Submission in response to the inquiry on

NDIS Support Rules

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Who is the Physical Disability Council of NSW?

The Physical Disability Council of New South Wales (PDCN) is the peak advocacy organisation for people with physical disabilities in NSW. We stand up for the rights of people with physical disabilities, advocate for disability inclusion across Government and business, and drive systemic reform around accessibility.

The objectives of PDCN are:

- To educate people with physical disabilities in NSW about the range of services and programs available to support them.
- To develop the capacity of people with physical disability in NSW to identify their own goals and build the confidence needed to achieve their goals (i.e. self-advocate).
- To educate and inform stakeholders (i.e.: about the needs of people with a physical disability).

PDCN also convenes the NSW Disability Advocacy Network (NDAN), which is a network of disability advocacy organisations across NSW. We are funded by the NSW Department of Communities and Justice. Collectively we deliver systemic, representative and individual disability advocacy services across the state and represent people with disabilities in NSW at the National level.

The following submission draws on the knowledge and experience of people with lived experience of physical disability (and the lived experience of all people with disabilities shared through NDAN).

Introduction

The Department of Social Services opened a public consultation on the NDIS Support Rules. The NDIS Support Rules are ‘transitional’. The legislative changes in October 2024 enabled the drafting of the NDIS support ‘in’ list which lists the supports that can be purchased using NDIS funds. This list was accompanied by the NDIS ‘out’ list which lists the supports that cannot be purchased using NDIS funds.

There is also a ‘replacement support list’ which is used to substitute a more expensive disability support for something less expensive. These lists can only be finalised once all state and territory governments come to an agreement about what can and cannot be purchased through the NDIS. Once agreed the NDIS Support Lists will become a rule under the NDIS Act 2013.

This submission responds to the public consultation about the NDIS support lists. It does not address the consultation survey or individual consultation questions. Instead, the submission shares PDCN’s perspective about the NDIS rules and the NDIS more broadly. And it reports the experiences people with physical disability (PDCN members) have had with the rules.

It is important to note that PDCN’s strategic plan lists the NDIS as a key strategic priority. PDCN is closely monitoring reforms to the NDIS. This submission draws on the knowledge and expertise of disability advocates through the NSW Disability Advocacy Network NDIS Sub-working group and the Interagency Disability Policy working group.

It also draws on the lived experiences of people with disabilities who shared through the PDCN Lived Experience Advisory Panel (LEAP), PDCN member survey’s community consultations and conversations with individuals. In preparation for this submission, PDCN administered a member survey (in July 2025) to collect information about people’s experiences with the NDIS supports list.

Executive Summary

This submission is divided into five sections. The first section addresses the broader problems and challenges with the disability service and support sector. Section 1A discusses how the success of the NDIS is dependent on the implementation of foundational supports and inclusive mainstream systems. It offers a recommendation around reducing costs to NDIS through needs assessments of priority cohorts.

Section 1B talks about how the sequencing and transparency of reforms to the disability service and support sector are problematic. Mainly that NDIS sustainability measures are being implemented before the system of Foundational Support has been delivered. This section recommends implementing foundational support before contracting the NDIS.

Section 1C talks about people with disabilities being removed from the NDIS or having their funding cut which is causing emotional and mental harm. It talks about people with disabilities who are not on the NDIS and are unable to afford or access disability services and support. This section recommends focusing sustainability measures on removing disreputable providers from the market instead of removing people with disabilities from the NDIS.

Section 2 of this submission reiterates the advice previously provided by PDCN about the NDIS Support Lists. First, PDCN responded to a public consultation on Friday 23 August 2024 about the NDIS Transitional Rules. In this submission PDCN offered a series of principles to guide staff at the National Disability Insurance Agency (NDIA) to guide decision-making when approving NDIS support for NDIS participants. The NDIA has confirmed it will not take a principle-based approach to decision making. However, in this submission, in section 2A, we propose those same principles can be applied in addition to the NDIS support rules, especially the ‘replacement’ support rule.

In 2024 PDCN drafted a submission about the proposed changes to the National Disability Insurance Scheme (Getting the NDIS Back on track) Bill 2024. In this submission we discussed (among other things) that the NDIS Support Rules may unfairly restrict what constitutes and NDIS support. Section 2B discusses that problem and recommends a formal process for amending the NDIS support rules if needed.

Section 3 discusses the impact funding cuts for NDIS supports are having on people with physical disabilities since the legislative amendments in October 2024. The information presented in this section has been collected through consultation with Lived Experience Advisory Panel (LEAP) members, regional community consultations, stakeholder meetings and member surveys. The specific NDIS supports referred to in this section are transport, Auslan Interpreters and allied health support. This section also discusses the three-month funding periods policy and the impact this has on accessing emergency NDIS supports.

Section 4 centres on the outcomes from the member survey administered to PDCN members in July 2025 about the NDIS support lists. This section offers a series of recommendations based on survey respondent feedback. Section 4A recommends the NDIS Support Lists are written in plain English. Section 4B recommends additional education and training for local area coordinators, support coordinators and plan managers (soon to be 'navigators'). Section 4C recommends the NDIS support lists are attached to NDIS participant plans. Section 4D recommends more supports are delivered for social and community participation, 'critical transition points' and for parents of children with disabilities. Section 4E makes recommendations around the replacement support rules and process.

Section 5 of this submission offers concluding remarks about how to improve the disability service and support sector more broadly, considering all the issues raised in this submission.

Section 1 Problems and challenges with the broader disability service and support sector.

Section 1A - The system of disability services and support should focus on sustainability through support need assessments of priority cohorts.

The quality of the NDIS is dependent on the delivery of Foundational Supports and the inclusiveness of mainstream services (ie health, education and transport).

In terms of general foundational support it is not clear when this will be delivered and note that it will not be available to people aged over 65 years. In terms of targeted foundational supports the NDIS review report recommended that these supports should also be available to all people with disabilities. "*This requires increased investment, redesign, and implementation of a "communitywide rollout of inclusive and accessible mainstream services and foundational supports to sit side-by-side with individualised supports funded by the NDIS."* The NSW Government is yet to make a formal response to the NDIS review report. However, disability advocates were confident that this message was received by the NSW Government.

Disability advocates have since been advised that targeted foundational support will extend only to children under 9 with developmental delay. There was an informal suggestion that foundational support will extend to children with other disabilities including physical disabilities. The message at this stage is that foundational support will not extend to adults with disabilities.

Further to this issue, the recent NSW state budget did not allocate specific funding for disability inclusion and accessibility training in mainstream services. In the context of NDIS sustainability measures and limited funding for disability inclusion in mainstream services it is reasonable to assume that there will be large numbers of adults with disabilities unable to access affordable disability supports and services. This is of grave concern to disability advocates and people with disabilities.

To focus now on NDIS sustainability measures, a suitable approach is to undertake a needs assessment of priority cohorts to ensure people with significant and profound disability are supported under the NDIS. In terms of the physical disability community the following disabilities should be considered in a needs assessment. People with spinal cord injury, cerebral palsy, Muscular Dystrophy, multiple sclerosis and other degenerative conditions, people who are blind or have low vision, people who are Deaf or hard of hearing, a person with an amputee or limb difference, Short stature, polio, paraplegia, quadriplegia, spina bifida, motor neuron disease, arthritis, Parkinson's disease, acquired brain injury, or someone who has suffered a stroke, chronic pain and autoimmune condition.

The NDIS must provide people with significant and profound physical disability with what they need to live independently and have a good life.

Recommendation 1 - The Commonwealth Government should undertake needs assessment and support priority cohorts for whom the NDIS was intended to address greatest need and drive sustainability.

Section 1B - The sequence of NDIS reforms, transparency of cohort removal from the NDIS and funding reductions risks leaving people with disabilities without access to affordable disability services and support.

In being reformed and made more sustainable the NDIS is contracting. A key issue with the current approach taken by the NDIA is ‘sequencing’ and transparency of cohort removal or reduction in funding. People with disabilities are being removed from the NDIS and being subject to NDIS funding cuts before Foundational Supports are available. People with disabilities are falling through the cracks.

Sequencing of NDIS reforms

The NDIS is undergoing its most significant reforms in over a decade. While these reforms aim to ensure sustainability, many people are already finding themselves ineligible for the scheme, without alternative supports in place.

NSW disability advocates representing 1.4 million people with disability across the state are urging the federal government to provide clear timelines, transparent information, and strong assurances about the delivery of foundational supports. These supports must be available to *all* people with disability—not just those eligible for the NDIS.

This is not just a matter of policy, it is a matter of dignity, access, and wellbeing.

Case Study – Issues with sequencing NDIS contraction before delivering Foundational support.

A Bankstown man with multiple disabilities, was excluded from the NDIS and left to navigate life without support. When his wife was diagnosed with multiple sclerosis and his son with Asperger's Syndrome, he had no option but to keep working, against medical advice. He eventually lost his job, his family filed for bankruptcy, and he became partially paralysed. Still, no supports were available.
"I've always suffered alone," he says. "I was told community supports existed, but they didn't."

His experience reflects a growing cohort of people now in 'no man's land', caught between a changing NDIS and yet-to-be-delivered foundational supports.

Transparency of cohorts being removed from the NDIS or being subject to funding cuts.

It isn't clear what cohorts of people will be removed from the NDIS in the future or be subject to funding cuts. This is causing anxiety for people with disabilities.

It isn't just children that are being removed from the NDIS. PDCN is aware of cases where adults with significant and permanent disability such as cerebral palsy and multiple sclerosis are having their NDIS funding significantly reduced.

" The reforms have directly impacted many of my clients very significantly reducing their capacity to have productive and positive life. They have become self-harmers, clinically depressed and have suicidal thoughts. The reforms have been catastrophic." PDCN Member Survey about NDIS Support Rules 2025.

Transparency will enable planning and preparation for a response to NDIA decisions.

Recommendation 2 - NDIS contraction should slow down until there is agreement on the scope of foundational support and timeframes for delivery. The NDIA should be transparent about the cohorts that are being removed from the NDIS or having their funding cut.

Section 1C –The NDIS sustainability measures should focus on removing disreputable disability service providers.

The NDIS is reducing expenditure by removing people from the NDIS, reducing funding and delaying decision making. The NDIS, for those that were eligible, made people with disabilities feel cared for and enhanced their independence, and took costings pressure of health, housing and emergency services. NDIS contraction makes people feel that the challenges they experience as a person with disability, and the suffering that comes with it, are not acknowledged. There is so much anxiety, fear and frustration around the NDIS.

The NDIS was originally intended to support approximately 200,000 people living with profound and significant disability. Which is interesting given the Australian Bureau of Statistics said in 2010 there was 6.8 million people living with disability and/or long-term health condition.

The NDIA approved access and funding in a far greater numbers than originally anticipated. Now the NDIS is contracting to ensure the scheme is sustainable. However, this is happening without Foundational support having been implemented as agreed by Cabinet in December 2023 or needs analyses being conducted across priority cohorts

NDIS sustainability measures should continue to identify and prosecute fraudulent providers. Efforts have already prevented over $400m being diverted away from genuine participants by disreputable providers whilst also delivering over $200m in savings to the Scheme. Sustainability measures should continue to focus on removing fraudulent providers instead of removing people with disabilities from the NDIS or reducing NDIS funding.

Recommendation 3 - NDIS sustainability measures should be slowed but continue to focus on removing disreputable disability providers.

Section 2 Information extracted from a previous submission made by PDCN in response to the public inquiry on Transition Support Rules in August 2024 and the submission in response to the public inquiry on the NDIS Bill (Getting the NDIS back on Track) in 2024.

Section 2A – the principle-based approach to decision making (extracted from the Transitional Rules Submission).

Principle-based approach to decision making

The NDIA has confirmed that in terms of NDIS support, the NDIA will not adopt a principles-based approach to decision making. This is understandable as complex decision making is demanding. However, the principles PDCN recommended in the Transitional Rules Submission in 2024 can still be applied in conjunction with the NDIS supports lists. This is especially true for the 'replacement support list'. The principles, and an explanation of those principles, are listed below.

NDIS support category decision making

The NDIS must remain sustainable while balancing the need for people with disabilities to be cared for, included in society and be assisted to make economic contributions. When deciding what supports people can access and/or substitute the following principles should apply:

- <u>The NDIS is an insurance program for people with significant and permanent disability that affords people with disability the dignity everyone deserves</u>. Supports must be based on what provides people with disability with dignity and to allow them to achieve their aspirations. It is also important to remember that the nature of disability fluctuates. For example, the effects of Multiple sclerosis can vary creating episodic poor vision, the symptoms of cerebral palsy can worsen overtime, a stroke patient might make a full recovery or be left paralysed on one side etc

- <u>The NDIS is an economic investment in our country.</u> People with significant and permanent disability might need supports that enable them to attend school, higher education and employment. This carries a significant economic benefit. The NDIS might fund, for example, a support worker to wash and dress a participant, but that participant might then go to work and contribute economically through income tax and stimulating the economy with spending on local businesses.

Research indicates that $1 of disability support investment creates $2.25 in social value across the economy. The NDIS is of great benefit. “The NDIS has changed the lives of hundreds of thousands of people with disability and their families for the better. Its introduction has transformed the nation, creating social and economic benefits. It has made our country stronger and fairer.” *NDIS Review Report 2023 page 20*.

- <u>The NDIS contributes to preventative health and future savings</u>. The NDIS should be able to provide people with permanent disability with supports throughout their entire life, at whatever point they may acquire a disability. Yet, NDIS supports do not always have to be ongoing. They can be used to provide medical and health intervention to prevent significant and permanent disability. A good example is stroke recovery. Following a stroke medical and rehabilitation supports can greatly enhance the chances of a person avoiding long term physical disability. This in turn, reduces the need for greater amounts of financial support from health and NDIS in the future, and can help people return to workforce earlier. Short term NDIS funding to prevent significant and permanent disability is a good economic investment.

- <u>The NDIS and/or Foundational Supports should invest in early intervention.</u> Children who are born with or acquire significant and permanent disability need support from the Government and their families. In this capacity NDIS is an investment in a civilised, resilient and robust future state. Children should be supported so they can fulfil their potential, engage with their peers, learn at school and, eventually, engage in higher education and employment. Early intervention is also about parental support. Helping parents understand and navigate their child’s disability will benefit the children in the long term. NDIS could fund a support worker to assist a child, or it could teach parents how to manage their child’s disability now and into the future. Early intervention is about the needs of the child *and the parents*. NDIS supports should reflect this approach.

Early intervention is not only applicable to children. The principle of early intervention is also essential at the diagnostic stage of disability. Take for example a degenerative disability like Multiple Sclerosis. Early intervention such as peer support, medicinal intervention, allied health etc can delay and reduce the physical impact of disabilities. Early intervention is essential for maintaining an individual's health and wellbeing and reducing pressure on health services and the NDIS over time.

Recommendation 4 - Clear guidelines about what supports can be purchased with NDIS funds are important for local area coordinators, support coordination and plan managers, but this should be supplemented with training in good decision making and applying a principle-based approach to decision making.

Section 2 B – Establish a process for Governments to review and amend the NDIS Support Rules (extracted from the NDIS Bill submission).

In the NDIS Act is it states that the sunsetting regime set out in the Legislation Act 2003 does not apply. This is a consequence of the amendments made by item 123 which amends the Legislation (Exemptions and Other Measures) Regulation 2015 to clarify that instruments made under the Act are exempt from sunsetting.

On one hand this provision provides stability for the NDIS Act, on the other hand there needs to be a requirement that the NDIS rules will be reviewed routinely to ensure they remain useful, meaningful and up to date.

It is worth noting that the NDIS support rules are not the only rules that will be in operation. There will be rules that proscribe many NDIS processes including access criteria (disability requirements and early intervention requirements), the needs assessment and the methods to be applied to make an assessment and the allocation of a reasonable and necessary budget. The rules basically outline the entire operation of the NDIS. Furthermore, these rules (category A) must be agreed to by all states and territories. If an unfair rule is accidently agreed to, it will be difficult to amend.

Recommendation 5 – The NDIS Support List Rules, and other rules, will provide clarity around the operation of the NDIS. However, there must be a plan or framework for reviewing and amending these rules to ensure they are fair, current and up to date.

Section 3 The experiences that people with physical disabilities have had with funding cuts for NDIS supports lists since the legislative changes in October 2024.

Since the legislative changes in October 2024 PDCN has received reports of people with disabilities havingNDIS funding being reduced and people have lost access to specific supports. People with disabilities feel they have lost choice and control and there is growing sense of fear, anxiety and stress. The information from this section has been drawn from the member survey administered by PDCN in July 2025, the regional community consultation held in June 2025, the LEAP meeting held in July 2025 and sector wide meetings.

Section 3. 1 NDIS Funding Cuts have affected people with significant and permanent physical disabilities.

People with significant and permanent physical disabilities are seeing their NDIS funding significantly cut. This is causing anxiety and stress among NDIS participants.

"I had to cancel 80 percent of my services because NDIS cut my funding dramatically. [now I don't have much for] every day living. Because of this [funding cut] I'm frightened to have a fall at home. [In this case I will have] no support services because NDIS cut this part of my funding".

Funding cuts for Auslan Services

NDIS participants used to receive around $43,000 for interpreting services in core support funding. This amount has been reduced to $300 which is a single interpretation service. The rationale behind this decision was that people who are deaf or hearing impaired can access the National Interpreting Service. However, this service is only for people who are not NDIS participants. All NDIS participants who rely on interpreting services can only access approximately one interpreting service for the whole year. This will also impact people from cultural and linguistically diverse communities.

Recommendation 5: As a matter of urgency, the NDIA should either allocate more funding for interpreting services in people's NDIS budgets or negotiate with the National Interpreting Service to provide this service to NDIS participants.

Funding cuts for Allied Health therapy

One of the members on the PDCN Lived Experience Advisory Panel who has cerebral palsy said that even though her condition is significant and permanent her funding for speech and physiotherapy was recently reduced.

Case Study: PDCN LEAP Member

"I was advised in June 2025 by the LAC that I had only been given $18,115.30 for therapy over the next two years, which was a significant drop from my last plan, where I received $17,133.12 for 12 months. I was told if I wanted to increase my funding to do a functional capacity assessment. Even though I had just given the NDIA a 34-page functional capacity assessment from an occupational therapist.

I sent a report from a podiatrist about my risk of falling over, requesting $840 for orthotics to reduce this risk. The delegate refused this request and offered a $50 for a walking stick instead, which is more dangerous for me, as I trip over the walking stick every time I use it.

In addition, I have complex psychosocial disabilities and provided three reports stating this, but all my funding for a psychologist was cut.

My funding has been cut every year since 2022, which has resulted in a decline in my overall functionality. Every year I have provided evidence that the cut to my funding has resulted in a decrease in my mobility and the use of my hand to complete everyday tasks."

Transport Funding Cuts

From July the NDIA reduced travel subsidies paid to allied health providers by 50%. This has a significant impact on people with physical disabilities who rely on private transport options and mobile disability services. PDCN consulted with people with physical disabilities in regional areas of NSW. It was confirmed by a local MP that people in regional communities need access to more travel options to attend medical appointments, disability services and engage with the community. Cuts to travel funding disproportionately impact people with disabilities living in regional and rural areas.

Recommendation 6: Funding for travel is a critical support for people with disabilities and needs to be increased to meet demand. People with physical disabilities (especially people who use wheelchairs or power wheelchairs) are limited in their ability to navigate public transport. The most suitable solution is private transport or mobile disability support services. This is especially the case for people with disabilities living in rural and regional areas of NSW.

The new policy around three-month funding period is causing issues accessing NDIS support in emergency situations.

The NDIA has introduced 3-month funding periods to enable NDIS participants to manage their budgets and reduce the likelihood of funds running out. The NDIA advised that this would not be a default policy and would only apply to people that need this extra level of support and management. However, according to people with disabilities this is not the case, and this policy is a default.

Restricting funds to 3-month intervals has negatively impacted on a person with physical disability and we are concerned this might occur again.

PDCN received a call from a Community Centre about one of their clients who has severe cerebral palsy and relies on two support workers to help him out of bed, bathe and get dressed. The client ran out of NDIS funding as services were not costed properly. The community centre contacted the NDIA to request urgent funds. The NDIA advised they can provide $1000 in emergency funding which will only cover two weeks of disability support work. The community centre tried to escalate this issue in the NDIA. The NDIA advised there is no escalation process for urgent matters.

Recommendation 7: In terms of the NDIS support lists, there should be a policy that enables participants to access their funds, or apply for additional funds, to purchase emergency supports in life and death situations.

Section 4 The outcomes from the PDCN member survey, administered in July 2025, about the NDIS Support Lists.

Section 4A – Recommendation 8 The NDIS Support lists (NSL) should be written in Plain English and accompanied with real-world examples of how to use the NSL.

One of the survey questions asked about people's experience using the NSL. Of the people that were aware of the support lists, 43.5% of respondents said their experience of using the NSL was confusing, difficult and they found the NSL unhelpful.

The NDIS is a complex scheme that is designed to support a cohort of people that struggle with communication compared to their mainstream counterparts (ie vision impairment, cognitive impairment). Complex written communication can be difficult to digest, whether a person suffers with a disability or not. Misunderstanding the NSL can leave people without support they are entitled to, or it can lead to purchasing unauthorized support and accruing debts.

Leading on from this, members were also asked in the survey what they thought would make the NSL easier to use. Approximately 48.2% of respondents said they wanted the support lists to be written simply and clearly. More specifically, respondents wanted to see the lists written in plain English (layman's terms) and provide real world examples of how supports can be used.

Section 4B – Recommendation 9 Local area coordinators, support coordinators and plan managers (navigators) require training and education around the NSL.

The government has invested 20 million in designing the new Navigator function in consultation with people with disabilities. This initiative is welcomed as it coincides with the recommendations from the NDIS Review Report 2023. The navigator role takes on the functions of the support coordinator, specialist support coordinators and Local Area Coordinators. (It is not clear if these Navigators will replace or work alongside Plan managers).

Navigators must be qualified and skilled. Navigators should be trained in 'good decision - making' which means they perform their jobs in a way that enhances choice and control for the participants and does not make unfair assumptions about what a person with disability needs from the NDIS. Some of the challenges with the current workforce underpinning this recommendation are listed below.

Inconsistent decisions about NDIS support are being made

Approximately 29.2% of respondents highlighted how there is an inconsistent application in the NDIS supports list across local area coordinators, plan managers and support coordinators.

Respondents identified possible reasons for this inconsistent decision making. First, survey respondents noted that the NSL has changed, and this change is creating uncertainty among decision makers. One survey respondent identified that there is no list that outlines the supports that have been moved from the 'in list' to the 'out list'.

Other survey respondents raised the issue of 'streamlined communication'. People with disabilities are not sure how the NDIA communicates across the local area coordinators, plan managers and support coordinators. But there is a desire from people with disabilities for one source of truth to ensure consistency in decision making.

"It would be great if the NDIS knew what I was able to spend my NDIS funds on. I've emailed them 5 times this year and they can't answer my question. They only give me suggestions for everything that I've haven't asked them about. I had to resort to asking the NDIS directly because my Plan Manager & Support Coordinator have no idea what they're doing."

Limiting choice and control

Another challenge is that support coordinators and local area coordinators can make people feel disempowered and micromanaged. There have been reports of local area coordinators and plan managers adopting a 'gatekeeping' mentality since the legislative changes in October 2024.

"*The biggest failure of the NDIS isn't what's missing from the list—it's how easy it is to be misdiagnosed, misrepresented, and managed under assumptions. Once that happens, participants can lose control of their plans, their voice, and even their legal rights, with very little recourse. Independence should never be treated as a risk. It should be the goal. We need reforms that support capacity, not just contain it.".*

"I cannot manage changes, they make me frightened. I do not trust the NDIS Staff to understand things or to administer them equitably and fairly. I feel sick from all this micro management that is unnecessary. I have not done anything wrong but feel like I am being treated like a criminal."

Limited knowledge of disability

Another key challenge is that local area coordinators and plan managers do not understand how to connect supports with the individuals need. "The line between 'everyday expenses' and 'reasonable supports' is unclear and inconsistently applied. For example, transport assistance, technology for communication or safety, and household help all fluctuate based on subjective judgement—not participant need. What's approved for one person is denied for another with no clear rationale."

Local areas coordinators, support coordinators and plan managers have the capacity to enhance people's experience with the NDIS. For example, 19.4% of respondents said that trained NDIA staff that help explain the lists and help people make decisions would make lists easier to understand. Furthermore, the people who reported positive experience using the NSL linked this experience with supported decision making. For example, they worked with a qualified plan manager or support coordinator to read and understand the list.

The new navigator function should be professionalised. Navigators need training in the clinical aspects of disability and the social model of disability. Navigators need a good understanding of the disability service providers in their geographical area and have a relationship with those providers. Navigators need a comprehensive understanding of the NSL which is delivered through an online learning course that can be referred to at any time.

Section 4C – Recommendation 10 The NDIS Support Lists should be provided to NDIS participants to accompany their NDIS plans.

An interesting outcome from the survey administered by PDCN was the finding that 11.3% did not know what the lists were and another 37.2% of respondents said they did not know what the replacement support list was. This finding was interesting because most of the survey respondents (96%) were on the NDIS, or were a family member of a NDIS participant, and had been for some time.

A key challenge for people with disabilities is that they are too anxious to engage with the NDIA and clarify issues around support. Too many people have had poor experiences with the NDIA and now there is a culture of fear. There have been reports of people engaging with the NDIS to clarify what support they can access and have found themselves in an impromptu review meeting and been subject to funding cuts.

It is critical that NDIS participants can access, read and understand the support lists. These lists should accompany NDIS plans. There was also a recommendation from a survey respondents that the NDIA should have a database that enables NDIS participants to enter support and see if it can be purchased with NDIS funds (or not).

Section 4D – Recommendation 11 NDIS supports that should be included in the NSL are more supports for social and community participation, supports for critical transition points and support for parents of children with disabilities.

When asked about additional NDIS supports 46.15% of respondents expressed the need for more support to be included in the NDIS supports list. This included the need for an understanding from the NDIA of supports beyond assistance to just "survive", and to focus also on supports that maintain independence and allow for greater flexibility.

Social and Community Participation

Many respondents would like to see increased support for social and community inclusion eg. Cooking classes, affordable personal technology, sports and recreational activities, and relationship building.

Additional Supports needed for critical transition points

Supports for critical transition points are key for assisting people to be independent and self-reliant. Transitioning to school, high school, tertiary education and employment is difficult for everyone. But people with disabilities feel this challenge more greatly because there is no certainty that adjustments will be made by the institution that is receiving them. Transition supports are critical for supporting people with disabilities to grow and develop as people, engage in education and learning and be able to work and live independently in the future.

Supports for parents of children with disabilities

A cohort of NDIS participants that has been affected is children and their parents. Children have lost supports they need to participate in in school including occupational therapy, speech therapy, paediatric physiotherapy and home care for the parents. The loss of supports requires parents to rebuild child routines and create stability all over again.

"We have lost choice and control of our package. Constantly removing supports is detrimental to our health and wellbeing and No participant can fit into a box with any other participant."

Section 4E – Recommendation 12 The scope of the Replacement support process should be expanded, timeframes for substituting supports be removed and NDIS participants should be made aware of this process.

Expanding the scope of the replacement process

A replacement rule will enable participants to substitute an approved NDIS support for a different type of support that costs less. For example, having your hair washed at a hairdresser for $25 instead of paying $250 for a support worker to do it. It is not clear what the parameters are for the replacement support process.

The replacement process is a good thing. One issue is that it is unclear if the replacement list is final. There is mixed information. For example, on the My Care Space website it indicates that the replacement support list is final. However, on the NDIA website it says the replacement process will be considered for items on the exclusion list (meaning there is scope for other replacement items).

The replacement support list includes two categories: standard commercially available household items and smartwatches, tablets, iPhone and communication apps for accessibility and communication. The scope of this list should be expanded, and it should be a living document. For example, the NDIS does not cover the cost of consumables and sensory items. As a sustainability measure this makes sense. It is critical that needs assessments do consider what people with disabilities need to live independently.

However, the ability to exchange a more expensive service with a low-cost item will enhance choice and control for the participant, open the disability service market and reduce costs for the NDIA. *"I want to purchase an item and it costs $300 from the NDIS approved company. I can by it for $50 from Temu."*.

Approximately 29.2% of respondents raised issues around consumables and off-the-shelf items. People with disabilities would like the option of purchasing items from mainstream retailers instead of disability providers. The main reason for wanting flexibility to purchase consumables is because of cost. It terms of 'needs assessment' we can understand the NDIA wants to draw the line at consumables and sensory items. However, if these items can be purchased *in exchange* for other more expensive support at a lower cost, this is beneficial. Reasonable flexibility with funding will also benefit people with dynamic disability without the need for formal reassessment. This will reduce the workload for the NDIA.

Timeframes to make a replacement request

Another issue is that a request to replace/substitute a support must be made immediately after a NDIS plan has come into effect. If the replacement request is not requested immediately, it is difficult to negotiate this change later. If the replacement support is used without approval, then there is a time limit for correcting this 'mistake' before debt is accrued. Plan managers have 30 days to correct a mistake, and participants have 12 months to correct the mistake.

Noting the replacement process has the capacity to save money this rule should be removed and a formal process for substitution implemented.

Ensuring NDIS participants are aware of the replacement support process.

The survey asked if people have heard of the replacement process. Of the respondents 50% said they had not used the replacements support process and 37.1% respondents said they have not heard of the replacement support process.

The replacement support process is an opportunity to make the disability service and support market more competitive. The replacement process is a cost-saving initiative. It is common knowledge that, for the most part, disability service providers increase the price of goods and services for NDIS participants. This increases the cost of services for the taxpayer and government. Enabling participant decision making enhances choice and control and has the potential to reduce the cost of the NDIS.

Section 5 - Conclusion

The benefits of disability support are substantial. People with disabilities are worried about losing access to the NDIS and people with disabilities outside the NDIS are concerned over the lack of affordable disability services and support. People with disabilities are falling through the cracks.

The Commonwealth Government should slow down the pace of NDIS reform. Sustainability measures should come from the right place. Sustainability measures should focus on needs assessments for priority cohorts, the delivery of foundational support and removing disreputable disability service providers from the market – not removing people with disabilities from the NDIS or reducing funding.

NDIS funding cuts for people with significant and profound physical disabilities must be reconsidered. There should be a focus on maintaining allied health support, ensuring the National Interpreting Service can be accessed by people who need it, and funding for transport be increased to meet demand. A process for accessing NDIS funds in an emergency should be made available.

Local area coordinators, support coordinators and decision makers should receive education and training around the support lists. This training should also assist staff to undertake a principle-based approach to decision making. The NDIS Support lists should be drafted in plain English and accompanied with real world examples and a copy provided to NDIS participants. The replacement support process should be flexible and used as a sustainability measure. All NDIS support rules should be formally reviewed and subject to amendments.

General foundational support must be delivered as soon as possible. Targeted support for children and young people with disabilities should be rolled out by 2026 which is the new agreed timeframe. And mainstream services delivered by NSW Government should make an ongoing commitment to people with disabilities to ensure services are inclusive and accessible.

The Government must continue to work with disability advocates at the National and State level to ensure the disability service and support sector is co-designed with people with disabilities. Co-design will ensure disability services and support are fit for purpose.

A consistent and stable disability service and support sector will carry benefit for people with disabilities and Governments.