



# **Delivering on the promise: a better and fairer NDIS**

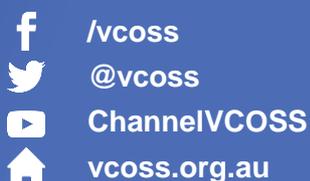
VCOSS Submission to the Review of the  
NDIS Act and the new NDIS Participant  
Service Guarantee

October 2019

The Victorian Council of Social Service 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 Victorians experiencing poverty and disadvantage, and advocates for the development of a sustainable, fair and equitable society.



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A fully accessible version is available online at [vcoss.org.au/policy/](https://vcoss.org.au/policy/)



VCOSS acknowledges the traditional owners of country and pays respect to past, present and emerging Elders.

This document was prepared on the lands of the Kulin Nation.



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# Making the NDIS work for everyone

The Victorian Council of Social Service (VCOSS) welcomes the opportunity to provide this submission to the Review of the *NDIS Act 2013* (Cth) and the new National Disability Insurance Scheme (NDIS) Participant Service Guarantee being undertaken by the Department of Social Services.

VCOSS is the peak body for social and community services in Victoria. VCOSS supports the community services industry, represents the interests of Victorians facing disadvantage and vulnerability in policy debates, and advocates to develop a sustainable, fair and equitable society. As part of our sector leadership, VCOSS provides backbone support for Victorian disability advocacy organisations to undertake collaborative systemic advocacy, under the banner of the 'Empowered Lives' campaign<sup>1</sup>.

Our submission reflects the voices of our members – both advocates and service providers – and is intended to inform positive change to ensure the NDIS can deliver on its potential and provide people with disability the support they want and need.

VCOSS notes that people with disability, together with advocacy organisations (including many 'Empowered Lives' members), service providers and the wider community, have voiced their concerns and frustrations in accessing and navigating the NDIS for many years and through many previous forums.

Most of the recommendations within this submission are unfortunately, and frustratingly, not new. Successive reports by the Joint Standing Committee on the NDIS and hundreds of submissions from a range of individuals and organisations have been calling for most of the changes outlined in this submission for three years.

There is a burning platform for change. Confidence and trust in the scheme – from the perspective of participants, families and carers, advocates, service providers, and the broader community – has been substantially eroded. Understanding, accessing and navigating the NDIS has become so complicated that the scheme is inaccessible for some of the very people who need it most.

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<sup>1</sup> <http://empoweredlives.vcooss.org.au/>

VCOSS and our member organisations are concerned that people experiencing disadvantage and isolation are unable to connect to supports through the NDIS at all, or in a timely way, and are caught in the fraught mainstream interface issues that have not been satisfactorily resolved at a jurisdictional or systemic level.

We urge the Australian Government and the NDIA to improve equity in participant access and experiences through the *NDIS Act* review and the development of the Participant Service Guarantee.

We also note the concurrent work of the Joint Standing Committee inquiry into NDIS Planning<sup>2</sup>, and suggest the submissions and recommendations to that inquiry are integrated into the development of the NDIS Participant Service Guarantee and the review of the *NDIS Act*.

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<sup>2</sup> Joint Standing Committee on the NDIS, *NDIS Planning inquiry submissions*, [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/NDISPlanning/Submissions](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/NDISPlanning/Submissions), accessed 25 October 2019.

## Summary of recommendations

### Making a meaningful NDIS Participant Service Guarantee

#### Promoting a rights-based, timely and quality participant experience

- Embed the rights and agency of people with disability at the centre of the NDIA Service Principles and the NDIS Participant Service Guarantee
- Develop and report on meaningful performance measures for each stage of the NDIS participant journey
- Use performance measures to drive positive change and continuously improve scheme design

### Getting started: Understanding and accessing the NDIS

#### Delivering clearer communications and targeted outreach programs

- Continue investment in tailored, co-designed communications strategies and resources to reach and engage people experiencing disadvantage and isolation
- Ensure resources developed through the National Information Program and by the NDIA are shared widely to reduce duplication, promote what's working well, and build a shared understanding of the NDIS
- Prioritise and fund strategic, assertive outreach initiatives to identify and connect with hard to reach communities, including engagement with the broader services sector

#### Enabling fairer and easier access the scheme

- Provide a complex needs gateway at the access stage
- Make the Access Request Form publicly available in a range of accessible formats
- Share clearer information about evidence requirements for access requests

#### Improving the access process

- Improve the transparency, timeliness and consistency of the access request process by removing the staffing cap, reviewing the operational costs cap, and increasing staff training
- Work collaboratively with people with disability, carers and families, providers, advocates and health professionals to continue exploring the use of validated functional assessment tools
- Enable people with psychosocial disability to access Continuity of Support funding without having to complete the NDIS eligibility process
- Provide additional and ongoing funding for independent disability advocacy

## Providing pathways to support for people who are not eligible for the NDIS

- Ensure people who are ineligible for the NDIS are connected to relevant, timely and funded support by addressing the outdated National Disability Agreement and delivering on the promise of the Information, Linkages and Capacity Building (ILC) program

## Publish detailed data on timeframes, ineligibility and pathways

- Establish timeframes for access decisions and processes, and release regular, detailed reporting

## Planning: Creating NDIS plans

### Promoting the voices and choices of people with disability through the planning process

- Enable greater, meaningful participant inclusion in the planning process through supported decision making, advocacy and self-advocacy
- Improve equity in planning experiences through investing in pre-planning support, disability advocacy and the knowledge and skills of Planners
- Enable participants to review a draft of their plan
- Provide participants with the opportunity to request plan amendments, while retaining components of their plan that are working well

## Planning: Using NDIS plans

### Providing support for people to understand and implement their funding plan

- Ensure people are supported to implement and coordinate their first plan and subsequent plans through support coordination or specialist case management

### Enabling flexible options regarding plan length including interim plans

- Provide flexible options in plan length, based on participant needs, including interim plans, short-term plans and longer term plans

### Boosting the NDIA's role in fostering a thriving, responsive market

- Boost the NDIA's role in market oversight and stewardship to ensure the supply of services adequately meets demand – including which services are offered, where they are delivered, and protecting their quality
- Increase NDIS pricing to reflect the true costs of service delivery, promote access to best-practice, evidence-based support and improve provider sustainability

- Build and support the workforce required to deliver the NDIS through strategic planning and analysis, addressing gaps and increasing training and employment pathways into the sector

#### Addressing service gaps and interface issues to ensure no-one is left behind

- Urgently address interface issues with mainstream services and provider of last resort arrangements to ensure equitable, timely access to support

#### Publishing data on planning timeframes, satisfaction and outcomes

- Publish regular data on the planning experience including waiting times, plan reviews, funding changes between packages, plan utilisation and participant satisfaction
- Collate and share more detailed and frequent market data to drive strategies for market development and workforce planning

### Reviews and appeals

#### Providing fairer, transparent review and appeal processes

- Provide clearer, accessible information about review and appeal processes
- Establish timeframes for each stage of the review and appeal processes, and avenues for people to seek assistance if the timeframes are not met
- Improve communications from the NDIA in regards to review and appeal procedures, timelines and templates
- Increase funding for independent disability advocacy and legal assistance to enable participants to exercise their rights
- Improve the quality of planning experiences to reduce the number of reviews and appeals

#### Sharing data on reviews and appeals including timeframes, satisfaction and outcomes

- Publish detailed data on reviews and appeals, including quantities, timeframes, responsiveness and outcomes

## Making a meaningful NDIS Participant Service Guarantee

### Promoting a rights-based, timely and quality participant experience

#### RECOMMENDATIONS

- Embed the rights and agency of people with disability at the centre of the NDIA Service Principles and the NDIS Participant Service Guarantee
- Develop and report on meaningful performance measures for each stage of the NDIS participant journey
- Use performance measures to drive positive change and continuously improve scheme design

VCOSS strongly supports the goals of the NDIS to provide people with disability greater choice and control over their support services, and to improve social and economic inclusion. The proposed National Disability Insurance Agency (NDIA) Service Principles<sup>3</sup> should be grounded in the rights and agency of people with disability and complemented by measurable performance standards.

People with disability are the experts in their own lives and their voices need to be both heard in the development of the Service Principles and amplified within the descriptions connected to each principle.

VCOSS advises changes to the 'Expert' principle<sup>4</sup> in particular. This principle should be revised to acknowledge at the outset the lived experience of participants, as well as the expertise of families and carers. This principle should commit NDIA and Local Area Coordinator (LAC) staff to draw on this expertise to guide their understanding of what supports are most effective in meeting a participant's needs. The principle should also establish clear expectations around the qualifications and experience of NDIA and LAC staff. VCOSS agrees that NDIA staff should have a high level of disability training – this should include training that builds skills, knowledge, confidence and accountability in relation to person-centred practice and disability rights.

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<sup>3</sup> Department of Social Services, *NDIS Act Review and NDIS Participant Service Guarantee discussion paper*, p.5.

<sup>4</sup> Ibid.

There is also an opportunity to strengthen the proposed 'Engaged' principle. Meaningful engagement involves power-sharing and interactive, two-way processes. It is not clear that this is the commitment or intention of the proposed principle as it is currently set out in the discussion paper. Rather, the framing appears to put the NDIA in control and puts limits around the scope, through the description's focus on having application to the development of operating procedures and processes only. If the intent of the NDIA Service Principles is to genuinely support a more positive participant experience, then the 'Engaged' principle should be amended to reflect a commitment to authentic collaboration with participants to continuously improve the NDIS experience. Engagement must be much more than just the NDIA soliciting feedback on predetermined issues. The Government can draw on the well-regarded International Association for Public Participation's Spectrum of Public Participation to improve the 'Engaged' principle.

The UN Convention on the Rights of People with Disability (CRPD) should be used to underpin the proposed NDIA Service Principles, and complement the existing general principles of the *NDIS Act 2013 (Cth)*, which VCOSS believes should be retained.

The development of the NDIS Participant Service Guarantee presents a critical opportunity to provide clarity for participants, carers and families and to rebuild confidence in the scheme. Central to the success of the Guarantee is the development of meaningful performance standards, specific to each stage of the participant journey, and aligned to the NDIA Service Principles.

During consultation with VCOSS members, confusion and delays were overwhelmingly identified as the most significant issues experienced by people navigating the NDIS. From lengthy waits regarding access or planning decisions, to unclear processes and poor communication, the journey for many participants is long, complex and frustrating.

Choosing the measures that matter and identifying accessible, inclusive ways to record performance, should be driven by co-design with people with lived experience of disability. For example, the Guarantee should include performance standards that reflect quantitative data in regards to access decisions, planning outcomes, reviews and appeals, as well as qualitative insights from participants about their experiences and satisfaction.

To ensure the Guarantee delivers on its promise, the Government must make clear to the NDIA and LACs that the principles and performance standards of the Guarantee are neither aspirational nor discretionary.

The specified performance standards must be adhered to, reported on quarterly, shared publicly, and feed into a cycle of action learning and continuous quality improvement. The performance measures should cover:

- timeliness of responses and decisions
- outcomes regarding access, eligibility, planning, reviews and appeals
- quality of plans, based on how they meet a participant's goals and needs, and how effectively they can be implemented
- the number and value of individual funding plans, and information and linkages support provided to people with disability, carers, families, and in particular, disadvantaged and isolated communities, including the effectiveness of outreach programs and increases in participation of specific communities and groups
- satisfaction of participants in their experiences with the NDIA and LACs, including communication, responsiveness, knowledge and understanding of disability and mental health.

By tracking and reporting on these performance standards, the NDIA will be better placed to identify problems, create positive solutions, escalate scheme design issues and continuously improve the participant experience.

We welcome the Government's commitment to fund the Commonwealth Ombudsman to monitor the NDIA's performance against the Guarantee and support participants to pursue complaints about timeframes<sup>5</sup>. Updates about the work of the Commonwealth Ombudsman should also be included in quarterly reporting to provide a full picture of the experiences of NDIS participants.

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<sup>5</sup> Department of Social Services, *NDIS Act Review and NDIS Participant Service Guarantee discussion paper*, p.3.

## Getting started: Understanding and accessing the NDIS

### Delivering clearer communications and targeted outreach programs

#### RECOMMENDATIONS

- Continue investment in tailored, co-designed communications strategies and resources to reach and engage people experiencing disadvantage and isolation
- Ensure resources developed through the National Information Program and by the NDIA are shared widely to reduce duplication, promote what's working well, and build a shared understanding of the NDIS
- Prioritise and fund strategic, assertive outreach initiatives to identify and connect with hard to reach communities, including engagement with the broader services sector

Learning about and accessing the NDIS continues to be difficult for the very people it is intended to support. These challenges are particularly pronounced for people experiencing disadvantage, isolation and additional barriers, including First Nations people, culturally and linguistically diverse communities, women, LGBTIQ+ people, and people living in poverty.

Access to the NDIS relies heavily on individuals being literate, including digitally literate; understanding and navigating the system; identifying their needs and goals; having the skills and confidence to exercise choice and control when managing their plan; and having the confidence and capacity to self-advocate.

The NDIS is a complex support system and a sea of key terms, acronyms and ‘magic words’ have flourished as the scheme has evolved.

***“You have to have the special code words to go through their programme, you've got to say it's - oh, what is it they told me? Someone told me ‘psychosocial disability’ or something... so you can't even say what it is as a mental illness, you have to know these special code words, which makes it hard for anyone to get through because, if you don't know the special code words, you can't even get through the front door, so to speak.”<sup>6</sup>***

The prevalence of cheat sheets, blogs and resources that aim to explain the NDIS and NDIS-related phrases demonstrates just how murky the messages have become. The information overload, and conversely the absence of information, presents an overwhelming barrier to people commencing the access process and navigating the participant pathway.

While information is available in many formats and ways, the onus is on participants and their support networks to put the pieces of the puzzle together and make sense of the NDIS<sup>7</sup>. This is likely to be even more challenging for people who have never received funded disability support before, either because they did not receive supports from previous state-funded disability services, or because they have recently acquired a disability.

As identified in our previous submissions to the Joint Standing Committee on the NDIS<sup>8</sup>, VCOSS and our members are concerned that many people experiencing disadvantage are not adequately informed and prepared to engage with the NDIS.

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<sup>6</sup> Mavromaras et al, *Evaluation of the NDIS: Final Report*, National Institute of Labour Studies, February 2018, p.191.

<sup>7</sup> D Warr, H Dickinson, S Olney et. al., *Choice, Control and the NDIS: Service users' perspectives on having choice and control in the new National Disability Insurance Scheme*, Melbourne: University of Melbourne, May 2017.

<sup>8</sup> VCOSS, *Active market stewardship for the National Disability Insurance Scheme: VCOSS Submission to the NDIS Thin Markets Project*, June 2019; *Strengthening the NDIS: VCOSS submission to NDIS Joint Standing Committee inquiry into market readiness for provision of services under the NDIS*, March 2018; *A smooth NDIS transition: VCOSS Submission to NDIS Joint Standing Committee inquiry into Transitional Arrangements for the NDIS*, August 2017; *Delivering high quality services for all mental health consumers: VCOSS submission to the Joint Standing Committee on the NDIS*, February 2017.

People need assistance to understand the NDIS before they make an access request, however this preliminary support is largely dependent on people having a strong network including family, friends, service providers and/or advocates who know about and understand both the scheme and the applicant's needs and goals, and whose interests and motivations align with the applicant's.

We share the concerns of people with disability, families, carers and advocates, and the broader social services sector (both specialist and mainstream), that complex communications about the NDIS may inadvertently entrench disadvantage by making the scheme less accessible to people who do not have high literacy or self-advocacy skills<sup>9</sup>.

These concerns are well-founded. For example, in a pilot survey of people experiencing socio-economic disadvantage in the Wollongong roll out region, 31 per cent of survey participants were not aware of the NDIS and 41 per cent had heard about the NDIS but decided not to apply<sup>10</sup>. Factors such as low literacy, unemployment, poverty, mental health concerns and isolation made it more difficult for them to understand and access the NDIS. In addition, only 12 per cent felt they could count on family or friends to assist them with the application process<sup>11</sup>.

While there has been some progress in promoting clearer information through the development of new resources and a refreshed NDIS website<sup>12</sup>, further clear and accessible communications approaches must be implemented to support people experiencing disadvantage to engage with the scheme.

This includes the development or expansion of tailored resources for First Nations people, people from culturally diverse communities, women, families of children with disability, young people and other cohorts who experience social, cultural and other forms of economic exclusion and marginalisation. For some communities, there remains a cultural stigma around disability and a distrust of government, which can contribute to some individuals and families not wanting to identify as having a disability<sup>13</sup>.

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<sup>9</sup> F O'Mallon, 'Disability advocates demand change', *The New Daily*, 8 October 2019; J Gailberger, 'Getting NDIS help is too complex for many families, warns child health body', *The Advertiser*, 7 October 2019.

<sup>10</sup> F Hui, C Cortese, M Nikidehaghani, S Chapple and K McCombie, *Hard to Reach: Examining the National Disability Insurance Scheme Experience, A Case Study in Wollongong*, University of Wollongong, 2018.

<sup>11</sup> Ibid.

<sup>12</sup> NDIA, 'New website launched', 22 January 2019, <https://www.ndis.gov.au/news/1244-new-website-launched>, accessed 24 October 2019.

<sup>13</sup> Settlement Services International, Still outside the tent: cultural diversity and disability in a time of reform – a rapid review of evidence, October 2018, p.14.

Some information sharing initiatives are underway across Australia that work with communities to design and implement communications resources, including those funded by the National Information Program grants<sup>14</sup>.

We recommend the NDIA and the Australian Government continue investing in communications strategies and resources tailored for and co-designed by hard to reach communities, and that these approaches are supported by robust outreach programs. Resources developed through National Information Program grants and NDIA communications strategies should be shared widely to reduce duplication, promote what's working well, and build a shared understanding of the NDIS.

**Assertive outreach and engagement is also crucial to connect people experiencing disadvantage to the NDIS.**

As highlighted in our previous submissions, VCROSS members are concerned that many people eligible for the NDIS will not access the scheme without proactive assistance and engagement. Without additional, intensive support, there is a high risk that people with disability experiencing disadvantage or isolation may fall through the cracks, be unable to access the NDIS and become disconnected from services.

Though the NDIA and LACs have grown their physical presence across Australia, online communication channels continue to be the main gateway for people to learn about and access the scheme. This is problematic as people with disability living in rural and regional areas or on low incomes are more likely to be 'digitally excluded', with limited access to the internet, lower digital literacy, and cost barriers to accessing technology<sup>15</sup>. Dropping in to a local NDIA or LAC office is simply not an option for many people in regional communities in Victoria, some of whom are a four-hour round trip from their nearest site.

Despite the development and release of specific strategies by the NDIA<sup>16</sup>, the engagement of First Nations people and culturally and linguistically diverse communities remains below expectations.

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<sup>14</sup> NDIA, *Information, Linkages and Capacity Building (ILC) National Information Program Grant Round: Summary of Funded Activities*, October 2019.

<sup>15</sup> J Thomas, J Barraket, CK Wilson, E Rennie, S Ewing, T MacDonald, *Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2019*, RMIT University and Swinburne University of Technology for Telstra, September 2019.

<sup>16</sup> NDIA, *Aboriginal and Torres Strait Islander Engagement Strategy*, 2017; NDIA, *Cultural and Linguistic Diversity Strategy*, 2018.

An estimated 38,100 First Nations people live with a severe or profound disability<sup>17</sup>, yet only 16,417 First Nations people with disability (or 5.7 per cent of NDIS participants) have an approved NDIS plan<sup>18</sup>. Culturally and linguistically diverse communities are underrepresented as NDIS participants. Initial estimates anticipated 20 per cent of NDIS participants would be people from culturally and linguistically diverse backgrounds<sup>19</sup>, however people from culturally and linguistically diverse backgrounds represent just 8.4 per cent of NDIS participants with approved NDIS plans<sup>20</sup>.

Families of children with disability continue to report challenges in understanding and accessing the NDIS, with 50 per cent reporting issues with information about the scheme<sup>21</sup>. A lack of clear communications about the scheme, and inconsistent messages from NDIA staff and LACs, was not only frustrating for families but in some instances led to reduced funding for supports.

Many young people are still not aware of the NDIS, and the information they receive is too generic and complex for their needs<sup>22</sup>.

Of the 6,048 young people living in aged care, only two-thirds are active participants in the NDIS despite being very likely to be eligible<sup>23</sup>.

People experiencing homelessness, who are potentially eligible for the NDIS, also may find the process too difficult to access, or may try to engage but do not have the skills or skilled family or friends to assist them<sup>24</sup>.

Additionally, recent research identified that women, rural and regional Australians and people from low income households may be more likely to miss out the NDIS<sup>25</sup>.

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<sup>17</sup> Australian Institute of Health and Welfare, *'Disability support for Indigenous Australians'*, 11 September 2019, <http://www.aihw.gov.au/reports/australias-welfare/disability-support-for-indigenous-australians> accessed 24 October 2019.

<sup>18</sup> NDIA, *National Public Dashboard 30 June 2019*, 2019.

<sup>19</sup> NDIA, *Cultural and Linguistic Diversity Strategy*, 2018.

<sup>20</sup> Ibid.

<sup>21</sup> Children and Young People with Disability Australia, *Improving the NDIS planning process for children and young people with disability and their families: Submission to the Joint Standing Committee on the NDIS*, September 2019, p.8.

<sup>22</sup> Youth Disability Advocacy Service and Youth Affairs Council Victoria, *Submission in response to the Productivity Commission Position Paper: National Disability Insurance Scheme (NDIS) Costs*, September 2017.

<sup>23</sup> GM Bishop, J Zail, L Bo'sher and D Winkler, *Young People in Residential Aged Care (2017 – 2018) A Snapshot*, Summer Foundation, August 2019.

<sup>24</sup> K Peterson, *Homelessness and the National Disability Insurance Scheme – Challenges and solutions*, CHP – Homelessness and the NDIS – Challenges and Solutions, Council to Homeless Persons, May 2017.

<sup>25</sup> E Malbon and G Carey, *'Women, rural and disadvantaged Australians may be missing out on care in the NDIS'*, *The Conversation*, 11 July 2019.

People with psychosocial disability are reluctant to apply for the scheme. Earlier this year, the National Mental Health Commission found that half of all Commonwealth community mental health program clients had not applied for the NDIS because they were in the process of applying or had not yet applied, or because information about them was unknown<sup>26</sup>. The most frequently reported reasons for not applying were client distrust of the NDIS system, clients being too unwell, and clients being overwhelmed by the process of collecting evidence<sup>27</sup>.

### ***Early intervention support for people experiencing psychosocial disability***

The Early Intervention Psycho-Social Response (EIPSR) program, a new Victorian Government funded initiative that commenced in the first half of 2019, supports people with psychosocial disability who access clinical mental health services. The EIPSR program is delivered through partnerships between health and service providers to support adults who are hard to engage due to the nature of their mental health condition, who may also be experiencing homelessness, multiple disadvantage, current or past engagement with the justice system, or increased risk of suicide or self harm. Through an intensive case management approach, the program supports people to build their capacity to better manage their mental health, develop practical life skills, connect to their community and if eligible, transition to the NDIS.

As identified in Mental Health Victoria and Victorian Healthcare Association's joint submission to the Royal Commission into Victoria's Mental Health System, this program could be scaled and expanded in the short term<sup>28</sup> to support both people who are ineligible for the NDIS, and people who need assistance to navigate the application process.

We welcome the recent Council of Australian Government (COAG) Disability Reform Council (DRC) commitment to improve access and experiences for people with psychosocial disability<sup>29</sup>. We encourage meaningful engagement with people with lived experience to inform this work, in addition to consultation with government and the sector.

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<sup>26</sup> National Mental Health Commission, *Monitoring mental health and suicide prevention reform: National Report 2019*, October 2019.

<sup>27</sup> Ibid.

<sup>28</sup> Mental Health Victoria and Victorian Healthcare Association, *Joint Submission to the Royal Commission into Victoria's Mental Health System*, July 2019, p.28.

<sup>29</sup> Council of Australian Governments, *Meeting of the COAG Disability Reform Council Communiqué*, 9 October 2019.

We renew our previous recommendations that assertive outreach should be prioritised, funded and implemented to identify and connect with isolated people and communities who cannot otherwise engage in the NDIS. Currently, many of our members continue to provide hours of unfunded work to engage hard to reach people, and this expectation is not reasonable or sustainable.

The implementation of effective outreach programs requires funding for skilled and experienced workers, who can take the time needed to identify potential participants and build trusting relationships. To increase capacity and understanding across intersecting services, we recommend further engagement of the broader social service sector. By harnessing the collaborative spirit of the sector, and building a ‘no wrong door’ approach, more people experiencing disadvantage can be supported to access the scheme.

It is important to emphasise that the sector’s capacity to do this ‘joining up’ work has been substantially eroded in a marketised environment, and can only happen with intentional government investment. Service providers cannot continue to do this work unfunded. Outreach strategies should be embedded within the NDIA’s long overdue ‘Hard To Reach Strategy’<sup>30</sup>. This strategy and its implementation cannot wait any longer if we are to provide equitable access to the NDIS.

## Enabling fairer, easier access the scheme

### RECOMMENDATIONS

- Provide a complex needs gateway at the access stage
- Make the Access Request Form publicly available in a range of accessible formats
- Share clearer information about evidence requirements for access requests

The processes involved in accessing the NDIS present many barriers for people experiencing disadvantage. From getting the form itself to through to completing each step, our members report the process is often inaccessible, intensive, invasive and long.

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<sup>30</sup> Australian Government, *Response to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) report: Transitional arrangements for the NDIS*, June 2018, p.11.

When people are in crisis or experiencing multiple layers of disadvantage, there is no dedicated avenue for their access request to be escalated or addressed with sensitivity. While the complex needs pathway has been established for the planning phase of the scheme, our members report there is no equivalent specialised support available on the ground before or during the access stage.

This intensive support is usually provided by service providers, who are not funded to provide this kind of assistance, and advocates, who are equally stretched and underfunded. As providers complete the full transition of their business into the scheme, this unfunded work will not be sustained. Additional pressure will be placed on families, carers and advocates, who will not be able to sustain their efforts either.

The first step in the access process is to complete an Access Request Form, which is only available via phone call. A participant must answer eligibility questions and provide a mailing address for a hardcopy form. This initial stage of the process unfairly and negatively impacts many people, in particular:

- people with a hearing impairment
- people who cannot afford or access a reliable phone service
- people with low literacy, or with English as a second language
- people who do not have a fixed address, including people experiencing homelessness or fleeing family violence.

During a consultation forum, VCOSS members expressed their frustration with this barrier and the implications it has in preventing hard to reach communities from connecting with the NDIS. Waiting for the form to be posted out, instead of being able to access it online, or collect it from a local office, adds an unnecessary time delay.

Making the form easier to access, in a range of online and offline accessible formats, would provide greater opportunities for staff in intersecting services to support people through the NDIS access process.

There should also be more flexible options for people to submit their forms, including online, mail and face-to-face at NDIA or LAC offices. At the moment, people who want to drop in their form at a local office need to have an appointment with a duty officer. People should be able to easily submit their form in the way that suits their needs, with staff at offices available to provide responsive, timely assistance.

### ***Chloe's story***

Chloe\*, a bubbly 9-year-old living in regional Victoria, was diagnosed with a rare bone condition three years ago; it is so rare, she is one of less than two dozen people in Australia living with the condition. There is no known cure and the symptoms, which can fluctuate, impact her everyday life including walking, dressing, going to school and playing sport. Chloe's team of doctors have advised she is likely to have this disease for many years, if not life. Despite the expertise and advice of medical professionals, who are best placed to understand the impact of Chloe's condition given its rarity, Chloe's NDIS application was rejected. After a three month wait, Chloe's family were advised her application did not meet the criteria for substantially reduced functional capacity or for early intervention support.

On the advice of their paediatrician and paediatric rheumatologist, Chloe's family decided to appeal this decision, but to do so needed more evidence in the form of an occupational therapy assessment. The waiting list for occupational therapy services in Chloe's area is six months, and as there are no public funded assessments available, her family had to privately pay \$170 per session. If her family did not have the means to pay for assessment privately, they would be unable to request a review, which presents a serious equity issue.

After submitting a request for a review, Chloe's application disappeared into the ether. There was no acknowledgement of receiving the request for a review, let alone any timeframes. Her review documents sat in an email inbox for weeks and when Chloe's family called to follow up the enquiry, they were advised the email inbox wasn't being checked because it was too full. Missed calls from review officers couldn't be directly returned, as call centre staff would take messages to pass on instead of transferring calls through.

Chloe's family are still waiting for a decision regarding their access review. In the meantime, Chloe is without some of the supports she previously accessed, including a state-based psychology program which had its funding absorbed in the transition to the NDIS. Chloe remains on a waiting list to see a child psychologist, which her family will have to pay for privately.

\*Name has been changed

**People navigating the access process often feel unclear about the steps involved and overwhelmed by the emphasis on medical evidence.**

Some disabilities or diagnoses are pre-identified as being likely to meet NDIS eligibility, known as Lists A, B and D, however these lists may inadvertently contribute to confusion or exclusion.

Medical assessments are often expensive and the wait lists are usually lengthy. This is particularly evident in some regional and rural communities, who do not have adequate or timely access to specialists such as pediatricians and allied health providers.

For example, in the Gippsland area, people can spend many months on waiting lists and often rely on therapists travelling from Melbourne for home-based assessments. The travel times across this large region add to the expenses and barriers experienced by participants. Some people seek out private services at their own cost, or travel long distances to see a specialist; however, this simply isn't an option for participants and families on fixed or low incomes, and those without reliable support and transport. Even when participants finally secure an appointment, finding a support worker who can assist them to get to the appointment in areas where providers and staff are limited can be difficult.

The emphasis on medical evidence appears to be even more pronounced for children with disability or developmental delay. Although the Joint Standing Committee recommended in 2017 that the NDIA “clearly communicate to families, Planners and ECEI Partners that assessment reports are not needed unless requested by the NDIA”<sup>31</sup>, many prospective participants continue to seek costly diagnostic reports to support their access request.

In reviewing the assessment process for autism, the largest primary disability group supported by the NDIS<sup>32</sup>, it is clear that the availability and costs of assessments may disproportionately impact disadvantaged or isolated communities. Wait times in the public system average 16 weeks, while private wait times average four weeks, and people in regional and rural areas experience waiting lists twice as long as those in metropolitan areas<sup>33</sup>. Additionally, the costs for private assessments – which can range from \$200 to \$2750 – are out of reach for families on low incomes<sup>34</sup>.

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<sup>31</sup> Joint Standing Committee on the NDIS, *Progress Report*, March 2019, Recommendation 9, p.113.

<sup>32</sup> NDIA, *COAG Disability Reform Council Performance Report - National 30 June 2019*, 2019.

<sup>33</sup> L Taylor, P Brown, V Eapen, S Midford, J Paynter, L Quarmby, T Smith, M Maybery, K Williams and A Whitehouse, *Autism Spectrum Disorder Diagnosis in Australia: Are we meeting Best Practice Standards?*, Autism Co-operative Research Centre, 2016.

<sup>34</sup> Ibid.

In addition, girls and women with autism are often underdiagnosed or misdiagnosed<sup>35</sup>, which may reduce their access to appropriate supports and services.

People with psychosocial disability, particularly those without existing connections to services, also face challenges in accessing evidence to support their applications<sup>36</sup>.

Clearer information about evidence requirements and the access request process needs to be promoted to potential participants and the broader community.

## Improving the access process

### RECOMMENDATIONS

- Improve the transparency, timeliness and consistency of the access request process by removing the staffing cap, reviewing the operational costs cap, and increasing staff training
- Work collaboratively with people with disability, carers and families, providers, advocates and health professionals to continue exploring the use of validated functional assessment tools
- Enable people with psychosocial disability to access Continuity of Support funding without having to complete the NDIS eligibility process
- Provide additional and ongoing funding for independent disability advocacy

VCOSS members report wide variances in access request decisions, depending on the approach of the NDIA or LAC in their community. Some potential participants have received different reasons for the rejection of their access request between their first and second attempts. Medical assessments are also viewed inconsistently. Our members report some people with no evidence are being accepted into the scheme, while others with a wealth of evidence are being assessed as ineligible.

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<sup>35</sup> Amaze, *Position Statement: Autistic Women and Girls*, March 2018; M Blakemore, G Robertson, S Hansford, T Richardson, J Dalcombe, S Smith and N McCaffrey, *Multiple and intersecting forms of discrimination against autistic women: For the attention of the Special Rapporteur on Violence against Women*.

<sup>36</sup> Joint Standing Committee on the NDIS, *Committee Hansard*, 26 February 2019, p.9.

These variances may be attributed to procedures, training, staffing levels, and in some instances, the absence of validated functional assessment tools.

**For a better, faster and more consistent and equitable participant experience, the NDIS must build its capacity and capability by improving the transparency of the access request process, increasing the number of staff delegated to process access requests, and investing in staff training.**

The Productivity Commission initially envisaged 10,000 people would be required to deliver the NDIS<sup>37</sup>, however due to the initial staffing cap of 3,000 placed on the NDIA, much of the implementation of the scheme has been outsourced to community partners<sup>38</sup>. In addition, the NDIA is subject to a cap on operating costs of 7 per cent of package costs<sup>39</sup>.

While VCOSS welcomes the moderate increases to the staffing cap and investments in training announced in August 2018<sup>40</sup>, we believe better outcomes will only be possible through the removal of the staffing cap and a review of the operational costs cap to empower the NDIA to do its job well.

As recommended by the Productivity Commission<sup>41</sup>, we believe the NDIA needs to be given greater resources and independence to deliver the NDIS effectively, especially as the scheme evolves and matures. It is important that staff are provided with the tools and training they need, including procedures and assessment tools. The employment of staff with lived experience of disability and caring should also be prioritised to enhance participant experiences of the scheme.

**Further progress is required in exploring the use of functional assessment tools to drive consistency and fairness in access decisions.**

The Independent Assessment Pilot (IAP), conducted from November 2018 to April 2019, enabled potential participants to complete a functional impact assessment, with an independent assessor using standardised tools. While this pilot was intended to inform further access and planning process improvements, there have been no recent announcements regarding how standardised assessment tools will be used by the NDIA.

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<sup>37</sup> Productivity Commission, *Study report: National Disability Insurance Scheme (NDIS) Costs*, October 2017, p.412.

<sup>38</sup> Department of Social Services, *Submission to the Productivity Commission Study into National Disability Insurance Scheme Costs*, April 2017, p.24.

<sup>39</sup> Ibid. p.42.

<sup>40</sup> The Hon Dan Tehan MP, *Media release: Improved experience for NDIS participants and providers*, 24 August 2018

<sup>41</sup> Productivity Commission, *Study report: National Disability Insurance Scheme (NDIS) Costs*, October 2017, p.412.

We encourage the NDIA to collaborate with people with disability, carers and families, providers, advocates and health professionals to further develop or refine assessment tools, particularly for people with autism, psychosocial disability or intellectual disability, who have experienced wide variations in access and planning decisions. It is critical that the assessment process remains independent, and that tools are used by staff with appropriate training and expertise, to ensure the responses gathered and reports developed are a fair and accurate representation of participants' needs.

**People with psychosocial disability who make an access request experience significant rejection rates.**

33 per cent of people with a primary disability of psychosocial disability were found to be ineligible for the NDIS – the rejection rate is even higher for people supported by Commonwealth services (41 per cent access not met) and people who are new to receiving support (50 per cent)<sup>42</sup>.

To receive Continuity of Support (CoS) funding, people with psychosocial disability must first go through the NDIS access process and be rejected, despite recommendations to cease this additional and unfair practice<sup>43</sup>.

While this approach was originally designed on the premise that most people would be eligible for the scheme, and it would be in their best interests to receive lifetime support<sup>44</sup>, as the rejection rates demonstrate high ineligibility, this practice needs to be reviewed.

The high stress and administrative burden of completing the NDIS access process is unnecessarily cruel and traumatic for people with psychosocial disability who are unlikely to be eligible for the scheme.

We urge the Government to revisit recommendations to review the eligibility process for CoS funding for people with a psychosocial disability to reduce unnecessary trauma and ensure people receive ongoing support.

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<sup>42</sup> NDIA, *People with a psychosocial disability in the NDIS*, June 2019.

<sup>43</sup> Joint Standing Committee on the NDIS, *Progress Report*, March 2019, p. 25.

<sup>44</sup> *Ibid.*, p. 72-73.

**Independent disability advocacy protects and advances the rights and interests of people with disability, and promotes these rights to the wider community.**

It empowers people with disability and their support network to understand their human and legal rights, communicate their needs, and have their needs met<sup>45</sup>. It is an important safeguard to help prevent and report abuse<sup>46</sup>.

The NDIS has already had, and will continue to have, a significant impact on the workloads of disability advocates. From supporting people to access and navigate the scheme, to requesting a plan or decision review, or making a complaint, disability advocates can play an important role in each stage of the participant journey. Access to a disability advocate is particularly important for people with complex needs or facing disadvantage, or those with limited informal supports or networks<sup>47</sup>.

Disability advocacy organisations are currently swamped with requests for assistance, with many maintaining long waiting lists or closing their books.

***“Our agency has just shut its books again, and that’s the third time over the last year. So when I say shut our books, it means that we’re saying no to people who are asking for assistance. Across the state, I understand this is happening at all of the agencies. We’re saying no to advocacy assistance; and that’s the people who are coming to us. With disability advocacy, if they’re not complaining, it’s assumed they’re OK.”<sup>48</sup>***

***Melanie Muir, Board Member, Disability Advocacy Victoria and Advocate, Leadership Plus***

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<sup>45</sup> Disability Advocacy Resource Unit, *What is disability advocacy?*, 2016, [http://www.daru.org.au/wp/wp-content/uploads/2011/12/What-is-disability-advocacy\\_final-June-2016.pdf](http://www.daru.org.au/wp/wp-content/uploads/2011/12/What-is-disability-advocacy_final-June-2016.pdf), accessed 24 October 2019.

<sup>46</sup> VCOSS, *Submission to the Victorian Parliament’s Inquiry into Abuse in Disability Services: Stage 2*, November 2015.

<sup>47</sup> VCOSS, *A smooth NDIS transition: VCOSS submission to NDIS Joint Standing Committee inquiry into Transitional Arrangements for the NDIS*, August 2017.

<sup>48</sup> *Strengthening Disability Advocacy Conference 2019: Advocacy under pressure*, 2 September 2019, <http://www.daru.org.au/conference-session/opening-address-3>, accessed 27 October 2019.

In recognition of the unprecedented demand pressures, the Victorian Office for Disability provided State-funded disability advocacy organisations with a 25 per cent increase in their core funding for 2018/19 and 2019/20. Despite this welcome short-term increase in resourcing, organisations are still unable to meet all requests for assistance.

This has had adverse flow-on impacts for other parts of the system. For example, over the past financial year, 28 per cent of enquiries fielded by Victoria's Disability Advocacy Resource Unit (DARU) have related to the NDIS. DARU is a state-wide service funded by the Victorian Government to build the capability and impact of the disability advocacy sector in the state through the provision of an information gateway, customised training and professional development, networks and linkages to disability advocates. Individual and systemic advocacy are not in DARU's remit. While this is widely known and understood, at a time when disability advocacy organisations are not able to meet requests for service, advocates, participants, families and carers are turning to DARU in desperation.

VCOSS welcomes Commonwealth<sup>49</sup> and State Government funding commitments to extend disability advocacy funding through until 2020<sup>50</sup>, and to support related sector projects<sup>51</sup>, however a longer term strategy and funding commitment is required. VCOSS's call to action is consistent with the position of the Productivity Commission which, in 2011, affirmed the important role of independent advocacy in the NDIS environment, and recommended the continuation of the-then funding arrangements through FaHCSIA and various State and Territory Governments.

The significant challenges that have since emerged during scheme rollout have only served to highlight that not only is there a vital ongoing role for disability advocacy and a need for long-term funding certainty for the advocacy sector, but that the advocacy sector requires increased investment to respond to demand pressures associated with both the NDIS and its mainstream interfaces.

For example, recent data from the National Disability Advocacy Program (NDAP), which provides funding for over 60 advocacy organisations, show that 35 per cent of advocacy sessions were dominated by NDIS access, planning and internal review issues<sup>52</sup>.

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<sup>49</sup> Hon Christian Porter, *Media release: Turnbull Government investing \$60 million in disability advocacy*, 9 August 2017.

<sup>50</sup> Hon Martin Foley, *Media release: Expanding Disability Advocacy Across Victoria*, 5 September 2018.

<sup>51</sup> Hon Luke Donellan, *Media release: Speaking Up For Victorians With Disability*, 16 January 2019; *Media release: New Funding To Strengthen Disability Rights*, 16 July 2019.

<sup>52</sup> Mary Mallet, CEO of Disability Advocacy Network Australia (DANA) speaking at the *Strengthening Disability Advocacy Conference 2019: Advocacy under pressure*, 2 September 2019, <http://www.daru.org.au/conference-session/opening-address-3>, accessed 27 October 2019.

While some NDAP-funded organisations have received additional funding to support participants to pursue reviews and appeals, no additional funding has been provided to support other NDIS-related requests for support. In some cases, early engagement of an advocate may prevent an issue being escalated to a review or appeal.

Organisations who do not receive national funding are also being inundated by NDIS-related requests, as outlined on the previous page.

In Victoria, sector consultations for the Disability Advocacy Futures plan identified that the influx of NDIS-related requests for support has significantly impacted the capacity of advocacy organisations to work with people with disability in regards to mainstream and universal services. The pivotal role of independent disability advocacy, and its broad remit beyond the NDIS, needs to be recognised and resourced.

We urge governments to provide funding certainty beyond 2020, so every person with a disability can access independent advocacy as needed. Funding increases must reflect the real and significant growth of requests for support driven by the introduction of the NDIS.

This is not only the right thing to do, but represents a smart investment. Funding for advocacy delivers a significant return on investment to government<sup>53</sup>. As identified by the Productivity Commission, independent advocacy would provide a net benefit of almost \$600 million to Australia over a 10-year period, with a benefit cost ratio of 3.5:1 (or a \$3.50 return for every dollar spent). This is a particularly important consideration for governments and the NDIA in terms of providing for the financial sustainability of the NDIS.

More resources are needed to expand disability advocacy service coverage across Australia, particularly in rural and remote areas, and improve access for people likely to be underserved. For example, access can be increased for Aboriginal people, people from CALD backgrounds, people identifying as lesbian, gay, bisexual, transgender and intersex (LGBTI), people with complex communication needs, and people with an intellectual disability or mental health issues.

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<sup>53</sup> A Daly, G Barrett and R Williams, *A Cost Benefit Analysis of Australian Independent Disability Advocacy Agencies*, Disability Advocacy Network Australia, 2017.

## Providing pathways to support for people who are not eligible for the NDIS

### RECOMMENDATION

- Ensure people who are ineligible for the NDIS are connected to relevant, timely and funded support by addressing the outdated National Disability Agreement and delivering on the promise of the Information, Linkages and Capacity Building (ILC) program

People who are ineligible for the scheme often remain in limbo, or are forced to persevere through a jungle of red tape and bureaucracy. VCOSS members play an active, typically unfunded, role in supporting people to find alternative services or funds, as the pathways for people deemed ineligible for the NDIS are either narrow or non-existent.

The Australian Government has committed to uphold and respect human rights, as a signatory to seven human rights treaties and the Universal Declaration of Human Rights<sup>54</sup>.

The UN Committee on the Rights of Persons with Disabilities recently reviewed Australia's achievements in regards to the Convention on the Rights of People with Disability. The Committee acknowledged the introduction of the NDIS, however raised concerns regarding the scheme's continued reliance on the medical model of disability and inequitable access to support for people who are ineligible for the scheme<sup>55</sup>.

The review of the *NDIS Act* cannot take place in isolation from the current funding and service landscape. We urge governments to collaborate to ensure reliable, continuous and equitable support is available for people with disability.

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<sup>54</sup> Australian Human Rights Commission, *What are human rights?*, <https://www.humanrights.gov.au/about/what-are-human-rights>, accessed 24 October 2019.

<sup>55</sup> UN Committee on the Rights of Persons with Disabilities, *Concluding Observations: UN Report on Australia's Review of the Convention on the Rights of Persons with Disability (CRPD)*, 24 September 2019.

**Central to the provision of support for people who are ineligible for NDIS funding packages, and their support networks, is the effective operation of the Information, Linkages and Capacity Building (ILC) program, formerly known as tier 2 of the scheme.**

While the ILC program was originally intended to assist all people with disability, their families and carers, regardless of their eligibility for individual packages<sup>56</sup>, our members report that limited assistance is available.

It is anticipated that 460,000 people will be eligible for individual funding packages as part of \$22 billion in disability services funding by 2020<sup>57</sup>, however the comparative investment in support for those who are ineligible for the scheme is low.

The two key streams of the ILC policy framework – the role of LACs in connecting people to services, and the capacity-building grants program – are not working as envisaged and require further attention and investment to ensure people are connected to the supports they need.

Based on funding arrangements with the NDIA, LACs are expected to spend 20 per cent of their time supporting people with disability through information, referrals and building community capacity<sup>58</sup>. Through the NDIS access process, potential participants share a wealth of personal information; however, if they are deemed ineligible, this information is not then effectively used to direct people to appropriate supports. VCROSS members report LACs have been directed to prioritise planning over other functions due to the large workload and high targets. This limits the capacity of LACs to assist people who are ineligible for the NDIS and their support network to connect with services.

The ILC grant program, which has provided 222 grants totaling \$85.9 million since 2015<sup>59</sup>, has funded organisations to deliver a series of short-term, state-based and national activities and projects. VCROSS members, many who have applied for or received ILC funding, report challenges in administering and implementing effective projects to annual funding timelines.

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<sup>56</sup> NDIA, *A framework for Information, Linkages and Capacity Building*, 2015.

<sup>57</sup> NDIA, *NDIS Market Approach: Statement of opportunity and intent*, November 2016, p. 3.

<sup>58</sup> NDIA, *Submission to Productivity Commission Issues Paper on NDIS Costs*, March 2017, p.56.

<sup>59</sup> NDIA, *Strengthening ILC: A National Strategy towards 2022*, December 2018, p.4.

We welcome the release of 'Strengthening ILC: A National Strategy towards 2022' by the NDIA in December 2018, which seeks to address issues with the fragmented approach of previous grant rounds, reduce duplication and refocus the program towards longer term, scalable and measurable activities.

The shift from short-term grants to mostly three year investments will enable organisations and the community to deliver more effective, holistic support for people who are ineligible for individual NDIS funding packages. Under the new ILC strategy, the program will have a budget of \$398.3 million over three years<sup>60</sup>; the grant pool represents less than 0.65 per cent of the \$22 billion anticipated full scheme annual investment in the NDIS. When considering ILC programs are largely intended to support an anticipated 3.94 million people who are ineligible for the NDIS, as well as carers and support networks, this funding pool is inadequate.

As identified in our 2017 submission to the Joint Standing Committee<sup>61</sup>, we recommend the amount of ILC funding should be increased as a percentage of the overall NDIS budget and indexed annually. LACs should also be provided additional resources or direction to emphasise the community connection component of their role. If LACs are no longer best placed to deliver this function, Governments and the NDIA must review how people who are ineligible for the scheme can be effectively supported. Through the imminent review of the ILC Framework by COAG<sup>62</sup>, further opportunities may be available to strengthen the ILC program, and we look forward to this progress.

### ***Older people***

People with disability aged over 65, or Aboriginal and Torres Strait Islander people aged over 50, are not eligible for the NDIS. People who have accessed disability supports in the past can continue to do so under CoS arrangements, however people who are new to receiving support will be directed to the aged care system<sup>63</sup>.

VCOSS members are concerned that older people living with disability unrelated to ageing may not be receiving appropriate or timely support.

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<sup>60</sup> NDIA, *Information, Linkages and Capacity Building Program (ILC) Program Guidelines 2019-20 to 2021-22*, 2019, p.10.

<sup>61</sup> 'VCOSS, *A smooth NDIS transition: VCOSS submission to NDIS Joint Standing Committee inquiry into Transitional Arrangements for the NDIS*, August 2017.

<sup>62</sup> Council of Australian Governments, *Meeting of the COAG Disability Reform Council Communiqué*, 9 October 2019.

<sup>63</sup> Department of Health, *Eligibility for CoS*, <https://agedcare.health.gov.au/programs/commonwealth-continuity-of-support-programme/eligibility-for-cos>, accessed 25 October 2019.

Aged care funding through the Commonwealth Home Support Programme (CHSP) and Home Care Packages, however supports available are not necessarily disability-specific, funding is not always adequate and there are significant waiting lists<sup>64</sup>.

The interface between aged care and disability funding systems needs to be addressed to ensure people receive the right support for their needs, regardless of the funding stream.

### **People who are ineligible for the NDIS are often caught in the middle of Government funding handballs and confusion about which system pays for what type of support.**

As State-funded and Commonwealth-funded programs continue to transition to the NDIS, or have their funding shifted to the scheme, service gaps are appearing and in some cases growing.

The cruel and frustrating game of funding football is exacerbated by the outdated National Disability Agreement (NDA) for funding arrangements<sup>65</sup>, and piecemeal policy and funding fixes drip fed by the COAG Disability Reform Council (DRC)<sup>66</sup>.

As identified by the Productivity Commission earlier this year, the NDA no longer reflects the disability services landscape, which has changed significantly since the agreement was signed in 2008<sup>67</sup>.

While discrete agreements have been reached by the COAG DRC in regards to funding and interface issues between health related supports<sup>68</sup>, funding extensions for taxi subsidy schemes<sup>69</sup> and specialist school transport and personal care<sup>70</sup>, this patchy policy approach cannot continue. A new NDA is sorely needed to identify and address service gaps, clarify the roles and responsibilities of Governments and ensure all people with disability, families and carers can access the supports they need.

<sup>64</sup> L Alderslade, 'Peak bodies say Home Care Package waitlist is still in crisis', *Aged Care Guide*, September 2019.

<sup>65</sup> Productivity Commission, *Study report: Review of the National Disability Agreement*, January 2019.

<sup>66</sup> Department of Social Services, *Disability Reform Council*, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/government-international/disability-reform-council>, accessed 24 October 2019.

<sup>67</sup> Productivity Commission, *Study report: Review of the National Disability Agreement*, January 2019.

<sup>68</sup> Council of Australian Governments, *Factsheet: How the National Disability Insurance Scheme (NDIS) and health services will work together*, June 2019

<sup>69</sup> Council of Australian Governments, *Meeting of the COAG Disability Reform Council Communiqué*, 9 October 2019.

<sup>70</sup> Council of Australian Governments, *Meeting of the COAG Disability Reform Council Communiqué*, 10 December 2018.

## **Carers and families**

Carers and families often provide extensive support to people with disability, while experiencing social, economic and financial disadvantage and living with disability themselves<sup>71</sup>. One in eight Victorians provide unpaid care to family or friends, valued at \$15 billion annually<sup>72</sup>.

The transition to the NDIS, and navigating the access and planning processes, has increased the support many carers and families provide.

*“For me there’s been increased work for carers in terms of paperwork. It hasn’t been negative, but information-wise it’s been heavy. You spend all day googling things, it’s all on the carer to find things.”<sup>73</sup>*

The personal and financial impact of providing care impacts carers’ capacity to work, their income and their retirement<sup>74</sup>.

While the importance of carers is referenced in the NDIS Act, VCOSS members report reduced support is being provided for carers of people who are deemed eligible or ineligible for the NDIS.

Around one-third of carers do not feel the NDIS has helped, and feel unable to access services, programs and activities<sup>75</sup>. More than half of carers report the NDIS has reduced their ability to provide care<sup>76</sup>, and the majority do not access any carer-specific supports<sup>77</sup>.

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<sup>71</sup> Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings 2015*, October 2016.

<sup>72</sup> Deloitte Access Economics, *The economic value of informal care in Australia in 2015*, June 2015.

<sup>73</sup> T Papworth, ‘Carers call for more out of NDIS’, *Star Weekly*, 8 October 2019.

<sup>74</sup> B Nepal, L Brown, G Ranmuthugala and R Percival, *Lifetime health and economic consequences of caring: Modelling health and economic prospects of female carers in Australia*, Commonwealth Financial Planning, Commonwealth Bank of Australia, 2008, p.27.

<sup>75</sup> NDIA, *COAG Disability Reform Council Performance Report - National 30 June 2019*, 2019.

<sup>76</sup> Mavromaras et al., *Evaluation of the NDIS: Final report*, National Institute of Labour Studies, February 2018, p. 29.

<sup>77</sup> *Ibid.*, p. 54.

The NDIS planning process does not assess carers' needs and the supports listed in plans are framed largely from the participant's perspective. When funding for respite-like services is included in a participant's plan, participants and carers then face the additional challenge of finding a suitable and available service. A survey of parents of children with disability and young people found 63 per cent had difficulty accessing the right services and supports; this challenge which was even greater in regional, rural and remote communities<sup>78</sup>.

As funding for many carer support services, such as Mental Health Respite Carer Support, has transitioned to the NDIS, many carers no longer receive direct support for their caring role.

Federal reforms and investment in carer support has not kept pace with the roll out of the NDIS. Though digital services including online peer support, online training, and short-term phone-based counselling were launched in 2019 through the Carer Gateway website<sup>79</sup>, many carers no longer receive direct, face-to-face or personalised support.

The next phase of the Carer Gateway model, commencing in April 2020, will build upon these platforms and include additional funding for respite<sup>80</sup>, as well as up to 5,000 targeted financial packages of up to \$3000<sup>81</sup>, however we fear this may be too little, too late.

Recent reports reveal that at least 500 children with disability have been relinquished by their families since the introduction of the NDIS<sup>82</sup>, and many more struggle with the financial and emotional impacts of navigating the scheme. The situation is particularly challenging for parents and carers of children and young people who have multiple and complex needs, who do not have funding or are otherwise unable to access specialised positive behaviour support.

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<sup>78</sup> Children and Young People with Disability Australia, *Improving the NDIS planning process for children and young people with disability and their families: Submission to the Joint Standing Committee on the NDIS*, September 2019.

<sup>79</sup> Department of Social Services, *Integrated Carer Support Service Model*, <https://www.dss.gov.au/disability-and-carers-carers/integrated-carer-support-service-model>, accessed 16 October 2019.

<sup>80</sup> Hon Anne Rushton, *Media release: Unprecedented support for Australia's carers*, 21 August 2019.

<sup>81</sup> Department of Social Services, *Factsheet: More funding for carers services*, 2019 Budget, <https://www.dss.gov.au/about-the-department/publications-articles/corporate-publications/budget-and-additional-estimates-statements/budget-2019-20/more-funding-for-carers-services>, accessed 16 October 2019.

<sup>82</sup> R Morton, *Exclusive: 500 children forfeited to state in NDIS standoff*, *The Saturday Paper*, 12 October 2019.

*"I've voluntarily gone to child protection and said 'Help, I can't cope anymore...' Three times I've connected back with child protection on a voluntary basis, because I don't know what the answer is. When you have a child who is being violent in the home and it's causing so much distress to other children and it's a safety issue for myself... it's a terribly difficult situation."<sup>83</sup>*

To support carers' health and wellbeing, all carers must have access to appropriate levels of carer-specific support and services to meet their needs, irrespective of whether the person they care for is eligible for the NDIS. This includes access to general carer support, carer advocacy, counselling, and carer respite services.

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<sup>83</sup> ABC 774, 'Melbourne mum may have to give up disabled son due to inadequate NDIS support', 16 October 2019, <https://www.abc.net.au/radio/melbourne/programs/mornings/melbourne-mum-wants-to-give-up-her-child-due-to-inadequate-ndis-/11606662>, accessed 24 October 2019.

## Publish detailed data on timeframes, ineligibility and pathways

### RECOMMENDATION

- Establish timeframes for access decisions and processes, and release regular, detailed reporting

As outlined in our NDIS Participant Service Guarantee feedback, the availability and transparency of data needs to be improved and measured in relation to access outcomes.

While the NDIA Operational Guidelines state that access request decisions will be made within 21 days unless additional information is requested<sup>84</sup>, VCOSS members report that people are waiting many months to find out if they are eligible for the scheme. These delays are especially stressful and concerning for people with no supports, and people who need early intervention support.

A clear process for access decisions needs to be made publicly available, including specific timeframes for access decisions. The NDIA should release regular, detailed reporting on:

- the number of people deemed eligible or ineligible for the NDIS, by disability and service type
- the average wait times experienced by people at each step of the access stage, including if these wait times meet performance expectations
- the number of people ineligible for the NDIS successfully connected to alternative supports
- the engagement and satisfaction of people with disability, carers, families, and in particular, of disadvantaged and isolated communities, with the access and eligibility process.

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<sup>84</sup> NDIA, *Operational Guidelines 4.8*, <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/access-ndis-operational-guideline-general-matters-relating-access-requests#4.8>, accessed 24 October 2019.

## Planning: Creating NDIS plans

### Promoting the voices and choices of people with disability through the planning process

#### RECOMMENDATIONS

- Enable greater, meaningful participant inclusion in the planning process through supported decision making, advocacy and self-advocacy
- Improve equity in planning experiences through investing in pre-planning support, disability advocacy and the knowledge and skills of Planners
- Enable participants to review a draft of their plan
- Provide participants with the opportunity to request plan amendments, while retaining components of their plan that are working well

The vision of the NDIS is to provide people with disability greater choice and control in their lives and the services they access, however many participants continue to experience more doing “to” than “with” during the planning process.

While the objects and general principles of the *NDIS Act* reflect a rights-based approach, the voice and agency of participants is not consistently or effectively promoted through the planning process.

After navigating the access process, which is focused on impairment and deficits, participants are expected to shift their thinking towards their goals and needs, which can be overwhelming. A strengths-based approach throughout the whole participant journey, that reflects the social model of disability, could improve experiences and outcomes for participants.

VCOSS members believe the planning process needs to become more inclusive, accessible and safe for people with disability to share their views and be heard. This includes enabling participants to share their goals and needs through supported decision making, and empowering participants of all ages to access advocacy services and build their self-advocacy skills.

In addition to engaging participants directly, our members would like the planning process to carefully consider the involvement of participants' carers, families and support networks. Parents of children with disability and families often experience significant financial and emotional stress during transition to the NDIS, particularly if their child has been recently diagnosed with a disability or developmental delay<sup>85</sup>. As children mature into young adults, it is important they have opportunities to express their views and wishes, and the support to build their confidence to do so. Often planners defer to carers or families to make decisions on behalf of young people, people with intellectual disability and people with psychosocial disability.

Women with disabilities report they often do not feel heard or understood through the planning process, which can result in poor planning outcomes<sup>86</sup>. Women with Disabilities Victoria works with women to let them know about their rights in the planning process, including requesting a different planner if they do not feel comfortable and choosing the people they want involved in their planning meeting.

A gender-sensitive approach to planning, and the participation of carers and support networks through the planning process, must also include screening and safeguards in regards to family violence and power imbalances. For example, through the planning process, a perpetrator of family violence may seek to limit the supports a victim can access that would provide greater independence. Without an understanding of power and violence, a Planner may inadvertently make decisions or statements that reinforce a perpetrator's control.

**Receiving a good plan too often appears to depend on a participant's literacy, tenacity, support network and social capital.**

Our members are concerned that the most well-resourced participants and families are more likely to receive quality, adequately funded plans, while disadvantaged or isolated participants have poorer planning outcomes.

While our members report the introduction of the complex needs planning pathway<sup>87</sup> has delivered improvements for some participants, meeting the criteria to access this stream is

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<sup>85</sup> Children and Young People with Disability Australia, *Improving the NDIS planning process for children and young people with disability and their families: Submission to the Joint Standing Committee on the NDIS*, September 2019.

<sup>86</sup> Women with Disabilities Victoria, *Submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) on NDIS Planning*, September 2019

<sup>87</sup> NDIA, *Complex support needs pathway*, <https://www.ndis.gov.au/about-us/ndis-pathway-reform/pathway-reform-whats-happening-2019#complex-support-needs-pathway>, accessed 24 October 2019.

difficult. Many components of this pathway that are working well – from the quality of service to the flexibility to make adjustments – could be expanded across the board to improve participant experiences.

To ensure equity in planning experiences, investment is needed in:

- impartial, thorough pre-planning support
- independent disability advocacy
- Planner knowledge and skills.

**To prepare for transition to the NDIS, many organisations have provided participants with unfunded assistance to identify and articulate their goals and needs.**

The Productivity Commission recognised the importance of this support, finding that inadequate pre-planning assistance can leave many participants unprepared for their NDIS planning session<sup>88</sup>.

Assisting participants to undertake comprehensive meeting preparation can help people to better describe their goals and aspirations, and improve the quality of their plans. People with complex needs and groups experiencing disadvantage or vulnerability especially require this type of assistance to navigate the NDIS and receive meaningful plans.

Without adequate pre-planning support, participants may be more likely to receive inappropriate plans. One example was described by the Victorian Mental Illness Awareness Council (VMIAC) in a roundtable discussion with the Joint Standing Committee on the NDIS in regards to psychosocial disability:

*“We need more intensive support for people to get into the NDIS and around the planning process. To give you an example, I advocated for a person who was given a \$1 NDIS plan. He had \$1 in his plan and that's because he walked into the planning meeting and didn't know much about the NDIS and was asked these questions. Because of his history of trauma and mental illness he just shut up and said, 'Oh, no, I'm fine with this; I'm fine with that,' when he was very not fine. This person was homeless for a number of years. He's in a precarious living situation now, but he's got a place to live. I had to work with him for a number of hours to get him to feel like he could tell his story at the next planning session.”<sup>89</sup>*

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<sup>88</sup> Productivity Commission, *Study report: National Disability Insurance Scheme (NDIS) Costs*, October 2017, p. 28.

<sup>89</sup> Neil Turton-Lane, NDIS Manager, VMIAC speaking to the Joint Standing Committee on the NDIS, *Committee Hansard*, 26 February 2019.

While the initial intention was for LACs to perform this function, the speed of the roll out and the number of people requiring support meant this did not eventuate as anticipated<sup>90</sup>.

There are a number of ways pre-planning support could be strengthened, and to meet the diversity of community needs, VCROSS recommends a combination of increasing the capacity of LACs to perform this function and funding for intersecting or specialist services to provide this role for people who experience additional barriers, complexities and disadvantage.

**As outlined in our access and eligibility recommendations, independent disability advocacy delivers crucial support to people with disability through each stage of the NDIS journey.**

In the planning phase, advocates can support participants to express their needs and ensure their plan aligns to their individual goals. As the Victorian Government has stated:

*“The role of advocacy and self-advocacy will continue to be important in building participants’ capacity to meaningfully exercise choice. Particularly during transition, some participants may need additional assistance to navigate the planning and plan implementation processes.”<sup>91</sup>*

Advocates play a crucial role in supporting NDIS participants through the planning process to ensure their goals and needs are heard and reflected in their funding package. Advocacy is also a key enabler in driving service quality and safety.

The NDIS Quality and Safeguards Commission, which commenced in Victoria in July 2019, is responsible for registering providers, responding to complaints, overseeing reportable incidents and providing behavior support leadership. The Head of the NDIS Quality and Safeguards Commission Graeme Head has publicly acknowledged the role of a strong advocacy capability in supporting people to speak up about any concerns, and in protecting people from abuse and neglect<sup>92</sup>.

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<sup>90</sup> Productivity Commission, *Study report: National Disability Insurance Scheme (NDIS) Costs*, October 2017, p. 213.

<sup>91</sup> Victorian Government, *Productivity Commission Review of NDIS Costs: Whole of Victorian Government*, April 2017, p.19.

<sup>92</sup> Graeme Head, Head of the NDIS Quality and Safeguards Commission, speaking at the *Strengthening Disability Advocacy Conference 2019: Advocacy under pressure*, 2 September 2019, <http://www.daru.org.au/conference-session/plain-talking-from-the-top>, accessed 28 October 2018.

**Planners' varying levels of time, knowledge, expertise and understanding have been established as some of the key factors impacting the quality and consistency of plans<sup>93</sup>.**

Too often, receiving a good plan is dependent on the skills of an individual Planner and their interpretation of the reasonable and necessary criteria. The stakes are too high for positive planning experiences to be a game of chance.

Inconsistencies in planning processes and outcomes for participants are well-documented and are an ongoing concern for the sector<sup>94</sup>. VCOSS members report varying experiences with the planning process, depending on the Local Area Coordinators or individual Planners, and concerns that Planners do not have the time or skills to take a person-centred approach to their role.

Planners appear to be under significant pressure to bring people into the scheme, which our members fear is contributing to a quantity versus quality culture and inadequate direct engagement with participants.

Despite the lengthy and costly investment in specialist assessments and reports before or during the access stage, this evidence is often disregarded during the planning phase, with participants advised to get more or new assessments. This duplication is demoralising, expensive and delays participant access to supports. When assessments are available and disregarded, participant plans are often not comprehensive enough to deliver evidence-based, best practice support.

For example, we heard from our members of a participant who provided a therapy report during the access stage that recommended 76 hours of support was needed; however, when it came to the planning stage, this participant only received 12 hours of therapy support.

In addition, participants are often asked to get new assessments done, even when recent and relevant evidence is available. This extends the delays experienced by participants, given the waiting lists and access issues previously outlined in regards to assessments, which often have a greater impact on people experiencing disadvantage and people from regional and remote communities.

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<sup>93</sup> Ibid.

<sup>94</sup> Joint Standing Committee on the NDIS, *Progress Report*, March 2019.

Through the plan development stage, the needs of carers are often not fully understood or recognised, including the support needed to sustain caring relationships.

We recommend further training is provided for all Planners and that the overall planning workforce is boosted to enable greater time and attention to be paid to the planning experience. A robust training program for Planners should include:

- communication, empathy and listening skills
- understanding disability – types of disabilities, disability rights and the social model of disability
- person-centred practice
- training for working with priority groups, such as First Nations people, people from culturally diverse backgrounds, refugees and asylum seekers, LGBTIQ+ people and around particular areas such as gender, family violence and homelessness.

We welcome the introduction of the complex needs planning pathway<sup>95</sup>, which VCOSS members have noted is improving experiences and outcomes for participants. As eligibility for the complex needs pathway is narrow, building the knowledge of all planners in working with people experiencing disadvantage and isolation is critical to ensuring participants can develop a plan that reflects their individual goals and needs.

Investing in quality planning will improve outcomes for participants and the financial sustainability of the scheme, by reducing the need for lengthy and costly plan reviews and appeals.

**Under current legislation, participants do not have the opportunity to review their plan before it is sent to the NDIA for approval<sup>96</sup>.**

This presents many issues, and according to our members, contributes to many plan reviews. Despite this issue being identified and action recommended in 2017<sup>97</sup>, there has been no progress in enabling participants to review a draft of their plan. Providing participants with a draft of their plan would enable mistakes or omissions to be addressed quickly, and reduce the need for long, stressful and expensive reviews and appeals.

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<sup>95</sup> NDIA, *NDIS pathway reform*, <https://www.ndis.gov.au/news/1215-ndis-pathway-reform>, accessed 24 October 2019.

<sup>96</sup> *NDIS Act 2013* (Cth), s.37 and s.38.

<sup>97</sup> Joint Standing Committee on the NDIS, *Progress Report*, March 2019, Recommendation 1, p. 121.

We support the Discussion Paper's suggestion of allowing plan amendments. The current design of the scheme doesn't allow for changes and modifications – any variations trigger the replacement of a Plan<sup>98</sup>. VCOSS members say many participants are afraid to ask for a plan review, in case they end up worse off and face further funding cuts. Participants feel threatened by the plan review process and the potential unintended consequences of speaking up about their needs<sup>99</sup>. It is important that the plan amendment process focuses on the specific issues or requests raised by participants, and does not seek to reduce or remove supports from other parts of a plan.

### **Case study: Simple category mistake goes to AAT**

*“A participant had a suitable plan with all the supports she needed for achieving her goals. When she sought supply of one of her supports from a service provider, she was told that the Planner had placed the funding for that support in the wrong category and that the service provider wasn't authorised to supply supports in that category.*

*She contacted the NDIA, seeking to have the plan adjusted so that the support was in the right category. The agency did not adjust the plan, but treated it as a request for a plan review, which was denied, resulting in the participant taking the issue to the Administrative Appeals Tribunal (AAT).*

*Some nine months after the original request, at the AAT case conference, the NDIA representative agreed that correcting the plan was the appropriate action and the correction was subsequently made. Simple adjustments at the front line could prevent waste of time, money and reputation.”<sup>100</sup>*

Enabling participants to review draft plans and make plan amendments would reduce the delays and bottlenecks in the internal reviews process, and more importantly, would empower people with disability to interact with their plan more confidently.

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<sup>98</sup> NDIS Act 2013 (Cth), s.37.2.

<sup>99</sup> L Michael, “They see it as a threat’: People with disability warned not to challenge NDIS decisions’, Pro Bono News, 8 October 2019.

<sup>100</sup> Leadership Plus, *Unreasonable and unnecessary risks to NDIS' mission: A submission to the Joint Standing Committee on the NDIS Re: NDIS Planning*, September 2019

## Planning: Using NDIS plans

### Providing support for people to understand and implement their funding plan

#### RECOMMENDATION

- Ensure people are supported to implement and coordinate their first plan and subsequent plans through support coordination or specialist case management

To access services with NDIS funding, participants are required to manage services, often across large and multiple service systems. Implementing an NDIS plan, by finding, purchasing and managing services, isn't easy. It takes time for participants to feel confident in understanding and using their funding.

The shift of administrative responsibilities towards people with disability and their support network presents additional challenges for already stretched participants and families<sup>101</sup>. Additionally, managing services can be particularly difficult for people with multiple and complex needs or in crisis situations, including people experiencing homelessness or family violence.

The latest data from the NDIA shows 22 per cent of people who recently received their NDIS Plans were unclear on what happens next, and 17 per cent don't know where to go for more help<sup>102</sup>. Support coordination, funded through the NDIS, is intended to assist people to understand and implement their plan, by finding and connecting to services and coordinating their supports.

VCOSS members share the concerns of many across the sector that the role of support coordination is not appropriately recognised or funded. While the intention of support coordination, and more broadly of the scheme, is to promote participants' choice and control, it is important to recognise that participants are coming into the scheme with no history of having received disability support, or are transitioning into the scheme from an old 'welfare' model characterised by rationed support and therefore negligible choice.

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<sup>101</sup> D Warr, H Dickinson, S Olney et. al., *Choice, Control and the NDIS: Service users' perspectives on having choice and control in the new National Disability Insurance Scheme*, Melbourne: University of Melbourne, May 2017, p. 55.

<sup>102</sup> Ibid

Consequently, many NDIS participants need support to build their capacity and confidence to step into their power as consumers and fully exercise choice and control.

It is therefore surprising that, over the past financial year, just 42 per cent of participants received funding for support coordination<sup>103</sup>. Support coordination is especially critical for people with complex needs<sup>104</sup>, who need intensive and ongoing support to navigate the NDIS.

Without support coordination, people experiencing disadvantage or additional challenges may be less likely to activate and use their plan. 7.4 per cent of NDIS plans approved from March to June 2019 have not been activated – that means people haven't started their plans, used any of their funding or accessed services<sup>105</sup>.

VCOSS members working in family violence organisations reported a number of instances where women and children fleeing family violence had NDIS plans they either did not know about or did not know how to access. When families are in crisis, having access to specialist disability supports could make a substantial difference for participants and the whole family.

Our members report that it's becoming increasingly difficult to receive any or sufficient funding for support coordination. The number of NDIS participants has grown by 157 per cent over the past two years, however support coordination funding is at its lowest level yet, representing just 2.8 per cent of total annualised committed support<sup>106</sup>

In 2018 the Joint Standing Committee on the NDIS recommended ensuring “support coordination is adequately funded in Plans to meet Participants’ needs and not limited to a fixed period,”<sup>107</sup> however little progress has been made in this respect<sup>108</sup>.

The NDIA is exploring low plan utilisation and the potential drivers, including the extent of support coordination in a participant's plan<sup>109</sup>. We recommend the NDIA reviews its approach to support coordination to take into account this analysis and the feedback and recommendations provided by the sector to date. Support coordination should be included in all first plans, and ongoing as needed, to enable people to implement their plans effectively.

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<sup>103</sup> Ibid

<sup>104</sup> Ibid.

<sup>105</sup> NDIA, *COAG Disability Reform Council Performance Report - National 30 June 2019*, 2019.

<sup>106</sup> NDIA, *NDIS Performance Dashboard reports*, review of data 2017-18 and 2018-19.

<sup>107</sup> Joint Standing Committee on the NDIS, *Transitional Arrangements for the NDIS*, February 2018, Recommendation 21, p.77.

<sup>108</sup> Joint Standing Committee on the NDIS, *Progress Report*, March 2019, p.102.

<sup>109</sup> NDIA, *Annual Report 2018–19*, October 2019, p.26.

While case management is not funded under the NDIS, advocates and organisations maintain this is an essential function to support people to engage with the NDIS and access the services and supports they require<sup>110</sup>.

Case management facilitates important information sharing and collaboration functions, including coordinating care teams, that can greatly improve outcomes for people with multiple or complex needs. Traditional case managers can provide more in-depth and sustained assistance, which can include assessment, planning, facilitation and advocacy<sup>111</sup>; whereas support coordinators deliver time-limited assistance, and are not funded to provide advocacy-type support<sup>112</sup> and have reduced capacity to coordinate care teams. This is a valuable function that has been lost in the transition to the NDIS that is still vital and relevant.

In recognition of these issues, the Victorian Government currently provides intensive support to individuals “experiencing significant issues in their NDIS transition,” working across the pre-planning, planning and post-planning stages<sup>113</sup>. This type of support is seen as critical by the sector, and governments and the NDIA should work together to ensure that ongoing case management can be provided to participants with complex and challenging support needs<sup>114</sup>.

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<sup>110</sup> Victorian Office of the Public Advocate, *The illusion of ‘Choice and Control’*, September 2018.

<sup>111</sup> F Marfleet, S Trueman and R Barber, *National Standards of Practice for Case Management*, Case Management Society of Australia & New Zealand 3rd Edition, 2013

<sup>112</sup> VALID, What to expect from your support coordinator, <https://www.valid.org.au/what-expect-your-support-coordinator> accessed 27 October 2019; Disability Services Consulting, ‘Update: Support Coordinators in Planning Meetings’, 13 December 2019, <https://www.disabilityservicesconsulting.com.au/resources/support-coordinators-plan-meetings-update>, accessed 27 October 2019.

<sup>113</sup> Victorian Department of Health and Human Services, *National Disability Insurance Scheme (NDIS) – child and family system interface: Practice guidelines for Child FIRST, The Orange Door, Integrated Family Services, Child Protection and Out-of-Home Care*, September 2018, p.44.

<sup>114</sup> Victorian Office of the Public Advocate, *The illusion of ‘Choice and Control’*, September 2018, Recommendation 11, p.37.

## Enabling flexible options regarding plan length including interim plans

### RECOMMENDATION

- Provide flexible options in plan length, based on participant needs, including interim plans, short term plans and longer term plans

The current planning process is designed to provide participants with an annual funding plan. While an annual plan length works for some, it does not work for everyone – some people’s circumstances may change more rapidly, while others may have more predictable or stable goals and needs.

Enabling choice and control in the length of plans would deliver benefits for participants and scheme sustainability by better aligning administration processes to the goals and needs of participants. Where participants are new to receiving support, being able to receive a shorter term or interim plan may enable them to connect to services sooner. For example, children with a developmental delay, or people diagnosed with Motor Neurone Disease, may require faster support than the current NDIS processes provide. On the other hand, where a plan is working well, it may make sense to extend the funding plan rather than conducting a plan review and creating a new plan.

We welcome the recent introduction of interim plans for children who have been waiting more than 50 days between an access decision and receiving a plan. Under the new initiative, children can access an interim six-month plan for \$10,000 and work towards developing a full NDIS plan<sup>115</sup>.

To increase access to individualised NDIS funding, we recommend all participants are provided with options in regards to the length of their plan, and that all participants have the opportunity to access an interim plan.

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<sup>115</sup> Hon Stuart Robert MP, *Media release: Children to get faster access to NDIS supports*, 26 June 2019.

## Boosting the NDIA's role in fostering a thriving, responsive market

### RECOMMENDATIONS

- Boost the NDIA's role in market oversight and stewardship, to ensure the supply of services adequately meets demand – including which services are offered, where they are delivered, and protecting their quality
- Increase NDIS pricing to reflect the true costs of service delivery, promote access to best-practice, evidence-based support and improve provider sustainability
- Build and support the workforce required to deliver the NDIS through strategic planning and analysis, addressing gaps and increasing training and employment pathways into the sector

While \$9.2 billion of individualised funding was allocated to participants across Australia in 2018-19<sup>116</sup>, just 64 per cent of funds committed for NDIS supports were used in the past financial year<sup>117</sup>. As outlined in our submission to the NDIS Thin Markets Project<sup>118</sup>, VCOSS and our members are concerned that market failures – in this case, low plan utilisation or low uptake of certain services in participants' plans – are being interpreted as market signals and taken to mean participants' have less need for services in general.

### **The causes of low plan utilisation need to be viewed in the context of plan quality, participant capacity and market supply.**

For example, organisations report that certain activities such as group sessions may be included in participants' plans regardless of their desire to engage in these activities (often due to the relative cost of group versus one-on-one support). When the participant does not engage in particular activities (as it is not their preferred service), there is concern this will be read as an indication that the participant requires fewer services, and that their plan's funding may be reduced in future years.

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<sup>116</sup> NDIA, *COAG Disability Reform Council Performance Report - National 30 June 2019*, 2019.

<sup>117</sup> *Ibid.*

<sup>118</sup> VCOSS, *Active market stewardship for the National Disability Insurance Scheme: VCOSS Submission to the NDIS Thin Markets Project*, June 2019.

Our members report that participants feel pressured to justify underspending when their plan is reviewed, despite the varying reasons behind an underspend, including changes in needs and the availability of services. Funding is often reduced over time on the assumption that either improvements have been made or supports are no longer needed.

This is particularly concerning for participants with a psychosocial disability, whose support needs are likely to be episodic. Rather than plan under-utilisation being seen as a reduced need for support, the causes are commonly related to participants being too unwell to activate their plan and connect to services, extended hospital stays, not having support coordination and a lack of appropriate services<sup>119</sup>.

The process of finding and connecting to services can be overwhelming for participants, particularly those who are new to receiving support services. While some participants receive funding for support coordination, 58 per cent of people don't receive this service<sup>120</sup> and are usually supported by their LAC to activate and use their plan. As outlined throughout this submission, LACs are already stretched and may not have capacity to support plan implementation.

One of the biggest barriers to plan utilisation is thin or immature markets, where there are few or no services available for participants. This challenge is even greater for participants experiencing disadvantage, those living in regional and rural areas, and people with complex needs.

***“The issue is trying to access the supports. You can have money sitting there, but unless you’re able to use it... it’s not helpful. I have a support coordinator who has been great, but still, we’re knocking on doors of different organisations who may or may not have the right supports.”<sup>121</sup>***

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<sup>119</sup> N Hancock, B Gye, C Digolis, J Smith-Merry, J Borilovic and J De Vries, *Commonwealth Mental Health Programs Monitoring Project: Tracking transitions of people from PIR, PHaMs and D2DL into the NDIS*, The University of Sydney & Community Mental Health Australia, September 2019.

<sup>120</sup> NDIA, *COAG Disability Reform Council Performance Report - National 30 June 2019*, 2019.

<sup>121</sup> ABC 774, 'Melbourne mum may have to give up disabled son due to inadequate NDIS support', 16 October 2019, <https://www.abc.net.au/radio/melbourne/programs/mornings/melbourne-mum-wants-to-give-up-her-child-due-to-inadequate-ndis-/11606662>, accessed 24 October 2019.

The NDIA is working across jurisdictions and regions to explore the drivers of under-utilisation, noting potential factors such as access to information, pricing, support coordination, funding flexibility and market capacity<sup>122</sup>. Without effective intervention, the NDIS is likely to create or perpetuate inequitable service coverage for some NDIS participants, particularly those facing multiple layers of disadvantage.

We welcome the work underway by the Melbourne Disability Institute to assess plan utilisation and plan equity<sup>123</sup>. While we hear from VCROSS members that people with fewer resources, experiencing disadvantage or from community and cultural groups often receive smaller or inadequate plans, this project presents an opportunity to establish an evidence base.

A strong, vibrant market is crucial in enabling participants to access the support they need and truly exercise choice and control. As part of a holistic view of NDIS participant experiences, we recommend greater collaboration between governments and the NDIA to:

- Boost the NDIA's role in market oversight and stewardship, to ensure the supply of services adequately meets demand – including which services are offered, where they are delivered, and protecting their quality
- Increase NDIS pricing to reflect the true costs of service delivery, promote access to best-practice, evidence-based support and improve provider sustainability
- Build and support the workforce required to deliver the NDIS through strategic planning and analysis, addressing gaps and increasing training and employment pathways into the sector.

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<sup>122</sup> NDIA, *Annual Report 2018–19*, October 2019, p.26.

<sup>123</sup> The Brotherhood of St Laurence, *'Brotherhood Talks podcast NDIS: What's working, what's not? Part Two' transcript*, <https://www.bsl.org.au/media/podcasts-brotherhood-talks/ndis-whats-working-whats-not-part-two/>, accessed 24 October 2019.

## Addressing service gaps and interface issues to ensure no-one is left behind

### RECOMMENDATION

- Urgently address interface issues with mainstream services and provider of last resort arrangements to ensure equitable, timely access to support

VCOSS and our members are concerned about growing service gaps and increasing interface issues, and in particular, the impact on people experiencing disadvantage and those with complex needs.

In 2018, 13 per cent of providers reported they had discussed ceasing their disability services, a 4 per cent increase from 2017<sup>124</sup>. Over a third have considered merging with another organisation, while 12 per cent recently completed or are currently undertaking a merger<sup>125</sup>. Over half of providers are concerned they will not be able to deliver services at current prices (58 per cent) or will have to reduce service quality (54 per cent)<sup>126</sup>. In regional and remote communities, the closure or merger of services is particularly concerning, as participants may be left with fewer or no options.

System boundaries continue to limit access to integrated, holistic and outcomes-focused support from different service systems<sup>127</sup>. The interface between NDIS and mainstream services, including health, education, justice and aged care, is often unclear.

When the funding football is handballed between Commonwealth and State-funded services in a game of who pays for what, NDIS participants are almost always worse off. In a justice context, unclear processes and planning can contribute to delays to discharge or release, and inadequate or ineffective supports being in place, which may make people more vulnerable to re-offending<sup>128</sup>.

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<sup>124</sup> National Disability Services, *State of the Disability Sector Report 2018*, November 2018.

<sup>125</sup> Ibid.

<sup>126</sup> Ibid.

<sup>127</sup> D Warr, H Dickinson, S Olney et. al., *Choice, Control and the NDIS: Service users' perspectives on having choice and control in the new National Disability Insurance Scheme*, Melbourne: University of Melbourne, May 2017.

<sup>128</sup> Victorian Legal Aid, *Ten stories of NDIS 'Thin Markets': Reforming the NDIS to meet people's needs - Submission to the Department of Social Services and the National Disability Insurance Agency's NDIS 'Thin Markets' Project*, June 2019.

Our members report that parents who do not know whether supports are best funded by the NDIS or the education system end up paying the gap themselves, or missing out on the services their child is entitled to receive. In public housing settings, our members also report that responsibilities are unclear in regards to who pays for what.

While there have been some steps towards clarifying responsibilities through COAG communiques<sup>129</sup> and State-based practice guidelines<sup>130</sup>, on the ground, people with disability are still caught in the middle.

Provider of last resort arrangements also remain frighteningly unclear, despite consecutive Joint Standing Committee recommendations over the past three years highlighting this ongoing issue<sup>131</sup>.

VCOSS members remain concerned that without appropriate and responsive crisis and provider of last resort arrangements, vulnerable people are falling through the cracks in the system or are forced to stay in inappropriate or unsafe settings.

Participants who are eligible for NDIS support remain in hospitals, residential aged care<sup>132</sup> and jail<sup>133</sup> because there are not appropriate or enough services to support their needs.

As of July 2019, 80 Victorian patients with disability were stuck in hospital for more than three months after they were ready for discharge because of NDIS-related delays<sup>134</sup>, and many other stories have emerged across Australia of long hospital stays<sup>135</sup>.

Women and children with disability may also be unable to escape family violence without access to specialised crisis supports that meet all their individual needs.

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<sup>129</sup> Department of Social Services, *Disability Reform Council*, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/government-international/disability-reform-council>, accessed 24 October 2019.

<sup>130</sup> Department of Health and Human Services (Vic), *Practice guidelines: NDIS and mainstream services*, <https://providers.dhhs.vic.gov.au/practice-guidelines-ndis-and-mainstream-services>, accessed 24 October 2019.

<sup>131</sup> Joint Standing Committee on the NDIS, completed inquiries in the 45th Parliament.

<sup>132</sup> GM Bishop, J Zail, L Bo'sher and D Winkler, *Young People in Residential Aged Care (2017 – 2018) A Snapshot*, Summer Foundation, August 2019.

<sup>133</sup> L Milligan, 'Emergency intervention to remove disabled man left in prison after NDIS providers refused to care for him', *ABC News*, 10 November 2017; E Baker, 'He was returned to prison: Detainees fall prey to NDIS process', *The Canberra Times*, 9 June 2018; C Schelle, 'NDIS failing jailed Vic woman: report', *AAP*, 14 December 2017.

<sup>134</sup> N Towell and M Cunningham, '\$700 million dollars guaranteed to Victorians with disabilities following NDIS agreement', *The Age*, 17 June 2019; A Cooper, 'Unconvicted, Indigenous, disabled man is free after 543 days in jail', *The Age*, 18 June 2018.

<sup>135</sup> C Campbell, 'Federal Government under pressure to repay state taxpayers for NDIS delays', *ABC News*, 14 February 2019; S Meixner and T Cassidy, 'Parents of quadriplegic man say NDIS delay extended hospital stay by six months at \$1,500 per day', *ABC News*, 3 March 2019.

The 'provider of last resort' function in the disability sector has traditionally been undertaken by state governments, but with the implementation of the NDIS the responsibility for this role remains unclear and has become disputed<sup>136</sup>. As with most examples of thin markets in the NDIS, it is participants who bear the cost of this – with many documented cases of people experiencing significantly negative outcomes.<sup>137</sup>

While the Productivity Commission and the Joint Standing Committee have recommended that the NDIA clarify its Provider of Last Resort policy as a matter of urgency<sup>138</sup>, there has been limited progress to date and there is little accountability in this area. As noted by the Victorian Office of the Public Advocate, "the NDIA has reframed the concept of Provider of Last Resort as 'critical support' arrangements"<sup>139</sup> and has been piloting a project titled 'Maintaining Critical Supports'<sup>140</sup>. However there is limited public information available on the project and its outcomes,<sup>141</sup> and it has not yet been extended across the country.

VCOSS and our members strongly recommend that appropriate provider of last resort arrangements are clarified and implemented as soon as possible. We support the Office of the Public Advocate's recommendation that "the NDIA should publish, consult on and implement... [this] policy and framework as a matter of urgency."<sup>142</sup>

Funding interfaces between the NDIS and other support systems, and provider of last resort arrangements, must be agreed by Commonwealth, state and territory governments and the NDIA, and included in bilateral agreements and operational plans.

The current approaches to addressing interface issues and crisis arrangements are fragmented and piecemeal. To deliver better outcomes for people with disability, a longer term strategy and funding agreement is required.

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<sup>136</sup> Joint Standing Committee on the NDIS, *Progress Report*, March 2019; Victorian Office of the Public Advocate, *The illusion of 'Choice and Control'*, September 2018; Joint Standing Committee on the NDIS, *Committee Hansard*, 26 February 2019.

<sup>137</sup> Joint Joint Standing Committee on the NDIS, *Progress Report*, March 2019, Victorian Office of the Public Advocate, *The illusion of 'Choice and Control'*, September 2018; Victoria Legal Aid, *The NDIS: Six priority issues and models that are working well Submission to the Joint Standing Committee on the National Disability Insurance Scheme: Inquiry into general issues around the implementation and performance of the NDIS*, March 2019.

<sup>138</sup> Joint Standing Committee on the NDIS, *Market readiness for provision of services under the NDIS*, September 2018, Recommendation 24, p.78; Productivity Commission, Study report: *National Disability Insurance Scheme (NDIS) Costs*, October 2017, Recommendation 7.1, p.54; Joint Standing Committee on the NDIS, *Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, Recommendation 18, p.xv; Joint Standing Committee on the NDIS, *Transitional arrangements for the NDIS*, Recommendations 9 and 18, p.xii and xiii.

<sup>139</sup> Joint Standing Committee on the NDIS, *Progress Report*, March 2019, p.46; Victorian Office of the Public Advocate, *The illusion of 'Choice and Control'*, September 2018, p.33.

<sup>140</sup> NDIA, *From the CEO – March 2018*, <https://www.ndis.gov.au/news/ceo/ceo-march-2018>, accessed 24 October 2019.

<sup>141</sup> National Disability Services, *NDIS Market Dynamics Study: National Disability Services Victorian NDIS Sector Development Project*, April 2019.

<sup>142</sup> Victorian Office of the Public Advocate, *The illusion of 'Choice and Control'*, September 2018, Recommendation 8, p.37.

We urge governments to hasten work on the National Disability Agreement (NDA) and National Disability Strategy (NDS), to drive a consistent, long term approach towards providing holistic support for people with disability.

The NDA and NDS should include contingency funding and frameworks that ensure support is available when crises arise for NDIS participants, including crisis and respite accommodation that can be secured at short notice<sup>143</sup>.

## Publishing data on planning timeframes, satisfaction and outcomes

### RECOMMENDATIONS

- Publish regular data on the planning experience including waiting times, plan reviews, funding changes between packages, plan utilisation and participant satisfaction
- Collate and share more detailed and frequent market data to drive strategies for market development and workforce planning

As per our Guarantee feedback, planning experiences need to be connected to tangible timeframes and performance measures. These measures are important to build visibility of the planning process and participant satisfaction. Key metrics to capture and report may include:

- maximum waiting times between access request approvals and planning commencing
- the number of scheduled and unscheduled plan reviews
- funding changes between plans ie. packages increasing or decreasing
- plan utilisation as a sign of market health, not market demand
- participant satisfaction with the planning experience and the contents of their plan

In its role as a market steward, we also recommend the NDIA publishes more detailed and frequent market data about participants, committed supports, providers and plan implementation.

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<sup>143</sup> Victorian Office of the Public Advocate, *The illusion of 'Choice and Control'*, September 2018.

The availability of data to drive strategies for market development and workforce planning will enable Governments and providers to deliver better services for people with disability. Initiatives such as the National Disability Data Set<sup>144</sup> and the Democratising Disability Data Coalition<sup>145</sup> have great potential to support evidence-based policy and service delivery.

In addition, access to further information regarding the disability workforce would help identify patterns and skills gaps to support the sector now and into the future. We recommend the Australian Government provides funding to the Australian Bureau of Statistics to regularly collect and publish information on the qualifications, age, hours of work and incomes of those working in disability care roles, including allied health professionals.

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<sup>144</sup> Council of Australian Governments, *Australian Data and Digital Council Communique 6 September 2019*, 2019.

<sup>145</sup> Melbourne Disability Institute, Democratising disability data, <https://disability.unimelb.edu.au/research/democratising-disability-data>, accessed 24 October 2019.

## Reviews and appeals

### Providing fairer, transparent review and appeal processes

#### RECOMMENDATIONS

- Provide clearer, accessible information about reviews and appeals processes
- Establish timeframes for each stage of the reviews and appeals processes, and avenues for people to seek assistance if the timeframes are not met
- Improve communications from the NDIA in regards to review and appeal procedures, timelines and templates
- Increase funding for independent disability advocacy and legal assistance to enable participants to exercise their rights
- Improve the quality of planning experiences to reduce the number of reviews and appeals
- Publish data on reviews and appeals, including quantities, timeframes, responsiveness and outcomes

Despite Principle 4.7 of the *NDIS Act 2013* that “People with disability have the same right as other members of Australian society to pursue any grievance”, the reviews, appeals and complaints process is confusing, slow and frustrating for many people.

People experiencing disadvantage face additional barriers to engaging in these processes, as the capacity to pursue a review, appeal or complaint is largely dependent on a participant’s support network and privilege. In addition, the literacy level required to understand and access the reviews, appeals and complaints processes is unfairly high and may work to exclude people experiencing disadvantage, people with an intellectual disability or an acquired brain injury, and people from culturally and linguistically diverse communities.

VCOSS members believe the current processes trigger trauma and deepen the divide for people experiencing disadvantage, with the participants who are the least resourced being the most likely to fall through the cracks. A fair and accessible reviews, appeals and complaints process is crucial to ensure people with disability can exercise their rights and have choice and control.

**The reviews and appeals processes are intimidating, adversarial and inaccessible for most participants, and especially challenging for people experiencing disadvantage and isolation.**

Participants can request an internal review of a decision, and if they are not satisfied with the outcome of the internal review, they can lodge an appeal with the Administrative Appeals Tribunal (AAT).

The literacy requirements to understand the legal jargon and engage in the review and appeal processes are unreasonably difficult and may act as a deterrent for people to confidently represent their views and needs.

The language about reviews within the legislation itself is confusing, with the word 'review' used in multiple places for different purposes, such as plan reviews<sup>146</sup> and reviews of reviewable decisions<sup>147</sup>. The steps involved are not clearly communicated to participants. Participants often do not know where to go or what to do if they believe a decision is unfair or unreasonable, and their capacity to seek answers or pursue justice is largely dependent on having a strong support network and an advocate.

VCOSS members report participants experience lengthy delays through the internal review process. The current legislation does not mandate any timeframes in regards to participant-requested plan reviews<sup>148</sup> or reviews of reviewable decisions<sup>149</sup>.

A Commonwealth Ombudsman report in May 2018 found the NDIA was receiving over 600 requests for review each week, with reviews taking up to nine months to be completed<sup>150</sup>. Over the past financial year, the Commonwealth Ombudsman received 1,711 complaints about the NDIA, of which 33 per cent focused on the review experience<sup>151</sup>.

Timeframes must be established and clearly communicated regarding each stage of the internal review process. Where these timelines are not met, VCOSS members suggest people should be able to escalate their review to the AAT or another body, such as the Ombudsman or an independent conflict resolution body.

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<sup>146</sup> NDIS Act 2013 (Cth), s.48.

<sup>147</sup> NDIS Act 2013 (Cth), s.100.

<sup>148</sup> NDIS Act 2013 (Cth), s.48.3.

<sup>149</sup> NDIS Act 2013 (Cth), s.100.6.

<sup>150</sup> Commonwealth Ombudsman, *Administration of reviews under the National Disability Insurance Scheme Act 2013*, May 2018.

<sup>151</sup> Commonwealth Ombudsman, Annual Report 2018-19, October 2019, p.62.

While our members believe there is a role for internal reviews as part of the process, they also share concerns about how internal reviews are handled to reduce conflicts of interest and promote the best interests of participants. We recommend that at a minimum, internal reviews should be conducted by a Planner or NDIA representative who is not already connected to the participant or the decision in question.

**VCOSS members report that communications and interactions through review and appeals processes are inconsistent, or absent or unfair.**

Our members highlighted a range of issues including:

- Participants receiving phone calls from the NDIA about a review not being told the nature or purpose of the call or the caller's contact details
- Reviewers using jargon and legislative language to confuse participants and families
- Reviewers being called at inappropriate times, such as public holidays, or in the absence of key supports including trusted family, friends and advocates

The Commonwealth Ombudsman has received a range of complaints regarding communication from the NDIA about internal reviews, including requests for review not being acknowledged and status updates not being provided<sup>152</sup>.

We also heard from our members that trade-offs are being offered by reviewers, where participants are asked to remove their request for a review in exchange for their scheduled annual review being brought forward.

The pressure in the reviews and appeals pipeline appears to be driving reviewers and participants to desperation. Our members report participants and families are increasingly turning to the media or their local MP to speed up decisions; an avenue that is simply out of reach for disadvantaged people and families.

The Commonwealth Ombudsman identified a number of communications-related recommendations in 2018, including establishing standard procedures, timelines and templates for acknowledging and conducting reviews<sup>153</sup>. While the merit of these recommendations was accepted by the NDIA, and some improvements were noted as being underway<sup>154</sup>, the experiences of participants remains inconsistent.

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<sup>152</sup> Commonwealth Ombudsman, *Administration of reviews under the National Disability Insurance Scheme Act 2013*, May 2018.

<sup>153</sup> Ibid. Appendix 1.

<sup>154</sup> Ibid. Appendix 2.

**Many people who want to lodge a review or an appeal are advised to contact an independent disability advocacy organisation, however as noted throughout this submission, advocates are swamped with requests for assistance.**

As recommended throughout this submission, more funding is desperately needed for independent disability advocacy to ensure people can be appropriately supported to exercise their rights.

***“Again and again, the role of advocates – which is irreplaceable – is in supporting people to present evidence in really complex statutory frameworks....When we don’t fund advocacy, it’s not that we’re not funding people who can argue, we’re actually damaging the scheme, because you won’t get quality decisions and you’re just replicating advantage.”<sup>155</sup>***

***Dr Darren O’Donovan***

Legal aid services are also increasingly being engaged by NDIS participants to navigate AAT appeals, with Victorian Legal Aid and Legal Aid NSW supporting 370 people through appeals since 2013<sup>156</sup>.

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<sup>155</sup> Dr Darren O’Donovan, *Getting it right: Decisions that make a real difference*, Strengthening Disability Advocacy Conference 2019: *Advocacy under pressure*, Monday 2 September, <http://www.daru.org.au/conference-session/getting-it-right-decisions-that-make-a-real-difference>, accessed 27 October 2019.

<sup>156</sup> National Legal Aid, *NDIS Planning: Submission to Joint Standing Committee on the NDIS*, September 2019, p.4.

**VCOSS members reported that participants often wait from 6 to 12 months for a decision regarding an internal review, and in the interim, participants are left in the dark about the status of their request.**

This is particularly concerning for potential participants who are appealing access decisions, who can in some instances have no supports in place while battling bureaucracy.

Review delays and decisions are the highest source of complaints to the Commonwealth Ombudsman<sup>157</sup>. When people do receive a decision regarding their internal review, letters and phone calls are often laden with legal language and do not clearly explain how the decision was made<sup>158</sup>.

People who are not happy with the outcome of an internal review can appeal a decision through the Administrative Appeals Tribunal (AAT), whose role is to independently review administrative decisions related to Commonwealth laws. Since 2015, the AAT has received 2,271 applications regarding the NDIS<sup>159</sup>, with appeals growing by 50 per cent over the past year<sup>160</sup>.

***“It means that a person with disability is sitting across the table from the very agency whose decision they are challenging. The NDIA may also have their internal lawyer or external legal representation. A person with little or no knowledge of the system is faced with the experts in the system who have both an interest and the skills to persuade the person to accept a reduced claim, or even to give up.”<sup>161</sup>***

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<sup>157</sup> Commonwealth Ombudsman, *Administration of reviews under the National Disability Insurance Scheme Act 2013*, May 2018.

<sup>158</sup> Ibid.

<sup>159</sup> Administrative Appeals Tribunal, *Annual Reports 2018-19, 2017-18, 2016-17, 2015-16*.

<sup>160</sup> Administrative Appeals Tribunal, *Annual Report 2018-19*, p.29.

<sup>161</sup> Ibid.

The AAT procedure for NDIS matters is to facilitate negotiation between the NDIA and the participant initially through a case conference, to try to reach an agreement before proceeding to a hearing<sup>162</sup>.

Only a small percentage of AAT appeals are actually heard by the tribunal, with the majority being negotiated by the NDIA in a case conference setting<sup>163</sup>. The case conference approach to conflict resolution has the potential to create unfair power imbalances between participants and the NDIA.

The financial and emotional impacts for participants and families engaging in the appeals process cannot be underestimated. The adversarial nature of the process can be lengthy, traumatic and expensive. VCOSS and our members are concerned that once again, this process may impact people experiencing disadvantage and isolation the most.

There is a heightened risk that people with the least resources are the least able to pursue an appeal without appropriate, funded supports. When considering the outcome of an appeal could mean tens of thousands of dollars in additional services, the stakes are high and the supports available are worryingly low.

While participants with the financial means to do so may engage private legal services to support their AAT appeal, very few people have the means to engage legal representation. Advocates, who have significant expertise and knowledge, can and do support people through the appeals process well, however can find themselves in situations where they are facing an extensive and expensive team of NDIA staff, lawyers and even QCs.

The high costs of the reviews and appeals processes are at odds with the vision and principles of the NDIS. When considering the administrative and legal expenses incurred by the NDIA in fighting appeals, versus the costs of providing reasonable and necessary supports, it could be perceived that the visibility of the scheme's financial sustainability is considered more important than the needs of participants.

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<sup>162</sup> Administrative Appeals Tribunal, *Practice Direction: Review of National Disability Insurance Scheme Decisions*, <https://www.aat.gov.au/landing-pages/practice-directions-guides-and-guidelines/review-of-national-disability-insurance-scheme-dec>, accessed 16 October 2019.

<sup>163</sup> G Southwell, 'The Administrative Appeals Tribunal affirms less than 2% of NDIS decisions appealed by participants', Pro Bono News, 15 October 2019.

Advocates are concerned the AAT case conference practice is being manipulated to the advantage of the NDIA to avoid a legal outcome or a public hearing that could establish precedents. Through case conference negotiations, advocates and participants report that decisions appear to be financially driven, rather than based on a person's goals and needs.

Improving the NDIS planning experience by truly listening to participants' goals and needs, and adequately funding supports, would prevent or reduce many reviews and appeals from escalating through internal or AAT processes. Where reviews or appeals are required, appropriate and funded supports should be available for participants to pursue their rights.

### Sharing data on reviews and appeals including timeframes, satisfaction and outcomes

#### RECOMMENDATION

- Publish detailed data on reviews and appeals, including quantities, timeframes, responsiveness and outcomes

Despite consecutive and consistent recommendations from the Joint Standing Committee on the NDIS<sup>164</sup> over the past 3 years, data about the number of participant-requested reviews and appeals, outcomes and timelines are not publically released. As part of establishing the Participant Service Guarantee, timelines and performance measures should be developed for each stage of the review and appeals process. For example, this may include:

- the number of scheduled plan reviews and the number of participant-requested reviews and appeals
- mandated response times to acknowledge a request for review or appeal, including a requirement to communicate with participants about the outcome of their request
- a set timeframe to commence a review or appeal
- data on the average duration of reviews and appeals
- participant satisfaction with reviews and appeals.

This information should be made publically available on a regular basis and, where appropriate, used to inform future funding needs of related support services including, advocacy and legal aid.

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<sup>164</sup> Joint Standing Committee on the NDIS, completed inquiries in the 45th Parliament.



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