

# Jack's courageous journey



Jack in the humidi crib at Liverpool Hospital.

One of the aims of the Bethany Early Intervention Program is to assist families access the best educational setting for their child when the child becomes of school age. In this article the Bruce family share their story of how they used the services of Bethany and how this year Jack successfully transitioned into a mainstream school.

**B**orn at Liverpool Hospital by caesarean section, Jack was very premature. At 24 weeks gestation he weighed just 825 grams. Understandably, we were grief stricken and anxious as our daughter had been stillborn just 8 months earlier.

Jack was ventilated at 11 days old as breathing had become a chore for him. He remained under new born care at Liverpool Hospital for 8 weeks and was

then transferred to Campbelltown Hospital Special Care Unit, which was closer to our home, for another 8 weeks.

While in the humidi crib Jack wore a bonnet so small that it would fit a Barbie doll or could be used as an egg cosy. He wore miniature nappies and was bathed in a dish not much bigger than a cereal bowl. On day 8, Jack had an ultrasound that showed a cerebral haemorrhage on the right side of his brain. This was really frightening as it could have left him brain damaged. The ultrasound was repeated at day 40 and the result was clear. Our relief was enormous.

After 105 days in hospital and at 15 weeks old, we took Jack home. This was the occasion for great celebrations! He weighed 2.82 kilograms and he was on constant oxygen. The oxygen continued for 2 years as the ventilator necessary for him to breathe in the humidi crib had caused chronic lung disease.

Once home Jack immediately started a physiotherapy program to encourage muscle development and to stop him arching his back. We also went on a waiting list for speech and occupational therapy at Allied Health. These services started when Jack was about 2.

I felt Jack was a bit different and I suspected he had autistic traits. He used to line his toys up and would not make eye contact. He had repetitive behaviours like walking perimeters, running his hand along the walls or fence and staring into space. Shopping was near impossible as he became frustrated with so much going on around him. He just couldn't cope and would throw himself on the ground and bang his head. I felt terrible for Jack as I thought he might injure himself and I couldn't do anything for him but just pick him up, cuddle him and go home.

When Jack was 3 we enrolled him in pre school but after a few months he was unable to cope and we withdrew him. However, while he was at pre school the teacher also suspected that Jack had autistic traits and suggested we should get a referral and contact Bethany, an Early Intervention Program for kids with developmental delay. Our paediatrician actually came out to pre school to observe Jack during play. He diagnosed Jack with Childhood Autism Spectrum Disorder. Tony was not convinced but at least now that we had a diagnosis we were in a sense relieved. At least we had some idea of what we were dealing with.

We were anxious but keen to do whatever we could to help Jack's development. We transferred all our services to Bethany.

Within about 12 months of starting at Bethany, Jack's development had increased dramatically and the original diagnosis of Autism was lifted due to more early intervention and therapy. He was re diagnosed with Developmental Delay due to prematurity by

the Rainbow Clinic at Liverpool. To us this was great news. It proved all the work people were doing with Jack was paying off. His fine and gross motor skills, speech and language were all improving.

Jack's program with Bethany required both home visits and his participation in centre based groups with about 5 other children. We understood that children learn through play so groups were helpful. The home visits with the therapists were good and helped Jack a lot. We were able to learn from the therapists. We put in the effort and continued the therapy at home. This was tiring but we were willing to do anything that would help Jack.

*"While in the humidi crib Jack wore a bonnet so small that it would fit a Barbie doll or could be used as an egg cosy. He wore miniature nappies and was bathed in a dish not much bigger than a cereal bowl".*

When Jack was about 4 it was like someone turned on a light. It just all came. He had limited speech but his comprehension was improving. He was able to make good eye contact and his autistic behaviours started to decrease. At 4 years and 6 months he was toilet trained. He had improved so much we decided to try pre school again and he coped really well with 2 days each week. We were overjoyed and proud that Jack had come so far and felt fortunate that Jack's delay was not more severe.

We felt ready to consider options for Jack's schooling and had yet another assessment at the Rainbow Clinic. It was reported that he now had a mild delay and to our surprise we were told that we could begin planning for him to attend a mainstream school.

Jack started his transition to school program in Term 4 of last year. Each Friday when he would spend two hours in a classroom and became familiar with the routines, teachers and classrooms. This year Jack started in Kindergarten at Narellan Vale Public School. He has settled in well and even though his fine motor skills are slow, they are improving, as are his speech and social skills.



Jack in Kindergarten at Narellan Vale Public School.

We are grateful that Jack had the opportunity to attend an early intervention program and believe that he has developed the skills he has now because of his involvement with the Bethany team. We encourage all parents who have a child with a developmental delay like Jack's to participate in an early intervention program.... the earlier the better to give their child the best chance possible.

*Narelle and Tony Bruce*