foetal alcohol exposure is the leading known cause of intellectual disability in the Western world, and according to international studies, it is estimated that one in every 100 children is born with FASD (Audi-Farro, 2002; British Medical Association, 2007; May and Gossage, 2001; Plentz, 1985; Plant et al, 1990; Sampson et al, 1997). This is greater than the combined incidence of children born in any year with Down syndrome, cerebral palsy, cystic fibrosis and spinal tuberculosis. In a culture which sees binge drinking on the increase (Donaldson, 2009), the number of children with FASD is set to rise. Based upon the above estimate in the context of annual birth figures produced by the Office of National Statistics, there are likely to be 6-7,000 babies born with FASDs of varying severity in the UK each year.

Teachers and teaching support staff will undoubtedly meet students with FASD in their classrooms. They need to know how to respond to their learning needs effectively, enable them to maximise their potential, improve their life chances, and take their place alongside their mainstream peers as citizens of the 21st century. To do this, teaching staff will need training and support to raise their awareness of FASD, and to understand the implications for their practice. The following information is intended to provide a starting point for this. For more information, see the following links: <http://nationalstrategies.standards.dof.gov.uk/> (Carpenter, 2009; in preparation). In other countries (eg Canada, USA), research outcomes have led to improved educational support for students with FASD.

Criteria, including growth deficiency, specific facial features, central nervous system damage and confirmed prenatal alcohol exposure must all be met for a full diagnosis of FAS. However, many students with FASD do not meet the full diagnostic criteria but may still be affected and experience difficulties. For these students, the following characteristics may be observed:

- FAE include attention deficits, behaviour disorders, sight/hearing problems, joint defects, etc
- facial dysmorphism (eg facial dysmorphism) is not necessarily indicative of the severity of the impairment associated with FASD, so they can recognise and accommodate their learning at a level consistent with their chronological age. They appear physically normal, but their basic literacy demands and to use relatively sophisticated language skills are even more so (Simpson et al, 1998). A lack of awareness of the implications of their difficulties can lead to consistently unrealistic expectations. Without the

Three briefing sheets to each pack

Three different functions



Topics

- Fetal alcohol spectrum disorder (FASD)
- Attachment
- Premature birth
- Rare chromosome disorders
- Mental health
- Sensory impairment
- Drugs & smoking
- Attention deficit hyperactivity disorder
- Fragile X syndrome
- Autism





Tiers of Professional Learning



Access for Teaching Assistants

‘We put our most vulnerable children with our least trained people. We do not value our Teaching Assistants enough. They are the people that deliver’.

Fiona Forbes
President: SPEPN
Australia





Engaging Learners with Complex Learning Difficulties and Disabilities

A RESOURCE BOOK FOR TEACHERS AND TEACHING ASSISTANTS

Barry Carpenter, Jo Egerton, Beverley Cockbill,
Tamara Bloom, Jodie Fotheringham,
Hollie Rawson and Jane Thistlethwaite



Inclusion..

- ... requires Inclusive Pedagogy.



Definition of engagement



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“Sustainable learning can only occur when there is a meaningful engagement. The process of engagement is a journey which links a child and their environment to enable learning and achievement”.

From CLDD Project –

<http://complexid.ssatrust.org.uk>



‘For students with disabilities, research has suggested that engaged behavior is the single best predictor of successful learning’

*(Iovannone, Dunlap, Huber & Kincaid, 2003;
Bulgren & Carta, 1993; Kamps, Leonard & Greenwood, 1991;
Sindelar, Smith, Harriman, Hale & Wilson, 1989)*



**Engagement is the
bridge to inclusion.
It offers a pedagogy
which responds to a
child's educational
needs in any setting**



**“Engagement is the
antidote to pedagogical
vulnerability. It is key to
successful inclusion.”**

*Carpenter (2011) Complex Needs: booklet 1
London; DfE/SSAT*

[Project information](#)[Project resources](#)[How to use the resources](#)[Promising CLDD approaches](#)[Professional development](#)[Links](#)[Contact us](#)

This project is supported by the

Department for
Education

Complex learning difficulties and disabilities research project

Developing meaningful pathways to personalised learning



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Welcome

Welcome to the SSAT's Complex Learning Difficulties and Disabilities (CLDD) Research Project website.

The Department for Education identified through feedback from schools that educators needed a new

<http://complexld.ssatrust.org.uk>

Photography by Andrew Hendry and Michelle Brookes

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www.barrycarpentereducation.com



‘The only real voyage of discovery consists not in seeking new landscapes, but in having new eyes’.

Marcel Proust

