

[REDACTED]

[REDACTED]

As long-term registered foster-carers in Queensland, we had a two-year-old baby placed with us in 2002. This child was Indigenous and had multiple medical and developmental problems: [REDACTED]

[REDACTED]. At nearly two and a half he could not walk or talk.

He was given multiple medical and psychological/behavioural diagnoses for the first few years of his life, [REDACTED]

[REDACTED]. But eventually, with my intense advocacy, he was diagnosed with Foetal Alcohol Syndrome – a severe form. He was considered “difficult” even amongst health professionals, even “untreatable” by some.

My husband and I had spent many years working in the disability sector and fostering children with special needs, but never had we encountered a child whose needs were so universal and all-consuming. We fought to keep him alive through multiple surgeries in the first few years, then we fought to find him the best educational and social opportunities.

From the beginning, this child was in a too-hard basket – medically, socially, educationally and in every context imaginable. We could not get appropriate respite care for him, which took an enormous toll on us as a family over the years. Both government and non-government agencies, and individual professionals all abdicated responsibility for him over and over again, saying that “he did not meet their criteria”. Apparently he did not meet anyone’s criteria, because no one was required to acknowledge FASD as a legitimate disability. He, and by association the whole family, became a hot potato in nearly every context. This systemic neglect left us impoverished and exhausted.

This child’s behaviour and development were affected in every way: he had major learning disabilities, poor impulse control, poor memory and concentration, inability to understand or learn social mores and consequences, no empathy, poor gross and fine motor skills, inability to grasp abstract concepts such as numbers. The education system ascertained him as merely having a speech impairment, allocating a laughable two hours teacher aide time per week. This child could not perform even basic self-care tasks without support and supervision.

Due to his lack of progress and some serious incidents indicating inadequate supervision, the child had to be removed from the mainstream school system when he was seven years old. After a year of home-schooling (for which we could not get any help or support), he was enrolled in the nearest Special School, which was almost 100 kms away – there was no support given to him for travelling, which placed an extra financial and logistical burden on us for the next three years.

After eight years of struggling to meet this child's needs, without access to even the minimal supports available to other families, we were forced to relinquish him back into care, as we suffered a series of major health crises. Queensland child protection services, health services, disability services and advocacy services all failed to give us even minimal support in this crisis situation as the child – and the family – fell between the cracks of their “criteria”. Even personal appeals to individual politicians fell on deaf ears.

The result has been utter devastation for this family. The child is back in care, the Department of Child Safety has happily severed all contact and refused to mediate or even give us news of the child's wellbeing. Their tactic was to downplay the child's needs completely, thus negating our eight years of hard work with him.

FASD is cruel, insidious and wholly preventable. Without proper diagnosis, early intervention and recognition of the problems as valid disabilities, the outlook for children like my foster-son is bleak. There needs to be an holistic and non-judgmental response to this problem in terms of both preventative strategies, and in the way that services are set up to deal with victims and their families.

What happened to this child, this family, did not need to happen. If services and individual professionals had acknowledged and treated the FASD symptoms as real and valid, offering us the same level of support that other families receive, I believe we would still be together as a family now. As it is, we will now grieve for him for the rest of our lives, and the child is at high risk of ending up in some form of institutional care.

In the course of searching for help online, given the lack of anything in Queensland or Australia, I have found a wealth of Canadian, American and UK research and information. As a nation which actually prides itself on its culture of alcohol consumption, why are we thirty years behind the rest of the developed world? Other countries have warning labels on alcohol, specialist FASD multi-disciplinary teams working in early intervention, specialist education strategies and facilities, extensive research into FASD-related issues – what is wrong with us that we cannot see the need?