

# Navigating The System





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Margaret Meaker takes an unexpected ride from working in disability services to being a recipient of such assistance.

I was single and mortgage-free when I stepped into the world of disability services. I had studied Social Welfare at TAFE, but had no idea what an influence working for a small non-government organisation would have on my professional and personal life. My role was to assist adults with intellectual

disabilities (many of whom were living in appalling institutional settings) to move into the community and support them to become active participants in society and to access services.

I learned never to make assumptions about what people can and can't do. I learned how powerful language and



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## YOURSTORY

terminology can be. These people were categorised by a diagnosis or label that had been placed on them, often incorrectly, and I witnessed the enormous consequences of this. I also experienced the power and control that services and organisations have over the people they are meant to support. At times, practices were questionable. I left after seven years, disillusioned and vowing never to work in disability services again.

Falling pregnant wasn't easy for me, but after four years I became a mother. My daughter, Lilian, was born a healthy baby. At eight weeks, Lili contracted bacterial meningitis. She deteriorated quickly, and soon after being admitted to Westmead Children's Hospital's paediatric intensive care unit, Lili was placed on life support. For 10 days she was on life support. It was a traumatic experience that will never leave me; I was broken in mind, body and spirit. Yet Lili's determination to live led to her unexpected survival. We were told that it was highly likely that Lili would be profoundly disabled physically and intellectually, as she had sustained significant brain damage. Little can be compared, in scale or scope, to that life-changing moment when we received that prognosis and became the parents of a child with a disability. I left the hospital with an 11-week-old baby, a strong belief in the human spirit and the name and phone number of a physiotherapist. It was at this point that I became a recipient of disability services, rather than a provider.

I embarked on a journey into the unknown, which was stressful financially and emotionally. I found myself on a merry-go-round of therapy and medical services, trying to find affordable services

fortunate to have a DADHC (Department of Ageing, Disability and Home Care) caseworker who worked closely with Lili's therapists. She gently encouraged me to accept respite assistance when my

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that would best meet Lili's needs and recognise her abilities. The focus was often on what was wrong with her, and there was no time to celebrate her small achievements as we moved onto the next problem. The advice and information was often conflicting, and at times I simply didn't know what to do.

Lili smiled her way through the intensive therapies that helped her to crawl at 17 months, walk at two years and develop her fine motor skills. It was all-consuming; everything I did became a form of therapy. Lili's ability to communicate was significantly delayed, and stepping outside her familiar environment was very traumatic. I was

second daughter, Ella, arrived. At first I resisted help because it felt as if I would be admitting failure; not coping. I thought I should cope because I had a professional background in disability services. Finally, I accepted in-home respite assistance, and since then I have never looked back.

Wondering whether therapy was the only answer, I sought early-education options. I had resisted having Lili formally assessed, feeling strongly that a formal label would only serve to segregate her and place limitations on her, but I went ahead when I learned we needed it to get her into preschool and attract funding.

It was a difficult and confronting day when Lili was diagnosed with a

mild to moderate global developmental delay. I felt as if she had been placed in a box.

My search for a suitable preschool for Lili was extensive – I went to six in my local area. I was met with such complacency, as well as limited resources. A sense of urgency consumed me. Then I heard that a team from Macquarie University Special Education Centre (MUSEC) was establishing a program for children with disabilities at a Meadowbank childcare centre. I look back at that news as one of our biggest breaks. Lili was enrolled in the program there for three years. She began to lose her fear of the unknown and her dependence on me decreased. Her language skills developed dramatically with the guidance of professionals and also through her interaction with typically developing children. I knew my child was being stimulated, not babysat. This was true inclusion.

Unfortunately, at that time Lili began to have seizures. We were forced back onto the medical treadmill as we tried to manage a diagnosis of uncontrolled epilepsy. Over the next 18 months, we experienced some very traumatic seizures, and Lili fought for her life again, several times.

The school experience could only be resisted for so long; at the age of six, Lili simply had to go. We needed another formal assessment for the school application. This time Lili was assessed as having severe global developmental delay.

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I was devastated, as I knew a mainstream school was no longer an option.

There is so much anxiety associated with starting school. Although I took comfort in the thought that Lili would be understood in the special school that had accepted her, I still felt she was vulnerable because of her uncontrolled epilepsy. After 18 months, I received a call from the principal asking me to find Lili another school, as they simply couldn't cater for her needs. I was shocked and began to wonder if there was a place for her. We moved her to another special school with a very holistic approach to education. We have learned that changing schools is not always a bad thing. At her new school, Lili is embraced for all she can do and contribute.

As Lili has become older and her difference more obvious, we have learned to accept that we will be noticed wherever we go. There are many wonderful moments when children, encouraged by their parents, try to communicate with her and play with her. There are other times when people stare or laugh or parents pull their children away. I realise that I need to be prepared for these events, the good, bad and ugly. I have a selection of interesting and informative responses ready to go, depending on the circumstances.

A network of wonderful people, including professionals, has always surrounded Lili. She is part of a very loving and supportive extended family and a group of friends who have actively

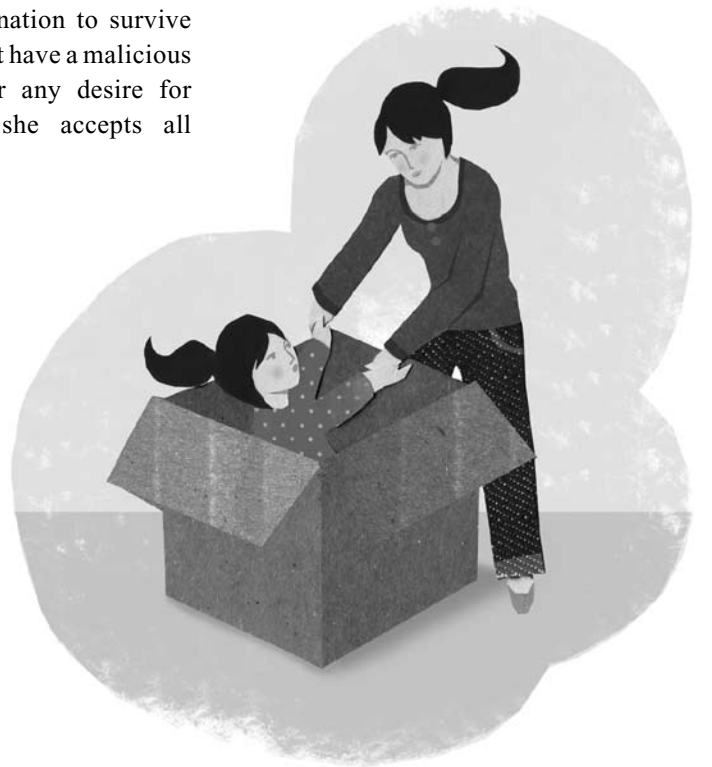
participated in all aspects of her life. Day-to-day struggles and difficult decisions are always discussed openly. The many and varied celebrations of Lili's achievements have always far outweighed the difficulties. Her first poo in the toilet will never be forgotten!

As Lili's mum, I have witnessed the triumph of the human spirit time and

me back to working in disability services, and I am now comfortable with the dual role of provider and recipient.

Lili is a beautiful 10-year-old girl who has touched the lives of so many with her sheer determination to survive and achieve. She doesn't have a malicious bone in her body, nor any desire for material goods, and she accepts all

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time again. Yet I grieve every day the loss of what might have been. I get angry at the injustice of her disabilities and the continual exclusion she experiences. At times I feel depressed that her disabilities will not go away, but I am empowered by my inner strength and trust that I know Lili better than anyone. I also recognise that being a service recipient is not a sign of weakness. It is ironic that Lili has led

people for who they are regardless of race, age or appearance. We all learn so much from her, yet society perceives her as a burden. I want Lili to grow up not dwelling on her differences, but focusing on what she can accomplish. Having a child with a disability is not something I would choose for my family. It is an unexpected journey and a challenge, but it is not a disaster. ■

Margaret Meaker is General Manager of the STaR (Special Teaching and Research) Association. The STaR program is operating in 14 childcare centres across the Sydney metropolitan area. STaR is a member of the Early Intervention Service Provider Panel, which provides services to children with autism spectrum disorders. For more information or consultancy, call 9888 3717, email [office@star.org.au](mailto:office@star.org.au) or visit [www.star.org.au](http://www.star.org.au)

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