

Foetal Alcohol Spectrum Disorder

Case studies



A Worcestershire practitioner's perspective

A practitioner case study of working with children with Foetal Alcohol Spectrum Disorders (FASD) in an early years setting.

Social and emotional development

Initially, the child needed lots of reassurance and prompts, as well as time, to get to know the nursery routines, and then prompts to help him remember. He would repeat an activity over and over, and it was a challenge to encourage him to move to another activity.

He was generally a well behaved child who loved routines, but he was also very quiet, and sometimes we had to remind ourselves that he was there. He could also at times be disruptive and impulsive, so his behaviour was very inconsistent. He would laugh really loudly if we ever reprimanded him for unwanted behaviour.

Transition times could be difficult, and he needed a lot of support at these times. At snack time, he would sometimes go and get his lunch bag. He was a sociable child who loved to be with other children, but he just followed their lead and always looked lost and far away.

He also needed a lot of emotional support. He would mainly play alongside other children, and would always join a small group of children or a group where an adult was present. He was very immature for his age and very impulsive. If something popped into his head, he would just go and do it, without any sense of his own safety.

Physical development

His whole development was very delayed. He was still in nappies when he joined the nursery at the age of three, and only went into pants near to his fourth birthday. Everything took a lot longer, and there would be accidents because he would just forget.

He needed an operation to correct a visual difficulty, and he was very clumsy and fell over a lot. He was tiny in stature, so he was a lot smaller than his peers. His head was noticeably small in relation to other children's. He often had colds and coughs, and seemed not to be as robust as the

other children – not frail, but not strong and hearty – so he was absent from nursery a lot.

Facially, he was different to other children around the eyes and nose. I wondered about his hearing, and he seemed to be quite trance like sometimes as well. His motor co-ordination improved a lot in the time he attended the nursery, but he struggled a lot in the early days to go up and down steps.

He was also a poor sleeper, and his mum would often come in really tired because he had been up a number of times in the night.

Language development

His speech and language was unclear, and he would get very frustrated and cross with us if we could not understand him. He did not seem to pick up on verbal cues, and relied on watching what the other children were doing and on visual and picture cues.

Intellectual development

He had a very short attention span and needed very short tasks. Even then you had to keep re-focussing him. He did not seem able to grasp any concepts that were not concrete. Learning was very slow, and he needed a lot of prompts and reminders. He would often seem to be learning things, and you would think that something had finally clicked, and then the next day or the next week you had to go back to square one.

A family perspective of Foetal Alcohol Spectrum Disorders (FASD)

by Gloria, Peter and Matthew Armistead

Matthew entered our lives at seven months old with no name. He had been left at Tygerburg Hospital, Cape Town, South Africa, by his university student mother. Within days of being born, he was experiencing seizures. He was deemed unadoptable. We were also advised by the resident neurological professor not to adopt, due to Matthew needing lots of medical care, and because, whilst he was fostered, the South African Government had to provide his medical care. Also, if we had adopted him, he would not have been covered by the private medical aid that we had in place.



Peter, Matthew and Gloria in Cape Town.

Source: Gloria, Peter and Matthew Armistead (FASawareUK)

This photo was taken when we took Matthew back to Cape Town to give him closure. He was desperate for his birth mother. He said he did not want “fat, ugly, old parents”. He wanted “a trendy mum like his school friends”. We said we had no idea where she is. He needed to know she was not waiting for him at Cape Town Airport.

Matthew was a very sick baby, but Foetal Alcohol Syndrome (FAS)* was not brought to our attention until he was 18 months old, when a chance observation by the independent social worker at the children’s home where we worked

as house parents, alerted us to FAS. I found *The Broken Cord* by Michael Dorris which scared me and sent me on the journey to find a diagnosis. It took us two and a half years from the social worker’s observation to get Matthew diagnosed. He was diagnosed by a Professor employed by the Genetics Department of Cape Town University when he was four years old. We were told by the Professor to “give him back” as we would be on a daily beating for the rest of our lives. RUBBISH! Once we had a diagnosis, we searched in Cape Town for support without success. There was no awareness there of FAS, and even less support available when we returned to the UK in 1999.

Matthew was excluded from three private crèches. He always had big green candles dripping from his nose. The other parents did not like this. Also Matthew used to copy all the other children. He used to always lash out, kick and bite. He never learnt. He was always on his own. He never got invited to parties or had any friends to play.

Because FAS in the Cape was not known or accepted, the educational establishment made no adaptations to Matthew’s educational plan. Yet Cape Town (a huge wine growing area) has the highest incidence of FASD throughout the world. Peter and I set up an awareness raising group in Cape Town called FASSA. The aims were the same as here with FASawareUK, which is to raise awareness of FAS and to share the message of informed choice. He needed educators who would understand and give him all the same treatment/strategies that a child with brain damage or an ‘in your face’ disability receives.

As a family, we needed more flexibility and co-operation from professionals. Many of Matthew’s medical appointments were during hours which made it difficult for Peter to attend each and every appointment. Peter gave up holiday days to support and attend many of them. Now Peter is retired through ill health, he attends all the medical appointments with Matthew. Matthew prefers his DAD to his mum.

continued on next page

The professionals involved in Matthew's life have included:

- Community Paediatricians
- Occupational Therapists
- Speech Therapists
- Physiotherapists
- Child/Adolescent Psychiatrists
- General Practitioners
- Behavioural teams
- Educational support teams
- Neurologists
- Clinical Psychologists
- Audiology/Plastic Surgeon
- Ophthalmic Surgeon
- Orthopaedic Surgeon
- Educational Psychologists
- Special Needs Teachers
- Learning Support Assistants
- Asthma Nurses
- Social Workers
- Consultant Psychiatrist

Education has been the biggest minefield for us. Peter ended up being a School Governor at two schools to get Matthew's needs met. What we are finding from people making contact via the forum on www.fasaware.co.uk, email, telephone and the face-to-face support group is the lack of help, support or direction within education for families that have children with FASD. If the children do not achieve the right input and early intervention, then it is possible the secondary disabilities will surface. For many people I speak to, their children have been excluded from school. Many, many parents cannot get a statement. Many parents are treated as dysfunctional.

Family support has been non-existent. Peter and I are in our 60s, and our own extended family think we have lost the plot. Our own adult children do not want to be involved or, as they say, "landed with him" when we die. They said it was our choice to take on this child not theirs. Our social life ground to a total halt when Matthew arrived. We feel our friends that have stood by us all consume alcohol. We feel this is not the best environment for him.

Matthew's interests and hobbies include being a Cub helper, though he did not continue on to Scouts because he felt insecure, and could not interact with his age appropriate peer group. He also attends Air Training Corps (ATC) twice a week. Matthew used to horse ride, but after riding for over eight years, in 2007, he decided he did not want to go any more. We have our own feelings on this. We feel that, as he was the only young lad in the yard, the young girls were coming on to him. He may be 15, but at times can act very like an eight year old.

He loves Lego. He has two model power boats, which he and his dad take to the model boating lake near his home. He has all the gadgets young people have (Play Station, Game Boy, MP3 player, etc). What we have observed is that if they are not in his face he forgets about these items. He is also prone to giving his belongings away.

Matthew achieved his Duke of Edinburgh Bronze Award last week with the Air Training Cadets. He is now looking to embark on his Silver Award. We are so very proud.

* FAS describes a condition within FASD which includes specific physical features caused by developmental damage from alcohol drunk by a mother-to-be during the first three months of pregnancy. FASD is an umbrella term used to describe a range of birth defects caused by maternal alcohol consumption including FAS.

To the best of our knowledge all information was correct at the time of printing: February 2009