

# Families of the disabled still wait for a fair go

Elizabeth McGarry, [THE AGE, NATIONAL TIMES](#), September 30, 2010

**After 30 years of lobbying, carers are still losing the right to care for their own.**

Having a child with a disability or chronic health condition dramatically changes the job description for parents. No consultation, training or preparation, but plenty of closed doors and condemnation if your child looks or acts differently. As well as the traditional qualities of resilience and love, you need to be an advocate, planner, financier and marathon runner. Oh, and if you can find an open and compassionate society in which to live.

Sadly, the Association for Children with a Disability has seen a rise in families calling for help because they feel they have no alternative but to relinquish their child.

Caring for our children is our expectation when we start a family but we don't expect that it will be a 24/7 job in some cases for the rest of our lives. Hanging in for the long haul is one hell of a challenge. There are often inspirational stories and magic moments along the way and many people have received the support they need in early childhood, education and disability services but it's not everyone's journey. Gaps still exist.

Many struggle every day. Families are heartbroken when they run out of physical and emotional energy. Often they have sustained injuries from constant heavy lifting as a result of caring for their child. If behaviours of concern are evident, then other children in the family are invariably at risk of injury.

The journey for many families who say "enough is enough - we can't do this any more" is littered with complexities: Systems that are fragmented and difficult to navigate, waiting lists for services that seem never-ending, a revolving door of workers in and out of their lives, and a sense that you only get support when you argue and complain and reach crisis point.

We advocate alongside them in an effort to avoid such a heartbreaking outcome, sometimes successfully, but not always. Families who feel the only course of action open to them is to give up the care of their child are at the end of the road.

They are physically and emotionally exhausted and they are angry - very angry. They are worn down by the caring they do, tired of fighting for supports that haven't met their needs and often socially isolated as family and friends drift away. Relinquishment often means being confronted by the regulatory environment of Protective Services, which adds insult to injury. They've neither abused nor neglected their child, yet they find themselves catapulted into a system that was never developed to support the unique situation in which they find themselves.

Feelings of guilt and sorrow are part of the mixed emotions they then face, but what always shines through for families we have supported, is their desire never to give up loving and looking out for their child. They want to make sure that their child is safe and cared for in a proper manner . . . they just can't carry the full caring role any longer.

There are many good workers and educators who provide learning opportunities, care and support but they are hamstrung by systems that are not properly geared to intervene when and where it is needed. Disability ministers and education ministers constantly compete for a bigger piece of the Treasury pie. Governments need to allocate more resources to early childhood development, education and disability supports so children and families can thrive and workers who support them are properly trained and properly paid.

Service systems need to get smarter in the way they provide support - decisions should not be driven by service capacity but by the expressed needs of those they support.

When families break down, governments are left to pick up the pieces that result in fractured lives, guilt-ridden mums and dads, distraught brothers and sisters and a child bewildered by what is happening to them.

As our association celebrates its 30th birthday this month, we can be excused for wondering how far we have come as a society in understanding and supporting children with a disability and their families.

Advances in medical science and information technology have made a big difference. Broader recognition, through public policy, of the citizenship rights of people with a disability, is challenging all of us to rethink our attitudes to disability and how service systems should be structured to promote dignity and respect.

At an individual level we need to examine our attitudes towards children who require extra support, whether they have a physical or intellectual disability or whether they interact with the world differently to others.

We need to ensure that we do not jeopardise their chances in life. Don't be too quick to judge a child experiencing a "meltdown" in a public space. It doesn't mean that their parents are doing a bad job of rearing them.

Greater tolerance and a belief that all people are entitled to a fair go and to be treated with dignity and respect should be our goal.

Then, when governments are confident that its citizens are willing to better support those most in need, we will embrace new and innovative funding structures, Treasury purse strings will loosen and a decent life for children with a disability and their families will shift from an aspiration to a reality.

**Elizabeth McGarry is chief executive officer of the Association for Children With a Disability.**