

# Framing the big picture for Australians with disability

**Submission to the Productivity Commission's review of the National Disability Agreement** 

7 September 2018



#### **About VCOSS**

The Victorian Council of Social Service (VCOSS) is the peak body of the social and community sector in Victoria. VCOSS members reflect the diversity of the sector and include large charities, peak organisations, small community services, advocacy groups, and individuals interested in social policy. In addition to supporting the sector, VCOSS represents the interests of vulnerable and disadvantaged Victorians in policy debates and advocates for the development of a sustainable, fair and equitable society.

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VCOSS acknowledges the traditional owners of country and pays its respects to Elders past and present.

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## **Abbreviations**

CALD Culturally and Linguistically Diverse

COAG Council of Australian Governments

LACs Local Area Coordinators

NDA National Disability Agreement

NDIS National Disability Insurance Scheme

NDS National Disability Strategy

SPP Specific Purpose Payments

VCOSS Victorian Council of Social Service

## Introduction

The Victorian Council of Social Service (VCOSS) welcomes the opportunity to provide a submission to the Productivity Commission's review of the National Disability Agreement (NDA).

VCOSS is the peak body for Victoria's social and community services. VCOSS members reflect the diversity of the sector and include large charities, peak organisations, small community services, advocacy groups and individuals interested in social policy. In addition to supporting the sector, VCOSS represents the interests of vulnerable and disadvantaged Victorians in policy debates and advocates for the development of a sustainable, fair and equitable society.

The Productivity Commission's review is occurring in the context of significant changes to the policy and service delivery environments for people with disability. Access to specialist supports meets specific needs of people with disability so they are able to participate fully in life. While the National Disability Insurance Scheme (NDIS) has brought opportunity and the chance for greater choice and control over services for many people with disability, a range of gaps exist between the NDIS and state-funded services, and for people with disability who are not NDIS participants.

Funding for many existing state and federal programs is being 'rolled into' the NDIS, leaving few services available for people who do not qualify for an individual package. By the time the NDIS is fully rolled out, approximately 105,000 Victorians are expected to be part of the scheme, leaving around one million Victorians with disability who will require support outside the NDIS. A similar situation exists in other states and territories. In particular, emerging and anticipated service gaps exist for mental health consumers, people aged 65 or over, and carers.

People with disability, their families and carers should receive high quality services that meet their needs, regardless of their eligibility for NDIS packages. Without adequate support, people's physical and mental health is at risk, and this will likely increase pressure on other health and social services, including the acute health, welfare and justice systems, at potentially greater cost. Inadequate support for people with disability may also increase reliance on family and carers.

As agreed in the National Disability Strategy 2010-2020 (NDS), ensuring "the broader community and mainstream services and facilities that are part of ordinary Australian life [are] available and fully accessible for people with disability" is a responsibility of all governments.<sup>2</sup> While the NDIS provides disability-related supports for some people with disability, the Australian Government and state and territory governments remain responsible for providing an inclusive and adequately

<sup>2</sup> Commonwealth of Australia, *National Disability Strategy 2010-2020*, an initiative of the Council of Australian Governments, 2011, p.13.

<sup>&</sup>lt;sup>1</sup> NDIA, NDIS Victoria roll out: Participant Information Pack, 2015.

funded mainstream service system, so people with disability and their carers – including those who are not eligible for the NDIS – can access services to achieve meaningful, flourishing lives in the community.

Given the changing policy landscape with the introduction of the NDIS and NDS since the NDA commenced in 2009, VCOSS supports the need for an updated high-level cross-jurisdictional national disability agreement and greater clarity around the roles and responsibilities of different tiers of government.

There remains confusion between states and territories, and the Australian Government, about the ongoing roles and responsibilities of each jurisdiction. Governments must resolve demarcation issues and continue to fund services for all people with disability, and the supports they need to participate fully in life.

Establishing a national agreement with clear objectives, outcomes, outputs and performance indicators – and articulating the roles and responsibilities of different tiers of government – can help guide the delivery of services and supports to people with disability. The new agreement should reflect Australia's obligations under human rights treaties to recognise people with disability have agency, promote self-determination and maximise choice and control.

This new agreement should articulate funding responsibilities of each tier of government. VCOSS members are particularly concerned that at full scheme, existing National Specific Purpose Payments (SPP) to states and territories will be redirected to the NDIS. This may compromise states and territory capacity to support continuing access to services, demonstrated by the withdrawal of funding for services.

VCOSS members recommend adopting a co-design process to develop new NDA objectives, outcomes, outputs and performance indicators. In the absence of further consultation and co-design, outputs should be clarified, strengthened, and clearly linked to performance indicators to promote measurability, accountability and stimulate further policy development to achieve the outcomes to which governments are committed. Better data collection will also help support measurement of the effectiveness of the agreement, alongside improved performance indicators and benchmarks.

## Recommendations

## Support strong services for people with disability

#### Provide continuity of care

- Report on boundary issues at regular COAG meetings, to identify and address service gaps.
- Develop and embed protocols and training for service collaboration to provide integrated support for NDIS participants.
- Avoid gaps in health service delivery

#### Avoid gaps in health service delivery

- A revised NDA should outline governments' responsibilities to provide smooth transitions between the disability and health service systems. This includes:
  - Undertaking and publishing rigorous mapping to identify gaps in disability and mainstream health services during the roll-out of the NDIS
  - Providing transition funding for health services to continue delivering services to people with disability until interface arrangements are resolved
  - Working with health services to establish protocols and guidelines for good interface practice with the NDIS
  - Adequately resourcing community mental health services outside the NDIS to support those ineligible for individual funding packages

#### **Guarantee quality crisis response services**

- Ensure quality crisis response services are available for people with disability, whether or not they are NDIS participants.
- Governments should work with the NDIA to clarify responsibilities for the provision of crisis response services urgently, including provider of last resort arrangements.

#### Make the child protection system work for people with disability

- Clearly define responsibilities between child protection systems and the NDIS.
- Develop a multilateral agreement for joint provision of support for children with disability who cannot live in the family home.

#### Develop smoother transitions for people in the justice system

- Map disability care pathways for NDIS participants moving between the community and the justice system.
- The revised NDA should articulate the roles and responsibilities to support people with disability in their contact with the justice system

#### Build education systems for students with a disability

 Clarify roles and responsibilities of the NDIS and state and territory education systems so students with disability have access to the supports they need and have the same educational opportunities as others.

#### Provide appropriate services for carers

- Include carers in the NDA.
- The NDA should outline responsibilities of governments, services and the NDIS for provision of carer support services.
- Ensure carers are well supported by policy architecture and implementation to address and identify their own needs.

#### Deliver culturally safe and gender responsive services

- Ensure a revised NDA recognises and addresses the need for culturally safe, gender responsive planning and service delivery, including:
  - o Funding and working with existing services which have rapport with local communities
  - Resourcing Aboriginal community controlled organisations to provide disability services to the community.

### **Towards a new Agreement**

#### **Support effective National Agreements**

• Develop a high-level, cross-jurisdictional NDA that is human rights focussed and supports the needs of all people with disability.

#### Clarify governments' roles and responsibilities

• Clarify ongoing roles and responsibilities of each tier of government, including for funding.

#### Reflect changes in the policy and service landscape

• Implement a co-design process for the development of the new NDA's objective, outcomes, outputs and performance indicators.

#### **Revisit the NDA vision**

• Revise the NDA's objective to better reflect and support the delivery of inclusive service systems and human rights obligations, with a focus on achievability rather than aspiration.

#### **Update the NDA outcomes**

- Update the current NDA outcomes in line with the principles of the NDIS and NDS.
- Clarify the meaning of economic participation, and recognise the valuable contribution of volunteer work as an input into the economy and form of participation.
- Retain outcomes 2 and 3.

#### Use data to support performance and improve accountability

Improve accountability through better data collection and reporting of future NDAs.

#### **Develop new performance indicators and benchmarks**

- Introduce new overarching and operational performance indicators.
- Retain the breakdown of performance indicators into subgroups, such as Indigenous people, CALD, and other people facing additional disadvantage.
- Revise existing performance benchmarks.

#### **Ensure greater accountability**

- Require the Australian Government and states and territories to prepare Implementation Plans or alternative mechanisms that are attached to National Agreements.
- Consider mechanisms for supporting the independent review of performance agreements to promote greater accountability and improve public confidence.

# Support strong services for people with disability

Problems with the specialist disability support system are being magnified by the pace and scale of change through the NDIS roll-out. Challenges include access, planning and plan reviews, and a lack of clarity and emerging gaps at the 'interface' of the NDIS and other service systems, including health, crisis response, child protection, transport, justice, education and carer support. These are particularly significant for people with complex support requirements, who are ineligible for the NDIS, or who have difficulty engaging with services.<sup>3</sup>

A revised NDA should assign clear roles and responsibilities to different levels of government to support accountability for meeting the needs of all people with disability, including people not eligible for the NDIS. By more clearly articulating responsibilities, the relevant government or agency can be made accountable for responding to gaps in service provision. VCOSS recommends that the Australian Government act as a system steward and manager, so Australians with disability and their carers are able to access the services that they need.

## **Provide continuity of care**

#### Recommendations

- Report on boundary issues at regular COAG meetings, to identify and address service gaps.
- Develop and embed protocols and training for service collaboration to provide integrated support for NDIS participants.

Governments have promised 'continuity of care' for people with disability and their carers during the transition to the NDIS, however large service gaps are emerging, and lack of certainty around funding is creating distress for people and organisations. VCOSS and our members are concerned about the type and level of support remaining for many people with disability during and after the NDIS transition.

<sup>&</sup>lt;sup>3</sup> Centre for Community Child Health, <u>Engaging Marginalised and Vulnerable Families</u>, Policy Brief No 18, The Royal Children's Hospital, 2010.

Even when all service systems meet their obligations, the multiple different systems can create fragmented experiences for people. VCOSS members report many NDIS participants find it challenging to navigate different service systems to meet all their needs.

"Participants also expressed frustration with system boundaries that limited the ways in which support and resources from different systems could be accessed and integrated to achieve optimal outcomes for people living with disabilities"<sup>4</sup>

VCOSS members are concerned service gaps are being created between NDIS and other mainstream services. The 'principles to determine the responsibilities of the NDIS and other service systems' (the Principles) agreed by the Council of Australian Governments (COAG) provide some clarity about funding responsibility across 11 areas.<sup>5</sup> However, in some circumstances, funding arrangements are still unclear given the complex nature of the supports required, such as when participants have interrelated health and disability issues and other comorbidities. In other cases, the distinction between funding responsibilities is clear but remains problematic because mainstream service systems are not meeting their obligations to support people with disability. The NDIA's position is "if another system is responsible for support, the NDIS cannot fund that support, even if the system responsible does not provide it."<sup>6</sup> This is obviously deeply distressing for people with disability, leaving them without necessary support from either system.

The Australian Government and state and territory governments have a joint responsibility to identify service gaps and to take action to address them, so NDIS participants are not stuck in the gaps. A revised NDA provides a timely opportunity for governments to clarify and commit to their respective roles and responsibilities.

## Avoid gaps in health service delivery

#### Recommendation

A revised NDA should outline governments' responsibilities to provide smooth transitions between the disability and health service systems. This includes:

- Undertaking and publishing rigorous mapping to identify gaps in disability and mainstream health services during the roll-out of the NDIS
- Providing transition funding for health services to continue delivering services to people with disability until interface arrangements are resolved
- Working with health services to establish protocols and guidelines for good interface practice with the NDIS
- Adequately resourcing community mental health services outside the NDIS to support those ineligible for individual funding packages

<sup>&</sup>lt;sup>4</sup> D Warr, H Dickinson, S Olney et. Al. Choice, Control and the NDIS, Melbourne, University of Melbourne, 2017, p.54

<sup>&</sup>lt;sup>5</sup> COAG, <u>Principles to determine the responsibilities of the NDIS and other service systems</u>, November 2015.

<sup>&</sup>lt;sup>6</sup> NDIA, The NDIS and mainstream interfaces How the NDIS works with other mainstream systems, January 2014.

People with disability can experience complex health needs related to their disability, and the boundary between health- and disability-related needs can be blurry.

Too often, people with disability describe cracks in the interface between the NDIS and health services; neither part of the system accepts responsibility for providing a particular service or support, leaving the person stuck without the help they need. For example, in-home nursing support, discharge planning, rehabilitation support and medication are all areas where the division of responsibilities is at times unclear or problematic.

There are also gaps emerging for people who are ineligible for the NDIS, including people with some chronic illnesses. Some previously available services and supports for this group, like nursing care, are no longer taking new clients or are not available outside of the NDIS.

VCOSS understands the Victorian Government is closely monitoring and mapping the service system through the transition to the NDIS, and expects other state and territory governments are doing the same. Publishing this information will help inspire community confidence, in line with the Productivity Commission's recommendations.<sup>7</sup> This will also garner attention and help problem-solving for affected communities, including by identifying the appropriate level of government to provide resources.

Robust data collection could identify emerging gaps in service provision, and establish the need for interim measures until problems are resolved. VCOSS believes that governments should fund a transition package for health services to continue providing services to people with disability until the interface arrangements between the NDIS and state and territory health systems are resolved.

Governments could also continue to work with hospitals and health services to support and encourage good interface practice with the NDIS, including by developing protocols and guidelines.

Victoria has a history of strong community mental health services, and has long provided treatment, support and rehabilitation services for people with serious mental illness, to help them manage their illness and build life skills. However, because Victoria allocated all its community-based mental health services funding to the NDIS, people that were deemed ineligible for the NDIS are now missing out on services.

The revision of the NDA can address the gaps that people with psychosocial disabilities are experiencing in service delivery. VCOSS believes that service mapping could identify gaps in service delivery for people with psychosocial disabilities.

NDIS individual funding packages are targeted at people with severe and permanent psychosocial disability resulting from their mental health conditions, but a large number of mental health consumers and their carers do not meet the eligibility criteria. These people continue to require

<sup>&</sup>lt;sup>7</sup> Productivity Commission, National Disability Insurance Scheme (NDIS) Costs: Study report, 2017, Recommendation 6.2.

support, but are being denied NDIS packages because they fail to meet the requirements of a 'permanent' diagnosis, or are unable to present the right evidence from doctors and specialists.<sup>8</sup> The NDIS application and review process are complex, time consuming, and can negatively impact people's mental health.

Victoria's community-based mental health services need to be funded independently of the NDIS, alongside clinical and acute mental health treatment services. Flexible services should continue to provide for people with mental illness and psychosocial disability who do not meet the eligibility for individual funding packages. This is a joint Australian and state government responsibility. Without adequate support, people with mental health conditions' recovery and mental wellbeing is at risk, and it increases pressure on other health and social services, including acute health, welfare and justice systems. Inadequate support increases reliance on family and carers.

## **Guarantee quality crisis response services**

#### Recommendations

- Ensure quality crisis response services are available for people with disability, whether or not they are NDIS participants.
- Governments should work with the NDIA to clarify responsibilities for the provision of crisis response services urgently, including provider of last resort arrangements.

Crisis response services, including 'provider of last resort' arrangements, are currently not being provided through the NDIS transition. At the moment, if a crisis happens in the life of an NDIS participant (such as a criminal incident, mental health crisis or family emergency), service providers can withdraw services if they choose, and there is no clear responsibility for government or the NDIS to fill the gap. This has led to people being kept for long periods of time in inappropriate settings, such as hospitals and prisons, because they have nowhere else to go.<sup>9,10</sup>

#### CASE STUDY

Andrea is in prison for minor charges but she has been on remand for 16 months. Most of this time has been spent in a specialist mental health unit.

Numerous clinical assessments and diagnostic discussions have been held between professionals in regard to Andrea and her ongoing complex presentation. She has a diagnosis of pervasive developmental disorder. A jury has found her unfit to stand trial.

<sup>&</sup>lt;sup>8</sup> The University of Sydney and Community Mental Health Australia, Mind the Gap: the NDIS and psychosocial disability; Final Report: Stakeholder identified gaps and solutions, January 2018.

<sup>&</sup>lt;sup>9</sup> Victoria Legal Aid, Clients and market failure by the NDIS, webpage, 9 November 2017.

<sup>&</sup>lt;sup>10</sup> R Morton, 'NDIS abandons disabled to state hospitals', The Australian, 16 January 2018.

Despite numerous assessments, Andrea remained in custody because no effective discharge accommodation could be found.

With the NDIS rollout, Andrea became eligible for the NDIS and was accepted as a participant. This opened up some new possibilities, however, there are significant limitations on what can be funded by the NDIS when a participant is in prison.

Andrea's guardian experienced significant difficulty in engaging NDIA personnel and was unable to persuade NDIA staff to attend any of her case conferences.

This is despite the fact that it is the NDIS which will be required to fund accommodation and support services for Andrea on release and it is only the development of these arrangements which will facilitate her release.

However, a support coordinator and service provider willing to work with Andrea and funded through the NDIS were found. The various agencies involved have now pulled together a support plan that is consistent with the reasonable and necessary adjustments required by the NDIS.

The plan is now awaiting approval by the NDIA and, until then, it cannot be implemented and Andrea must remain in prison. 11

The Victorian Government has recognised the priority need for appropriate crisis response services for people with disability and to clarify these arrangements. 12 COAG should work with the NDIA to urgently clarify responsibilities for the provision of crisis response services, including provider of last resort arrangements. A revised NDA would provide a good opportunity to articulate these responsibilities and arrangements.

The lack of appropriate crisis response is also a concern for people who are not NDIS participants, as available services are increasingly patchy and a poor response risks re-traumatising people and may affect their support-seeking behaviour in the future. Governments must ensure appropriate crisis response services are available for all people with disability when and where they need them, regardless of whether they are NDIS participants.

<sup>&</sup>lt;sup>11</sup> Case study from OPA's Annual Report 2016-17, p.26.

<sup>&</sup>lt;sup>12</sup> Victorian Government, Submission to the Joint Standing Committee on the NDIS: Inquiry into Market Readiness, 2018.

# Make the child protection system work for people with disability

#### Recommendations

Recommendation 21

- Clearly define responsibilities between child protection systems and the NDIS.
- Develop a multilateral agreement for joint provision of support for children with disability who cannot live in the family home.

Challenges for families are increasing through the NDIS implementation. Advocates and organisations report increasing stress on families of children with disability, inadequate planning and support, and lack of clarity around the responsibilities of the NDIA and state systems.

In one example, a Victorian family was unable to secure ongoing services for their six year old daughter, who had an NDIS package, because providers were unable to deliver appropriate supports under the NDIS pricing framework.<sup>13</sup> Currently a not-for-profit provider is working at a loss to provide supports, but the family recognises this is unsustainable. When they approached the NDIA about the evident market failure, they were advised to speak to child protection.

The NDIS will only provide support for children, families and carers directly related to a child's or parent's disability,<sup>14</sup> but for some families the situation is more complex, and the right support for the family – not just an individual within the family – could help them to remain safely together and reduce the risk of entering the child protection system. Greater clarity is urgently required around the roles and responsibilities of different systems, to provide appropriate support for families at risk of entering the child protection system, and to avoid situations where parents are being asked to relinquish their children, or where this is seen as the only option.

Governments should also work with the NDIA to clarify and communicate responsibilities, including for children with disability who are not able to live in the family home. One option would be to establish protocols between child protection systems and the NDIS, such as used to exist in Victoria between child protection and disability services. This should include 'explicit statements around the roles and responsibilities of the different service agencies'. <sup>15</sup> Provisions should also be included for appropriate support for children who have specialist support needs but are not NDIS participants.

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<sup>&</sup>lt;sup>13</sup> Victoria Legal Aid, *Submission on Market Readiness to the Joint Standing Committee on the National Disability Insurance Scheme*, 16 March 2018. Available at <a href="https://www.legalaid.vic.gov.au/sites/www.legalaid.vic.gov.au/files/vla-submission-to-joint-standing-committee-on-the-national-disability-insurance-scheme.docx">https://www.legalaid.vic.gov.au/sites/www.legalaid.vic.gov.au/files/vla-submission-to-joint-standing-committee-on-the-national-disability-insurance-scheme.docx</a>, accessed 23 May 2018.

<sup>&</sup>lt;sup>14</sup> COAG, <u>Principles to determine the responsibilities of the NDIS and other service systems</u>, November 2015.

<sup>15</sup> P Cummins, D Scott and B Scales, <u>Report of the Protecting Victoria's Vulnerable Children Inquiry</u>, Volume 1, 2012,

The Australian and New South Wales Governments have recently reached an agreement for joint provision of support for children with disability who are not able to live in the family home. <sup>16</sup> A similar agreement could be pursued in other states and territories.

## Develop smoother transitions for people in the justice system

#### Recommendations

- Map disability care pathways for NDIS participants moving between the community and the justice system.
- The revised NDA should articulate the roles and responsibilities to support people with disability in their contact with the justice system

Effective and equal access to justice is a human right for people with disability, who are more likely than others both to experience legal problems and to be victims of crime. Too often people with disability end up in the justice system because other systems fail to provide appropriate support.

People with disability are over-represented in the criminal justice system at all points of the process, and particularly in detention. One study found that one third of women and over 40 per cent of men in Victorian prisons have an acquired brain injury, compared with 2 per cent of the general population,<sup>17</sup> and mental health conditions are also prevalent.<sup>18</sup>

A recent Human Rights Watch report showed that prisoners with disability, including Aboriginal and Torres Strait Islander prisoners, are at serious risk of bullying, harassment, violence, and abuse from fellow prisoners and staff. In particular, prisoners with psychosocial disabilities or cognitive disabilities can spend days, weeks, months, and sometimes even years locked up alone in detention or safety units.<sup>19</sup>

The COAG principles indicate the NDIS will support people involved in the criminal justice system in the community, but will not provide supports upon entering prison, whether on remand or during a custodial sentence.<sup>20</sup> This creates a lack of service continuity for people in the justice system, particularly given the limited supports available for people with disability in the justice system. Disrupted care may compromise their health and wellbeing and increase their chance of reoffending.<sup>21</sup>

A revised NDA could assign roles and responsibilities between governments, NDIS, the justice system and services in the community. VCOSS believes that at a system level, governments can map disability care pathways for NDIS participants moving from the community to the justice

<sup>&</sup>lt;sup>16</sup> The Hon Dan Tehan MP, <u>Supporting out of home care for children with severe disability</u>, media release, 8 May 2018.

<sup>&</sup>lt;sup>17</sup> Department of Justice, <u>Acquired Brain Injury in the Victorian Prison System</u>, Corrections Victoria Research Paper Series, Paper No. 04, 2011.

<sup>&</sup>lt;sup>18</sup> Victorian Ombudsman, *Investigation into deaths and harm in custody*, 2014.

<sup>&</sup>lt;sup>19</sup> Human Rights Watch, "I Needed Help, Instead I Was Punished": Abuse and Neglect of Prisoners with Disabilities in Australia, February 2018.

<sup>&</sup>lt;sup>20</sup> COAG, <u>Principles to determine the responsibilities of the NDIS and other service systems</u>, November 2015, p.21.

<sup>&</sup>lt;sup>21</sup> J Young and S Kinner, *Prisoners are excluded from the NDIS – here's why it matters*, the Conversation, 14 March 2017.

system, and back into the community. This would allow for the identification of gaps in service delivery, and provide opportunities for the players to agree on roles and responsibilities.

## Build education systems for students with a disability

#### Recommendations

 Clarify roles and responsibilities of the NDIS and state and territory education systems so students with disability have access to the supports they need and have the same educational opportunities as others.

COAG principles stipulate Education Departments and schools are responsible for providing supports primarily related to a student's educational attainment.<sup>22</sup> However, education systems and schools are not meeting the needs of all children and young people with disability and there is a lack of clarity around which components are covered by the NDIS.

For example, VCOSS members report cases of students with complex communication needs enduring their entire schooling without any means of functional communication, such as access to equipment, or speech therapists with expertise in specialist communication methods.

Interface issues also extend to situations when funding is available. For example, VCOSS members report examples of schools not allowing therapists funded by the NDIS to enter classrooms or school grounds. This is supported by early findings from the recent Melbourne University study of participants' experiences with the NDIS.<sup>23</sup>

## Provide appropriate services for carers

#### Recommendations

- Include carers in the NDA.
- The NDA should outline responsibilities of governments, services and the NDIS for provision of carer support services.
- Ensure carers are well supported by policy architecture and implementation to address and identify their own needs.

Carers include parents or siblings who care for people with disability, and people supporting their ageing parents. More than 770,000 Victorians are unpaid carers,<sup>24</sup> 31 per cent of whom report living with a disability themselves.<sup>25</sup> Recent estimates indicate almost two billion hours of care

<sup>&</sup>lt;sup>22</sup> COAG, <u>Principles to determine the responsibilities of the NDIS and other service systems</u>, November 2015, p.12.

<sup>&</sup>lt;sup>23</sup> D Warr, H Dickinson, S Olney et. Al. Choice, Control and the NDIS, Melbourne, University of Melbourne, 2017, p.40

<sup>&</sup>lt;sup>24</sup> Carers Victoria, <u>Take Action for Victorian Carers: Pre-Budget Submission 2016-17</u>, 2017.

<sup>&</sup>lt;sup>25</sup> ABS, *Disability, Ageing and Carers, Australia: Victoria, 2015*, Catalogue #4430.0.

were provided in 2015 alone nationally, and it would cost more than \$60 billion per year to replace this with paid services and supports.<sup>26</sup>

At the service level, all carers must have access to appropriate levels of carer specific support and services to address and identify their own needs, irrespective of whether the person they care for is eligible for an NDIS individual funding package. This includes access to general carer support, carer advocacy, counselling, and carer respite services.

VCOSS members raise concerns at inadequate support for carers of people both eligible and ineligible for NDIS. In particular, our members report significant shortfalls in available respite care. Funds from existing carer support services such as the Mental Health Respite: Carer Supports are being redirected to the NDIS, raising questions whether services will remain for carers of people ineligible for the NDIS. Organisations also report situations where support groups have stopped because of the discontinuation of block funding for services.

VCOSS members report reduced support is being provided even for carers of people deemed eligible for the scheme. The NDIS planning process does not assess carers' needs and the supports listed in plans, including respite, are framed largely from the participant's perspective. The NDIS interim evaluation has found support for carers, both inside and outside the NDIS, has reduced since the introduction of the NDIS.<sup>27</sup>

The NDA should acknowledge carers' roles and rights as citizens. During consultations we have heard that 'carers can get lost in these policy documents'. VCOSS members support the inclusion of carers in the NDA and advocate for the mapping and identification of gaps in services for carers be included in a revised NDA. This would help to provide a picture of the current service environment for carers – in the context of the development and introduction of the Integrated Carer Support Service<sup>28</sup> – and may help to provide evidence to show whether changes are needed with regards to funding direction or roles and responsibilities of governments, services, and the NDIS.

## Deliver culturally safe and gender responsive services

#### Recommendations

Ensure a revised NDA recognises and addresses the need for culturally safe, gender responsive planning and service delivery, including:

- Funding and working with existing services which have rapport with local communities
- Resourcing Aboriginal community controlled organisations to provide disability services to the community.

Deloitte Access Economics, <u>The economic value of informal care in Australia in 2015</u>, commissioned by Carers Australia, 2015, p.iii.
 K Mavromaras, M Moskos, S Mahuteau, <u>Evaluation of the NDIS</u>, <u>Intermediate Report</u>, National Institute of Labour Studies, Flinders University, Adelaide, September 2016, p.xvii.

<sup>&</sup>lt;sup>28</sup> Australian Department of Social Services, ICSS: Regional Delivery Model – Discussion paper, 2018.

People from culturally and linguistically diverse backgrounds (CALD) and Aboriginal and Torres Strait Islander communities face additional barriers accessing services, including the NDIS and other disability services. For example, they may have low levels of English literacy, lack awareness or understanding about the NDIS and how to navigate the system, or may have been reluctant to access services due to cultural attitudes and stigma towards disability and mental health. <sup>29,30,31,32</sup>

VCOSS members working with Aboriginal people identified service inflexibility as a significant problem. Providing culturally safe service planning and service delivery, which uses appropriate concepts and language around mental health and disability inclusive practice, such as being open to working with carers or extended family, could help engage people from Aboriginal and CALD communities.

A revised NDA must help develop culturally safe and gender-responsive services. This could include employing Aboriginal and CALD workers in NDIS roles and delivering comprehensive cultural competency training to Local Area Coordinators (LACs) and other service staff to help improve the cultural safety of services. Ensuring services are gender responsive will also help the NDIS and broader mental health system to be accessible to all members of the community. Providing accessible and culturally appropriate information in different languages and through trusted sources, such as Aboriginal community controlled organisations and CALD-specific organisations, can also help raise the community awareness of the NDIS and mental health support services.

<sup>&</sup>lt;sup>29</sup> Ethnic Communities Council of Victoria, *Talking Disability; under-representation of culturally diverse communities in disability support*, 2014.

<sup>&</sup>lt;sup>30</sup> First Peoples Disability Network, <u>Ten-point plan for the implementation of the NDIS in Aboriginal and Torres Strait</u> <u>Islander Communities</u>.

<sup>&</sup>lt;sup>31</sup> J Barney, "Listen Up" Aboriginal & Torres Strait Islander people with disabilities living in Victorian yarns: Discussion on the Victorian State Disability Plans Discussion Paper 2017-20, Victorian Council of Social Service, June 2016.

<sup>32</sup> Federation of Ethnic Communities' Councils of Australia, Access and Equity in the Context of the National Disability Insurance Scheme, June 2015.

## **Towards a new Agreement**

## **Support effective National Agreements**

#### Recommendation

• Develop a high-level, cross-jurisdictional NDA that is human rights focussed and supports the needs of all people with disability.

National Agreements are most useful when they set out clear objectives, outcomes, outputs and performance indicators – and articulate the roles and responsibilities of different tiers of government to guide the delivery of services in a sector.<sup>33</sup>

Securing social policy goals requires a nationally coordinated approach to be effective so the different tiers of government work collectively to achieve nationally important reforms.

#### **Effective National Agreements:**

- develop coordinated action improving people's wellbeing, irrespective of where they live
- improve the lives of people experiencing disadvantage through targeted assistance and improved service delivery
- can provide targeted financial support to state and territory governments and can alleviate increased costs to state and territory governments associated with Australian Government policy changes
- improve the quality and consistency of service delivery for those facing poverty and disadvantage, and for the general population.

VCOSS and our members believe the NDA should be a high-level cross-jurisdictional agreement. It should be re-shaped to reflect the changing policy context and implementation of the NDIS and NDS. The NDA also provides clarity on the obligations governments have under the Convention on the Rights of Persons with Disability.<sup>34</sup>

A revised NDA provides an opportunity to clarify the roles and responsibilities of different tiers of government and ensure that there is an ongoing commitment to providing services for *all* people

<sup>&</sup>lt;sup>33</sup> Australian Government, <u>A Short Guide to the IGA and the federal financial relations framework</u>, 2016, p.3.

<sup>&</sup>lt;sup>34</sup> https://www.humanrights.gov.au/news/speeches/convention-rights-persons-disabilities

with disability, particularly given the large proportion of people with disability who will not be eligible for the NDIS.<sup>35</sup>

This review also presents an opportunity to promote greater accountability, and clarify ongoing funding arrangements between states and territories and the Australian Government for the provision of disability services. While we note that when it reaches full scheme, existing National Specific Purpose Payments (SPP) to states and territories will be redirected to the NDIS, we are concerned about how this will affect access to support and services for people with disability who are ineligible for the NDIS. In particular, we are concerned about the cost-shifting and demarcation issues that are occurring between states, territories and the Australian Government, and how this will affect eligibility and access to services.

As outlined above, significant gaps are emerging in service systems as funding and service delivery is transitioned to the NDIS – and there is considerable risk that people with disability, especially those experiencing mental illnesses, with complex needs, or over 65 years, will not be able to access all the services they need. Addressing these gaps will require urgent action by all governments and the NDIA.

## Clarify governments' roles and responsibilities

#### Recommendation

• Clarify ongoing roles and responsibilities of each tier of government, including for funding.

VCOSS strongly supports the need for greater clarification of the roles and responsibilities of state/territory and the Australian governments as identified by the Productivity Commission in its issues paper. The NDA provides a timely opportunity to do this. It can act as a high level policy framework setting out clear responsibilities and accountabilities for the Australian Government and states and territories, for *all* people with disability, not just NDIS participants.

In clarifying the roles and responsibilities of each tier of government, VCOSS members recommend the Productivity Commission consider the importance of:

Ensuring access to services and supports for people with disability who are not considered
to be eligible for the NDIS, including people with mental illnesses and people aged over 65
years, should be a priority. There is serious concern about the loss of various services resulting
from the transition to the NDIS, for example, psychosocial rehabilitation services in Victoria. As
well as providing appropriate disability services for all people with disability (whether or not they

<sup>35</sup> http://www.statedisabilityplan.vic.gov.au/application/files/2314/8062/9382/1610033 Victorian state disability plan 2017-2020 Text WEB.pdf p.3

are NDIS participants), the NDA could reinforce governments' commitment to improving access of people with disability to mainstream services, in line with the NDS.

- Implementing quality and safeguarding arrangements so there are high quality services for all people with disability and clear pathways for making complaints or reports. The NDA provides an opportunity to articulate the responsibilities of different governments clearly, and how these arrangements will interact. Clarification can ensure quality and safeguarding functions effectively transition from a state/territory responsibility, and are considered to be a national consideration under the NDIS for example, incorporating supported decision-making arrangements.
- **Providing continuity of care** for people with disability during the transition to the NDIS, as service systems are changing, and at full scheme.
- Addressing service gaps emerging through the NDIS transition, such as community mental health services, and access to disability services in regional and remote areas.
- Maintaining advocacy services for people with disability. Advocacy organisations are facing
  increasing workloads with the introduction of the NDIS, and cases are becoming more
  complex.<sup>36</sup> VCOSS members report that their staff are under considerable stress and risk
  burning out. Regional and rural areas are particularly under-serviced.
- **Implementing Australia's obligations** under the Convention on the Rights of Persons with Disabilities.

## Reflect changes in the policy and service landscape

#### Recommendation

• Implement a co-design process for the development of the new NDA's objective, outcomes, outputs and performance indicators.

VCOSS and its members strongly consider that the vision and contents of a revised NDA should be developed through a co-design process with people with disability and carers. This would allow the diverse experiences and knowledge of people with disability across Australia – and their experiences of disability service systems and transitions between other services – to shape the policy framework and decisions that will affect them.

"Co-design involves coming alongside people who experience vulnerabilities, to work with them in creating interventions, services and programs which will work in the context of their lives, and will reflect their own values and goals...

<sup>&</sup>lt;sup>36</sup> DARU, <u>Disability Advocacy by the Numbers:</u> Statistics from July 2012 to June 2016 from the Victorian Office for Disability Advocacy Program Quarterly Data Collection, August 2017.

... Co-design begins with the people – their experiences, perspectives, values, challenges and understandings."<sup>37</sup>

In the absence of a co-design approach, VCOSS members have provided feedback on the current objective, outcomes, outputs and performance measurement framework in the NDA. We outline our recommendations for strengthening these below.

#### Revisit the NDA vision

#### Recommendation

 Revise the NDA's objective to better reflect and support the delivery of inclusive service systems and human rights obligations, with a focus on achievability rather than aspiration.

VCOSS notes that the objective of the current NDA is a "long-term, overarching aspiration that governments should strive for in the provision of disability services" and states:

"People with disability and their carers have an enhanced quality of life and participate as valued members of the community."

This objective should be revised to better reflect and support the delivery of inclusive service systems, with a focus on achievement rather than aspiration. The objective should reflect an understanding of the social model of disability, as articulated in the Convention on the Rights of Persons with Disabilities, whereby disability occurs when a person with an impairment interacts with a system or environment that is not inclusive and is filled with many barriers. The objective should be on removing barriers – in services and the community – for greater inclusion and should reflect Australia's human rights obligations.

A recent collaborative project with people with disability, advocates and organisations working across the disability community in Victoria envisages:

"an inclusive Victoria where people with disability have the same opportunities as other Victorians" 38

## **Update the NDA outcomes**

#### Recommendations

- Update the current NDA outcomes in line with the principles of the NDIS and NDS.
- Clarify the meaning of economic participation, and recognise the valuable contribution of volunteer work as an input into the economy and form of participation.
- Retain outcomes 2 and 3.

<sup>&</sup>lt;sup>37</sup> VCOSS, <u>Walk alongside: Co-designing social initiatives with people experiencing vulnerabilities</u>, July 2015, p.3.

<sup>&</sup>lt;sup>38</sup> VCOSS, Empowered Lives: Securing Change for Victorians with Disability, 2018.

Under the current Agreement, there are three outcomes:

- 1. People with disability achieve economic participation and social inclusion
- 2. People with disability enjoy choice, wellbeing and the opportunity to live as independently as possible; and
- 3. Families and carers are well supported.

Whilst VCOSS and our members broadly support the current NDA outcomes, in the absence of a co-design process to update the NDA, we recommend that the outcomes be updated in line with the principles of the NDIS and NDS, recognising these will be achieved through multiple service platforms.

The outcomes should reflect an understanding of the social model of disability, as discussed above. At the moment, Outcome 1 focuses on people with disability achieving economic participation – however we note that many people with disability face a range of structural barriers to securing and maintaining employment, leading to significant under-representation in the workforce.<sup>39</sup> Because of these barriers, many people rely on the Australian Government's social security system, which is insufficient and has not kept up with the cost of living, thereby effectively limiting their economic participation.<sup>40</sup> Additionally, in clarifying the meaning of economic participation, VCOSS would suggest that this should not solely focus on the opportunity to earn an income, but also recognise the valuable contribution of volunteer work as an input into the economy and form of participation.

To support families and carers, we believe the NDA should continue to recognise carers as stakeholders in their own right, and support them to address and identify their own needs. Unpaid carers continue to provide significant support to people with disability - many of whom are carers themselves. 41 This support underpins the service system, and significant costs would shift to government should carers no longer be able to perform their caring role.

## Strengthen the NDA outputs

#### Recommendation

Clarify and strengthen existing outputs and clearly link to performance indicators to promote measurability and accountability.

Under the current Agreement, there are four outputs:

- 1. Services that provide skills and supports to people with disability to enable them to live as independently as possible;
- 2. Services that assist people with disability to live in stable and sustainable living arrangements;

<sup>&</sup>lt;sup>39</sup> VCOSS, Empowered Lives: Securing Change for Victorians with Disability, 2018, p. 50.

<sup>&</sup>lt;sup>40</sup> Ibid.

<sup>&</sup>lt;sup>41</sup> Ibid, p.24.

- 3. Income support for people with disability and their carers; and
- 4. Services that assist families and carers in their caring role.

VCOSS and our members are broadly supportive of the intention of the current outputs, but would recommend that these be clarified and strengthened in a new agreement – with a clear link to performance indicators to promote measurability and accountability.

## Use data to support performance and improve accountability

#### Recommendation

Improve accountability through better data collection and reporting of future NDAs.

If we are to achieve the outcomes of a revised NDA and commit to improving the lives of all Australians with disability, performance must be monitored and governments made accountable where they have not achieved agreed performance targets. We note that the Australian Government can use funding as a lever for improving state and territory performance, and that while funding is being redirected into the NDIS, additional resources will be needed if we are to achieve the outcomes in the revised agreement and support the service needs of all people with disability.

VCOSS members are strongly of the view that there needs to be greater accountability and better data collection in order to measure the Agreement's effect. Data should be collected at the population level (e.g. surveying people with disability and carers) as well as at the provider level, to build a strong picture of the landscape and current service gaps. Data needs to be collected regularly enough that it is actually useful for governments, policy-makers, and the sector, and both qualitative and quantitative data should be collected.

One VCOSS member has suggested that the data collection processes through WorkSafe Victoria are an example of what can work well – where data collection is mandated, and information is returned back to service providers.

VCOSS is also concerned that the performance of the NDA has not been assessed and reported since 2016 (which relied on 2012 data)<sup>42</sup> thereby effectively limiting the Productivity Commission's ability to review the effectiveness of the Agreement and government's understanding of performance, as well as stakeholders' analysis of the success of the Agreement and their ability to effectively input into this review.

<sup>42</sup> Department of Prime Minister and Cabinet, Council of Australian Governments: Report on Performance 2016, March 2016, pp.19-21.

## **Develop new performance indicators and benchmarks**

#### Recommendations

- Introduce new overarching and operational performance indicators.
- Retain the breakdown of performance indicators into subgroups, such as Indigenous people, CALD, and other people facing additional disadvantage.
- Revise existing performance benchmarks.

VCOSS members are of the view that a new NDA should include both overarching and operational indicators. Data reported by the NDIA through its quarterly reports provides an example of operational indicators.

Under the current agreement, there are nine performance indicators including:

- 1. Proportion of people with disability participating in the labour force;
- 2. Proportion of people with disability who participate in social and community activities;
- 3. Proportion of income support recipients with disability who report earnings;
- 4. Proportion of people with disability accessing disability services;
- 5. Proportion of people with disability who are satisfied with the range of services available, and with the adequacy and quality of services provided;
- 6. Proportion of younger people entering, living in, and exiting, permanent residential aged care:
- 7. Proportion of carers of people with disability participating in the labour force;
- 8. Proportion of carers of people with disability who report their health and wellbeing as positive; and
- 9. Proportion of primary carers of people with disability who are satisfied with the range of services available, and with the adequacy and quality of services provided, to the person with disability and to the carer.

While there is some support for existing performance indicators, for example 7 and 8, VCOSS members have suggested that a number of the existing indicators should be changed, updated, clarified or broken into separate indicators (e.g. 5 and 9). For example, in relation to indicator 1, we note that this focuses solely on labour force participation, but it does not reflect the nature or quality of the employment, including pay. Additional indicators should also be considered, for example on promoting wellbeing outcomes. VCOSS supports the approach in the current agreement to break down performance of the indicators into subgroups, such as Aboriginal and Torres Strait Islander people, people from CALD communities and people facing additional disadvantage.

As discussed earlier, VCOSS' preference is for the revision of these indicators and other elements of the NDA to be undertaken through a co-design process.

Under the current agreement, there are three benchmarks including:

- Outcome A: People with disability achieve economic participation and social inclusion Between 2009 and 2018, there will be a five percentage point national increase in the proportion of people with disability participating in the labour force.
- Outcome B: People with disability enjoy choice, wellbeing and the opportunity to live as independently as possible
   Between 2009 and 2018, there will be a five percentage point national decrease in the proportion of people with disability who report a need for more formal assistance.
- Outcome C: Families and Carers are well supported

  The Parties agree that further work will be undertaken to develop a benchmark with a
  quantifiable target for Outcome C following the Standing Council on Federal Financial
  Relations' review of funding adequacy in 2013.

VCOSS members expressed some concerns about the performance benchmarks relating to Outcomes A and B. Noting earlier comments about measuring labour force participation and whether this includes people volunteering, and the structural barriers to employment, VCOSS is concerned about whether these measures are an appropriate benchmark as a tool of assessing the success of the Agreement. VCOSS would also suggest that Outcome B should be revised in light of the NDIS and NDS. Additionally, an appropriate benchmark for Outcome C should be determined in consultation with stakeholders.

VCOSS and our members would be keen to participate in a co-design process to inform the development of new indicators and new benchmarks.

## Ensure greater accountability

#### Recommendations

- Require the Australian Government and states and territories to prepare Implementation Plans or alternative mechanisms that are attached to National Agreements.
- Consider mechanisms for supporting the independent review of performance agreements to promote greater accountability and improve public confidence.

Ensuring greater transparency and accountability for governments to achieve the outcomes, outputs and benchmarks in National Agreements is a challenge for all intergovernmental agreements. To help resolve this problem, clearer outcomes and more achievable and measurable benchmarks are needed.

National Partnership Agreements often have subsidiary Implementation Plans, which help outline what each jurisdiction will do and provide a roadmap for policy action and funding. This or another mechanism could be considered as a vehicle of promoting increased accountability for

jurisdictions, supporting new policy development and highlighting the need for additional or reprioritisation of funding to achieve the agreed outcomes.

In the case of the NDA, VCOSS members are concerned that annual reporting has not occurred for a number of years and that this reduces confidence in the effectiveness of National Agreements to achieve the outcomes to which the Australian Government and states/territories have committed. An option would be for an independent agency, such as the Productivity Commission or the Auditor-General's office, to be given responsibility to independently review the performance of the NDA, as a mechanism to promote greater accountability and improve public trust and confidence.

Another approach the Productivity Commission could consider is that taken by the Victorian Government around its State Disability Plan – where annual reports against the indicators are tabled in Parliament and targeted benchmarks offer an additional vehicle to promote accountability.<sup>43</sup>

<sup>&</sup>lt;sup>43</sup> Victorian Government, <u>Absolutely everyone: state disability plan annual report 2017</u>, June 2018.



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