

## Robyn and Sophie's Story

Sophie was born a few days before Christmas, 35 years ago. She wasn't due until mid-January so her early birth was a surprise. Our four other children were so excited and wrote to Santa saying that they had a little sister, so could he please bring her a gift. I have to say that this was the last thing on my mind!



## My early memories are:

- Sophie was in hospital for a month before she learnt to suck, I worried she would never get there. She was very slow to feed and we had to find the quickest flow teat we could, but it all worked out!
- The hospital gave us a DSNSW pack which had great resources, including a video our whole family could watch which showed children with DS of different ages doing all sorts of regular activities! It also included the name of a parent liaison I could call at any time, which I did. It was so comforting to speak to someone who understood.
- People weren't sure what to say to us. They mostly said they were sorry, which irritated. But we understood they meant well. Some said congratulations and it was marvellous to hear.
- I became sick of hearing people say that DS children are ALL so loving and eventually I got the courage to tell them otherwise, nicely!



As the months rolled on I realised that Sophie needed what our other children did - love, care and the ability and willingness to investigate helpful ideas. The worry about what DS meant for Sophie and our family was not the prime focus anymore. It became one of the many challenges we have faced raising our children.

Fortunately Sophie was a healthy child (and still is) and met her milestones eventually - I had a love/hate relationship with Early Intervention, attending weekly sessions and trying to fit in the exercises with the demands of family life.

As I said, Sophie made her milestones but each of her stages were longer than my other children - she was a baby for longer, a toddler for longer plus a teenager for longer!! This didn't matter to me but it did mean that the physical part of parenting (lifting, feeding, chasing, watching) was more taxing for me.





Preschool came along and then the decision as to what school Sophie should attend, do we go with a 'special school' or a general mainstream school? Our local catholic school had quite a number of students with disabilities so it was a perfect fit for Sophie, it was part of our community and she met friends there whom she still sees. One of her friends continued through high school with her. I won't pretend that it was all plain sailing but there are often issues with any school and any child.



Sophie joined our local Special Olympics region when she was about 8. It had everything: fun, exercise, community and friendships. Sophie competed in swimming and basketball, she won medals and went to the Nationals, but those achievements are secondary to the life it helped her live.

The worry I felt in those early days might still be there a little but that goes for my other children too. Sophie's ability fills me with so much pride and she has taught me more than I can say. She has lived out of home for seven years with a friend, she loves her job, she has a boyfriend, and she enjoys life – just like her siblings.

We have been to many, many DSNSW picnics, walks, dinners, lunches and meetings over these 35 years and DSNSW are still supporting Sophie through innovative social activities plus there are age-related information sessions for me. We are so fortunate to be a part of this community.



