

# **Senate Standing Committee on Community Affairs Inquiry into Out of Home Care**

**Submission**

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## Children with Disability Australia

Children with Disability Australia (CDA) is the national peak body that represents children and young people with disability, aged 0-25 years. The organisation is primarily funded through the Department of Social Services (DSS) and is a not for profit organisation. Additional project funding is also currently received by the Australian Government Department of Education. CDA has a national membership of 5000 with the majority being families.

CDA provides a link between the direct experiences of children and young people with disability and their families to federal government and other key stakeholders. This link is essential for the creation of a true appreciation of the experiences of and challenges for children and young people with disability and their families.

CDA's vision is that children and young people with disability living in Australia are afforded every opportunity to thrive, achieve their potential and that their rights and interests as individuals, members of a family and their community are met.

CDA's purpose is to advocate systemically at the national level for the rights and interests of all children and young people with disability living in Australia and it undertakes the following to achieve its purpose:

- **Education** of national public policy-makers and the broader community about the needs of children and young people with disability.
- **Advocate** on behalf of children and young people with disability to ensure the best possible support and services are available from government and the community.
- **Inform** children and young people with disability, families and care givers about their rights and entitlements to services and support.
- **Celebrate** the successes and achievements of children and young people with disability.

The work of CDA is guided by the following principles:

- **Children first:** the rights and interests of children and young people with disability are CDA's highest priority consistent with Australia's obligations under the UN Conventions on the Rights of the Child and the Rights of Persons with Disabilities.
- **Right to childhood:** children and young people with disability are children first and foremost and have a right to all aspects of childhood that children without disability are afforded.
- **Right to participation:** children and young people with disability have the right to participate, in whatever capacity, in decisions that impact on their lives.
- **Inclusion:** children and young people with all types of disability, from all cultural and religious backgrounds and all geographic locations are supported by the work of CDA.
- **Recognition:** for the contributions made by families and care givers to support the rights and interests of children and young people with disability.
- **Partnerships:** CDA works collaboratively with relevant government, non-government and private sector agencies to promote the rights and interests of children and young people with disability.
- **Transparency:** CDA is accountable, effective and ethical as the national peak body charged with the mandate of advocating for children and young people with disability.

## Introduction

CDA welcomes the opportunity to contribute to the Senate Standing Committee on Community Affairs Inquiry into Out of Home Care. This submission will provide a brief overview of the experiences of children with disability in out of home care and highlight relevant considerations for the Inquiry.

CDA has to date not done extensive work in the area of out of home care. The disadvantage typically confronting any child with disability in the Australian community is profound. As such, in this submission CDA briefly highlights some important considerations around the disadvantage typically faced by children with disability, as well as the additional considerations specific to children with disability using out of home care services.

## The Current Experience of Children with Disability in Australia

In Australia, 6.8% of children and young people aged 0-24 years have a disability.<sup>1</sup> The disadvantage typically confronting children and young people with disability is profound. CDA members frequently report experiences of discrimination, low expectations, limited resources and opportunities, inadequate services and support, exclusion, abuse and violation of human rights. Major barriers to full participation and inclusion in social and economic life exist for children and young people with disability in all life areas including education, employment and social inclusion.

Recent research and statistics clearly illustrate the disadvantage and social isolation experienced by children and people with disability across a number of areas:

- 26% of people with a disability do not go beyond year 10, compared to 18% of people without a disability.<sup>2</sup>
- 36% of people aged 15-64 years with reported disability have completed year 12 compared to 60% of people without disability.<sup>3</sup>
- Children with disability are estimated to be 3.4 times more likely to experience abuse and neglect than children without disability.<sup>4</sup>
- Children with disability experience more bullying than their peers without disability.<sup>5</sup>
- 53% of people with disability are employed compared to 83% of people without disability.<sup>6</sup>
- 38% of young people (15–24 years) with disability either study full time, work full time, or study and work part time compared to 56% of young people without disability.<sup>7</sup>
- 27.4% of people with disability live in poverty compared with 12.8% of the total population.<sup>8</sup>
- 30% of people with disability don't leave the house as much as they'd like.<sup>9</sup>

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<sup>1</sup> Australian Bureau of Statistics (ABS) 2009, 'All persons: Disability Status by Age and Sex – 2009,' *Survey of Disability Ageing and Carers*, Commonwealth of Australia, Canberra.

<sup>2</sup> ABS 2009, 'Persons Aged 15-64 years, Selected Characteristics – by Level of Highest Educational Attainment,' *Survey of Education Training and Experience 2009: State and Territory Australian tables*, Commonwealth of Australia, Canberra.

<sup>3</sup> ABS 2012, Disability, 'Disability - Education and Employment,' *Ageing and Carers, Australia: Summary of Findings*, Commonwealth of Australia, Canberra.

<sup>4</sup> P. Knutson, J. Sullivan 2000, 'Maltreatment and Disabilities: A Population-based Epidemiological Study,' *Child Abuse and Neglect*, Vol. 24, No. 10, p. 1257.

<sup>5</sup> S. Robinson, J. Truscott 2014, *Belonging and Connection of School Students with Disability*, Children with Disability Australia, Melbourne.

<sup>6</sup> ABS 2012, *Australian Social Trends*, Commonwealth of Australia, Canberra, p. 20.

<sup>7</sup> Ibid, p. 20.

<sup>8</sup> Australian Council of Social Services 2014, *Poverty in Australia 2014*, Strawberry Hills, p. 10.

<sup>9</sup> ABS 2011, 'Getting out of the House,' *Social Participation of People with a Disability*, Commonwealth of Australia, Canberra.

Children with disability are evidently one of Australia's most disadvantaged groups. This disadvantage is further illustrated in the high usage of out of home care services by children with disability.

## **Representation in Out of Home Care**

Children with disability are known to be frequent users of out of home care. There is no official national data regarding the number of children with disability in out of home care, but available research and the experiences of CDA members reflect this high representation. For example, the Victorian Equal Opportunity and Human Rights Commission found that in June 2011, of 4,064 children in out of home care in Victoria, 579 or 14% had a disability.<sup>10</sup> This is more than double the prevalence rate of children with disability in the total Australian population (6.8%). The same research suggests that children with disability are more likely to be in residential care than children without disability in the out of home care system.<sup>11</sup>

A further point of consideration is that each state and territory has a different definition of disability, making it difficult to collect nationally consistent data regarding the number of children with disability utilising out of home care services.

In addition, CDA believes that any estimates that do exist are likely to underestimate the actual number of children with disability who use out of home care services. CDA is aware that many children with disability are often not recognised as they do not have a formal diagnosis. Moreover, at times the knowledge and expertise is not available within the out of home care system to identify if a child has a disability. These factors combined mean that available data most likely underrepresents the prevalence of children with disability using the out of home care system.

Having an unidentified disability means that children may not access specific services and supports which may be of assistance. Further, it may lead to misunderstanding a child's behaviour and inappropriate intervention. For example behaviours may be seen as 'delinquent' rather than a response to unmet disability support needs.

These factors combined – the lack of national data; differing definitions of disability; and the issue of unidentified disability – make it difficult to obtain accurate data about the exact prevalence of children with disability in the out of home care service system. However, there is no doubt that the representation is substantial.

## **Key Considerations**

### ***Services and Supports***

It is important to examine how the demand for out of home care services for children with disability is influenced by the inadequacies characterising the present disability services and support system.

The NDIS was introduced due to a national recognition that the present disability service system is grossly inadequate. The Productivity Commission into Disability Care and Support found that the current disability service system "is underfunded, unfair, fragmented, and inefficient, and gives

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<sup>10</sup> Victorian Equal Opportunity and Human Rights Commission 2012, *Desperate Measures: The Relinquishment of Children with Disability into State Care in Victoria*, Carlton, p. 7.

<sup>11</sup> Ibid, p. 7.

people with a disability little choice and no certainty of access to appropriate supports.”<sup>12</sup> CDA hears daily of the exasperation that children and young people with disability and their families experience due to the constant and often insurmountable barriers within the disability service system to receiving adequate services and supports. Often children do not receive adequate early intervention supports, which progressively compounds disadvantage as children grow, placing a significant burden on children with disability and families.

The NDIS involves a completely new system of funding disability support, focused on the needs and choices of people with disability. Existing services and supports will need to adjust to ensure they fit with the aims and functions of the new Scheme and as a result, some services will cease. Presently many disability services and supports are in transition with a consequence being that access to services for children and young people with disability is disjointed. The NDIS is being progressively established and will be fully implemented by 2019.

CDA acknowledges the momentous effort to date in implementing the NDIS but the reality is the scheme is in its infancy. As of September 2014, 7316 people were accessing supports under the NDIS.<sup>13</sup> This is a very small fraction of the 460,000 people who will be covered once the Scheme is fully implemented.<sup>14</sup> The barriers to accessing services and supports therefore remain a practical reality for most children and young people with disability and their families.

CDA is concerned that the inadequacies of the disability service system continue to place pressure on children and young people with disability and families. It should not be assumed at this time that the NDIS is greatly alleviating the immense difficulties children and young people with disability face in accessing services and supports. It is the view of CDA that this continues to be a causal factor as to why children and young people with disability are highly represented in the out of home care system.

### ***Out of Home Respite Services***

CDA notes that the definition of out of home care in the terms of reference does not specifically mention out of home respite. This is a highly utilised service of children with disability and their families. As such, CDA requests that out of home respite is included for consideration by this Inquiry. Out of home respite comprises a wide range of services that aim to provide families with a break from caring. These services can be more formal, such as day or overnight respite centres or day outings with respite workers. Out of home respite can also involve less formal and voluntary out of home care. It is the view of CDA that the scope of the Inquiry should be broader than traditional considerations regarding state-provided out of home care.

### ***Relinquishment***

CDA is concerned that a small but growing number of families of children with disability turn to out of home care services for permanent care options due to ongoing failure to access services and supports. This sustained lack of support places an inexorable amount of pressure on families who can become unable to cope and are forced to relinquish the care of their children to the state. However, the term ‘relinquishment’ is problematic as it conveys that families have ‘given up’ or abandoned their children. It is the experience of CDA that relinquishment is an absolute last resort by families who are at breaking point due to the lack of support they receive to care for children.

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<sup>12</sup> Productivity Commission 2011, *Disability Care and Support: Productivity Commission Inquiry Report Overview and Recommendations*, Commonwealth of Australia, Canberra, p. 2.

<sup>13</sup> National Disability Insurance Agency 2014, *Report on the Sustainability of the Scheme, 1 July 2013-30 June 2014*, Geelong, p. 2.

<sup>14</sup> National Disability Insurance Scheme 2014, *General Backgrounder*, Geelong, viewed 28 October 2014, <http://www.ndis.gov.au/general-backgrounder>.

It is CDA's experience that the decision to relinquish is rarely sudden, but builds up over time after all alternative options have been exhausted. While there is no typical family that relinquishes care, a common feature is extended and sustained failures to receive services for children with high support needs. In addition, it can be a constant struggle with state and territory departments to secure funding for more than short periods, creating additional uncertainty and stress. It is therefore important to consider the effects of the inadequacies of the disability service system on children and young people with disability utilising permanent out of home care options.

It has been reported to CDA that for children with disability in out of home care, remaining connected to their family of origin can be challenging following relinquishment. Families have spoken of the requirement to relinquish through the child protection system. For example, a family reported that in order to relinquish, they had to inform child protection officials that they were at risk of harming their child if they could not get any support. This can lead to parents being treated like they have abused and neglected their children, causing further isolation and profound stress to children, young people and their families. It is critical to ensure that children's rights to continued and regular contact with their families are met.

### **Lachlan's Experience**

The following is an extract from an article in the *Whittlesea Leader* by Melissa Merrett from 7 October 2014. It illustrates the current crisis within the out of home respite system for young people utilising permanent out of home care options.

*A WHITTLESEA 18-year-old with severe autism placed in state care is moved from one accommodation service to another several times a week due to a lack of respite facilities, his mother says. Mary Hullin, who lives outside Whittlesea township, relinquished Lachlan into state care...Ms Hullin, whose other son has cerebral palsy, said it had become too difficult to look after Lachlan.*

*She said Lachlan was living under a Family Options shared care arrangement, under which he moved between respite facilities in Epping, Glenroy and McLeod, his family home and the house of a Whittlesea-based carer every week...Ms Hullin said she was happy for the shared care arrangement to continue in the short-term, but was concerned by the uncertainty of finding permanent residential care for her son.*

*"We want Lachie in our lives, but he just can't live with us; it's simply impossible...It's a crisis-fed system and they only step in when things become so bad," Ms Hullin said.*

*"We are considered a high priority for a residential place when one becomes available, but there are just no places"...*

*Respite Alliance Whittlesea spokesman Trevor Carroll said the lack of facility-based respite for children and adults with disabilities was at a crisis point in Whittlesea.*

The article can be viewed at <http://www.heraldsun.com.au/leader/north/whittlesea-18yearold-with-severe-autism-moved-frequently-due-to-lack-of-respite-care/story-fnglenug-1227081160626>

### **Boyde's Experience**

*The SBS television program Insight ran an episode on relinquishment in 2012. One of the families interviewed had relinquished their son Boyde into permanent out of home respite. Boyde has high behaviour support needs and requires constant support, particularly to ensure he is safe. Over a number of years, his parents frequently requested assistance from the Victorian Department of Human Services but received minimal supports and respite. Boyde's parents became increasingly unable to cope. This experience was highly distressing to both Boyde and his family, who felt they had no other option than to relinquish.*

The program can be viewed at <http://www.sbs.com.au/news/insight/tvepisode/breaking-point>

### **Conclusion**

Children and young people with disability warrant specific consideration by this Inquiry into the out of home care system due to their high representation and the distinct disadvantage they currently face in the Australian community. CDA believes a key factor for the high representation of children and young people in the out of home care system is that families and other caregivers are finding it increasingly difficult to meet the needs of their children due to the inability to access adequate services and supports within the community.

There is significant work to be done to: enable the better identification of children and young people with disability currently in the out of home care system; ensure children and young people with disability in the out of home care system can access necessary services and supports; and in the long term, children with disability and their families must be able to access appropriate early intervention, services and supports whilst in the family home so there is a reduced need for families to seek alternative care of their child with disability.

As a community we are very much centred on the value of a family, and it is indeed a right of child to have a family.<sup>15</sup> Children with disability also share this right. This Inquiry into the out of home care system is a significant opportunity to identify what action can be taken to ensure greater protection of this right for children and young people with disability.

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<sup>15</sup> United Nations General Assembly 1989, *Convention on the Rights of the Child*, United Nations, Article 5.

## References

ABS 2009, 'All persons: Disability Status by Age and Sex – 2009,' *Survey of Disability Ageing and Carers*, Commonwealth of Australia, Canberra.

ABS 2012, *Australian Social Trends*, Commonwealth of Australia, Canberra.

ABS 2012, Disability, 'Disability - Education and Employment,' *Ageing and Carers, Australia: Summary of Findings*, Commonwealth of Australia, Canberra.

ABS 2011, 'Getting out of the House,' *Social Participation of People with a Disability*, Commonwealth of Australia, Canberra.

ABS 2009, 'Persons Aged 15-64 years, Selected Characteristics – by Level of Highest Educational Attainment,' *Survey of Education Training and Experience 2009: State and Territory Australian tables*, Commonwealth of Australia, Canberra.

Australian Council of Social Services 2014, *Poverty in Australia 2014*, Strawberry Hills.

P. Knutson, J. Sullivan 2000, 'Maltreatment and Disabilities: A Population-based Epidemiological Study,' *Child Abuse and Neglect*, Vol. 24, No. 10, pp. 1257-1273.

National Disability Insurance Agency 2014, *Report on the Sustainability of the Scheme, 1 July 2013-30 June 2014*, Geelong.

National Disability Insurance Scheme 2014, *General Backgrounder*, Geelong, viewed 28 October 2014, <http://www.ndis.gov.au/general-backgrounder>.

Productivity Commission 2011, *Disability Care and Support: Productivity Commission Inquiry Report Overview and Recommendations*, Commonwealth of Australia, Canberra.

S. Robinson, J. Truscott 2014, *Belonging and Connection of School Students with Disability*, Children with Disability Australia, Melbourne.

United Nations General Assembly 1989, *Convention on the Rights of the Child*, United Nations.

Victorian Equal Opportunity and Human Rights Commission 2012, *Desperate Measures: The Relinquishment of Children with Disability into State Care in Victoria*, Carlton.