

## NEW WRITING

### *Josh's Story*

*Kimberley Reid*

Kimberley and her son Josh have been supported by the same Kurrajong Early Intervention Service that features in the lead article in this issue of IQJ by Sue Davies. Kimberley describes how a good service became even better when the outreach service was established. This development gave Josh improved opportunities for learning, saved the family much stress, time and money, and supported Josh in his transition into mainstream school.



#### **March 2006**

My name is Kimberley Reid. I live on a farm 20 km east of Temora with my husband, Tony and two small boys, Josh and Sam. Life has been very difficult living on the land for a number of years now due to the worsening drought. This year we're anticipating our worst harvest ever with very little to nil grain stripped from our crops. In addition to this, the rising fuel prices have placed extra financial strain on my family. We are presently finding it very difficult to remain positive about our future on the farm. On top of

these concerns, Tony and I also have to battle with the every day struggles of raising a child with a severe disability. Our eldest child Josh (five years old now) was diagnosed with severe Spastic Quadriplegia Cerebral Palsy at four months of age. Josh requires full-time assistance for all daily activities. He is unable to sit, walk, talk, feed, toilet, bathe and dress himself.

Josh's Cerebral Palsy was caused by a lack of oxygen which resulted in widespread damage to his brain. We were given this information after Josh had a MRI scan on his brain at one

week of age at the Children's Hospital at Westmead, in Sydney. Josh had been transferred from the Wagga Wagga Base Hospital shortly after birth because he was suffering seizures and apnoeas (cessation of breathing). We spent ten days in Sydney before going home with the knowledge that our new little baby was most probably going to have difficulties in all areas of his physical development. It was also highly probable that he would have problems with his vision, hearing and cognition. At this time, the extent of Josh's disability was unknown. This would become more evident to the doctors as Josh achieved or did not achieve his milestones.

After returning home, I found myself struggling to cope with an extremely unsettled baby. Josh was very difficult to feed – a result of his inability to suck effectively. It was also very hard for Josh to settle, which meant he spent most of his time crying. This was an exceptionally emotional time for me. My self-confidence was at an all-time low, I had no direction for where my life was heading and I felt very isolated from family and friends. At four months of age, Josh had a check-up with medical staff at the Children's Hospital at Westmead. Tony and I were hoping for good news, but the prognosis delivered was very poor. Doctors did not see Josh respond to visual stimuli or sound. His head circumference had grown only one and a half centimetres in four months (which is extremely poor) and his muscle tone was changing from floppy to quite stiff. This confirmed the results of the MRI scan, that Josh had been severely neurologically compromised.

A week after given this news, we had our first visit to Kurrajong Early Intervention Centre. Even though we were outside the boundary for accessing this service, we were given special consideration because of the high level of therapy services that Josh was going to require. This I am truly grateful for and do not know how I would have coped if I did not have the staff at Kurrajong Early Intervention Service (KEIS) providing therapy services and family support. They played a major role in helping Tony and I adjust to the diverse needs of raising a child with a severe disability.

Even though I was grateful to be able to access regular Physiotherapy, Occupational Therapy, Speech Pathology (Speech Therapy in UK terms), Early Learning Groups and Family Support, it was very exhausting travelling one hour and

twenty minutes to Wagga Wagga each week. At this time, I was averaging about five hours broken sleep each night because of Josh's difficulty in settling. On top of this, Josh had an incredible dislike of the car seat and would scream the entire journey to and from Wagga Wagga. As a result, we were both exhausted on arrival. Often, what was hoped to be achieved during a therapy appointment, was not accomplished. However, I unfailingly attended because what the therapists taught me during sessions I was able to consistently apply at home to help Josh develop to his full potential.

I also enjoyed meeting with other parents/carers at KEIS who were facing similar challenges. Throughout my association with the Service, staff have provided many opportunities for families to socialise. This has considerably helped my emotional wellbeing. It is good to talk with other people who understand the daily struggles of raising a child with a disability.

At the beginning of 2004, KEIS began providing services to families with children with disabilities and/or developmental delays living in small country towns surrounding Wagga Wagga. I cannot emphasise enough the difference the outreach service has made to my family. Less travelling has been the biggest advantage, especially financially. It also has the added benefit of Josh being less exhausted, so the quality of therapy achieved during sessions is of a much higher standard.

Another advantage of the outreach service has been the regular home visits made by the Physiotherapist and Occupational Therapist to adjust Josh's equipment. Because his disability is severe, he has nine pieces of equipment to assist in proper positioning. Before outreach was provided to Temora I would have to transport this equipment to Wagga Wagga. This was time consuming as most pieces had to be disassembled to fit in the car. Some of the equipment is reasonably heavy which also made the task physically demanding, especially when suffering from a bad back, as I was.

An additional benefit of having a Special Educator, Physiotherapist, Occupational Therapist and Speech Pathologist based at Temora, is their active involvement in the transition process to preschool and school. Before Josh started at the local preschool the Therapists and Special Educator held an

information night to educate the staff about Josh's additional needs. They also regularly attend Josh's preschool to discuss his progress. We are currently in the transition process for Josh's admission to school at the beginning of next year. The Therapists and Special Educator have visited the school on a number of occasions to talk with the teachers. With the support from the staff at KEIS I feel confident that this transition will be a positive experience.

KEIS has also provided families in Temora the opportunity to participate in programs like the 'Care for Caring Parents' and 'Triple P' (Positive Parent Program). These courses, providing valuable knowledge and skills about how to be better parents, improved my confidence in my ability to cope with the daily struggles of raising a child with a disability. Additionally, the knowledge and skills I have gained through Therapy Sessions, Early Learning Groups, Information Nights, Newsletters and Parent Support Groups has empowered me to believe that I am the most important intervention person in my son's life.

It's not easy raising a child with a disability. There's never a week that goes by that a problem doesn't arise. These can include:

- Medical issues like the detection of possible seizures, operations to rectify tight muscles, teeth being extracted because of bad decay due to reflux or the constant struggle for Josh to eat more so he's not classified as underweight.
- The never-ending appointments to the Paediatrician, Rehabilitation Physician, Neurologist, Orthopaedic Surgeon, Gastroenterologist, Orthotist, Ophthalmologist and Dietician.
- Making sure Josh's equipment and splints are regularly maintained so they do not cause pressure sores.
- Dealing with the ignorance of some people in our communities who do not understand or appreciate the difficulties that people with disabilities and their families have to deal with.

However, through all the difficult times since Josh's birth, it has been reassuring to know that I have a team of people at KEIS I can turn to when I need support and advice. Josh has had access to consistent therapy services since he was four months of age. Nevertheless, there are many

families I know in Temora who have had to manage without Speech Pathology, Occupational Therapy and Physiotherapy for extended periods of time. It is through the KEIS 'Rural Beginnings Project' that equitable access to therapy and family support has occurred. I applaud what Sue Davies and the rest of staff at KEIS have done to provide such a great service to families living in the outreach towns. There was a lot of hard work behind the scenes to get this project up and running. I hope other families appreciate that the quality of services that we are receiving is unmatched anywhere else in Australia.

### **Update June 2008**

Josh is nearly halfway through his second year at our local mainstream Primary School. His transition to school was a phenomenal success. We have gone from one great team at KEIS to another wonderful team at his school. The Principal, Classroom Teacher and two Teacher Aides have worked closely with us to develop a program to meet Josh's additional needs in the regular classroom curriculum. It has been remarkable how dedicated the staff (and children for that matter) have been at including Josh in all aspects of the school life.



**Josh keeping an eye on the pigs**

Josh is now sitting in his wheelchair for the majority of the day. His ability to operate a switch has improved enormously now that he is sitting in his wheelchair. A switch has just been mounted to his left footplate so that he can use his foot to operate a computer and he is now learning switch-scanning which will help him to make choices on it.

The children at the school have been absolutely amazing to Josh. He has made some really great friends. He had his first sleepover at his mate's place last weekend. Tony went with him, but told me it was my turn next time. The children, including Josh in his own unique way, talked to half past three in the morning. There is no way his transition to school would have been as successful as it was without the enormous effort by Physiotherapist, Occupational Therapist, Speech Pathologist and Special Educator at KEIS. Mainstreaming a child with a severe disability is not an easy road to take, but it has definitely been worth all the stresses involved in making it happen.

Life is good for our family at the moment, which has extended since the last time I wrote. Tony and I had a baby girl named Chelsea just before Christmas last year. The drought has continued and our 2007 harvest was actually worse than our 2006. However, having Josh so happy at school and continuing to achieve the goals that we set for him, has improved our attitude towards our life on the farm to a more positive one.