

WDS Family Case History Notes 1

The Early Years

Primary

Our older child initially went to a small mainstream infant school for two years with a full time 1:1 support.

When we realised that he was falling far behind his peers and was unable to access the curriculum we moved him to our local SEN school, naively thinking that he would be offered more therapy and support. Unfortunately we realised very quickly that they did not have the expertise to support a child with such a severe speech, language and communication disorder. The SaLT that was working with him was a specialist AAC therapist brought in for 60 hours a year. Although excellent she was unable to see him every week due to her large caseload and he could go for weeks with no SaLT support and a communication book that was not accessed by staff and of any use to him or them. She advised that the placement was not right and the school agreed eventually that they could not meet his needs. The local authority had no choice but to look elsewhere and we pushed very strongly for Meath School, a specialist school for children with severe and complex communication difficulties based in Ottershaw, Surrey. After us commissioning independent therapist and EP reports they eventually accepted that this really was the closest school that could meet his needs and he started there aged 7. As it was too far to commute daily he was residential for four nights a week. He had 8 words when he arrived and within a term had over 50 words plus his signing improved significantly. He had daily SaLT and a speech therapist worked with his teacher in the class room supporting them and also weekly 1:1 and group OT. He coped very well with residential and grew to love it. He still talks about Meath and wishes he was still there!

Our younger child stayed at their specialist preschool until the start of Year 1. We wanted him to go to Meath School to but The LA wanted to place him in the school that our older son had been at which had not been appropriate. Another expensive battle ensued however we were very lucky as the SaLT who assessed him on the LA's behalf agreed with us that he needed to go to a specialist provision so blew their argument out of the water!! He started at Meath for Year 1. He and his brother only coincided for a year but it definitely helped him to settle in. He was residential for 4 days a week from 5 years old and despite my misgivings he has been very happy and thrived there right from day one. His speech and signing is improving continually and he has a lot of confidence which I feel comes from being in the right school and having an appropriate peer group around him from the very beginning. He looks forward to going to school every Monday morning and is busy packing his bag the night before in anticipation!

Both boys are taken to and from school by taxi.

To have the boys placed in the best school that we can find for them has been such an amazing weight off our minds. We know that they are getting the specialist support that they require and are busy and happy with friends and activities that they are able to access.

Secondary

Our first child with WDS had to move schools aged 11 as Meath is only a primary school. He is now at another specialist provision (another fight required first...) and is at St Mary's School and College, Bexhill. He is residential for five nights a week as it is so far away but he is happy there and making good progress.

Transition

Further Education

Living independently

Living with WDS

As a parent

Being parents of two boys with WDS is not easy. We have to fight for everything twice and deal with all the idiosyncrasies of the syndrome twice. We have an older child who finds it very isolating having her disabled brothers and does find life tricky at times when the reality of it hits her. We try not to burden her with being a carer although she is very aware that one day she is going to have to help look after them. We are lucky in that we have supportive parents although due to age, ill health and geography they aren't able to physically help us much anymore.

Although we miss the boys during the week, it also helps us to reserve our energy and patience for the weekend when it is full on! They are busy active boys and need a lot of stimulating activities laid on - swimming, cycling, bowling etc. It is fun seeing our older boy really embrace becoming a teenager even within the limitations of his disability. It does bring its challenges though too. Our younger boy gets very frustrated when we can't understand him which is a regular occurrence.

We try to lead as normal a life as possible within the restrictions that we have. We are mindful of how lucky we are as we are financially secure and are able to help the boys to access fun and confidence building activities such as skiing. We are also able to pay for a few hours of care when we need to which helps to us not to feel too trapped in our lives.

One of the initial lessons learned following our first son's diagnosis with WDS was to reset our expectations surrounding various facets of life. Whilst it was hard to hear our friends talk about what their children were doing, what teams or plays they were in, by learning not to try and compare what our sons were or were not able to do meant that it was easier to hear of our friends' childrens successes, rather than be too bitter about it. As parents we both individually sought professional support to cope with the change in our lives. As one of our professional councillors put it "having a disabled child is like losing a life of a loved one"or in our case two. It is

only understandable to mourn the life you might have had. Whilst this might sound rather over the top, it is important to come to terms with your own feelings and find ways to deal with your low moods. One of us took up running, and managed to complete the London Marathon and raise a significant sum. The support we received from friends and family gave us a huge boost to know that we had the support behind us.

It is also worth saying that your children will amaze you with what they achieve, however small and however long it takes. It took our first son till he was nearly 8 years old before he could say the letter 'd' and say 'Daddy'. Our second son is currently 8yrs old and has still to master saying the letter 'd' but he is getting there. It will be a precious moment when it happens!