Your say
Advocacy Tasmania

Your Say Advocacy Tasmania (AdvoTas) provides client-directed, issues-based advocacy support to individuals accessing or seeking to access the NDIS, as well as across broader domains of disability, mental health, older persons and alcohol, tobacco and other drugs.

The client-directed model means that AdvoTas cannot provide advice on any issue where clients have not reported experiences and given direction which directly applies to the issue. AdvoTas does not provide best interests advice, on the understanding that clients are the primary experts on their own lives and experiences, and should be given full choice and control in having their voices heard.

The following responses to the discussion paper are collated based on the reported experiences and advocacy issues of AdvoTas' NDIS and disability clients, collected from over the rollout to full scheme until present.

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1. **Which of the [suggested] principles do you think are important for the NDIA to adhere to, and why?**

Your Say Advocacy Tasmania's (AdvoTas) NDIS clients have indicated they feel strongly about all of the indicated principles. Client feedback around these principles, gathered over the course of NDIS issues for which they sought AdvoTas support, showed different emphasis depending on the issues in question.

Timeliness: Timeliness was considered critical by all clients. Even where clients acknowledged it would not be possible to resolve their issue quickly, they indicated that it was important to them to have a clear idea of how long a given process would take at a maximum. Clients generally stated that this was important for them to be able to make alternative arrangements in the time until their issue was resolved. These alternative arrangements generally pertained to physical health and safety, maintaining existing supports or therapeutic relationships, sustainability of informal supports during a period of high stress, and childcare or other carer commitments.

Connected: Smooth connections and interfaces between the NDIS and other services were viewed as very important for maintaining safety and for preventing clients from "falling down the gaps".

Transparent/Merit-Based Decisions: Clients indicated that transparency and clear communication in decision making is critical in client empowerment and engagement. Clients felt that clear, merit-based decision making would prevent a significant proportion of issues, and allow issues which do occur to be addressed much more effectively.

Expert vs Valued: While some clients indicated that they wanted NDIS staff to have more specialised training in specific disabilities, others stated that they would be satisfied with knowing that NDIS staff valued the lived experience of the client and informal supports as the most important evidence, and that staff would have the resources to fully consider expert evidence that was provided. Where clients met with a Planner or LAC who had lived experience of disability, clients reported a higher level of confidence in Planning processes and decisions, stating that no amount of training can substitute for lived experience.

Engaged: Clients indicated that they believed it was critically important for NDIS board members and all high level executives to have personal lived experience of disability, and that it would otherwise be impossible for executive decision-makers to understand the real-life implications of policy and strategic decisions.

Accessible: Clients indicated that they felt properly accessible processes would allow for the prevention of a significant proportion of issues, and that for NDIS processes to be properly accessible to people with disabilities, the other suggested values must also be fulfilled.

2. **Do you think [the NDIA has] fulfilled the above principles? If not, how are they falling short?**

Timely: Clients indicated that processes took so long that they experienced moderate to severe negative consequences in their lives, in the domains of safety, physical and mental health, maintenance of existing supports or therapeutic relationships, sustainability of informal supports, and childcare or other carer commitments.

Many clients expressed a belief that in particular, Access and Appeals processes had been designed to take so long that clients would be practically unable to utilise them- either not being able to gain access to the Scheme, or being unable to challenge planning decisions where supports were inadequate.

Engaged: Clients expressed a belief that people with disabilities should be *making and deciding* operating procedures and processes rather than just being consulted in their development. In this context, clients expressed a strong desire for NDIS executive and board positions to have a requirement for lived experience of disability.

Expert vs Valued: Clients indicated that they increasingly felt treated like numbers over time, particularly in comparison to their treatment under Trial. Clients felt that the majority of decision makers did not “get” what living with disability was like. Many clients indicated that they did not want to be assessed according to their diagnosis, but rather as an individual; while it was important for operational staff to be familiar with various disability types and needs, it was more important for the individual’s self-reported needs and experiences to be believed and prioritised.

Connected: A high proportion of NDIS client issues reported to AdvoTas were described by clients as originating from a gap between the NDIS and other mainstream services. This applied equally between Access issues (e.g. inadequate support from existing support services, such as state Mental Health, for clients to understand and access NDIS processes) and Reasonable & Necessary/support level issues (e.g. support gaps in NDIS interfaces with mainstream health/hospitals, public transport, parenting/childcare supports, Centrelink and Education).

Transparent/Merit-Based Decisions: Clients repeatedly indicated frustration with unclear communication from the NDIS regarding the reasons for decisions, as well as the meaning of the decisions themselves. Clients felt disempowered and unable to make progress when information about decisions made regarding their issues was delivered inconsistently and inaccessibly.

Accessible: The majority of clients indicated that they felt current processes were not accessible to people with disabilities in general, without even considering those with more specific needs such as clients from Aboriginal and Torres Strait Islander, CALD or LGBTI+ communities. Processes and communications were not considered flexible enough to meet the highly variable needs of people with disabilities.

3. **What other key principles are important for the NDIA to follow, that could be included in a Participant Service Guarantee?**

During the course of NDIS issues since the rollout to full scheme, AdvoTas clients have expressed transparency, flexibility and person-centred practice as highly valued principles in the ideal delivery of the NDIS.

4. **One way to measure these principles is through a set of Service Standards. Do you think [the suggested Service Standards] are fitting? Are there other standards you believe should be included?**

Timely: While clients agreed that a "deadline" of events occurring within a specific number of days of information provision would be welcome, they also indicated that timeliness should be enabled through more effective/appropriate support for clients to provide necessary information. For example, clearer guidance on exactly what evidence is required- potentially through direct NDIA communication with evidence providers- and direct support to access appropriately qualified experts to provide evidence.

Engaged: Clients have indicated that measures concerning the number or proportion of executives/strategic or policy decision-makers with lived experience of disability are necessary. External consultation should be considered supplementary to this.

Expert: Most clients felt that NDIA staff should have training in general disability support needs, but that NDIA staff should defer to the client's medical and allied health specialists with regards to which supports will be "most effective".

Connected: Clients have indicated that the NDIA should work more pro-actively to prevent gaps, and where an interface is unclear, the NDIA should take an inclusive stance on which supports can be covered for an individual while further investigation is undertaken. Clients should feel secure that their support needs will be met in the first instance, regardless of where departmental responsibility is ultimately determined to lie.

Valued: In addition the suggested standard, clients suggest that they should be given adequate time and flexible format options for their interactions with the NDIA, and that NDIA staff are specifically trained in person-centred service and support.

Decisions are made on merit: In addition to the suggested standard, clients have requested clearer mechanisms for accountability.

Accessible: In addition to the suggested standard, clients have indicated that they frequently feel unsafe to disclose their membership in a specialised group (e.g. Aboriginal or Torres Strait Islander communities, LGBTI+ communities). Clients should feel safe and supported to disclose specialised needs to the NDIA.

5. **Do you have any ideas on how we can measure how well the NDIA has delivered on each principle?**

As AdvoTas can only represent client voices and does not take a "best interests" approach, and clients have not given direct indication of suggested performance indicators (beyond proportions of NDIA board/executive/general staff with lived experience of disability), AdvoTas cannot formally comment on this discussion point.

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6. What are some of the significant challenges faced by NDIS participants during the Access process?

Financial barriers: The highly specific evidence requirements for NDIS Access mean that clients invariably require new, specific reports from treating practitioners. This presents a significant financial burden on clients, often significantly delaying or entirely preventing NDIS Access. This becomes even more the case where an application is rejected- either further evidence will be requested as part of the initial application or appeal, or enough time may elapse that existing reports are considered out of date and new reports must be obtained. Many clients reported experiencing significant financial hardship from the Access process.

Information barriers: Clients received highly inconsistent advice from other disability and health services regarding whether they would potentially be eligible for the NDIS, or whether the NDIS was relevant to their needs. The majority of GPs were unable to provide meaningful or accurate advice to clients on how, or whether, to proceed with an NDIS application, and were not aware of any support clients might receive to make an application. Without appropriate advice or referrals, many clients initially did not apply for an extended period, or made applications without needed support, leading to rejection. Even where clients were aware that LAC support was available for Access, and received support, the LACs involved often lacked the necessary training to judge whether the evidence obtained was appropriate. Multiple clients reported being told by LACs that their evidence would be enough, only for their application to then be rejected by the Access team.

Expertise barriers: Clients who were able to identify and afford appropriately qualified professionals to provide evidence for their Access application were often still rejected from their initial Access attempts. Clients found that their treating professionals were inexperienced or untrained in providing NDIS evidence and did not have the appropriate skills to write evidence to the required standard, despite being fully in support the client's Access bid. Other clients discovered that, despite later being found eligible, their initial evidence providers had deliberately written adverse evidence based on misconceptions of what the NDIS was. When one client questioned their doctor on why they had provided adverse evidence, the doctor was quoted as saying, "I don't think the government should be paying for people to go out for coffee."

Accessibility barriers: Due to the impacts of their disabilities, many clients did not have the functional capacity to coordinate or undertake the necessary appointments, paperwork, and communications required by the Access process. Many clients required case management in order to navigate the application process, which was generally not available except in a volunteer capacity from an informal support person or previous support provider. Where no such support was available, clients were often unable to apply successfully, or at all.

Transparency barriers: In the majority of cases presenting to AdvoTas, clients were unable to determine whether their Access request had been rejected or was still awaiting further information. Many clients, seeking advocacy support because of extended delays, were completely unaware that their application was "on hold" awaiting further information. As the client was unaware that further information was required at all, let alone the specific evidence requirements that were unmet, no progress could be made. Where applications were formally rejected, letters of explanation did not actually give practical reasons for rejection, rather just citing criteria under the Act and giving no explanation of how they actually applied to the client's circumstances. For example, "Failure to demonstrate permanency of impairment" would be cited where the functional reason for rejection was actually that the client's evidence was out of date, did not argue why specific treatments were not appropriate for the client to pursue, or did not use the correct language around functional capacity as distinct from disability.

7. How long do you think it should take for the NDIA to make an access decision?

Clients felt 21 days from receipt of required evidence was acceptable; however, they felt that the NDIA should be required to provide much more proactive support in obtaining any additional evidence that is required.

8. What do you think the NDIA could do to make it quicker or easier to access the NDIS?

Clients indicated that the NDIA needed to communicate much more clearly and accessibly *when* further evidence is needed, and specifically *what* further evidence is needed. A single phone call or letter to the client or their evidence provider was considered extremely insufficient. Clients also felt that the NDIA should be obliged to provide funding for any new assessments and reports required for the Access process, and formal case management for prospective Participants to assist in obtaining these and coordinating the Access request itself as soon as possible.

9. Does the NDIA provide enough information to people when they apply for access to the NDIS? If not, what else could they provide that would be helpful?

Clients indicated that formal case management, specialised to access requests, would be an appropriate support for the majority of clients seeking access to the NDIS.

10. Is the NDIA being transparent and clear when they make decisions about people's access to the NDIS? What could the NDIA do to be more open and clear in decisions?

Clients felt strongly that Access decisions were not at all transparent or clear. Clients indicated that Access decisions should be individualised, communicated entirely in plain language, accompanied by practical and specific next-steps advice- for example, "We will contact you to set up an appointment within XX days", "You should ask your specialist to update their report so that it describes the day-to-day tasks that you struggle with", or "You should get an LSP-16 or HoNOS assessment from your psychologist". Where an Access decision was a rejection or a request for further evidence, clients considered it absolutely critical that this information be provided in a format accessible to the individual, with appropriate support people present, rather than being via a phone call or formal letter citing the Act.

10(2). What are some of the significant challenges faced by NDIS participants during the planning process?

Accessibility- trust and disclosure: Many common disabilities make it difficult for clients to build rapport with new people, particularly Autism and other forms of neurodivergence. Many clients also have specific and individual communication needs due to the impacts of their disabilities. NDIS participants generally also come from a lifetime of trauma in dealing with government or medical/disability systems, creating further difficulty in communicating sensitive issues. When engaging with the Planning process, especially for a first Plan, it is functionally impossible for many clients to disclose the information required by LACs or Planners within only one or two meetings. Participants are not given the necessary time required to build trust and rapport with their LAC or Planner.

Accessibility- fatigue and overload: The common structure of Planning and Preplanning- only one or two extended and intense meetings, whether on the phone or in person- is not accessible where a client's disability causes fatigue issues, sensory or emotional overload, or information processing difficulties. Clients should be offered a choice of flexible formats to allow them to engage effectively.

Value of lived experience: Many clients described feeling like their self-reporting of their lived experience was not considered reliable, believable, or "enough", with NDIA representatives instead seeking to identify which "disability box" clients could be placed in. Clients felt their individual differences were often discounted in favour of "general knowledge" of a disability diagnosis. Clients and their nominees should be treated as the primary source of evidence, and supported to communicate their lived experience effectively.

Evidence preparation: Clients indicated that they were not adequately supported to understand what evidence to gather to support their cases, and what format that evidence should be in.

Scope of funded supports: Most clients indicated that they felt they did not adequately understand what funded supports were possible under the NDIS, and reported that they had received inadequate, inconsistent or incorrect information from NDIA representatives in this regard.

Goal formulation: Clients reported feeling they were not given enough support to understand how Plan goals should be formulated to link to funding- many clients indicated that they knew exactly what Plan supports they needed, but were unclear on how to describe goals linked to those supports. Clients also often felt the Plan goals they ended up with were not reflective of their individual needs. Clients stated that they often felt LACs and Planners defaulted to generic goals in order to save time, even if these goals were not meaningful to the client's experience; this effect was compounded by difficulties with trust and disclosure of personal information.

Delays in process/communication of progress: Clients reported that they felt they had no certainty or control over the amount of time between their Planning or Preplanning meetings, and the approval of their Plan. Clients indicated that attempts to seek "progress updates" or estimated completion times for their Plans were generally unsuccessful, or the responses inaccurate. Clients described feeling anxious and helpless during this waiting period.

Continuity of support: Clients who had received previous disability support services reported potential or actual gaps in service between being exited from pre-NDIS services, receiving their new Plan, and implementation of new funded supports.

Availability of drafts: Clients stated that they had difficulty when seeking to see a draft version of their Plan before its submission for approval. Clients indicated that draft requests were often refused entirely, or when draft content was provided, clients were not able to give feedback on the content or have errors corrected prior to the Plan being submitted.

11. Are there stages of the planning process that don't work well? If so, how could they be better?

Clients stated that they felt many issues could be prevented by a thorough and responsive drafting process. Clients indicated that they understood this would potentially lengthen the amount of time before a Plan was approved, but stated that they felt it would save time in the long run to avoid needing to review or appeal Plans to correct errors. In a similar vein, some clients indicated that they wanted the option to have multiple Preplanning or Planning meetings, to address issues of accessibility, trust/rapport, and information overload.

12. How long do you think the Planning process should take? What can the NDIA do to make this quicker, remembering that they must have all the information they need to make a good decision?

Clients gave a variety of responses on how long they felt the Planning process should take, based on the complexities of individual cases. Almost all clients agreed that Plan funding should either be approved within two weeks of the final Planning meeting, or within two weeks of the client's final sign-off of the draft.

13. Is the NDIA giving people enough, and the right type of information, to help them prepare for their planning meetings? If not, what else could they provide?

Most clients indicated that they wanted more information prior to their planning meetings, particularly with regards to evidence that might be required (including statements of lived experience). Clients generally felt they did not understand the scope of what funded supports were possible under the NDIS.

14. Is the NDIA being responsive and transparent when making decisions in participants' plans? If not, how could this be improved?

Clients reported similar issues around responsiveness and transparency for Planning decisions as for Access decisions. Clients reported that their own requests for information would often be ignored or dismissed, while identical requests made by an advocate would receive a much more meaningful response.

15. **If you have been in the NDIS for more than one year, is it easier to make a plan now than when you first started? What has the NDIA improved? What still needs to improve?**

Clients who entered the NDIS during the trial phase generally reported significantly decreased satisfaction with processes over time. These clients indicated reduced flexibility in processes, lack of communication and transparency, and less individualisation of Plans. They also indicated that support coordination was discontinued before appropriate capacity had been built, leaving clients vulnerable when navigating changed NDIS processes.

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16. **What are some of the significant challenges faced by NDIS participants in using the supports in their Plan?**

Clients universally indicated uncertainty around the flexibility of funded supports in their NDIS Plan. Clients reported that service providers were unwilling to create flexible service bookings where these did not match the originally stated hours or support types, despite changes being within allowed flexibility.

The majority of clients reported inadequate support to implement their Plan, even where a Coordinator of Support was funded. LACs and Support Coordinators were perceived as inconsistent and often disengaged or too busy.

17. **Is the NDIA giving people enough, and the right type of, information to help them use their plan? If not, what other information could the NDIA provide?**

Clients universally indicated that they received inconsistent information on how their Plan could be used, and believed that much greater funding for coordination, and training for quality of coordination, should be provided. Many clients stated that they felt all first Plans should include intensive support coordination or case management while participants adjusted to the NDIS.

18. **What other advice, resources or support could the NDIA provide to help participants to use their Plan and find supports?**

AdvoTas clients did not provide specific feedback with regard to other resources or support for Plan implementation. Clients were primarily focused on in-person support coordination and case management.

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19. **What are some of the significant challenges faced by NDIS participants in having their Plan reviewed (by planned or unplanned review)?**

Unclear processes: Clients stated that it was difficult to identify where a Plan should have an unscheduled review rather than appealed. Some clients were advised that they should attempt an unscheduled review first, which was often rejected, which then created difficulties in appealing the original decision. Some clients were advised to appeal the decision not to hold an unscheduled review rather than the original funded supports decision, resulting in the client then being unable to take the issue of their funded supports to an external appeal.

Clients indicated they were unclear as to what constituted a “change of circumstances”. While the Act indicated that new Plan goals do not qualify as a change of circumstances, clients often felt that their new goals required their funded supports to be adjusted.

Timeliness: Change of circumstances reviews often occurred in response to a crisis in the client’s life. With no specific timeframe in which an unscheduled review should be completed, clients often reported being placed at risk of significant harm while they waited for their new Plan to be created and approved. Formal escalation processes were generally not communicated to clients and risk assessment criteria were not transparent.

Fear of reduced supports: Where clients were seeking a review on the basis of a single funded support, many expressed fear that they would lose other, unrelated funded supports in the process of a review.

20. What can the NDIA do to make this process easier or more effective?

Some clients requested the option of a “quick fix” review, so that stop-gap crisis funding could be implemented to ensure safety while issues were more comprehensively assessed. Other clients indicated that a “minor” review option, where only a single funded support was adjusted rather than the whole Plan being reviewed, would be ideal.

21. How long do you think Plan reviews should take?

Clients gave various timeframes for what was considered “reasonable” for a Plan review to occur, but generally considered that scheduled/annual reviews should generally take less time than unscheduled/”change of circumstance” reviews. All clients agreed that reviews should take less than one month to complete unless exceptional circumstances applied.

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22. What are some of the significant challenges faced by NDIS participants when they seek a review of an NDIA decisions?

Application timeframes: Many clients indicated that they had been given inconsistent or inadequate information regarding the amount of time allowed for an appeal application to be made. Others stated that, due to inadequate support to understand or implement their Plans, the allowed appeal timeframe had lapsed before they realised there was an issue that needed correction.

Completion timeframes: Almost all clients reported significant frustration with the lack of a completion timeframe for internal reviews. Many clients experienced internal reviews dragging out over multiple months, with no indication of progress or an expected completion date. The lack of an indicated “reasonable” completion date left many clients unsure of their rights with regard to external appeal, complaints action, or other measures. Clients often reported their appeal (internal or external) being abandoned because it took so long that their scheduled review arrived.

“Moving goalposts” for evidence: All clients indicated that they felt the requirements for supporting evidence were poorly communicated by the NDIA. Some clients stated that they perceived evidence requirements as having changed over the course of an internal review, with evidence initially being requested in general terms only when a specific format was actually required, or with stricter requirements being implemented after evidence had been received, requiring new reports to be written.

The Technical Advisory Team: Clients reported the TAT as a “black box” process, in which issues would get lost for very extended periods with no communication. Clients expressed frustration that the TAT were effectively the decision makers on funded supports, without any mechanism to be held accountable, as they were not the formal delegates. Some clients worried that an appeal on their issue would be assessed by the same members of the TAT as for the original decision. As the TAT never met with or spoke to the client directly, clients felt the TAT frequently provided advice based on incomplete evidence or inappropriate expectations for the client’s region.

Fear of reduced supports: Where clients were seeking a review on the basis of a single funded support, many expressed fear that they would lose other, unrelated funded supports in the process of a review.

Lack of “lasting effect”: Some clients reported that they felt there was no point pursuing an appeal, as any outcome of the appeal would apply for the remaining duration of the current Plan only, and the result would likely be ignored in the next annual review, requiring the argument to be started over almost from scratch.

Documentation of processes: Multiple clients found their attempts to seek an external appeal invalidated by incorrect documentation of processes by the NDIA. Where applications for internal review, plan review meetings, or outcomes of internal review were not appropriately recorded, AAT jurisdiction was negated and clients were denied their right to an external appeal.

Implementation of Tribunal orders: There being no required timeframe in which the NDIA implements the outcome of an external review settlement or judgment, some clients reported difficulty in receiving the outcomes agreed at the AAT in a timely fashion (or at all).

23. Are there other issues or challenges you have identified with the internal and external review process?

(See response to 22.)

24. How could the NDIA improve the decision review process?

Clients indicated that decision review processes could be improved most effectively by clearly indicating a “reasonable time” in which a review should be concluded. For external appeals, this would include a timeframe in which tribunal/settlement orders should be implemented. Clients also expressed frustration with the structure of the TAT process but did not suggest specific alternatives.

25. How long do you think reviews of decisions should take?

Clients acknowledged that internal reviews could not be expected to take the same amount of time, given the differing complexities of the issues involved. However, clients generally agreed that all internal reviews should take less than three months, and in the majority of cases less than one month, particularly where risk factors have been identified. Legislated time frames should be built flexibly to account for different levels of complexity and urgency.

26. **Do you think there are parts of the NDIS act and Rules that are not working or make things harder for people interacting with the NDIS?**

AdvoTas clients generally did not give opinions on the content of the NDIS Act or Rules, except insofar as expressing frustration at the lack of legislated timeframes for the completion of reviews and appeals.

27. **What changes could be made to the legislation (if any) to:**
    a. **Improve the way participants and providers interact with the Scheme**
    b. **Improve the access request process**
    c. **Improve the participant planning and assessment process**
    d. **Better define "reasonable and necessary" supports**
    e. **Improve the plan review process**
    f. **Improve the Internal review process**
    g. **Improve the way other govt services interact with the scheme**

AdvoTas clients did not make reports which could be interpreted to suggest specific changes to legislation.

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28. **What are the significant challenges faced by NDIS participants in changing their Plan?**

(See responses to 19 and 22.)

29. **How do you think a 'plan amendment' could improve the experience for participants? Are there ways in which this would make things harder or more complicated for people?**

Most clients expressed a hope that a "plan amendment" option could reduce waiting times as well as reducing the risk of other supports being cut or errors being introduced to other aspects of the Plan. Clients expressed difficulty in interpreting the differences between unscheduled reviews and internal appeals and using the appropriate mechanism; this risk would also exist for the introduction of a "plan amendment" option, without adequate support for clients to understand their options.

30. **How long should people have to provide evidence that they need the changes they are requesting in a Plan amendment?**

AdvoTas clients generally stated that it was impossible to say how long it would take to provide evidence in Tasmania, given restricted availability of specialists and long waiting lists for appointments.

31. Are there other situations during the Planning cycle where a quicker and easier way to make changes may be necessary?

Many clients indicated that a way to quickly fix general errors made in the creation of a Plan would be welcome; however, most discussed this in the context of a “plan amendment” option. A similar attitude was taken regarding the inclusion of new funding as a result of specialist assessments funded elsewhere in the Plan, for example, speech therapy or physiotherapy recommendations.

32. How else could the NDIA improve the process for making changes to a Plan?

AdvoTas clients gave no specific direction on this issue.