



Sofia's Story



Early Childhood Intervention Australia
Victorian Chapter

On Mother's Day 2004 we received the diagnosis confirming our daughter Sofia had been born with Down syndrome. Even though my husband and I embraced the diagnosis, nothing can prepare you for the emotional turmoil and difficulties you will face trying to meet your child's basic needs for growth and development.

Anxiously passing the time on waiting lists to access services for our daughter, was our introduction to the disability service system. We felt isolated and alone and really worried that precious time was ticking away without support for our child and family.

Perhaps one of the most difficult stages in our family's journey with Sofia so far, has been our fight to have her educated in an inclusive preschool setting.

Under the current criteria, Sofia was unable to access kindergarten Inclusion Support Service (KISS) funding, which, in most cases, provides an additional assistant for a percentage of the time a child attends kindergarten. To be eligible for this funding, the child with a disability must be either at significant risk of injury to themselves or others, have exceptional medical needs or be extremely limited in their ability to move. There is no funding for children with disabilities to be "included" in preschool programs, therefore there is no acknowledgement Sofia learns differently, has seriously impaired communication skills, is incontinent and can demonstrate challenging behaviours. This combination of challenges made kindergarten really difficult for Sofia, her peers and the teachers - many days ended in conflict and tears!

It wasn't until her fourth and final semester that Sofia finally became eligible for KISS funding for seven out of 12 hours a week. Things then began to change significantly. Sofia was able to be provided with real opportunities for engagement and learning. She became much happier, the other children could begin to relate to her, and the teachers could get on with teaching.

Our greatest wish it that never again will any family have to WAIT for things to become so desperate before they receive services which should be their child's basic right from the beginning.

Our daughter is now at school. However, sadly, even though the research tells us children with disabilities do better when sharing the same social and learning environment as their peers, we are sending our daughter to a 'special school'. After our pre-school experience, we don't have the confidence current 'inclusive' programmes are fully supported and resourced within mainstream education.

The government recognises our children's early years are their most important, surely then they need to adequately invest in these formative years for all children.

