

'Early Support helped us to laugh again'

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'Our youngest son, A, is almost three and is profoundly autistic, a diagnosis that he was given at just 21 months old.

The few months after the diagnosis were a complete roller-coaster of emotion for us all. I forget quite how many people we met and how many times we had to repeat our family history. I totally lost my confidence and didn't want to go out anywhere. I spent most of the time crying or chasing up appointments on the phone. My husband didn't want to talk about it and our older son, who was six at the time, thought that A was dying because we were spending so much time at the hospital.

I soon began to feel like I was going under and then in the midst of all the darkness and confusion, there came a flicker of light. Early Years arranged an ASD support group. It was my first chance to meet other parents in the same situation. Each week we had a speaker to help us through issues such as behaviour, education, food, etc. Most of us mums spent the early session taking it in turns to cry and going completely off task, but the speakers were all sympathetic and allowed us that all-important time to offload.

I had briefly heard about the East Sussex Care Co-ordination scheme [Early Support] and thank goodness I listened to their advice because what a huge difference having C as our key worker has made to our lives.

C explained the scheme to me and introduced the *Family Pack*. The book on autism alone was worth its weight in gold – it was so user friendly and contained all the advice and information that we had been lacking before. We agreed to meet about once a month, but I could phone C in between times if I needed help or a shoulder to cry on.

After a few meetings we began to think about our Family Service Plan. We were pleased with the support that A was receiving, but felt the support would be more effective if all the agencies met together and offered some shared support. Ensuring that all the key people were there was a challenge for C, but perseverance paid off. C took care of all the planning and admin, taking all the stress from us. The meeting went brilliantly and our pre-planned agenda had made everyone really focused and we had soon agreed our plan.

'Since [we started the Family Service Plan], I feel that everyone has bent over backwards to co-ordinate support and focus on our needs... We are a much happier family and we are coping a lot better with day to day living.'

Since then, I feel that everyone has bent over backwards to co-ordinate support and focus on our needs. There have been joint sessions with Early Years and the Children's Therapy Service; sessions with Playlink, Sure Start and Early Years and everyone involved has provided the service they agreed to at that meeting. A's key worker from nursery has also attended several of these sessions in her own time. I am no longer constantly phoning round to organise things.

A is making good progress and is a much happier child than he was a year ago. Consequently, we are a much happier family and we are coping a lot better with day to day living. We know that the future is not going to be easy but thanks to the support from the Care Co-ordination Scheme, we have all learned to laugh and enjoy life again.'

Parent, East Sussex