

NDIS Review Feedback Report

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Introduction and key issues

The Minister for the National Disability Insurance Scheme, the Hon Bill Shorten MP, announced a review of the National Disability Insurance Scheme (NDIS) on Tuesday 18 October 2022. The NDIS Review was commissioned to look at the design, operations and sustainability of the NDIS. It will also look at ways to make the market and workforce more responsive, supportive and sustainable.

An overarching goal of the Review is to put people with disability back at the centre of the NDIS. It aims to help restore trust, confidence and pride in the NDIS.

Limbs 4 Life are aware that some individuals (Participants) are not willing to make submissions and as such developed a survey in line with the questions proposed by the NDIS Review and shared the link to the survey with our stakeholders nationally. The NDIS Review and link was shared via our social media channels, on our website and promoted via our Amplified magazine.

Some of the responses and feedback were very upsetting and amputee stakeholders indicate that while the NDIS has been beneficial, some of the red tape has increased their levels of mental distress.

Based on the feedback that Limbs 4 Life has received from Participants, it is worth noting that the Australian Orthotic and Prosthetic Association (AOPA) members and/or those providing prosthetic services could be vulnerable. The sheer discrepancies in costs (for the same items – both consumables and assistive technology) were concerning, especially in comparison to those being funded by the state-based artificial limb scheme funding programs and/or insurance bodies like the Transport Accident Commission (TAC) in Victoria.

Limbs 4 Life welcomes the opportunity to provide feedback to this Review on behalf of people in Australia living with amputation. The participant feedback in this report highlights the need to make some significant changes to improve the Scheme and also offers recommendations for ensuring the Scheme’s viability into the future.

There are a number of key issues highlighted throughout the report. These range from access into the Scheme, navigating the Scheme, concerns relating to providers over prescribing and cost of items when the NDIS is footing the bill. The NDIS was developed for the people, and it’s important to remember that this Scheme was not set up to ensure the longevity of providers, but to ensure that Australian’s living with a disability could access the vital services and supports they need to live an ordinary life.

About Limbs 4 Life

Limbs 4 Life has been operating in the disability sector for nearly 20 years is the peak body for people with limb-loss. The organisation works to empower amputees through knowledge and support. Limbs 4 Life builds community connections among stakeholders, ensuring that people and their families do not go through amputation alone; Limbs 4 Life works to ensure that people pre or post amputation have access to our national best practice peer support program, along with the provision of resources and current information to assist them to transition back to independent living.

Limbs 4 Life's mission is to provide information and support to amputees and their families while promoting an inclusive community. Our philosophy is to empower amputees with knowledge and support to make a real difference, because no one should go through limb loss alone.

Limbs 4 Life provides services to thousands of amputees and their care givers, who rely on its programs and support for assistance prior to or after a limb amputation. Limbs 4 Life is supported by over 200 trained Peer Support Volunteers and is governed by a board and operated by staff with a majority representation from those with the lived experience of amputation or close contact with someone who does. Since its formation, Limbs 4 Life has greatly extended the supports available to amputees, their families, primary care givers and healthcare staff. Limbs 4 Life's services include provision of:

- Best practice Peer Support Programs
- Evidence-based health literacy resources and wellbeing information
- Independent support and advocacy to assist people to navigate healthcare and disability systems and pathways
- Access to social and economic inclusion activities.

Limbs 4 Life advocates for amputees by initiating or taking part in research, providing recommendations to government, responding to submissions, and educating the community about amputation and limb loss.

Amputee population and limb loss impacts

Of the 160,395 people who have undergone amputation in Australia, 42,007 are living with major limb loss and are potential prosthetic users, however not all are NDIS participants. In fact, as of December 2022, amputees made up 1% of Australia's NDIS participant population (n=4,060/573,340; <https://data.ndis.gov.au/data-downloads#participant>). The main causes of amputation include diabetes, cancer, vascular disease, infection, birth deficiencies and traumatic related injuries.

Notably, Australia has an appalling record when it comes to diabetic-related amputations with the rate of such limb loss increasing by 30 per cent in the past decade and resulting in our country having the second highest rate of such amputations in the developed world. Of grave concern is the fact that major limb amputations are 38 times more likely in Indigenous Australians aged 25- 49 years than in the general population. Scientific literature reports that over the past few decades the amputee community has identified problems with the function and comfort of their prosthetic products, as well as challenges with patient-prosthetist communication (Hagberg and Brånemark 2001, Pezzin, Dillingham et al. 2004), and that these issues compromise amputee choice and control, limit independence and contribute to prosthetic abandonment for 1 in 5 amputees (Laskovy, Long et al. 2023).

Amputation recovery and rehabilitation

The loss of a limb is considered a major health and disability event which can impact on a person's functionality, mobility, independence and mental health. Following an amputation and acquiring this physical disability, restoring functionality and daily living abilities, reducing dependency on others, increasing mobility and optimising a person's quality of life and satisfaction are key rehabilitation and disability adjustment goals.

People who undergo amputation spend a period of time in acute hospital settings recovering from the surgery, after which, in most cases, they are transferred to sub-acute rehabilitation facilities to learn to adjust to the loss of a limb/s. Rehabilitation involves a multidisciplinary healthcare team to support amputees build capacity and to learn how to:

- ambulate safely;
- regain functionally, mobility and balance;
- use a wheelchair and/or other mobility aids (assistive technology);
- overcome fears;
- prepare for the fitting of a prosthesis (assistive technology); and,
- plan for socioeconomic re-entrance into the community.

With respect to lower limb amputations, it is estimated that recovery post-amputation occurs over a 12 to 18 month period and is inclusive of activity recovery, reintegration into society, and prosthetic management and training. It is also during this period that amputees seek funding supports, particularly the NDIS, to facilitate independence, community engagement and socioeconomic participation.

The impact of acquiring an amputation / disability

It is worth noting that people who undergo amputation (limb loss) are required to face a number of complexities including:

- Coping with and processing the impact of limb loss can require psycho-social support;
- The impact of limb loss on their day to day lives, including selfcare, employment and income, social and recreational activities and relationships;
- Trying to understand a sometimes complex healthcare system (which healthcare provider delivers which service);
- Working to physically regain mobility and balance;
- Learning and working to physically regain functionality; and,
- Navigating and engaging with funding streams such as the National Disability Insurance Scheme.

Understandably, the myriad and complexities of this amount of information can increase anxiety and a person's mental health.

Consultation process

The purpose of The NDIS Review is to seek feedback from NDIS Participants to determine what is working and what is not working. Participants were asked to respond to four questions:

1. What are your three main problems or concerns with the NDIS?
2. How do these three main problems affect you and/or others?
3. What do you think are possible solutions to those problems?
4. What parts of the NDIS are working well for you?

To support Participants Limbs 4 Life created a survey using the four questions above. The survey was shared nationally via social media, our website and across Limb 4 Life publications. The survey was deidentified and personal details were not collected. Using a thematic approach, survey responses were consolidated to form feedback and provide this report by way of a submission to the NDIS Review.

Limbs 4 Life also facilitate a closed/private Facebook group which engages amputees and their family members. This group boasts 2.4K members nationally. We utilised this platform to seek feedback to the questions above as some community members prefer this platform for communication purposes. Each question attracted an average of 107 responses, with members sharing copies of invoices for the same item but with significant price differences.

Participants were also encouraged to submit their own response to the NDIS Review. A total of 297 individuals took part in the survey.

Question 1: What are your three main problems or concerns with the NDIS?

Participants outlined a number of factors where they expressed problems and concerns. There were six main themes identified in their response:

- a) The application process, accessing the scheme and navigating the website.
- b) Reports and requirements to access services.
- c) The timeframe to access services and lack of support ranging from Local Area Coordinators to Support Coordinators.
- d) The fact that some Local Area Coordinators and Support Coordinators have no clear understanding of disability and/or the specific needs of people with disability.
- e) The implications of living in rural and remote communities.
- f) Providers inflating costs and over prescribing.

a) The application process, accessing the scheme and navigating the website

Participant responses indicated frustration at the length of time and the amount of administrative work required to apply for access to the NDIS. Once accepted into the scheme, participants reported that they found it difficult to understand their funding packages, what services and supports they can/cannot access and what proportion of their funding package is available for the services and supports that they require.

Participants stated the following:

- The website is not user friendly.
- The application system and process is confusing and difficult to navigate. The process should be more straightforward.

- There was an increase in hospital stays while waiting for NDIS approval.
- Lengthy wait times for approval of vital assistive technology.
- My needs change over time and this is difficult to reflect in my plan or to change.

b) Reports and requirements to access services

Engaging individual external advocates for the amputee community is a current concern. In part, because the amputee community have such specific needs, use complex and expensive assistive-technology, are required to undergo DASH (disabilities of the arm, shoulder and hand) assessments by an occupational therapist for upper-limb assessments and AmpPro (amputee mobility predictor assessment tool) lower-limb assessments by a physiotherapist, as the clinical justification process to be deemed eligible for NDIS supports. Due to the complex nature and long-term relationships participants have with their prosthetic providers (custom-made items, i.e. not off-the-shelf), there are complexities for engaging external advocates, eg: participants are required to re-share their stories with people who don't understand their unique situation, and often the re-telling has adverse effects.

Participants stated the following:

- Lack of understanding of people's disabilities and how they choose to live their lives.
 - Lack of knowledge of my disability and challenges I face.
 - LACs planning your life who know nothing about my disability.
 - As an amputee and previous occupational therapy provider I am concerned that the Allied Health professionals don't receive the training, mentoring and ongoing supervision they need for ongoing competencies that are required.
 - The appropriateness, qualifications and understanding of the panel of people approving plans or making decisions about an appeal.
- "LACs not listening, therefore initial plan and funding not correct/doesn't support my needs and goals, support coordinators and occupational therapists not supportive or helpful continuously state that "the NDIS is an insurance scheme therefore you get what you are given."***

c) The timeframe to access services and lack of support ranging from Local Area Coordinators to Support Coordinators

Most lower limb amputees require assistive technology devices (prosthetic limbs and/or wheelchairs) to undertake daily tasks that require mobility. The requirement for reports and the associated approval processes to prescribe devices and items can result in long wait times for NDIS participants who are amputees. High demand and the lack of availability of Occupational Therapists, especially in rural areas, add to the wait times and can result in frustration and despair for people who require a report and/or prescription to access their assistive technology. Survey respondents also indicated dissatisfaction at the lack of understanding from NDIS staff regarding their basic mobility needs and the requirement of time-critical support.

Participants stated the following:

- Time waiting for approval of vital Assistive Technology

- Waiting for answers regarding my bathroom modifications. 4.5 years after becoming an amputee and still waiting for my bathroom modifications. Major falls and injuries because of the wait
- How slow they respond to changes in circumstances.
- Reports requested in my instance is required from an Occupational Therapist (OT). The lead time to secure the services of the OT and indeed the cost of the report is ridiculous. The whole process disempowers the client/me. A comprehensive report was submitted when I applied for NDIS, this should suffice, rather than making life more complex and frustrating for people to have their needs met.

d) The fact that some Local Area Coordinators to Support Coordinators have no clear understanding of disability and/or the needs of people with disability

NDIS participants are reliant on NDIS staff for the implementation and utilisation of their plans, amendments to their plans and the appeal/complaint process. There is the expectation that NDIS staff will exercise not only professionalism, but also empathy toward people with disabilities. It has been highlighted by community members that there are also knowledge and/or experience gaps with regard to understanding peoples' disabilities and the implications of disability in everyday living.

Participants stated the following:

- Lack of knowledge of my disability and the challenges I face.
- The appropriateness, qualifications and understanding of the panel of people approving Plans or making decisions about an appeal.
- Decision makers who are not amputees themselves or persons with disability.
- Lack of empathy.
- Understanding and training of those who work in the NDIS.
- ***“General attitude of LAC's and mistakes. Reviews that put you up against lawyers with tribunals that make you feel like a criminal and these lawyers have no or very little disability experience. Worse than a legal court case”.***

e) The implications of living in rural and remote communities

Participants in rural and regional communities face in some cases extensive wait times for access to service providers. There are significant staff shortages and delays to gain an appointment seems to be increasing over time.

Participants stated the following:

- There are delays and difficulties accessing services in rural areas.
- We have experienced significant wait times sometimes longer than 3 months.
- There is minimal on the ground support in remote communities adding to the difficulty to understand the process, access services and know who to contact for what.
- The staff turnover of Planners and LAC's is an ongoing problem.

f) Providers inflating costs and over prescribing

The current system makes it very difficult for Participants to know if they are getting 'value for money' or not. Unless requested or self-managing, transparent quotes are not generally provided to the end user. It should be a mandatory practise that providers share itemised quotes with participants so that they can be more involved in the process of being informed and exercising choice and control; this in turn would enable participants to 'shop around.' The Victorian Transport Accident Commission (TAC) provides quotes to all clients who are receiving services. This helps to build capacity of Participants with regard to market costs and trends. By having access to this information means that some Participants will be better equipped to self-advocate with increased levels of confidence, and more so if changing providers and costs comparisons.

For example: there is a vast difference in charges for the same item i.e. consumable suspension liners. This is based on evidence provided by Participants where there is a significant variation in costs for same item.

Participant feedback:

- I believe that the NDIS costs far exceed general provider costs, NDIS rates for providers are excessive. I'm a participant my wife is not. Her physiotherapy costs are half the rate that I pay.
- ***"Since when did it cost \$440 dollars to put 2 boxes (silicone liners) into a prepaid Express Post pack and send it? Please don't tell me that it took a qualified professional 2 hours to complete this task? Outrageous!"***
- The costs in the price guide are excessive.
- ***"I would like to be able to see a price list for prosthetics. How do I know if I am being ripped off or not?"***
- I have self-funded stump socks, sheaths and liners in the past. Now that the government is paying, the prices have gone nuts!
- ***"Prosthetists telling you that you need something new all the time when you really just want the one you have repaired or rectified".***
- Since when did a report from an Occupational Therapist take 15 hours to complete? Seems that there needs to be more focus placed on the providers of services and their rorting of the NDIS.
- ***"I'm a below knee amputee and use a wet leg for showering. My shower leg is 6 years old but only ever used for a maximum period of 45 minutes per day. It serves my needs perfectly. Why am I constantly offered a 'new' one?"***
- My prosthetic provider won't make changes to my socket as he recently told me that my socket only has a one month warranty. This information was not written on the initial quote and I believe that this is a breach of Consumer Law.
- ***"When I was covered by the public system my prosthetic liners were \$750.00. Now that I am funded by NDIS, why does the exact same product now cost me \$1,250.00"***
- I'm really happy using the products I have but my provider continues to up-sell me on other items that I don't need.
- ***"If I have to pay up-front for 12 months of prosthetic maintenance and then choose to change provider, does my previous provider refund the unspent monies back to my plan? If not, why not?"***

Question 2. How do these three main problems affect you and/or others?

Participants expanded their response to the previous survey question and gave insights and examples of how their NDIS experience impacts their quality of life based outcomes. Participants outlined a number of factors where they expressed problems and concerns. There were five main themes identified in their response:

a) The application process, accessing the scheme and navigating the website

Participant feedback:

- People need substantial computer skills to get through the on-line process, it is not intuitive. How much testing is done?
- Suffered massive anxiety and depression due to not being able to get what leg would have worked for me. Now just using a wheelchair, supplied by the NDIS, which I had to pay back and now have no funding for it. Its broken twice now and come out of my own pocket, \$500 for one wheel!
- The system is hard to understand. Having to do review to get funding as \$5,000.00 for 3 years for equipment that doesn't buy an electric wheelchair or other stuff I need.

b) Reports and requirements to access services

Participant feedback:

- The complexity of securing an available OT or other professionals who are willing to work with an NDIS client. Long lead times to secure said services.
- *"I want to be able to get assistive technology when I need it, not have to use rental equipment that is not set up for me for months because my OT has to provide 60-page reports. I need my prosthesis to be renewed at various times, but I have to wait months for permission to get things done and I can't walk while I'm waiting".*
- Timeframes required to get approvals and the number of loopholes are insane.
- Very slow to get the items I need.
- Plans and quotes can take forever, and this affects me because I can't walk without different assistive technology/aids. This in turn has a flow-on affect for my family that have to help me out.
- *"I have had serious injuries due to mobility aids breaking because of the delay of waiting for NDIS to approve new aids. The threshold is unrealistically low, so the approval takes longer. This gets more frustrating when my case is handled by different people".*
- Prolonged waiting time for trial equipment. Concerns that if my plan is not reviewed before the expiry, I may not be able to have my supports until the review is completed.
- Funding example: NDIS participant, OT and Social Support Worker inform NDIS staff that participant is independent (does not need support apart from transport) but will need vehicle modification, but most of the money in my Plan is allocated to support. Assistive Technology money is then not sufficient, and OTs are being paid to write up additional reports for more funding when there are still funds available.
- *"It affects me as I cannot do anything until I have seen someone. Which means if I need something, I need to have an OT assess if I actually need it. So whilst waiting I have to either*

purchase it myself out of my own pocket or in my current situation wait until the OT has assessed me. Because I am new to the NDIS, I fear once my 12 months is up and I have not been able to use the allotted funds that they will not be available once I have been assessed by the OT for the following year”.

c) The timeframe to access services and lack of support ranging from Local Area Coordinators to Support Coordinators

Participant feedback:

- It takes forever to cut through the red tape to get anything done.
- *“Nothing has happened in 15 months. Small things like crutches take 3 months and I am trapped in my house.”*
- Very slow to get the items needed.
- NDIS were aware my home wasn't suitable for a wheelchair it has so far taken nearly 2 years and my home is still not suitable for me. I as an amputee have fallen numerous times because of the ongoing delays for even the basic items like a ramp to get into my home.
- Timing for plans and quotes can take forever and this affects me because I can't walk without different aids and in turn has a flow on affect for my family and friends that have to help me out.
- *“Extremely stressful when dealing with anything that has to do with NDIS. The time it takes to resolve any issue with your plan causes anxiety. It can and does, take months”.*
- A request for bathroom renovations took over 12 months to get an approval. The continually need to complete new agreements every time there is a new plan, this just creates more unnecessary paperwork.
- My disability affects me and my family. Slow response puts more stress on my family.
- I have been waiting now for a bathroom for over a year.
- Frustrating. Waiting and wondering adds to challenges that I face.
- Difficult to get what is needed in a timely manner.
- Prolonged waiting time for trial equipment. Concerns that if my plan is not reviewed before the expiry, I may not be able to have my supports until the review is completed.
- Poor plans which do not provide support necessary to participate fully in society.
- *“Plans are not long enough for things to be put in place, they called my review 2 months early! Why? Because they can... my review was dreadful and I was asked if I still need home mods and my ramp! My mental health has suffered heaps, I thought they were supposed to support me, but they don't”.*
- My house is not suitable for my disability. I need family members together with me not push them away, enough funding for my disability and to not have to wait for a long to for stuff to arrive.

d) The fact that some Local Area Coordinators to Support Coordinators have no clear understanding of disability and/or the needs of people with disability

Participant feedback:

- Only my first LAC actually had any experience with amputees, how are they supposed to help if they have little knowledge of the disability?
- *"I need to consistently build a relationship with a new Local Area Coordinator all the time and as a result they have not got an understanding about what has been. It is exhausting to consistently having to build a relationship with different people. If the person completing my review doesn't have an understanding about my disability it is very difficult for them to help me complete or review my plan."*
- LACs are not prepared to listen to how you want to live and do things, so you end up with nothing. They do not understand that none of us are alike and what we need is different.
- LACs for amputees don't understand the individuality of the types of amputations. I have a very rare amputation and their decisions can affect my life.
- *"I have been through hell with the NDIS because the Planners, the reviewers, the rejecters, and the approvers have had zero to minor knowledge of my disability and are tasked with making decisions about it. How is this possible? I have a prosthetic leg, assigning me a Planner whose only "qualifications" were that they had done the course, have a relation (or know someone) who has a similar disability, or is in a wheelchair, does NOT equate to someone who is medically or professionally qualified to assess me properly or make decisions about a disability. They have to have experience in my disability."*
- Important to have a consistent case officer so they can be familiar with your case.
- The lack of knowledge about my disability is awful... they have no idea, when you explain; I know that they are not listening.
- When talking to staff half the time they have been given your case even when they have no understanding or experience in the sector

e) Providers inflating costs and over prescribing

Participant feedback:

- *"It looks like the admin people want the money for themselves and don't want to help the people who need things. Since the NDIS started, the price of everything disability related has gone through the roof".*
- You get a provider that is on the NDIS preferred provider list that charges \$800 for a review and sends a 10-line email. They know their responsibilities and Full Capacity Report but choose to ignore. I reported this 2 years ago and got nowhere. I needed to go to 3 separate departments, got no responses, had to get my NDIS Support Coordinator involved and still no resolution. I should have had the funds refunded because I needed to get yet another review from another OT. Reporting people trying to rip off the NDIS is difficult, long, and tedious. This OT should have been removed from the provider list and made to pay back his bogus \$800 invoice for 10 lines in an invoice and not even on letterhead!

- *“Outrageous cost difference of a service offered to a person with a disability as opposed to able bodied meant all my funding gets chewed up in a short time. Costing is discriminatory when e.g. cleaning costs no more for you, than it does for me. Equipment that costs the same as a small car is ridiculous and needs to be policed.”*
- The differences in price if you say you are on the NDIS compared to not is insane. It’s like being treated as a commodity just because you are disabled.
- *“I called out one provider for over charging me. They rectified the problem but only after I told them I may dob them in to the NDIS commission. I can no longer use the provider because I don’t feel safe using their service anymore. In the case of budget this can affect me and my family because they are put out because they have to help me with transportation and general house duties”.*
- Seemingly higher than market value fees being charged by service providers (and therefore the quotes provided by them for my NDIS plan).
- Less than 50% of NDIS funding benefits the end user.
- *“I have had limb makers tell me all the time that this new product is better, and I believed them for a while, all they were doing was propping their boss’s business at the expense of the NDIS. They kept telling me that the NDIS won’t knock back a quote, well I am sorry I can now prove them wrong thanks to one Limb Manufacturer over quoting.”*
- The moment you mention NDIS the price triples. Charges for services that are not performed. I was charged \$45 for a 15 second phone call to a provider.
- I have to hide that I am NDIS funded to get the “normal” price which can be difficult for managing the invoices with my plan manager.

Question 3. What do you think are possible solutions to those problems?

Participants provided their feedback on possible improvements to the scheme. Participants outlined a number of factors where they expressed solutions. There were four main themes identified in their response:

a) Reports and requirements to access services

Participant feedback:

- *“Cut the amount of paperwork for prescribing by OT’s. I have been quoted 12 hours to prescribe a commode. There is only one that is suitable for my situation as I have narrow doors and need a foldable unit to fit through them”.*
- A more streamlined process
- Train and employ OTs to make decisions instead of those with no concept or idea of what it’s like to live as an amputee. Trust that the OTs we have are working in the best interest of us.

b) The timeframe to access services and lack of support ranging from Local Area Coordinators to Support Coordinators

Participant feedback:

- For me, the LAC layer is costly impersonal bureaucracy with no benefit, just a process that I have to use. Even if I have to deal with a new person each time, they should at least be familiar with my NDIS history before the process starts.
- ***“Allocating one local area coordinator to a participant for as long as possible. Providing the Local Area Coordinator with professional development about the disability of the participants that are under their care”.***
- LACs should go out in the field and learn about disability and the people they are looking after. They need to read reports before meetings.
- Educated LACs that must respond promptly. Also they must advise the best route not the route that’s easiest for them
- ***“When an LAC goes on leave, I would appreciate being given another LAC’s email address to ask simple questions. Similarly, when my LAC ‘vanishes’ (maternity leave or left the job??) I would appreciate being sent a simple email stating who my new LAC is. In both cases, I have found it’s up to me to ring the main phone number & find out who to contact”.***
- Why have LACs? Monitor Support Coordinators - I was verbally abused several times by one woman... Specialists are the people who work with the client and have knowledge of their needs and the beneficial products and services that are available.
 - LACs should not push clients to have long plans.
 - More staff able to help on the phone. The Local Area Coordinator to keep in contact with participants.
 - Cut down the amount of people involved in working for the NDIS. Listen to the main requirements of the person with the disability when setting up the plan.

c) The fact that some Local Area Coordinators to Support Coordinators have no clear understanding of disability and/or the needs of people with disability

Participant feedback:

- People within the disability community are able to help others, but are not utilised enough. The Limbs 4 Life organisation is wonderful at getting peer supporters trained, I am sure other groups do also - but they need to be given credibility by the NDIS.
- Disabled people as assessors can give much input into the needs of those who ask for help
- Knowledge & communication - get more ‘disabled people’ as consultants for budget planning. E.g. An amputee has quite different needs to a wheelchair user or intellectually disabled person
- Employ people who have either personal experience and/or specific training and knowledge
- Budget problems can be fixed with experts on different disabilities being employed by the NDIA so there is an understanding of issues. More staff could improve wait times on plan reviews and quotes.
- ***“The people involved in planning need to have experience in disability. A Certificate in Business doesn't do much in the way of understanding what is needed or what is involved. The dollars are***

all most are interested in and that will always be the main focus - not the person or their disability”.

- Actual interaction with those 'with' the disabilities, rather than the 'I think' belief that many have; what they've been told; what they have read. i.e. speak with Amputees.
- Ensuring that people from an appropriate profession are correctly allocated to make decisions. Especially when a claim has been rejected and it is going to appeal. A panel of "experts" who have no background in someone's disability is never appropriate.
- Staff that listen, read. Have some basic understanding of disability. Simplify the information we see.
- Plans being designed by personnel with experience in a particular disability to balance what is essential and what is not.

“Actually listening to us and going with what we really need, not some guy on the phone saying, not everyone gets what they want. Some contact asking how we are, if the plan’s working etc”.

- Longer review times, more than 12 months. Training on disabilities, for not just young people but us oldies too. Get staff trained properly. Less paperwork ... Compassionate and caring staff are needed. We are more than just a NDIS number.
- Integrate amputees into the decision-making process.

d) Providers inflating costs and over prescribing

Participant feedback:

- Reporting fraudulent services providers should be easy, taken seriously and resolved quickly. The person making the report should be given updates and asked for their valuable input throughout the process, not that it’s privacy even when they (the participant) is making the complaint and trying to help the system by reporting providers clearly ripping off the system

“Look into price gauging on products & services. Funding from our taxes would go a lot further if it was used for the benefit of the client & not the provider”.

- Some providers need to be spot audited and maybe surprise visits like WorkSafe do. Keep them on their toes!
- Insist on primarily NDIS-funded services having accreditation, quality improvement strategies and KPIs in customer satisfaction and value for money. Active auditing and more fraud control
- Set a law that prevents companies from charging NDIS more than they would for any other client. This includes medical or health professionals as well as other companies who provide service for payment. Eg building companies. One example is podiatry. I was charged \$195 for a one-hour appointment through NDIS, when without NDIS, the charge was \$90. Another example - NDIS Review I received a \$4,000 grant that was to help me with physiotherapy costs. Half of this had to be refunded/credited back when I queried the cost of physiotherapy. I was charged at NDIS rates, despite not being associated with NDIS.
- Ensure that those that legitimately need NDIS and the services/products provided are protected by law. Ensure the consistency of services to participants without reducing the services or money needed. The current laws are needing to be changed immediately to prevent further overcharging.
- More scrutiny on quotes and feedback by client

- *‘Compare prices of things like stump socks, liners etc - before and after the NDIS and take action accordingly.’*

- Suppliers to be audited and to justify questionable charges.
- Making providers to be up front on costs they should be reviewed yearly. To make sure they know the rules and regulations.

- *“People/participants need to be allowed to approve or disapprove a quote for their needs. So, if I don't need a new leg, I should be able to see that quote and veto it. There are still going to be some providers I guess who will try to upsell the needs of some people, but then maybe the NDIS could send someone around now and then to audit participants and providers just to check. I had one limb manufacturer put in a quote for 38,000 dollars when all I needed was one replacement socket for my spare leg, fortunately it got knocked back”.*

Questions 4. What parts of the NDIS are working well for you?

- My current prosthetic Provider is well organised to deal with the approval and payment process. I changed providers as the previous one (Canberra Health) was taking 3 months or more to process invoices.
- I am well funded
- I do my own payments when I have received allowance from NDIS
- *“Knowing I have the support and can pay for the support to do the sports, travelling, life I want to live is amazing! What has been created is good, but we all need to work on the kinks. Having more disabled people able to be in the public's eye makes the world improve”.*
- My quality of life has improved markedly and I am able to participate in activities and live a more independent, confident and full life, without having to worry about the cost or impact on my family and friends.
- I like having control over my own choices of care and support. The new NDIS app makes self-management much easier.
- The services I have in place like physiotherapist, prosthetist and exercise physiologist.
- I am finally receiving physio & support in the home & a little in the community after having nothing for my first 26 years of disability. I raised my babies with zero help, one leg & no family support, looking back it is all a blur really which is sad
- It has allowed me to access some of the things I otherwise wouldn't be able to
- My electric wheelchair and support workers are great.
- *“Without the NDIS I would not have legs and would not be able to participate so fully in my life”.*
- It gives me independence.
- The flexibility in my self-managed plan Core. So far funding has been more than adequate for activities of daily living, consumables and supports.
- I have been satisfied with my plans (once they arrive and we all agree on the details!) I was able to get a purpose-built neutral buoyancy water leg that I never had before so that I can get into the water at the beach. This is a big improvement. I have also been able to replace my worn out prosthesis with one to fit to my needs and have been provided with the liners, cosmetic stockings,

etc. that I need. I have good access to my prosthetist. I have been funded under capacity building/health and wellbeing for exercise programs that have really helped me maintain strength and flexibility in my hips and keep me more mobile and pain free.

• ***“My Support Coordinator helps me. Having choices how I spend my NDIS plan. The NDIS has improved my quality of life and more access to services and equipment”.***

- The funding with physiotherapy as this is much needed.
- I have had great success with getting larger items like my wheelchair, my prosthetics, a bed that suits me.

Recommendations

It is without a doubt that the NDIS has made a positive impact on the lives of many Australia's with disability. Access to services previously unattainable or assistive technology which was out of people's financial reach is being acquired by those who need it most.

1. Partners in the community organisations funded to deliver Local Area Coordination (LAC) supports need to ensure that staff have access to training tools to upskill them about people living with disability. Some funding should be set aside to ensure that LAC's who deal directly with Participants have some knowledge of Participant needs.
2. Onerous reports are costly and leading to extended wait times. Establish a pricing structure based on cost ranges of items and set reporting requirements accordingly. For example, an item worth 5K should not need a 20-page report to justify the device.
3. Given the comments and concerns raised by Participants about Providers overcharging, Participants need to be provided with price lists of items and assistive technology products so that they can oversight public money being spent.
4. Ensure that all quotes from providers are itemised and detailed to help educate and build the capacity of Participants.
5. Ensure that Participants are made aware that they can exercise choice and control and change Providers as required. (It is evidenced from the responses that many Participants believe that they do not have that choice or control).
6. It should be made standard practise that all Participants are provided with quotes for Assistive Technology regardless of how their Plan is managed.
7. Cut the red tape with regards to the Quality and Safeguards Commission. Make the process more streamlined and user friendly to submit a complaint about a Provider.
8. Providers need to be aware that Participants should always be at the centre of the conversation. Consultations must involve the Participant. Every part of the NDIS market should have a clear understanding of the Convention on the Rights of People with Disability (CRPD) using a Participant centred approach.