



Blind Citizens Australia

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Submission to the NDIS Review

Lodged via: <https://www.ndisreview.gov.au/have-your-say>

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Contents



Blind Citizens Australia

1. Key Themes	3
2. Online Consultations	
Consultation 1: Access, Eligibility and Planning.....	3
Consultation 2: Service Providers, Support Workers, Assistive Technology	5
Consultation 3: Mainstream Services and Supports Outside the NDIS	9
Consultation 4: Exploring Key Themes from Consultations.....	10
3. In Person Consultations	
Perth	15
Melbourne.....	20
Adelaide.....	24
Hobart.....	28
Canberra.....	31
Sydney.....	33
Brisbane.....	35

1. Key Themes

- The planning and plan review process remains a key chokepoint. Across the consultations, members felt that the only way to receive adequate supports and services is to become an expert in 'NDIS Speak' and have experience navigating government systems.
- The concept of 'goal setting' is divisive among people who are blind or vision impaired, especially those with life long, or long term, blindness. While members acknowledged that short term, clearly defined goals can be useful (e.g. "I want to learn how to get to my local shops independently"), anchoring the entire plan and budget around goals can feel "patronising", "condescending" and "infantilising".
- Members agreed that training and ongoing professional development for support workers is crucial; but differences of opinion remain on who is responsible for funding this training.

2. Online Consultations

Consultation 1: Access, Eligibility and Planning

Applying and Getting A Plan

- There was a discussion about local area coordinators (LACs). Some people felt very strongly about this, using words like 'pathetic', 'disheartening', 'double handling' and 'huge bureaucracy'.
- One member described LACs as part of the 'NDIS lottery'. Some members thought that LACs were trying as best they could, but that they were simply unaware of the technology used by people who are blind or vision impaired.
- Others agreed that LACs were unaware of what their plan entailed and so could not offer any practical assistance. Others mentioned how frustrated they were to have had several LACs during their time on the NDIS.
- A point was made about how LACs were, "ironically for their name", sometimes based outside of the local area or even interstate. One member raised the possibility of LACs being returned

to their original function and that this is a point that Bruce Bonyhady, co-chair of the NDIS Review, has also made.

- Several members commented on the inaccessibility of documents for people who are blind or vision impaired. It often took weeks, and sometimes even years, for documents to arrive in an accessible format, and that it would take longer still if any amendments to the text were required. One member went so far as to say they were 'shocked' when their NDIS paperwork arrived in their preferred format.
- There was a brief discussion around the utility of support workers, with one member suggesting that their funds would be better spent in another area.
- There was also some discussion about the NDIS in general terms, with members using words like 'scary', 'stressful', 'arduous' and 'onerous' to describe their experience.

Defining Reasonable & Necessary

- There was considerable disappointment when it came to the term 'reasonable and necessary'. One member found that occupational therapists had actively worked against their best interests and that 'people need to listen more' when it came to assistive technology.
- Another member found that LACs and planners needed to be more interested in listening to participants than in ticking boxes. Other members felt that they had to 'prove' their disability and that people associated with the NDIS often did not understand the spectrum of blindness. The need for people with lived experience to be employed by the NDIA was apparent.

Achieving Long Term Outcomes

- Members expressed their concerns with arbitrary funding cuts and the inflexibility of plans. One member said they felt 'apprehension' and 'trepidation' whenever a change of personal circumstances required a change of plan. They felt there was a lack of transparency and accountability when it came to plan changes.
- Reference was made to the difficulties faced by people with secondary conditions and people from culturally and linguistically diverse backgrounds. There was a feeling that NDIS plans were unable to accommodate the fact that people's capacities can be built over time and that removing funding in these areas was counterproductive.

- Finally, a point made about how people on the NDIS may go out in public, but that if it was only ever with their support workers then the Scheme could not bridge the gap between people with disability and the broader community.

Consultation 2: Service Providers, Support Workers, Assistive Technology

The Support and Service Marketplace

- Members noted there are fewer skilled or qualified workers in regional areas, further distance requires higher travel costs which are not appropriately accommodated in NDIS plans – addressing this could be part of a solution for improving the marketplace.
- One member had questions around how the NDIS and disability sector more generally could increase the workforce for people with specialist skills such as orientation and mobility (O&M). Others shared their disappointment disappointed that O&M is not recognised by the NDIA, and that the reports written by O&Ms are largely dismissed by the Agency.
- Members also identified the thinness of markets for occupational therapists (OTs) in Melbourne – one member noted that people with physical disabilities requiring capacity assessments and home modifications absorb most of the OT workers, pushing people who are blind or vision impaired ‘to the side.’
- One member shared their experience of studying the experience of people who are blind and vision impaired on the NDIS for her PhD. They were disappointed by how many young, inexperienced and unqualified people are wanting to be high-paid support workers. As part of her capacity-building funding, this participant paid a freelance O&M specialist to train her support workers as to how she uses a white cane and navigates the world – this included blindfolding the workers to allow them gain firsthand experience of her life. Other members of the group were impressed with the creativity and innovative way this participant used her funding, but noted this sounded like a very involved process, and some people won’t even have the funding to be able to do that.
- Members discussed the fact that disability support work ‘is not valued’ given the proliferation of young and inexperienced support workers. Members expressed concern that unless there is a specific line item for training support workers, that funding could be syphoned away from a

participant's plan. Members agreed that the small base of blindness-specific providers produces negative outcomes for participants.

- One member expressed a belief that 'training should be recognised in your funding.' After requiring support workers to undertake several training shifts.
- The group agreed with a feeling that NDIA is unaware of the needs of people who are blind or vision impaired to have trained workers and believed there needs to be a way of improving outcomes for the support workers to encourage them to work with people who are blind or vision impaired. Members also discussed the need for a wider market for blindness specific support services.
- One member noted that in Queensland, Community Resource Incorporated offers a two-day course for support workers to gain the skills to work with anyone with disability.
- In discussing the disability workforce, some members expressed a preference or requirement for university- or TAFE-educated support workers, preferably over the age of 35; while others felt that this was unnecessary for their circumstances and valued an awareness of surroundings, safety, communication and a willingness to listen as the most important things when selecting a support worker
- The group agreed that employing more support workers with lived experience would improve the quality of services and reduce the unemployment rate for people with disability. The group also felt that 'transferrable skills are very important' – the NDIA could use an assessment tool when screening potential support workers to incorporate the experience of people like nurses.
- Members also commented that Support Coordinators should be aware of the fundamental needs of the client before support workers are employed and also need training to help them support participants.
- Members shared experiences of when the wrong types of support have been sent, including when a prospective support worker appeared at one participants front door with no prior arrangement, offering to take her out for coffee and the gym – things which she did not need at the time. Others shared their experience of support workers drinking alcohol while on shift, doing their own shopping when they have taken a participant to the shops, and even purchasing items and billing them to their participant's NDIS plan.

- Members also discussed the added challenges for people with acquired sight loss, who are dealing with so many changes before encountering the ‘debacle’ that is the NDIS.

Measuring Outcome and Performance

- One member asked: ‘Has the NDIS made people less independent?’ to which there were mixed feelings. Several members felt that the NDIS has made people less independent through funding decisions they have made. One member noted that the pursuit of independence ‘should not be an excuse to save money.’
- There was concern that providers are not doing enough to foster participants’ independence. Members talked about how they would like to see support workers used to help people make friends and involve themselves in the community, rather than just relying on the support worker themselves for social interaction. Would like there to be follow-up conversations about participant goals. Perhaps the aged care system’s gold star framework could be applied to the disability sector.
- Members expressed uncertainty around the performance of community engagement and other outcomes. Sometimes outcomes referred to service providers can be ‘tokenistic’.
- Other members noted that since having an NDIS plan, they have been asked for more personal information than ever before (i.e., who they are, where they live, what their condition is etc.). Members talked about providers ‘price gouging’, and their frustration with the exorbitant prices applied by allied health providers simply because they are on the NDIS.
- Members then discussed the idea of ‘goal setting’ with several agreeing with the question asked: “What if I don’t always want to achieve new goals?”. Many members expressed their view that sometimes, consolidating previous goals and just living life should be enough.
- One member noted “I’ve been blind for 50 years, that isn’t changing for better or worse; so why would my goals?”. Several members agreed with the comment that “people without disability don’t have to justify their goals to the government every couple of years”.
- In this discussion, members also acknowledged that there are some goals that are short-term and can be ticked off as a useful way of measuring progress; but others are ongoing (such as having a clean and tidy home) and won’t change much throughout the participants’ journey. Members discussed the need for real ‘capacity building’ for people to manage their own plan where this is a possibility.

Assistive Technology

- Members discussed the challenges of dog guides under the NDIS (dog guides are considered assistive technology). One challenge is when a dog retires or needs to be replaced and barriers the NDIA puts up around that. Several members agreed that the NDIA does not sufficiently account for participants whose dogs have to retire early: 'It should never be the handler's problem'. Others expressed their view that 'owning a dog guide is like owning a car' and so are disappointed to be contractually forbidden by a dog guide school from using certain support workers. Members were in agreement that while there are legitimate reasons for an annual checkup by the school, the rest of the time they should be left alone unless they require assistance.
- Several members shared that they have found having a dog guide puts pressure on other parts of their package such as support workers because the NDIA interprets it as a duplication of services. A common question members reported from Planners and LACs was "why do you need a support worker if you have a dog guide?" or the alternative "you don't need a dog guide, you've got enough support worker hours".
- Members felt that it was inappropriate for dog guides (and assistive animals in general) to be considered 'technology' and should be in a separate category.
- Members talked about the complication of technology purchases for devices such as phones and Smart TVs, which are considered 'mainstream' in the sense that most members of the general community use these; but the accessibility features of newer devices are crucial for people with disability. Members discussed refusals by the NDIA to fund purchases of modern smartphones (such as iPhones or Androids) on the basis that "everyone buys a phone"; however someone who is sighted has a wider range of options including purchasing a second hand or older model without accessibility features, than someone who is blind or vision impaired. Members agreed that there could be some work done by the NDIA to work out the 'average obsolescence rate' of devices that are mainstream, but provide important accessibility features, and build a method for a replacement to be claimed in a plan based on this model (for example every two or three years).
- Members noted that there is no consistency across the different state-based AT programs: 'Everyone is passing the buck and no one is taking responsibility for it.' Members agreed that there should be specific funding set aside for training on AT usage.

- Members discussed how difficult it is to compare AT products between providers. There was a discussion about the AT ‘expos’ that used to run that would allow people to compare items under the one roof; however there was an acknowledgement that providers no longer have the time to run AT expos because they are too busy providing NDIS services and there is little time or money for anything else.

Consultation 3: Mainstream Services and Supports Outside the NDIS

A Complete and Joined Up Ecosystem of Support

- One member mentioned the inconsistency of supports, such as the construction of disability parking spaces in public places but a lack of disability-friendly drop-off zones.
- There was a member who was totally blind but unable to join the NDIS because they were over 65 years of age. They had the support of their spouse and knew they would struggle without it.
- One member mentioned that the removal of block funding for individualised plans that had occurred with the advent of the NDIS had resulted in many Tier 2 supports withering away over the last decade.
- This member also mentioned that it would be nice to have the option of social get-togethers and classroom sessions with other people who are blind or vision impaired rather than one-on-one training for the use of assistive technology, but that they had been told that is simply not how the NDIS works.
- Another member noted how important it was for there to be an underlying network of disability support in Australia. ‘We need supports that are beyond the NDIS,’ they said.
- Another member added that the supports offered by the My Aged Care system were simply not as good as the ones offered by the NDIS.
- There was further discussion about how LACs should perform their intended role of connecting people with disability to their local community, rather than the planning role that has been foisted on them. Another member mentioned that they had had eight or nine different LACs during their time on the NDIS.
- Several members spoke of the balance between not making the NDIS the go-to for all disability issues even as mainstream services did not adequately support people with disability.

- The importance of the NDIS was reiterated, with two members describing the Scheme as a ‘godsend’.

Help Accessing Supports:

- One member mentioned that promptness and a basic understanding of blindness was essential for effective support.
- Another expressed their disappointment at staff turnover for LACs, planners and support workers, lamenting that they were ‘constantly changing’. This was echoed by a member who had had their plans reviewed by a different person each time since joining the NDIS.
- Another member posed a question: ‘To what extent are people with lived experience represented at all levels of the hierarchy of the NDIA?’
- A question was raised about the Disability Gateway – that the lack of updated information meant people with disability simply did not use it as a resource. Another member said that it would be nice if support coordinators would inform participants of any new supports and services as they are made available.
- Another member summed up one of the main structural problems with disability in Australia, saying that they had actively sought out Tier 2 services only to be told to stay within the confines of the NDIS.

Consultation 4: Exploring Key Themes from Consultations

Access, Eligibility & Planning

- A feeling there is too much rumour and not enough fact around constant changes to the Scheme
- Members discussed their feelings there should be less of a focus on new goals and more on ways to maintain existence. Members agreed how tiring it is to constantly have to show progress for people who have stable conditions. The average person in the community doesn't have to prove they are getting better in their life, they just allowed to live it.
- Members agreed that while there may be circumstances where the setting of goals is important as part of building an NDIS plan, the key issue is whether the goals are meaningful to the quality of life of the NDIS participants concerned. The more worrying issue is that NDIS

participants often feel pressured to set unmeaningful goals and worse have such imposed on them against their wishes.

- The group discussed the feeling that the views of carers and family are only very superficially consulted in the setting of goals and the building of a plan; but the agency regularly makes assumptions and expects 'informal supports' to be provided.
- The importance of ensuring NDIS participants from CALD communities have goals that are compatible with their respective cultural background was also raised.
- One member highlighted the damage of having to repeat story to different people at the NDIS. This is leading to inconsistencies. Noted that people with disability are not having direct access to the decision-making person who is actually making the decisions and that is harmful.
- Members feel there is limited choice and control. It gets back to proving that we're worthy of the support, lack of description when you look on the NDIS portal. Can't find supports for orientation and mobility instructors.
- Some members talked about ways they have been able to convince the Agency to let them have a longer (three year) plan, low maintenance, since circumstance not changing. Members agreed that far more support and suggestions come from within their own community than formal support in navigating the scheme by the Agency.
- Other members talked about their concern in contacting the Agency, despite their condition changing, as they have negative anticipations. Fundamentally it's about being believed. Participants should be able to communicate and have an open conversation without there being the fear of negative consequences.
- One member brought up the new record keeping system being implemented in coming months (PACE), in the hope that some of these concerns will be addressed. They also noted that there are regularly changes in staff at the LAC and Agency levels and that is not helping participants
- Members agreed on the importance of having access to plan before changes come into effect. People should have the right to change that plan if they wish.

Service Providers and Support Workers

- One member commented how difficult it is to find a list of one-on-one support workers and was disappointed when they discovered a support worker saying not very nice things behind their back
- Members noted that the rules around functional capacity assessments are flawed - for example Occupational therapists are not qualified to assess assistive technology - and involve significant time, energy and money on the part of the participant. There is also no confidence that the NDIA is actually reading the reports they ask for.
- One member commented that the issues around pricing is a problem of the NDIS's own making because they set the price guide. The NDIS has been setting themselves, and participants, up for failure. It's a fact that prices have gone up with the cost of living, but the NDIS has added to this through its price guide.
- Members discussed the roles of 'non-client facing work', and when was the best time for Support workers to do their note taking.
- One member shared an experience of a Plan Manager who told a cleaner providing supports that they could charge this participant more per hour and questioned who's side they are on. Members shared their experiences in providers assuming that they can just interchange support workers without any notification.
- The group agreed that a participant should be contacted by the service provider as soon as there is an issue with a support worker attending, and the provider should be willing to negotiate. For many participants, there is a total lack of communication from providers, and no options are given.
- One member noted that "If I cancel in less than seven days, I'm still billed but they can cancel service anytime".
- Members agreed that a feeling of price gauging under the NDIS is not only with cleaners, but across a range of supports, with one member sharing a similar experience in installing a handrail.

Mainstream Supports and Services Outside NDIS

- Members discussed the feeling that no matter how good the NDIS gets, until all elements of society and community are working together to improve accessibility, there are limits to the

benefits. One member shared their experience, of a local council that has consistently failed to acknowledge fixing a bus stop crossing. When this individual asked for the installation of an audio signal, the Council claimed it would cost too much because there are not enough pedestrians using that crossing, but if people can't be free to cross by themselves of course there aren't pedestrians crossing. This person was told by the council they should use a support worker to get me across the street, which they found degrading and made a lot of assumptions about the NDIS and how it works. Members agreed this is similar across Public Transport, where there are standards, but these are frequently not enforced.

- Another member agreed, noting that when studying at university they assume that you have a support worker and hence the premises has not left any space for any other options such as a taxi parking or any option for people wanting to be independent.
- Members agreed that more communication and disability awareness needs to happen. One member commented on the importance of people with lived experience working in the NDIS would be so helpful in making this happen, commenting “my disability influences the way I see the world”.

Open Discussion

- Members discussed the recent revelation by the NDIA of the data breach of HWL Ebsworth, with impacts for many NDIS Participants¹. Members shared their anger and frustration that there has not been better communication about this “It’s actually disgusting”, noting they first learned about it through communication from disability advocacy groups like People With Disability Australia (PWDA) as well as BCA. Members agreed that the legal firm that got hacked needs to come clean about exactly what and how much data was affected, and so does the government.
- One member with experience in teaching computer security, shared their concern that it is easy to build a fake profile with very little data and so the government needs to do something about this.
- The group discussed how in earlier high profile data breaches (such as those involving Optus and Medibank), they were required to set up all sorts of hotlines and helplines and counselling services to help people, and governments stepped in to help ensure normal administrative costs were waived for any documents that were compromised and needed to be replaced

¹ NDIA. [HWL Ebsworth data breach update](#). 2023.

(passports, drivers licence etc.). One member commented “I don't really see why the NDIA hasn't been expected to do that and the only thing I think it's just treating people with disability with less respect than you would treat the average citizen”.

- The group also agreed that the NDIA will probably also help people to avoid scams if they didn't actually send texts that encourage you to click links.
- In discussing possible solutions, members agreed that providing a specific hotline to help people understand what data has been breached and what is being done about it could be helpful.
- Members then discussed the way NDIS needs to address the information asymmetry between NDIS participants and NDIA, which has not been open in sharing its policies especially those related to decision making criteria.
- One member shared their experience of working with a Dog Guide - the increase in the veterinary bills is up by 23% between 2019 and 2023 however the increase in allowance from the NDIS to support the dog has gone up by \$58, so only 2% and that doesn't include the cost of food which continues to go up.
- Members agreed this applies to other areas such as the cost of transport which has increased significantly, but this hasn't been reflected in plans.
- Members also discussed how difficult it can be to get equipment replaced, including one member who had equipment that got damaged in floods, but was told he must wait for next plan.
- Members discussed the frustration with never receiving acknowledgements from the NDIS for documents sent through, and then resend because you are told by different people that they can't find the paperwork.

3. In Person Consultations

Perth

Access, Eligibility and Planning

- At the outset, one member expressed frustration at the multitude of NDIS Reviews: 'Why are we having this consultation?'
- People who are deafblind still often receive phone calls from the NDIA.
- People who have been blind their entire life have missed getting onto the NDIS before the 65-year cut off because of inaccessible documents.
- One member would like to receive an email/SMS letting them know of plan updates instead of having to trawl through the MyGov website.
- Several members noted that support coordinators 'all seem to be crap' and 'don't understand' and 'just take money off you'.
- From Blind Citizens WA's perspective, 'we don't necessarily need' support coordinators but they should still be available.
- Said one member: 'I'm not really sure what plan management does for you.'
- Another member added that plan managers often think they are NDIS planners and are under the misapprehension that they are the ones who determine what assistive technology a person receives.
- For one member, the process of applying for and getting the NDIS has been 'fantastic' and 'lifechanging' for the better. They stressed that their NDIS planner listened to their needs.
- Another member said their NDIS experience had also been 'fairly good' and that people working for the NDIA are often 'pretty helpful'.
- One member knows two people with albinism who were rejected from the NDIS on multiple occasions despite it being a List A condition. Speaking on their behalf, they asked: 'What more do I need to prove my disability?'

- Just yesterday, a member spoke to a person who is deafblind and needing to pick which disability they should classify as primary and secondary in order to apply for the NDIS. The person making decisions at the planning session 'doesn't get' what deafblindness is.
- One member who is deafblind spoke of the difficulties of having a phone that does not connect to their hearing aid.
- One member said they would like the 65-year NDIS age limit eliminated.
- Another member was dubious about this: 'If there's not an age cut off, everyone will end up on the NDIS.'
- A rhetorical question was raised by one member about how differentiations are made between disability and age-related decline in functionality.
- Said one member: 'My Aged Care packages are not a shadow of what is available on the NDIS.'
- A general feeling amongst the group that My Aged Care needs to be improved.
- Said another member: 'I don't need a support worker to go to an outing, but the transport to get there is valuable.'
- Another member had surfing included in their NDIS package and was very thankful as that hobby has always been an important part of their life.
- Some members said they would like the option to transfer funding from areas they were not using so much (such as gardening and cleaning) to ones they were using a lot (such as transport).
- Members who need to visit regional areas often struggle to find suitable transport due to the lack of buses, taxis and rideshares.
- One member, who is associated with Guide Dogs Australia, has found that NDIS participants often have their support worker hours cut because they have a dog guide.
- Plan reviews 'all come down to who you get' looking at the plan, said one member.
- Reviews make 'things uncertain' as 'they make take me backwards,' said another member.

- One member was confused whether they were having a check-in or a full plan review – they asked the NDIA official eight times and were told it was merely a check-in. Based on their answers, however, this member had \$5,000 cut from their plan.
- A member worried that some people run out of funding in their NDIS plan and are then deprived of essential services such as having support workers assist them with bathing.
- One member said his children had left home but he had not informed his reviewers of this development as he ‘didn’t want to rock the boat.’
- One member had their plan rolled over despite needing a new piece of assistive technology. They then received \$5,000 of capital funding, which necessitated a change to their plan just two months after the roll over.
- Two members who are on blind pensions said they were immediately signed up to the NDIS when they applied.

Service Providers, Support Workers, Assistive Technology

- Several members were concerned about how much ophthalmologists charge for their reports. One attendee said their ophthalmologist had only written a five-word report.
- According to one member, orientation and mobility specialists are ‘hugely expensive’ but their opinions are not as highly valued as those of physiotherapists, occupational therapists, or speech therapists.
- One member’s opinion on tertiary-educated support workers: ‘I don’t need a uni-qualified person to drive me somewhere.’
- Another member said support workers ‘need to be compatible with you’ as a participant.
- Most members were concerned about how much support workers can charge despite their skill level. According to one member, if a person who merely drives a participant to the shops can charge as much as a person trained to do highly technical work such as changing feeding tubes, ‘the NDIS is going to run out of money.’
- Most members felt that the NDIS makes people more independent and integrates them into the community. The general view was that people with disability would not be going out into the community without the aid of support workers.

- According to the member who uses a support worker to drive them to the beach and help them with surfing: 'I'm getting what everyone else takes for granted.'
- Said another member: 'Support workers are not the same as peers.'
- A member said they often avoid social events because they feel guilty that their support worker only has to guide them into the building and is then paid to sit outside in the car for the next couple of hours.
- The members generally viewed transport as more valuable than having a support worker.
- A member gave the example of a person from Geraldton who requires a support worker with them to make the 10-hour round trip to Perth for an hour-long medical appointment.
- Said one member: 'A support person needs to do what the participant employs them to do.'
- Another member had a negative experience with a support worker who refused to go into a restaurant with them.
- There was a general agreement that people with disability should have the power to change their support workers when they are not performing to standard.
- A support worker who listens to you is 'wonderful,' said one member.
- One member said they would like to be able to pay family members when they provide support.
- A member who is deafblind said they miss out when they do not have a communication partner to help them.

Mainstream Services and Supports Outside NDIS

- The NDIS needs to work more closely with public transport providers, education departments, health departments, Centrelink: 'The NDIS should not be a silo, but it is.'
- According to another member, state, territory and federal governments 'need to work together' because 'the right hand doesn't know what the left hand is doing.'
- '[There is] no funding for advocacy unless you're one of the big six [disability providers] in WA,' said one member. All other disability organisations end up providing non-paid advocacy to help people.
- BCWA has no resources to help people with Centrelink issues.

- BCWA needs more BCA staff on the ground in WA to provide advocacy.
- When asked about the Disability Gateway, one member responded: ‘What is it?’ There was a general lack of familiarity with the Gateway, and those who have tried it have not returned to it.
- According to another member, the general push to move government services online is excluding people who lack computer access/literacy: ‘You cannot get an 80-year-old person who does not feel comfortable using technology using technology.’
- Call centres are terrible ‘for everyone,’ added another member, not just people who are blind or vision impaired.
- Another member noted that the ‘I am not a robot’ security safeguards on websites are inaccessible for people who cannot see the images.
- According to one member, there should be an NDIA technical advisory committee that allows experts with lived experience of blindness or vision impairment the opportunity to provide feedback on documents and assistive technology requests.
- A person with lived experience of being in a wheelchair does not necessarily understand the needs of a person who is blind or vision impaired, noted another member.
- One member has an LAC who is on the NDIS themselves – this member has found the service offered by this person with lived experience to be excellent.

Other Comments

- One member said they know a person who is blind on the NDIS who was given a stand-up chair for three times the standard retail price. The ability to get a secondary quote would be appreciated.
- ‘I never tell service providers I’m with the NDIS’ to prevent overcharging, said one member.
- A member who works for the Department of Veterans’ Affairs tried looking for a job with the NDIA but chose not to because the application process was inaccessible.
- Another member said they knew three people who had taken the NDIA to the Australian Human Rights Commission over the inaccessibility of their internal systems.
- It should be possible to move funds from capacity-building or capital to other areas.

- Frustration with the inconsistencies of the NDIA at ground level – having senior bureaucrats fly to Canberra and Geelong does not help this.
- Regarding self-employment – many people who are blind or vision impaired are self-employed – the information around payment of GST is unclear: ‘Don’t complicate it; make it a yes or a no.’
- Price guides can be unclear, with support work falling under four different categories.
- People often do not attend NDIS information sessions unless they are directly impacted. Advocacy services need to be better funded to help people when needs arise.
- Some members express frustration with the WA Office of Disability.
- An increase in transport allowance at all levels would be greatly appreciated.
- Barriers in society still exist that make it difficult to live as a person with disability.
- ‘I don’t even know what LACs do,’ said one member.
- Another member questioned whether NDIS participants are being convinced to sign up for certain services they do not really need.
- ‘The NDIS should help people live their best life and the greatest barrier to this is the NDIS itself,’ said one member, adding that the NDIA is ‘disabling’ people with disability.
- One member said they would like more support with self-management.
- Another member would like greater flexibility in funding without the need for a plan review.
- More support for people living in remote and regional areas would be appreciated.
- More phone support for people to get the information they need without needing to go online would also be appreciated.
- Using the NDIS app ‘is quite painful,’ concluded one member.

Melbourne

Access, Eligibility and Planning

- The discussion started with a question by a member around comments by the Agency/Government that NDIS supports can diminish over time, noting that for some groups

that is not going to be possible. Members discussed that there are some supports that could possibly be reduced over time; but only if the right steps are put in place. For example there are examples of support workers doing really basic tasks for participants because it is considered 'easier'; but if a support worker (supported by an orientation and mobility specialist) works with the participant to build their skills in doing that task, the need for support work hours may reduce over time. However, this should not be considered the default.

- Members agreed the NDIA should make it clear what types of support could reduce, and how that might be achieved; without making people worry that all supports might be at risk.
- Members shared their frustrations with the time and money that is spent getting reports written to provide to the NDIA. This is especially the case where a report is not accepted by the NDIA and the participant needs to arrange for it to be done again. Members agreed there should be a way for the costs involved to be reclaimed.
- Members discussed the application of the terms 'reasonable and necessary' by people who don't have a strong understanding of the disability types they are making decisions about. Members agreed that there is a need for some calibration across the Scheme to ensure consistency in plans and supports; but still allowing for flexibility and individualized approaches.
- One member expressed that it would be interesting to see the data the NDIA has on what people consider 'reasonable and necessary', and how that compares with what the NDIA agrees to fund.
- Members strongly agreed that one way to have better, more appropriate planning decisions being made is to boost the numbers of Lived Experience of Disability at all levels of the Agency.
- This led to a discussion about the culture of the NDIA, and the interaction between the Agency and participants. Members shared their feelings of a 'power imbalance', where participants don't know what messages staff are receiving internally, and that it felt like some people in the Agency see their role as saying 'no'. There is also a feeling that there is no accountability for the timeframes they provide participants.
- Other members noted that there was no way to contact the Agency out of business hours, which makes it very difficult for people who are in employment, especially with the expectation

of long delays. Members commented this was made worse by the way seemingly everything goes through the main switchboard and how difficult it is to get a consistent contact point in the Agency.

- Members discussed that there are reports in the media of high turnover within the Agency call centre, which comes as no surprise given how little discretion the responsibility they are given as the first point of contact when things go wrong, but with little power to help. It is possible that costs of the Agency would decrease if they valued their staff better, and encouraged a culture of helping and supporting participants.
- Members agreed that one solution to the concerns around planning would be that any time a major decision is taken (a delegate altering a plan, supports being deemed unnecessary etc), a name and direct point of contact be given to discuss the situation further.

A joined up Ecosystem:

- Members shared their frustrations with the ‘buck-passing’ that has become prevalent around the NDIS. In the community and around mainstream services, there is an expectation that any and all supports will be ‘looked after’ by the NDIS; but in reality, the NDIS has very firm rules and often claims they cannot provide a service or support “because it is provided by other mainstream services”.
- Members discussed how all the governments (state and federal) seemed to say the right things when it comes to disability, but no one is prepared to take the responsibility and everyone wants to reduce their financial obligations. The recent announcement by the Victorian Government to reduce the number of Visiting Teachers in classrooms (reported on in The Age, and opposed by BCA and other Disability Representative and Advocacy Organisations²) was discussed in this context.
- Members also discussed their concerns that people with disability who happened to be over the age of 65 years when the NDIS rolled out receive even lower levels of support and services, and the anxiety that comes with thinking about My Aged Care.

² Reported in [Vulnerable children to lose classroom support in big cut to specialised teachers](#). Response by disability organisations including BCA available here: <https://www.acd.org.au/wp-content/uploads/2023/08/Open-letter-to-the-Minister-for-Education-15082023.pdf>

- In this discussion members shared experiences (their own and those of people in the community) of feeling pressured to move over to My Aged Care when they turned 65, to reduce the 'burden' on the NDIS.
- One member mentioned a recent submission by Disability Advocacy Network Australia (DANA) with a recommendation for a Disability Inclusion Agency - a central body that could liaise with other government agencies and departments to ensure they keep a focus on disability³. The group agreed this was an excellent idea.

Support workers and Service Providers:

- Members talked about the importance of having a professional and high quality workforce, perhaps with a minimum of Certificate 4 qualifications for support work, but noted this would be difficult to achieve with the current workforce crisis.
- Members acknowledged that it is not surprising that service providers don't want to spend money on training when there is high turnover, and no way to re-claim these costs. For many it won't be financially viable, which has a flow on impact to participants.
- However there are also concerns that d service providers still do fundraising, and get money from the community; but still charge high prices.
- Members discussed the need for a better understanding by everyone on what their roles were. Support Coordinators are often reluctant to put any effort into ensuring the correct support workers are engaged, and the support workers often do not understand how they can support a person who is blind or vision impaired other than "doing things for us"
- Members talked about their frustrations with price gauging under the Scheme. One mentioned that when it comes to getting supports and services it's similar to trying to get things for a wedding: "As soon as you reveal what it's for the price jumps dramatically!"

Other comments

- Members felt that the NDIS was intended as a way for people with disability to "live life the way you want – to give us the supports we need, but then to get out of the way"; however this was not the experience. The group agreed that it is only when you have a lot of education and knowledge about government services, a good advocate, or both, that you can get good

³ DANA. NDIS Review: Mainstream and Tier 2 "Rethinking 'Tier 2' of the NDIS: Investing in real inclusion of people with disability. Recovered at <https://www.dana.org.au/wp-content/uploads/2023/08/DANA-Discussion-Paper-NDIS-Review-MainstreamTier2.docx>

supports under the NDIS – and that this is unfair. Participants shouldn't be expected to become experts in navigating government services or in negotiating prices with big service provider organisations

- Members were in agreement that one of the key things that could help improve the Scheme was a 'no wrong door' helpline; where people could be connected through warm handovers to the appropriate part of the Agency, or even other departments. There was a discussion about the frequently heard excuse of 'privacy', but the group agreed that governments collect so much data about us anyway, it should at least be shared in a way that is useful.
- This led to another conversation about the recent data-breach impacting HWL Ebsworth. Members agreed with the solution proposed in the earlier consultation that in circumstances like this, at the very least, the NDIA should set up a dedicated hot line with operators who would be able to provide information and support for people affected by the breach, including linking in with other agencies as necessary (banks, passport office etc).

Adelaide

Access, Eligibility and Planning

- 'LACs have no concept of blind or vision impaired services,' said one member.
- Some members have found the high turnover of LACs means emails are not answered.
- Two members have had six LACs in the space of four years.
- 'You don't expect the same LAC for each year's review,' said one of them.
- Members said that an LAC with lived experience makes a huge difference.
- One member said they knew of people spending up to \$4,000 on occupational therapists to get an NDIS plan.
- Reports written by occupational therapists 'clearly aren't read' by planners or reviewers, said one member.
- A member, for whom English is their second language, is new to the NDIS; they did not receive support coordination as their LAC did not recommend it and they now feel that they missed out: 'I could not use my plan for six months.'
- 'Support coordination should be obligatory,' added another member.

- LAC 'is an appropriate' acronym, said a member, as they are 'often lacking' in knowledge and skills.
- The NDIS 'shouldn't depend on luck,' said another member.
- The group has found that communication by email is the most accessible.
- A member who works for See Differently said most people do not ask for documents in braille anymore.
- When the topic of 'reasonable and necessary' was raised, a member quipped: 'Do we have two hours?'
- One member said an NDIA official had once recommended they use a miner's light on their forehead to enhance their vision.
- 'Judgements are made subjectively by people with no lived experience,' said one member.
- Regarding the NDIA, another member said: 'They're insurers, aren't they, and we know about insurers. They try to disprove a need.'
- iPads are highly useful tools for people who are blind or vision impaired, but they are often rejected by NDIA planners, said one member: 'As soon as you mention mainstream technology, it's discontinued.'
- 'If they spent less time and money on making us get assessments' there would be less money wasted on the NDIS, said one member.
- 'There is no knowledge passed between' the LAC and different workers at the NDIA, said another member.
- One planning determinations, one member asked: 'Why is it so subjective?'
- 'You hope they just roll it [your plan] over,' added another member.
- A member described waiting for plan changes as 'a form of begging worse than standing on the street in the 1800s.'
- 'I feel very nervous' about having a plan change, said another member. 'You [the NDIA] don't understand my needs. Everything is an argument.'
- 'I'd like to be better informed about my rights and the appeals process,' said one member.

- 'I've had more reports written on me than the Pentagon,' added another member.
- 'I'd like more information sessions like tonight about what my rights are,' added another member.
- According to a member who runs a NDIS business, people who are vision impaired do not receive support coordination as a rule, so when they have a review, they are on their own.
- One member had a review in December and said 'it was an easy one' despite their support coordinator having resigned and the member not being informed of this beforehand.

Service Providers, Support Workers, Assistive Technology

- One member said they had a support worker who just played on their phone, another support worker who drove erratically, and another who destroyed their personal vacuum cleaner.
- 'Is a service agreement compulsory?' asked another member.
- A member said they had witnessed support workers breaching other participant's privacy by taking calls and speaking via Bluetooth in the car whilst travelling.
- 'There is a thin market' for blindness-aware support workers in South Australia, said one member. As such, participants get general support workers who come in and simply do not understand how to help people who are blind or vision impaired.
- 'There's no encouragement' to improve blindness-awareness amongst support workers, said another member.
- One member booked a support worker for six hours to attend a medical consultation. The consultation only went for four hours but they were still charged for six.
- 'A support worker may only watch one half-hour video' on blindness before going out to work with people who are blind or vision impaired, noted one member.
- 'Where do you go to find out where you stand' regarding your service agreement, asked another member.
- According to one member, the NDIS is a bonus for people who have been blind or vision impaired their entire life. However, younger people with disability who have known nothing but the NDIS are less resilient and, therefore, imperilled when their funding is cut.

- The blindness sector was very resilient before the NDIS, but to get onto the Scheme you ‘have to demean yourself,’ said one member.
- According to an older member who has been vision impaired their entire life: ‘We don’t necessarily want hand-holding support; we want people to be trained for capacity-building.’
- One member said they struggled to use their core funding ‘because how many times do you need your lawn cut?’
- If a person has a dog guide, said another member, they are often unable to receive funding for other items such as white canes: ‘They’re [the NDIA] looking for reasons to exclude.’
- Said one member: ‘When I’m with a support worker, I want them to be my eyes. That takes a lot of initiative’ on the part of the support worker. This member said they want their support worker to describe if their personal appearance and house are clean and tidy.
- Another member responded that some people are ‘super sensitive’ to any comments about clothing or appearance, and so the first member could not expect such feedback.
- Another member added that support workers lacked initiative: ‘You have to tell support workers everything’ you want.
- ‘There’s no quality control’ with support workers on Mable, said another member.

Mainstream Services and Supports Outside NDIS

- Local councils have cut back gardening services for NDIS participants, members noted.
- Some members feared the South Australian government is going to cut the disability taxi scheme.
- ‘There are people whose lives are debilitated’ by mental and physical disabilities and yet they are not receiving Tier 2 support, said one member.
- A member who works at See Differently said the typical journey for a person with an eye disease is five to seven years before they become legally blind. Managing that person’s journey relies on Tier 2 supports.
- One member said they were confused that their request for an exercise bike had been rejected even as they were encouraged to take a support worker with them to the gym.
- ‘We’re bureaucratic beggars always trying to jump through hoops,’ said one member.

Other Comments

- Members disliked that the NDIA does not accept Centrelink's verdict on a person who is blind; the NDIA requires their own report from an ophthalmologist.
- A member said that people with retinitis pigmentosa (RP) can have their degenerative journey mapped out and so should be able to receive a 10-year NDIS plan.
- One member said they had a fear of one day being audited.
- 'Why are there so many people with their fingers in the pie?' asked one member.
- 'They're paying too many third or fourth parties,' added another member.
- 'I've learnt more from being here in two hours than I have on the NDIS in two years,' said one member.
- Members had a brief discussion about whether driverless cars could one day be covered by the NDIS.

Hobart

Access, Eligibility and Planning

- Members discussed that getting a plan in an appropriately accessible format was often a challenge, and even when it was provided in a form that could be used with screenreaders, because of the 'dry and repetitive nature' of the way plans are written, it can be hard to follow and pick up on mistakes. One member who has had a recent deterioration of their vision after being sighted for most of their life described how they have never been an 'auditory learner', preferring to read things than listen to them, and how difficult it was to process the specific details of their plan.
- Members discussed that although the NDIS, and Australia's obligations under the UN Convention on the Rights of Persons with Disability (CRPD), are predicated on the 'social model of disability', the way the Scheme has been implemented relies heavily on a 'medical model' approach where participants have to prove their disability and present themselves 'on their worst day'.
- Members feel like they are not being believed about their needs, and are often asked very intrusive (and seemingly unrelated) questions.

- Members shared their frustrations that only an individual will know what supports are 'necessary' for them to live their lives in a meaningful way, yet it is Agency staff that decides what is 'reasonable'.
- Members discussed the focus on 'goals' during the planning process. One member noted that there seem to be expectations on people with disability to set and achieve goals throughout their lives, that is not true of people without disability. Members used the words 'condescending' and 'infantilising'.
- One member noted "you have to be so careful with the wording of your goals, because that's what determines what supports you might or might not get".
- The group agreed that the way the NDIS has been set up, it is theoretically possible to get some really helpful and lifechanging supports; but only if you were a strong advocate, and familiar navigating complex government systems and bureaucracies: "People shouldn't have to spend months of their lives understanding how to navigate the system, just to get the supports they are entitled to".
- The group discussed that LACs in their area have said they are said no longer collecting reports, and it is up to individual to do. Members expressed frustration that the LACs could not even advise which reports would be needed.
- Members discussed how it seemed the NDIS was either unknowing or uncaring about how the importance of the planning meeting can leave participants feeling stressed and anxious. This is compounded by their lack of flexibility in the scheduling of planning meetings.
- One member shared how they received a phone call from the Agency unexpectedly, which turned out to be from a planner, and how unprepared and stressed they felt from that conversation.
- Members shared their concern that there seems to be very little in the way of skills and qualification requirements for LACs or planners, and agreed that it should be a requirement for people in these roles to have a disability, or at least have direct lived experience.

The support and service marketplace

- Members discussed that Tasmania only has one blindness specific provider, which severely limits any real exercise of 'choice and control'. This is especially true for anyone who has an

issue with a dog guide instructor, as there are very limited options. One member noted that “market decisions can have a big impact on a low incidence population like blindness”.

- Member shared their frustrations with the way service agreements lock in a ‘false economy’, and how they make it very difficult to change supports and providers when things aren’t working. This led to a discussion that since the NDIS, previous ‘drop in’ services have disappeared and people are instead locked into longer sessions (1 – 3 hours).
- Members discussed the difficulties in finding reliable support workers with a good knowledge of blindness and vision impairment. Members agreed that support workers needed better skills, knowledge, and training; but had different views on whether individuals should be able to claim for the training of workers under their plan, or whether there should be some return to a type of ‘block funding’ for disability service providers on the proviso that money is used for ongoing training and development of their workforce.

Other Comments

- The ‘marketplace’ is more limited at many levels for people living in Tasmania. Members shared their experiences of being required to fly to Melbourne to get reports and assessments completed.
- The planners and LACs seem to have a very limited understanding of blindness, and of disability in general. This has led to limitations in what has been approved in terms of Assistive Technology, and things that are approved are often of a lesser quality than what has been recommended by an expert.
- Members commented that budgets provided for care of a dog guide has not kept up with inflation: “every week it effectively costs me more to just feed my dog guide, and I don’t get that money back”.
- Members expressed frustration with how complicated the Scheme is in general: “it shouldn’t be so cumbersome if you run out of a particular item of support, people just want the scheme to allow them a positive experience”
- Members felt that the NDIA should be leading the way and “beyond reproach” when it comes to disability awareness.

Canberra

Access, Eligibility and Planning

- Members agreed that many planners seem to have no knowledge of blindness and vision impairment, or to understand what supports are needed. This lack of knowledge also applies to Support Coordinators, leading to challenges finding appropriate services and supports.
- An ongoing frustration was how hard it is to access the right information and material: “even when you can find the right resource, many documents and parts of the website are inaccessible”
- Members felt there was “too many people and roles between the participant and the decision makers”, expressing frustration that this lead to buck-passing – especially between the LACs and the Agency.
- Members expressed their concerns about going for plan reviews, and the fear that if any funding had been left unused that it would be considered unnecessary and removed from the next plan.

Support and Service Marketplace

- Members discussed the way that even in metropolitan city like Canberra, thin markets have occurred in terms of services that have solid knowledge and skills about working with people who are blind or vision impaired. This is also true for finding appropriate Plan Managers.
- Members shared their frustrations with the difficulties in procuring Assistive Technology. It was noted that the seemingly endless number of assessments and reports that are required can sometimes cost more than the actual technology being claimed.
- Members expressed their frustration that the budgets provided for the maintenance and repair of Assistive Technology is very small and often leaves people out of pocket.
- Members also agreed that the entire process around Assistive Technology and ‘Consumables’ in general was unclear and confusing, in relation to what could and could not be claimed as well as what items were allowed to be purchased under the ‘cap’ without needing to provide evidence.

- Members expressed frustration with the number of services and supports that seem to be using the NDIS as an excuse for price gauging: “as soon as you mention it’s for the NDIS, the prices go up’.

A complete and joined up ecosystem of support

- A member shared their experience of having something listed on a goal (attending aerobics classes), but not knowing what the NDIS will fund: “Would they just pay support workers to take me, or would they require I to use Transport Funding? Could the class itself be funded as part of community engagement and capacity building, or is it seen as ‘mainstream’? Where do I even find out this information?”
- Members expressed exasperation around the complexity of knowing which level of government, and then which government agency, is responsible for what supports and services. One member noted that no matter what improves with the NDIS, if the other systems aren’t supportive. Another noted: “this is the same old argument about Federal vs State Governments, but people with disability are in the middle and missing out”.
- Members agreed that the Australian Disability Strategy needs significant and long-term funding to meet its goals.

Safeguarding Participants

- Members shared their concerns that for people with some knowledge and experience of dealing with government services, or experience self-advocating, the Scheme can deliver real positive outcomes; however those with limited capacity to do this, who are likely to be those most in need of supports, are left to fend for themselves.
- This led to a discussion about the potential conflict of interest present for people who are ‘Agency Managed’, as the same Agency responsible for decisions around funding and budgets is then responsible for the implementation of the plan.
- Members expressed their frustration with the long queues every time you try to contact the NDIA, and the fact that no one is able to give any timelines of when decisions will be made or communicated. Members agreed that the frontline staff of the Agency either need to be given more authority and discretion to provide information, answer questions, and resolve issues; or an easier process for escalation needs to be established.

Sydney

Access, Eligibility and Planning

- Members discussed feeling like there was a lack of ‘natural justice’ in the administrative processes of the NDIS, especially in relation to the approval of plans, and the supports in them. Members shared their frustration that “it’s almost impossible to go back to the NDIS if you forgot to say something in the meeting, or weren’t able to articulate your goals just right at the time”.
- This ‘power imbalance’ is also demonstrated in the way there is very little in the way of negotiation offered on when plan review meetings are set: “it’s take it or leave it, and you can’t leave it or they might cut your supports”.
- Members felt it would be useful to have some form of advocacy or case management for navigating what supports are available across different systems, as well as in preparation for planning meetings and plan reviews. It was acknowledged that this is supposed to be part of the role of a support coordinator, but many support coordinators do not have an appropriate level of knowledge or experience with blindness and vision impairment.
- Members also shared their frustration with the level of turnover in Support Coordinators, and how unsettling it can be when “the person who is supposed to help navigate the Scheme and implement your plan, leaves and is replaced and no one tells you”.
- Members expressed frustration with the ‘siloes’ nature of the planning process, and the weighting the NDIS gives to a participants primary disability. One member who is deafblind shared their experience of needing to fill out two questionnaires – one for blindness and one for deafness – and the lack of knowledge by the planner about how this might impact the participants unique needs.
- This focus by the NDIS on a participants primary disability also risks minimising the attention (and supports) given to disabilities that are acquired throughout a person's life.
- Members shared frustration in general with the lack of knowledge and understanding about the full spectrum of blindness and vision impairment, or “just enough to do some damage” when a planner or delegate feels they have some knowledge and therefore knows better than that participant.

- Members expressed their concern with plan review meetings coming up. One member shared their worry that because of the impacts of the pandemic and lockdowns, their community engagement budget has not been heavily used and they may lose this money in the next plan because the Agency will deem it unnecessary.
- Several members shared their view that “capacity building is a ridiculous notion for many people with long term blindness”, noting that people who have been blind their whole life have already developed tips and tricks for every day life, but there are just some things they need support with as a result of their disability.

Support and Service Marketplace

- Members discussed the issue of training for workers. All agreed there was a lack of knowledge and skills about blindness and vision impairment, as well as just disability awareness in general, amongst the workforce.
- Some members shared their views that if participants were given the right funding, they could skill up their own workers; but others felt that should not be the role of the participants and felt that responsibility should be on the providers to train up their staff, or on the workforce itself.
- Members also debated the merits of services such as Mable and HireUp. While members appreciated the level of choice these service provide, they acknowledged there was even less regulation on the knowledge, skills and experience of these workers.
- Members complained that service providers seem to just assign workers based on the needs of the company, without any consideration of the participants actual requirements. This has led to support workers who are unfamiliar with the local area or how to support someone who is blind or vision impaired.
- Members felt that service providers receive far too much sensitive and personal information about participants. They agreed that participants should be in charge of what gets sent to who.
- Members shared their frustration that many service providers are moving to cloud based databases, featuring ‘portals’ for staff and participants – but many of these are inaccessible for people who are blind or vision impaired.

Other Comments

- One member shared their feelings of stress and anxiety trying to get accepted into the scheme “racing the clock” before turning 65 because “I don’t want to be forced over into My Aged Care”.
- Members agreed that being forced to share their story and their history over and over again is not only traumatic and depersonalising, it also a huge waste of time and money.
- Members felt that the NDIA should be allowed some discretion to fund things that may not be ‘in scope’ under for the Scheme, if that support or service helps fulfill social and community participation.

Brisbane

Access, Eligibility and Planning

- Members discussed the frustrations of the lack of understanding of accessibility of documents and information from the NDIS, including inaccessible plans (eg. password protected PDFs), and braille not provided in a timely manner (if at all).
- Members discussed the number of people and positions involved in the planning process and questioned “is this an efficient way of doing things?”; also noting that with so many people involved, everything needs to be lined up to get results – and it can be luck of the draw as to getting the required outcomes depending on “do I have a good LAC, a planner who listens, a delegate who understands my disability, a support coordinator who is willing and able to find the right supports?”
- This was felt to be especially true for Local Area Coordinators (LACs). Members noted they were originally set up to connect with community supports in local areas, but they’ve ended up just being an extension of the planning process. There are then inconsistencies, and a sense of luck of the draw as to whether the LAC listens and collaborates, and one member shared their experience of a plan changing on review without being told.
- However, one member had an example of an LAC with great understanding of their needs, who had good knowledge and awareness of blindness and vision impairment (even confirming whether the participant would require the plan in grade 1 or 2 braille), and were communicative at all steps. Ultimately this resulted in a plan the participant was very happy with. Members

agreed this is what the process should be, but often isn't. Several cases of participants having not heard from their LAC for several years.

- Members shared frustrations that participants (and potential participants) need to pay to get reports and medical assessments which are costly and not reimbursable, only for these reports to be lost, or not read, or not understood by planners and other decision-makers.
- Members discussed the need for transparency in decisions made. They agreed there is no ability to talk to decision maker, or to find out more information or provide any justification before having to go to review. Members described needing to “know the right language of the NDIS” in order to get the right supports
- One member shared their hope that the rollout of the new computer system that has been trialled in Tasmania (PACE) will help with some of these issues; however previous experience with the NDIA has left everyone feeling unhelpful.
- Members discussed the idea of a dedicated advocate or case manager to support participants navigate the NDIS and other services: “Do we need an individual person within/alongside the NDIS to connect with and work with on an ongoing basis?”
- Members discussed the importance of training for all NDIS staff to give an understanding of the full diversity of disability.
- Members discussed the culture of the NDIA, including a feeling there is too much bureaucracy in the way the Scheme operates, but simultaneously there are not enough staff and the Agency and its partners are overworked and can't meet deadlines. Members felt the organisational structure is not clearly defined or publicly available.
- Members felt there was inconsistencies in the transfer from the previous state government block funded schemes over to the NDIS. There seems to be a higher burden of evidence of disability and more medical proof needed under the NDIS than there was under previous systems.
- A member shared their concern that health insurance companies have started moving into the Plan Management marketplace – as these are public companies, their number one focus and responsibility is to their shareholders, not participants; and there is likely to be a lack of understanding of, and a reluctance to sign off on, NDIS supports. Other members agreed that For Profit companies should not be allowed in this space.

Support and Service Marketplace

- Members discussed issues of training for support workers. There was some debate and disagreement around the room as to whether the best option would be allow training to be billed as part of a participants budget, or whether Service Providers should receive funding from government, or whether support workers themselves should be responsible.
- Members agreed that governments (state and federal) had a role to play in more strongly regulating the sector to ensure more professionalism, but that this will require greater valuing of disability work.
- Members noted the discrepancy between what is billed for under the price guide (roughly \$65), compared with what an individual worker receives (usually around \$20/hour); unless the worker operates as a sole trader.

Measuring Outcomes and Performance

- Members had a lengthy discussion about the role of goals in plans, and whether they are relevant for people who are blind or vision impaired. Some members found the process condescending, and found it difficult to articulate goals that aren't either too specific to be rejected by the agency, or so broad as to be seemingly meaningless.
- Others noted that in their experience, keeping goals broad and generic (e.g. 'To improve enjoyment and life both at home and in the community') was important in order to be flexible enough for a 2-3 year plan.
- One member noted that for all the importance given to goals, the NDIA often still questions things. This member shared their experience of trying to get a dog guide when they first entered the scheme, even listing it as their number one goal. However, the NDIA questioned and blocked this because this individual was on record returning a previous dog guide – despite this occurring over 40 year prior and being the dog guide of a family member that had died.
- Some members noted that the goals are a way of working towards independence or 'building capacity', but questioned how that is/should be measured. Members discussed what 'good goal setting' looked like and agreed it should consider current capacity vs future capacity. An example that was given was wanting to learn to cook more confidently, and the services and

supports (e.g. O&M services, dog guide, support workers, training in particular areas etc.) that would be required.

- Members noted a good goal setting process takes away a standardised checklist, and puts the focus on the individual's quality of life at different life stages, and their (often non linear) journey through it. Members agreed that if goals are to stay part of the NDIS, the importance of having skilled and trained people employed within the agency who can help participants develop and achieve those goals.
- Members discussed the need for more clarity around how performance is measured. An example was given of shopping: "if I end up with all the items, is that success? If further skills are developed in that process, should they get paid more?"
- Members discussed the frustration of needing to be constantly vigilant to avoid being ripped off. Members discussed that Consumer Law is still relevant to NDIS services provided; however perhaps ACCC should be given more authority (perhaps a special division) to follow up NDIS services. Quality and Safeguard Commission doesn't resolve consumer complaints for services provided. Seems to be some buck-passing when these complaints are raised.