

BRINGING UP CHLOE

BY LUKE STICKELS



Jane Lamble and her grand-daughter Chloe

In the mid-1990s, a palm reader told my mother, Jane Lamble, then aged in her 40s, that she would raise a fourth child, in addition to the three she already had, and that the child would be of her “genetic line”. If it wasn’t the strangest thing Mum had been told, it was certainly strange when it came true. In May 2009, the Children’s Court of Victoria ratified a kinship care agreement that placed my niece, Chloe Anne Stickels, in the primary care of my mother – for whom, at 57 years of age, decades of ‘strange’ began to look like fate.

My older brother, Justin, phoned Mum in December 2007 with the news that his then-girlfriend, Susie, was pregnant. Which part of this, exactly, was strange? Well, Justin had been born with a mysterious complex of

physical and cognitive disabilities: severe microcephaly, resulting in a small skull and attendant brain damage, a congenital malformation of his heart, a cleft soft palate, and a malformed nostril and eustachian tubes in his ears; these resulted in acquired deafness, convulsions as an infant, and adolescent onset poly-arthritis. Given a previous marriage without pregnancy, it was assumed Justin could also be sterile.

Mum and Dad were told variously over my brother’s early years that he was/wasn’t fine and would/wouldn’t live, go to school, walk, speak or even be continent. Somehow, however, this didn’t qualify my parents for a carer’s pension or qualify Justin for government subsidies or support throughout his childhood or adult life. So it is entirely ironic



Chloe with her parents Justin and Susie

that the State intervened last year to say Justin was too disabled to provide a safe and reliable level of care for Chloe.

Justin always wanted to be a dad. The thought of holding down a job, being able to support a loving wife and child, framed his hopes and dreams. But the palm reader’s prediction represented a serious danger for everyone in our family. We had each already gone well beyond our limits making Justin’s life as rewarding as possible, given his difficulties: 28 operations, years of speech therapy, and dealing with all the behavioural, emotional and social integration issues stemming from a compromised ability to see cause-and-effect, show initiative or apply sound judgment in many areas of life. We had all been tested by divorce, financial hardship and ongoing alienation between family members.

If fate is strange, it was also in this case significantly bureaucratic. Pre-natal care and planning services cranked up immediately, underscored by nagging worries about a possible late-term termination should ultrasounds reveal any severe disabilities. Without underestimating anxieties of the unknown during any pregnancy, our anxieties operated as much on what we already knew. Susie had physical and cognitive disabilities of her own, inherited at least in part from her parents, and while Justin’s disabilities were congenital rather than genetic, there was a significant chance his own disabilities could be transferred genetically.

Years before, Justin underwent genetic testing to investigate the possibility of a particular genetic mutation which matched many of Justin’s complex of physical and cognitive problems. We had Justin retested for Chloe’s sake, but the results were indicative rather than conclusive. People born with disabilities so often represent the boundary of the known, and remain something of an enigma to the medical sciences.

It was five months into Susie’s pregnancy before major abnormalities could be ruled out. That’s a long time to hold

your breath. Microcephaly is only detectable in the final trimester, but nevertheless we finally allowed ourselves to get excited. Close medical observation during this time was matched by case management initiatives, aimed at ensuring both Susie and Justin had the parenting, domestic and personal independent living skills they were going to need.

These programs ranged in quality from excellent to poor to completely inappropriate, but overall there was a committed, interdisciplinary approach to a multifaceted complex of problems. We also counted ourselves fortunate for the assistance, with case management meetings featuring seemingly ever more volunteer advocates, pre-natal, disability and counselling specialists. In the meantime, when they weren’t preparing for their baby, Justin and Susie prepared for their wedding, certainly very much in love.

Yet obliged by compulsory reporting laws, the midwife conveyed her concerns about Justin and Susie’s capacity to be independent parents to the Child Protection authorities. As a result, around two months before Chloe was born, Mum and I were called in to meet Child Protection officials, where it was strongly indicated that Mum would have to volunteer as primary carer to prevent the baby being taken into foster care. This was quite a bombshell. Mum feared being trapped into providing care to generations of disabled children all her life, and there was apparently a 50 percent chance Chloe would inherit disabilities from either of her parents.

Nevertheless, by the time Chloe arrived in the world, she was met by supportive family on both sides, and a resolute grandmother who perhaps never expected what sheer joy this new baby would bring. Amid our greatest hypersensitivities for any signs of lethargy, non-responsiveness or cognitive delays, Chloe quickly established her own brand of bubbly delight, soothing calm and earnest interactions. An easier baby could not be imagined.

But the case management meetings went on, with an ever-increasing cast of people coming and going. In the first few months of Chloe’s life, her case file changed hands several times at the Child Protection agency, and we suffered each time. Then, with no prior warning, a new agency official announced a complete back-flip: their main goal was now to keep Justin, Susie and Chloe together at all costs. Great in theory, but after a week of Mum and I supervising the new parents, doing their best with Chloe at home, we were convinced the task was beyond them. It wasn’t only an inability to problem-solve and adapt to sudden changes, or to think logically through the layered systems of care that many of us would do under so-called “common sense”. It was also the emotional thresholds of both parents to stay calm with a screaming baby, to assert a level of confident control that neither, arguably, had ever experienced in their lives.

■ continued page 27

It is impossible to quantify the emotional cost of transition for my mother, moving from being Justin's primary advocate and case manager for over 30 years – arguing, pleading and openly fighting for his rights, voice and cause with hospitals, schools, councils and other parents – to arguing for a limit to those rights and that voice. Mum and I both argued that Chloe was in danger, not from any lack of love or intention on the part of either Justin or Susie, but from a limit to their capabilities. Mum had to admit to herself that Chloe's needs were now a higher priority than Justin's.

'Keeping the family together' is a powerful aspiration, and we strove for that before and after Chloe's birth. Getting everyone to agree that this was not realistic or safe, including Justin and Susie themselves, as well as the latest Child Protection officer, was a lesson in patience, and dare I say,

strategy. Reconciling practicality with our hopes and dreams is the task of every individual and family, every government department, ministry and cabinet. But the argument is no longer relevant in our particular case, with Justin and Susie currently separated and continuing to develop their parenting and independent living skills, and with Chloe now placed in my mother's primary care.

Chloe sees her mother and father twice a week each, sometimes more. They can be left alone with her for up to an hour or so at a time, so long as Mum, myself, or Susie's aunt and uncle are only a few minutes away. These rules of access were ratified by the Children's Court at Mum's and my urging, sometimes through tears and heated correspondence. We wanted to be protected by the law as much as we wanted Justin, Susie and Chloe's rights to be protected. Every second weekend, Chloe stays with Susie's aunt, uncle and their four girls, with Susie's dad seeing his granddaughter whenever possible. As a result of such diverse love and support, we have an exceptionally healthy, happy and profoundly unaffected baby to be proud of as an extended family. Strange, this fate. 🌀