

BACKGROUND

I am submitting this paper as a carer of a young child with a disability. My daughter is nearly 4 and was diagnosed with a rare genetic syndrome when she was 3 months old.

THE PAST

The first 2 years after my daughter was born were very difficult. She spent the first 4 months in hospital and had a number of operations. For my husband and me it was a difficult time as we didn't only struggle with trying to find time for our older child as well as spending time with our younger one in hospital but also to come to terms with having a child with a disability.

It was a steep learning curve as we had to try to understand a lot of medical terms we'd never heard of before and it was hard having so many decisions affecting our child's life taken out of our hands.

For a long time we didn't know how long our daughter would have to stay in hospital for, then suddenly we were told she could come home. We were given a very last minute CPR course and then we were sent home with a child who had been in special care all her life and had severe sleep apnea and were told to just look at her colour to work out if she was ok or not. She was on a sleep apnea monitor overnight that went off every few hours because one of the dots had come off her chest and in hindsight I don't know how we coped.

When our daughter was sent home from hospital we were assigned a liaison nurse who came to visit us once a week. There was no case worker involved, there was no information about early intervention service, nothing.

I spent every minute my daughter was asleep during the day on the phone trying to find out information.

I had no choice but to become her case worker. This was my full-time job for 3 years. Once I found out about early intervention service it was of course me who took her to all early intervention classes.

So this means I didn't go back to work for 3 years.

THE PRESENT

At the moment I feel that we're coping very well. My daughter has made wonderful progress, my husband and I have been able to accept the fact we have a child with a disability and embrace the change this brings with it, our older child seems to be coping very well, we have supportive grandparents and live in a very understanding community.

I work part-time now as my job as case worker for my younger daughter hasn't changed – I'm just getting better at it. I'm very involved with one of the early intervention services my daughter is receiving services from and am very aware of what's going on in the not for profit sector.

My younger daughter still has a lot of medical appointments but we are lucky as we see all specialists through the Children's Hospital and don't have to pay for any private appointments.

I only realised this recently while talking to a few mothers of children with a disability who haven't spend their early months in hospital.

THE FUTURE

I normally try not to think about the future too much. I guess it is too scary and I feel that I can't do anything about it anyway.

The National Disability Scheme is something very different though. This is an issue that I feel I can influence and it's wonderful to see so much support for it.

At the moment I am pretty confident that my daughter will go to a mainstream school. When she gets older I hope she will be able to get a job in one of the major fast-food chains or something similar. She will not be able to live off the money she earns and we will need to support her financially in the future.

A National Disability Insurance Scheme will mean more stability for families like ours. Hopefully it will provide additional services and will make it easier to access them.

Nobody chooses to have a disability and society has a moral obligation to look after all its people. The National Disability Insurance Scheme is just a small part and a first step.

Thank you.