

Submission  
No 329

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL  
DISABILITY INSURANCE SCHEME AND THE PROVISION  
OF DISABILITY SERVICES IN NEW SOUTH WALES**

**Organisation:** People with Disability Australia

**Date Received:** 29 August 2018

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**PEOPLE WITH DISABILITY**  
**AUSTRALIA**

**A voice  
of our  
own**

# **Realising the State of Inclusion:**

**The role of the NSW Government for  
people with disability**

**Submission to the NSW Legislative Council Inquiry into the  
Implementation of the National Disability Insurance Scheme  
and the provision of disability services in New South Wales**

## About PWDA

**People with Disability Australia (PWDA)** is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are the only national, cross-disability organisation - we represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation.

PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement.

We have a vision of a socially just, accessible and inclusive community, in which the human rights, belonging, contribution, potential and diversity of all people with disability are recognised, respected and celebrated with pride. PWDA was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

PWDA is a NSW and national peak organisation and founding member of Disabled People's Organisations Australia (DPO Australia) along with Women with Disabilities Australia, First Peoples Disability Network Australia, and National Ethnic Disability Alliance. Disabled Peoples Organisations (DPOs) are organisations that are led by, and constituted of, people with disability. The key purpose of DPO Australia is to promote, protect and advance the human rights and freedoms of people with disability in Australia by working collaboratively on areas of shared interests, purposes, strategic priorities and opportunities.

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## Introduction

There are 1.3 million people with disability living in NSW,<sup>1</sup> and at full scheme rollout, the National Disability Insurance Scheme (NDIS) is estimated to provide supports to 140,000 of those people.<sup>2</sup> This equates to around 10.5 per cent of people with disability in NSW who will be receiving NDIS supports. Most people with disability in NSW, including the growing number of people with disability over the age of 65, will not be eligible or able to rely on the NDIS for support, so will need to rely on inclusive mainstream services and, in many cases specialist disability support that will need to continue to be provided by the NSW Government.

With this in mind, the NSW Government must consider seriously the actions required to ensure that NSW is the *State of Inclusion*<sup>3</sup> for all people with disability.

PWDA is concerned that the NSW Government has withdrawn from its responsibility to provide inclusive and accessible services, including disability supports because of a pervasive, but erroneous view that the NDIS will cover all responsibilities for people with disability. We strongly reject this. The concerns highlighted throughout this submission illustrate clearly that the NSW Government must continue to provide a role in disability support for NSW people with disability. Parallel to the implementation of the NDIS, and critical to its success is the reform required to realise all the human rights of people with disability as articulated in the United Nations Convention on the Rights of Persons with Disabilities (CRPD). These rights are outlined in the National Disability Strategy (NDS) 2010-2020, and agreed by the Council of Australian Governments (COAG). The NDS commits all governments to achieve for people with disability:

- inclusive and accessible communities
- rights protection and justice
- economic security
- personal and community support
- learning and skills, and
- health and wellbeing.<sup>4</sup>

The NDIS is the critical implementation measure under the NDS Outcome Area 4: Personal and community support. However, it is only one part of the disability reform

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<sup>1</sup> Australian Bureau of Statistics, 2015, available at: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02015?OpenDocument>

<sup>2</sup> NSW Government, available at <http://ndis.nsw.gov.au/about-ndis-nsw/>

<sup>3</sup> NSW Government 2017 *NSW Disability Inclusion Plan Update 2017: A report on the implementation of the NSW Disability Inclusion Plan and Disability Inclusion Action Planning across NSW Government Clusters and Local Councils*, available at: <https://www.parliament.nsw.gov.au/la/papers/DBAssets/taledpaper/webAttachments/73353/Disability%20Inclusion%20Plan%20Update%202017.pdf>

<sup>4</sup> Council of Australian Governments, 2011, *National Disability Strategy*, available at: [https://www.dss.gov.au/sites/default/files/documents/05\\_2012/national\\_disability\\_strategy\\_2010\\_2020.pdf](https://www.dss.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf)

agenda and requires reforms in all other NDS outcome areas. There is much left to be done by the NSW Government to move toward an inclusive and accessible state.

While the Federal Government may have responsibility for the NDIS, the NSW Government still retains responsibility to ensure that all people with disability in NSW are able to receive the disability supports they require, are able to access mainstream services and are able to participate fully in community life. NSW retains responsibility and leadership in many areas of life that impact the lives and rights of people with disability.

These areas of responsibility include but are not limited to:

- Health
- Education
- Early childhood and family support
- Transport
- Justice, including criminal justice and victim services
- Representation, advocacy and rights protection
- Development and planning for accessible built environment
- Domestic violence and family services
- Oversight and regulation of disability services

NSW can lead inclusion and recognition of the rights of people with disability in all of these NSW-specific areas.

The realisation of an inclusive society for people with disability requires leadership, planning and resourcing. For the NSW Government to take a leadership role in transforming NSW into the most accessible state in Australia, it must:

- Establish a Disability Inclusion Minister with a budget for reform, and responsibility for leadership in disability rights and inclusion, including in the following areas:
- the implementation of the Inclusion Act 2014:
  - the application of anti-discrimination law for people with disability
  - implementation of the NSW Disability Inclusion Plan, including formal public reporting on disability inclusion
  - engagement and cooperation in the Coalition of Australian Governments (COAG) Disability Reform Council
- Provide oversight and regulation of quality and accessible services in NSW, with well resourced and appropriate powers, including committing to full and ongoing funding of independent disability advocacy and peak representation of people with disability
- Invest in accessible mainstream services for people with disability in NSW.

While there are some mechanisms to drive inclusion in NSW, they are currently incomplete. For example, PWDA has welcomed the *Disability Inclusion Act 2014*, but the process of disability inclusion planning undertaken by NSW Government departments is not substantially resourced.

As the largest state, NSW also has a key role to play in advocating for a fair, effective NDIS. While PWDA is supporting the implementation of the NDIS, we have largely limited our comment on implementation to reiteration of material which has been provided to those with authority over the NDIS. We do, however, emphasise that the NSW Government can influence both the interface of the NDIS with NSW services, and maximise its effectiveness by providing inclusive parallel systems and services.

For the above reasons, PWDA has focused our expertise on the following terms of reference for this inquiry:

- (a) the implementation of the National Disability Insurance Scheme and its success or otherwise in providing choice and control for people with disability*
- (b) the experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans*
- (c) the accessibility of early intervention supports for children*
- (d) the effectiveness and impact of privatising government-run disability services*
- (e) the provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the National Disability Insurance Scheme*
- (f) the adequacy of current regulations and oversight mechanisms in relation to disability service providers*
- (i) incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services*
- (j) policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales.*

PWDA is happy to provide further information or clarification to the Committee on any matter covered in this submission, and looks forward to engaging on these matters in the hearing process.



# Summary of recommendations

## Term of Reference (b) - Experience of People with Complex Care Needs

- That the NSW Government advocate to the Commonwealth Government and NDIA to include those in segregated settings in their complex pathway.
- That the NSW Government highlight and advocate to the Commonwealth Government for My Aged Care to provide equity of service provision to people with disability that is equivalent to the NDIS.
- That the NSW Government develop a Disability and Ageing Action Plan that aligns and integrates the provision of specialist disability support across service systems, including aging, NDIS and health; and that ensures equity in the provision of specialist disability supports to older people with disability, regardless of NDIS eligibility.
- That NSW establish a case management support system for people with disability, regardless of age to assist them to with identifying and interacting with appropriate, multiple service systems and supports, including the interface with the NDIS. This could be incorporated into the existing Ability Links NSW program or be a newly established program within the Department of Family and Community Services (FACS)

## Term of Reference (c) - Early Intervention Supports for Children

- That the NSW Government continues to provide access to inclusive early intervention supports with mainstream settings such as schools, health and community services for children over the age of seven years.
- That staff in mainstream services such as health and education as well as in specialist services such as family support and child and family welfare have knowledge about the NDIS and skills in delivering effective early intervention supports in the context of their services
- That training be provided for mainstream and specialist service providers on how to undertake effective outreach and referrals to the ECEI Partners to enable young children and their families to access the supports available through the ECEI approach.
- That funding be provided for capacity building and organisational development for mainstream and specialists services (both government and non-government services) on inclusive service delivery and practice
- That the NSW Government ensure local and state-wide independent advocacy services are available to address issues of access to services for children with disability and developmental delay and their families.
- That NSW Government continues to meet its obligations under the National Disability Strategy, the Disability Standards for Education and the NSW Disability Inclusion Act to ensure children and young people with disability have

access to mainstream services, such as health, early childhood education, school and tertiary education.

- That an early intervention approach continues to be a strong focus for supporting children with disability and developmental delay, noting that young children's development is rapid and delays in access to early intervention supports may adversely impact on the child's growth and wellbeing.
- That the NSW Government continues to monitor and advocate for the implementation of the recommendations from the Joint Standing Committee on the National Disability Insurance Scheme
- That the NSW Government invests in capacity building, professional development and policy and program development to enable mainstream services, such as health and early childhood education, to provide support as well as make effective referrals to Early Childhood Partners. These initiatives are also extended to targeted early intervention programs that support child wellbeing and child safety.

#### **Term of Reference (d) – Impact of Privatisation**

- That the NSW Government urgently recognises its role in the delivery of disability services for those who are not NDIS eligible and re-establish the necessary disability support role as a provider of last resort.
- That the NSW Government reviews current exemptions under the NSW *Anti-Discrimination Act 1977* to ensure that non-government disability services are not able to discriminate in service provision.

#### **Term of Reference (e) - Provision of Support Services**

- That the NSW Government funds the full implementation of NSW Health Disability Inclusion Plan across all the departmental levels, including for health services delivered by non-government organisations.
- That a cross-departmental NSW Government professional development project be established, to increase the capacity of NSW Government officers with referring and supporting clients to access the NDIS.
- That the NSW Government takes on the recommendations of the Deadly Disability Discrimination campaign, and increase funding from \$4.7 million per annum to \$17 million per annum for specialist health services.
- That the confusion regarding funding of critical supports between NSW Health and NDIS, such as responsibility for tracheostomy changes, be clarified between agencies immediately, that this be communicated to staff and people using the services, and that responsibility be allocated at the NSW Government level to monitor this concern.
- That the NSW Government works with the NDIA and through the COAG Disability Reform Council to address the issues in failures in continuity of support and to identify measures to ensure that promised continuity of support is delivered.

- That the NSW Government funds a HACC or HomeCare type service that provides short-term home and community care to people with disability who are not eligible for the NDIS, but who have a significant health and disability support needs, to deliver on the NSW Government's promised continuity of support arrangements.
- That NSW Government undertakes an in depth analysis of those who have not been transferred to the NDIS, and employ case workers to attempt to have in-person conversations about the transfer, and provide support to assist people to apply to access the NDIS.
- That the NSW Government works with the NDIA and through the COAG Disability Reform Council to address the issues in failures in continuity of support and to identify measures to ensure that promised continuity of support is delivered.
- That the NSW Government funds a HACC or HomeCare type service that provides short-term home and community care to people with disability who are not eligible for the NDIS, but who have a significant health and disability support needs, to deliver on the NSW Government's promised continuity of support arrangements.
- That NSW Government undertakes an in depth analysis of those who have not been transferred to the NDIS, and employ case workers to attempt to have in-person conversations about the transfer, and provide support to assist people to apply to access the NDIS.
- That the NSW Government proceeds with the statutory review of the Boarding Houses Act 2012 and its accompanying legislation to ensure that the rights of people with disability are upheld.
- That the NSW Government works with the NDIS Quality and Safeguards Commission to ensure that the review of NDIS registration of service providers prioritises insecure and lightly regulated residential environments such as boarding houses.
- That the NSW Government provides access to appropriate therapeutic and disability supports for people with disability while they are imprisoned. Supports should be planned for and delivered during incarceration and reassessed in advance of release
- That the NSW Government, in collaboration with people with disability and their representative organisations, reforms the forensic system so that it is compliant with the CRPD
- That the NSW Department of Justice works with other cross-government agencies such as the Department of Health, the Department of Housing, and the NDIA to identify prisoners who require support, provide that support, and develop a holistic reintegration plan prior to their release into the community.
- That the NSW Department of Justice develops a holistic strategy for engagement with people with disabilities that works with the NDIS to deliver

community-based early intervention and outreach strategies to prevent people with disability being at high risk of coming into contact with the criminal justice system.

- That the NSW Department of Justice Disability Inclusion Action Plan (DIAP) draws together recommendations from previous reports and research, including those listed under 'Justice' in Selected References at the end of this document.
- That discrete funding be allocated to provide disability support for women with disability who need it upon leaving violence, based on the Victorian Disability and Family Violence Crisis Responses Initiative.
- That the Safer Pathway model is amended in the following ways:
  - Other modes of communication, including face-to-face discussion, must be enabled
  - Disability advocacy organisations should be funded to provide support in engaging with victims with disability living in institutional settings
  - Institutional settings must be legally required to provide access to Safer Pathways programs and disability advocacy organisations providing this function
  - Safety Action Meetings, a key part of Safer Pathways, must include representatives from disability advocacy organisations, the NDIS (as it rolls out), and the victim's service provider
  - Safety plans must include the provision of disability support to people with disability (whether in institutional settings or living in the community).

#### **Term of Reference (f) – Adequacy of Current Regulations and Oversight**

That NSW Government, at the very least:

- Works collaboratively with the NDIS Commission to monitor the impacts of the NDIS Commission and its role in protecting people with disability in NSW;
- Identifies gaps and areas of concern that require stronger NSW regulatory and oversight protections, and greater collaboration with the NDIS Commission to ensure effective protections for all people with disability in NSW regardless of NDIS eligibility;
- Evaluates the role of NSW regulatory and oversight mechanisms in protecting all people with disability in NSW, and implement measures and actions for improvement.

#### **Term of Reference (i) – Impacts of Inadequate Disability Supports**

- That NSW Government and its agencies review what services and supports will not be provided within NDIS plans for people with disability, and that NSW Government strengthens investment in these services and supports as part of their Disability Inclusion Action Plans.

#### **Term of Reference (j) – Improving the Provision of Disability Services**

- That the NSW Government recognises that people with disability are equal citizens of NSW and have the right to have their full potential and contribution recognised and respected.
- That the NSW Government recognises their key role in providing access to mainstream and disability services for people with disability, to ensure they can participate equally in civic life
- That the office of the Minister for Disability Services becomes the Minister for Disability Inclusion
- That an office located with the Department of Premier and Cabinet is established with responsibility for:
  - implementation the NSW Disability Inclusion Plan across government
  - oversight and co-ordination of funding arrangements for the Disability Inclusion Action Plans
  - co-ordinating and reporting on progress under the legislation, COAG agreements and state-wide disability strategies and plans
  - leading inter-jurisdictional negotiations in relation to the improvements to the NDIS, NDA and NDS
  - recurrent funding and resourcing for representative peak organisations of people with disability and independent advocacy non-government organisations to ensure that the voice of people with disability is represented.
- That the NSW Government develops a clear resourcing strategy to enable the implementation of the State Disability Inclusion Plan
- That the NSW Government provides clear funding streams and reporting obligations for the implementation of Disability Inclusion Action Plans
- That the NSW Government provides an annual report that demonstrates progress made for inclusion of people with disability, so that NSW can meet and substantiate how it is the State of Inclusion<sup>5</sup>
- That the NSW Government examines and addresses barriers to implementation that may arise.

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<sup>5</sup> NSW Disability Inclusion Plan Update 2017, page 14. Website

# Terms of reference

## Term of Reference (a) - The Implementation of the NDIS

*(a) The implementation of the National Disability Insurance Scheme and its success or otherwise in providing choice and control for people with disability*

PWDA has advocated for and is committed to the individualisation of disability support services, in line with the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Determining how and when we receive support is a fundamental concern for people with disability, as it is likely to impact our capacity to live a full and meaningful life with family and community. This was a key rationale for the National Disability Insurance Scheme (NDIS).

The NDIS has contributed significantly to achieving greater choice and control for many people with disability in NSW. However, NDIS implementation has not been smooth and there are many issues and concerns that people with disability are consistently raising with representative bodies such as PWDA and with the National Disability Insurance Agency (NDIA) directly. Numerous implementation issues have arisen in the period since the NSW trials and the wider rollout in NSW and nationally. We have articulated these concerns in submissions to the Commonwealth Joint Standing Committee on the NDIS, to the Commonwealth Government, the NDIA and other stakeholders.

In brief, some of our recent key recommendations to improve the NDIS have been as follows:

- That the NDIA urgently establish robust procedures to respond to urgent and crisis situations, particularly those that constitute risks of abuse, neglect and exploitation. This would mean that the market based system could protect people's rights and interests from both NDIS and market failure.<sup>6</sup>
- That processes to encourage self-management and plan management by people with disability and their supporters be urgently reviewed and strengthened by the NDIA, in consultation with people with disability.<sup>7</sup>
- That ongoing support co-ordination is funded ongoing for people with complex needs, including those who lack negotiation skills, or who have a complex network of support providers, and that the NDIA formally recognise that some people will always require support co-ordination.<sup>8</sup>

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<sup>6</sup> PWDA, 2018, *Are people with disability in control? Markets, service provision and the NDIS*, available at: <https://www.aph.gov.au/DocumentStore.ashx?id=26c97f2f-4934-42b5-8b39-eeef2d7d9131&subId=564130>

<sup>7</sup> Ibid.

<sup>8</sup> Ibid.

- That the Joint Standing Committee review and make recommendations on the underfunding of needed supports and whether there is a pattern of reduced funding for core supports and at plan review.<sup>9</sup>
- That the NDIA urgently review and release findings on the patterns of funding for core supports from the start of trial to the present and patterns of change to funding at plan review.<sup>10</sup>
- That independent price setting and monitoring take place outside of the NDIA, and that the Joint Standing Committee inquire into and report on options for this measure as part of this inquiry.<sup>11</sup>
- That the NDIA urgently investigate and report on options to provide services itself when private providers are not available or appropriate, using a combination of direct service provision with appropriate oversight and incentivising private provision.<sup>12</sup>
- That the NDIA release a draft of the 'Maintaining Critical Supports' policy and undertake thorough consultation with people with disability as soon as possible. This policy should include government provision of services where needed.<sup>13</sup>
- That the NDIA consistently train planners on the NDIS's own operational guidelines regarding the responsibilities of NDIS to fund health support needs when this is connected to the participant's needs to live independently. Further, we recommend that improved measures for co-ordinating cross-disciplinary care be implemented.<sup>14</sup>
- That the NDIA implement a step in the planning process through which participants are able to check their goals, support needs and circumstances prior to a final plan being produced. This would enable participants to have more control over the quality of their plans, and would likely mean more accurate and high quality plans, and therefore less appeals and reviews.<sup>15</sup>

While these recommendations need to be addressed by the NDIA and the Commonwealth Government, they are of importance to the NSW Government given the interface between the NDIS and NSW service systems. Both must work seamlessly and in an integrated way to provide the choice and control, and the inclusion in community life for people with disability. The NSW Government must use its position in the Disability Reform Council to highlight and advocate for the rights of NSW people with disability with regard to the NDIS, using these recommendations raised by PWDA and other representative organisations as a guide.

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<sup>9</sup> Ibid.

<sup>10</sup> Ibid.

<sup>11</sup> Ibid.

<sup>12</sup> Ibid.

<sup>13</sup> Ibid.

<sup>14</sup> PWDA, 2017, Letter to Joint Standing Committee, available at:

[https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/Transition/Submissions](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/Transition/Submissions)

<sup>15</sup> Ibid.



## Term of Reference (b) – Experience of People with Complex Care Needs

*(b) the experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans*

It is imperative that the rights of people with disability with complex needs are upheld and attended to, as they are likely to experience additional vulnerability and barriers to inclusion. The NDIA is in the process of developing a pathway for people with complex needs to access the scheme. The NDIA defines the term ‘people with complex needs’ as “participants who are expected to require a higher level of assistance to navigate the pathway.”<sup>16</sup> This definition includes people who are also interacting with other service systems such as health, child protection, mental health and justice, who have multiple diagnosis, clinical complexity or complex behavioural needs, and people with minimal supports for decision making, no family or informal supports.<sup>17</sup>

In addition, PWDA strongly argues that accommodation settings are also a critical indicator of complexity. People living in institutional, isolated and congregate settings, such as boarding houses, large residential centres and institution and group homes, are highly likely to experience a number of the factors listed above, but in addition will experience minimal contact with people independent from their services or paid supports. They may not have family, carers or independent advocates who can advocate on their behalf.

Some of the issues experienced by people with complex care and support needs in NSW are highlighted under Term (e) in this submission.

We recommend that the NSW government strongly advocate to the Commonwealth government and NDIA to include segregated settings as a key indicator for people with disability who will need to utilise the NDIS complex pathway.

A critical issue for people with complex care and support needs in NSW is the lack of case management currently available. Case management was a service provided by Ageing, Disability and Home Care (ADHC) for people with disability. However, this is not something the NDIS provides.<sup>18</sup> Given the complexity of the transition for people who need multiple services and specialised supports, a significant gap in case management is requiring independent advocates, such as those at PWDA to fill. However, this is not, nor should it be the role of independent advocacy, which provides short-term support to address issues. Advocates need to remain impartial regarding service provision to avoid a conflict of interest.

A person living in a boarding house, for example, may need assistance to:

- apply for the NDIS
- communicate their support needs

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<sup>16</sup> NDIA, 2018, *Improving the Participant and Provider Experience*, available at <https://www.ndis.gov.au/medias/documents/pathway-review-report/Report-NDIS-Pathway-Review.pdf>

<sup>17</sup> Ibid.

<sup>18</sup> NDIA, *Local Area Co-Ordination*, available at: <https://www.ndis.gov.au/communities/local-area-coordination>



- understand options and make decisions
- negotiate their living arrangements at the boarding house
- arrange other services such as health.

If the person is deemed ineligible for the NDIS or is over 65 and unable to apply for the NDIS, the difficulty of finding supports will be greater. While the NSW service, Ability Links NSW aims to connect people with disability to service systems and the community, it does not provide case management, nor was it ever intended to do so, and it does not support people with disability over the age of 65.

For those over 65, it is expected that they will receive support through My Aged Care. However, My Aged Care is not focused on providing specialist disability support and is underpinned by principles such as choice and control. It requires co-payment that can be expensive and it is not always available to those who are deemed ineligible for NDIS.

## Our Experience

Peter has complex needs and has lived for many years in supported accommodation at the mental health inpatient service. Peter has been moved from that supported accommodation to a boarding house, where there is not usually support staff on site except for two hours in the mornings four days a week.

Residents have to manage their own medications, and meals are delivered frozen by Meals on Wheels each day.

There is no assistance with any daily living tasks and no-one appears to know if Peter has an NDIS plan or if he is eligible for one. One support program only is provided, where staff come to the boarding house and watch a movie with residents once a week.

This level of support is not sufficient to meet Peter's needs.

PWDA recommends that NSW establish a case management support system for people with disability, regardless of age to assist them to with identifying and interacting with appropriate, multiple service systems and supports, including the interface with the NDIS. This could be incorporated into the existing Ability Links NSW program or be a newly established program within the Department of Family and Community Services (FACS)

## Recommendations

- That the NSW government advocates to the Commonwealth government and NDIA to include those in segregated settings in their complex pathway.
- That the NSW government highlights and advocates to the Commonwealth government for My Aged Care to provide equity of service provision to people with disability that is equivalent to the NDIS.
- That the NSW government develops a Disability and Aging Action Plan that aligns and integrates the provision of specialist disability support across service systems, including aging, NDIS and health; and that ensures equity in the provision of specialist disability supports to older people with disability, regardless of NDIS eligibility.

- That NSW establishes a case management support system for people with disability, regardless of age to assist them to with identifying and interacting with appropriate, multiple service systems and supports, including the interface with the NDIS. This could be incorporated into the existing Ability Links NSW program or be a newly established program within the Department of Family and Community Services (FACS)

## Term of Reference (c) - Early Intervention Supports for Children

*(c) - the accessibility of early intervention supports for children*

Early intervention must be available to children with disability so that they can exercise their right to participate fully in the community. The intent of early intervention is that it will increase future and evolving capacities of the child. The Joint Standing Committee on the National Disability Insurance Scheme “Provision of services under the NDIS: Early Childhood Intervention Approach” highlights the distinction between young children who may or may not be able to access the NDIS:

*“By 2019–2020, it is expected that 47,000 of the 460,000 total NDIS Participants with approved Plans will be children aged between 0–6. The NDIA estimates that a further 59,000 children aged between 0–6 may identify as having a developmental delay or disability but are not expected to need individualised funded supports.”<sup>19</sup>*

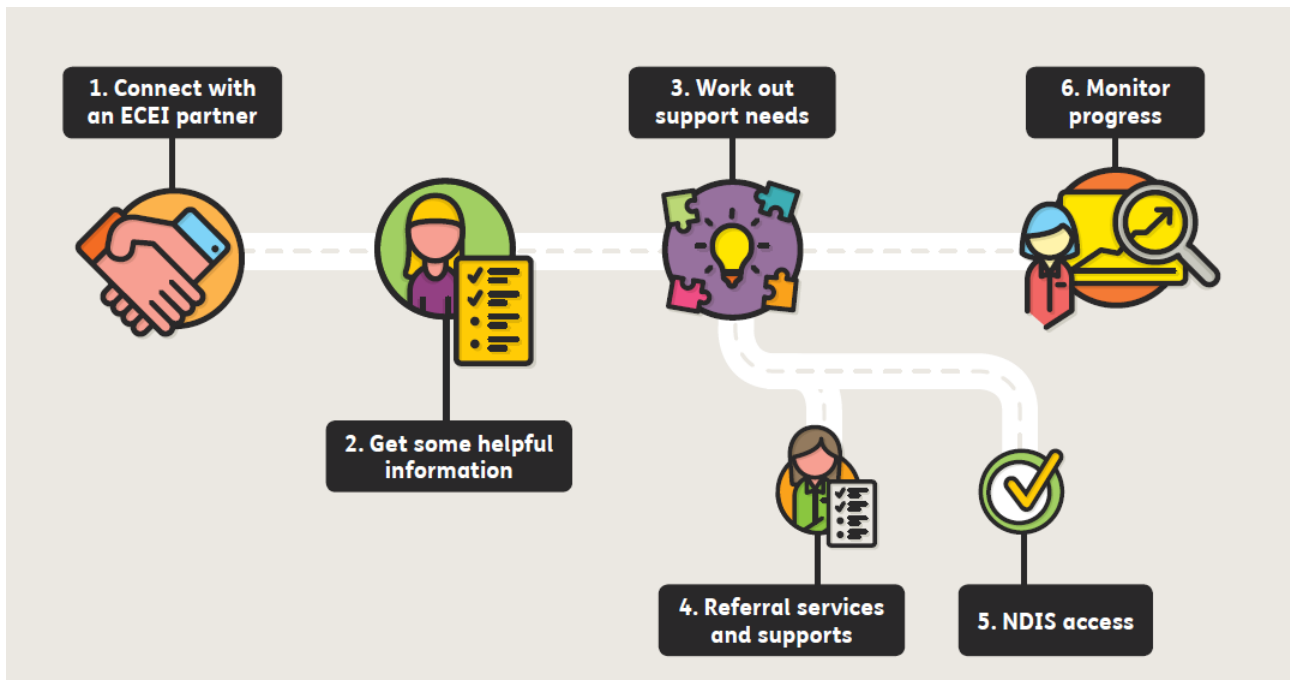
This means a key function for the Early Childhood Early Intervention (ECEI) approach under the NDIS is to determine, when families reach out for support or are referred for support, whether the child or children:

- has disability or development delay that means they are eligible for an NDIS package
- has disability or development delay where they would be best diverted from the NDIS into mainstream or community-based services and supports.

To undertake this triaging and referral, NDIA has created approved Early Childhood Partners (ECEI Partners) who will work with the family.

The diagram below outlines the process, once a referral to the ECEI partner has been made.

<sup>19</sup> Joint Standing Committee on the National Disability Insurance Scheme, 2017, Provision of services under the NDIS Early Childhood Early Intervention Approach, Commonwealth of Australia 2017.



**Figure 1: NDIS: support for your child**<sup>20</sup>

For the system to work well, “access to early intervention supports” for children aged birth to six years under the ECEI approach relies upon:

- effective “connection” of a child with disability or developmental delay with an ECEI Partner – initiated by direct contact from the family or through referrals of children and their families by a health or education professional
- timely, accessible, culturally appropriate information and support
- effective access and interface with mainstream services and supports as well as NDIS registered service and support providers.

However, the recent report from the Joint Standing Committee on the NDIS *Provision of services under the NDIS: Early Childhood Intervention Approach* regrettably highlights a number of shortcomings with the ECEI approach and children’s access to early intervention supports.<sup>21</sup> These include:

- lack of clarity and inconsistency in the role of the ECEI Partners
- lack of accessibility and poor quality information to support early childhood intervention strategies and supports
- inconsistency of plans
- high-level concerns about access to the ECEI approach for groups that are marginalised, disadvantaged and already at risk of not accessing services

<sup>20</sup> NDIA, available at: <https://www.ndis.gov.au/ecei>

<sup>21</sup> Joint Standing Committee on the National Disability Insurance Scheme, 2017, *Provision of services under the NDIS Early Childhood Early Intervention Approach*, Commonwealth of Australia 2017

- limited access to ECEI Partners as well as services and supports in rural, regional and remote areas of Australia.<sup>22</sup>

PWDA's experience confirms that pathways for children and their families under ECEI are not always delivering on the principles of early childhood intervention and the goals of timely early action for children.

## Our Experience

Tim is six years old and will soon be turning seven. He has been diagnosed with autism spectrum disorder. He is eligible to access the ECEI approaches, however, his eligibility for an NDIS package has not been approved. This assessment is currently being appealed.

In the meantime, Tim continues to have an identified disability which may benefit from an early intervention approach. This includes access to the speech therapy, which will help Tim participate in family and community life as well as with his learning at school.

Currently, without access to an NDIS package, Tim's pathway through the ECEI approach means his access to early childhood intervention is through Medicare's Chronic Disease Management plan. This plan is put together by the family's GP and entitles Tim to five sessions of speech therapy per year. Tim has attended these sessions, and is progressing well.

However, the speech pathologist has recommended further sessions. Tim's family are unable to take up these additional sessions because they cannot afford the out-of-pocket expenses.

They are also not in financial position to afford private health insurance. Tim's family is appealing the NDIA's decision for eligibility to the NDIS because the ECEI approach of accessing mainstream (non-NDIS) services is not meeting Tim's support needs.

The Joint Standing Committee has made 20 recommendations to improve children's access to NDIS early intervention packages and supports under the ECEI approach.<sup>23</sup> These recommendations focus on a range of changes that the NDIA must make in order to ensure that pathways and access to the ECEI packages are improved for children. While these matters must be addressed at the Commonwealth level, which holds responsibility for funding, implementation and outcomes of the NDIS, the NSW Government continues to have a role in ensuring that mainstream services and specialist services are available to meet the needs of children and their families who may not be eligible for NDIS packages.

The interface between the NDIS and mainstream services is critical for all people with disability. The significance of interface issues is thrown into sharp relief for young children aged birth to six years because the formalised ECEI approach relies on referral into mainstream service for the majority of children. The ECEI approach recognises that many children with disability and developmental delay and their families will only require short-

<sup>22</sup> Ibid.

<sup>23</sup> Joint Standing Committee on the National Disability Insurance Scheme, 2017, Provision of services under the NDIS Early Childhood Early Intervention Approach, Commonwealth of Australia 2017. pp.xiii-xv.

term supports and adjustments to support their inclusion and participation in everyday activities within the home, and within mainstream services. However, recent research from Social Policy and Research Centre (SPRC) shows that further development and capacity-building is required for mainstream service providers. A key recommendation from their research is:

*“NDIA can inform mainstream services about the NDIS, including ECI good practice guidelines such as trans-disciplinary approaches and inclusion, or liaise with sector peak bodies such as ECIA to disseminate such information. NDIA could further support collaborative practice between the ECI sector and mainstream services.”<sup>24</sup>*

While SPRC’s recommendation points to the role of the NDIA in strengthening the interface between the NDIS and mainstream services, the NSW Government, which both funds and delivers mainstream generalist and specialist services, must ensure that the interface and collaboration between services works well and effectively.

### **Strengthening the focus on children with disability and development over seven years of age**

Once children reach seven years of age, they must have permanent and significant disability to access the NDIS. The NSW Government currently funds Ability Links NSW to support people, including children from the age of seven, to take part in sport, education, volunteering and other activities.<sup>25</sup> While Ability Links NSW provides an important pathway to support children, young people and adults with disability to participate more fully in the community, it is not designed to provide the same kind of referral pathways into early intervention supports for children with disability and developmental delay.

For children who are over the age of seven, they will rely on access to early intervention supports through mainstream services, such as through health and education. This means not only do mainstream universal services such as, health and education (provided by both government and non-government agencies) need to be fully accessible and inclusive but agencies also need appropriate policies, resources and staff training to be able to provide the appropriate adjustments and supports for children with disability who are not eligible for the NDIS.

### **Recommendations:**

- That the NSW Government continues to provide access to inclusive early intervention supports with mainstream settings such as schools, health and community services for children over the age of seven years.
- That staff in mainstream services such as health and education as well as in specialist services such as family support and child and family welfare have knowledge about the NDIS and skills in delivering effective early intervention supports in the context of their services

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<sup>24</sup> Christiane Purcal, Trish Hill, Ariella Meltzer, Nirosha Boden, Karen R Fisher (2018). Implementation of the NDIS in the early childhood intervention sector in NSW – Final report (SPRC Report 2/18). Sydney: Social Policy Research Centre, UNSW Sydney. p.ii.

<sup>25</sup> Ability Links NSW, available at: [https://www.abilitylinksnsw.org.au/about\\_us.html](https://www.abilitylinksnsw.org.au/about_us.html)

- That training be provided for mainstream and specialist service providers on how to undertake effective outreach and referrals to the ECEI Partners to enable young children and their families to access the supports available through the ECEI approach.
- That funding be provided for capacity building and organisational development for mainstream and specialists services (both government and non-government services) on inclusive service delivery and practice
- That the NSW government ensures local and state-wide independent advocacy services are available to address issues of access to services for children with disability and developmental delay and their families.
- That NSW Government continues to meet its obligations under the National Disability Strategy, the Disability Standards for Education and the NSW Disability Inclusion Act to ensure children and young people with disability have access to mainstream services, such as health, early childhood education, school and tertiary education.
- That an early intervention approach continues to be a strong focus for supporting children with disability and developmental delay, noting that young children's development is rapid and delays in access to early intervention supports may adversely impact on the child's growth and wellbeing.
- That the NSW government continues to monitor and advocate for the implementation of the recommendations from the Joint Standing Committee on the National Disability Insurance Scheme
- That the NSW Government invests in capacity building, professional development and policy and program development to enable mainstream services, such as health and early childhood education, to provide support as well as make effective referrals to Early Childhood Partners. These initiatives are also extended to targeted early intervention programs that support child wellbeing and child safety.

## Term of Reference (d) – Impact of Privatisation

*(d) the effectiveness and impact of privatising government-run disability services*

Prior to the introduction of the NDIS in NSW, disability services were primarily delivered by government with some funding through grants and service contracts to the non-government sector.

In 2011, the Productivity Commission's *Disability Care and Support* report outlined significant and unsustainable shortcomings and failings of the disability care and support system in Australia.<sup>26</sup> These shortcomings included poorly organised funding arrangements, fragmented and inefficient services, limited innovation within service

<sup>26</sup> Productivity Commission, 2011, *Disability Care and Support*, available at: <https://www.pc.gov.au/inquiries/completed/disability-support/report>



delivery and, most worryingly, little, if any, choice and control for people with disability about their services they need and how they are delivered.

The introduction of the NDIS has meant a shift from a model of “block and grants funding” to a “market-style or market-based” system, where funding is provided to NDIS participants to choose the services and supports that they purchase. This approach aims to provide NDIS participants with greater choice and control over which services they need and where and how they are delivered. Within the market-style approach for the NDIS, disability service providers include a mix of:

- not-for-profit, non-government organisations
- government service providers
- for-profit businesses and corporations.

In NSW, however, government run disability services ceased in July 2018. This market-style approach mirrors the service delivery and governance arrangements within other human service delivery areas. Sectors that use mixed service delivery models, and indeed in some sectors, for decades include:

- Early childhood education and child care
- Aged care
- Home care
- Out-of-home care.

The strengths of a mixed service delivery approach are that services can be:

- more accessible and embedded within the local community
- provided at different scale and scope to better meet the needs of users
- more likely to have greater adaptive capacity to meet the changing needs of users in their local community
- better positioned to respond to changing local and community need
- better able to build local partnerships and connections between services and service users.

A mixed service model fits with the goals of the NDIS to be more responsive to the needs of people with disability and drive person-centred service delivery.

Up until the introduction of the NDIS, the NSW Government, through ADHC was responsible for providing the majority of support and direct services for people with disability including:

- Case management
- Therapeutic services such as speech pathology, occupational therapy, physiotherapy
- Early intervention programs for childhood and young people
- Respite services

- Supported accommodation, including group homes and large residential centres.

However, with the introduction of the NDIS, the NSW government not only transferred its allocation of disability funding to the Commonwealth under the bilateral agreement for the NDIS but also transferred delivery of its disability services to the non-government disability service sector. In some cases, the NSW Government has also enabled the private sector to take on disability services, such as with Home Care, which is now provided by Australian Unity.

In compliance with the CRPD, the NSW Government also committed to the closure of its' large residential centres to increase potential for community living. The NDIS was viewed as the mechanism for people with disability to be able to choose where and with whom they could live in the community. PWDA has strongly supported these closures, although is disappointed and concerned that closure has led to the building of more outdated group home models instead of genuine housing options within the community. The vision of the NDIS, underpinned by the CRPD, requires a shift away from groups of people with disability sharing accommodation and support arrangements, as this impacts on choice and control and the ability to live in the community on an equal basis as everyone else.

The transfer of government disability services to non-government service providers has been described as "privatisation" of government services. However, the use of this terminology overlooks the fact that many disability services continue to be delivered by not-for-profit services which are themselves community-owned and managed. It also overlooks the role that the NSW Government needs to continue to play in facilitating a non-NDIS disability services market, including through the non-government sector.

In addition, within the growth of services under the NDIS, opportunities for the expansion of 'disability-led' or 'service-user-led' services has emerged which provide peer-to-peer disability support services.

While the transfer of disability services to the non-government sector, or 'privatisation' is not in itself necessarily problematic, it does require the NSW Government to ensure that rigorous service standards and protections are in place, as well as recognition of market failures.

It is also important to recognise emerging risks and cracks in the system with the withdrawal of the NSW Government from disability service delivery in its entirety.

### **The impact of withdrawal of the NSW Government from the direct provision of disability services in NSW**

From 1 July 2018, the NSW Government is no longer delivering a range of disability services which have been transferred to a range of non-government providers.

The withdrawal of the NSW government as a disability service provider means that key roles and functions in disability services are no longer available. These include:

- A guaranteed access to services through the NSW Government acting as the provider of last resort
- Access to services and supports to enable inclusion of all people with disability, particularly the high numbers of people who are not eligible for the NDIS



- Co-ordination, case management and access oversight where people with disability (with or without an NDIS plan) interface with and need to access mainstream services such as health and education and/or specialist services such as child and family welfare services (early intervention/child protection/out-of-home care), mental health or justice services
- A non-discriminatory service delivery approach, given the transfer of formerly run government disability services to faith-based organisations, which may rely on exemptions on the basis of religious grounds to legal obligations under the NSW Disability Discrimination Act 1977, and prevent or reduce people with disability's access to services
- The delivery of specialist programs for people who may not have been able to receive support from the disability support service, such as people with disability receiving specialist support in the criminal justice support programs, or for those requiring specialist behaviour support plans and programs.

### **Provider of last resort**

A key area of concern is that NSW no longer has a system where the NSW Government remains the provider of last resort. Having a provider of last resort is vital where there are:

- 'thin' markets or no services available for people with disability such as in rural, regional or remote communities
- a particular group or individual with disability may have specific and complex challenges, which leads to situations where they are not able to access services and/or are refused access services.
- Particular groups or individuals with disability, such as those over 65 years of age that are unable to receive the disability supports or the equity of supports within a designated service system, such as My Aged Care.
- there is a gap between service systems, such as the health and disability systems where no service provision exists

While it is only a few months since the NSW Government Agency of Ageing, Disability and Home Care wound up, PWDA is consistently receiving reports and working with people with disability who are unable to access services under their NDIS plan and/or have had services withdrawn. Many people who are not eligible for the NDIS no longer have access to disability support at all.

The sale of Home Care several years ago to a private corporation has led to many people with disability experiencing poor quality services, with a loss of disability expertise and understanding.<sup>27</sup> Home Care and other disability services now restrict their services to those who are NDIS participants, excluding those who are not NDIS eligible.

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<sup>27</sup> See for example: Ian Kirkwood, 'Privatised NSW Home Care service has big problems say clients', Newcastle Herald, 12 February 2017

There are now no equivalent services for people with disability who are not in receipt of an NDIS package, leading to significant hardship among many people with disability who come to PWDA.

### **Recommendation**

That the NSW Government urgently recognise its role in the delivery of disability services for those who are not NDIS eligible and re-establish the necessary disability support role as a provider of last resort.

### **Exemptions under the NSW Anti-Discrimination Act 1977 for religious or faith-based organisations delivering disability services**

With the transfer of government-run disability services to the non-government sector, PWDA is concerned that some services are being provided by faith based non-government organisations that may have exemptions under anti-discrimination legislation. This could prevent people with disability, such as those who are from the LGBTIQ+ communities from receiving services.

For example, there are non-government not-for-profit disability services that currently use exemptions under the NSW Anti-Discrimination Act 1977 to avoid engaging with and offering services to diverse people and communities. This could reduce the overall range of services available to people with disability from diverse backgrounds and communities with any of protected attributes under the Anti-Discrimination Act.

### **Recommendation**

That the NSW Government reviews current exemptions under the NSW Anti-Discrimination Act 1977 to ensure that non-government disability services are not able to discriminate in service provision.

## **Term of Reference (e) - Provision of Support Services**

*(e) the provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the National Disability Insurance Scheme*

Like all people, people with disability use many services at the NSW state level, including health, education, transport, housing, family services and advocacy. The accessibility of these services for people with disability is essential, regardless of whether they are accessing the NDIS. The capability of NSW services to work with the NDIS where necessary is also essential. PWDA proposes a cross-departmental professional development program for the NSW government, so that all NSW government officials can work with the NDIS, and with people with disability.

In this submission, we only address key concerns in some NSW support services. However, there are numerous reforms required across NSW Government service system to ensure compliance with the CRPD. The ones we outline here illustrate the ongoing need for the NSW Government to retain Ministerial oversight and leadership for people with disability in NSW.

## Health

Access to quality and appropriate health care is just as essential for people with disability as for everyone in NSW. However, health can be an area of service where people with disability struggle to get adequate care. This can lead to harm and even death<sup>28</sup> and has been highlighted by the NSW Council for Intellectual Disability's campaign on Deadly Disability Discrimination.<sup>29</sup>

At times the responsibility for people's health care and disability support has been shifted between disability, health and other services, leaving people confused, stressed and not receiving the care they need. PWDA has recently supported three people with disability who have not been able to receive funding through the NDIS or the NSW Government equipment provider, EnableNSW to enable them to pay for Registered Nurses (RN) to change tracheostomy tubes and this has led to them being at risk of suffocation. EnableNSW, the NSW government equipment provider, funds the change of tracheostomy; Southern Cross Health is funded by the NDIS to source the Registered Nurse (RN) or care worker.

The failure for either NDIS or NSW Health to fund the RN for the tracheostomy change more than once a fortnight, despite this being needed to maintain the person's health, work and life, has led to clients being at significant risk of sickness and even death.

### Our Experience

For Joan, who uses a tracheostomy and has a severe physical disability, there was no clarity around who would change her tracheostomy. Community nursing kept telling her they needed to pull out and that it was NDIS responsibility, but no service providers were equipped to provide the service.

Equipment relating to her tracheostomy and her severe asthma were not funded under NDIS but equipment relating to other conditions were.

The uncertainty around EnableNSW services remaining, the NDIS and community nursing, meant Joan felt scared and confused.

Accessible health supports are more necessary than ever in the NDIS environment. Compromised health conditions may lead to or exacerbate disability, and health supports have a role to play in both critical and longer-term care. Currently, PWDA is finding that when the NDIA identify a person's impairment as health related, even if it results in permanent impairment, often access to the scheme is denied. However, it is often likely that a person might require both disability and health supports, such as those with arthritis, Ehlers-Danlos syndrome, Chronic Fatigue Syndrome (CFS)/ Myalgic Encephalomyelitis (ME).

<sup>28</sup> Trollor J, Srasuebkul P, Xu H, *et al* 'Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data' *BMJ Open* 2017;7:e013489. doi: 10.1136/bmjopen-2016-013489

<sup>29</sup> Council for Intellectual Disability, available at: <http://www.nswcid.org.au/deadlydiscrimination.html>

## Our Experience

PWDA has supported Clara to apply for a review of an access decision which denied her entry to the NDIS. Despite acknowledging that her impairment limited her daily functional capacity in many areas, and that she had daily living support needs, the NDIS argued that these supports were best funded through mainstream services like health.

However, health services are not set up to provide long term daily living supports, the need for which have typically been a defining feature of disability support services.

The NSW Government may not be responsible for the operation of the NDIS, but it does have a responsibility to people with disability in NSW to be working with the NDIS to ensure that interface issues are not preventing appropriate disability supports to be provided. It is also critical that NSW Health services are accessible and inclusive of people with disability, and provided integrated services with the NDIS.

It is important that the NSW Government communicates to its Commonwealth colleagues that the exclusion of people with health-related disability from the NDIS is leaving people without appropriate long-term disability support services.

PWDA is also concerned that NSW health workers are referring people with disability to the aged care system with greater frequency than the NDIS. It is possible that health workers may feel more comfortable with the system of Aged Care. PWDA proposes a cross-departmental NSW government project of professional development to increase the competence of NSW public servants in working with the NDIS.

People with disability who are not eligible for the NDIS are experiencing a significant and widening gap between the health and disability service systems. The wind-up of ADHC, including the end of Home Care services to all people with disability who do not have an individualised NDIS funding package, has caused significant hardship for people with disability.

### Recommendations

- That the NSW government funds the full implementation of NSW Health Disability Inclusion Plan across all the departmental levels, including for health services delivered by non-government organisations.
- That a cross-departmental NSW government professional development project be established, to increase the capacity of NSW government officers with referring and supporting clients to access the NDIS.
- That the NSW government takes on the recommendations of the Deadly Disability Discrimination campaign, and increase funding from \$4.7 million per annum to \$17 million per annum for specialist health services.
- That the confusion regarding funding of critical supports between NSW Health and NDIS, such as responsibility for tracheostomy changes, be clarified between agencies immediately, that this be communicated to staff and people using the

services, and that responsibility be allocated at the NSW Government level to monitor this concern.

### **Continuity of supports and the impact of loss of ADHC**

An additional concern for people with disability in NSW is the lack of continuity of supports from NSW services to the NDIS. For many people, including those previously receiving Home and Community Care (HACC) under ADHC and currently receiving Community Care and Support Program (CCSP) under various service providers, they are missing out on services that they used to rely on and that they were assured would continue under the continuity of service arrangements.

### **Our Experience**

Graham is a 53 year old man from rural NSW. He previously received home care from ADHC but was informed by his service provider that his services (personal care and domestic assistance) were to cease. He has lymphoma with bone metastases and spends a significant amount of time in bed.

He requires personal care, domestic assistance, transport, and community access supports and is in residential respite. The lack of supports is a major barrier to his return home.

Graham has made repeated attempts to access the NDIS, and was first rejected in 2017, but then sought a review. Graham was referred through the My Aged Care portal in late 2017 as a last resort, and was determined eligible for a Home Care Package 4 with a high priority.

In dealing with NDIS on Graham's behalf, PWDA queried whether the support that he was receiving under CCSP should make him automatically eligible for the NDIS but was advised this was not the case.

Graham was rejected on the basis that his 'disability arises from a health condition' and therefore his supports are not most appropriately provided by the NDIS.

However, the supports provided through My Aged Care are not likely to prevent a high risk that Graham will end up in permanent residential aged care without substantial supports.

PWDA is also concerned that the methods used by ADHC, up until 1 July, to inform clients about transfer arrangements to the NDIS have been inadequate. ADHC, while it remained, sent letters and made phone calls, however, for many people with disability, these methods were not suitable and face to face contact, preferably with a trusted person, is necessary to explain the transition.

## Our Experience

Georgia is a woman in her 40s, living in Sydney, who used to receive HACC supports from ADHC. She has a physical and psychosocial disability.

With the introduction of the NDIS, and the withdrawal of NSW government services, Georgia's support workers have told her they can no longer provide supports and she must apply for the NDIS.

She has been denied access to the NDIS, and despite two attempts in working with her GP to reapply, and with the support of PWDA, she is struggling to do so.

As a result of this situation, Georgia feels increasingly desperate. Her lack of domestic and personal supports is affecting her quality of life. For example, her house is increasingly unclean and uncomfortable and she struggles to perform daily tasks.

These case studies highlight that the NSW government needs to undertake an in depth analysis of people who previously received supports and have not been able to be contacted in the transfer to the NDIS. PWDA proposes that FACS must employ case workers to attempt to have in-person conversations about the transfer, and provide support to assist people to apply to access the NDIS.

### Recommendations

- That the NSW government works with the NDIA and through the COAG Disability Reform Council to address the issues in failures in continuity of support and to identify measures to ensure that promised continuity of support is delivered.
- That the NSW Government funds a HACC or HomeCare type service that provides short-term home and community care to people with disability who are not eligible for the NDIS, but who have a significant health and disability support needs, to deliver on the NSW government's promised continuity of support arrangements.
- That NSW government undertakes an in depth analysis of those who have not been transferred to the NDIS, and employ case workers to attempt to have in-person conversations about the transfer, and provide support to assist people to apply to access the NDIS.

### Housing

People with disability live in all kinds of housing, including private ownership and rental, with family, subletting in share houses, social housing, boarding houses, group homes, and institutions. Most housing in NSW has not been built according to universal design standards. People with disability are over-represented in housing that does not meet their needs and makes them more vulnerable to social isolation and experiencing barriers to access to services and supports.

In NSW, there is not enough social housing to meet demand, and people with disability are particularly poorly accommodated.



Housing NSW policies exclude people with disability in a variety of ways. The system of three housing offers before being moved to the end of the wait list is unfair when applied to people with disability who are offered houses that are inaccessible.

## Our Experience

Housing NSW offered John, a man with disability, a flat which did not meet his access needs. He was forced to pay for an OT assessment to demonstrate this, however Housing NSW would neither pay for the assessment nor make the modifications needed to the apartment for it to be accessible for him.

PWDA requested for the offer to be withdrawn rather than declined by John, otherwise he would have had three declines.

PWDA is concerned that the NSW government is considering further reducing the offers of social housing down to one offer only. This has the potential to significantly impact on people with disability as it is very likely that the housing may not be accessible.<sup>30</sup>

## Recommendations

- That the NSW Government ensures that all new social housing stock is designed and built to be fully accessible in line with universal housing design standards and principles
- That FACS prioritises its assessments and modifications of its current social housing stock to ensure it meets the needs of people with disability
- That the NSW Government does not proceed with the proposed change to reduce the number of offers to social housing applicants to one offer only.

## Boarding Houses

In NSW, due to limited choice and affordability and the risk of homelessness, boarding houses can often provide last resort accommodation for some people with disability. The NSW Government recognised the particular vulnerabilities for residents living in boarding houses and the need for improved oversight and regulation with the introduction of the specific standalone legislation, *Boarding Houses Act 2012*.

The legislation aimed to improve accommodation arrangements by:

- ensuring that all residents had access to their own room unless agreed by the resident and
- introducing occupancy agreements to clarify arrangements for services provided by the boarding house provider.

Under the legislation, boarding houses in NSW fall into two categories:

- assisted boarding houses which have two or more people with disability as residents

- general boarding houses.

Assisted boarding houses, as defined in the *Boarding Houses Act 2012* provide accommodation for people with 'additional support needs'. This might include people with psychosocial, intellectual, physical and/or sensory disability.

People with disability living in boarding houses are sharing with many other people, and they may require and receive supports in the form of help with daily tasks like bathing, meals, medication, and going about their day as part of their occupancy fee.

PWDA's long history of experience working with people living in assisted boarding houses highlights that services and supports can vary significantly in quality and consistency. Often residents do not have any choice and control over how their daily services and support are delivered and provided, nor do they have options to move to more appropriate forms of housing. Boarding houses have also been found to engender inherent risks that lead to violence and abuse of residents.<sup>31</sup>

The current legislation is due to be reviewed in 2018.

PWDA is concerned that the NSW Government has indicated that this review is now on hold. However, a wide-ranging and thorough review of boarding house legislation and practice is required due to:

- emerging issues with the introduction of the NDIS and the registration of boarding houses as NDIS providers of support;
- uncertainty as to whether people without an NDIS plan are being displaced from their current boarding house accommodation
- lack of access to case management for people with disability entering (assisted/general) boarding houses
- boarding house providers not meeting the requirements of the Act, particularly in relation to residents having access to their own room and choice and control over services.

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<sup>31</sup> Price-Kelly, Sonya, and Maria Attard, 2010, 'Accommodating Violence: The experience of domestic violence and people with disability living in licensed boarding houses', available at: <https://www.aph.gov.au/DocumentStore.ashx?id=234bfc3d-677a-4a8f-b5e0-d4956ca7df8b&subId=299778>



## Our Experience

Jimmy is 63 years old and lived in Peat Island institution until 2005. He now lives in an assisted boarding house. He has a cognitive impairment and a psychosocial disability and a complex history of trauma.

His impairments are not necessarily apparent on first meeting, and he is unlikely to disclose them to people he has just met. His planning meeting with the NDIS was very short, and he received only \$10 000 in supports.

This is about a quarter of the value of what he would have received under the NSW disability support system, and more importantly, will not equate to enough hours to see him through the year.

In other cases, where this inadequate level of support has been allocated, services have threatened to withdraw before a review has been finalised.

## Recommendations

- That the NSW Government proceeds with the statutory review of the Boarding Houses Act 2012 and its accompanying legislation to ensure that the rights of people with disability are upheld.
- That the NSW Government works with the NDIS Quality and Safeguards Commission to ensure that the review of NDIS registration of service providers prioritises insecure and lightly regulated residential environments such as boarding houses.

## Access to justice in NSW

The NSW government has primary responsibility for the delivery of justice services and design of the justice system in NSW. Research shows people with disability are overrepresented in the justice system. The NSW government has a number of strategies to improve this. However implementation and investment will need to continue if outcomes are to improve.

PWDA has a long history of advocacy on access to justice for people with disability. We provide individual advocacy support to many people with disability who have experienced various forms of violence. The following comments and recommendations are drawn from this previous policy work.

People with disability are not treated equally across the full spectrum of the justice system in NSW. In 2013, the Committee on the Rights of Persons with Disabilities expressed its concern that people with disability are overrepresented in the Australian justice system.<sup>32</sup> Relevant facts include:

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<sup>32</sup> Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Australia, Adopted by the Committee at its Tenth Session (2-13 September 2013)', UN Doc CRPD/C/AUS/CO/1 (4 October 2013), [31]

- Adults with intellectual disability are overrepresented in prisons, with between 12-30 per cent of the prison population having some form of intellectual disability (despite comprising 2-3 per cent of the general population).<sup>33</sup>
- Between 46-78 per cent of prisoners experience a 'psychiatric disorder', compared to 11 per cent of the general population.<sup>34</sup> These estimates are approximate, as disability is often under-recognised in the correctional system, and also by police.<sup>35</sup>
- In New South Wales, 50 per cent of all young people in juvenile detention centres have intellectual disability,<sup>36</sup> and 39 per cent of these are young Aboriginal and Torres Strait Islander people.<sup>37</sup> In addition, 85 per cent of young people in juvenile detention centres in NSW have a 'psychological condition', with 73 per cent reporting two or more 'psychological conditions'.<sup>38 39</sup>

Provision of adequate, timely and appropriate support for people with disability at risk is critical. One key human rights issue which must be addressed in NSW is indefinite detention. People with disability who are accused of a crime can be diverted from criminal proceedings through legislative provisions that find them 'unfit' to stand trial or not guilty by reason of 'mental impairment'.<sup>40</sup> This can lead to people with disability being detained indefinitely in forensic services without conviction, sometimes for periods longer than the maximum sentence had they been convicted.<sup>41</sup> In this respect, PWDA notes with concern that the most recent draft of the NSW Mental Health and Cognitive Impairment Forensic Provisions Bill 2018 has not engaged with the significant reforms required under the CRPD that would end many of the practices experienced by forensic persons, such as forced and non-consensual treatment, indefinite and arbitrary detention, and lack of supports for decision-making or exercise of legal capacity.

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<sup>33</sup> Baldry E., Clarence M., Dowse L. & Trollor J., 2013. 'Reducing vulnerability to harm in adults with cognitive disabilities in the Australian criminal justice system.' *Journal of Policy and Practice in Intellectual Disability* 10:222-9; NSW Law Reform Commission, 2010. 'People with Cognitive and Mental Health Impairments in the Criminal Justice System: An Overview' (Consultation Paper No 5, January 2010), pp13-15.

<sup>34</sup> Ibid.

<sup>35</sup> PWDA, 2015b. 'Royal Commission into Institutional Responses to Child Sexual Abuse Issues Paper 10: Advocacy and Support and Therapeutic Treatment Services', p12. Available: <http://www.childabuseroyalcommission.gov.au/getattachment/ac1328d3-fe86-485c-9d9b-511e030d6b1e/99-People-with-Disability-Australia>

<sup>36</sup> Horin, A. 2010. 'Report Finds Disability and Disadvantage Common in Young Offenders', *Sydney Morning Herald* (Sydney) 27 February 2010. [www.smh.com.au/nsw/report-finds-disability-and-disadvantage-common-in-young-offenders-20100226-p95r.html](http://www.smh.com.au/nsw/report-finds-disability-and-disadvantage-common-in-young-offenders-20100226-p95r.html) and

Devon Indig et al. 2011. '2009 NSW Young People in Custody Health Survey: Full Report' (Report, Justice Health, NSW Health and Human Services Juvenile Justice, NSW Government, 2011) 15.

<sup>38</sup> Ibid.

<sup>39</sup> PWDA, 2017 'Submission to the NSW Department of Justice Disability Justice Strategy', available at: <https://pwd.org.au/news/submissions/submission-archive-2017/>

<sup>40</sup> Bevan, N. and Sands, T. 2016. *Submission to the Senate Inquiry into Indefinite Detention of People with Cognitive and Psychiatric Impairment in Australia*, Australian Cross Disability Alliance; Sydney, Australia. Available: <http://dpoa.org.au/wp-content/uploads/2016/04/ACDA-IndefiniteDetention-Submission-April2016.pdf>

<sup>41</sup> Ibid.

If a person with disability is convicted of a crime and imprisoned, they must have access to appropriate therapeutic and disability supports while imprisoned.<sup>42</sup> This includes access to the right kinds of supports for their impairment/s (including relevant communication devices, sign language and community language interpreters), mental health services and supports, therapy and access to education and training.<sup>43</sup> Supports should be planned for and delivered during incarceration and reassessed in advance of release.<sup>44</sup>

Following on from this, correctional facilities have a responsibility to identify prisoners who require support, provide that support while they are incarcerated, and develop a holistic reintegration plan prior to their release into the community. It is essential that the Department of Justice work with other cross-government agencies such as the Department of Health, the Department of Housing, and the NDIA.<sup>45</sup> This will help to ensure that recently released prisoners with disability don't fall through the gaps in service provision, and may help to minimise their risk of further contact with the criminal justice system.<sup>46</sup>

The NSW Department of Justice must develop a holistic and coherent strategy for their engagement with people with disability that works across government. This includes integrating with the NDIS to deliver community-based early intervention and outreach strategies to prevent people with disability being at high risk of coming into contact with the criminal justice system.<sup>47</sup> PWDA welcomes the review of the NSW Department of Justice Disability Inclusion Action Plan (DIAP) and recommends that the NSW Government ensure that the DIAP draws together recommendations from previous reports and research.

## Recommendations

- That the NSW Government provides access to appropriate therapeutic and disability supports for people with disability while they are imprisoned. Supports should be planned for and delivered during incarceration and reassessed in advance of release
- That the NSW Government, in collaboration with people with disability and their representative organisations, reform the forensic system so that it is compliant with the CRPD

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<sup>42</sup> Ibid.

<sup>43</sup> PWDA, 2015. 'Royal Commission into Institutional Responses to Child Sexual Abuse Issues Paper 10: Advocacy and Support and Therapeutic Treatment Services', p12. Available: <http://www.childabuseroyalcommission.gov.au/getattachment/ac1328d3-fe86-485c-9d9b-511e030d6b1e/99-People-with-Disability-Australia>

<sup>44</sup> PWDA, 2017 'Submission to the NSW Department of Justice Disability Justice Strategy', available at: <https://pwd.org.au/news/submissions/submission-archive-2017/>

<sup>45</sup> Bevan, N. and Sands, T. 2016. *Submission to the Senate Inquiry into Indefinite Detention of People with Cognitive and Psychiatric Impairment in Australia*, Australian Cross Disability Alliance; Sydney, Australia. Available: [http://dpoa.org.au/wp-content/uploads/2016/04/ACDA\\_IndefiniteDetention\\_Submission\\_April2016.pdf](http://dpoa.org.au/wp-content/uploads/2016/04/ACDA_IndefiniteDetention_Submission_April2016.pdf)

<sup>46</sup> PWDA, 2017 'Submission to the NSW Department of Justice Disability Justice Strategy', available at: <https://pwd.org.au/news/submissions/submission-archive-2017/>

<sup>47</sup> Ibid.

- That the NSW Department of Justice work with other cross-government agencies such as the Department of Health, the Department of Housing, and the NDIA to identify prisoners who require support, provide that support, and develop a holistic reintegration plan prior to their release into the community.
- That the NSW Department of Justice develop a holistic strategy for engagement with people with disabilities that works with the NDIS to deliver community-based early intervention and outreach strategies to prevent people with disability being at high risk of coming into contact with the criminal justice system.
- That the NSW Department of Justice Disability Inclusion Action Plan (DIAP) draws together recommendations from previous reports and research, including those listed under 'Justice' in Selected References at the end of this document.

### Domestic and family violence and violence prevention

NSW continues to hold key responsibility for domestic and family violence services. This is demonstrated in the *Domestic and Family Violence Prevention and Early Intervention Strategy 2017-2021*<sup>48</sup> and the *NSW Domestic and Family Violence Blueprint for Reform 2016-2021*.<sup>49</sup> PWDA has extensive expertise in the area of violence prevention, including domestic and family violence. We provide advocacy support for many people with disability who have experienced violence, including those affected by the Royal Commission into Institutional Responses to Child Sexual Abuse (the Royal Commission). In addition, we have also provided disability specific policy advice to the Royal Commission.<sup>50</sup>

We refer the committee to our response to the development of 'A Blueprint for Family and Domestic Violence Response in NSW', which is included in the references for this submission. In brief, however, our comments and recommendations are as follows:

- Domestic and family violence (DFV) efforts are rarely inclusive of people with disability. People with disability are typically taken less seriously when reporting violence than people without disability. When perpetrators of violence against people with disability are carers or support workers, the assumption of 'carer sacrifice' can be seen to mitigate the crime.<sup>51</sup> The killing of Kim Hunt, the media

<sup>48</sup> NSW Government 2016 *Domestic and Family Violence Prevention and Early Intervention Strategy 2017-2021* available at: [https://www.women.nsw.gov.au/violence\\_prevention/dfv-prevention-intervention-strategy](https://www.women.nsw.gov.au/violence_prevention/dfv-prevention-intervention-strategy)

<sup>49</sup> NSW Government 2016 *NSW Domestic and Family Violence Blueprint for Reform 2016-2021* available at: [http://domesticviolence.nsw.gov.au/\\_data/assets/pdf\\_file/0004/379849/dfv-blueprint-for-reform.pdf](http://domesticviolence.nsw.gov.au/_data/assets/pdf_file/0004/379849/dfv-blueprint-for-reform.pdf)

<sup>50</sup> PWDA submissions to the Royal Commission which may be of particular interest include: PWDA, 2015a. 'Royal Commission into Institutional Responses to Child Sexual Abuse: Issues Paper 8 – Experiences of Police and Prosecution Responses'. Available:

<http://www.childabuseroyalcommission.gov.au/getattachment/5d0dcca4-9166-442f-a8ac-e6f76821e005/17-People-With-Disability-Australia-Inc> and PWDA, 2016a. 'Royal Commission into Institutional Responses to Child Sexual Abuse: Submission regarding Criminal Justice' April 2016. Available: [http://www.childabuseroyalcommission.gov.au/getattachment/e7f22c43-46d2-4dbf-8e32-6fd70792549a/People-with-Disability-Australia-\(PWDA\)](http://www.childabuseroyalcommission.gov.au/getattachment/e7f22c43-46d2-4dbf-8e32-6fd70792549a/People-with-Disability-Australia-(PWDA))

<sup>51</sup> PWDA, 2016, *Response to 'A Blueprint for Family and Domestic Violence Response in NSW'*, available at: <https://pwd.org.au/news/submissions/submission-archive-2016/>

response and even the Coroner's Report on her murder, all show that victims with disability tend to be blamed for the crimes committed against them.<sup>52</sup>

- Another key barrier to reporting crime experienced by people with disability, particularly women with disability is fear of having their children removed from their care. Children of parents with disability are removed at 10 times the rate of other children.<sup>53</sup> In particular, women with disability who have experienced domestic and family violence may have their children removed, despite not being the perpetrator, as they are deemed 'inadequately protective' of their children's welfare.<sup>54</sup> This not only places blame on the victim for the violence they are experiencing, but understandably increases the hesitance of women with disability to contact the police or access support services in these cases.<sup>55</sup> As previously mentioned, the NSW Disability Justice Strategy must be integrated across Government, with an emphasis on the provision of support required by people with disability. Through a holistic approach, women in these circumstances should be supported to pursue justice whilst receiving appropriate parenting and family support to ensure their children are not removed unnecessarily.<sup>56</sup>
- The NDIS is not set up to deal with crisis. The processes for amending a plan or bringing someone into the scheme are lengthy, and are likely to remain so. Additionally, people with disability in NSW should be able to access the universal state-provided domestic and family violence support services, on an equal basis with all other residents of NSW.<sup>57</sup>
- Violence that occurs in residential institutional settings such as aged care facilities, psychiatric facilities and group homes for people with disability, is frequently not identified as domestic violence. Of the 521 violent incidents reported as happening in these settings in 2015-2016 (including physical assaults, sexual assaults and harassment), only 79 were identified as domestic violence related incidents.<sup>58</sup> Thus, overall statistics on domestic violence are likely to be lower than they should be. People with disability experiencing violence in these settings, whether at the hands of co-residents or support workers, are not given the same kinds of support as other domestic violence victims. There are circumstances where this violence is not recognised as a police matter, but as a 'service incident.' This is inappropriate, and leads to a

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<sup>52</sup> See Young, S, 'Disability and murder: Victim blaming at its very worst' on ABC Ramp Up. 16<sup>th</sup> Sep 2016, at <http://www.abc.net.au/news/2014-09-16/young-victim-blaming-at-its-very-worst/5745346>; and NSW Coroner, (2015) *Inquest into the Deaths of Geoffrey Francis Hunt...* available at: <http://www.coroners.justice.nsw.gov.au/Documents/Hunt%20Family%20Inquest%20Findingsv2.pdf>

<sup>53</sup> DPO Australia, 2014, op cit.

<sup>54</sup> PWDA, 2015, op cit., p7.

<sup>55</sup> Ibid.

<sup>56</sup> PWDA, 2017 'Submission to the NSW Department of Justice Disability Justice Strategy', available at: <https://pwd.org.au/news/submissions/submission-archive-2017/>

<sup>57</sup> PWDA, 2016, *Response to 'A Blueprint for Family and Domestic Violence Response in NSW'*, available at: <https://pwd.org.au/news/submissions/submission-archive-2016/>

<sup>58</sup> Information from Bureau of Crimes Statistics and Research, sr15-13438



double standard in accessing justice for family and domestic violence: one for people with disability, and another for the rest of the community.<sup>59</sup>

- This can mean that people with disability are being denied processes developed for victims of domestic violence, such as video collection in Domestic Violence Evidence in Chief or Domestic Violence Forensic Unit collection of physical evidence. Physical evidence may matter even more in cases where people with disability are excluded from participation in court proceedings due to inadequate supports, or because of the inadmissibility of certain kinds of evidence provided by them (in some cases including evidence given through Auslan interpreters).<sup>60</sup>
- The Safer Pathway model has been a positive intervention in the domestic and family violence service system for many people, but less so for people with disability. Domestic violence victims residing in institutional settings are not served well by the structure that assumes the victim will have access to a telephone. For instance PWDA has received reports from services of victims living in institutional settings, and when they call them on the telephone, it is answered by a staff member. These staff members either refuse to allow access to the client, or say that the telephone call would be confusing for the victim. Thus people who live in institutional settings are excluded from the Safer Pathway approach, which is designed to provide victims with wrap-around services that assist them in leaving violence by including representatives from Health NSW, Housing NSW, and domestic and family violence services. These are precisely the services that people with disability, especially those experiencing domestic violence in institutional settings, need access to.<sup>61</sup>
- Finding housing is one of the greatest difficulties for people with disability who need to escape violence in institutional settings. It is often assumed that they can only move into another institutional setting. This means victims are forced to continue living with perpetrators, who may also go on to perpetrate against other residents. Successful moves for victims of domestic violence in institutional settings have been where either the perpetrator is moved into their own residence, or where the victim has moved into their own house in the community.<sup>62</sup>

## Recommendations

- That discrete funding be allocated to provide disability support for women with disability who need it upon leaving violence, based on the Victorian Disability and Family Violence Crisis Responses Initiative.<sup>63</sup>
- That the Safer Pathway model is amended in the following ways:

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<sup>59</sup> PWDA, 2016, *Response to 'A Blueprint for Family and Domestic Violence Response in NSW'*, available at: <https://pwd.org.au/news/submissions/submission-archive-2016/>

<sup>60</sup> Ibid.

<sup>61</sup> Ibid.

<sup>62</sup> Ibid.

<sup>63</sup> Ibid.

- Other modes of communication, including face-to-face discussion, must be enabled
- Disability advocacy organisations should be funded to provide support in engaging with victims with disability living in institutional settings
- Institutional settings must be legally required to provide access to Safer Pathways programs and disability advocacy organisations providing this function
- Safety Action Meetings, a key part of Safer Pathways, must include representatives from disability advocacy organisations, the NDIS (as it rolls out), and the victim's service provider
- Safety plans must include the provision of disability support to people with disability (whether in institutional settings or living in the community).<sup>64</sup>

## Term of Reference (f) – Adequacy of Current Regulations and Oversight

*(f) the adequacy of current regulations and oversight mechanisms in relation to disability service providers*

On 1 July 2018, the NDIS Quality and Safeguards Commission (the NDIS Commission) came into operation in NSW. The NDIS Commission has powers to register and regulate NDIS providers, respond to complaints about poor quality service provision and incidents of violence and abuse, develop national worker screening standards and oversee behaviour support and the use of restrictive practices by NDIS registered providers. The NDIS has extensive compliance, enforcement, monitoring and investigation powers in many aspects, and these are critical for people with disability to have protections from violence, abuse and neglect when using supports and services under the NDIS.

However, the NDIS Commission will not provide comprehensive protection against violence, abuse and neglect for all people with disability across a broad range of service systems and situations. Its focus will be on NDIS registered providers and NDIS participants, providing protection and oversight to the 10% of people with disability who directly access NDIS supports. It will not have a mandate to address individual or systemic issues outside of the NDIS. This means that the majority of people with disability, as well as NDIS participants when interacting with other service systems, will only have protection through existing regulatory and policy frameworks that have to a large extent been shown to provide inadequate protection.<sup>65</sup>

This means that the effective role of NSW regulatory and oversight mechanisms is critical for people with disability in NSW. If a person is not an NDIS participant but receiving

<sup>64</sup> Ibid.

<sup>65</sup> Senate Community Affairs References Committee, 'Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability', Commonwealth of Australia, November 2015.

disability or other community supports they should still be able to seek that support and protection from the NSW Ombudsman, for example.

In addition, the more people with disability receive services through the mainstream service system, they will need to be able to seek support and protection from agencies such as the Department of Fair Trading. This will require all NSW regulatory and oversight mechanisms to implement measures and actions to ensure they are fully accessible to people with disability. Agency Disability Inclusion Action Plans have an important role to play in this regard.

While the impact of the NDIS Commission and its effect in regulating and overseeing disability service providers is still to be determined, the adequacy of NSW regulatory and oversight mechanisms will need to adapt to ensure that all people with disability in NSW have robust protections. It is critical that NSW Government, at the very least:

- Work collaboratively with the NDIS Commission to monitor the impacts of the NDIS Commission and its role in protecting people with disability in NSW;
- Identify gaps and areas of concern that require stronger NSW regulatory and oversight protections, and greater collaboration with the NDIS Commission to ensure effective protections for all people with disability in NSW regardless of NDIS eligibility;
- Evaluate the role of NSW regulatory and oversight mechanisms in protecting all people with disability in NSW, and implement measures and actions for improvement.

In addition, in its recent report, the Australian Human Rights Commission recommends six key elements to ensure effective quality, safeguarding and oversight mechanisms to give effect to the rights of persons with disability and provide protections for people with disability from violence, abuse and neglect:

1. A human rights-based approach
2. A connected and integrated system
3. Independent oversight and monitoring
4. Robust prevention and response elements
5. Accessibility for people with disability
6. Continuous system improvements through data.<sup>66</sup>

These elements should be incorporated and implemented into the NSW regulatory and oversight mechanisms.

For the purpose of this submission, PWDA highlights three areas of concern regarding current inadequacies in existing NSW regulatory and oversight mechanisms:

- The authorisation of restrictive practices

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<sup>66</sup> Australian Human Rights Commission, 'A Future Without Violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings', June 2018, Australian Human Rights Commission 2018, p.8.



- The role of guardianship
- The transitional approach to resourcing peak representation of people with disability and independent advocacy.

### **Authorisation of restrictive practices**

The NDIS Commission has responsibility for providing policy oversight and guidance to NDIS providers in the area of restrictive practices, which will be led by a national Senior Practitioner and underpinned by the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the disability Service Sector (the National Framework).

The Senior Practitioner will provide “leadership in behaviour support, and in the reduction and elimination of the use of restrictive practices, by NDIS providers” by building capability, assessing skills and experience, providing education, training and advice, monitoring registration compliance, undertaking data collection and analysis and undertaking research.<sup>67</sup> State and Territories will continue to authorise restrictive practices within behaviour support plans using the legislative and policy processes within each jurisdiction.

PWDA is very concerned that this oversight function for the NDIS Commissioner is very weak given that restrictive practices cause significant breaches of human rights, and can constitute torture, cruel, inhuman or degrading treatment or punishment.<sup>68</sup> There is a strong relationship between the use of restrictive practices and other forms of violence, abuse and neglect against people with disability, which undermines the ability of people with disability and support workers to recognise violence and respond to it as a crime.

In addition, if authorisation of restrictive practices in behaviour support plans is to be conducted at the State and Territory level, then there needs to be agreement at the State and Territory level for nationally consistent regulatory mechanisms for authorisation of behaviour support plans. While a key role for the Senior Practitioner will be to coordinate a nationally consistent regulatory framework, current mechanisms at State and Territory level are varied and inconsistent. In NSW, there is a relatively weak policy function that sits within FACs and which will make decisions to authorise practices that significantly impact on the human rights of persons with disability. There is no understanding that this policy function has a role in progressing the elimination of restrictive practices, or have any role in overseeing restrictive practices that may be applied by a service provider not registered with the NDIS to a person with disability who is not an NDIS participant. Other States have independent regulatory bodies and mechanisms with legislative powers, and are focused on reduction and elimination.

It is critical that the NSW Government urgently acts to establish a more robust regulatory mechanism with legislative powers, at the same time as working with the NDIS

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<sup>67</sup> National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Act 2017 (Cth), Section 181H

<sup>68</sup> Frohmader, C., & Sands, T. (2015) *Australian Cross Disability Alliance (ACDA) Submission to the Senate Inquiry into Violence, abuse and neglect against people with disability in institutional and residential settings*. Australian Cross Disability Alliance (ACDA); Sydney, Australia.

Commission to establish a nationally consistent regulatory mechanisms focused on the elimination of restrictive practices.

### **The role of guardianship**

PWDA contributed extensively to the NSW Law Reform Commission's review of the NSW *Guardianship Act 1987*. In summary, the NSW Law Reform Commission's goal was to provide proposals to update the Guardianship Act to provide a legal framework for supported decision making rather than substitute decision making. The NSW Law Reform Commission tabled its final report in Parliament on 15 August 2018.<sup>69</sup> PWDA has worked with many people with disability dealing with the perverse outcomes of guardianship law and policy.

## **Our Experience**

Edith has a physical disability, and at one time was placed under enduring guardianship due to a previous decline in her health. However, she is well enough now to make her own decisions again.

She currently lives in an aged care facility, and wants to return home. With a view to this, she, her husband, and support, made a plan for this and were approved for a Level 4 My Aged Care package with in home support.

Despite submitting plans and Occupational Therapist reports to her guardian (who changed five times over the course of 12 months) she was unable to get a decision. With the support of her PWDA advocate, she appealed the enduring guardianship order, so that she might return home.

Though the appeal board recommended in her favour, they are not able to overturn original orders, and so Edith remains in limbo. She has been attempting to leave residential aged care for two years, despite having adequate supports and loving family available to her at home.

The recommendations from the Report substantially change the current substitute decision making regime to focus on a new assisted decision-making framework with an emphasis away from 'best interests' to 'rights, will and preferences' of the person. It also recommends for the establishment of a separate Office of the Public Advocate to support people in need of decision-making assistance and to investigate cases of abuse, neglect and exploitation. These recommendations would bring NSW closer to compliance with the requirements of the CRPD, but unfortunately do not entirely comply. There is still provision for substitute decision-making and a focus on assessing decision-making ability as opposed to assessing the supports required for an individual to make decisions.

In responding to the Report, the NSW Government should carefully consider adopting recommendations that are CRPD compliant, and establish the independent Office of the Public Guardian. However, it should not adopt recommendations that are not compliant with the CRPD.

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<sup>69</sup> New South Wales Law Reform Commission, 2018, 'Review of the Guardianship Act 1987', report 145, May 2018, New South Wales Law Reform Commission, Sydney.

## Representation of people with disability and independent advocacy

People with disability need and deserve a voice of our own. Advocacy and representation are the heart of PWDA; we were founded by and for people with disability, and we represent ourselves both on individual matters and in policy processes. In all areas of life, people with disability might need someone to stand beside them, fight for them when the barriers to community life and economic and social participation are impacting their rights.

NSW has a strong history of funding independent advocacy and representation by and for people with disability, in recognition of the barriers we face and the contribution that we make to policy and inclusive practice in NSW. In recent years, however, our organisations have remained under constant threat of defunding. PWDA has come together with other advocacy and representation bodies to form the NSW Disability Advocacy Alliance, and take a leading role in the Stand by Me campaign. In the wake of the Stand by Me campaign, the NSW government guaranteed funding of \$13 million for independent advocacy and representation – but only until the end of June 2020.

We fully endorse the submission of the Stand by Me campaign to this Inquiry, and make the following points:

- The NDIS and its project funding arm, Information, Linkages and Capacity Building (ILC) do not replace the need for independent advocacy and representation. The Commonwealth Government's own guidelines state that "we will not fund individual or systemic advocacy in ILC."<sup>70</sup>
- The NDIS increases, rather than reduces the need for advocacy and representation. The new system is challenging to navigate, rendering useless the knowledge of the NSW system that people with disability have built up over years. Only around 10 percent of people with disability will gain access to the NDIS. The rest rely on mainstream, NSW-based services – many of whom are under the misapprehension that the NDIS solves all problems for people with disability.
- Independent advocacy and representation are system savers. They identify issues, gaps and failures early and can assist in identifying solutions.
- They are critical to the development of the NSW Disability Inclusion Plan, the Agency Disability Inclusion Action Plans, and the implementation of the actions within those plans.

## Recommendations

That NSW Government, at the very least:

- Works collaboratively with the NDIS Commission to monitor the impacts of the NDIS Commission and its role in protecting people with disability in NSW;
- Identifies gaps and areas of concern that require stronger NSW regulatory and oversight protections, and greater collaboration with the NDIS Commission to

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<sup>70</sup> NDIA, 2016, *ILC Commissioning Framework*, p.21 available at: <https://www.ndis.gov.au/medias/documents/hf4/ha1/8799111970846/ILC-Commissioning-Framework-PDF-3MB-.pdf>

ensure effective protections for all people with disability in NSW regardless of NDIS eligibility;

- Evaluates the role of NSW regulatory and oversight mechanisms in protecting all people with disability in NSW, and implement measures and actions for improvement.

That the six elements for effective regulatory and oversight mechanisms identified by the Australian Human Rights Commission should be incorporated into NSW regulatory and oversight mechanisms by the NSW Government

That the NSW Government urgently acts to establish a more robust regulatory mechanism with legislative powers, at the same time as working with the NDIS Commission to establish a nationally consistent regulatory mechanisms focused on the elimination of restrictive practices.

That in responding to the NSW Law Reform Commission Report, the NSW Government should carefully consider adopting recommendations that are CRPD compliant, and establish the independent Office of the Public Guardian. However, it should not adopt recommendations that are not compliant with the CRPD.

That the NSW Government recognise the safeguarding value and contribution to an inclusive NSW by committing to ongoing funding for independent disability advocacy and representation in NSW.

## **Term of Reference (i) – Impacts of Inadequate Disability Supports**

*(i) incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services*

It is crucial to understand that lack of disability supports exist *within* community services, rather than simply in the disability sector itself. In this sense, the strain that is created is, in fact, primarily on people with disability and their families, as well as on additional demand within different parts of the community service system. Where there are failures of mainstream services to adequately include and accommodate people with disability, this will put a strain on disability services and systems; and where a person with disability is not receiving the disability-specific supports they need, this may create a greater demand on other service systems, such as health. A very simple example of this might be where a person injures themselves in the completion of a daily task like showering, and requires an ambulance or hospital care.

PWDA has supported people with disability experiencing problems with the lack of interface between Family and Community Services (FACS), Juvenile Justice, education and child protection services. PWDA notes, as an extension of points made under Term E, that for children or young people at risk of engaging with the police, early intervention is crucial, and could support desired outcomes from NDIS or education. The current review of the Department of Justice Disability Inclusion Action Plan 2015-2018 provides an important opportunity to not only to strengthen supports for children and young at risk of

contact with the juvenile justice system but also to improve the linkages and interface between FACS, juvenile justice and education.<sup>71</sup>

## Our Experience

In one family supported by PWDA, two boys with disability were being fostered by their grandmother. The boys have complex behaviour support needs but had no core supports included in NDIS Plans, despite their obvious need.

One of the boys was 17 years old and at risk of engagement with the justice system. This was exacerbated by the lack of formal supports at home and for after school activities, despite the fact that he was well engaged at school.

A lack of accessible transport also proved a barrier to continuing engagement in school and out of school activities.

This example shows that NSW Government has a strong role in providing wrap-around community-based supports that would not be included in an NDIS plan. Without these supports, children and young people with disability may be at risk of contact with police and at risk of entering the juvenile justice systems.

### Recommendation

That NSW government and its agencies review what services and supports will not be provided within NDIS plans for people with disability, and that NSW government strengthens investment in these services and supports as part of their Disability Inclusion Action Plans.

## Term of Reference (j) – Improving the Provision of Disability Services

*(j) policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales*

People with disability are equal citizens of NSW and have the right to have their full potential and contribution recognised and respected.

People with disability currently do not have equal access to public services in NSW, including adequate disability supports. Many people with disability are excluded from participation in the civic life of NSW citizens through poor provision of accessible and affordable services and environments.

In the last decade, Australia has embarked on significant development of its policy framework, funding and service delivery arrangements to ensure that people with disability have access to the supports and services they need, as well as equal access to mainstream public facilities and services.

These reforms are long overdue. Despite anti-discrimination legislation at the Commonwealth and State levels – namely the National Disability Discrimination Act 1992, the Disability Standards for Education 2005, Disability (Access to Premises— Buildings)

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<sup>71</sup> NSW Department of Justice, 2018, available at:

[https://www.justice.nsw.gov.au/justicepolicy/Pages/lpclrd/lpclrd\\_consultation/disability-inclusion-action-plan-consultation.aspx](https://www.justice.nsw.gov.au/justicepolicy/Pages/lpclrd/lpclrd_consultation/disability-inclusion-action-plan-consultation.aspx)

Standards 2010 and the NSW Anti-Discrimination Act 1977 – repeated inquiries and reports have highlighted that people with disability are individually and systemically excluded, marginalised and experience high-levels of disadvantage. All policy reform must address this marginalisation and exclusion of people with disability.

In 2008, Australia ratified the United Nations Convention of the Rights of Persons with Disabilities (CRPD). This was a significant step forward in realising the rights of people with disability. However, the provisions of the CRPD have not been fully integrated into significant policy reform that will address the significant challenges in participating in civil and political life and in accessing education, health, employment and the appalling rates of violence, abuse and neglect against people with disability.

When Australia signed the CRPD, the Australian Government developed a national policy framework to implement the provisions in the Convention that ensure that the rights of people with disability are at the centre of policy, law reform and justice and the provision of disability services. This was important because most disability services at the time were funded and delivered by the state and territories and were inconsistent, fragmented, and inadequate to meet the needs of people with disability.

### **National Disability Agreement 2008**

The National Disability Agreement, signed in 2008, aimed to strengthen policy development across levels of government, and make sure that the needs of people with disability were central to developing policy, service provision, monitoring and reporting. The NDA commenced in 2009. The NDA's purpose is to enable national, state and territory governments to provide services that enable "[p]eople with disability and their carers [to] have an enhanced quality of life and participate as valued members of the community."<sup>72</sup>

This is achieved through:

- Services that provide skills and supports to people with disability to enable them to live as independently as possible
- Services that assist people with disability to live in stable and sustainable living arrangements
- Income support for people with disability and their carers,
- Services that assist families and carers in their caring role.<sup>73</sup>

The Australian Government has recently referred the NDA to review by the Productivity Commission.<sup>74</sup>

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<sup>72</sup> Council of Australian Governments, National Disability Agreement, our addition, available at: [http://www.federalfinancialrelations.gov.au/content/npa/national\\_agreements/national-disability-agreement.pdf](http://www.federalfinancialrelations.gov.au/content/npa/national_agreements/national-disability-agreement.pdf)

<sup>73</sup> Ibid, p. 3

<sup>74</sup> Productivity Commission, 2018, National Disability Agreement Review, available at: <https://www.pc.gov.au/inquiries/current/disability-agreement#issues>



## National Disability Strategy 2010-2020

In addition to the NDA, Commonwealth, State and Territory Governments and the Australian Local Government Association, developed and endorsed the National Disability Strategy 2010-2020 (NDS) in 2011.

The NDS is the key national policy framework for “protecting, promoting and fulfilling the human rights of people with disability”.<sup>75</sup> It has been agreed by all Australian governments as the strategy to implement the CRPD and to report to the United Nations (UN) against progress in achieving the CRPD.<sup>76</sup> The NDS “adopts the principles set out in Article 3 of the CRPD”<sup>77</sup> and the “six policy areas of the Strategy are aligned to the articles of the CRPD”.<sup>78</sup>

The NDS widens the lens from the NDA’s focus on “disability service provision” to strategies to improve people with disability’s inclusion and participation in Australia life and community.

The NDS aims to drive tangible change for the rights of people with disability as expressed in the CRPD. The NDS focuses on improvement in the accessibility of mainstream or universal services as well as shifting community attitudes.

A review of the NDS has also commenced in 2018 and is being led by Department of DSS.

Both the NDA and the NDS provide clear direction for the NSW Government in how to implement their legislative requirements to ensure the rights of people with disability.

In relation to the NDS, the *NSW Disability Inclusion Act 2014* enables the NSW Government to meet its jurisdictional objectives and obligations. This Act sets out the objectives and principles of “accessibility of mainstream services and facilities, the promotion of community inclusion and the provision of funding, support and services for people with disability”.

## NSW Disability Inclusion Plan

A key provision, under the *Disability Inclusion Act 2014*, is that “all NSW Government Departments, some government agencies and all local councils have been required to develop a Disability Inclusion Action Plan (DIAP).”

- In February 2015, the NSW Government released its state-wide Disability Inclusion Plan.
- In December 2015, all Government Agencies were required to complete their DIAPs.
- On 1 July 2017 all Local Governments were required to complete their DIAPs.

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<sup>75</sup> Council of Australian Governments, *National Disability Strategy 2010-2020*, Commonwealth of Australia 2011, p. 9

<sup>76</sup> Ibid, pp. 16-17

<sup>77</sup> Ibid, p. 22

<sup>78</sup> Ibid, p. 17



These plans, both individually and collectively, represent important policies and mechanisms to make sure that all people with disability in NSW are included in mainstream services, and have the specific disability supports they need.

However, investment in the NSW Disability Inclusion Plan and the cascading NSW Government agency and Local Government DIAPs is difficult to track from a whole-of-government perspective. It is not clear how access to services has improved, or how barriers to participation are being removed.

At this stage, progress on initiatives under the NSW Disability Inclusion is not reported in terms of measurable targets and outcomes that clearly demonstrate positive change for people with disability in relation to the four performance areas:

- Developing positive community attitudes and behaviours
- Increasing meaningful employment opportunities
- Creating liveable communities
- Improving access to mainstream services through better systems and processes.

Greater transparency and reporting on the levels of investment in the delivery of these plans by the NSW Government, its agencies and local government is urgently required.

### **Opportunities to strengthen investment and accountability on Disability Inclusion**

Currently, the NSW Government identifies “Transitioning to the National Disability Insurance Scheme (NDIS) as one of the 18 State Priorities<sup>79</sup>. The Government states:

*“The National Disability Insurance Scheme (NDIS) will introduce a national, person-centred approach to empower people with disability to exercise choice and control over their support services. NSW was the first state to sign up to the NDIS and will transition to the full scheme from July 2016 to July 2018, providing support for up to 140,000 people in NSW. All NSW Government agencies will need to work together and with the Commonwealth to ensure the successful delivery of this reform.”<sup>80</sup>*

However, the transition to the NDIS represents only one part of the NSW Government’s broader responsibilities to make sure that people with disability are included in all mainstream services, and have the specific disability supports that they need.

The NSW Disability Inclusion Plan Update 2017 confirms that “1.4m people live with disability in NSW”.<sup>81</sup> This figure contrasts with the most recently published National Disability Insurance Scheme (NDIS) Quarterly Report (Quarter 4, 2017-18 Report), which

<sup>79</sup> NSW Government, *Projects and Initiatives*, available at: <https://www.nsw.gov.au/improving-nsw/projects-and-initiatives/>

<sup>80</sup> Ibid.

<sup>81</sup> NSW Government, 2017, NSW Disability Inclusion Plan Update 2017, <https://www.parliament.nsw.gov.au/la/papers/DBAssets/tabledpaper/webAttachments/73353/Disability%20Inclusion%20Plan%20Update%202017.pdf>

states that 89,622 people living in NSW, including children and young people, are current participants in the NDIS.<sup>82</sup>

Most people with disability in NSW, 1.3 million people, will not be eligible for individual supports through the NDIS.

These people with disability will need the NSW Government to continue to play a significant role in developing policy and monitoring progress to ensure that all people with disability, including people who are able to access the NDIS, are able to access services and supports needed to be fully include in our community.

Further, as outlined above, the NSW Government continues to have significant commitments under:

- The Convention on the Rights of Persons with Disabilities
- COAG's National Disability Agreement
- COAG's National Disability Strategy
- NSW Disability Inclusion Act 2014
- NSW Disability Inclusion Plan, and
- Oversight of the Government Agency Disability Inclusion Action Plans.

From this perspective, the NSW Government, despite its transfer of disability service provision to the NDIS, still holds whole-of-government policies and responsibility to ensure people with disability have access to government services, including disability support where they are not NDIS eligible, and can participate fully in civic and community life.

Further the NSW Government has responsibility for the provision of disability specific services, supports and adjustments across its many portfolios including education, transport, housing, health, policing and criminal justice, child protection and community services.

To ensure effective policy development, resourcing and oversight, PWDA proposes the establishment of an Office of Disability Inclusion that is located in the Department of Premier and Cabinet, so that this office can drive cross-agency change and improvements, while also co-ordinating monitoring and reporting on progress made with the NSW Disability Inclusion Plan and the Government Agencies Disability Inclusion Action Plans. The proposed Office of Disability Inclusion would report to a Minister within Cabinet for Disability Inclusion.

## **Recommendations**

- That the NSW Government recognises that people with disability are equal citizens of NSW and have the right to have their full potential and contribution recognised and respected.

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<sup>82</sup> NDIA, 2018, *Quarter 4, 201702018* Report, available at: <https://www.ndis.gov.au/medias/documents/info-states-q4-y5/NDIS-infograph-states.pdf>

- That the NSW Government recognises their key role in providing access to mainstream and disability services for people with disability, to ensure they can participate equally in civic life
- That the office of the Minister for Disability Services becomes the Minister for Disability Inclusion
- That an office located with the Department of Premier and Cabinet is established with responsibility for:
  - implementation the NSW Disability Inclusion Plan across government
  - oversight and co-ordination of funding arrangements for the Disability Inclusion Action Plans
  - co-ordinating and reporting on progress under the legislation, COAG agreements and state-wide disability strategies and plans
  - leading inter-jurisdictional negotiations in relation to the improvements to the NDIS, NDA and NDS
  - recurrent funding and resourcing for representative peak organisations of people with disability and independent advocacy non-government organisations to ensure that the voice of people with disability is represented.
- That the NSW Government develops a clear resourcing strategy to enable the implementation of the State Disability Inclusion Plan
- That the NSW Government provides clear funding streams and reporting obligations for the implementation of Disability Inclusion Action Plans
- That the NSW Government provides an annual report that demonstrates progress made for inclusion of people with disability, so that NSW can meet and substantiate how it is the State of Inclusion<sup>83</sup>
- That the NSW Government examines and addresses barriers to implementation that may arise.

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<sup>83</sup> NSW Government, 2017, NSW Disability Inclusion Plan Update 2017, page 14.  
<https://www.parliament.nsw.gov.au/la/papers/DBAssets/tabledpaper/webAttachments/73353/Disability%20Inclusion%20Plan%20Update%202017.pdf>



**PEOPLE WITH DISABILITY  
AUSTRALIA**

For individual advocacy support contact the **Disability Rights Information Service (DRIS)** between 9:00 am and 5:00 pm (AEST) Monday to Friday on (02) 9370 3100 or Toll Free on **1800 422 015** or TTY Toll Free on **1800 422 016** or email [dris@pwd.org.au](mailto:dris@pwd.org.au)

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