

'A' for Adjustment Framework

Session 3 – Desensitisation case study

When my son – who has Down's Syndrome and learning disabilities – was 18 months old, he had to have a blood test to see if he had problems with his thyroid, which is common for people with Down's Syndrome. The nurse told us to hold him down and we did as we were told. This was repeated every year and I had a growing concern about how this would be handled when he was bigger and stronger.

As he got older, we had to have more people to help hold him down and he became more and more distressed, biting, struggling and screaming. When he was 5 years old, he was put on thyroid medication and to get the dose right, he had to have monthly blood tests. I begged the staff at the hospital to work with us to help with his now very obvious needle phobia, but they just didn't have the time to sing songs and use play therapy, which was what I was suggesting. This all became more of a problem when my son was diagnosed with Type 1 Diabetes when he was 9 years old. It took a couple of weeks to diagnose, as at first the GP thought it was a urinary tract infection.

Diagnosis can take a long time for some young people and they can become very ill before the correct diagnosis is given. It is really important for families and GPs to be aware of the signs and symptoms of Type 1 diabetes, so that it can be picked up early. There are significantly higher cases of Type 1 diabetes in disabled children who have a lower immune system; as in my son's case, he caught a virus which killed the cells in his pancreas.

When my son was first diagnosed, it was really difficult because of his already embedded fear of needles and being held down for his blood tests for his underactive thyroid. The first thing the A+E Department did when he was sent to hospital by the GP as he tested positive for diabetes, was to hold him down for a blood test and the insulin injections he now needed. He had to have numerous finger prick tests and 2 injections per day and we were in hospital for a month. This was because I needed to be able to give him the injections on my own in order to go home. They tried to organise community support to help with this, but this didn't happen as the hospital was not in the same Health Authority as where we live, which seemed to make liaison more difficult.

After a few days I realised the only thing the staff could think of was to keep holding him down to take blood, do finger pricks and give insulin. This holding made the situation worse and extremely traumatic for everyone, but most of all for my son. Eventually, I suggested we make some picture cards (PECS) and start charts for him which helped to explain why he had to have injections now and also gave him incentives to sit still to have them. Some play therapy was incorporated, but it was sporadic and not really age appropriate.

We should have been given advice and counselling at the beginning. My son needed people trained in learning disabilities and communication techniques to help him. It must have been very expensive for us to be in hospital for a month, when it would only be a couple of days for other people. There is a learning disability team at the hospital, but they only work with adults and so didn't get involved. It is a good example of how adult and children's services should work together. I think things would have been better if he had access to therapy for his needle phobia from the beginning and the Diabetes support should have been available in the hospital, with joined up treatment when he went home. I have tried to get some therapy for him through various services but he has had limited input.

Finally, a couple of years later, after much work and encouragement, my son was able to inject himself. With better support this could have happened much earlier on. He has now got an insulin pump (called an Omnipod) which doesn't have tubes and is waterproof. It looks a bit like a computer mouse and can be stuck on to the body. It also has a remote controller. My son did a trial for one week with a dummy one and now has been using it very successfully for about 5 years. Again, this is something that staff and parents need to know about as it can make life much easier for everyone.

Diabetes UK have been really helpful, but we only found out about them after a long time. It would have been helpful if we had been told about them at the beginning. They do family support weekends. They are not specifically for parents of children with learning disabilities, but it was really helpful for my son to see other children injecting themselves. I think he thought he was the only one until then.

My son is now 21 years old and we have all got used to his Diabetes, the highs and lows and the daily management. The blood tests remained a problem so I again asked for help. During the last two years he has had support from a wonderful Learning Disability Nurse attached to the local 0 to 25 Team. She has taken time to get to know my son and befriended him with visits and days out over many months. She has shown him Easy Read information about blood tests and why we have to have them. She has been compassionate and encouraging, allowing him to take some control over the situation around the pathology room, the equipment and the actual test. A lot of the problem was the holding down. He has now had three blood tests with only a nice nurse to hold his other hand. He is very proud of himself!


Health Education England



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