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THE NDIS UTILISATION PROJECT - VICTORIA

Summary report of qualitative findings



**Melbourne
Disability
Institute**

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Acronyms

Acronyms	Description
AAT	Administrative Appeals Tribunal
AFDO	Australian Federation of Disability Organisations
CEH	Culture, Ethnicity, and Health
CHS	Community Health Services
DHHS	Department of Health and Human Services
ECCV	Ethnic Communities' Council of Victoria
ECEI	Early Childhood Early Intervention
FPDN	First Peoples Disability Network
IAs	Independent Assessments
LAC	Local Area Coordinator
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDIS frontline worker	For the purpose of this report, this includes Local Area Coordinators and planners
OT	Occupational Therapist
PITC	Partners in the Community
PLS	Plain Language Statement
PPE	Personal Protective Equipment
SIL	Supported Independent Living

Executive summary

The National Disability Insurance Scheme (NDIS) Utilisation Project – Victoria, commissioned by the Victorian Department of Health and Human Services (DHHS) and now being managed by the new Department of Families, Fairness and Housing, aims to better understand how and why NDIS plan utilisation may vary between Victorian NDIS participants.

The qualitative component of this project focused on understanding this issue from the perspectives of NDIS participants, particularly those who are recognised as more likely to experience barriers within the current complexities of the system in utilising their plans in a way that best meet their needs and aspirations. This includes participants with psychosocial disability, participants who identify as Culturally and Linguistically Diverse, and participants who identify as Aboriginal and Torres Strait Islander (First Nations). In doing so, the research team interviewed more than 100 NDIS participants and plan nominees between April and December 2020.

This document outlines key factors participants highlighted as influencing the effective utilisation of their NDIS plans and proposes policy considerations for the Victorian government which - in collaboration with other jurisdictions – may enable more effective NDIS plan utilisation to support participants to achieve their goals and aspirations.

Overarching findings

Overwhelmingly, participants reported NDIS plan utilisation improved access to services and supports to help them meet their disability related needs. This in turn created opportunities for enhanced independence, community participation, and enriched interpersonal relationships. Nonetheless, many participants wanted more opportunities to engage in more innovative and mainstream opportunities.

Utilisation was more effective when participants had plans that accurately reflected and adequately resourced for their individual needs and priorities. This was facilitated when participants had:

- Experience with pre-existing programs and systems as this helped them to more easily navigate the complexity of the NDIS, as well as start using plans with their existing services, when compared to participants without such experiences.
- Access to accurate, timely, consistent and targeted information to help them understand about the NDIS and access, planning and review and plan management processes.
- Self-advocacy capabilities and/or access to advocacy supports to help them articulate (and document) information about their disability, circumstances, needs and preferences.
- Sustained, collaborative relationships with skilled frontline NDIS workers and planners that respect the expertise of participants (and their informal supports) when developing current plans and identifying short- and longer-term priorities.
- Trusted and skilled (formal and informal) supports to understand, implement and manage plans, alongside support to recognise and report issues of risk and exploitation.
- Sufficient time to identify and access appropriate and available services to meet priority needs (e.g., equipment, mental health), with minimal stress, as well as time to develop capabilities for ongoing utilisation.

Many barriers to effective plan utilisation were also identified through the research, providing important insights into why effective plan utilisation has been lower than expected since the inception of the NDIS. These multiple barriers highlight that optimising plan utilisation and, hence implementation of the NDIS is multi-dimensional. There are no “silver bullets”. Gaps in the availability – particularly in areas outside of Metro Melbourne - of quality services, skilled therapists and support workers that meet the diverse mental health, disability and cultural needs and preferences was the most commonly reported barrier to effective utilisation. Limited availability of services and supports priorities constrained effective utilisation in a few key ways:

- The most direct barrier was that participants were not able to spend the funding in their plans as the services and supports they require were not always readily available or of sufficient quality. This problem is more acute the further a participant lives from Melbourne.
- Subsequently, delays in spending in one area (e.g., could not access an OT to process an assessment for equipment/home modification) lead to difficulties in utilising other components of plans (e.g., capacity building for independent living). Limited availability of specialist services and therapists was a frequent complaint.
- Utilisation could then be further disrupted by delays in NDIA approvals.

Further factors relevant to the design and implementation of the Scheme which continue to undermine effective plan utilisation, particularly for the cohorts of interest in this project included:

- Considerable confusion in participants’ understanding of what was often described as a complex system to understand.
- Inconsistencies in the provision of information and communication, particularly in relation to meeting cultural and language specific requirements and preferences.
- Delays and challenges in access, planning and review processes - including experiences of negative treatment within participant engagement with NDIS frontline workers- contributing to deteriorations in conditions and subsequent difficulties in utilising plans to meet changing needs.
- Insufficient support to understand plans and what and how they could be utilised.
- Experiences of negative treatment and exploitation in participant engagement with service providers, alongside challenges in reporting such treatment (e.g., fear of losing services, delays in having complaints followed-up or appropriately handled).
- Impact of marketisation on the cost, availability and access to services as well as the quality of supports.
- Extensive delays in access and procurement of equipment, assistive technology and home modifications.
- Limited support for plan nominees within or external to the NDIS to address their own unmet needs (e.g., health, respite, well-being), undermining their capabilities to support participants.

These barriers were further compounded by intersecting challenges experienced by participants with psychosocial disability, First Nations participants, and Culturally and Linguistically Diverse participants. While each reported specific barriers, there was a shared perception among participants that many of the challenges they experienced, stemmed from the fact that these cohorts had all been less well consulted during the original design of the NDIS. Subsequently - and despite progress - participants reported inconsistencies in the cultural competencies and understanding of psychosocial disability within the NDIS, undermining the Scheme’s capacity to appropriately engage and support these cohorts. The limited - and disrupted – availability of skilled workers, services and supports for these cohorts further undermined effective plan utilisation.

Finally, the role of the NDIS in shifting often lifelong and systemic barriers experienced by many NDIS participants on account of their disability and other intersecting identities (e.g., Indigeneity, ethnicity) has not advanced as much as was hoped when the NDIS commenced. This has constrained access by NDIS participants to mainstream services and adversely affected effective plan utilisation. Yet broader policy and social change are also necessary before the NDIS can achieve its true potential in supporting all NDIS participants to effectively utilise their plans in a way that helps them improve their lives and attain their self-determined aspirations and goals.

Key policy considerations

The following policy considerations represent opportunities where the Victorian government could encourage and work closely with other jurisdictions and stakeholders to address factors undermining NDIS plan utilisation. In effect, these policy considerations highlight that shared stewardship and close coordination across governments and multiple agencies, are essential for effective plan utilisation and the full success of the NDIS. Potential strategies in response to each of these considerations is outlined on page 48.

1. **Invest in strategies to stimulate and monitor the availability of a skilled, inclusive, stable and valued workforce to match the varied disability, mental health and cultural needs and preferences of Victorian NDIS participants.**
2. **Provide ongoing support to Victorian advocacy, community and peer-led organisations that work with people with disability and their communities to understand and navigate the NDIS and services and supports.**
3. **Encourage greater investment in the human resourcing and training of the NDIA and NDIS workforce to improve the retention of skilled staff, enabling participants and workers to develop trusting working relationships, and, improving consistency of planning processes and outcomes. Further investment in the Scheme could also focus on encouraging more targeted market stewardship to help identify and address shortages in the quantity, quality and geographic availability of services and supports.**
4. **Encourage and provide guidance to all stakeholders (participants, families, frontline workers and other supports) involved in access, planning and review processes to use these opportunities to develop a shared understanding of factors influencing individual plan utilisation, and to support understanding of how plans can be utilised and managed.**
5. **Develop a better understanding of the bottlenecks in the supply and procurement processes of equipment, assistive technology and home modifications, in order to inform appropriate solutions.**
6. **Enhance the prevention and monitoring of risks and exploitation experienced by NDIS participants.**
7. **Progress work with NDIA advisory boards and other people with disability and their representative organisations to co-design strategies to address specific barriers experienced by people with psychosocial disability, First Nations and Culturally and Linguistically Diverse communities in their access and engagement with the NDIS.**
8. **Continue to collaborate with all jurisdictions and stakeholders to develop and support state and national level policies and programs that enable the inclusion and active participation of all Australians with disability and their families across all life domains and systems.**

Background

The NDIS is recognized as the largest social policy reform implemented in Australia in nearly fifty years. It aims to place people with disability at the centre of decision-making around what and how services and supports are purchased across their lifetime, through individualised budgeted plans, to achieve self-determined goals (Bonyhady 2014). While the NDIS is administered by the National Disability Insurance Agency (NDIA), its effectiveness relies on collaboration and coordination across all jurisdictions, and, with interfacing sectors such as health, education and justice.

A key role of the NDIA is to work with participants and their support networks to develop capacity to effectively utilise their plans in a way that helps them achieve their goals. Consideration of what constitutes effective utilisation cannot simply be made by examining the amount of a plan that is utilised, but rather what is equally important is the quality of utilisation and how this contributes to enabling participants to move towards their goals and improve their quality of life. Effective utilisation, however, is proving challenging for a number of participants (Productivity Commission 2017, Tunc 2019).

Particular concern has been raised that certain cohorts experience barriers in accessing the NDIS, as well as difficulties in effectively utilising their plans when they do. This includes people with psychosocial disability, those who identify as Culturally and Linguistically Diverse, and First Nations participants. Several inter-related reasons for low utilisation have been posited. This includes insufficient supply of services and supports to meet the demand and needs of participants (Joint Standing Committee on the NDIS, 2017, Productivity Commission 2017). Utilisation also varies geographically, with participants living in urban areas more likely to have higher utilisation when compared to those living in rural, regional and remote locations. Others have reported limited support being available to help participants navigate the complex disability service system, leaving some people with disability unable to implement their plans (Joint Standing Committee on the NDIS, 2017, Productivity Commission 2017, Avery 2018, Smith-Merry, Hancock et al. 2018, Ethnic Communities' Council of Victoria (ECCV) 2019, Tunc 2019).

While it is expected that utilisation rates will increase as the NDIS matures, better understanding of the facilitators and barriers to effective plan utilisation remains essential to inform policy and practice that will support both the quantity and quality of utilisation (Productivity Commission 2017). As such, the NDIS Utilisation Project – Victoria aims to better understand how and why plan utilisation varies across Victorian NDIS participants. The broader project used a mixed methods approach, drawing on quantitative and qualitative data. This report focuses on the qualitative component (here in referred to as the project) of the broader project, which aimed to understand this issue from the perspective of NDIS participants. The project had a specific focus on understanding factors contributing to the generally lower utilisation among participants with psychosocial disability, people from Culturally and Linguistically Diverse backgrounds, and First Nations participants. The key research questions guiding the project were:

1. How do NDIS participants utilise their NDIS plans?
2. What are the key facilitators and barriers influencing utilisation?
3. Why does NDIS utilisation of plans vary across the different cohorts of interest?

The next section outlines the methods used in the qualitative component of the project. This is followed by a presentation of the key findings which address the above research questions. A reflection on these findings and the emerging policy consideration is then shared.

Methods

The project involved semi-structured qualitative interviews with 75 NDIS participants, 27 plan nominees and two advocacy organisations.¹ The project was implemented in two phases. The first phase focused on the impact of COVID-19 on utilisation, the findings of which have been reported separately. The second phase explored utilisation more broadly and is the focus of this report.

Recruitment and data collection

Recruitment and data collection were initiated on 30 April 2020. Participants were recruited through both purposeful and snowball sampling, drawing on the networks of the research team, and, our advisory committee members and their organisations. Information about the project and how to contact the research team to express interest in participating were circulated via email and social media (e.g., Facebook, Twitter, e-newsletters). Potential participants who made contact with the research team were provided with a Plain Language Statement (PLS). A time was then made to conduct the interview with individuals who confirmed they would like to participate.

In person interviews were not possible due to the COVID-19 pandemic. Interviews were therefore conducted via Zoom or phone depending on the preference of the participant. As required, captioning and interpreting were made available to participants who require these supports during the interview. Each interview generally lasted between 60 to 90 minutes. Interviews were audio and/or video recorded and transcribed. All participants were 18 years or above. Participants were reimbursed for their time. Ethics approvals were obtained from the University of Melbourne's Human Research Ethics Committee (ID 1955426.3).

Data analysis

Data analysis began with three research team members completing multiple readings of a sample of fifteen transcripts, and deductively (drawing on the research questions and interview guides) identifying key emerging themes. Each research team member then utilised an inductive process (not constrained by research questions or interview guides) to identify further themes emerging from the data. A thematic coding framework was then developed based on the various themes identified by each researcher. This coding framework was then used to analyse and code all transcripts using a thematic approach to analysis (Braun and Clarke 2006). To facilitate this process, transcripts were categorised into groups (psychosocial disability, Culturally and Linguistically Diverse, complex needs, and First Nations)² with a research team member responsible for leading the analysis of at least one group of transcripts. Comparisons were then made across and within each cohort, enabling the research team to progressively refine the various themes.

Key themes were then grouped in relation to the three main research questions (e.g., use of plans, barriers and facilitators influencing utilisation, and cohort specific utilisation experiences and issues). The research team then identified sub themes relevant to each of the overarching key themes. This was done by identifying both issues more frequently identified by participants and/or groups of participants, as well as identifying factors that helped further explain why such issues may be occurring, or for whom issues were of particular relevance to their

¹ Noting some interviewees were NDIS participants or plan nominees that also worked for advocacy organisations.

² Noting where a person identified as both CALD and having a psychosocial disability, the corresponding transcript was reviewed under each sub-category.

utilisation experiences. Prominent findings responding to each research question were then drafted and re-checked against the coding framework by each of the three research team members responsible for the analysis process. At various stages of the analysis, these researchers presented the thematic analysis and progress reports of draft findings with the broader research team and research advisory committee, as well as through relevant workshops and other stakeholder engagement platforms (e.g., Victorian Ministerial COVID-19 Taskforce Committee). This helped ensure that the interpretation of the data remained relevant and informed by a broader understanding of the context in which the research was taking place.

Limitations

These findings provide important in-depth, insights into factors influencing NDIS plan utilisation from the perspectives of Victorian NDIS participants themselves. While we intend to work with colleagues undertaking a quantitative data analysis of NDIA and Victorian government data to triangulate our findings, it is just one of many studies and analyses focused on better understanding the NDIS and the experiences of participants within it. While the sample size was more than sufficient to address the research questions, the findings may not be representative of the experiences of all NDIS participants within Victoria or in other jurisdictions.

This project privileged the lived experiences and voices of NDIS participants themselves. We therefore only spoke to a small number of advocacy organisations and/or participants who also held positions within advocacy organisations. It would nonetheless be beneficial to triangulate these findings through interviews and consultations with other advocacy and community organisations, as well as service providers and other stakeholders.

The original design of the project envisaged the research team would focus on various districts that were known to have either higher or lower than average utilisation. It was hoped that the research team would be able to travel to these districts to work with local NDIS branches and Partners in the Community and other organisations to support targeted recruitment and conduct interviews. This was not possible due to the COVID-19 pandemic. Nonetheless, the cohort provides for a representative sample in terms of the key areas of interest i.e. cohorts of interest, level of utilisation, and geographical location.

Similarly, due to social and travel restrictions the research team conducted interviews via telephone and Zoom, instead of face-to-face as was originally intended. Using different mediums for interviewing is not uncommon within qualitative research, and we believe that they provided for rich discussion with participants. Indeed, many participants found this approach suited them well. We do, however, acknowledge that the combination of the travel restrictions and loss of the opportunity to meet with participants face-to-face may have meant that we did not capture the voices of some participants that are perhaps more isolated and harder to reach through online recruitment.

Finally, this study was implemented at a time when there were several proposed changes to the NDIS muted and/or out for consultations. This was alongside multiple reviews, consultations and commissions into other areas of disability and mental health systems. While necessary, it has nonetheless been an overwhelming time for many participants, their families and organisations working across these spaces. This too may have influenced the response to our study, as well as the focus of some of the interviews. We also acknowledge that the NDIA are in the process of working to address a number of issues identified in this report.

Findings

This section begins with a brief overview of participant demographics and plan related information (see Tables 1-3). Key findings that were relevant to all groups of participants are then described with a focus on 1) how NDIS participants are currently using their plans and their future aspirations; and 2) key facilitators and barriers influencing effective utilisation. This is followed by findings that were experienced more specifically by First Nations participants, Culturally and Linguistically Diverse participants, and participants with psychosocial disability.

Participant demographics and plan related information

The overall cohort consisted of slightly more females than males with the majority of participants over the age of 35 years. The most common primary disability reported were psychosocial and multiple or complex disabilities. Around thirteen per cent of the cohort identified as First Nations, with just under a fifth identifying as Culturally and Linguistically Diverse. The cohort were generally well-educated with nearly a third reporting attaining university qualifications, yet less than a third were currently employed or looking for work. There was an even spread of participants across Metro and Regional areas. (See Table 1).

Of the twenty-seven Plan Nominees interviewed, most were the NDIS participant's mother. Around two per cent identified as First Nations, with almost a fifth identifying as Culturally and Linguistically Diverse. Contrasting with the overall cohort, of the thirty-four NDIS participants represented by Plan Nominees, the majority were aged under 24 years. Gender distribution was consistent with the overall cohort, and reporting multiple or complex disabilities as the most common primary disability. Consistent with the age demographic of these NDIS participants, nearly half were currently at primary or high school, though by contrast with the overall cohort, almost a third were reported as not currently employed or looking for work. Similar to the overall cohort, distribution across Metro and Regional areas was evenly reported, with the vast majority reported as being in private housing. (See Table 2)

Table 1. NDIS participant demographics

		n (%)
Gender	Female	55 (50.5%)
	Male	48 (44%)
	Non-binary	6 (5.5%)
Age	0-11	10 (9.2%)
	12-17	10 (9.2%)
	18-24	8 (7.3%)
	25-34	17 (15.6%)
	35-49	34 (31.2%)
	50 and over	30 (27.5%)
First Nations	Yes	14 (12.8%)
Culturally and Linguistically Diverse	Yes	20 (18.3%)
Primary disability *	Physical	21 (19.2%)
	Sensory	9 (8.3%)
	Neurological	8 (7.3%)
	Psychosocial	27 (24.8%)
	Intellectual	13 (11.9%)
	Multiple/complex disabilities	31 (28.4%)
Highest level of education	Not specified	3 (2.7%)
	Not yet at school	3 (2.7%)
	Currently at primary or high school	18 (16.5%)
	Completed some high school	21 (19.3%)
	Completed high school (including in specialist setting) no post-secondary	14 (12.8%)
	Certificate	5 (4.6%)
	Diploma/apprenticeship/TAFE	12 (11%)
	University degree	32 (29.4%)
Employment	School-age and under or over 65/retired	23 (21.1%)
	Currently in paid employment/ self-employed	26 (23.8%)
	Not currently in employment but looking for work	6 (5.5%)
	Not currently employed or looking for work	47 (43.1%)
	Looking for training	1 (0.9%)
	Voluntary work	4 (3.7%)
	Not stated/Unknown	2 (1.8%)
Location	Metro Melbourne	55 (50.5%)
	Outer Melbourne (approx.. 50-80kms from metro)	10 (9.2%)
	Regional/rural	44 (40.4%)
Housing	Private (own or rental, independent or with family)	86 (78.9%)
	Public/social/community housing	17 (15.6%)
	Specialist Disability Accommodation	1 (0.9%)
	Community Care Unit	2 (1.8%)
	Unstated/not known	3 (2.7%)
TOTAL		109

*Participants were categorised as having a multiple/complex disability through self-identification and/or when they were reporting multiple and/or interrelated primary conditions contribute to significant levels of support needs, often across multiple domains of functioning (e.g., physical, intellectual). We also note that the targeted recruitment approach, including through the networks of partners, accounts for the higher numbers of participants with psychosocial disability and multiple/complex disabilities.

Table 2: Plan Nominee Demographics

		n (%)
Total no. of interviews with plan nominee³		27
Gender	Female	25(92.6%)
	Male	2(7.4%)
Age of Plan Nominee	18-24	0(0.0%)
	25-34	3(11.1%)
	35-49	12(44.4%)
	50 and over	10(37%)
	Unidentified	2(7.4%)
Relationship to participant(s)	Mother	22(81.5%)
	Father	3(11.1%)
	Wife	2(7.4%)
First Nations	Yes	2(7.4%)
Culturally and Linguistically Diverse	Yes	5(18.5%)
Plan Nominee for	1 participant	22(81.5%)
	2 participants	4(14.8%)
	More than 2 participants	1(3.7%)
Total participants represented		34
Age of participants	0-11	9(26.5%)
	12-17	9(26.5%)
	18-24	8(23.5%)
	25-34	3(8.8%)
	35-49	3(8.8%)
	50 and over	2(5.9%)
Gender of participants	Female	16(47.1%)
	Male	17(50%)
	Nonbinary	1(2.9%)
Primary disability of participant	Physical	1(2.9%)
	Sensory	1(2.9%)
	Neurological	6(17.7%)
	Psychosocial	3(8.8%)
	Intellectual	6(17.7%)
	Multiple/complex disabilities	17(50%)
Highest level of education	Not specified	1(2.9%)
	Not yet at school	3(8.8%)
	Currently at primary or high school	16(47.1%)
	Completed some primary or high school	5(14.7%)
	Completed high school (including in specialist setting) no post-secondary Certificate	5(14.7%)
	Diploma/apprenticeship/TAFE	3(8.8%)
	University degree	0(0.0%)
Employment	School-age and under or over 65/retired	18(52.9%)
	Currently in paid employment/ self-employed	2(5.9%)
	Not currently in employment but looking for work	1(2.9%)
	Not currently employed or looking for work	10(29.4%)
	Looking for training	1(2.9%)
	Voluntary work	1(2.9%)
	Not stated/Unknown	1(2.9%)
Location	Metro Melbourne	16(47.1%)
	Outer Melbourne (approx.. 50-80kms from metro)	2(5.9%)
	Regional/rural	16(47.1%)

³ 4 of the 27 interviews were conducted with two Plan Nominees. Only demographic data for the primary Plan Nominee is included in this table.

The majority of participants had been in the Scheme for between two and three years. Most participants had had between two to four plan, yet this did not always correlate with the length of time in the Scheme (i.e. some participants may have required numerous small reviews in a short period of time that led to a larger number of plans). Just under half of all participants reported they had utilised less than half of their plans proportionate to the length of the current plan, with a further third unsure about their level of utilisation. (See Table 3.)

Table 3. NDIS plan related demographics

		n (%)
NDIS District	Barwon	6 (5.5%)
	North Eastern Melbourne	12 (11%)
	Central Highlands	2 (1.8%)
	Loddon	3 (2.7%)
	Inner and Outer Gippsland	10 (9.1%)
	Ovens Murray	2 (1.8%)
	Western District	7 (6.4%)
	Inner Eastern Melbourne	6 (5.5%)
	Outer Eastern Melbourne	11 (10.1%)
	Hume Moreland	13 (11.9%)
	Bayside Peninsular	11 (10.1%)
	Southern Melbourne	3 (2.7%)
	Brimbank Melton	3 (2.7%)
	Western Melbourne	4 (3.7%)
	Goulburn	14 (12.8%)
Unknown	2 (1.8%)	
NDIS year of enrolment	2014 - 2015	7 (6.4%)
	2016 - 2017	27 (24.8%)
	2018 - 2019	69 (63.3%)
	2020	4 (3.7%)
	Unknown	2 (1.8%)
NDIS plan number	1-2	54 (49.5%)
	3-4	37 (33.9%)
	5+	14 (12.8%)
	Unsure/not stated	4 (3.7%)
Utilisation of current plan	0-25%	13 (11.9%)
	26-50%	35 (32.1%)
	51-75%	12 (11%)
	76% or more	16 (14.7%)
	Unknown	33(30.3%)

*Where possible, this was estimated for the previous 12 months. If the participant had been on the Scheme for less than 12 months the approximate corresponding utilisation was estimated. I.e. if a participant had used approximately 30% of their plan at the 6-month mark, this was equated to 51-75% utilization.

1. How do NDIS participants utilise their NDIS plans?

Overwhelmingly, participants described that the NDIS had contributed to positive outcomes across their lives. Reaching these outcomes often involved diverse utilisation pathways in relation to what and which order services and supports were accessed. There were nonetheless commonalities in how participants were utilising their plans as further described below.

Support for daily living

- Across the cohort, participants were commonly utilising plans to **engage support workers to help meet disability-related daily living needs** (e.g., showering) as well as support to go out into the community (e.g., social participation, shopping). The extent to which these services were utilised was influenced by the type and level of disability, availability of services and supports, as well as available funding: *I don't think I realised how hard it was. ... I was getting up at the crack of dawn and not getting to bed till past midnight just trying to do sort of the things – with my disability I was struggling. And this has made a huge difference to my life.* (NDIS participant with complex disability, female, Metro).
- Participants with physical disability often reported trying to prioritise utilisation to access **necessary equipment and/or home modifications** required to support their disability needs and improve their independence. Further plan utilisation was enabled when these needs were met. For example, using plans to access services such as hydrotherapy could only be achieved when participants had access to equipment such as an appropriately fitted wheelchair and car modifications so they could travel to appointments.
- Using plans for support with **garden maintenance and home cleaning** was also frequently reported across the cohort.
- A smaller number of participants across this cohort – generally with intellectual and/or complex disabilities - were using their plans to **access Specialist Disability Accommodation and/or day programs**.
- Some participants were utilising plans for **meals and support for food preparation**. While some described complexity with utilising this line item, when it did work well, it enabled plan utilisation across other life domains such as engagement in work.

Looking after myself with a disability, it takes up a huge amount of time ... and NDIS, having given me supports, has almost given me back time, and it's given me back energy that I can use to actually have time to go to work and actually get a job again. Before NDIS I could only do casual, like, a couple of hours here and there, and now I'm managing three days a week ... I need support there to come home and be able to have meals prepped. ... Some things disappeared from the plan. Like, I had some assistance with meals, which I had to fight for in the previous plans, but that's disappeared. (NDIS participant with neurological disability, female, Metro)

Allied health professionals for therapy, assessments and reporting

- Most participants were engaging with some form of **allied health** (e.g., Psychologist, Occupational Therapists (OT), Speech pathologist, Physiotherapist) for **capacity building support and therapy (for younger clients)**: *Financially we would not be able to afford it. He wouldn't be having any access to OT or psychs ... he has come a long way since having access to early intervention. ... He would definitely fall through the cracks and he*

wouldn't be in mainstream school. ... He wouldn't even probably be in school. (Plan nominee for young son with complex disability, Regional)

- As such, participants may **utilise the capacity building component** of their plan to engage with a Psychologist and/or OT to address mental health concerns and **develop their confidence and independence**, in the hope this would enable them to **then utilise other components of their plans** such as social participation.
- Allied health professionals were also commonly engaged for **assessments and reporting** to enable access to the Scheme, as well as document ongoing needs (e.g., home modifications, equipment, capacity building) for planning and review processes.
- Participants valued assessments being completed with trusted professionals that they had been engaged with for a long time. Yet, the **associated costs reduced available plan funding** that would have otherwise been available for capacity building, therapy or other supports. This was frustrating for participants if multiple reports and/or quotes for supports were challenged or only approved after significant delays.

I had to not see my psychologist in order to see the OT. And that's not one appointment. The OT assessment's pretty expensive. ... Now that I have finally got that funding do you think there are any available OTs? I have to wait until mid-July (NDIS participant with psychosocial disability and co-occurring conditions, female, Outer Metro)

Aspirations for plan utilisation

- Some participants were managing to utilise their plans to **engage in mainstream community activities (e.g., sport, recreation)**. To do so, participants often required help from support workers to facilitate their access and participation, particularly if they had limited funding for or no access to transport.
- Many participants wanted **more opportunities to utilise their plans to engage in mainstream activities** (e.g., life-long education, sport and recreation, cultural community events) as well as peer-led programs. For example, some participants were hoping to use plans to develop participant-led social networks and online platforms to support NDIS participants to share information and support participants to more effectively utilise their plans.
- There were also participants and plan nominees who were also striving to develop **more innovative and individualised opportunities for plan utilisation**. For example, in response to the limited availability of tailored education and skills training for young adults with complex disability, one plan nominee was hoping to engage a provider or workers to develop and implement a long-term one-to-one or small group program specifically designed to meet the life-long learning needs of their family member, to promote their capabilities to find a meaningful role in the community, such as volunteering.

One of my very long term goals ... is for him to be productive somehow, but I don't know how that looks at the moment. ... We've got a long way to go till we get there ... I'm not sure if the community is quite ready for [participant] yet in doing something, but ... you just never know. Every now and again you come across somebody terrific. So, it would be nice to get more of those terrific people. (Plan nominee of adult son with complex disability, Metro)

2. What are the key facilitators and barriers influencing utilisation?

2.1 Facilitators of effective utilisation

Experience with pre-NDIS systems and services, alongside access to knowledgeable supports often facilitated prompt and effective utilisation. For others with less experience and fewer links to services, utilisation generally improved the longer participants remained on the Scheme. As such, participants often required time to identify and access appropriate services, build trusting relationships with workers, and build their capacity to more effectively utilise plans.

Experience with pre-existing programs and systems

- Generally, participants with significant levels of long-term disability had previously received services through **pre-existing systems and/or defined programs which enabled them prioritised NDIS access**.
- Compared to participants with less experience of existing systems, these participants were more likely to be **able to use their knowledge of how to navigate pre-existing systems** to more effectively navigate the NDIS system, and, demonstrate their eligibility with existing evidence (or have access to knowledgeable professionals to support this process) and clearly articulate their ongoing needs and priorities.
- Many were **already accessing well-established disability services that had effectively made the initial transition across to the NDIS** (e.g., support for daily living, day programs). In turn, these participants were more readily able to start utilising their plans upon access.
- **Pre-NDIS experiences also influenced perspectives on services received after access**. Some were optimistic that outcomes would improve through the NDIS. Others preferred previous programs and now felt they experienced less security and greater complexity within the NDIS.

Probably 80% or 90% [utilisation]. The biggest thing that I use it for is daily support workers. ... I was one of the few people that had good funding ... from the previous funding scheme before NDIS. So I didn't have like a big backlog of OT ... I had an [ISP] ... Which were very similar to NDIS, in that it was done with goals and individual budgets ... so I was very familiar with kind of how to do it even before. And I had all the same service providers, so when I joined NDIS, it was kind of like a difference of administration, but that was pretty much all. So I know a lot of people kind of don't use their plans at the start, because they need a lot of help getting set up and getting started, but I actually didn't have that problem. (NDIS participant with complex disability, agender, Metro)

Advocacy capabilities

- Navigation of NDIS processes was more straightforward for participants who were independently – or with supports – able to **strongly advocate their needs and rights**. Such participants often had greater capabilities to effectively engage with services and supports in a way that met their needs and aspirations, and therefore **facilitate more effective utilisation of their plans**.
- Within this, participants highlighted the **critical role of Victorian advocacy organisations** in helping individuals and families learn about the NDIS and navigate its processes.
- This was enough support for some, yet for other participants with less advocacy capabilities or experience navigating disability systems, **higher levels of advocacy support** was generally required. Such supports were not always known about or readily available, or were inadequately resourced to meet demand.

I'm looking for someone to help me review my goals and that when it comes to review time that I have someone to be in the meeting with me. Because I mean, I'm very intelligent and very capable, but it's very intimidating... to go into that thing [planning/review meeting] and your whole life is dependent on how the meeting goes. Just somebody to be in the meeting with you and advocate for you. (CALD NDIS participant with physical disability, female, Metro)

Availability and expertise of informal supports

- For participants with more complex needs, less experience or support for self-advocacy, and/or, those who prefer to draw on supported-decision making mechanisms, **informal supports remain critical in their NDIS engagement and effective plan utilisation.**
- The more knowledgeable and experienced such informal supports were, the greater the level of support they were able to provide to utilise plans effectively and in a way that met the needs and priorities of the NDIS participants they supported.

My experience and understanding of working with marketized systems stems back quite a long way. ... I'm not a typical plan nominee. ... And we can very easily substantiate his needs on the basis of past and recurring behaviours of concern, which I am comfortable to speak about. (Plan nominee for adult son with psychosocial disability and co-occurring conditions, Metro)

Positive collaboration and continuity with NDIS frontline workers⁴

- Positive processes (e.g., planning and reviews) were described as occurring when skilled and knowledgeable NDIS frontline workers took time to **build and sustain trusting relationships with participants**. Whereby participants were able to **meet with the same (skilled) frontline worker** and when all stakeholders used these processes to listen to and respect the expertise of participants to **generate a shared understanding of their needs** and – often changing – circumstances, what services and supports may best meet these needs, and what can and cannot be included in responding plans.
- When subsequent plans accurately articulated this shared understanding and information, it was more likely to lead to **plans that better matched needs**, participants felt **better informed about how they could utilise their plans**, and it **reduced the need for multiple reviews**. All of which improved utilisation outcomes.
- Further, whilst not commonly reported, when participants were able to consistently engage with the same (skilled) worker, they were able to **develop a life-course approach to planning**.
- Of course, the converse holds true that when these processes are negative, it can hinder effective plan development and utilisation.

The first time I went to the NDIS office ... I had the most extraordinary experience. I hand-wrote all my stuff because my computer wasn't working ... I walked in and I shook her [planner] hand and gave her a copy ... we spoke for three hours and she was great. And I was on my own. ... She went over and beyond. ... Within 24 hours of our meeting, I got an email saying you have something in your myGov box and it was my plan. She'd written it, had it approved, and it was \$85,000 worth. (NDIS participant with psychosocial disability, female, Metro)

⁴ For the purpose of this report, an NDIS frontline worker includes Local Area Coordinators and planners

Support to implement and utilise plans

- **Ongoing support from skilled and trusted NDIS frontline workers** was seen as critical to effective utilisation. This included providing support to:
 - understand individual plans and its components and what each component could be used for
 - understand different ways to manage plan funding (e.g., agency, plan managed, self-managed) and the processes involved with each
 - identify appropriate and available services in their area that could meet individual needs and priorities so they could start implementing their plans.
- Many participants, however, described **not receiving this level of support from their frontline worker**, leaving them feeling lost and not knowing where to start.
- For eligible participants, access to **independent and quality Support Coordination** played a beneficial role in individualised and effective utilisation. This is particularly important for those who experience difficulty in utilisation. Effective Support Coordinators were described as:
 - taking time to understand participants and their needs
 - offering independent advice and support to link into services
 - being transparent in how they were supporting participants to utilise their funding.
- Participant **experiences in relation to Support Coordination were also diverse** and not always beneficial. Concern was raised that the level of Support Coordination funded in plans was often insufficient, making it difficult for individuals to perform this role adequately and support effective utilisation.
- The growing **emergence of peer-to-peer online networks and consumer advocacy groups** was described as a valued source of information. These sources were often cited as providing an independent perspective that service organisations were not always relied upon to provide. Utilisation was also facilitated through such peer-led knowledge sharing networks.
- Yet, it can take **time to build these networks**. They are also **not always accessible to some populations** including those who are less connected to community – physically and/or virtually – and participants from Culturally and Linguistically Diverse communities.

She [NDIS participant] didn't even know what to be asking for, how to do ... anything like that, and she did it on her own not asking for any help from me ... because she didn't want to burden me ... then once the plan came through the person who wrote the plan for her rang up, basically said, "Well it's nowhere near as much funding as I had hoped you'd have," and "bye". So she had no guidance whatsoever as to where she went next, who she was meant to talk to ... how she made it all happen, and she was funded for plan management and she had no idea how she was meant to set that up. She was just completely in the dark. (Plan nominee for one adult daughter and three other children with complex disability, Regional)

Length of time in scheme

- Participants were **more effectively able to utilise their plans in a way that met their needs the longer they remained in the Scheme**. For some, time was needed to get used to the idea that they required support and now had the resources to do so.
- Others required **time to more clearly identify their needs and priorities**: it could then take time to **identify appropriate and available supports** to engage with.
- Once supports had been secured, participants required **time to build trusting relationships** with workers to address key concerns and **build confidence and capacity to further utilise their plans**.
- Yet, **these processes were easily disrupted**, particularly for participants that may have experienced any kind of trauma, and/or, have experienced other barriers to utilisation such as thin markets.

I am very grateful for [NDIS] and it definitely means that I could do things that would be way out of reach on the disability pension. ... Definitely helped me to engage in the community more ... So I would say it this way, through the intensive work with the psychologist, I then got to the point where I'm able to leave the house. ... Then I finally left the house and joined a choir. ... I know they like social participation ... but they need to know how people get to that point. ... It's not just about ... the availability of a support worker, it's about background work, the hard yards that people put in to get to the point where they can actually get the support worker to take them somewhere. (NDIS participant with psychosocial disability and co-occurring physical health conditions, female, Regional)

Enhanced utilisation through perceived benefits of the NDIS

- NDIS budgets provided critical resources that helped participants improve **access to services and supports** and **reduce the level of financial and emotional stress** individuals experienced in meeting basic and disability specific needs. This was particularly recognised by those who previously could not afford, or, did not have sufficient access to supports.
- Increased access to services and supports helped participants **enhance independence, improve community participation**, and, **enrich relationships** with informal supports – all of which contributed to substantial **improvement in quality of life** and enabled participants to **consider previously unimaginable opportunities** (e.g., living independently).
- The benefits of accessing supports as early as possible in life was recognised as critical to **enabling early intervention and improving life trajectories** and outcomes.
- **Participants experiencing these benefits felt encouraged and had greater capabilities** to proactively continue to try to further **utilise their plans**.
- The benefits from NDIS utilisation, however, were **not universal and can feel precarious without ongoing work** and advocacy by participants and their supports. When benefits were less well perceived or experienced, participants reported feeling less engaged with the NDIS and were less likely to be using their plans.

I used to be a public servant. I used to earn \$120,000 a year. Now I'm unemployed ... living in community housing, earning \$22,000 a year on a government pension. And thank God for the NDIS, otherwise I would have no hope. ... I feel like the NDIS has made me feel like friendship is possible. So I have some social interaction now. ... The NDIS has encouraged me to access other services. I don't have those barriers for getting places, and getting out of the house anymore. ... I'm working on five to ten year goals. ... My plan before was just like live another 10 years and then just wait for the sweet release of death once my daughter's able to look after herself. Now things are changing. (NDIS participant with psychosocial disability, gender non-binary, Metro)

2.2 Barriers to utilisation

Participants often encountered multi-faceted barriers occurring within and across various levels (e.g., individual, NDIS system-level, broader societal level) that interact in different ways to influence the experience of disability, NDIS engagement, and subsequent utilisation of plans. Delays and barriers in utilising one component of a plan can also negatively influence capacity to utilise other plan components.

Complexity of the Scheme

- Acknowledging improved understanding over time, the NDIS was commonly described as a **complex bureaucracy** that was **challenging to understand and navigate**. This included **difficulty in understanding the roles and responsibilities of the NDIS workforce**, as well as of the **various processes, policies and regulations**. This makes it **difficult to know who to engage with and seek clarification from** in relation to navigating these processes.
- There was also frustration at what participants consider to be a **lack of transparency within how different roles (e.g. LACs, planners, delegates) interact** with each other and participants, and, **how this influences planning and decision-making**.
- Further, participants **did not always feel the NDIS workforce are well-versed in the (often changing) NDIS landscape or have the capacity to communicate accurate and consistent information** and advice between themselves and participants.
- Inconsistencies across these processes were highlighted as leading to **discrepancies in plan development, avoidable plan errors, and confusion around how and what plans can be utilised for**: all of which contribute to less effective utilisation.

I'm not even sure if the NDIA is actually clear in terms of how it's meant to work. ... It's really unclear whether the planners are meant to be your advocates in the system and trying to maximise the supports you get, or whether they're sort of a delegate of the NDIA and they're trying to limit the overall spend with the NDIA budget and dampening down your expectations ... one of my biggest gripes with the system is the complete lack of transparency as to what happens with this planning process and what their roles are [and] what their relationship is with the NDIA. ... You don't get to see what they submit to the NDIA, what they're actually asking for on your behalf or your draft plan. (Plan Nominee for young daughter with complex needs, Metro)

Inconsistencies in the knowledge and experience of NDIS frontline workers

- Participants felt there had been **insufficient investment in the human resourcing and training** of the NDIS workforce, leading to **inconsistencies in the disability expertise and cultural competencies** across the system, all of which contributed to subsequent **discrepancies and delays across NDIS processes and a high-turnover of NDIS staff** with whom participants interact.
- In turn, this made it **hard for participants to develop trusting relationships** with frontline workers, relationships that are **critical to effective planning and provision of ongoing support to help participants implement their plans**.

- It can also be **(re)traumatising for participants to have to re-tell their stories**, and, re-justify their needs and priorities to multiple frontline workers. Such situations can also **create delays in processes and fatigue participants trust and engagement with the Scheme and undermine their efforts to proactively utilise their plans.**
- Further, participants felt **Local Area Coordinators (LACs)** in particular were **not always resourced in a way that enabled them to fulfil their roles and responsibilities** as originally envisaged in the design of the Scheme, around creating linkages within communities and providing a level of stewardship of local NDIS markets that participants are expected to be able to link into, navigate and utilise their plans within.

Inconsistent information and communication

- While improvements were acknowledged, many participants reported **difficulties accessing accurate and consistent information and communication** in a format that met their language and accessibility requirements.
- This was described as contributing to **barriers in initial access, understanding Scheme changes, and understanding what plans can - and cannot – be utilised for.**
- When participants encounter challenges (i.e. not being reimbursed for services they were told they were covered for) it **undermines their confidence in using their plans and their trust in the system.**
- It can also be incredibly **overwhelming and burdensome for participants to review and stay abreast of information** provided by the NDIA on all the changes to the Scheme, which in and of itself can negate positive engagement with the NDIS.
- Participants were also often frustrated when **frontline workers did not provide them with tailored information**, such as about specific services in their area that may best meet their needs. If such information was available, many participants felt they would have been more effectively able to utilise their plans.

It is unbelievably difficult. ... Imagine what it would be like if you were someone who'd experienced what I have and then add on there that English wasn't their first language, they didn't know how to navigate the system and then didn't have a way to try and learn, like know who to call or know where to look up things online or they weren't learned in technology. They are sitting there terrified and then you read online things like parents are being contacted [by NDIS frontline workers] and asked things like, "Does your child still have cerebral palsy?" (NDIS participant with psychosocial disability and co-occurring conditions, female, Outer Metro)

Negative planning and review experiences

- Participant experiences were often described as coming down to the **"luck of the draw"** due to **inconsistencies in the skills and expertise of NDIS frontline workers.**
- **Challenges and negative experiences within planning and review processes** were described as **undermining the confidence participants** have in relation to **advocating for what they need**, as well as their **confidence that these processes result in appropriate and adequate plans** that meet their needs. Negative interactions can also **hinder trust in the Scheme and subsequent utilisation**, especially when participants feel their mental health and well-being are at risk during these processes.

I'm in a hired chair that's too small for me, so it's done actual physical damage to me. But I've been in a hired chair for 12 months and my last planner decided "you don't get your own wheelchair until your home modifications are done." ... that's why we escalated it above the normal complaints process, because my support coordinator went through their legislation ... there is nothing to state, you do not deserve to have your own wheelchair unless your house is modified. The things that she has said to me in front of my support coordinator are just, "Don't think once your house is modified that you're entitled to this level of care." I'm like, "Okay, because clearly once my house is modified I will be healed. (NDIS participant with physical disability, female, Metro)

- For example, whilst the NDIA draws on a functional approach to disability that considers participant circumstances, participants felt processes remained underpinned by a **'one-size fits all' medicalised understanding of disability**. As such, participants felt there was insufficient recognition that individuals with the same diagnosis can have different levels of impairment and circumstances, and thus diverse needs and priorities that should be better reflected in plans. Within this was a **limited recognition** and consideration of the impact on functioning and corresponding support needs associated with **interrelated and/or co-occurring conditions**.
- Inappropriate plan development was compounded when **frontline staff didn't collect, store and consistently utilise information and documentation** provided by participants.
- The constant **emphasis on 'deficits'** was further described as challenging, with participants advocating for greater emphasis on strength-based and person-centred approaches.
- Similarly, participants felt there was **insufficient information, guidance and transparency** (for themselves, frontline workers and service providers) around what may **constitute 'reasonable and necessary' supports** and the corresponding level of funding that is required to purchase these supports.
- Participants also felt **undue comparisons were made with the general community** in relation to making decisions about what is 'reasonable and necessary'. i.e., participants felt workers unrealistically expected them to be able to access and afford mainstream activities (e.g. attending yoga classes) on a similar basis as people without disability, or, that workers did not always understand that without adequate support parents can find it difficult to help their children with disability attain skills (e.g. riding a bike) that parents of children without disability do not require support for.
- Frontline workers also appeared to **inconsistently draw on and appropriately document the evidence** and expertise provided to adequately communicate needs and priorities within draft plans to inform higher-level decision-makers. Regardless of how this evidence was collected or presented, these factors contributed to **discrepancies within what was deemed 'reasonable and necessary'** across participants with seemingly similar needs.
- Beyond this, there were reports of **derogatory treatment of participants** within their engagement with the NDIS, influenced by workforce understanding of disability and the level of respect demonstrated towards the expertise of participants. This was **(re)traumatising** for some participants, particularly **for those who had endured a lifetime of having their expertise and rights undermined**.

- (Re)traumatisation can also occur when frontline workers make **inaccurate assumptions about what they think participants may need** or include specific services and supports in plans that participants themselves know will undermine their mental health and well-being. For example, when it was suggested to participants who have been completely Deaf since birth to see an audiologist, or when workers do not understand the complex relationship between trauma and weight, suggesting to individual with psychosocial disability that they should prioritise seeing a dietician to help the lose weight.

I've had it thrown around that I should be doing physiotherapy and dieticians and all that, but I never ask for that and I don't want it. ... But because I'm a fat person, I think that they made assumptions. Because I come from a background of pretty intense trauma and part of the trauma has also involved anorexia. And it's a no-go zone. Finding workers who are trauma-informed is quite hard at the moment here. (NDIS participants with psychosocial disability and co-occurring conditions, female, Regional)

- More broadly, there was an overwhelming sense that society and the frontline workers within it, still struggle to understand **how challenging life can be** for people with disability and their families when they **do not receive the supports they require** and that they feel would help improve their quality of life.

Delays and challenges across NDIA processes

- Delays and challenges in access, planning and review processes contribute to difficulties in utilisation in various ways. For example, stressful delays in access - often due to having a rare, undiagnosed and/or episodic condition - can contribute to **deteriorations in conditions for both the intended NDIS recipient and their informal supports**. Initial plans did not always reflect subsequent needs or include increased levels of supports to address these deteriorations.
- Similarly, participants who experience deteriorations in their conditions associated with ageing or the degenerative nature of their diagnosis, often found it difficult and **time-consuming to advocate for corresponding increases in support needs**. This can establish a cycle of unmet need, sub-optimal utilisation and deterioration.

I said to my wife, "The only way I'm going to get my NDIS plan working the way we want it to work is for me to give up work." And I wanted to work but I couldn't work ... I was working fulltime ... any breaks that I had I was on the phone with my own personal stuff. And in the end, it was becoming that much of a hassle trying to get onto people ... It was just so stressful, and I wasn't getting anywhere. I could see myself going backwards ... I actually finished up work so I could get the full benefit out of my package. (NDIS participant with physical disability, male, Regional)

- **Restrictions around categorisation of funding** often meant participants had too much funding in one category and not enough in another. Despite the recent changes in this area, participants believe that **increased flexibility without funding adjustments still meant they would have to prioritise needs** and go without some needed supports.
- More broadly, **when plans don't accurately reflect need, provide for timely and appropriate supports,** and/or enable participants to engage with services to progress towards their goals, it can be **difficult to utilise plans in a holistic manner**. For example, inadequate support for psychology, can make it difficult for

participants to address mental health concerns and develop capacity to utilise other components of their plans. This is further discussed under thin markets.

- **Fear and anxiety around planning and reviews was common.** Alongside concern that plans would not provide sufficient support to meet needs, participants were acutely **concerned that under-utilisation would lead to funding being reduced**, even if they could describe numerous factors that had contributed to under-utilisation and there was an ongoing need for services. The cumulative effect of these factors had a significant impact on the health and well-being of participants and their supports.

They actually cut some of my payment from my last plan as well. And I think they were just trying to – I know it sounds weird, but like cut me off completely. ... In my other plan I had a Support Coordinator ... and I feel like if I had the Support Coordinator I would of kind of knew what was going on for those three weeks of nothing kind of thing. It was kind of like how they said it was, “You didn’t spend that money.” But I’m like, “Well, there was no kind of way for me to spend it.” ... There needs to be more for me to do kind of thing, for me to spend it. And eventually she was just going to kind of cut it ... The explanation I got is that ... I wasn’t disabled enough, because it was something I can do for myself. Which kind of is a judgement on her part.... And I didn’t know what else to say. (NDIS participant with psychosocial disability, female, Regional)

- In some cases, participants felt actively **discouraged from requesting a review** as their support team were also fearful of loss of funding, despite a clear need for review on the grounds of changes in circumstances, deteriorating conditions, or, for the replacement of equipment no longer fit for purpose.
- There was also concern that **if participant functioning had improved** - because of the support they had received - the **incorrect assumption would be made that fewer supports and services were required going forward.**

One carer that I know who had a plan with the value cut in half when everything was working really well and they’ve moved him to a SIL and everything was working ... because it was working well it was seen that he didn’t need all that support. ... And he ended up into homelessness. He ended up in hospital again and discharged to homelessness and ended up in an SRS. And his behaviours have spiked ... that carer is living with the knowledge that well we almost got there and now we’ve created so much more trauma for this person two years into a roundabout ... what is the human cost of that? And so I think it would be great for the ... government to represent the need for common sense in planning and review decisions that hold people in a safe space and acknowledge their history of complexity and systems and maybe having some levers that indicate well, these factors indicate that we can’t keep spinning this person just for us to get more data. (Plan nominee for adult son with psychosocial disability and co-occurring conditions, Metro)

Marketisation and cost inflation

- Concerns were raised over the **impact of marketisation on the cost, availability and access to services, as well as the quality of supports**. A rapid inflation of the cost of many services (e.g., OT, psychology, support workers), for example, was equated to having **less service hours** with concerns that remaining budgets will not be sufficient to meet needs, **influencing how and what participants feel they can utilise their plans on**.

I was previously paying \$135 for my psychology sessions, which is already well above the Medicare rate, and now they've gone to \$230 for exactly the same service.... In effect, it's a reduction in service. So this is the thing that they give you an overall amount and I'm actually concerned too that my current plan may not meet all of my needs ... not just the psychologist, this is quite a few services who previously had a particular price who have just upped it, massively upped the price when the NDIS came in (NDIS participant with psychosocial disability and co-occurring conditions, female, Regional)

- Marketisation was described as leading to a **loss of collaboration between services**, with some providers reported as **less willing (and some genuinely financially less able) to 'go the extra mile'** when compared to previously block funded services that perhaps had more flexibility in how they used resources to meet the needs of participants.
- Within this, there were reports of **services being selective in which participants they took on**. Whilst there was an acknowledgement of the challenges experienced by previously block funded not-for-profit services in providing diverse and innovative services, these factors were described as **threatening the choice in and availability of services** that participants can utilise their plans to engage with.

I think getting the money out of the NDIA is only the first hurdle... My worry as I always said was whether I'm going to have anything to spend it on. ... I think there hasn't been this great uptake in services ... I'm not unsympathetic to the service side of thing ... if they're not going to be able to survive then we've got nothing anyway. ... A lot of them are then being really picky and choosy because they can now. They've got a lot more people with a lot more money ... They don't want the complex kids because they're too hard. They're claiming they don't get really enough money to support them properly... I think they're probably right. But our kids do take a lot of money and they don't have the workforce, knowledgeable and skilled workforce to be able to support people properly. (Plan nominee for adult son with complex needs, Metro)

Geographical availability of services and supports

- As observed more widely, **availability of services and supports decreased the further away participants lived from Metro Melbourne**. This contributed to **inevitable delays in direct plan utilisation**.
- Utilisation was further complicated when participants had **difficulty getting to services that were not close to where they lived because of lack of accessible transport and/or lack of budget for transport**.
- Regional participants also **struggled to find support workers and therapists that were willing to travel to them**, particularly for shorter shifts or specific times of the day, and when wages (for some services or workers) don't always allow for transportation costs.
- In some cases, service providers **charged additional fees or charged for 'additional' hours (not for direct service delivery) to cover travel time and expenses**. Such costs not only 'eat into' plans but can mask under-utilisation. i.e., participant's budget spend may indicate 'efficient' utilisation, yet they may not be able to stretch budgets to cover the cost of meeting their needs.
- There were also **'unintended consequences' associated with the limited regional supply of Community Health Services (CHS) being contracted as Partners in the Community (PITC)**, making it difficult for some participants to transition across to the NDIS, whilst retaining access to much needed specialist services (e.g., continence specialists) embedded within CHS/PITC organisations.
- Finally, some **regional disability markets were significantly disrupted by the January 2020 bushfires. The COVID-19 pandemic made it even more difficult for service providers to bounce back and respond to the existing and additional needs of their communities**. This was of particular concern for individuals with complex support needs - and/or who were experiencing loss of informal supports - where consistent access to quality supports is a matter of survival.

The other reasons I haven't used all of my plan, are that things I'd like to use it for aren't funded. Also because up here we've had bushfires and the bushfires meant that not only the mental health service but all of my support services were unavailable ... the major change with the COVID-19 has been not all supports can be done remotely ... The other problem has been during this time providers have been cancelling on me. (NDIS participant with psychosocial and physical disability, female, regional)

Limited availability of skilled disability support workers

- **Insufficient availability of skilled disability support workers** made it very difficult to effectively utilise plans to access quality supports across all components of participants' plans (e.g., daily living, capacity building, and social participation). This was particularly so for participants with high levels of care needs and/or complex disabilities.
- Participants attributed the limited availability of skilled workers to **issues within a very precarious disability workforce**. This included:
 - Poor remuneration (of support workers) and resourcing
 - Limited opportunities for professional development and career progression
 - Persistent de-valuing of people with disability and support workers.
- These factors also contribute to a **high turnover of workers**, making it even more **difficult to find and retain skilled supports to develop and sustain trusting participant-worker relationships**. For some, this can lead to a reduction in utilisation, as a high turnover of workers was perceived as actually creating more harm than good, with participants foregoing services.
- It also meant participants and their supports were often required to **repeatedly identify and build the capacity of new workers to be able to respond to their needs**. Again, these processes take time and significantly disrupt utilisation and outcomes.
- Whilst this was recognised as an issue across all geographical regions and for all types of disability, it was more commonly reported by regional participants.

Anyone who has a pulse thinks they can be a support worker. People who have complex issues need competence. ... Everyone who wants to be a support worker needs to go and get educated. ... That education process needs to be looked at, because that's a bit hit and miss as well. There's too many that are just second-rate courses that they can do. ... That's a real problem because we need the workforce ... Our people are very devalued. Anyone can support them? No, anyone can't and saying anyone can do it, it's like devaluing [NDIS participant], you know, he's not worth it. Yes, actually he is They probably need to be paid a lot better than they are at the moment. ... there needs to be a career structure so that people can get increments of pay increase. ... If it's done well, it means that the support is a lot better rather than the babysitting model that used to be ... How do we rectify that? And the NDIA economists needs to really look at that if you're going to want a quality service and you're going to want all of these services to be viable and stay and do a good job for all of us (plan nominee for adult son with complex needs, Metro)

Limited availability of specialist services and therapists

- Even when participants were able to identify available services, **services may have long waiting lists and not be close to where participants live.** This was particularly so for specialist services (e.g., physiotherapists specialising in neurological conditions).
- Service shortages meant participants are required to organise services well ahead of time - which can be difficult for a variety of disability and life related reasons. **Incurring cancellation fees** contributed to further stress when appointments had to be cancelled.
- Utilisation spending was greatly reduced - as was capacity building -when participants experienced **limited access across a range of services and supports.** This also contributed to a cycle of reduced capacity to utilise other components of plans. For example, until participants had built capacity in one area - such as mobility training – it can be difficult to access other supports – such as social participation.

We couldn't find a speech therapist ... so we didn't use the speech funding and also it is very hard to get appointments consistently with some of our therapists. ...The waitlists here are incredibly long. ... I have other friends who are on waitlists for psychology for their children and they have said it's probably up to a two year wait. ... Autism-specific that do help with behavioural difficulties ... to try to get into those is quite difficult. ... Mental health-based things are more difficult because they sort of seem to put that under a general practitioner rather than a disability. ... With people with disabilities, mental health is obviously always a significant factor and I do think that might need to be more included in the NDIS to help with mental health, both of the participant and the carer. (Plan nominee for young son with complex disability, Regional)

- Limited availability of specialist services was also seen as **impeding choice and control.** As such changing to an alternative service if they are dissatisfied is not always possible.
- Some felt these issues could be partly addressed if they had **better access to skilled and independent Support Coordination.** However, these were difficult to come by, particularly in regional areas.

They say they're independent and they say they will refer you to someone outside of their organisation, but I find that they don't ... They are very loyal to their institution ... They're referring you to people that they have a business relationship with. I find NDIS and everything to do with NDIS always comes back to money. The first thing they ask is what is your total budget? ... That's the bottom line. (NDIS participant with complex disability, female, Regional)

Delays in access to equipment and home modifications

- **Limited availability of permitted and skilled therapists that can conduct assessments and gain quotes to justify needs** – including equipment and home modifications – created **substantial direct and subsequent delays in utilisation**: *I contacted dozens of NDIS service providers who had OTs that do home modification [assessments]. Almost all of them said that they were not accepting new clients. ... That is definitely the biggest barrier I've encountered to actually being able to use my funding.* (NDIS participant with physical disability, female, Regional)
- As previously described, if a participant does not have access to appropriate equipment - such as a well-fitting wheelchair - they may not be able to access other services and supports - such as hydrotherapy. This was particularly so for participants with physical and/or complex disabilities:
- Such delays were **compounded by delays waiting for NDIA approval** – even when participants were made to submit multiple requests/quotes for the same purpose, alongside the difficulties – especially in regional areas – of sourcing the required NDIS registered providers to undertake home modifications.

I'm not one of the parents that are going my budgets not right... I have budget, I can't use it. That's my issue ... and things that I desperately need, like the bathroom - I can't get either. ... That's why I'm just going to roll this plan over. I've got nothing in me to fight at the moment ... It chips you down to the point that you just give up ... Sometimes I feel like that's their MO. It's like, if we're difficult enough people will just stop asking, and sadly people do. But ... I can't stop asking when it comes to the bathroom because I've got nothing ... I can't wash him, and I've got this big giant commode that is waiting ready for a shower, but it's never been wet. (Plan nominee for young son with complex disability, Metro)

- In some cases, participants were **required to have the approving therapist present** for equipment fittings to take place or to explore different options. Participants were frustrated at the increased cost associated in paying for the time of the therapist and other specialists, leaving less funding to access other services. These factors are all within a context of **limited market capacity in equipment, home modifications and specialised technology**, with participants often experiencing significant delays - or no access - to necessary equipment.
- **Delays in access** to these required supports placed participants (and their informal supports) in a vulnerable position and **contributed to deteriorations in functioning and independence**. All of which again led to direct and subsequent underutilisation of plans.

I had so many hassles. The physiotherapist couldn't do much because I had seating issues with my wheelchair ... I was waiting on a wheelchair that I had to fight for. ... She wrote that many letters – the funding was there but they wouldn't release it. ... I spent so much time on the phone. It was so stressful. ... But it was all – it wasn't enough funding. ... She [physiotherapist] said, "I'm really only doing a band-aid ... we can't do too much more really until you get the chair." ... I sort of went backwards to be honest. (NDIS participant with physical disability, male, Regional)

Limited access to innovative programs and mainstream opportunities

- Regardless of geography, participants often felt they were **funnelled into disability specific programs** and continue to **experience numerous barriers (within and external to the NDIS) to accessing mainstream opportunities**. This was a particular issue for participants with intellectual and/or complex disabilities, with many articulating strong aspirations to use plans to access more individualised and innovative programs (e.g. more tailored one-to-one or small group supports, and/or more innovative day programs) and mainstream opportunities (e.g. access to ongoing education, community participation, employment).

Really trying to create something for ourselves because the services just are not out there, but it's a bit challenging and then COVID hit ... It's actually given me a chance to rethink some things, and I don't want to do some of them to be honest. ... Not what providers think that we want, and claim they do things, but we know perfectly well they don't. Because providers still can be quite rigid. ... These services don't do very good things to some of our kids, to be honest ... I'm not going to accept that. Because I'm not spending it for the sake of spending it. Why are we using disability services all the time? Why are we not using the mainstream stuff out there? I think there is a huge untapped market in every area of society. The disability sector they have not tapped into properly. It is a huge market. (Plan nominee for adult son with complex needs, Metro)

- Participants also felt that service providers gave them **limited opportunities to provide feedback on current programs or provide input into and collaborate on developing more innovative service design and delivery**. This re-iterates the **cycle of participants being stuck in programs that don't meet their needs or aspirations**.

Due to the education department, they made it so difficult for us that we can't really do any decent, sort of, studying. ... Unless we got a high, I don't know, high educational, we can't do it. We can only do casual things. [I]: And so, what do you use your NDIS plan for? [P]: Day-to-day program. [I]: And you really like your day program? [A]: It could do with a good kick to update and change a few things. And ask clients a bit more say. Sit down with the staff and clients. ... To sit down and say what we want, how we should have our programs. ... Because the staff don't let us know certain things and that's what, really, can make it really difficult. (NDIS participant with cognitive disability, gender non-binary, Outer Metro)

- More broadly, participants – particularly those in regional areas – generally felt there were **limited mainstream opportunities that were affordable, inclusive of and accessible to people with disability**. In these circumstances, participants would have liked more flexibility to use their plans to help travel to mainstream opportunities, access required equipment and materials, and more support to cover the cost of participation.
- **Limited mainstream opportunities** also meant participants **did not always have sufficient autonomy in relation to the recreation** (i.e., they may only have opportunities to participate in group activities when the activity is not something that they enjoy). Even when they could identify and access an activity that they wanted to engage with, they did not always have other individuals available to participate in recreation with. It can be very **isolating for people when support workers don't fill this gap**.

I go to the day program 3 days a week... I love bowling... this is sometimes hard to do cos of my hand but the ramp and thing I roll the ball down helps me. ... but the workers don't play with me, so I don't do that anymore cos I only be doing it on my own. (First Nations participant with physical disability, male NP006aJBSAM03)

Limited support for plan nominees

- Many **plan nominees – who are often the primary carer - required more support to develop their own capabilities to then help family members navigate the NDIS and effectively utilise their plans.** Specific challenges occurred when individuals and their families were not supported to develop a shared understanding of the Scheme and how to navigate it. For example, some plan nominees of people with significant psychosocial disability reported that despite all eligibility criteria being met, access to the NDIS had been denied as the intended participant and their family were not provided with sufficient support to collaboratively navigate the consent process. This issue and the reason why was then not communicated to the plan nominee.

Mental health is a very broad area where there could be people quite high functioning but need a little bit of support and encouragement around specific things, and then there's other people where they're flagrantly unwell and even getting them in where the Scheme relies so much on their consent to get in, places unfair barriers on the family. So one example from last week for me, as an advocate, the mother said, "Well, I've called here, and they've told me they're not on the scheme." I did a conference call, called NDIA with her, they said, "Oh, but there's actually been an access request and it's been rejected. ... your name wasn't listed there so we can't talk to you anymore."... the family are cut out from helping to advocate. (Plan nominee for adult son with psychosocial disability and co-occurring conditions, Metro)

- In these circumstances, highly skilled frontline workers are required to **facilitate processes that incorporate relational understandings of disability,**⁵ whilst ensuring individuals with disability are fully supported to make decisions and articulate their needs and priorities, even if they require (or desire) support to do so. This would **lead to more appropriate plans and more effective utilisation of plans towards positive outcomes.**
- Most plan nominees were spending **significant time and energy trying to support participants to utilise their plans,** often at the **expense of their own employment, social participation and health and well-being.** Plan nominees **did not feel these needs were adequately being addressed** within or external to the NDIS system. When left unaddressed, they **undermine the capacity of plan nominees to support participants to utilise their plans more effectively.**
- Similarly, **parents with young children with disability** felt there were **limited opportunities to access services that incorporated peer support for parents,** which they felt would help develop their capacity to provide support for their children, as well as providing much needed social opportunities.

I used to be in employment before my daughter came along and during the time. But now it's no longer. [I] It is not possible? [P]: It is impossible... I haven't been out in the community. I used to volunteer sometimes, in the distant past rather. I couldn't do anything on a regular basis, I couldn't even shop on a regular basis. ... I am constantly managing the rosters for people that don't turn up, trying to pull from one place to another, constantly looking for more supports. It is a full-time job. (Plan nominee for adult daughter with complex disability, Metro)

⁵ I.e. understanding the circumstances of individuals in the context of their relationships with family, informal supports and community, to inform plans that optimise positive outcomes across these relationships.

Perceptions of risk and exploitation

- When **participants experienced risk or exploitation** in their engagement with the Scheme or service providers, this **undermined their trust in the system and compromised direct plan utilisation and subsequent utilisation**. For example, participants described **disengaging from services when they felt workers or providers had breached their confidentiality or delivered services that undermined their safety**. This had both a direct (e.g., stop using required services) and subsequent impact on utilisation (e.g., deterioration in conditions that undermined capacity to utilise other components of plans).

I had major issues when we first started. I had the support of the cleaner, but the company – I believe it was a bit like the paying back system with the government - they had all these supports put in, nobody was properly qualified, there was no confidentiality ...I had a cleaner who was helping me, and all of sudden half the people in the town knew what she was doing, what I was doing, they knew what I earned. ... It turned me away from actually using the supports, to the point where I actually cancelled them for quite a while. And that's when I ended up having a lot more falls. (NDIS participant with complex disability, male, Regional)

- In other examples, participants described having **payments deducted from their plans without services delivered**. Sometimes funds were eventually reimbursed, but this often took a significant length in time, leaving participants with insufficient funds to meet needs and feeling disconnected from their plans, and disrupting utilisation. This issue was of particular concern when **participants were not provided with or did not know how to access information about their plan budget, how it was managed, and ultimately utilised**.
- Participants also felt **some services were excessively focused on plan budgets**, making them wary that some **providers are using this information to direct participants to utilise their plans through a narrow selection of not always independent services**, or, for an increased number of hours that participants have not requested.
- The existing **onus on people with disability to identify, collect evidence and call out practices** that place them at risk is **very problematic** – particularly when they may be in **unequal or dependent relationships** with the **person causing harm**.
- Some participants had **limited awareness of their right to complain, limited knowledge of who to complain to, and/or support to navigate complex complaint processes**. Participants also expressed **fear of losing supports if they made a complaint**, particularly if they were reliant on thin markets. These factors lead to participants feeling silenced and disempowered without choice and control over how to utilise their plans.

I noticed that [NDIS participant] will get really upset and told her [support worker] "please take him out [for a walk]". ... And she replied "So what? You're spoiling him like that. Don't give him whatever he wants." ... Because the service provider doesn't provide interpreter for services and they asked this lady [support worker] to interpret...So [NDIS participant] got upset and he pulled her hair and it was very difficult to let his hands go from her hair. ... After this, the lady didn't want to come out and she said to her husband, the owner of the service provider. They came two times and knocked on the door and asked me to sign a report that was in English. I said I can't read English. But he asked me to sign it. I didn't sign, and I just took it. We stopped working with this service provider because of this incident. We went to another service provider and showed them the report. And the report said, [NDIS participant] pulled her hair, AND bite her, AND that [NDIS participant] broke the chain that she was wearing on her neck. I said "No. I was there, he only pulled her hair". ... The new service provider said "Don't sign

this one. Because they may want some sort of compensation or something.” (CALD refugee and plan nominee for young son with intellectual disability, Metro)

Systemic barriers

- Many participants have experienced **systemic barriers across systems** (e.g., education, employment, health, justice, housing). These barriers **undermine health, functioning and independence**: all of which contribute to **greater levels of disability, increased need for supports and reduced capabilities for utilisation**.

Sorry taxpayer, you are now paying twice for the same thing, but I don't feel guilty ... because the system failed him. It failed him miserably. It shouldn't be like that but look at the system. The health system fails, the education system fails, the disability system fails these kids miserably. (Plan nominee for adult son with complex disability, Metro)

- These barriers can also make it difficult to effectively utilise NDIS funding. For instance, **experiences of discrimination and abuse** meant that some participants were **reluctant to use plans to support social participation**. Similarly, participants **can't effectively utilise their budget for employment supports**, when they experience numerous barriers to gaining employment.
- For some participants, the **introduction of the NDIS had complicated their access to services and supports across other systems**, as there has not always been clear guidance around which system or program is responsible for what type of services.
- As a result, **participants sometimes fell through the gaps between systems**. For some, this meant they had **more pressing issues to address** (e.g., insecure housing, poor general and/or mental health, interactions with the justice system) before they could begin to contemplate utilising their plan. **Delays in addressing these issues**, often through other systems, could lead to long delays in effective utilisation.

They've given us the funds to go out in the community. ... There are times where she's been out and they've been abused by people ... It just gets to a point where we kind of feel really isolated and we don't want to send her anywhere. There's nowhere safe for her to go. ... They got abused by two different people on one day. ... Basically called [NDIS participant] 'a thing', and how dare we bring her down where there were other kids. It was horrible. ... The words that came out of his mouth were despicable. ... He went away and then came back and was just watching them the whole time they were there until they left. And the carers were really shaken. (Plan nominee for young daughter with complex disability, Metro)

3. Why does NDIS utilisation of plans vary across the different sub-cohorts of interest?

The previously described facilitators and barriers to plan utilisation commonly applied to participants across the broader cohort. These barriers, however, were often further compounded by specific challenges experienced by participants with psychosocial disability, First Nations participants, and Culturally and Linguistically Diverse participants. Each of these sub-cohorts experienced unique challenges as discussed in the following sections. Yet there was a shared perception that they had all been less well consulted during the original design of the NDIS. As such, participants felt the NDIA were still trying to play catch-up in fully understanding and responding to their needs, alongside developing its competencies to appropriately reach and engage with individuals and communities across these cohorts. Once on the Scheme, participants across these cohorts often encountered significant gaps within the NDIS market's availability of culturally sensitive services and supports. All of these factors contributed to challenges in utilisation, both in terms of actual spending and being able to utilise plans in a way that effectively met their diverse needs, priorities and aspirations

The NDIS and how it's not right for our mob if we aren't at the table having the yarn in the planning. Well I heard that and thought I better get myself sorted for Bub you know and so I did some reading about it. Then when it came to [Regional area], I was ready, well I thought I was ready. (Plan nominee of young daughter with complex disability, connected to Yorta Yorta country)

3.1 Experiences of First Nations NDIS Participants

As articulated by Scott Avery in his research: "Colonisation had a particular impact upon Aboriginal and Torres Strait Islander people with disability. ... The exclusion, dispossession, violence, racism and discrimination has caused, and continues to cause, significant trauma and suffering."⁶ These experiences across multiple systems also contributed to what was perceived as limited engagement with First Nations in the original design and ongoing implementation of the NDIS, and how First Nations participants subsequently engage with the Scheme.

Navigating systems not designed with First Nations participants in mind

- First Nations participants described **challenges in accessing culturally appropriate information and support** to understand the NDIS. This included challenges in understanding how the Scheme interacted with Aboriginal Community Controlled Health systems that may be less familiar with the diverse disability needs of individuals and communities, **compiling the required evidence** to gain access to the Scheme, as well as knowing who they could engage with for **support to navigate ongoing NDIS processes**.

⁶ Avery, S. (2018). *Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*. First Peoples Disability Network (Australia). Sydney, Australia. Page 8-9.

I never heard about it. ... Had no idea how to go about applying for. ... During this COVID [I] was rung up by the NDIS mob ... they've said to me "Hey listen, it's great to apply for NDIS now." Because of all this kind of stuff, they don't need all the paperwork and things like that. It took luck what they said what a year or so it has been around. Because son didn't have a proper diagnosis on his medical records at [ACCHO] ... I've tried to enrol [NDIS participant] in the NDIS in the past ... because we didn't have that paperwork it was always the bit that stopped there and then. His application was rejected. ... I don't have money for that day. ... His paediatrician, he's then gone and take it in time out of his own private day to write out a letter. One to send to [ACCHO] and to give me two hard copies so I could give one to the NDIS for his actual diagnosis. ... I think I applied three times before I got to fit it to them. (Plan nominee with young son with cognitive disability, connected to Yorta Yorta country)

- Even when this information was made available, **limited trust and fear in systems meant that participants often delayed their engagement** with the Scheme. Within this, some participants described a fear in their community that engaging with the NDIS may lead to the removal of their children.
- Participants therefore highlighted the important role and need for **resourcing of (diverse) First Nations-led organisations, advocates and workers** to help bridge gaps between individuals, communities and the NDIS, as well as **supporting participants to access and benefit from the Scheme**.

I would love to see a hub set up in every city and town where there are our mob, so that they can go and get all the stuff done in the one place. It's safe, they see other parents with kids or even people like ya self, who are there to see and show families that disability isn't shame job. That we have our own leaders and mentors that help us out and get paid for it. It would be good to have a great hub that allows us mob to go there to get the assessments done all at once. That the hub is disability only for us mob. Health services are for medical needs. We need them too. But unless Bub is sick, I don't go there. I don't engage with them; they don't get it. I would love to see money spent from our plans to help set that up, so we have a place to go and hang out and get that information, support etc in our own way. ... It's just done wrong way for us. ... Us mob need our own place and space to go and sort it out that is only about disability for us mob. I don't go to the co-op because it's clicky and mob there are all thinking of their own families and not thinking of the way we should go about helping each other out yeah. (Plan nominee of young daughter with physical disability, connected to Yorta Yorta Country)

Engagement with NDIS frontline workers

- Participants described **inconsistencies in the cultural competencies and knowledge** of NDIS frontline workers. This included insufficient acknowledgement of their Indigeneity and respected cultural roles in their communities, as well as **limited recognition of how their diverse cultural and disability understandings, experiences and needs are interwoven**, and should be considered as such when developing and resourcing plans.

I've never been asked was we Indigenous ... It's on the form, I think. But nothing since asking that at the start like tick a box question makes me wild. ... I didn't want to engage in NDIS because we live and breathe our culture, a lot of them mob [NDIS] don't ask like for someone to help me out, I can't reach out to anybody else if I can, what do I do with this process I prefer to speak to someone who is of our culture. ... I just feel uncomfortable with white mob. (Plan nominee with young son with cognitive disability, connected to Yorta Yorta country)

- Within this, participants felt the often overly bureaucratic ‘white mob’ NDIS processes (e.g., planning and reviews) **did not always allow for cultural ways of sharing experiences and communicating**. This again meant that plans did not adequately reflect the disability and cultural needs and priorities of participants and were therefore less likely to be utilised.
- Participants also felt that frontline workers did not provide them with **sufficient support to understand how to initiate implementing their plans** or the different approaches to plan management. The latter was sometimes linked to what was perceived as **low expectations of the capacity of First Nations participants to self-manage their plans**.
- Conversely, when participants had **positive, culturally supportive and ongoing engagement with frontline workers**, they felt more **confident in their understanding of their plans and their abilities to manage and utilise them**.

Utilising plans to meet disability and cultural needs and aspirations

- First People participants commonly reported **frustration at their inability to use plans in a way that they felt would most appropriately address their needs**. In part, this often reflected an even **greater level of difficulty in meeting basic and disability related needs** when compared to non-Indigenous participants. This frustration sometimes led to disengagement and further under-utilisation.

I couldn't be bothered and thought what I am doing this for. If I can't use the money like on what he needs then I was like wait, what's with all this money and yeah and I can't use it like, wow, that's what I was sent then I am not gonna even bother. ... I haven't explained to them, not just the culture aspect then his needs. Because every single case is different ... I've said "so why don't we use the money for them things he needs" So he gets speech therapy and occupational therapy at school. So, what can I even set aside a bit ... cos he needs bedding and stuff and that special mattress to help with cleaning and stuff that he's got now, and he needs a bigger bed, and I can't afford it, and she's like "oh no you can't use that" and I'm like, "Well, can you tell me what it can use it for?" (First Nations' plan nominee with young son with cognitive disability, connected to Yorta Yorta country)

- Participants expressed significant concern over the **limited availability of First Nations led services and disability support workers**. This was particularly an issue if they did **not feel as comfortable engaging non-Indigenous workers**, especially to provide personal daily supports, engage in cultural events, and spend time on country. More broadly, participants also reported **challenges identifying and accessing culturally sensitive services and supports**. Both these issues were major barriers to their effective plan utilisation.

It's all about being culturally safe and that once you hear the stories of who you are or the people around you feel better because of those relationships ... My aunties are busy with funerals and how to raise money for them. So, I am mindful no to humbug anyone to help me, so I rarely go on country to enjoy my time sitting and doing nothing but being on country. Reconnection for me is so important as I have been everywhere, living with anyone, or turning up as a kid to find my folks had given my bed to others It's shame we don't have mob who can do the work, I have a few friends who said they would work with me and I was excited, but they couldn't get a job with me ... Its cos been in trouble with the law and they can't get the police check they need. ... I don't use my plan a lot because I want to be with mob and the workers don't take me to events or activities that are cultural cos, they said

they don't feel safe. ... My aunties get wild and say that I need to use my plan more, but they don't understand I don't want woman workers doing my private stuff ay... so I want Aboriginal men to help me so I feel culturally safe, but they can't find the workers. (First Nations participant with physical disability, male, connected to Yorta Yorta country)

- Conversely, **when culturally sensitive supports were available**, participants described plan utilisation had helped them **improve their independence, decrease reliance on informal supports, enhance links with their community and culture** in line with their goals, and go some ways to healing the multiple and ongoing traumas incurred.

But it helped me be a better mum and nan. The burden of them not having to care for me is great. I don't lose my independence as their mother or nan you know. Like I can get a support worker to take me to a park and I can enjoy the BBQ and watch the kids run around and if I'm tired or overdone it a bit, I just go home. They don't have to pack up and leave cos I am tired you know.. that's what I love about being able to control my life in a way that makes it easier on everyone else. ... I think what I like about the NDIS more than anything is the right to have a choice, the right to speak my thoughts and say what is important to me. Know that if I don't like the people who come to work with me then I can have the power to change that. To learn and grow about what is happening to me and what my MS does to me cos it changes and that makes me more simple for me in the long run ay. (First Nations participant with physical disability, female, Metro, connected to Woi-Wurrung country).

I think of all the systems that have been thrown at me since my birth and the disadvantages that I have suffered, and I think the NDIS has been something that has helped me overcome some of the challenges to get me back to a way of life that I am happy with. It doesn't heal my hurt or my trauma, but it does help me not to relive it in a negative way because of having no access to the systems that will help me keep moving forward. (First Nations participant with physical disability, male, Metro, connected to Boon Wurrung country)

3.2 Experiences of Culturally and Linguistically Diverse NDIS Participants

Participants highlighted Culturally and Linguistically Diverse individuals and communities often have very diverse understandings and experiences of disability, rights, and systems. For example, in some cultures and languages there is no word for disability. In others, there may be high levels of stigma and discrimination. For some individuals, this can result in very challenging circumstances in relation to having their needs understood and met by families, service providers, and NDIS systems.

In some languages there is no word [for disability] ... make it also difficult to identify what we mean by a person with a disability. So it would be good really to have the conversation with them perhaps by making them aware of what will we need ... Who are people with a disability and what are their rights, opportunities and what is available really to them because people don't even know about the services that are available to them. (CALD participant & advocate with physical disability, male, Metro)

Diverse cultural understandings and experiences of disability

- **Different cultural understandings and experiences of disability influence how individuals and families engage with and navigate the NDIS.** Families may be unaware or hesitant to identify if they have a family member who may be able to benefit from the Scheme or may not fully understand or communicate their family members needs and aspirations.
- Some communities experience uncertainty or distrust of government systems, whilst for others receiving government support is a relatively new experience.
- Some participants from **migrant and refugee backgrounds had limited access to appropriate services and support prior to living in Australia**, due to their socio-economic and political circumstances. These participants found it more difficult to access and engage with the NDIS as they required additional supports to address significant unmet needs and build capacity to enable plan utilisation. Such support is not always built into plans.

Most people are scared of saying I need assistance because it looks bad on them. It's shame. ... Until these kids are brought and understand it's their right and not going to be taken away and they're not going to be judged and they're not going to be humiliated, parents are not going to admit that they've got a child with a disability ... depending on where they come from it depends on what they think of government departments, because back in their culture they might have had a bad experience so they're not going to go up and say, "I need a wheelchair," because they might think you'll take their kids away. (CALD NDIS participant with physical disability, female, Regional)

Access to culturally sensitive supports and advocacy

- The above issues were made more difficult when individuals and their families had **limited access to culturally sensitive and language specific information** to adequately understand the Scheme and how to actively participate in processes within it. Without such supports, participants often felt disconnected from their plans, undermining utilisation and opening participants up to exploitation.
- Participants described the important role of **culturally sensitive and accessible advocacy organisations** in helping them understand the NDIS, gain access and receiving a plan reflecting their needs and aspirations.

- These organisations were also **critical in helping participants understand what types of supports they are entitled to, as well as engaging and training support workers**. Culturally sensitive peer-led groups and online networks are also an important source of information and support.
- Yet such supports were not always readily available or accessible, with **resource constraints often undermining the capacity of organisations to provide the level of support required**. This is particularly so as these organisations are often stretched across various advocacy efforts.
- When these supports were available, participants described that the **NDIS had played a critical role in raising awareness of disability** within families and communities, **enabled accurate diagnosis of conditions**, and provided new **opportunities to access services and supports**.

Disabilities are looked at in a different way. People don't know much information ... have limited views on it, because of their belief and culture... people with mental illness are frowned upon. So you want to just hide and say you're unwell. ... At the beginning I didn't have the right diagnosis... before I went on NDIS I had a fear of this. ... Now I found that the people are out there to help us... the nurses and social workers and everyone ... and my family told me that it's okay, ... if you need help use it. (CALD NDIS participant with psychosocial disability, female, Metro)

Cultural competencies across the NDIS and disability systems

- When participants were able to engage with **frontline staff who applied an intersectional approach (i.e. taking into consideration how a person's experience of disability is influenced by other intersecting identities, such as ethnicity, gender)** to identify participants' diverse cultural, language, and disability needs and aspiration, this led to **better planning processes** and outcomes including **more effective utilisation**.
- Participants, however, felt that there were considerable **inconsistencies across the NDIS workforce** in their understanding of how best to **engage with and support the needs of culturally diverse individuals and communities**. For example, participants did not always experience culturally appropriate communication methods tailored to address their community needs that could lead to active engagement with and participation in the Scheme.

Your disability can't be realised fully without your culture because that's a big part of your identity. So it's about intersectionality and services knowing how to approach families and getting to the individuals, rather than just getting it from hearsay. But the uncle or the elder might not [know] "Oh, no, this is what the person is capable of". Or "this is what they want." And the service goes with that without asking the person with the disability. ... If we're talking about those people that get spoken for, they often don't know about self-advocacy and human rights, and what they're entitled to, and what their choices are. (CALD NDIS participant and advocate with physical disability, female, Metro)

Access to culturally sensitive disability services and supports

- The **limited supply of disability services, therapists and support workers** that are currently able to meet the **diverse cultural, language and disability needs and aspirations** of participants was a key issue undermining effective utilisation.
- Participants also described **inconsistent access to independent interpreters with a sound understanding of disability and the NDIS systems**, creating barriers in meaningful engagement with the NDIS and service providers. This issue increases the reliance on family members, advocates, and service providers to act as interpreters, potentially leading to conflict of interest, inadequate service, and exploitation.

I had no access to [AUSLAN] interpreter in that time... When I saw the doctor, I had to say "I'm sorry. ... I don't have interpreter, you have to be patient, I have to write". ... Because, even with the doctors, there was barriers, you know, for example, the doctor was from overseas and had different accent and language... My mom helped me with some of that but it wasn't really fair it's a lot more stress. ... What if you know someday something... mum goes away. What do I do now? So I need to keep up with the process and learn how to access this NDIS. (CALD NDIS participant who is Deaf or hard of hearing, female, Regional)

3.3 Experiences of participants with psychosocial disability

Challenges associated with the transition of State and Federal mental health programs across to the NDIS, including loss of trusted relationships and supports, continue to impact on the plan utilisation of participants with psychosocial disability. The ongoing limited availability of skilled mental health workers, including recovery coaches, made it difficult for participants to find support to access the Scheme and then utilise appropriate services and supports when they did manage to get access.

Transition of mental health programs into the NDIS

- The transition of various State and Federal mental health programs into the NDIS market was described as significantly **disrupting an already stretched mental health system when the NDIS was not ready to address these gaps**, contributing to a **loss of coordination and collaboration** across mental health services, with **many workers leaving the system** and some organisations struggling to survive.
- The subsequent **loss of supports** experienced by people with psychosocial disability often **disrupted journeys of recovery** and made it difficult to find the required help to access and navigate the Scheme.
- Participants felt individuals in **other States had a smoother transition**, as they were more readily able to continue to access mental health services, as well as other community-based programs.
- Exacerbated **tensions between the mental health and disability interface during transition**, also made it **difficult for participants needing to continue to negotiate both systems**. I.e. some participants described being handballed between the two systems, with neither system seeming willing to take lead responsibility for addressing acute mental health concerns of NDIS participants.

I really did like and appreciate the support I had from [mental health service provider] prior to NDIS ... there was a bit of a grieving process I think with the loss of that support. Given that because it was taken away rather than voluntarily feeling like I was ready to leave the support behind. It felt like a real loss. ... With the NDIS I've got a range of different supports available to me that I didn't previously have access to, but the real one [recovery informed supports] that I really wanted it isn't available yet. (NDIS participant with psychosocial disability and co-occurring conditions, male, Metro)

Delays in navigating access can undermine utilisation capabilities

- The **nature of some conditions (including episodic conditions)** and **surrounding life circumstances** initially made it **difficult for some individuals to self-identify with challenges in functioning** which may benefit from engaging with the NDIS. This was particularly so if participants had **limited previous access to other services** that may have helped improve understanding about the NDIS as well as help to compile required evidence to gain access.
- Even so, many participants felt that in comparison to disability systems and services, **mental health systems and services were less well-positioned or adept at supporting individuals to compile the required evidence** to support access to the NDIS.
- For **those who had received prior supports**, some described their **mental health workers as instrumental in helping them gain access to and navigate the NDIS**.

- **Delays in NDIS access** meant that some participants were **less well when they did eventually receive plans**. In turn, this could **delay utilisation** as participants needed to **first address mental health concerns and/or build capacity to utilise their plans**.
- Significant **concern remained about the well-being of people** with mental health conditions and/or psychosocial disability who **no longer have as much support from pre-existing programs**, and are **not able to access the NDIS**.

I was actually in hospital at the time ... they said there was certain information they wanted ... I had begun that but then I fell down because I was basically unwell, and at that point you pretty much lose the capacity to advocate for yourself... Some people don't have family as support or anything like that and so it had to be put to the wayside. ... A good friend of mine was actually directly contacted by NDIA ... she asked me to go with her... She originally didn't want to go because she was terrified. ... When I was there, I asked, "I'm wondering why she was contacted, and I was not although we have got the same level of support". ... I did eventually get an appointment. ... They didn't look at any of my paperwork It was a very distressing experience. Now it always is when you're interviewed with psychosocial stuff, but it was made a lot more difficult than was necessary. ... I then had to fight for it even though it was evident that I had slipped through a crack. (NDIS participant with psychosocial disability and co-occurring conditions, female, Outer metro)

Accommodating for inter-related and co-occurring conditions

- **Inconsistent understanding** - across the NDIS workforce - of the **relationships between physical and mental health** and the impact on an individual's daily functioning were commonly described. This included a **narrow focus on the 'primary' psychosocial condition**. Whereas it is often not possible to disentangle experiences of primary and co-occurring conditions.
- For example, participants reported that frontline workers did not always understand - or believe - that their **mental health condition could make it extremely difficult to 'physically' undertake daily living tasks** such as cleaning the house or preparing meals.

When he [LAC] was talking to me, he didn't ... differentiate between NDIS participant for physical disability and mental disability. ... [The LAC] was saying, "You are not physically incapable to do your housework, why do you need daily living funding." (CALD NDIS participant with psychosocial disability, male, Metro)

- Similarly, frontline workers did not always understand that **mental health conditions are commonly associated with – and influenced by -inter-related and co-occurring physical conditions** (e.g., pain)
- When these **relationships are not sufficiently considered and a whole-of-person approach is not adequately understood or accommodated for within plans**, the **adequacy of plans and subsequent utilisation is undermined**.
- For example, participants reported that plans **did not always allow them to address physical conditions –** such as pain, poor sleep – that **undermined their mental health and functioning**. When these issues are not

addressed, **participants were less able to utilise other components of their plans**, e.g., capacity building and social participation.

I had an occupational therapy assessment and report; they recommended [equipment] would assist me with sleeping and not waking up in pain that might actually assist me being able to function at work. The agency doesn't agree that the pain can be disabling. So despite multiple reports from specialists, occupational therapists and psychologists and psychiatrists, they have been fighting it tooth and nail. ... It's only \$1500 or \$2000 or something. It's not exorbitant. This process has been dragging on for ... almost 18 months ... They've had a private lawyer engaged that whole time. That would have cost them thousands ... Such a false economy. (NDIS participant with psychosocial disability and co-occurring conditions, male, Metro)

Disruption to the mental health workforce and subsequent availability of services

- Of significant concern with the transition across to the NDIS was the **high turn-over and loss of skilled mental health workers from the workforce** that participants had built trusting relationships with.
- Participants often found it **difficult to find alternative 'NDIS ready' mental health services and workers with the required expertise** to directly utilise their plans with to address mental health concerns. Without such supports, participants also experienced **delays in building their capacity to further utilise their plan** in other areas such as social participation.
- Some participants were keen to utilise their plans to **engage with recovery coaches when these become more readily available**. Within this, participants hoped recovery coach line items would be **attached to appropriate costings to encourage a sufficient supply of skilled workers into the market**.
- Others were concerned that the focus on recovery coaches was **overshadowing the need to develop the supply of diverse psychosocial supports**, including improving access to trauma-informed mental health services. This appeared to be difficult not only due to the limited supply of such services, but by what participants described as the limited understanding within the NDIS workforce of the value of such services for people who have experienced trauma.

A lot of these trauma therapies are about making improvements that last. So they might be slow or incremental but they're lasting improvement, and surely that is the best way for the NDIS to be spending their money ... I'm not sure if the NDIS will acknowledge that they are becoming proven techniques to help traumatised people. ... I've got the funding there ... they're saying no to things that are known in the wider psychology community and the wider trauma care community to actually help people make profound, sustained improvements. (NDIS participant with psychosocial and co-occurring conditions, female, Regional)

Reflection on key findings

Overall, the limited availability of services, skilled therapists and support workers that meet the diverse disability, mental health and cultural needs and priorities of participants was one of the most critical barriers to effective plan utilisation. This issue impacts utilisation in two key ways. Firstly, participants are not able to 'directly' utilise their plans as the services and supports they require are not available or are not of sufficient quality for participants to feel safe or satisfied in accessing. Secondly, participants often rely on 'direct' access to one service or support (e.g., OT assessment for equipment) to then enable 'subsequent' utilisation of other services and supports (e.g., capacity building or social supports) which they may also experience barriers in accessing. When participants experience - often significant - delays in 'direct' utilisation, they then cannot effectively utilise in subsequent components of their plans. (See policy consideration 1).

'Direct' and 'subsequent' utilisation processes can be further disrupted by high turn-over of workers, delays in NDIA approvals, and broader constraints within markets (e.g., bottlenecks in the supply of standard and innovative equipment and technology). Better understanding of why these issues emerge and how they can be addressed, alongside stimulating more innovation in areas such as equipment and technology, will be critical to improving utilisation and improving outcomes in the future. (See policy considerations 3, 4 and 5). Similarly, the potential for further disruption to the already limited supply of allied health therapists should be acknowledged and investigated, if such workers are pulled towards filling roles in the proposed roll-out of Independent Assessments (IAs).

The critical role of Victorian organisations that work with people with disability and their communities to access, understand and navigate the NDIS was commonly emphasised by participants. This was particularly so for participants identifying as members of the key cohorts of interest, as these groups often experience multi-faceted challenges to navigating the complexity of the Scheme. Unfortunately, many organisations find it difficult to respond to the level of demand for their services as they are often stretched across a number of priority areas with limited resources and staff. Enhanced and sustained resourcing of such organisations would ensure they were more able to fulfil their important role in supporting individuals, families and communities to more effectively engage with the NDIS. (See policy consideration 2).

The NDIA's market stewardship role of monitoring the availability of quality services and supports, including the supply and procurement processes for equipment, technology, home modifications and indeed appropriate housing for Individualised Living Options, is more important than ever in ensuring participants can utilise their plans to access what they need in an efficient and cost-effective manner. Acknowledging that demand for a strong disability workforce is influenced by factors such as the supply and demand of skilled workers in other sectors such as the aged care and mental health workforce, as well as the quality and responsiveness of the skills and qualifications and career pathways across all of these workforces. This requires the NDIA to work closely across State, Territory and Federal governments to understand, monitor and respond to factors that influence the quality and availability of the disability, aged care and mental health workforce. (See policy considerations 3 and 4).

The influence on utilisation of participants' experiences in their engagement with the NDIS, disability markets and the broader systems in which they interact should not be underestimated. When participants have access to accurate and consistent information, and skilled workers that respect their expertise and autonomy, plans are

more likely to reflect needs and participants are more likely to have trust in the Scheme. When this is matched with quality and trusted supports to understand, implement and manage plans – alongside support to recognise and report issues of risk and exploitation – motivation and confidence to proactively utilise plans is enhanced. Of course, the converse holds firmly true. (See policy considerations 3 and 4).

Any circumstance where NDIS participants feel their safety, well-being or plans have been compromised or exploited should be treated with utmost concern and due diligence. Recognising that the existing onus on people with disability to identify, collect evidence and call out practices that place them at risk is very problematic – particularly when they may be in unequal or dependent relationships with the person causing harm. Unfortunately, participants who reported such experiences, often found it difficult to navigate the complaints process and/or get the support they required to report issues and have them appropriately addressed. Participants do not always feel the NDIA has enough oversight of these issues or adequately holds service providers and workers to account. More needs to be done to work with participants to understand these issues and co-design strategies to better inform and appropriately support NDIS participants to navigate and make a complaint to the relevant authorities and agencies. This is alongside determining how governments, the NDIA and service providers can then improve policies, practices and processes that are designed to prevent and monitor adverse events, risks and exploitation of people with disability. (See policy consideration 6).

Alongside the experiences that were commonly shared across the cohort, participants with psychosocial disability, First Nations participants, and Culturally and Linguistically Diverse participants experienced additional barriers to effective plan utilisation. Insufficient consultation and inclusion within the original design of the NDIS was frequently highlighted as contributing to ongoing issues within the Scheme's capacity to respond to the cultural and mental health needs and aspirations of these cohorts. Addressing these issues requires continual engagement with the relevant NDIA advisory boards and other people with disability and their representative organisations to co-design strategies to improve access, utilisation and outcomes across these cohorts. (See policy consideration 7).

The NDIS operates in a broader societal context where people with disability and/or mental health conditions continue to experience discrimination, systemic inequalities and unmet needs across numerous life domains. This often intersects with discrimination and inequalities based on Indigeneity, ethnicity, gender, and sexuality to influence experiences of disability, circumstances and capabilities to navigate the NDIS, as well as effectively utilise plans within it. There is no doubt that targeted approaches within how the NDIS engages with individuals and communities is absolutely vital in shifting these inequalities. Yet broader policy and social change is equally necessary before the NDIS can achieve its overarching ambitions and true potential in improving the lives of all NDIS participants and their families. (See policy consideration 8).

Implications for policy

Based on the findings, the following policy considerations are proposed as ways the Victorian government – in collaboration with other jurisdictions – can enable more effective NDIS plan utilisation to support participants to achieve their goals and aspirations.

- 1. Invest in strategies to stimulate and monitor the availability of a skilled, inclusive, stable and valued workforce to match the varied disability, mental health and cultural needs and preferences of Victorian NDIS participants.** Strategies may include:
 - Develop Standards of Practice for the delivery of diverse services and supports, and corresponding guidance for service providers, training providers and the workforce on the required pre-employment and on the job training and skills development, career pathways, levels of remuneration and recognition, and employment conditions.
 - Monitor the quality of and support access to skills and cultural competency training for the current and future disability, interpreter and mental health workforce.
 - Encourage and support service providers to work with participants to co-design innovative and individualised programs that meet the diverse needs and priorities of participants.
 - Ongoing monitoring of the gaps in the availability of services and supports across Victoria, alongside working with communities to identify locally informed and relevant solutions.
 - Provide additional support to service providers and communities to (re)build workforces in areas impacted by the January 2020 bushfires and the ongoing COVID-19 pandemic.

- 2. Provide support to Victorian advocacy, community and peer-led organisations that work with people with disability and their communities to understand and navigate the NDIS and services and supports.** Strategies may include:
 - Ensuring organisations are appropriately resourced to provide ongoing awareness raising and advocacy support to individuals and communities to understand and navigate the NDIS and services and supports, as well as act as a bridge between communities and the NDIS. This includes through direct funding for advocacy, sustained ILC grants, as well as the Community Connectors program.
 - Resource programs that develop the self-advocacy capabilities of people with disability to help them to identify and articulate their needs and aspirations, as well as actively engage in decision-making processes. This includes support for emerging peer-led networks and knowledge sharing platforms that meet diverse disability, communication, language and cultural needs. Again, this could be facilitated through increased investment through advocacy funding and ILC grant funding.

- 3. Encourage greater investment in the human resourcing and training of the NDIA and NDIS workforce to improve the retention of skilled staff, enabling participants and workers to develop trusting working relationships, and, improving consistency of planning processes and outcomes. Further investment in the Scheme could also focus on encouraging more targeted market stewardship to help identify and address shortages in the quantity, quality and geographic availability of services and supports.** Strategies may include:

- Encourage a change in the role of Local Area Coordinators to build supportive and trusted relationships with participants.
- Working with Partners in the Community to determine current and ongoing training needs and remuneration mechanisms required to attract and retain staff. Encourage strategies that ensure all people with disability have access to ongoing information and communication on all matters affecting their lives (e.g., accessing the NDIS and other disability programs, COVID-19, support for carers) in modes that meet their linguistic, cultural, and communication requirements (e.g., braille, sign and captioning, plain language, news and social media, community centres) and preferences (e.g., electronic or hard copy).
- Work with the NDIA and other stakeholders to continue to enable diverse opportunities to stay informed and provide direct feedback on factors influencing their NDIS engagement, plan utilisation and outcomes.

4. Encourage and provide guidance to all stakeholders (participants, families, frontline workers and other supports) involved in access, planning and review processes to use these opportunities to develop a shared understanding of factors influencing individual plan utilisation, and to support understanding of how plans can be utilised and managed. This includes:

- Encourage strategies that provide NDIS participants with more individualised support – including through NDIS frontline workers and access to independent and skilled Support Coordination - to help participants identify and link in with available services and supports that meet their needs, priorities and aspirations. This is particularly crucial within participants’ first plan. Having greater trust and recognition in the choice and control of participants to utilise their plans in ways that best meets their needs.
- Alleviate concerns that budgets will be reduced if participants have not managed to fully utilise budgets due to delays in procurement of services and/or equipment, or, if participants require more time to address key concerns and/or build their capacity to more effectively utilise their plans.

5. Develop a better understanding of the bottlenecks in the supply and procurement processes of equipment, assistive technology and home modifications, in order to inform appropriate solutions.

Strategies may include:

- Invest in further research with participants, service providers, industry and the NDIA to better understand factors contributing to challenges in supply and procurement of equipment, assistive technology and home modifications.
- Streamlining assessment and approval processes for equipment, assistive technology and home modifications.
- Working with industry to explore different approaches to stimulating innovation and supply of equipment, assistive technology, and individuals and organisations capable of undertaking home modifications.

6. Enhance the prevention and monitoring of risks and exploitation experienced by NDIS participants.

Strategies may include:

- Resource the co-design of strategies that can better inform and appropriately support NDIS participants to navigate and make a complaint to the Victorian Disability Worker Commission and/or the NDIS Quality and Safeguards Commission.

- Determine how governments, the NDIA and service providers can improve policies, practices and processes to better prevent and monitor adverse events, risks and exploitation of people with disability.

7. Progress work with NDIA advisory boards and other people with disability and their representative organisations to co-design strategies to address specific barriers experienced by people with psychosocial disability, First Nations and Culturally and Linguistically Diverse communities in their access and engagement with the NDIS. Strategies may include:

- Requiring NDIS Partners in the Community, service providers and disability workers to undertake training in the provision of culturally informed service design and practice. Such training should be co-designed and delivered by qualified First Nations and Culturally and Linguistically Diverse disability experts.
- Acknowledging current investment in providing specific streams of supports to participants from these cohorts to help them access and engage with the NDIS, work towards resourcing individuals and their representative organisations to design and deliver such targeted supports. I.e.: similar to the role of Aboriginal Liaison Officers within health systems.
- Encourage and support individuals with lived experiences and/or from First Nations and Culturally and Linguistically Diverse backgrounds from across geographical regions to move into the disability workforce.
- Improve the understanding of frontline workers and delegates of the relationships between physical and mental health and that the subsequent impact on functioning is appropriately accommodated for within plans.
- Explore mechanisms to build capacity and availability of culturally safe, trauma-informed services and supports that can be accessed through NDIS plans.

8. Continue to collaborate with all jurisdictions and stakeholders to develop and support state and national level policies and programs that enable the inclusion and active participation of all Australians with disability and their families across all life domains and systems. Strategies may include:

- Build the capacity at the interface of the NDIS and other systems (e.g., health, mental health, education) to provide more streamlined support to NDIS participants and their families reliant on both the NDIS and these other systems.
- Resourcing intermediary roles to support NDIS participants to understand and navigate between the NDIS and interfacing systems.
- Draw on resources such as the Information, Linkages and Communication (ILC) grants to support the development of new and existing local collaborative and knowledge sharing networks that help individuals and families to learn about and link into services and programs that they can access through their NDIS plans (e.g., school-to work training and employment pathways).
- Resource and build the capacity of organisations and programs that focus on enabling access to mainstream recreation, social and community participation for NDIS participants and their families.
- Ongoing collaboration, investment and monitoring in support of policy levers such as the National Disability Strategy, National Disability Employment Strategy, National Mental Health and Suicide Prevention Plan, and Closing the Gap and other Reconciliation Action Plans, that can guide National and State action to improve the inclusion and active participation of all Australians with disability.
- Resource community wide and targeted interventions that focus on changing attitudes and raising awareness, and, to let all people with disability know they have a right to support.

- Encourage greater representation and diversity of the lived experience of disability across all levels of government, the NDIA and the broader disability workforce, to ensure the knowledge and expertise of people with disability can better inform policy, and the design and delivery of innovative services and supports.
- Further investment in the provision of supports for carers to address unmet needs and enable them to continue to support individuals with disability.

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