



Queensland Advocacy Incorporated

Our mission is to promote, protect and defend, through advocacy, the fundamental needs, rights and lives of the most vulnerable people with disability in Queensland.

Systems and Individual Advocacy for vulnerable People with Disability

31 October 2019

Mr David Tune AO PSM
NDIS Consultations
Department of Social Services
GPO Box 9820
Canberra ACT 2601

By email: NDISConsultations@dss.gov.au

Dear David,

2019 Review of the NDIS Act and NDIS Participant Service Guarantee

We refer to the above and to our discussions at the face-to-face consultation in Melbourne on 3 September 2019. Thank you for the opportunity to provide written submissions to this review.

About Queensland Advocacy Incorporated

Queensland Advocacy Incorporated (**QAI**) is an independent, community-based systems and individual advocacy organisation and a community legal service for people with disability. Our mission is to promote, protect and defend, through systems and individual advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

QAI has an exemplary track record of effective systems advocacy, with thirty years' experience advocating for systems change, through campaigns directed to attitudinal, law and policy reform and by supporting the development of a range of advocacy initiatives in this state. In recent years, issues pertaining to the design and implementation of the National Disability Insurance Scheme (**NDIS**) have been a core focus of our systemic advocacy. QAI also provides highly in-demand individual advocacy through our individual advocacy services – the Human Rights Legal Service, the Mental Health Legal Service, Justice Support Program, National Disability Insurance Scheme Appeals Support Program and Decision Support Pilot Program.

Below, we make recommendations with respect to the following:

- key provisions of the *National Disability Insurance Scheme Act 2013* (Cth) (**'NDIS Act'**) which we submit should be introduced, amended or repealed;
- key provisions of the NDIS Act which should be protected; and
- important considerations relevant to the development of a Participant service guarantee.

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QAI endorses the objectives, and promotes the principles, of the Convention on the Rights of Persons with Disabilities.

Patron: His Excellency The Honorable Paul de Jersey AC

Review of the NDIS Act

QAI makes the following recommendations for amendment to the NDIS Act:

Section	Proposed amendment	Explanation
Submissions on specific provisions of the NDIS Act:		
4	The right to advocacy should be included within this section.	A Participant's right to advocacy needs to be clearly stated, not simply alluded to (s 4(9)) or referred to indirectly (s 4(13)). It is vital that the role of advocacy in supporting a person to exercise choice and control with respect to the NDIS is acknowledged and respected and upheld.
5	The Act should specifically acknowledge that the sexual identity status of Participants must be taken into account.	This is self-explanatory.
6	<p>This section should be amended to require the NDIA to support Participants and prospective Participants to obtain additional information requested by the NDIA, including by paying for information and reports required by the Agency which the Agency is satisfied that failure to do so would result in the experience of hardship by the Participant or prospective Participant.</p> <p>It is important that safeguards are included with such amendment to ensure that the Participant retains choice and control regarding the provider of any requisite assessments.</p>	<p>Paying for evidence sought by the NDIA can be highly problematic for Participants, who often lack recent and comprehensive functional assessments or are requested to provide additional information or clarification by their medical and allied health professionals that is beyond their financial capacity.</p> <p>Vesting the Agency with the proposed power would address a significant gateway issue with the Scheme, which is the affordability of obtaining the requested evidence for Participants and prospective Participants.</p>
9	The definition section of the Act omits to define key terms and should include definitions for the following:	It is important that the Scheme is transparent, consistent and easily understood, with clear parameters and consistent understanding by the NDIA, Participants and prospective Participants and the public.

	<ul style="list-style-type: none"> • “advocacy”; • “disability”; • “impairment”; • “permanent”; • “reasonably practicable”. <p>The definition of “advocacy” must include the requirement that it is provided by advocacy organisations which are audited and accredited against state and/or federal standards.</p> <p>The definition of “disability” should be consistent with the understanding of disability articulated in the United Nations’ <i>Convention on the Rights of Persons with Disability</i>, in which it is acknowledged that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (Preamble to the CRPD).</p>	The proposed inclusion of the definition is to ensure advocacy is free from conflicts of interest (such as registered providers claiming to provide advocacy services)
9	Participant’s impairment should encompass all impairments – not just those specified to meet access to the NDIS	Section 9 of the Act defines a “Participant’s impairment” to mean “an impairment in relation to which the Participant meets the disability requirements, or the early intervention requirements, to any extent”. Once a person becomes a Participant their function and needs should be viewed as a whole (in line with the social model of disability) and what support are funded should become a consideration of s 34.
9	Insert a definition of ‘reasonably	This is important to give clarity to the scope of

	necessary'	the CEO's power pursuant to s 26(1)(a).
22	Remove s 22(1) (the age requirement) from the Act	<p>The age requirement (imposed by s 22(1)(a)) is discriminatory and should be removed, as it potentially precludes late-onset disability such as Alzheimers, dementia, degenerative conditions such as Multiple Sclerosis, Parkinson's and Motor Neurone Disease.</p> <p>Section 22(1)(b) is no longer required as we are now at full roll-out. It is also very vague and open to be changed with the NDIS Rules.</p>
23	Amend the residence requirements so that they include New Zealand citizens	There is a significant issue with a lack of services for people who are New Zealand citizens and live Australia. It is inequitable and discriminatory and fails to recognise the contribution New Zealand citizens make to Australian society and the economy.
23(3)	Delete this sub-section.	This is no longer relevant following full roll-out of the NDIS.
24	Broaden the definition of "disability requirements" to include greater consideration of chronic health and mental health/psycho-social conditions.	This is vital to ensuring that the scheme is equitable and does not selectively discriminate in its coverage.
24	Amend the definition of "permanency"	The issue of permanency in s 24(1)(b) is most problematic and worthy of scrutiny and change. The notion should be expanded, in the very least it should be defined (perhaps in a definition section, as mentioned above). The requirement that a person is likely to need lifetime support imposed by s 24(1)(e) is superfluous and results in confusion and potentially deprives people with disability of much needed reasonable and necessary supports.
29 (1)(b)	Delete this provision	Because a person is 65 years or older does not mean their disability supports are funded by My Aged Care or in a residential setting. Many residential settings are private and this could mean elderly people have to pay privately for supports. In many cases people with disability

		residing in aged care do not have their disability support needs met.
30	Include a timeframe for notification of revocation of access status by the CEO, which must give the Participant at least three months' notice of revocation	This is necessary to ensure people who are facing revocation have the ability to review this decision and receive a decision on their review whilst still receiving supports.
31	Specifically include in s 31 a Participant's right to review their draft plan before finalisation and implementation	This amendment will provide the Participant with the opportunity to review their plan while it is still in draft format and to seek correction of any errors without recourse to an internal review. It is in line with s 17A.
32 / 33(4)	Impose a timeframe of 28 days for preparation of Participant plans	The requirement that a decision is made "as soon as reasonably practicable" is not sufficient and has resulted in excessive delay, with Participants are waiting for long periods of time for a plan (see ECEI strategy)
48	<p>This provision should specify that a person's circumstances need to change and define what constitutes a change of circumstances.</p> <p>The use of the term "review" should be reserved use for s 100 reviews. Consider using another word to mitigate Participant's confusion with specific 'review' decisions and processes. A couple of suggestions - "appraisal" or "reassessment".</p> <p>Any request for review of a plan made within 3 months should be treated as a s 100 review. Participants should not have to satisfy the requirement that their circumstances have changed if it is within 3 months.</p>	<p>This is very problematic provision of the Act. It is inappropriately used to thwart a Participant's right to proceed to an external appeal in a timely manner, as internal reviews are often inappropriately characterised as s 48 reviews, with the result that the next step is a s 100 review, rather than an external appeal to the Administrative Appeals Tribunal.</p> <p>The use of the word "review" is problematic in this section and is a cause of confusion and misinterpretation by Participants and Agency staff.</p>
48 (3)	Remove 'as soon as reasonably practicable' and include a	This is necessary to ensure Participants' needs

	timeframe of 28 days for completion of the review.	are met in a timely manner.
49	Insert a timeframe of 28 days for approval of change of s 48 plan	This is necessary to ensure Participants' needs are met in a timely manner.
Chapter 4, Part 2	Specifically include a 'restricted access' Participant's right to privacy in Part 2.	This is self-explanatory.
99	Include a right to review section 35 (2) as a reviewable decision.	Section 35(2) of the Act empowers the NDIA to make rules about the manner in which supports are to be funded or provided and by whom supports are to be provided. There is presently no right to review this decision.
100 (6)	Delete the reference to "as soon as reasonably practicable" and insert a timeframe of 28 days for the reviewer to make a decision.	This is necessary to protect the rights of Participants and potential Participants.
	Where a decision is made that a support that has already been paid for by the Participant was reasonable and necessary, it should be reimbursed by the NDIA within 7 days of the date of the decision.	This is necessary to ensure that Participants are not forced to self-fund reasonable and necessary supports whilst awaiting a decision.
	The Act should clarify the situation in which a new plan is issued by the NDIA while an appeal on a former plan is before the AAT. We note that Deputy President Forgie identified that s 42D of the <i>Administrative Appeals Tribunal Act 1975</i> (Cth) as the sole basis to prevent an NDIS plan elapsing while an appeal is on foot: <i>Williamson</i> [2019] AATA 2944.	The NDIA Act must protect Participants so that they are not penalised by the failure by the NDIA to perform its statutory duty under s 48(5) to review a Participant's plan before the plan's review date, or denied their statutory right to seek external review of their plan.
General submissions:		
The Act should better reflect the Participant's lived experience with disability.		
The Act should be drafted in plain English and should be accessible for people with disability.		

Recommendations regarding retention of key provisions of NDIS Act

We draw your attention to the following provisions of the Act, which we submit should not be amended or repealed:

Section	Explanation
6	'The Agency may provide support and assistance (including financial assistance) to prospective Participants...' This should allow a more equal opportunity to apply for the NDIS – not that we see this happening outside of the AAT.
25 (3)	The word 'offered' to ensure the responsibility is not passed on depending on what the NDIA believe another person or department 'should' offer.
34(1)(f)	The word 'offered'. This ensures responsibility is not passed to another government department – see <i>Burchell and National Disability Insurance Agency</i> [201] AATA 1256 (4 June 2019)
204	Longer timeframes cannot be more than twice the prescribed period.

Recommendations regarding associated amendments to NDIA policies and procedures

Issue	Explanation
Technical issues	Planners must rely on what is recorded into the NDIA's computerised system, yet the system currently does not allow for more than one primary disability to be entered. Disability advocates have raised this as a concern. Planners' discussions with Participants are typically informed by what shows up in the system. For example, if a client has physical and mental health impairments but only the physical impairment is recorded as a primary disability, the planners do not ask about the mental health impairment, as it is not recorded in the system. It should not fall to Participants to have to raise these matters with planners – and this is particularly the case with Participants who do not have the capacity/confidence to speak up for themselves. All disabilities should be accurately recorded in the NDIA's system at the time a Participant is granted access.
Clarification of planning matters	Clarification of who is providing the plan (ie planner or delegated decision-maker) would be helpful. Scope to query a draft plan and request a statement of reasons on the draft plan would be helpful.
Provision of a statement of reasons	All Participants should be able to obtain a statement of reasons to understand the basis for decision-making about their plan. The statement of reasons should be able to be requested orally or in writing, by the person, their plan nominee or advocate, and should be provided within 14 days of request.

	This would decrease the volume of internal reviews and appeals.
Making and provision of detailed notes of planning sessions	Participants and potential Participants should also be able to request and be provided with notes taken by the NDIA during their planning meeting(s), with the associated requirement that detailed notes should be made during planning meetings. Where a matter progresses to an appeal, these notes should be included in the T-documents.
Increase in appropriate staffing within NDIA	The timely progress of applications for internal review within the NDIA and external review in the Administrative Appeals Tribunal is frequently frustrated by the apparently limited number of decision-makers (instructors) within the NDIA. While legal representatives of the NDIA are accessible and generally responsive, they are powerless to act without instructions; instructions which, on any matter, including very simple matters of language used in a draft letter to an expert, generally take at least two weeks to obtain. This creates a bottle neck which causes frustration for the applicant and often leads legal representatives to feel the need to apologise on behalf of the NDIA. Repeated failure by the NDIA to comply with directions of the AAT is also often a result of the limited number of delegates (who are seemingly overworked and too time-poor to meet deadlines). QAI recommends increasing the number of delegates who can provide instructions in review proceedings. Delegates must attend all appearances at the AAT, including case conferences and conciliations so that timely instructions can be provided during those attendances.

Development of Participant Service Guarantee

QAI supports the development of a Participant Service Guarantee (**Guarantee**) and the Department's assurance that people with disability and their families, carers and supports will be involved in the design and development of the Guarantee. QAI supports:

- The imposition of new standards for shorter timeframes for people with disability to be given access to the NDIS and to have their plan reviewed. We have noted, above, our views with respect to the relevant timeframes that should be amended;
- A reduction in "red tape" throughout the review process;
- The introduction of specific service standards under the Guarantee to bring consistent, appropriate baseline service standards into the NDIA.

Possible principles for NDIA service delivery:

1. Which of the above principles do you think are important for the NDIA to adhere to, and why?

QAI considers that all of the articulated possible principles for NDIA service standards are relevant and desirable.

In terms of the principle of expertise, we agree that NDIA staff must be provided with a high level of

disability training and understand the impact particular disabilities have on people's lives and what supports are most effective for a person's disability. QAI recommends that LAC's and Planners must have intensive training to understand the social and other impact of disability and what makes people with disability vulnerable. The NDIA must undertake intensive training for planners and plan reviewers to ensure that the Scheme is implemented as it was envisioned and not as a savings exercise. This training must also encompass respectful engagement with Participants and plan nominees to overcome the fear and distrust that is being experienced as a result of bullying by planners. It is also vitally important that the NDIA include staff with lived experience of disability.

It is vital that people are given a person within the NDIA to connect with, with a full name and contact details, rather than a nameless and faceless information line as their point of contact.

2. *In your experience with the NDIA, do you think they fulfilled the above principles? If not, how are they falling short?*

QAI has made extensive submissions (available on request) documenting key issues with NDIA service delivery. We do not consider NDIA policy or practice is currently meeting adequate service delivery standards. In particular, the NDIA is:

- failing to act in a timely way in many instances;
- failing to engage appropriately with Participants and potential Participants;
- not providing adequate training for its staff. QAI submits that there is a need for transparency and accountability regarding the requisite base level training planners must undertake, along with the additional training provided. Some of the fundamentals of basic person-centred service are not practiced by staff of the NDIA. For example, the lack of return phone calls and emails to Participants or nominees is the cause of high levels of frustration and distrust amongst Participants and family members. To address the fear and mistrust of the planning processes, there must be clear and transparent information about how the NDIA communicates to planners about changes to policy and any directives on implementation of policy. Further to this, it is imperative that clear guidelines are published about how planners determine what are considered to be reasonable and necessary supports. QAI is concerned that there is a lack of training of NDIA staff in keeping assumptions in check, confirmation bias, dignity of risk, human rights, and innovative ways in which people with disabilities have their needs addressed through assistive technology;
- imposing unnecessary and inappropriate barriers to advocates, such as unnecessary consent requirements;
- failing to provide necessary information and support to Participants and potential Participants (for example, many of the necessary forms are not available and there are many links on the NDIA website that are not functional);
- making inconsistent decisions that often do not reflect the merit of a Participant's reasonable and necessary support needs, which includes failing to take into account recommendations by allied health professionals engaging with Participants.

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

QAI submits that the Guarantee should also include the following principles:

- supporting decision-making by Participants;
 - decisions are made equitably and transparently;
 - the NDIA actively respects and is responsive to issues that exacerbate the innate power imbalance between the NDIA and the Participant or potential Participant and takes steps to equalise this imbalance;
 - flexibility – with the NDIA understanding that each person’s needs and circumstances are unique;
 - taking a common sense approach to decision-making.
- 4. One way to measure these principles is through a set of ‘Service Standards’. Some ideas for what these Service Standards could be are listed in Attachment A. Do you think these Service Standards are fitting? Are there other standards you believe should be included?**

QAI agrees with the inclusion of the Service Standards. As noted in response to Question 3, we consider that principles of supporting decision-making, equitable and transparent decision-making, respect and responsiveness to issues of power imbalance, flexibility and a common-sense approach to decision making are critical to include.

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

The demand for advocacy is a clear indication of the deficiencies of the NDIA in meeting the needs of Participants and potential Participants. A decrease in demand would indicate improvement in the NDIA’s performance.

Timing of survey is important. The NDIA should conduct research on Participant satisfaction following approval and actioning of a plan, rather than at the conclusion of the planning meeting.

Eligibility and application:

6. What are some of the significant challenges faced by NDIS Participants in the access process?

When Participants are accessing the scheme, they are required to fill out an Access Request Form which has limited space to provide information. This can lead prospective Participants to believe a small amount of information is required to access the Scheme. However, as the Scheme has rolled out, the detail of supporting evidence has increased, without changes to the Access Request Form or Supporting Evidence form. There are also ‘unspoken rules’ as to what information Participants are to provide in order to access the Scheme. These rules consistently change.

Participants also lack access to up-to-date, relevant medical evidence. The NDIA will often verbally request additional information; however do not follow this up in writing. As it is not officially requested, Participants are unable to access financial assistance from the NDIA in order to obtain these reports. The cost associated with obtaining this evidence is a key barrier for Participants.

There are specific language requirements in order for the NDIA to understand allied health reports. For example, if a Participant’s report states they require ‘rehabilitative support’ to increase independence, they can be deemed access not met under s24(1)(b). However if the same

Participant's report states they require 'capacity building support' to increase independence, permanency is often not questioned.

7. *The NDIS Act currently requires the NDIA to make a decision on an access request within 21 days from when the required evidence has been provided. How long do you think it should take for the NDIA to make an access decision?*

QAI believes 21 days is sufficient for the NDIA to make an access request decision, once at full scheme due to a reduction in people accessing the scheme. However, during roll out, 42 days is sufficient. The NDIA should proactively request additional evidence during this period rather than automatically rejecting a Participant's request to access the scheme.

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

Prospective Participants should be encourage to provide self-assessment tools which clearly define a Participant's level of functioning, such as the World Health Organisation Disability Assessment Schedule 2.0 (WHODAS 2.0) and Life Skills Profile 16 (Life Skills Profile 16). Other readily available assessment tools such as the International Classification of Functioning (ICF) should be accepted from General Practitioners.

Participants should be encouraged to provide a statement of lived experience, which gives weight to their application, rather than their access being based purely on medical evidence.

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?*

No. The NDIA has many internal policies regarding access, which continually change. QAI has observed trends develop over time in relation to access and reasons for access not met decisions. The NDIA could provide their own functional assessment tools which are used internally for prospective Participants to have completed by their General Practitioner. They could also invest in developing the Access Request Form to be compatible with General Practitioners' systems, similarly to Medicare's development of their forms.

The NDIA could also provide a detailed list of questions, especially in relation to section 24(1)(b) or update the Access Request Form to reflect the information that is required.

For CALD Participants, the NDIA should provide funding for translation services in planning and to engage with support coordination services.

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 their decisions?*

There is very little transparency in the decision-making process at present. Currently, when a prospective Participant is deemed to have not met access, they receive a template 'access not met' letter which has no personalised information as to why the person was deemed to have not met the access requirements. These templates are often be incorrect. QAI submits that, at a minimum, the NDIA should be required to:

- Stipulate what section of the legislation they do not meet access under;
- Provide a detailed explanation as to why they did not meet the criteria for this section (and other relevant sections);

- Provide suggestions for information that may assist in changing this decision;
- Provide all correspondence in writing as well as verbally to ensure prospective Participants have the ability to seek advice based on hard evidence rather than hearsay.

Planning processes 1: Creating your plan

10. What are some of the significant challenges faced by NDIS Participants in the planning process?

LAC's and planners must have intensive training to understand the social and other impact of disability and what makes people with disability vulnerable. The NDIA must undertake intensive training for planners and plan reviewers to ensure that the Scheme is implemented as it was envisioned and not as a cost savings exercise. This training must also encompass respectful engagement with Participants and plan nominees to overcome the fear and distrust that is being experienced as a result of bullying by planners.

Participants report to NDIS appeals advocates that planners have suggested or expected them to undertake specialist and segregated supports, services or activities with other people with disability. This expectation or suggestion is clearly based on personal prejudices and lack of understanding or knowledge about the intent and objective of the NDIS. This coercive pressure by planners includes using transport as a financial incentive for people to attend group support and planners suggesting group activities '*with people like you*'. This does not respect the person's freedom of choice and control, and promotes marginalization and institutionalisation.

QAI has observed the NDIA compartmentalising Participants' needs according to their diagnoses. This makes it difficult to understand why one person might need certain supports whilst another might need something completely different, or not have that need at all.

Participants in rural, regional and remote localities face additional difficulties. Planners and LACs must be informed of the much higher cost of transport due to distances involved; the higher costs of living; and the various issues related to an isolated lifestyle. These matters must be appropriately factored into the processes to produce the Participant's plan. Planners (or LACs) must assume that all Participants have the greatest understanding and knowledge about their needs. There must be no assumption that distance equates to ignorance. It is insulting to be patronized or to have it assumed that a Participant, family member or nominee is less well informed as a result of where they reside. The same courtesy of simply asking the question rather than assuming the answer should be afforded to all Participants, regardless of where they live.

Participants with complex needs are exclusively managed by the NDIA, where other Participants are outsourced to NDIA partners – LAC's. Participants with particularly complex needs should be afforded the same respect by NDIA planners that other Participants are given when accessing LAC offices. LAC's often complete home visits to address the needs of the Participant, however planners currently refuse to leave the office. Participants with complex needs are often excluded from the planning processes themselves and the NDIA and providers create plans around the Participant, but not with the Participant.

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

The NDIA should invest in appropriate pre-planning (with independence from direct service provision organisations) so that there are fewer internal reviews and appeals, and to enable LACs to

return to their intended functions of linking and connecting people with generic and specialist services. Foster smaller and consultative community-based services that engage local staff particularly with pre-planning activities.

Interactions between QAI Advocates and LACs have indicated that LACs experience high caseloads. LACs with very high caseloads do not have sufficient time to carry out their intended functions of linking and connecting people with generic and specialist services. Also, QAI considers that this lack of capacity by LACs may be one reason why there are so many requests for support coordination.

QAI considers the planning process should be led by the Participant to ensure their 'choice and control' especially in terms of identifying their current and life needs, the supports required and how they are provided.

The NDIA should fund translation services for Participants from Culturally and Linguistically Diverse backgrounds during the planning process and to engage with support coordination services.

Implementation is a significant issue for NDIA Participants. LAC's workloads are too high, with the result that they are not able to provide the level of support coordination Participants need to understand their plan. Participants with support coordination funding can feel as though they have been left to fend for themselves, as requests for service to support coordinators do not occur in a timely matter. Support coordinators require training from the NDIA on how to proactively implement Participant plans.

Participants should be asked to submit a self-assessment about what they need in order to attain their goals and should be incorporated into the planning process. Planners must have skills in 'active listening'. It is the experience of QAI advocates working with Participants that the focus of Planners relates to the cost of support, rather than the quality of life that support would provide. This appears to be part of a broader trend towards Planners demonstrating a commercial attitude. QAI perceives that KPIs, staffing caps and time pressures impact what planners do. The preponderance of this attitude of commerciality means that Participants feel like they are being judged on their worth.

Planners must focus on inclusive approaches to supports while respecting the wants and wishes of Participants. Planning must remain person-centred. While all reasonable measures should be made to increase the speed and efficiency of the planning process, the introduction of Typical Support Packages (TSPs) has not been successful and have resulted in an increase in internal reviews and external appeals, as well as in Participant dissatisfaction.

The NDIA should ensure that supports that Participants and nominees discuss and agree to at planning meetings are included in the plan. When some Participants have contacted planners to discuss discrepancies in plans or areas of disagreement they have been told that this is seeking a review, and have threatened that plans will be reduced at each successive review. Other planners have returned plans to Participants with no changes or only minor ones. Participants have not got the plans to which they believed they had agreed.

The NDIA must assess informal supports in an open and equitable manner. The assessment of informal supports is a major flaw in the implementation of the Scheme. This is most evident for Participants who have children accessing the NDIS. Any family living within 30 minutes of a

Participant is often the determining factor that a family is perceived to have informal support. This results in a plan with dramatically reduced funding. There is little consideration that grandparents may not be willing or able to provide that support. If a family has no or very little informal support this is ignored and not addressed within the plan. Informal supports must not be factored into planning as a cost-savings exercise. Instead, informal supporters must be considered as enhancing the Participant's life if well-fortified. Where those informal supports are tenuous or struggling, planners must ensure that the Participant and their supporters are offered other funds to augment or replace that informal support depending on their wants and wishes.

The NDIA should conduct random audits of plans developed by NDIA Planners to determine consistency of content and supports.

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?

To assist in the process, QAI recommends that Participants should be asked to submit a self-assessment about what they need in order to attain their goals and should be incorporated into the planning process. This is clearly a high priority given the dearth of knowledge or understanding in the planner workforce about the social model of disability and support needs for individuals as mentioned above.

QAI contends that the NDIA should be able to approve plans within 28 days of a Participant attending a planning meeting. For urgent and emergency requests, we believe a 14 day limit should apply.

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?

Plan items for supports for some Participants with psychosocial disabilities may be unsuitable. For example community access is not always appropriate for someone experiencing severe agoraphobia. The results of this type of planning anomaly results in some people spending little or none of their funding, and the response from the NDIA is to revoke the funding altogether.

QAI is aware that many Participants are being denied home modifications within their plans, prompting external reviews to the AAT.

Attributing small amounts of funding to Participant plans for accommodation rather than delivering on the promised and promoted Specialist Disability Accommodation (SDA), is not only deeply disappointing but confounding and instils further distrust in the Scheme and its implementation.

For rural, regional and remote people, significant additional attention must be paid to communication in the lead up to the planning meeting, to afford every opportunity to be well prepared for a successful plan meeting – including provision of information resources and links to websites. The more remote the address, the greater attention should be paid to this. There should be better and more communication about alternatives to the traditional service provider/Participant relationship so that the Participant and their nominee may consider all alternative service delivery in their area especially when there are no traditional service provider options available – supporting an innovative, resourceful approach which also allowed for flexibility in funding allocations and fluidity between budget components.

The NDIA could also explain what type of supports are available under the scheme prior to the planning meeting, to help Participants plan their support requests. Too often, Participants are told what support is available after a plan has been approved, resulting in funding gaps for support services they were unaware was available.

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

Similarly to access issues with access, Participants often receive template information which may or may not apply to their personal circumstances. The reasons for decisions are very rarely provided in writing unless someone requests an internal review. The internal review outcomes are also templates which can often have other Participant's names and details on them.

The personal bias, experience and perception of the planner and their personal prejudices and beliefs seems to prevail over the legislation and expert opinion at times (for example, medical reports). QAI has observed the NDIA compartmentalising Participants' needs according to their diagnoses. This makes it difficult to understand why one person might need certain supports whilst another might need something completely different, or not have that need at all.

There is mystery surrounding the existence of "expert teams" to whom planners apparently can or do defer when they are uncertain about some matters. There is a need for transparency about what these teams do, where they are based and what expertise they are deemed to possess. When Participants complete a Freedom of Information request, they are often unable to access this expert opinion that directly affects them.

For Participants who are deemed to require 24 hours support 7 days per week (24x7), the NDIA Planners have undertaken to pressure them to Supported Independent Living (SIL) arrangements whereby the service provider eventually assumes most control of the Plan. Participants are not given adequate information about the inflexibility of SIL and the loss of autonomy and control of their Plan.

In most instances, the avoidance of information about alternatives and benefits of accessing the NDIS with a non-SIL funded Plan, and lack of transparency regarding the over-inflation of SILS quotes is forcing more people back to the archaic model of group or shared home living.

If a participant wants to share with another person and articulates a desire to share some supports with their chosen housemate, (ie: overnight support only, or a combination of one or two activities), each person is very possibly able to obtain a Plan that is not only going to meet their needs but also be less restrictive, more flexible should either housemate wish to relocate, and is possibly more efficient and effective.

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?

The shift from the initial phone-based planning to face-to-face planning has been welcomed.

The introduction of Typical Support Packages (TSPs), which were introduced following the Productivity Commission's report of October 2017, has been highly problematic. The introduction of TSPs has resulted in less individualisation in plans. The process is that a Participant answers questions and then a computer creates a plan with amounts. Prior to the introduction of TSPs, the NDIA built Plans from the ground up using spreadsheets. QAI recommends removing TSP to

reduce internal reviews, AAT appeals and Participant dissatisfaction. QAI considers it false economy to consider TSPs a time saver. It would be preferable to create a good plan in the first place. The NDIA would be able to address individuals' needs, rather than another template outcome.

Planning processes 2: Using and reviewing plans

16. What are some of the significant challenges faced by NDIS Participants in using the supports in their plan?

The NDIA should ensure that there are no service/support gaps and provide early intervention to Participants and nominees to ensure that supports are not withheld even if funds are expended before end of a plan.

Participants, especially those who have limited informal supports can struggle to understand their NDIS plan, as it is written in NDIA's own language. Without the correct support to implement their plan (such as support coordination), Participants are left to fumble through the implementation process.

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?

NDIA staff must give greater attention and consideration to the issues impacting Participants, nominees and supporters in regional and remote areas particularly with issues and costs associated with transport, thin markets and alternatives to traditional service provision.

When Participants have expended funds before the plan's expiry date, there is a risk of critical services being withheld and Participants experiencing a high degree of stress. Many have been erroneously informed by LACs or planners that they "shouldn't worry because plans don't expire". This treatment and lack of proactive support from the NDIA is unsatisfactory. Support and clear information must be provided to those impacted to allay concerns and ensure that supports and services are not withheld. Similar alarm and distress is caused when service providers submit service bookings on the Participant's portal, giving the appearance that funds have been expended. This practice should be discontinued and penalties imposed upon service providers who seek to "squirrel away" Participant funds.

NDIA staff and partners require a deeper understanding in how to communicate effectively with people of different levels of impairment. Again, a template approach to explaining information to Participants and their informal supports can lead to confusion and misunderstanding during implement.

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

The NDIA should inform all Participants of the availability of independent advocates to support them through the process. The NDIA should also invest in understanding local supports available. Many Participants are told they were not funded for certain items because it is provided by community or mainstream services, which in many places across the country is incorrect.

The NDIA also need to raise greater awareness of a Participant's rights in regard to engaging with service providers. Clearer information is required for Participants to understand what type of behaviour is unacceptable from providers such as convoluted service agreements, unreasonable

exit clauses and or unreasonable cancellation fees.

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

The NDIA has unfortunately created fear amongst Participants in relation to requesting plan reviews. This is due to the widespread issue of plan funding being reduced, even when there are clear and reasonable explanations for underutilisation. Plans must not be reduced unless Participants disclose they no longer require specific funds or support types. Many Participants are unable to properly utilise funding allocated to them due to thin markets (which may result from their location or their disability type or complexity) or inappropriate allocation of funding within the categories in their plans.

Other key issues include with plan reviews:

- Section 100 reviews being mischaracterised as s 48 reviews, which circumvents the Participant's right to proceed to an external appeal. It is QAI's experience that Participants are often not aware of the differences between s 48 reviews and s 100 reviews. For example – a significant number of QAI clients have requested a review under s 100 (using the template on the NDIS website), yet have received a letter from the NDIA misrepresenting the review as a section 48 change of circumstances review, or a letter refusing the request for review. Also, QAI has noticed a procedural and access issue: the template for requesting a section 100 review on the NDIS website was changed from Word to PDF. This reduced the number of words which can be included on the form and PDFs are also generally less accessible for people with vision impairments and screen readers. The NDIA must cease the manipulation of reviews under s 100 by either refusing the review request or attempting to thwart the process by deception and inserting the review under s 48.
- The NDIA must ensure that reviews are free from conflict of interest and breaches of confidentiality by warranting that no staff members involved in the original decisions are involved. Section 100 provides that the person reviewing the decision must not have been involved in making the reviewable decision. However, QAI is aware of examples where, in response to a request for a review under section 100, the person who made the original reviewable decision has telephoned the Participant to invite him or her to a meeting. This clearly is a breach of privacy, a conflict of interest and inspires no trust in the process. Strict penalties for breaches must apply.
- QAI is aware of a number of inconsistencies and inaccurate information being relayed to Participants and applicants via the 1800 number. Often Participants are told that they cannot submit a new access request form unless they have had an internal review.
- For rural, regional and remote Participants, plan reviews must take adequate account of any difficulties in sourcing service providers so there are no assumptions about reasons for unexpended funds.
- There is also concern regarding s48 reviews conducted by the NDIA at the discretion of the CEO. This ability to review plans at any point in time reduced confidence in the scheme and certainty over plans. S48 reviews are also being conducted in order to try and fix errors in planning outcomes, which should have been addressed by the NDIA at the planning meeting.

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

The NDIA must:

- Ensure Participants' needs are adequately assessed at the initial planning meeting to reduce internal and subsequent external reviews;
- Provide information and questions to providers who are providing supporting evidence (such as allied health therapists);
- Ensure equitable access to all forms including review request forms and not restrict word limitations by the use of PDF or other means;
- Participants should be able to request that their information be sent to the Technical Advisory Team for assessment;
- Improve liaison between the internal review team and the Early Response Team (ERT).

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

Participants should be notified of the outcome of their plan review in writing within 28 days.

Appealing a decision by the NDIA

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

The NDIA should whitelist formal advocacy organisations to reduce red tape and better enable advocates to assist Participants and applicants.

QAI is aware of at least four clients who applied for internal review and then subsequently progressed to the AAT. That is – they had lodged their application to the AAT, obtained legal advice from Legal Aid Queensland, and were booked in for a case conference. In all four of these cases, the NDIA agreed to the request and the matter was settled before the first case conference based on information provided at the internal review. No additional information was provided. This is an alarming trend. QAI asserts that best practice in decision-making must occur in the first place, thereby reducing applications for internal review and appeals to the AAT.

The Early Resolution Team ('ERT') is usually comprised of allied health professionals or lawyers. As mentioned above, Planners are not consistently well-qualified. ERT involvement begins after the AAT process is commenced. QAI strongly recommends better liaison between the internal review team and ERT.

Where the NDIA decides to deny the Participants application for review, the NDIS must appoint appropriately trained staff to personally contact the Participant soon after the Participant receives the letter denying the internal review. This NDIA staff member should discuss in greater detail with the Participant, their nominee or advocate the reasons for the negative outcome, and provide advice about evidence that may potentially produce a successful request outcome. This staff member would then confirm the Participant's right to pursue the matter further via the AAT, and provide suggestions to best utilise the existing plan in the meantime. Further advice must be offered regarding using the period to gather evidence to support their review claim. The offer of practical suggestions about options to have unmet needs addressed

via the next plan review or other schemes in addition to the NDIS would mitigate the antagonism and distressed caused by the current processes.

The external reviews process is designed to be an alternative dispute resolution, however, more often the NDIA are making Participants feel they are on trial. The NDIA appoints lawyers from first application, further increasing the power imbalance.

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

The National Reviews Team (NRT) have been a significant improvement on internal reviews. They are independent from the local office and have access to resources and decision making that local offices do not appear to have. The NRT are also more communicative. However, there are still discrepancies with communication and decisions. The NRT will utilise a triage system based on levels of emergency. Unfortunately, many people undergoing internal reviews are in emergency situations due to detrimental decisions made by the NDIA. Participants should not be disadvantaged due to frontline decisions.

The NDIA's AAT legal department is currently understaffed and overworked. Matters before the Tribunal are assigned legal representation for the NDIA at the 11th hour and they are not always across the issues at hand. This leads to poor quality statement of issues that are submitted to Participants and the Tribunal usually one day prior to the first case conference. The NDIA has been attempting to provide instruction in a timely matter, however as many matters are assigned and then reassigned to different legal representatives and NDIA instructors consistently, the crux of issues can be lost in translation, requiring the Participant to repeat themselves, often exacerbating duress and anxieties.

QAI also believes that this understaffing issue is impacting on how Tribunal resources are being used. A trend of offers being provided, or request for a case conference to be vacated due to various issues less than 24 hours before a case conference means the Tribunal is unable to use that timeslot for another matter. These offers or request for vacation could have occurred much earlier allowing the Tribunal to use these timeslots for urgent matters, as usually the NDIA has the information weeks prior to the vacation request.

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

The NDIA should provide a readily available means to track progress of reviews for advocates and Participants.

There is a lack of consistency and objectivity in the process of transition from one plan to another. If there is no need to change any aspect of a Participant's plan, and no change of circumstances, the Participant's situation and disability is stable, then an automatic rollover option could be requested by the Participant. There should not be the assumption to automatically roll-over without the consent of Participant as they may wish to review their goals, supports, services, and or to seek a review. QAI suggests that this option may apply if some funding is not used in one plan.

If a Participant's disability is stable, and their living conditions are safe and comfortable, and they are not anticipating any change in needs or circumstances, then QAI considers the option should be offered to the Participant to be provided with a longer plan of perhaps up to 5 years,

with the option to request a review through the current option of changed circumstances should such a need arise.

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

Participants should be notified of the outcome of the review of their decision in writing within 28 days.

Removing red tape from the NDIS: The legislative framework

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

Above, we set out our submissions on the key provisions of the legislation that require amendment.

In light of recent decisions through the Tribunal and recent agreements by the Council of Australian Governments, there should be amendments to the *National Disability Insurance Scheme (Becoming a Participant) Rules 2016 (Cth)* ('Becoming a Participant') and the *National Disability Insurance Scheme (Supports for Participants) Rules 2013 (Cth)* (Supports for Participants).

Becoming a Participant:

- Changes to age and residency requirements as set out above;
- Participants should be able to have choice and control over what medical interventions they are willing to undergo when it involves high risk procedures such as spinal surgery in order to satisfy permanency criteria.

Supports for Participants:

- The NDIA must seek expert opinion outside of the Agency when deciding whether supports or services are 'effective and beneficial'
- There should be definitions regarding the outline of what is reasonable for family members, carers, informal networks and the community to provide. Currently the Rules are open to interpretation and the wellbeing of informal supports are not appropriately being taken into consideration. The NDIA often use the notion of 'parental responsibility', as a reason for declining supports to those under 18 years of age and sometimes adult. A definition of parental responsibility will assist with staff and Participants alike with providing rational for funding;
- Updates and information are required for mainstream interface responsibilities: this includes Health; Mental Health; Child Protection; Early Childhood; School Education; Higher Education; Employment; Housing and Justice.

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 merit review process?

g. Improve the way other government services interact with the Scheme?

QAI has addressed these questions in other areas of this submission.

Plan amendments

28. What are the significant challenges faced by NDIS Participants in changing their plan?

Participants currently fear the unknown, especially when it comes to requesting changes to their plans. Participants require certainty that requesting a change in one section of their plan will not adversely affect their overall plan. Participants are also waiting extended periods of time for changes to plans.

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?

Plan amendments would be welcomed for administrative purposes such as updating goals and written information on the plan, or changing a management style to increase choice and control only. Plan amendments should not be used as a review tool, which the NDIA are currently doing through 'light touch plan reviews'.

Plan amendments should not be used for reviewable decisions as set out in s99 of the Act. This is to ensure Participants rights to external reviews are upheld. QAI is wary of plan amendments being incorrectly utilised by the NDIA similarly to how s100 reviews have been and continue to be mischaracterised as s48 reviews.

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

Ideally, a Participant would be able to explain their changes in a method which is preferable to them, and this information being taken at face value. However, if the NDIA requires supporting evidence to substantiate this claim, 28 days would allow Participants to gather information from those required bearing in mind that in many circumstances appointments for specialist reports may take many months. QAI asserts that a letter from an allied health professional should be accepted by the NDIA in the interim.

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

As noted previously QAI has addressed this question throughout this submission.

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

The NDIA should proactively engage with a Participant before, during and after changes to a plan. Open communication is severely lacking from the NDIA and QAI believes with better communication between NDIA and Participants, there will be less room for error and more room for positive outcomes and rebuild confidence in the Scheme and its processes.

We are happy to provide further information or clarification of the matters raised in this submission upon request.

Yours Faithfully,

A handwritten signature in black ink, appearing to read "Michelle O'Flynn". The signature is written in a cursive, flowing style.

Michelle O'Flynn
Director