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Ms Catalina Devandas Aguilar

United Nations Special Rapporteur on the Rights of Persons with Disabilities

United Nations Office at Geneva

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**RE: QUESTIONNAIRE ON THE ‘PROVISION OF SUPPORT TO PERSONS WITH DISABILITIES’**

Children and Young People with Disability Australia (CYDA) writes to provide an overview of the context and key issues impacting current provision of support to people with disability in Australia. Due to time and capacity constraints CYDA is unable at this time to provide detailed and specific responses to the questionnaire. CYDA could provide this if time was extended to respond.

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 Australian Government and has a national membership of 5500. CYDA’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.

The *National Disability Strategy 2010-2020* (the Strategy) is a national policy framework that seeks to ensure that the rights contained within the *Convention on the Rights of Persons with Disabilities* are reflected in all policies and programs affecting people with disability.[[1]](#footnote-1) It is a key mechanism to support the development of inclusive communities, services and programs in Australia.

One key area for reform identified under the Strategy is ensuring quality, person-centred provision of disability services and supports. This is being primarily implemented through the National Disability Insurance Scheme (NDIS), which is currently being rolled out across Australia.

There are currently high community and government expectations regarding the NDIS and the opportunities it will create. However, it is critical to recognise the considerable work that still needs to occur to ensure appropriate provision of support for all people with disability. Key considerations for future reform concern:

* How services and supports will be provided to the majority of people with disability who cannot access the NDIS;
* How to ensure access to mainstream services and supports for people with disability; and
* How to ensure mainstream sectors and the community see the inclusion of people with disability as a core responsibility.

**PREVIOUS PROVISION OF DISABILITY SERVICES**

The disability service system in Australia is currently undergoing significant reform with the implementation of the NDIS. Key characteristics of pre-NDIS disability services in Australia include:

* Block-funding primarily provided to service providers by state and territory administered programs;
* Insufficient resourcing and rationing of funding;
* Inconsistency across programs and jurisdictions; and
* Limited choice regarding services accessed.[[2]](#footnote-2)

Reform to disability services and supports in Australia was instigated by prolonged advocacy and community action from people with disability, families and advocates. This led to the commissioning of a national independent inquiry into ‘Disability Care and Support.’ The Inquiry found that the disability service system “is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports.”[[3]](#footnote-3)

These findings are consistent with the direct experience of children and young people with disability Australia reported to CYDA. It is typical for children and young people with disability to contend with insurmountable barriers to receiving appropriate services and supports. These include: limited availability of services; insufficient resourcing; and inadequate services that don’t meet the individual needs of children and young people.

National recognition of the inadequacy of the disability service system of Australia has led to the remodelling of the system with the introduction of the NDIS. However, it is important to note that the NDIS is in its infancy and is not presently available in most areas of Australia.

**CURRENT CONTEXT**

Below are some statistics about people with disability in Australia and access to support. They indicate significant barriers and challenges experienced by people with disability, including children and young people, across a range of life areas and service systems. This highlights the significant work required to address these poor outcomes and ensure access to appropriate, inclusive services:

* Over four million people in Australia have a disability. This represents 18% of the total population;[[4]](#footnote-4)
* 577 000 children and young people aged 0 to 24 in Australia have a disability. This represents 7.7% of the total population of children and young people;[[5]](#footnote-5)
* 2.4 million Australians (over 55%) with disability require support with at least one activity of daily life;[[6]](#footnote-6)
* 62.1% of people with disability who require support report that their needs are fully met, 35.3% report their needs are partly met and 2.7% report their needs are not met at all;[[7]](#footnote-7)
* Of people with disability who require assistance, 57.6% receive assistance from formal service providers;[[8]](#footnote-8)
* 41% of people with disability have completed Year 12, compared with 62.8% of people without disability;[[9]](#footnote-9)
* 46.6% of people with disability are not in the labour force, compared with 16.8% of those without disability;[[10]](#footnote-10)
* 49.4% of people with disability live in households in the lowest two quintiles for gross household income, compared with 24.3% of those without disability;[[11]](#footnote-11)
* 8.6% of people with disability reported experiencing discrimination or unfair treatment because of their disability in the last 12 months;[[12]](#footnote-12) and
* 20.5% of young people with disability (15 to 24 years) reported experiencing discrimination due to disability in the past year.[[13]](#footnote-13)

**National Disability Strategy 2010-2020**

The National Disability Strategyis a major policy framework to guide reform impacting people with disability. 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. The purpose of the Strategy is to:

* *establish a high level policy framework to give coherence to, and guide government activity across mainstream and disability-specific areas of public policy;*
* *drive improved performance of mainstream services in delivering outcomes for people with disability;*
* *give visibility to disability issues and ensure they are included in the development and implementation of all public policy that impacts on people with disability; and*
* *provide national leadership toward greater inclusion of people with disability.[[14]](#footnote-14)*

Six main policy outcomes are covered by the Strategy: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; and health and wellbeing. Identified under each of these outcomes are specific areas for future action and policy. [[15]](#footnote-15)

The Strategy is a significant framework to ensure the rights of people with disability are afforded across all life areas in Australia. Providing quality supports to people with disability is one focus area within the Strategy.

To date there has been limited progress in meeting the aims of the Strategy with mainstream sectors typically not embracing the required cultural shift and associated specific reform to support the inclusion of people with disability. As a consequence disability services and supports remain extensively siloed and not embedded in a broader context of inclusive mainstream services and communities.

It is the view of CYDA that a lack of progress under the National Disability Strategy is a critical consideration for the Special Rapporteur in examining the current context of support provision for people with disability.

**National Disability Insurance Scheme**

The Australian system for providing disability services and supports is currently undergoing unprecedented reform with the implementation of the NDIS. The NDIS represents a significant shift from the previous model of block funding disability services to providing portable funding packages, with a focus on enabling people with disability to exercise choice and control in relation to supports received.[[16]](#footnote-16)

Each eligible person will have their own ‘Individual Funding Package’ that will fund supports that meet the specific needs and goals of each person. This package is developed through a planning process with the National Disability Insurance Agency (NDIA), the body charged with administering the Scheme.

The NDIS also provides funding to services, initiatives and organisations through the *Information, Linkages and Capacity Building* (ILC) program. ILC provides information, linkages and referrals to connect people with disability, their families and carers with appropriate disability, community and mainstream supports.

The NDIS is designed to operate according to insurance principles, whereby all Australians contribute to the NDIS though taxation and are guaranteed reasonable coverage “against the potential costs of long term care and support associated with disability.”[[17]](#footnote-17)

The aims of the NDIS are to:

* Give effect to Australia’s obligations under the United Nations *Convention on the Rights of Persons with Disabilities* (in combination with other legislation);
* Support the participation of people with disability in social and economic life;
* Provide certainty around disability services and supports;
* Maximise the choice and control of people with disability around supports received;
* Promote the provision of high quality and innovative disability services; and
* Support people with disability to achieve their goals and live independently.[[18]](#footnote-18)

To be eligible for an individual plan through the NDIS, people must:

* Be an Australian citizen, permanent resident or hold a Protected Special Category Visa;
* Be aged under 65 years;
* Have a disability or condition that: is likely to be permanent; means the person is likely to require support under the NDIS for their lifetime; and impacts the person’s social and economic participation in the community; and
* Children aged under seven years with developmental delay can access the Scheme through the Early Intervention requirements.[[19]](#footnote-19)

The NDIS was launched in July 2013 in several trial sites across the country. It is currently transitioning from the trial sites to full implementation in 2019. This will involve an increase in people accessing individualised supports from around 35 000 to 460 000 within a short timeframe of three years.[[20]](#footnote-20) Experiences from the trial sites to date have also indicated that there are more people than expected entering the Scheme.[[21]](#footnote-21)

The NDIS represents an extremely complex reform that is currently experiencing challenges. There is significant complexity associated with implementing a completely new system that has shifted from state-based to national provision. Further difficulties arise from rolling in the many existing disability funding programs into a single scheme and reorienting disability services to create a market based on participant choice.

The NDIS is also experiencing inordinate pressures in terms of administrative and operational capacity as it expands significantly from the initial trial sites. This is impacting on access to services for people with disability in this early stage of implementation and CYDA has heard of lengthy delays in implementation of services.

The direct experiences reported to CYDA, community discussions and media reporting of participant and service provider experiences indicate that the NDIS, in this early stage, is highly stressed. A range of work needs to occur to ensure that the attributes of the previous disability services system do not become characteristic within the new service and support system.

**KEY CONSIDERATIONS GOING FORWARD**

The NDIS is presently dominating policy considerations and community discussions regarding services and support for people with disability. This fails to recognise the significance of the National Disability Strategy in articulating reform to ensure mainstream services and supports are accessible and inclusive to the needs of people with disability. Further, the aims of the NDIS to support social and economic participation of people with disability will not be achieved without corresponding progress in the other key areas identified by the Strategy.

It is the view of CYDA that the NDIS in isolation is an insufficient mechanism to provide the breadth of support required by people with disability. It is critical mainstream sectors and the broader community are inclusive of people with disability.

It is also important to note that the NDIS was not designed to provide supports to all people with disability. Rather, the NDIS funds individual plans for people with disability that is likely to be permanent and impacts on social and economic participation.[[22]](#footnote-22) It has been estimated that 460 000 of the four million people with disability in Australia will be eligible for an individual funded plan through the NDIS. Despite this, there has been limited focus within the present reform process on how services will be provided for people with disability outside the NDIS.

Some funding will be available through the ILC component of the NDIS. However, a limited funding pool of $132 million AUD has been allocated for these services in 2019-2020 and this will be provided to programs and organisations rather than individuals. [[23]](#footnote-23)

People will also be able to access Local Area Coordinators (LACs) through the NDIS. LACs are key workers within the NDIS who will provide support to connect people with disability to mainstream services and supports. However, the LAC position alone will not ensure mainstream services are accessible and inclusive.

In addition, work to develop appropriate interface arrangements between the NDIS and mainstream areas is not well advanced. This refers to the development of formal relationships, agreements and practical service provision arrangements between the NDIS and mainstream sectors such as health, education and housing.

These issues highlight that for the majority of people with disability in Australia, there is currently great uncertainty about how services and supports will be provided. This needs to be a core focus of reform going forward.

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2. Productivity Commission 2011, *Disability Care and Support: Productivity Commission Inquiry Report,* Commonwealth of Australia, Canberra, pp. 6-7. [↑](#footnote-ref-2)
3. Ibid, p. 2. [↑](#footnote-ref-3)
4. Australian Bureau of Statistics 2016, *Disability, Ageing and Carers, Australia: Summary of Findings, 2015,* Commonwealth of Australia, Canberra, viewed 20 October 2016, <https://goo.gl/cXkD3a>. [↑](#footnote-ref-4)
5. Australian Bureau of Statistics 2016, *Disability, Ageing and Carers 2015: First Results – Table 1.1 Persons with disability, by age and sex–2003, 2009, 2012 and 2015, estimate*, Commonwealth of Australia, Canberra. [↑](#footnote-ref-5)
6. Australian Bureau of Statistics 2016, *Disability, Ageing and Carers, Australia: Summary of Findings, 2015.* [↑](#footnote-ref-6)
7. Ibid. [↑](#footnote-ref-7)
8. Australian Bureau of Statistics 2016, *Disability, Ageing and Carers, Australia: Summary of Findings, 2015.* [↑](#footnote-ref-8)
9. Ibid. [↑](#footnote-ref-9)
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14. Council of Australian Governments 2011, *National Disability Strategy 2010-2020*, p. 9. [↑](#footnote-ref-14)
15. Ibid, p. 9. [↑](#footnote-ref-15)
16. *National Disability Insurance Scheme Act 2013 (Cth),* section 2.3. [↑](#footnote-ref-16)
17. Productivity Commission 2011, *Disability Care and Support: Productivity Commission Inquiry Report,* p. 11, 33. [↑](#footnote-ref-17)
18. *National Disability Insurance Scheme Act 2013 (Cth),* s. 2.3. [↑](#footnote-ref-18)
19. Ibid, s. 22, 23, 24, 25. [↑](#footnote-ref-19)
20. National Disability Insurance Agency 2016, *Report on the Sustainability of the Scheme: 1 July 2013 to 30 June 2016*, Geelong, p. 2. <https://goo.gl/NWZ0lr>. [↑](#footnote-ref-20)
21. Ibid, p. 3. [↑](#footnote-ref-21)
22. *National Disability Insurance Scheme Act 2013 (Cth),* s. 22, 23, 24, 25. [↑](#footnote-ref-22)
23. National Disability Insurance Agency 2015, *Information, Linkages and Capacity Building Commissioning Framework – Consultation Draft*, Geelong, p. 7. [↑](#footnote-ref-23)