

National Organisation on Fetal Alcohol Syndrome UK

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Facing the challenge and shaping the future for primary and secondary aged students with Foetal Alcohol Spectrum Disorders (FAS-eD Project)

## **EXECUTIVE SUMMARY**

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## EXECUTIVE SUMMARY

This summary is intended to give a brief overview of this research project and Foetal Alcohol Spectrum Disorders (FASD). It will introduce the rationale for the project, the salient issues around Foetal Alcohol Spectrum Disorders, and give an overview of outcomes and recommendations. A more detailed methodology can be found in the full report, and the project literature review is available online at [www.nofas-uk.org](http://www.nofas-uk.org).

### **What Are Foetal Alcohol Spectrum Disorders?**

Foetal Alcohol Spectrum Disorders (FASD) operates as an educational umbrella term to represent the range of effects caused by prenatal alcohol exposure. These include learning difficulties and physical disabilities. FASD encompasses the following diagnostic terms:

- Foetal Alcohol Syndrome (FAS)
- Partial Foetal Alcohol Syndrome (pFAS)
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Alcohol-Related Birth Defects (ARBD).

The complexity of the condition may be increased by any overlapping and co-existing conditions such as Attention Deficit Hyperactivity Disorder (ADHD), Autistic Spectrum Disorder (ASD), Oppositional Defiance Disorder (ODD), Reactive Attachment Disorder (RAD), Sensory Integration Disorder (SID), Tourette's Syndrome, mental health issues (all of which may be present in one individual student).

Other compounding factors for children with FASD may include their personal family history (e.g. multiple foster and/or adoptive placements), isolation and loneliness borne from being the only student in a school with this condition, lack of knowledge about the condition within the education, health and social care systems and society in general, barriers to accurate diagnosis and the hidden nature of students' difficulties.

Secondary disabilities, such as poor mental health and insufficient engagement with the curriculum, can result from lack of appropriate diagnosis, sensitive support and interventions in the early years and primary age.

## **Research Project Rationale**

Diagnosis is controversial, and under diagnosis is believed to be common, which suggests that there are more students in schools with FASD than are currently recorded. In addition, there is a paucity of knowledge in education, health and social services about FASD and how best to support students and families affected. There are currently no UK government guidelines or training available for the education workforce in connection with the support and education of students with FASD.

*I am surprised to have come across so many people who have no awareness of it (FASD), didn't seem to understand the impact it has on all aspects of children's development, but particularly on the way that they learn. We have talked to Educational Psychologists and they've often said that we probably know more than them and sometimes that's a little bit worrying." (Parent interview)*

*"We know our child and we know bits about schools. We assumed that there would be people who knew about people in our child's situation and which school would be best, which would give us a clearer idea about it. It's a difficult decision and we need first hand experience to draw on." (Parent interview)*

There was a need, therefore, to identify the issues and challenges faced by students with FASD and those working with them in UK educational settings, as well as to record solutions developed by teachers in supporting these students and their families.

## **Aims of the Project**

The aims of this research project were to:

- Develop teaching and learning frameworks for teachers and other professionals involved in the education and support of students with FASD.
- Share good practice across the education workforce.
- Investigate the educational implications of FASD in a UK context and their relevance to Initial Teacher Training and Continuing Professional Development.
- Raise appreciation among teachers for the need of close partnership with families in delivering effective education for these children.

The frameworks developed from this project aim to ensure that students with FASD can be included alongside their peers in the classroom, in any educational setting. They were trialled by the 9 teachers working with the project researcher, as well as a number of other education and health professionals.

### **Who Was Involved in the Research Project?**

The research team included a project director, a lead researcher and a research associate supported and advised by a research steering group. In each of 9 schools, the project researcher worked alongside a teacher (the ‘teacher researcher’) and their class team, who were supporting a student with a confirmed diagnosis of FASD. The views of trainee teachers from the University of Worcester and the University of Chester were also sought.

### **Methodology Overview**

The project was carried out using a qualitative case study and action research approach. Data collection included:

- Establishing the student voice: achieved by using a multi-method approach of ‘listening’ to children by talking to them, their parents and teachers
- Observing students and teachers in the classroom in order to identify effective teaching and learning strategies
- Observing and recording the challenges for inclusion.

Data collected from engagement observations, and as a result of talking to and observing students and teachers, and talking to parents, have been synthesised into a series of illustrative case studies. Data from interviews were also subject to categorical content analysis.

### **Project Participants**

The nine students (six female and three male) with FAS or pFAS involved in the projects, their parents and the schools were purposely selected. The students were aged between six and 19 years, and were educated in a range of settings including primary and secondary mainstream, and special schools. In addition to their primary diagnosis, five had additional diagnosed conditions. Two lived with birth parents, while the remaining students were adopted, one within the wider birth family. Education staff supporting the students, and the students’ parents (birth and adoptive) have

contributed to the research.

Since parents are children's first and most enduring educators, it was appropriate that parents were valued as co-educators of their children and their views on their child's educational experiences recorded as well as those of students themselves, and of the range of professionals working with them.

### **Main Findings of the Research Project**

Students with FASD experience a range of developmental, learning, behavioural, social, emotional and sensory difficulties which create barriers to learning. These not only have an impact within the educational context, but also on the subsequent acquisition of crucial life skills (e.g. telling the time; self-organisation; etc.) However, it is important to set the learning difficulties of children with FASD in the context of their strengths. These strengths will become the foundations on which to develop personalised curricula, to encourage and develop further strengths, and build emotional resilience. Therefore this overview of findings will begin with the children's strengths, before summarising their difficulties.

#### **Educational Strengths of Students with FASD**

- Students with FASD are often ambitious and have a range of practical strengths which are useful in their educational careers and throughout life.
- Many are articulate and have engaging personalities. They enjoy being with other people.
- Many have learning strengths around Literacy and practical subjects, such as Art, Performing Arts, Sport, and Technologies, although they often have difficulties with comprehension,
- While they have working/short-term memory difficulties, rote learning and long-term memory can be strengths.

#### **Educational Difficulties of Students with FASD**

##### *Developmental Difficulties*

- Significant delays in achieving developmental milestones such as toileting and hygiene skills, in some cases beyond the primary years.

##### *Medical Difficulties*

- Medical and health related difficulties including organ damage, poor sleep patterns, eating and

dietary difficulties, small stature, vision and hearing impairments.

### *Learning Difficulties*

- Understanding cause and effect
- Difficulty in understanding mathematical concepts, such as time, understanding money
- Cognitive difficulties, including poor short term memory, and poor concentration.
- Frontal lobe damage to the brain, which is associated with FASD, results in impaired executive functioning leading to deficits, such as impaired ability to organise, plan, understand consequences, maintain and shift attention, and process and memorise data. This has an impact on independence in a range of situations. Executive functioning impacts on daily living skills.

### *Behavioural Difficulties*

- Behavioural difficulties, including hyperactivity, inattention, aggression, obsessions with people and objects, agitation, can cause anxiety and frustration for students as well as parents and teachers. These difficulties, whilst often seen as behavioural issues, can also be related to sensory processing disorders requiring occupational therapy input.
- Teaching and Learning Frameworks resulting from this project recommend that teachers seek the assistance of an Occupational Therapist in order that a Sensory Profile can be completed and the students needs correctly addressed:

*“ In Science we’re hitting difficulties because of her impulsivity around behaviour, she’s very drawn to the apparatus, she likes anything that’s very pretty and sparkly and if you’ve got colourful flames and splints and nice things bubbling in jars that’s a temptation for her, she wants to get in there with her hands.” (Teacher in a Secondary School)*

### *Social Difficulties*

- Difficulty acquiring appropriate social and emotional skills, which impacted on relationships, friendships, and any activity which requires an understanding of the state of mind of others and predicting how this might affect their actions.

- Understanding boundaries: Students can be frustrated by their own behaviour, but seemingly unable to control it, leading to challenges in self esteem and peer relationships:

*“She’s not always aware of the impact of her behaviours on others and that upsets her, because after the event when people explain to her, she’s very apologetic. She doesn’t like to be like that but at the same time, she really cannot control it. This is the paradox, she’s aware that she can’t control herself and that’s frustrating for her.” (Teacher in a Secondary School)*

- Evidence from this project and the wider context suggests that, for students with FASD, the current focus in schools on assessing and addressing their cognitive needs omits full recognition of the impact of students’ social and emotional needs on their ability to learn and to function appropriately and effectively within their communities.

#### *Emotional Difficulties*

- The need to rely on external prompts from adults can result in low self esteem and frustration
- Students begin to identify the differences between themselves and peers (and vice versa) even in special school settings, again resulting in low self esteem.
- Secondary disabilities, such as mental health problems, disrupted school experience, trouble with the law, confinement, inappropriate sexual behaviour, problems with independent living and employment can result from a lack of identification/support when students are at primary age.
- Teachers and the professionals who support children with FASD in the classroom will require an understanding of the compounding factors associated with the condition, and ensure continuing multidisciplinary assessment that is necessary to allow identification of secondary disabilities so proactive action can be taken to ameliorate the effects. The importance of working closely with families and “putting families at the centre” of their child’s educational journey (David Braybrook 2010) in these circumstances cannot be overestimated.

#### *Transition*

- Parents and teachers share concern over the social and emotional vulnerability as students with FASD move through the education system and into adult life:

*“I’m a bit apprehensive, not sure how he’s going to manage and obviously there are certain restrictions he has with having to have 1:1 support ... there are certain grand ideas he has and things he’d like to do, some of them are totally unrealistic.” (Parent interview)*

*“It’s that sort of sickening feel about what’s going to happen next that I get.” (Parent interview)*

- Students with FASD will continue to need provision and support throughout their adult life, which ideally include:
  - ongoing multi-disciplinary assessment leading to appropriate and sensitive support packages
  - A commitment to maximising appropriate levels of independence
  - The provision of supported/sheltered living accommodation with access to assistance with daily living skills
  - Supported work and leisure opportunities.
- Schools can support families in finding appropriate and suitable placement for students and providing information to future placement about how best to support the student.

### **Implications for Learning**

- There is a necessity for extrinsic motivation to learn skills or complete tasks such as life skills, hygiene routines, and school based tasks, particularly in secondary aged students, requiring repetitive reminders and re-focussing from adults.

### **Feedback from Teachers**

All teachers reported that involvement in this project has been a useful and positive experience for their schools and that their professional development has benefitted. They also asserted that students have benefitted from the project.

The research model used – of a teacher-researcher implementing the action research cycle in educational settings with support from a lead researcher – was successful, suggesting this may be an effective model for future projects.

## **Recommendations from the Project**

The Project recommends that the following areas of development are considered:

### Education/Children's Services

1. The education workforce, together with the range of health and social care professionals who support it, need advice and information about what FASD is, an understanding of the complexity of needs and compounding factors, how it affects learning and how to support students responsively and flexibly in the classroom. This includes listening and responding to parents/carers as well as students' views. This would be supported by the findings of the Lamb Inquiry 2009 (Chapter1) and the Salt Review 2010 (p.26).
2. More detailed consideration needs to be given to the curriculum for students with FASD, particularly teaching approaches which recognise the need for specific interventions which match the unique learning profile (e.g. memory, organisational skills) of these children.
3. In planning curriculum programmes, teachers should be mindful that the emphasis on cognitive ability is distracting, as this is not necessarily an indicator of how able the student is in coping with a particular approach/task/educational setting or package of services.
4. A more robust process of assessment of needs for students with FASD needs to be put in place, which is better suited to the particular range of difficulties experienced by students with FASD, and more sensitive to the vulnerability they face as they move through the education system and into adult life.

*“My argument is education has to be more than just about meeting the academic criteria and socially, she is just way behind her peers in mainstream school. She's 8 and she's just about learning to play with dolls and she doesn't really have imaginary play, she's so far behind socially but our education system doesn't see that as the main criterion.”*  
(Parent interview)

5. Thought needs to be given to the lifelong implications of FASD, and in particular reflection

on an individual's social and emotional functioning and ability to acquire life skills would be helpful.

### Workforce Development

1. The outcomes of this project need to be widely disseminated and proactively advertised in order for as wide an audience as possible to receive information about the availability of the information.
2. Inclusion of material on supporting students with FASD should be considered for modules delivered at Universities on Profound and Multiple Learning Difficulties (PMLD), Severe Learning Difficulties (SLD), Moderate Learning Difficulties (MLD), Complex Learning Difficulties and Disabilities (CLDD), Behavioural, Emotional and Social Difficulties (BESD), Autistic Spectrum Disorder (ASD), Attention Deficit and Hyperactivity Disorder (ADHD), and Sensory Impairment (SI).
3. Attention should be given to methods of assessment for service support packages and educational provision available to students with FASD and their families. There needs to be quality information in educational provision available to families about the holistic support package available including therapies which may support students' individual needs.
4. Greater awareness of FASD amongst Educational Psychologists, Clinical Psychologists and others responsible for statutory assessment is necessary.
5. Trainee and practising teachers and the professionals who support them in meeting the complex needs of students with FASD need to be aware of the physical disabilities, health and medical aspects and learning difficulties faced by students with FASD and the implications for inclusive practice. They also need to know the similarities to and differences from other, apparently similar, conditions.
6. It is necessary for a range of professionals to be involved in the support package offered to students with FASD and their families. Teachers will need to be aware, therefore, of the range of professionals who may be involved and understand the role they play in strategies and interventions designed to support students, so that they may signpost parents to appropriate services and effectively implement such strategies and interventions in the classroom.

7. More information about FASD is needed in the education, health and social care services and society generally so that individuals affected and their families can be fully included in all aspects of life with proper understanding about the complexity of the condition, which is significant.

### Health

1. There needs to be development of Therapy Services (e.g. speech and language, occupational therapy) that are aware of the needs of students with FASD. The complex sensory profile of the student with FASD calls particularly for the skilled input of an Occupational Therapist and sensory integration programmes.
2. Students with FASD are prone to mental health problems. Mental health and emotional well-being should be assessed regularly in order to provide early detection of signs and symptoms so that students can receive appropriate support delivered in a timely manner through school and/or CAHMS.
3. As a public health risk, more information needs to be available within society generally about the implications of drinking whilst pregnant. In particular a focus within school PSHE programmes would be valuable.

### Families

1. Advice and support for parents/carers about the range of services available to them, and how they may be accessed through Aiming High for Disabled Children is necessary.
2. Many children with FASD are fostered or adopted. Respite care and short breaks should be offered to parents, to enable them to cope with the challenges of living with their child (or children) within the context of their family.
3. Information about FASD needs to be available to the range of professionals who might assess and support students with FASD and their families.
4. The provision of supported/sheltered living accommodation, possibly with work and leisure opportunities on site, where individuals may have a degree of independence at the same time

as being able to access assistance with daily living skills is required to ensure success for individuals with FASD throughout adult life.

### Research

1. Further educational research should be undertaken to investigate specifically and in more detail the levels of, and routes to, engagement (in particular of secondary aged students) with FASD in mainstream education. Specific interventions to improve levels of engagement, working memory, organisation skills, peer relationships and emotional development need to be investigated.

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