

**MISSION  
AUSTRALIA**



**Review of  
the NDIS Act  
2019**

## Review of the NDIS Act and the new NDIS Participant Service Guarantee (Department of Social Services)

Mission Australia is a national, non-denominational Christian charity that has been helping vulnerable Australians move towards independence for more than 160 years. In the 2017-18 financial year, we supported over 120,000 individuals through 461 programs and services.<sup>1</sup> We deliver a range of community and family services across Australia. Mission Australia is one of the large National Disability Insurance Scheme (NDIS) community partners, working with the National Disability Insurance Agency (NDIA) to deliver Early Childhood Early Intervention (ECEI) and Local Area Coordination (LAC) services since 2013. Over this period, we have supported thousands of people with disability and their families to access the NDIS, develop and implement their plans.

Mission Australia welcomes the opportunity to provide input into the Review of the NDIS Act and the new NDIS Participant Service Guarantee. This submission is based on a combination of research and insights from people with disability themselves, Parents of children with disabilities, participants within the Scheme, sector advocates and our experience as an NDIS partner and our community services across Australia.

### Recommendations

- To ensure that the Scheme is truly accessible and inclusive of all people with disability, immediate work is required to place people with disability and their needs at the centre of all decisions about the Scheme.
- Transparency should be increased at both a systems and individual level to ensure that there is clear, consistent and accessible communication between the Agency, partners, participants and their families and carers and service providers.
- Communication channels should be refined to ensure that participants have one point of contact they can ring or email directly to receive support relating to their plans.
- For people who find applying for access to the NDIS challenging and who may have complex needs, either the process needs to be streamlined to ensure it is simple and easy to navigate, or additional and targeted support is required to navigate the system, make an access request and develop an NDIS plan.
- Measures should be adopted to simplify evidence required to support NDIS applications and provide consistency whilst taking into account the challenges of gathering evidence, particularly in rural and remote areas.

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<sup>1</sup> Mission Australia, Annual Report, 2018, accessible at: <https://www.missionaustralia.com.au/publications/annual-reports/annual-report-2018>

- The Participant Service Guarantee should provide clear and achievable expectations for participants and not impose unrealistic timelines for them to produce evidence.
- Additional financial and human resources should be allocated to ensure that Participant Service Guarantees can be met in community service landscapes across Australia including in rural and remote areas and/or areas that are still transitioning into the Scheme.
- Better targeted supports should be made available for diverse communities, including the implementation of multiple strategies such as the Aboriginal and Torres Strait Islander Strategy and Cultural and Linguistic Diversity Strategy through Action Plans. These Action Plans should have measurable outcomes and be publicly available.
- Staffing capacity should be increased both within the NDIA and with the current partners in line with the Productivity Commission recommendation.
- More information should be made publicly available in relation to the special NDIS pathways to support for people experiencing complex needs including by providing details on what supports are available for people in the local communities to access these pathways.
- The quarterly reporting requirements of the NDIA should encompass clear reporting on the number of individuals accessing the pathways to evaluate effectiveness and to identify the requisite modifications to ensure that these pathways are effective and efficient for potential NDIS participants.
- NDIA should adopt a collaborative approach to ensure that the NDIS and other health and community supports operate collectively to provide holistic, wrap around support to people with disability, their families and carers.
- NDIA should fund a panel of service providers who are required to guarantee services to NDIS participants to ensure that participants in rural, remote and very remote areas are able to access high quality, clinically trained and therapeutic supports to prevent and mitigate the impact of market failure in rural and remote areas.

## General issues of concern

Although the National Disability Insurance Scheme (the NDIS/the Scheme) was meant to support approximately 460,000 people by July 2019,<sup>2</sup> recent reports indicate that the Scheme is supporting just under 300,000 individuals.<sup>3</sup> It is likely that a considerable proportion of people who are yet to engage

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<sup>2</sup> National Disability Insurance Scheme, Overview of the NDIS Operational Guideline - About the NDIS, accessible at: <https://www.ndis.gov.au/about-us/operational-guidelines/overview-ndis-operational-guideline/overview-ndis-operational-guideline-about-ndis>

<sup>3</sup> National Disability Insurance Scheme, COAG Disability Reform Council Quarterly Report 30 June 2019, accessible at: <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

with the NDIS are those who are experiencing significant disadvantages and are people who need additional support to navigate the complex service system and application processes.

The NDIS was intended to be easily accessible for people with disabilities and their families, however the very fact that people require additional support and advocacy to navigate the complexity of the system highlights the importance of ensuring the Scheme reflects the principle of ‘nothing about me, without me’ in all its systems and practices. To ensure that Scheme is truly accessible and inclusive for all people with disability, immediate work is required to place people with disability and their needs back in the centre of the Scheme.

Within the current system, the NDIS has underlying assumptions in relation to people with disability having capacity to advocate for themselves and navigate the system. It is expected that participants and their informal supports will gain a certain level of capacity and skills within a year to advocate or navigate the NDIS process for themselves and build the skills to implement their plans. However, while many people with supports from family, advocates or others who understand the system are able to navigate the system, there remains a considerable proportion of the population not having access to the appropriate supports.

For people who find applying for the NDIS challenging and those with complex needs, the process needs to be streamlined to ensure it is simple and easy to navigate and/or additional and targeted supports are provided to navigate the system, make an access request and develop an NDIS plan.

Thus, in addition to the suggested principles for NDIA service standards in the discussion paper, there should be specific measures introduced to ensure ongoing consultation of people with disability at all levels of the system, process, policies and decisions made by the NDIA. While the current complex system remains, targeted support is required for people who find the NDIS application process challenging and are experiencing complex needs.

## **Participant Service Guarantee**

The Government has already committed to introducing a Participant Service Guarantee to support a positive participant experience with the NDIS by 1 July 2020.<sup>4</sup> Mission Australia is supportive of measures to introduce a Participant Service Guarantee and timelines to ensure NDIS participants have a positive and a timely experience. In order to implement this guarantee and improve participant experience there will need to be changes to staffing and systems to overcome current challenges.

At a system level, transparency should be built into the Participant Service Guarantee through clear guidelines. This overarching guarantee should cover the use of inclusive language, timeliness of

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<sup>4</sup> The Department of Social Services, Media Release: New CEO of the National Disability Insurance Agency, 17 October 2019, accessible at: <https://ministers.dss.gov.au/media-releases/5211>

information shared with the providers, partners, participants, planners, and the community and other areas discussed below.

## Communication issues

### Overarching communication issues

Numerous reports and other evidence indicate that the language used in communication is technical and people with disability need assistance with understanding the communications. There are various NDIS guidelines and principles in relation to use of plain English and communication modes that the participants are most likely to understand.<sup>5</sup> Despite these, there are instances where the Agency does not adhere to the guidelines when communicating with participants.

Often the communication between the Agency and the participants are made via letters or phone calls despite the participants indicating a different form of communication as their preferred form of communication. The Participant Service Guarantee should reiterate the need to use the preferred methods of communication to engage with the participants and/or their families or carers at all times.

Another challenge for people with disabilities and services that support people with their Access Request Form (ARF) is the constant changes to NDIS policies and guidelines.

“The changes can be confusing for clients and services. The NDIA makes an announcement about some guideline but it doesn’t filter through to the NDIA staff on the ground. This can be very frustrating for a lot of people because they have been given conflicting opinions.”

Mission Australia, Program Manager SA

There is little information available in relation to the different stages of the NDIS application or appeals. Participants also struggle to understand why certain decisions are made or what reasoning the Agency has used to arrive at a decision.<sup>6</sup> Therefore, information and reasons for arriving at decisions should be provided to all participants in simple language and the reasoning for all decisions should be provided in clear and plain English.

### Case Study

Amy\*, a former Personal Helpers and Mentors (PHaMs) client from Victoria was approved as a participant by the NDIA and in the package she has funding to receive ‘support coordination’ without any funding for supports. It was unlikely that she would have access to fee-free supports to require

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<sup>5</sup> See further: National Disability Insurance Scheme, Improving the NDIS Participant and Provider Experience, 2018, accessible at: <https://www.ndis.gov.au/media/1068/download>

<sup>6</sup> See further: Commonwealth Ombudsman, Administration of reviews under the National Disability Insurance Scheme Act 2013, Report on The National Disability Insurance Agency’s Handling of Reviews, 2018, p.11, accessible at: [https://www.ombudsman.gov.au/\\_data/assets/pdf\\_file/0029/83981/NDIS-NDIA-Final-report-on-administration-of-reviews-under-the-Act.pdf](https://www.ombudsman.gov.au/_data/assets/pdf_file/0029/83981/NDIS-NDIA-Final-report-on-administration-of-reviews-under-the-Act.pdf)

coordinate. There were no reasons provided as to why she was only provided with funding for support coordination.

When providing information about daily life, she has referred to intentions of obtaining stable employment and engaging in recreational activities which are likely to require funded supports. PHaMs staff supported Amy to appeal this decision and receive funding for a range of supports to meet her needs and future goals.

\*Name has been changed for privacy

In addition, the Agency may not communicate the options adapted to meet the individual needs of Participants within planning meetings. For instance, people with Intellectual disabilities have stated that often a planner will direct questions to their support person rather than the participants themselves. To ensure people with disability are at the centre of all decisions about their lives, it is important that time and other resources are dedicated to ensure all participants understand the purpose and outcomes of their planning meetings and this is communicated to them in a way that meets their needs.

#### Communication issues for participants without a LAC

Under the current framework, the NDIA directly supports participants with complex needs and those in remote regions. There are merits to this model of operation, however, many people are experiencing challenges with getting the necessary implementation support from the NDIA due to a range of issues.

There is a clear need for a point of contact for each NDIS participant in the local community who is available at a physical location to support participants with questions, understanding the processes or plans and their support options.

“Whenever we need to ask a simple or complex question, I have to call the national call centre. We have to be on the phone to be connected to someone. I’m a single mother with 2 children with disabilities and no external support, I can’t spend hours on end waiting on the phone. Every time I call, I speak to a different person. There should be one point of contact within the agency who I can get in touch with by phone, email or face to face.”

Parent of a young NDIS participant with complex needs from a rural area

These communication issues coupled with not having access to a *consistent point of contact* similar to LACs can result in significant challenges and unnecessary administrative burdens on participants and their families.

In order to ensure that Participants are adequately supported through the whole Participant experience it is essential that support in rural and remote communities is delivered locally and integrated with local communities as an integral component of the new Participant Service Guarantee.

## Case study

Jane\* is the sole carer of 2 children with disability, both of whom are NDIS participants with complex needs. Her daughter's plan was developed by the NDIA and she self manages the funding for plans of her children as there are no plan management support services in her region.

At the last plan review, Jane was informed that her daughter's plan included funding for home modifications that had been requested two years prior. She was asked to submit quotes for the modification. She tendered the quotes and other supporting documents through to the NDIA in June 2019. As the upgrades were urgent, she hired a contractor to commence the upgrades after waiting for more than 2 months since the quotes were submitted.

Upon completion of the works, Jane submitted the invoices to the NDIA and contacted the national contact centre to arrange payment. She was informed that the payments were not approved despite the cost of upgrades being built into her daughter's plan. She was immensely stressed as she was not informed that she had to wait for the quotes to be approved. The construction company was pursuing her for payments which were close to \$10,000.

As she did not have a direct contact to liaise with within the NDIA, she rang the national NDIA contact centre. They informed her that her issue would be escalated internally. Jane contacted the Agency on numerous occasions to follow up on the matter and was told that it had been escalated. Even after several weeks, her issue was not resolved and the construction company was contacting her to resolve the unpaid costs.

She later learnt that due to a system error, her initial correspondence with the quotes had been marked as resolved in the NDIS system. Jane stated *'nothing was ever going to happen if we didn't find out that the claim was marked as resolved by accident. This miscommunication caused a significant delay in the payments being approved and unnecessary pressure on me ... it could have been easily resolved if there was a point of contact who knew about my daughter's condition and her plan.'*

This has since been resolved and the payments have been made. However, it is concerning that lack of transparency and communication pathways can result in creating significant issues for NDIS participants and their family or carers.

\*Name has been changed for privacy

## Relationship based service provision

The Local Area Coordination model, adopted by the NDIA and delivered by NDIS partners, was first established in Albany (rural Western Australia) in 1988.<sup>7</sup> Initially thought of as a small, local initiative, it was later implemented state wide, and disseminated to Queensland, New South Wales, ACT, and Tasmania, and internationally (Scotland, Ireland, England and Wales, New Zealand and Singapore).<sup>8</sup>

In Western Australia, Local Area Coordinators (LACs) were available for people with disabilities. They assisted people with disability and their families in planning and organising access to services, strengthening informal support and care, and working together to make local communities more inclusive and welcoming, including through education, advocacy and partnerships.<sup>9</sup>

Within the current NDIS model, the ability to spend time building trust with participants and within local communities ensures that there is an ongoing relationship with people with disability, their families, carers and the community members. This approach is much more effective than a transactional approach as it allows people with disability, their families and carers to feel comfortable with approaching the LACs and to have face to face meetings if they require further information or assistance.

The key success factor of a relationship approach is the ability to ensure that people with disability and their families are at the centre of the Scheme. The relationship based service delivery model is also a much more effective way of managing and identifying risks in local communities. The Partners on the ground understand the local issues around access to medical and other services, are able to observe what is working or not working well and provide services that are informed by the needs of the local communities.

## Introduction of timelines

The Participant Service Guarantee should identify methods of improving the quality of experience as well as the timeliness of the experience. There are certain timelines already in the NDIS implementation processes through NDIS legislation and guidelines that the Agency is currently unable to adhere to due to the high volume of participants and limited number of internal staff.<sup>10</sup>

### Case study

Codie\* is a 12 year old NDIS participant who has significant disabilities including the need to wear a halo brace living in a rural area. She is of short stature and the halo brace significantly restricts her

<sup>7</sup> R. Broad, Local Area Coordination: From Service Users to Citizens, 2012, accessible at:

<https://www.centreforwelfarereform.org/uploads/attachment/340/local-area-coordination.pdf>

<sup>8</sup> Ibid

<sup>9</sup> Ibid

<sup>10</sup> See further: Commonwealth Ombudsman, Administration of reviews under the National Disability Insurance Scheme Act 2013, Report on The National Disability Insurance Agency's Handling of Reviews, 2018, p.11, accessible at: [https://www.ombudsman.gov.au/\\_data/assets/pdf\\_file/0029/83981/NDIS-NDIA-Final-report-on-administration-of-reviews-under-the-Act.pdf](https://www.ombudsman.gov.au/_data/assets/pdf_file/0029/83981/NDIS-NDIA-Final-report-on-administration-of-reviews-under-the-Act.pdf)

independence including her ability to dress herself, shower, use the bathroom or walk independently. Codie is currently supported by her mother, who is a single parent. Therefore, Codie needs assistance and support with all daily activities, multitude of therapies and other forms of support. Codie accompanied her mother to the NDIS planning meeting. The NDIA approved her plan with \$9,000 of funding for the whole year.

Her mother, with support from a parent of another NDIS participant, lodged an urgent appeal in February 2019. To date, they are yet to hear anything about the outcome of the appeal after 8 months of lodging an application for a review. In a few months, the plan will be up for review without any redress for the significant inadequacy of funding for her supports. The lack of funding means that she is not receiving the necessary therapy and supports as there are no other complementary services or supports provided by the state government to fill the gap.

This has left Codie in significant pain as well as placing additional stress on her sole carer, and her younger siblings.

\*Name has been changed for privacy

One proposed measure is the implementation of NDIS plans for lengths greater than 12 months.<sup>11</sup> Although on the surface this would appear to provide Participants with greater funding certainty over a longer period, Participants themselves report resistance to taking up plans for longer durations as they are not confident any changes to their needs will be considered in a timely manner and appropriate adjustments made to funding. In addition to plan review timelines, it is important that unscheduled review timelines are introduced to give participants certainty and security that their changing needs can be addressed efficiently.

Additionally, it is imperative that the introduction of timelines do not impose unnecessary pressure on the participants and their families. Within the existing framework, participants have to produce evidence for plan reviews and assessments, however the high volume of applications to assess NDIS eligibility and reviews mean that there is a substantial strain on medical services and waiting lists to see medical specialists.

“Some people feel like they have no time for things other than waiting for or going from one assessment to the next. Sometimes the plans are reviewed while they are waiting for appointments from specialists. This can create perverse outcomes for people where they don’t get the right supports because they don’t have the required evidence ... If the reviewed plan was not sufficient, the request for the NDIA to review the plan can take months leaving people with little funding to access support.”

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<sup>11</sup> Australian Government, Media Release: NDIA introduces longer-term NDIS plans, 30 March 2019, accessible at: <https://formerministers.dss.gov.au/18814/ndia-introduces-longer-term-ndis-plans/>

## Parent of a young NDIS participant with complex needs from a rural area

If the Participant Service Guarantee process is to introduce timelines, there should be sufficient flexibility and support built into the process to ensure that participants and their families are not experiencing additional pressure to gather evidence and meet deadlines. The timelines should also be flexible to cater for the nuances such as the NDIS partners time to build relationships with local communities, operational priorities for different regional areas, availability of resources and market maturity.

### Increasing staffing capacity

Many of the current issues with the NDIS relate to the limited capacity within the Agency to support people to access the Scheme, review plans, and provide a range of other supports.<sup>12</sup> There has been some positive discussions in relation to lifting the cap on NDIA staffing levels. The Government announced that, in order to deliver improvements to the NDIS, the NDIA will be filling an additional 800 Australian Public Service (APS) positions capable of exercising delegations under the NDIS legislation, over the course of the 2019-20 financial year, taking the APS Average Staffing Level to 4,000 from 1 July 2020.<sup>13</sup> Considering the current issues participants are experiencing with communication and other supports with implementing their plans, we recommend that these new staff members are dedicated to direct participant related services.

The Productivity Commission states that capping staff levels could lead to poorer outcomes, especially early in the scheme's life when the agency is building capacity and institutional knowledge, and developing first plans for many participants.<sup>14</sup> With the limited number of staff and the pressure to transition people into the scheme and achieve targets, both NDIA and the partners efforts have a greater emphasis on completing NDIS plans than the key function of supporting individuals and communities to implement their plans and build capacity. Therefore, in addition to raising the number of NDIA staff, there needs to be an increase in the number for effective delivery and implementation of NDIS.

### Needs of diverse communities

It is encouraging that there are specific strategies in place to address specific challenges experienced by diverse community groups such as the Aboriginal and Torres Strait Islander strategy,<sup>15</sup> Cultural and

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<sup>12</sup> Commonwealth Ombudsman, Administration of reviews under the National Disability Insurance Scheme Act 2013, Report on The National Disability Insurance Agency's Handling of Reviews, 2018, p.11, accessible at: [https://www.ombudsman.gov.au/\\_data/assets/pdf\\_file/0029/83981/NDIS-NDIA-Final-report-on-administration-of-reviews-under-the-Act.pdf](https://www.ombudsman.gov.au/_data/assets/pdf_file/0029/83981/NDIS-NDIA-Final-report-on-administration-of-reviews-under-the-Act.pdf)

<sup>13</sup> Department of Social Services, Media Release: New CEO of the National Disability Insurance Agency, 17 October 2019, accessible at: <https://ministers.dss.gov.au/media-releases/5211>

<sup>14</sup> Productivity Commission, National Disability Insurance Scheme Costs, Study report, 2017, accessible at: <https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.pdf>

<sup>15</sup> National Disability Insurance Scheme, Aboriginal and Torres Strait Islander strategy, accessible at: <https://www.ndis.gov.au/about-us/strategies/aboriginal-and-torres-strait-islander-strategy>

Linguistic Diversity Strategy,<sup>16</sup> and Rural and Remote strategy.<sup>17</sup> However, there is little information in relation to action plans or implementation processes of these strategies. A clear and measurable process to implement these strategies should also be built into the Participant Service Guarantee. In addition, and a Lesbian, Gay, Bisexual, Transgender and Intersex strategy should be developed and implemented as a matter of priority.

Despite the current efforts and measures to address issues in the rural and remote areas, there are still significant issues with NDIS implementation in these areas. The introduction of service guarantees, especially time sensitive guarantees may not be viable in certain remote areas. Therefore, it is imperative that the review consider these and identify pragmatic solutions when introducing service guarantees. This could be achieved by meaningfully consulting people with lived expertise to identify their priorities.

### **Implementation of the Participant Service Guarantee**

Although the discussion paper provides details on the proposed service guarantee areas, there is limited clarity in relation to how these would be achieved or what resources would be dedicated to implementing any system changes required for the changes. Considering the issues experienced with the introduction of the NDIS IT system in July 2016, we recommend a meaningful and sustainable systems update concurrent to the Service Guarantee updates. It is important that the NDIA consults with participants and providers to ensure any systems changes to Participant or Provider Portals are implemented concurrently with any introduction of a Participant Service Guarantee.

Even where the NDIS supports are in place, people are not receiving the optimal benefits due to the siloed nature of the mainstream services. There needs to be better coordination between supports under the NDIS and mainstream services provided by State or Territory Governments. The measures under the service guarantee should be used to increase collaboration between diverse services that support NDIS participants.

It is also important to consider and understand the nuances of the bilateral agreements, current community and mainstream service landscape as well as roles and responsibilities of different arms of the State and Territory Governments and the Commonwealth Governments in developing a framework for the participant service guarantee.

For example, in Queensland, by July 2019, it was estimated that just over 90,000 people will transition to the NDIS, including around 48,000 from the existing Queensland disability system that will be replaced by the NDIS.<sup>18</sup> This means that approximately 50% of the NDIS participants are likely to be

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<sup>16</sup> National Disability Insurance Scheme, Cultural and Linguistic Diversity Strategy, accessible at:

<https://www.ndis.gov.au/about-us/strategies/cultural-and-linguistic-diversity-strategy>

<sup>17</sup> National Disability Insurance Scheme, Rural and Remote strategy, accessible at: <https://www.ndis.gov.au/about-us/strategies/rural-and-remote-strategy>

<sup>18</sup> Bilateral Agreement between the Commonwealth and Queensland for the transition to an NDIS: Transition to a National Disability Insurance Scheme, accessible at:

<https://www.communities.qld.gov.au/resources/dcdss/disability/ndis/qldbilateralagreement.pdf>

those who have not accessed or had limited interactions with government funded structured supports. This approach is different in other States and Territories where the majority of the NDIS participants will come from existing services. Thus, that more resources to engage potential participants are likely to be vital in Queensland compared to other states and territories.

The systems reliance on professional assessments to ensure sufficient evidence support identified needs leaves participants and their families feeling their voice is not heard and the NDIA does not consider them to be the experts in their own lives. The best measure of outcomes and impact of individual funding is the Participants story about how the supports have made a difference to their lives.

### Case study

Katy\* is a 13 year old NDIS participant with complex needs in a remote area. She was required to have a major spinal surgery, which meant that she needed a ramp to access her house post surgery due to being wheelchair bound. Katy's mother, who is managing her plan obtained records about her condition, the need for surgeries and reports from Occupational Therapists (OTs).

Initially, the NDIA agreed a ramp was needed. However, later informed the parent that it was a medical issue and therefore the medical system should provide funding for the ramp. After continuous advocacy, the NDIA agreed to consider Katy's funding application. The NDIA then informed that the OTs report contains information about a ramp at the back of the house and therefore, the modifications will not be funded as only one ramp is adequate to access the house. With the date of surgery fast approaching, Katy's mother had to furnish further evidence to demonstrate that the ramp at the back was not accessible from the driveway and that it was a temporary measure for her daughter to access the backyard, which would not meet the safety requirements after a major surgery. Although this was highlighted in the OT report, it was overlooked by the Agency.

The NDIA then approved the upgrade. Katy's mother was frustrated with the system and stated '*I have been with my daughter through over 12 years of medical interventions including over 40 surgeries as a direct result of her disability. I understand her needs better than anyone else in the world. But the Agency would listen and rely on the reports of an OT and not the parent. There is no consistency in their [The NDIA's] approach to these and the burden is on families to prove what they need constantly while trying to look after their children, work and manage other responsibilities.*'

\*Name has been changed for privacy

This should be the first and primary source of evidence that funding is adequate and effective, rather than the last. The system fragmentation between different stages of the NDIS including access, planning, implementation, additional pathways of access, plan reviews and unscheduled reviews means that

participants and their families are expected to provide the same information or relay their story multiple times to multiple people. This can be challenging for many people with disability.

In order to improve service quality and efficiency for participants, the Participant Service Guarantee needs to have introduced a greater emphasis on 'plan implementation support'. Although this support is an identified part already built into the Participant Pathway, through transition it has had less emphasis compared to plan development and approval. However, there needs to be recognition and strategies developed to identify and manage ongoing meetings as and when required, particularly recognising issues with market maturity, the impact of ongoing changes to NDIS related policies, price variations and the like. These continual changes continue and thin markets pose significant barriers to participants implementing their plans.

## People with psychosocial disabilities

According to available data, psychoses and mood affective disorders were the second largest long-term health condition in Australia.<sup>19</sup> Furthermore, anxiety and depressive disorders were among the top three highest non-fatal diseases and mental health and substance use disorders were the fourth largest disease burden in Australia.<sup>20</sup>

However, only 9% of the total NDIS participants with approved NDIS packages identify psychosocial disability as their primary disability. Although this is an improvement in the last quarter compared to previous quarters, the Agency acknowledges that the proportion of participants who have a psychosocial disability is lower than expected.<sup>21</sup> The recently released Productivity Commission draft mental health report also identifies these issues.<sup>22</sup>

There is growing concern about the transition rates of Commonwealth community mental health program clients into the NDIS, as they are lower than expected.<sup>23</sup> For instance, according to the *Commonwealth Mental Health Programs Monitoring Project* report found that even by 2019, around

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<sup>19</sup> Australian Bureau of statistics, Disability, 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015, accessible at:

<http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features202015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view=>

<sup>20</sup> Australian Institute of Health and Welfare (AIHW) 2019, Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2015, Canberra: AIHW, accessible at:

<https://www.aihw.gov.au/getmedia/08eb5dd0-a7c0-429a-b35f-c8275e7a1dbf/aihw-bod-21.pdf.aspx?inline=true>

<sup>21</sup> National Disability Insurance Scheme, COAG Disability Reform Council Quarterly Report 30 June 2019, accessible at: <https://www.ndis.gov.au/media/1612/download>

<sup>22</sup> Productivity Commission, Mental health draft report, 2019, accessible at:

<https://www.pc.gov.au/inquiries/current/mental-health/draft/mental-health-draft-overview.pdf>

<sup>23</sup> National Mental Health Commission, Monitoring mental health and suicide prevention reform: National Report 2019, accessible at: <http://www.mentalhealthcommission.gov.au/media/270709/National%20Report%202019.pdf>

one fifth of people had not commenced gathering evidence required or did not intend to test their eligibility for the NDIS.<sup>24</sup>

According to the Australian Bureau of Statistics, there are 4.3 million people with disability and 21.5% or over 920,000 of them identified having a mental or behavioural problem.<sup>25</sup> In many sites, a number of people have been rejected due to their mental health issues not meeting the 'severe and persistent' criterion despite having accessed mental health services for a long period of time or have a formal diagnosis. A vetting process may be required to determine who meets the criteria and identify their needs. However, these requirements result in creating additional and unnecessary challenges for people experiencing mental health issues.

The majority of people with mental health issues are unlikely to have accessed structured services in the past to provide evidence on their psychosocial conditions. These people are likely to have issues with providing medical evidence to support their NDIS applications.

Numerous reports have demonstrated the inadequacy of funded supports for people with psychosocial disabilities to meet their needs.<sup>26</sup> Even in instances where people are provided with funding in their NDIS packages for mental health supports, they may not have access to trained and qualified staff to deliver those services in areas where the markets are thin.<sup>27</sup>

Some rural and remote communities rely on medical and allied health professionals who visit intermittently, who are often on short-term contracts. This affects continuity of care and means that people have to regularly rebuild rapport with different professionals. The long waiting periods to obtain appointments with mental health professionals can result in significantly deteriorating mental health or discourage people from seeking help. These challenges are compounded for people who have started the NDIS application forms and are waiting for appointments with professionals to obtain medical assessments or supporting materials.

“In areas where local help is minimal, people have to wait for weeks to see a GP. It’s much worse if you need a specialist professional like a psychiatrist to get supporting letters.”

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<sup>24</sup> N. Hancock, et al, 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, 2019, accessible at: [https://cmha.org.au/wp-content/uploads/2019/10/CMHA-and-University-of-Sydney-NDIS-Transitions-Final-Report\\_September-2019.pdf](https://cmha.org.au/wp-content/uploads/2019/10/CMHA-and-University-of-Sydney-NDIS-Transitions-Final-Report_September-2019.pdf)

<sup>25</sup> Australian Bureau of Statistics, 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015, accessible at:

<https://www.abs.gov.au/ausstats/abs@.nsf/0/C258C88A7AA5A87ECA2568A9001393E8?Opendocument>

<sup>26</sup> See further: J. et al Mind the Gap: The National Disability Insurance Scheme and psychosocial disability, Final Report: Stakeholder identified gaps and solutions, University of Sydney, 2018 and ABC Sydney, B. Evans, Call for review as Adelaide Hills disabled man's support halved in transition NDIS, 18 October 2018, accessible at: <https://www.abc.net.au/news/2018-10-18/disabled-adelaide-mans-support-halved-ndis/10388620>,

<sup>27</sup>J. Smith-Merry et al, Mind the Gap: The National Disability Insurance Scheme and psychosocial disability, Final Report: Stakeholder identified gaps and solutions, University of Sydney, 2018.

## Mission Australia, Area Manager NSW

In addition to the challenges of having limited health professionals, the vast distances and scattered populations in rural and remote areas make it difficult for community organisations to deliver mental health services and retain trained and qualified staff.

The Council of Australian Governments (COAG) Disability Reform Council (the Council) communique indicates that there are a number of initiatives such as establishment of a Psychosocial Disability Recovery Framework to address some of these challenges.<sup>28</sup> However, there is limited information available about these on the NDIS website including how this will be implemented and timeframes.

### Complexity of NDIS application process

Some people with mental health challenges also have other complex needs including risk of homelessness and may lack support to access information and navigate multiple services and application processes.

#### Case study

Mark\* was a 61 year old who was referred from Community Mental Health in March 2018. He was a victim of an online scam and had lost \$60,000 which had a significant impact on Mark's mental health.

After accessing the Mental Health service, Mark was referred to a GP who diagnosed him with early onset dementia. Mark was referred to get an Aged Care Assessment however he was ineligible for the assessment because of his age. His case manager worked with the health services to get him a referral to see a Geriatrician, obtained the appointment, and accompanied him to the appointment.

His case manager contacted the local Dementia worker who provided information around supporting Mark with his medical condition. Together with the Dementia worker, they gathered evidence for the NDIS application, while supporting the client with his day to day functioning. The evidence gathering process took about 2 to 3 months.

The NDIS application was rejected in June 2018. The case manager worked closely with the GP, Dementia Australia, family members and other specialists to gather further evidence on the impact of his disabilities on his day to day living. At Mark's request, the case manager also organised a meeting with Legal Aid to assist with the appeal process. After lengthy discussions and email and phone correspondence, Mark's application was approved by the NDIA.

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<sup>28</sup> Council of Australian Governments Disability Reform Council, Communiqué, 9 October 2019, accessible at: [https://www.dss.gov.au/sites/default/files/documents/10\\_2019/communique-drc-9-october\\_2019.pdf](https://www.dss.gov.au/sites/default/files/documents/10_2019/communique-drc-9-october_2019.pdf)

The case manager also assisted him with the appointments with Local Area Coordinators and his plan is now complete and approved.

\*Name has been changed for privacy

This demonstrates that one NDIS application requires a significant amount of time investment and advocacy. In instances where people are unable to find such advocacy support, they are likely to accept their rejection and not receive the supports they are entitled to.

Many people accessing Mission Australia's mental health services feel overwhelmed by the NDIS application process. Concerningly, a significant number of people with complex needs are not applying for NDIS due to the complexity of the application process, despite their case workers opinion that the clients are likely to meet the eligibility criteria and offering to support them throughout the application process.

In many sites, a number of people have been rejected due to their mental health issues not meeting the permanent and significant condition criterion despite having accessed mental health services for a long period or not having a formal diagnosis, limiting their ability to access supports through the NDIS.

“A number of people we support feel that it's a personal rejection, like they are not being believed by the authorities. This can cause a lot of distress and have a negative impact on their mental health.”

Mission Australia, Program Manager SA

Numerous studies and research projects have demonstrated that providing people with the necessary holistic, wrap-around supports has significant financial benefits and positively impacts on the health and wellbeing of the individuals.<sup>29</sup> However, with the challenges created by the rollout of the NDIS, other mainstream services including community support services, health system and homelessness services are under further pressure to support those who fall through the cracks without additional funding or access to resources.

### Case Study

Mary\* was a PHaMs participant with a number of mental health issues. She has been involved in the program for 13 months. Her GP has given her a Centrelink Medical Exemption from job seeking

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<sup>29</sup> See further: Mission Australia, From Homelessness to Sustained Housing, 2010 – 2013, MISHA research report, accessible at: <https://www.missionaustralia.com.au/documents/279-from-homelessness-to-sustained-housing-2010-2013-misha-research-report-2014/file>

responsibilities. Mary engaged proactively and regularly in the PHaMs program and with her clinical mental health supports, a psychologist via a mental health care plan and her GP.

She was initially not planning on applying for the NDIS but later changed her mind due to the fear that she may not have access to any supports when the funding for PHaMs ends. She mentioned that she felt concerned by the changes to government policies and the transition of PHaMs to the NDIS when she is already very vulnerable.

After Mary's PHaMs caseworker explained the options, she decided to apply for the NDIS over the phone. The caseworker offered to advocate on her behalf throughout the application process, however, Mary said she was confident to go through the process herself.

Prior to the appointment with the assessor, the caseworker spent a considerable amount of time with her preparing for the phone assessment. However, Mary found the conversation overwhelming and traumatising as she found the questions confronting although the assessor was friendly and sympathetic to her life story.

She told the caseworker that she was not clear about how to answer some questions because they were technical. At the end of the assessment call she told the caseworker that she 'felt useless and incapable of being independent, maybe things were never going to get better'. The method of questions made her feel like she had to prove and justify how she felt, in order to get support causing distress and anxiety. The caseworker had to spend over 2 hours after the conversation to help her calm down as the conversation triggered many traumatic memories.

Mary's mental health issues depend on situational stressors, which can result in her feeling so debilitated that she cannot leave the house for days. However, Mary stated that she felt that her 'PTSD would never be recognised as a disabling condition because in between the days she feels so terribly low and helpless there can be a few good days where she's able to get on with her life'.

There are a number of constant stressors in her life including a dispute with her neighbour. Mary was unable to continue with the submission due to significant stressors in her life. She needed to prioritise safety and housing stability over her application for the NDIS.

*\*Name has been changed for privacy*

Once the application is rejected, the majority of clients decide not to challenge the NDIA's determination or reapply even with the support of PHaMs staff, despite their PHaMs case managers strongly believing that they are likely to be eligible for the NDIS. This is largely due to the stressful and protracted application process.

### Case Study

Amy\* a PHaMs client first made an intent to claim application in July 2017. Her PHaMs case management team gathered all required evidence of disability and submitted the application for NDIS in September 2017.

Her PHaMs case management team contacted the NDIA on a regular basis via telephone and email to follow up on the application. During this period while waiting for the approval process Amy's mental health deteriorated as she was concerned about the sensitive information that was enclosed in reports detailing trauma she experienced as a child. However, Amy was positive around how the NDIS was going to support her as she was aware that PHaMs services were going to end next year.

Amy's PHaMs case management team contacted NDIS each month for an update on the NDIS application. After 8 months of lodging the application, in May 2018 Amy was asked to provide more information to support her application. She was supported by PHaMs staff to compile all the necessary paperwork.

In June 2018 she was informed that she was not eligible for the NDIS. This had a serious impact on Amy and she felt that she will not be supported within the community around her mental health issues. She also stated that she is unable to access services due to services moving to a fee for service for NDIS participants.

Amy declined the offer to support her with an appeal due to the impact this will have on her mental health as she feels that there is no use and that most people she knows had been unsuccessful.

She has no informal supports within the community (outside of PHaMs) and all of her family live out of town.

\*Name has been changed for privacy

### Participant pathways for people with psychosocial disabilities

In order to address some of the challenges facing people with psychosocial disabilities, the NDIA has introduced several solutions. These initiatives include implementing psychosocial disability training for NDIA staff, streamlined access process including the complex support needs pathway and the psychosocial disability service stream.<sup>30</sup>

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<sup>30</sup> National Disability Insurance Scheme, COAG Disability Reform Council Quarterly Report 30 June 2019, accessible at: <https://www.ndis.gov.au/media/1612/download>

However, concerns remain for people with a psychosocial disability around consistencies in eligibility and planning outcomes, lack of understanding of psychosocial disability and how the episodic nature of mental illness and the recovery approach aligns with the NDIS assessment process.<sup>31</sup>

In order to ensure that people with psychosocial disabilities are supported adequately and appropriately, information about the complex support needs pathway and the psychosocial disability service stream should be communicated with individuals, community organisations and mental and mainstream health services.

There also needs to be more clarity in relation to what supports will be available under this stream for people who were already deemed ineligible prior to the introduction and implementation of this stream and have since disengaged from mental health services.

## Housing and NDIS

Secure and appropriate housing is an important aspect of a person's health and wellbeing. Numerous reports indicate that access to housing can have a significant impact on an individual, reducing their need to rely on the health and other community supports.<sup>32</sup> However, there is a significant lack of accessible and affordable housing for people with disabilities.

### Pathways and access related issues

Inability to access the NDIS or other disability supports can increase the risk of homelessness among people with disabilities. This risk is higher among people exiting institutions such as hospitals, rehabilitation facilities, prisons or other similar institutional settings. The delays in accessing the NDIS can also place people with disability at higher risk experiencing homelessness.

According to the census data, close to 6,000 people experiencing homelessness in 2016 indicated they needed help or assistance in one or more of the three core activity areas.<sup>33</sup> The ABS also predicts that these numbers could be higher than the reported rate.<sup>34</sup>

Procedures are in place for the NDIA and NDIS LACs are able to engage with those experiencing homelessness through homelessness services and shelters. However, according to available evidence, for

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<sup>31</sup> National Mental Health Commission, Monitoring mental health and suicide prevention reform: National Report 2019, accessible at: <http://www.mentalhealthcommission.gov.au/media/270709/National%20Report%202019.pdf>

<sup>32</sup> L. Wood, et al, What are the health, social and economic benefits of providing public housing and support to formerly homeless people?, AHURI Final Report No.265, Australian Housing and Urban Research Institute, Melbourne, 2016, accessible at: <http://www.ahuri.edu.au/research/final-reports/265>

<sup>33</sup> Australian Bureau of Statistics, 2049.0 - Census of Population and Housing: Estimating homelessness, 2016, accessible at: <https://www.abs.gov.au/ausstats/abs@.nsf/mf/2049.0>

<sup>34</sup> Ibid

many people with complex needs, particularly homelessness, applying for the NDIS was a lower priority that was put aside until these more pressing needs were addressed.<sup>35</sup>

Currently, there is limited information in relation to the types of support available for people with disability experiencing homelessness. In November 2016, an announcement was made in relation to the new Complex Support Needs Pathway to provide specialised support for participants living with a disability who have many different challenges affecting their lives such as mental health issues, incarceration or homelessness, and need a higher level of specialised supports in their plan.<sup>36</sup> However, further information is not available on the NDIS website in relation to the specific details of this pathway.

It is estimated that nationally 6% of the NDIS participants or 28,000 individuals need access to Specialist Disability Accommodation (SDA).<sup>37</sup> When the Scheme is fully implemented, the SDA is expected to account for NDIS spending of \$700 million a year.<sup>38</sup> It is also expected that the NDIS will contribute to create a \$5 billion disability housing market over the next five years.<sup>39</sup> This investment into disability accommodation is vital considering the acute shortage of affordable and accessible housing in the private rental market.<sup>40</sup> It is also important to note that the SDA investment alone will not be sufficient to address housing issues of the majority of the NDIS participants.

Thus, there is a clear need to increase accessible social and affordable housing for people with disability. Further, there needs to be better coordination between the community housing providers, state and territory governments and the NDIS related supports to ensure that the services meet the needs of individuals holistically.

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<sup>35</sup> N. Hancock, et al, 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, 2019, accessible at: [https://cmha.org.au/wp-content/uploads/2019/10/CMHA-and-University-of-Sydney-NDIS-Transitions-Final-Report\\_September-2019.pdf](https://cmha.org.au/wp-content/uploads/2019/10/CMHA-and-University-of-Sydney-NDIS-Transitions-Final-Report_September-2019.pdf)

<sup>36</sup> National Disability Insurance Agency, News and Events: Improved NDIS planning for people with complex support needs, 16 November 2018, accessible at: <https://www.ndis.gov.au/news/1002-improved-ndis-planning-people-complex-support-needs>

<sup>37</sup> National Disability Insurance Scheme, Specialist Disability Accommodation Provider and Investor Brief, April 2018, p.5, accessible at: <https://www.ndis.gov.au/providers/essentials-providers-working-ndia/specialist-disability-accommodation>

<sup>38</sup> D. Winkler, G. Taleporos and L. Bo'sher, How the NDIS is using the market to create housing for people with disability, The Conversation, accessible at: <https://theconversation.com/how-the-ndis-is-using-the-market-to-create-housing-for-people-with-disability-83144>

<sup>39</sup> Summer Foundation and PwC, NDIS Specialist Disability Accommodation Pathway to a mature market, August 2017, p.5 accessible at: <https://www.summerfoundation.org.au/resources/ndis-specialist-disability-accommodation-pathway-to-a-mature-market/>

<sup>40</sup> Anglicare Australia, Rental Affordability Snapshot, 2018, accessible at: <https://www.anglicare.asn.au/docs/default-source/default-document-library/final---rental-affordability-snapshotb811d9309d6962baacc1ff0000899bca.pdf?sfvrsn=4>

The *Planning Operational Guideline Appendix 1 - Table of guidance on whether a support is most appropriately funded by the NDIS* clarify that housing support and homelessness services are supports funded by other parties.<sup>41</sup> This does not include a discussion on the role of SDAs or other NDIS related supports to assist people experiencing homelessness.

There is little clarity or information available for participants to ensure they understand how these different guidelines and pathways are implemented to support those that require housing related supports or potential participants who are currently experiencing homelessness. This lack of transparency should be addressed through clear and concise guidelines about how these different guidelines and pathways intersect, clear and accessible information for people with disability about how these are implemented and modified to meet the needs of people with disability. There is also an acute need to increase accessible social and affordable housing for people with disability.

### **Intersecting issues between aged care and the NDIS**

The delays in accessing the NDIS or ineligibility should also not result in people with disability experiencing or being at risk of homelessness. Mission Australia is a provider of aged care services to people experiencing homelessness or at risk of homelessness in NSW through three aged care facilities. Currently, due to the complex needs and the range of supports needed, the aged care legislation does not stipulate an age to be eligible to access aged care services. However, with the roll-out of the NDIS, people are expected to exhaust the NDIS application process prior to entering aged care supports. Although this process ensures people are accessing the appropriate services, the significant time between lodging an application for the NDIS and the final determination can take months. This means that some people experiencing or at risk of homelessness were unable access services they need.

It is encouraging that the Federal Department of Health introduced *Aged Care Assessment Supplementary Guidelines for Younger People with Disability* in July 2019 to address this gap.<sup>42</sup> These changes will ensure that people experiencing homelessness but are under 65 year of age, are able to access aged care services pending the determination of their NDIS application.

### **Market maturity**

Providing people with disability choice and control is one of the key premises of the NDIS, which allows individuals to become active participants in the community. The NDIS is still in the early stages of development. The markets and demand to provide choice and control for consumers are expected to

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<sup>41</sup> National Disability Insurance Scheme, *Planning Operational Guideline Appendix 1 - Table of guidance on whether a support is most appropriately funded by the NDIS*, accessible at: <https://www.ndis.gov.au/about-us/operational-guidelines/planning-operational-guideline/planning-operational-guideline-appendix-1-table-guidance-whether-support-most-appropriately-funded-ndis>

<sup>42</sup> Department of Health, *Aged Care Assessment Supplementary Guidelines for Younger People with Disability*, accessible at: [https://agedcare.health.gov.au/sites/default/files/documents/08\\_2019/aged\\_care\\_assessment\\_supplementary\\_guidelines\\_for\\_younger\\_people\\_with\\_disability\\_july\\_2019.pdf](https://agedcare.health.gov.au/sites/default/files/documents/08_2019/aged_care_assessment_supplementary_guidelines_for_younger_people_with_disability_july_2019.pdf)

grow overtime. However, the choice of service providers is limited in some areas and people are forced to opt for services that are available to them as opposed to what they actually need. There are numerous challenges in finding appropriate providers with the skills and expertise to provide high quality services for people with complex needs.

“While we see the potential for the NDIS to support people in our area we also see that people are not getting what they really need ... Rather than waiting for services people need, they opt for services that are available in the area that they can purchase from their package or they wait hoping for the services to come to the area with unspent money and without the services.”

Mission Australia Program Manager, NSW

There are also some situations in which people face particular challenges to accessing services such as people in prison, hospitals and other similar settings. These people may not be able to get any services in a competitive market, let alone exercise choice and this can perpetuate cycles of disadvantage.

“We know of people who are not receiving the services although they have been approved a package. There are people in prisons in NSW with NDIS packages and nobody will deliver services to them. The competition in the market is not helping these people. There should be a better framework to pick up people like this, there should be a provider of last resort to make sure people don’t fall through the cracks.”

Mission Australia State Leader, Regional NSW

It is encouraging that the National Disability Insurance Agency (NDIA) will introduce Justice Liaison Officers (JLOs) in each state and territory to work across their justice systems.<sup>43</sup> The JLOs will provide a single point of contact for workers within each state and territory justice system, providing a coordinated approach to supporting NDIS participants in youth and adult justice systems.<sup>44</sup> Considering the challenges specific to this cohort, we recommend implementation of this measure as a matter of priority. In order to increase productivity and efficacy of these initiatives, information should be made publicly available about the implementation of these policies and guidelines.

### **Rural, remote and regional areas or thin markets**

People living in rural areas experience a higher prevalence of deprivation, generally higher rates of social disengagement, the highest rates of service exclusion, and higher rates of economic exclusion compared to those living in inner cities.<sup>45</sup> As a consequence, delivering services and raising awareness about

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<sup>43</sup> Council of Australian Governments Disability Reform Council, Communiqué, 9 October 2019, accessible at: [https://www.dss.gov.au/sites/default/files/documents/10\\_2019/communique-drc-9-october\\_2019.pdf](https://www.dss.gov.au/sites/default/files/documents/10_2019/communique-drc-9-october_2019.pdf)

<sup>44</sup> Ibid

<sup>45</sup> Australian Institute of Health and Welfare, *Australia’s Welfare 2017*, July 2017, accessible at: <https://www.aihw.gov.au/getmedia/088848dc-906d-4a8b-aa09-79df0f943984/aihw-aus-214-aw17.pdf.aspx?inline=true>

mental health issues, services available in the local area and engaging people is much more challenging and time consuming. Targeted strategies should be in place to support people with disabilities in rural, regional and remote parts of Australia.

Rural and remote areas of Australia have low levels of public transport access. Some remote areas have relatively low levels of vehicle ownership.<sup>46</sup> In outer-urban areas transport disadvantage is the result of a range of intersecting factors including poor public transport infrastructure, a higher proportion of low-income households and the need to travel further distances in order to get to places of employment, services and activities.<sup>47</sup> This may mean that the services need to be flexible to travel to these locations to deliver services. The NDIA should ensure that these people are supported by a panel of service providers who are required to guarantee services to NDIS participants to ensure the participants in rural, remote and very remote areas are able to access high quality, clinically trained and therapeutic supports to prevent and mitigate the impact of market failure in rural and remote areas.

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<sup>46</sup> Australian Institute of Family Studies, *the relationship between transport and disadvantage in Australia*, 2011, p.1

<sup>47</sup> Ibid