

## OUR JOURNEY

Around the world are 100's of 1000's of parents who have shared with us the shock and misery, followed by the grief, of being told that our child is not normal, mentally retarded, mentally handicapped, intellectually disabled or whatever the current term is or was. Rowan was born in 1957. This was a time when there was no public understanding about retardation. There was nothing to read. Doctors knew nothing except sometimes a correct diagnosis. Not always. So parents, shocked, filled with grief, were left with no help.

Rowan went to Kew on our doctor's advice: we were hopelessly ignorant. As the shock faded we looked for the best living environment for him. 46 years later that goal remains. But at first the institution was a haven.

Soon, Alan and I realized that so much was different for Rowan, than for the other five kids. I asked questions, talked to all sorts of people. We began to look for opportunities for Rowan and his companions at Kew, then for others in Victoria, then Australia and in the end anywhere in the world. Every decision, Alan and I made for Rowan, was aimed at helping him to have opportunities as an individual, which was what we did for each of the others. We wanted him to be truly included.

I used to pick up the other children from their different schools each day. So sometimes I got Rowan first and took him with me. In this way his brothers' and sister's friends met him.

As representative of the Kew parents, I visited schools and services in the other states, where conferences were held. I soon realised that those children who lived at home, and went to day school developed language, and social skills, and self-assurance, that I never saw at Kew. For most of these years, I was at Kew up to four times a week for various reasons.

When, out of the blue, we were offered a place in a day-school for him, we brought Rowan home the next day. It was April 24, 1972. He was 14½, behaved like a toddler, and spoke very indistinctly. He was even unable to choose which to pick from a plate of biscuits, or whether to use a ball or a pencil to play with. He had never had a choice before. Teaching him to choose took weeks.

He was now one in a household of 8. He had been one in 32. His models, now, had no speech or other disabilities. He had no such opportunity before. He learnt quickly.

After six weeks he made a choice to stay at home, rather than return for weekends. He also learnt to trust me when I suggested he go back to say goodbye and needn't go back after that.

Rowan learnt to use knife and fork; to bring his underpants and socks to be washed each day; not to walk naked through the house; to use a toilet responsibly; to trust dogs; to sort his clothes into drawers in his own bedroom; to masturbate only in private; to work with other people to get jobs done; to shop for a present suitable for the other person, rather than what he would like (Tricky, that was!)

He learnt to use matches responsibly. He learnt about our neighbourhood, and how to get home. He learnt that if the street lights came on, it was time to go home. He had many neighbourly acquaintances. Three years later he crossed a busy intersection to catch the school bus each morning.

He learnt from the social behaviour, manners and customs of the family and those around us. He made many personal choices. It was hard for him to realise ownership of personal belongings, because in his first 14½ years he could never own anything at Kew. Possessions disappeared.

Rowan shared all family activities: went to birthdays, to gallery openings, weddings, Christmas parties. He went camping with us, slept on the ground, helped his father make concrete, used hammer and nails, sand-papered old paint, played with the babies, fed the chooks, had his own family chores, scuffled with his brothers. Rowan had to learn NOT to put his arm around every woman he liked the look of, NOT to try to hitch lifts, NOT to purloin every small item, (loose change, keys, watches etc). And we learnt a lot from him as well as about him.

When he was 21, Rowan made a man's decision to leave home, and he knew where he wanted to live. This was long before we would have suggested such a move. Rowan has had many other experiences as an outcome of that move, and since his father died, 20 years ago, I have had, more recently, many persistent advocacy experiences. Situations change, and the world is never perfect.

Rowan has two close friends, a man and a woman. He, and each of the others, at separate hearings of the Intellectual Disability Review Panel, chose the other two for sharing a house, with a third man they know and like. This house has a devoted team of three who share the overnight support. The team leader has helped Rowan to lose excess weight, and the other members all co-operate.

Rowan is now 46, and apart from his poor speech he fits in anywhere, with anyone. He has known no adverse discrimination in the neighbourhood. Rowan is a gentle man, like his four brothers, and I can say that although lacking their natural capacities, and those of his sister, he is the one who has made the most personal progress in life from the "blob" the doctors called him in their prognosis report in August 1957. We are all proud of his progress.

All these years and developments can be encapsulated in the elements of one story:

At 14½ Rowan knew nothing about road safety. Unless he learnt this, he had no freedom, nor confidence. I relied on him to learn. He relied on me to teach him. It took a year. Then I gave him a graduation test: I told him I would shut my eyes, and asked him to take my hand and lead me across the busy road. So that's what we did, and we were both elated. So now he had his graduation certificate as a pedestrian. And we danced on the footpath in celebration.

Since that day, I have never undermined his self-reliance by cautioning him, and I never take his arm. Though he has a severe intellectual disability and cannot add two and one, I know it is important for him to maintain his self-esteem by taking personal ownership, and responsibility, for all his actions. An important thing I have learnt, is that Rowan is emotionally exactly like you, and me, and the rest of the world population

Ethel Temby  
14/11/03

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