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Review of the NDIS Act and the new NDIS Participant Service Guarantee

Via Email: NDISConsultations@dss.gov.au

Blind Citizens Australia (BCA) is the peak national representative body for people who are blind or vision impaired. Our mission is to achieve equity and equality by our empowerment, by promoting positive community attitudes, and by striving for high quality and accessible services which meet our needs.

Thank you for the opportunity to contribute to the review of processes through the NDIS Act and the new Participant Service Guarantee.

Consultation with BCA members over the last several years, as well as more focussed consultation, has identified the following broad concerns with current NDIS processes, especially in relation to planning and plan reviews. Following the below list are individual experiences and concerns from members, as well as collated feedback from a couple of BCA's state-based branches. This is followed by recommendations for change.

- Difficulties accessing information on the planning process
- Delays in receiving information in accessible formats (note that the NDIA is rolling out a more streamlined process for this, and there should be improvement in this area in the coming months)
- Delays in approval of plans
- Delays between plans, leading to disruption in service access
- Communication breakdown between planners and local area coordinators on planning process and decision making
- Number of approved plans requiring review
- Lack of understanding by planners of impact of funding levels across the plan – eg insufficient transport funding for those living in rural or remote areas impacts on social and economic goals funded in other areas of the plan
- Some sections of plans being approved, but delays or denial in others, leading to difficulties in implementing the plan as a whole eg appropriate

assistive technology denied, meaning it is hard to apply for jobs; or dog guide approved but transport allowance cut, leading to social isolation

- Lack of communication in wait time for plan approval
- Transparency in planning and approval process
- Inconsistencies in planning process and supports approval
- Lack of understanding of support needs of people who are blind or vision impaired
- Lack of understanding of low vision/degenerative/fluctuating vision conditions especially with dual sensory loss or co-morbidities where vision impairment may or may not be the primary disability
- Need for holistic view of person in assessment process, rather than diagnostic and disability focus

Note that some feedback received was positive, with a participant from Melbourne in Victoria receiving a referral via the state referral process, meaning that medical reports were not required. The planning process was smooth and timely. This person was happy with their plan and funding amount, and noted the control and flexibility of being offered a self-managed plan. The funded plan of approximately \$23,000 meets this person's current needs. From feedback received, this example is not the norm, however it does highlight the potential to share effective practice and feedback into what an effective and well managed planning process can look like.

1. Feedback from Individual:

The initial assessment process and related forms and questionnaires was very disability-focussed, and didn't have a functional assessment related to specific disability types.

"I had a call from the most senior approval person who I could barely understand and he asked me who fed me and who showered me every day. I was shocked and very upset and I told him so.

I did make a complaint through the NDIS complaints procedures and it was dealt with very quickly or so I was told"

2. Observed Feedback of others' experiences via a BCA Member:

There seems to be inconsistencies in individual's preparedness for their planning meeting, and identified goals. It was noted that blindness-specific service providers do have information and staff available to assist individuals with understanding the planning process.

There is significant funding inequality between similar plans in different states. An example provided was a participant in Victoria asking for assistive technology and being approved, and someone in Queensland asking for the same technology which was not approved. When assistive technology approval is based on reports and recommendations from Occupational Therapists or other professionals, often from the same blindness service provider organisation, these inconsistencies in approvals shouldn't be so prevalent.

3. Feedback from individual in South Australia. This BCA member has dual sensory disability, and is DeafBlind

- Local Area Coordinator came 3 weeks prior to Plan 1 ending but still took 9 weeks to get Plan 2. Therefore was not able to pay invoices in the interim & some of my services were curtailed due to this inability to pay.
- Accessibility formats were not addressed despite informing them via my LAC
- The new plan decreased my money allocated by 75%, did not allocate a set amount detailed for my guide dog, totally ignored the prior OT assessments which were submitted 3 months into Plan 1 & so I still cannot proceed & only allocated me \$100 for assistive technology. Consequently I have lodged an appeal. I have been informed the appeal could take 3-6 months.
- I faced the LAC telling me to contact my support coordinator who told me to contact NDIS who told me to contact the LAC – round & round in circles.
- The assessor found it hard to understand my disability & what DeafBlind means despite writing a report from my medical past career & referencing web sites.
- The lack of cross communicating within NDIS, ATO & Centrelink. I had already supplied significant information to Centrelink & the LAC but the assessor asked for the same material yet again.
- The argument that you don't need it as you did not use it despite pointing out that I was restricted in using as the OT assessments sat on their desk unattended to for 9 months.

4. Feedback on behalf of South Australian members from BCA's Adelaide branch

- Not supporting a replacement dog guide
- Service providers changing for the upkeep of the dog guide when initial contract pre dating NDIS was that the service provider would carry the cost. No new contractual arrangement was entered into.
- Assistive technology benefits not understood or appreciated, therefore not approved or not funded
- The issue over transport allowance in SA. For those who did not get an allowance the taxi subsidy in South Australia has not increased with CPI for over 10 years.
- People told you don't need transport allowance as you have a dog guide and can hence use public transport. This shows a total lack of wayfinding knowledge & that dogs need training for specified routes. This also does not take into consideration the transport difficulties for those who live in regional areas of South Australia.

5. Individual Feedback, Geelong, Victoria

- Lack of communication between NDIS office and LAC in plan review. Staff from both NDIS and the LAC called the participant, a day apart, with conflicting information about the requirement to have plan review

- Confusion regarding end date of plan, with a discrepancy of 2 weeks, resulting in not being able to access some services, as the new service agreement had not been signed with a provider.
- Lack of communication from LAC regarding the flexibility of the new plan. "I'd been told by the person conducting the plan review that she would phone me to explain aspects of my plan, but she failed to do this. Consequently I was unaware that the amount they'd given me was flexible (previously they'd allocated a specific amount for mobility). For the current plan they have allocated a larger sum which can be used for various things such as mobility, adaptive tech, etc. I had to phone the NDIA to find this out, then I had to phone the taxi company to figure out how much I should quarantine for mobility. Having a flexible plan is a positive thing, but it would have been good if someone had communicated this fact to me."
- Lack of understanding of low vision/degenerative/fluctuating vision conditions especially with dual sensory loss or co-morbidities where vision impairment may or may not be the primary disability

6. Individual Feedback

- Lack of identified timeframe for processing plan review requests
- My LAC / Planner reworded all my goals making them specific tasks eg to have Orientation and Mobility training to learn my way to local hospital, rather than broader goals. Having goals too narrowly stated limits my ability to benefit from my plan funding, which is very frustrating.

7. Individual Feedback

I had asked for my plan to be self-managed. Even though it was my first plan, it was not especially complex and I know from long experience in the workforce that I am entirely capable of managing it. The Local Area Co-ordinator said she had put it into the submission to the NDIA. The plan came back as agency managed. The LAC was as bewildered and disappointed as I was.

8. Two Individuals provided similar feedback

"So", I said to the LAC as we wrapped up our planning meeting, "I can expect to see a draft before it goes off to the NDIS planners? I'd like to be sure my goals and requests for support have been accurately represented.". "Oh no.", she said. "The next thing you will see is the completed plan as approved by the NDIS."

It was noted that the draft plan isn't always written in the same way that the individual identifies their goals and support needs. A couple of BCA members also identified that there are often mistakes on plans, which are very difficult to have corrected within a reasonable timeframe.

9. Feedback based on advocacy cases of 3 individuals

BCA assists individuals with their NDIS plan reviews when requested. These reviews are instigated by the participant, and are generally the result of not agreeing with decisions made in relation to their plan. The review has taken an extended period of time, in one case, having to be reviewed a number of times internally, as due process was not initially followed.

After going through the NDIS internal review process, and the outcome remaining the same, they consider a review via the Administrative Appeals Tribunal. Where a participant doesn't have the time or energy to go through the AAT process, they have decided to directly contact their Federal Member of Parliament to seek assistance. This external communication with their MP has in at least 3 cases, resulted in a direct and prompt response from the NDIA and a resolution of the issue.

This practice, while not ideal, seems to be one that does yield results in a timely manner. Feedback from members suggests that as a last resort, contacting their MP provides faster and more favourable results.

With timeframes and more solid processes in place within the NDIS, participants will have more control in the review process and outcomes.

10. Feedback provided from BCA's Tasmanian branch

The following amounts of NDIS transport funding would be required to support certain BCA Tasmania members:

- \$13,000 for a teacher without children;
- \$10,000 for an administrative worker without children;
- \$12,000 to \$16,200 for the bare necessities of being a working parent;
- \$13,000 for another working parent;
- \$28,000 for a working carer;
- \$2,500 and rising for a carer who retired due to the intensity of caring.

Without enough transport funding, these members will have to give up volunteering, education, paid work, caring, recreation, contact with family and friends.

Even with the highest level of transport funding (level 3 at \$3,456 per year, does not meet the needs of active participants. Level 1 funding is available for those not in the workforce, and is expected to support a participant's full range of social, cultural, civil and political participation.

11. Feedback from Individual

- Did have 2 previous plans, but in latest review, the budget was almost halved. The support needs had not changed in line with the cut in the budget. This person has a family and his wife works fulltime. He is a stay-at-home dad, with three children. After the plan was reviewed, the reasons for the reduction in budget was not detailed, but mentioned family support. It also said that it was due to the plan benefitting others. When questioned, an example was given: If you engage a

support worker to drive you and your child to an appointment, it is benefitting the child.

This situation does not consider the role of a parent who has disability.

- Another reason for cuts in the budget was that the participant has a dog guide. There was a feeling that the dog guide was a big investment, so that should cover much of the plan. This view does not promote the person as a whole, and how supports can work together in a person's plan.
- As outlined in the new process for provision of accessible information, the participant received a phone call asking his preferred format, which was audio. The next correspondence he received was in hard copy print, with no audio version provided.

12. Feedback from Individual

- Transport funding was included in previous 2 plans, but no transport assistance at all in current plan
- Assistive Technologies were denied with no explanation as to why
- Requested further support hours to be able to meet current goals, but this was denied
- This person has a dual disability – they are Deaf and also has a vision impairment

Blind Citizens Australia's Recommendations:

1. The NDIS planning process and tools should focus on functional capacity, looking at the person as a whole, and support required to live their life, rather than making assumptions based on disability types through current assessment forms and processes.
2. Communication gaps between NDIS planners, LACs and participants are prevalent. This extends to being upfront about wait times for plans, reviews, and reasons for denial of supports in plans. Clarity in these areas will give the participant time and space to consider their options and plan accordingly.
3. With the requirement for an Occupational Therapist or other professionals to recommend reasonable and necessary assistive technology, aids and equipment or other supports, these recommendations should be considered for approval in a more consistent manner.
4. Draft plans that are reviewed by participants will avoid unnecessary plan reviews, due to having a confirmed agreement to the wording and intent of the draft plan, before it goes through the approval process. Currently errors or wording that do not accurately convey the participant's goals in the draft plan, have no other recourse than to go through the review process.
5. The ability to view the approved plan before it starts, especially those that have a decreased budget, would allow the participant to make alternate arrangements, or plan for a review, which would allow them to adapt to the changes.
6. Planning for transport support should consider the participant's current and future needs and the impact on the implementation of other areas of the plan. Transport funding should also be tailored for those who live in regional or rural areas, to account for the barriers that exist in transport in these areas.
7. Where a person's circumstances have not changed, the plan could be automatically rolled over. This would be the participant's choice and where a review is required, it would be initiated by the participant.

These recommendations align with the proposed NDIA Service Standards: Timely, Engaged, Expert, Connected, Valued, Decisions are made on merit, and Accessible.