

Learning with Lili

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I stepped into the world of disability services 30 years ago having studied Social Welfare at TAFE. I had no idea what an influence working for a small non-government organisation would have on my professional and personal life. I learnt to never make assumptions about what people can and can't do, the importance of a positive image, both physically and socially, and how powerful language and terminology can be. I was in a role supporting adults with intellectual disabilities to move into the community and support them to become active participants and access services they needed. Unfortunately, they were categorised by a label or diagnosis 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/or organisations have over people they are meant to support. At times, practices were questionable and I left after seven years, disillusioned and vowing never to work in disability services again.

My daughter, Lilian, was born a healthy baby in 1998. At 8 weeks Lili contracted bacterial meningitis. She deteriorated quickly, and soon after being admitted to Westmead Children's Hospital Paediatric Intensive Care Unit was placed 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 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 number of a physiotherapist to contact. It was at that point that I became a service recipient, NOT a provider.

This unknown path was stressful financially and emotionally. The merry-go-round of therapy and medical services, trying to find affordable services that would best meet Lili's needs and recognise her abilities was exhausting. The focus was often what was wrong with her, and there was no time to celebrate the 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 intensive therapies that helped her to crawl at 17 months, walk at 2 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 fortunate to have a then DADHC (Department of Ageing, Disability and Home Care) caseworker who worked closely with my therapists. She gently encouraged me to accept respite as my second daughter, Ella, arrived. At first I resisted help because it felt like I was admitting failure, not coping. I thought I should cope because I had a professional background in disability. Finally, I accepted in-home respite, and from then I have never looked back!

Suffering "therapy fatigue" and wondering whether that was the only answer, I sought early education op-

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tions. 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 learnt we needed it to get her into preschool and attract funding. It was a difficult and confronting day. Lili was diagnosed with a mild-moderate global developmental delay. I felt 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 desperately searching for acceptance, skill and resources. A sense of urgency consumed me. I was told by my caseworker that people from Macquarie University Special Education Centre (MUSEC) were establishing a program for children with disabilities at a Meadowbank childcare centre. I look back on that referral as life changing.

Lili was enrolled in the STaR (Special Teaching and Research) Associations Childcare Placement and support program. STaR assists families of children with disabilities to find placement in regular early childhood services where their special educators coach and mentor the childcare educators to ensure these children are learning and included. She had a 3 wonderful years with STaR and together, with other STaR families, I worked to fundraise to ensure the program continued. I knew my child was being stimulated and meaningfully included, not just minded. Lili began to lose her fear of the unknown and decreased her dependence on me. Her language skills developed dramatically. Discovering special education so early in Lili's life changed my thinking from trying to fix Lili, to teaching her.

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 12 years we experienced some very traumatic seizures, and Lili fought for her life again, several times.

Transitioning from the early year's sector to school was somewhat terrifying but could not be avoided. We needed another formal assessment for the school application. This time Lili was assessed as having severe global developmental delay. I was devastated as at that time I knew a mainstream school was no longer an option.

There is so much anxiety associated with starting school. Although I took comfort knowing Lili would be understood in the non-government 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 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 a special school with a very holistic approach to education. Changing schools is not always a bad thing and Lili was embraced for all she could do and contribute. School was a place where Lili was at her happiest as she was surrounded by her peers and people that understood her and recognised her potential.

Things started to fall apart in year 10 as hormones and mental health reared their ugly head. We barely managed to cope as a family despite being surrounded by an amazing network of school, medical, family and community supports. Recognising that we could





no longer provide Lili with the care she needed, we made our hardest decision ever, to move Lili into supported living.

Good things seem to always happen when you hit your lowest, and for us, that was meeting Barbara Lewis, Manager of the Carers Support Unit Northern Sydney LHD and her promise to help has remained steadfast. Together, with Barbara and another family in the same situation we were unrelenting in our pursuit to secure a home for our daughters. We have established a home where Lili and her house mates (both school friends) live a good life. It is a place where they are safe and comfortable, where they know they belong and where they are treated with kindness and respect. This is achieved through strong relationships between the housemates, their families, the team of amazing staff and our provider under a family governance model.

Initially funded by ADHC (Ageing, Disability and Home Care) we transitioned to NDIS funding as Lili left school in 2016. Like most parents, I have found navigating this new funding system somewhat confusing and challenging. Despite this I am so grateful as this scheme, fought for and engineered by some extraordinary advocates for all Australians living with disability, means my daughter is living a good life. I used to beg

for services for Lili and suddenly we became sought after customers.....we were given choice and control.

Leaving school is something all parents dread. It is alarming that the assumption that learning is ending is commonplace. I am appalled by the lack of quality learning programs in post school settings. Expensive adult minding is not what I seek for my daughter. To date, our post school experience has been a very frustrating one and it alarms me that Lili's learning has diluted. Lifelong learning is a human right and I am proud to work for an organisation that is working to deliver lifelong learning to adults with disability.

As Lili has become older and her difference more obvious, we have learned to accept that we will be noticed wherever we go. There have been many wonderful moments when children, encouraged by their parents, try to communicate with her. There also continues to be times when people stare or laugh or parents pull their children away. I have become very resilient over the years realising that I need to be prepared for these moments and 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. This remains fundamental and over the years I have become more confident to "flick" the people who are not adding value to Lili's life in both a personal and professional sense. Disability is a family issue and we rely on this network to stay strong and together! Keeping good records of reports and medications etc has always assisted me to ensure the stressful, expensive and time limited medical consults and therapy sessions were efficient, informative and effective. This has enabled me to make good decisions with clarity and confidence.

As Lili's mum I have witnessed the triumph of the human spirit time and time again. It is ironic that Lili has led me back to disability services. As CEO of the STaR Association, I am now comfortable with the dual role of provider and recipient, in fact, they give me balanced insight.

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Lili is a beautiful woman 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 or any desire for material goods, and she accepts all people for who they are regardless of race, age or appearance. Whilst having a child with a disability is not something I would choose for my family, in no way is it a disaster. Lili has lead me to know many extraordinary people and a career that I never imagined. I continue to learn from her.

All views are the authors own.



Counselling and Support

Counselling and support is available to help you and your family through difficult times.

Every family is different, and everyone responds differently to challenges in life. It's a healthy positive action to seek help and talk about things with someone you trust. This can happen informally by talking with other parents and friends, or more formally by speaking with a health professional.

How can I get counselling and support?

You can get free counselling and support to help with depression and anxiety, parenting, financial pressure and relationship stress.

Talk to your Maternal and Child Health nurse or GP to find out what type of support would best suit you. This could include face-to-face counselling, telephone support, joining a group or accessing support online. Your GP can also tell you if you can access support through a Mental Health Care Plan where some of the cost is covered by Medicare.

Parents of children with disability can get counselling support through:

Carer Gateway

Call [1800 422 737](tel:1800422737) or visit the [Carer Gateway website](https://www.carergateway.gov.au)

How else can I get help?

A number of helplines also provide counselling support:

Parentline

Call [132 289](tel:132289) (8am to midnight, 7 days a week)

Maternal and Child Health Line

Call [13 22 29](tel:132229) (24 hours)

Family Relationship Support for Carers

Call [1300 303 346](tel:1300303346) or visit the [Each website](https://www.familyrelationshipsupport.gov.au)

Relationships Australia

Call [1300 303 346](tel:1300303346) or visit the [Relationships Australia Victoria website](https://www.relationships.com.au)

Lifeline

24-hour telephone and online counselling.

Call [131 114](tel:131114) or visit the [Lifeline website](https://www.lifeline.org.au)

MensLine Australia

Call [1300 789 978](tel:1300789978) (24 hours) or visit the [Mensline website](https://www.mensline.org.au)

National Debt Helpline

Free financial counselling.

Call [1800 007 007](tel:1800007007) (Mon-Fri) or visit the [National Debt Helpline website](https://www.nationaldebt.org.au)

1800 RESPECT

National Sexual Assault Family Domestic Violence Counselling Service

Call [1800 737 732](tel:1800737732) (24 hours) or visit the [1800 RE-SPECT website](https://www.1800respect.org.au)

This is a excerpt from the Association for Children with a disability website. [Please visit https://www.acd.org.au/counselling-and-support/](https://www.acd.org.au/counselling-and-support/) for more resources.