The hardest choice: families who give up disabled children

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The theme of abandonment runs like a current through our most pressing national dilemmas. Asylum seekers abandon their home countries in the hope of a better life in Australia.

Newly elected governments — most notably in Queensland — abandon their election pledges with claims of fiscal rectitude.

Then there is the desperation of families who abandon the care of their sons and daughters with disabilities. In May, the Victorian Equal Opportunity and Human Rights Commission’s report, Desperate Measures, exposed the tragedy of families who surrender the day-to-day care of children with disability to the Victorian government.

Rising numbers

Disturbingly, the commission’s report found that the relinquishment of children with disabilities in Victoria is more prevalent than it was just two years ago, with a rise from 40 children reportedly surrendered in Victoria in 2010 to more than 50 children in 2012.

While the commission’s findings were limited to Victoria, we can assume this scenario is replicated in the other states and territories in Australia. Public evidence of this was seen on when families across Australia revealed how they reach breaking point in an emotional and heartbreaking episode of SBS’ Insight.

A lack of assistance

Abandonment is a harsh word for harsh circumstances; circumstances in which governments across Australia — and it has to be said, communities too – evidently do not provide sufficient financial assistance, respite care and emotional support to struggling families. Some families have the opportunity to negotiate their relinquishment process over a period of time.

Some manage to retain access to their sons and daughters to the extent that their family unit is kept reasonably intact. Others are not so lucky.
The most commonly reported reason families give for relinquishing the care of their son or daughter with disabilities is the inadequacy of respite care facilities, followed by the lack of in-home support services. Alarmingly, 33,000 primary carers (90% of whom are parents) of children with disability across Australia have identified they need extra help in their caring role.

A growing number of these parents are now becoming so desperate they simply do not return to the respite care facility, school or hospital at which they have left their child ostensibly for a short-term break or treatment. They see no other option than to make the distressing decision to surrender the care of their child to the state. The trauma, grief, fear and confusion for the relinquished child and their families is unimaginable. But this wretchedness appears to be increasing. Surely such tremendous heartbreak can be avoided.

After all, an examination of the financial cost of relinquishment reveals it is cheaper for governments to provide families their in-home support than to accommodate a child with disability full time in a “residential service”.

But according to a 2006 report prepared by the Australian Healthcare Associates, only 6% of the federal budget allocated to disability services is specifically designated for respite services. This means that respite care is one of the lowest-funded forms of support available to families with children with a disability, even though the absence of such support appears to be one of the leading reasons families feel so “backed up against a wall” that they give up their son or daughter into the state’s custody.

Queensland

In Queensland, you can do something now. You can advocate for the needs of these families and the rights of their sons and daughters with disabilities by writing to the Queensland Child Protection Commission of Inquiry to “chart a new road map for child protection for the next decade”.

This $6 million inquiry does not include terms of reference for the protection of children with disabilities or support for families, but there is time to influence the direction of the inquiry.

The silence around the risk factors that lead families to give up the care of their children to the state must be shattered.

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