



**Children and Young People  
with Disability Australia**

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**RE: DRAFT SERVICE DELIVERY MODEL FOR A PROPOSED NEW CARER SUPPORT SERVICE SYSTEM**

Children and Young People with Disability Australia (CYDA) welcome the opportunity to provide feedback regarding the *Draft Service Delivery Model for a Proposed New Carer Support Service System*.

CYDA is the national representative organisation for children and young people with disability, aged 0 to 25 years. The organisation is primarily funded through the Department of Social Services and is a not for profit organisation. CYDA has a national membership of 5500.

CYDA provides a link between the direct experiences of children and young people with disability to federal government and other key stakeholders. The organisation'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.

This correspondence raises key issues of importance for families of children and young people with disability and reiterates concerns highlighted by CYDA in previous correspondence in response to the *Draft Service Concept for the Delivery of Interventions to Improve Outcomes for Carers*.

**Direct Experiences of Children and Young People with Disability and their Families**

Children and young people with disability typically experience profound disadvantage within the Australian community. Examples include barriers to accessing a neighbourhood playground, attending local childcare or schooling or being involved in after school activities. This has a profound impact on the sense of belonging and connection of children and young people with disability develop within communities and consequently many experience social isolation.

Despite the significant reform occurring with the implementation of the National Disability Insurance Scheme (NDIS) and associated roll out, many children and young people are not participants to date. Access to appropriate services and supports therefore remains extremely challenging for many.

To access services and supports and participate in the community, families typically must provide vigilant advocacy for their children across a range of life areas. Navigating complex service systems which are fraught with limited or unclear information is a significant source of exasperation and frustration.

## Human Rights Framework

All children have the right to be cared for by family, except in circumstances where this is not in the child's best interests.<sup>1</sup> This right is articulated in the United Nations *Convention on the Rights of the Child* (CRC) and the *Convention on the Rights of Persons with Disabilities* (CRPD).<sup>2</sup> Article 27 of the CRC obliges States Parties to "take appropriate measures to assist parents and others responsible for the child" to ensure that every child has a "standard of living adequate for the child's physical, mental, spiritual, moral and social development."<sup>3</sup>

Article 23 of the CRPD states requires States Parties to "ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families."<sup>4</sup>

Furthermore, these international human rights conventions clearly articulate the rights of people with disability to be included in all areas of the community. This is reflected in article 19 of the CRPD which outlines the obligations of States Parties to ensure:

- *Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; (and)*
- *Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*<sup>5</sup>

As a signatory to both conventions, Australia has clear obligations to ensure that services and supports provided for families of children and young people with disability are grounded in this human rights framework.

## Current Australian Policy Context

Domestic policy frameworks and associated reforms further reflect these human rights principles and seek to promote communities and mainstream service systems that are inclusive of people with disability, including children and young people and their families.

The *National Disability Strategy 2010-2020* (the Strategy) is a national policy framework that aims to ensure that the rights contained within the CRPD are reflected in all policies and programs affecting people with disability.<sup>6</sup> It sets a 10 year reform plan for all Australian governments to address the barriers faced by Australians with disability across a range of life areas.

One key area for reform identified under the Strategy is ensuring quality, person-centred provision of disability services and supports, which is being primarily implemented through the NDIS. The NDIS represents a new system of funding and delivering disability support focused on the needs and choices of people with disability. A key aim of the Scheme is to support the participation of people with disability in social and economic life.<sup>7</sup>

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<sup>1</sup> United Nations General Assembly 1989, *Convention on the Rights of the Child*, article 9.

<sup>2</sup> United Nations General Assembly 1989, *Convention on the Rights of the Child*, articles 7, 9, United Nations General Assembly 2006, *Convention on the Rights of Persons with Disabilities*, articles 6, 23.

<sup>3</sup> United Nations General Assembly 1989, *Convention on the Rights of the Child*, article 27.

<sup>4</sup> United Nations General Assembly 2006, *Convention on the Rights of Persons with Disabilities*, article 23.

<sup>5</sup> *Ibid*, article 19.

<sup>6</sup> Council of Australian Governments 2011, *National Disability Strategy 2010-2020*, Commonwealth of Australia, Canberra.

<sup>7</sup> *National Disability Insurance Scheme Act 2013 (Cth)*, s. 2.3.



These human rights and policy frameworks strongly articulate the importance of developing inclusive mainstream services and supporting the participation of people with disability within the community. However, CYDA is concerned that the proposed *Integrated Carer Support Service System* does not align with these principles, but rather re-entrenches a segregated and siloed model of service provision.

### **Comments on the *Integrated Carer Support Service System***

Throughout the reform and consultation process regarding the *Integrated Plan for Carer Support Services*, families of children and young people with disability have been included in the definition of 'carer' used and as an identified client group for carer support services.<sup>8</sup> While CYDA understands that some families identify as 'carers' and may wish to access services through the new service system, CYDA has significant concerns about the inclusion of families of children and young people.

All families engage in unpaid care of their children, however the term 'carer' is typically only applied in this context in relation to children with disability. In these cases, children with disability are defined primarily by their care needs, rather than being seen as a child first.

Further, the language and design of the draft service model includes assumptions that position children and young people with disability as a 'burden' on their families. An example is the assumed need for counselling that includes a focus on 'coping skills' and 'grief and loss' for families.<sup>9</sup>

CYDA strongly believes that mainstream children and family services should be inclusive of children and young people with disability and their families, rather than providing services through a 'carer specific' model.

It is the view of CYDA that there must be tangible actions to progress the development of inclusive children and family services, to better reflect the human rights principles previously discussed. Consideration therefore should be given to ways in which this can be supported and progressed. The National Disability Strategy represents a vital policy framework through which this important work can be coordinated.

CYDA notes that to date there has been minimal representation of children and young people with disability on related advisory groups for this initiative. This has limited opportunities for valuable input regarding the direct experiences of these children and young people in relation to the service system.

Thank you for the opportunity to contribute to this consultation and CYDA is available to provide further information or discuss these matters further if that would be of assistance.

Yours sincerely



Stephanie Gotlib  
CHIEF EXECUTIVE OFFICER

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<sup>8</sup> Australian Government Department of Social Services 2016, *Designing the New Integrated Carer Support Service – A Draft Service Concept for the Delivery of Interventions to Improve Outcomes for Carers*, Commonwealth of Australia, Canberra, p. 7, Australian Government 2016, 'Caring for Someone,' *Carer Gateway*, Commonwealth of Australia, Canberra, viewed 19 December 2016, <https://goo.gl/9wTcwP>.

<sup>9</sup> Australian Government Department of Social Services 2016, *Delivering an Integrated Carer Support Service: A Draft Model for the Delivery of Carer Support Services*, Commonwealth of Australia, Canberra, p. 12.