# Submission: Department of Social Services Review on Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape



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Department of Social Services

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### About Queenslanders with Disability Network (QDN)

Queenslanders with Disability Network (QDN) is an organisation of, for, and with people with disability. The organisation’s motto is “nothing about us without us”. QDN operates a state-wide network of over 2000 members and supporters who provide information, feedback and views from a consumer perspective to inform disability policy and disability advocacy. This submission is informed by the lived experience of our members and supporters, and our allies including Queensland Advocacy Incorporated, the Queensland Alliance for Mental Health and People with Disability Australia.

### Introduction

The National Disability Insurance Scheme (NDIS) was founded on transformational principles of choice and control and social and economic participation. QDN believes the National Disability Insurance Scheme (NDIS) is a critical investment in the supports and needs of people with disability to live their day to day life in their communities, based upon principles of choice and control. NDIS participants want to access quality, affordable and integrated supports across mainstream, community and specialist services.

QDN welcomes the opportunity to make a submission to the Department of Social Services on the review into *Improving the National Disability Insurance Scheme (NDIS) Experience: Establishing a Participant Service Guarantee and removing legislative red tape (the Review).* QDN looksforward to the outcomes of this Review improving the experiences of people with disability who have interactions with the NDIS from 1 July 2020. QDN believes that people with disability should have lead roles in developing the NDIS policies and procedures that affect them, and also be able to test NDIS processes before they are implemented.

QDN’s response to the Review is informed by Queenslanders with disability including QDN’s 2,000 strong membership and support base and QDN’s 21 Local Support Peer Groups across the state.

QDN’s submission responds to: (1) the possible principles for service standards; (2) participant experience; (3) appealing a decision by the NDIA, and (4) Legislative Framework, by focusing on the lived experiences of QDN members who have had interactions with the NDIS, as well as the experiences of our allied organisations. QDN’s recommendations in relation to these issues are below, and at Attachment A of this submission.

### Summary of matters for consideration by the Review

The NDIS offers an opportunity for significant change for Queenslanders with disability and many are experiencing access to essential, much-needed support for the first time under the scheme. QDN supports the establishment of the NDIS Participant Service Guarantee and its intention to improve and positively support the experience of participants through the entire NDIS pathway.

QDN notes the Commonwealth Government has committed an additional $2 million funding for the Commonwealth Ombudsman to monitor the NDIA’s performance against the Participant Service Guarantee’s timeframes and to support NDIS participants to pursue complaints about the timeframes they have experienced. QDN also notes that the legislative requirements under the Participant Service Guarantee will include appropriate standards and timeframes for the NDIA to report against as part of its existing quarterly reporting to the Disability Reform Council (DRC). QDN recommends consideration of measurement of Service Standards against Service Guarantee Principles beyond timelessness to include *Engaged, Expert, Connected* and *Valued, Decisions Made on Meri*t and *Accessible.* QDN also recommends a mechanism be established so that people with disability and their families and carers are engaged as part of the monitoring function of the Commonwealth Ombudsman to ensure the voice and lived experience of people with disability informs the data and performance measurement.

QDN member experience is that people with disability are already challenged to navigate the NDIS system and to talk to someone and to find out what is happening along their participant journey. QDN notes the Productivity Commission’s comment in the National Disability Agreement Review Report (January 2019) that disability advocacy is a shared responsibility between the Australian, State and Territory governments. QDN recommends additional funded supports be in-place to provide individual support and advocacy for people with disability who have complaints about the NDIA not meeting its obligations under the Participant Service Guarantee, so they can escalate their concerns to the NDIS Ombudsman.

Queensland’s transition to the NDIS differs from other jurisdictions. Queensland’s bilateral agreement outlines arrangements for 90,000 Queenslanders with disability to access the NDIS, with 45,000 being new participants to the scheme. Queensland’s phasing to the NDIS is unique, having 50 per cent of people entering the scheme not having specialist disability support in place, prior to their participation in the scheme. This brings unique challenges. During transition, QDN was funded to work with groups of people who had difficulty accessing the NDIS as they were not connected to the service system. This included people with disability who are homeless, at risk of homelessness, live in boarding houses and caravan parks, people living in social and community housing, people exiting corrective services, and children and young people in child safety and juvenile justice. Other specific targeted strategies have been undertaken in Queensland to engage with people from Aboriginal and Torres Strait Islander (ASTI) and Cultural and Linguistically Diverse (CALD) backgrounds, people who live in remote and very remote communities. It is QDN’s experience that these cohorts of people with will not necessarily access the scheme through engagement processes that rely on an them to initiate access through a phone call to a 1800 number.

While QDN acknowledges the efforts that the NDIA is taking to enhance the participant pathway experience, we are concerned that if people do not receive adequate support at the pre-planning and planning stages, this will lead to people not receiving the supports they need and a greater number of Plan Reviews. Queensland’s experience is that people with disability with complex needs are not being transitioned through the Complex Needs Pathway in a timely way. QDN recommends the urgent implementation of NDIA staff training in the Complex Needs Pathway in Queensland and its urgent implementation. QDN recommends all services interacting with the people with disability with complex needs adopt protocols to identify whether the person is likely to meet NDIS eligibility requirements, and to facilitate an access request as a matter of urgency.

Slower than expected progress against bilateral estimates for new participants, delays in activation of plans and underutilisation of plans have been consistent features across Queensland’s transition to the NDIS. QDN member feedback notes that participant experience with the NDIS is falling short in relation to the lack of support for prospective participants to access the NDIS, lack of assessor and planner expertise, lack of pre-planning support prior to NDIS planning meetings, and quality and timely review of access decisions and plan reviews. QDN members have provided feedback about how being able to review draft plans prior to plans being approved will enable participants to have greater say in the development of their plans and foster greater understanding of why particular decisions have been made and may lead to less unscheduled reviews and appeals.

The Quarter 4 2019 NDIS Report to the Council of Australian Governments (COAG) Disability Reform Council (DRC) noted only 57 per cent of Queensland’s prospective participants against bilateral estimates, had transitioned at 30 June 2019; only 41 per cent of participants had supports coordination in the plans; plan activation from initial plan approval to activation was between 30 to 59 days for 11 per cent of participants with 6 per cent participants of participants not activating their plans at all. Participants are also not spending all their funds with plan utilisation rates at 63 per cent. QDN recommends the NDIA include supports coordination more routinely in plans to help participants activate services and purchase supports, and that this funding is not be time-limited.

As at 30 June 2019, there were 5,964 NDIS registered service providers in Queensland, however only 45 per cent were actively providing supports to participants. QDN recommends the NDIA examine the relationship between low rates of plan utilisation and market performance data. Slow market and workforce growth, and provider concerns about NDIS pricing, including NDIS pricing caps, and regulatory requirements under the NDIS Quality and Safeguards Framework disproportionate to service provider size, are impacting on provider growth and viability, particularly in Queensland’s rural and remote regions.

Building an active and responsive labour market and the ability of service providers to attract and retain workers are issues for Queensland, as well as wage parity issues between disability and the aged-care industries. The NDIS Demand Data Map provides forecast data for the scheme once it is fully developed (expected to be by 2023). In Queensland, providers are requesting ‘real-time’ data from the NDIA, particularly around Supported Disability Accommodation (SDA). Lack of real-time demand data information about where there is likely need for growth in particular services, means that providers cannot make informed decisions about the investment in supports provision, staff training and development of SDA. The current situation appears to be reactive, so providers are not in a proactive position to build their workforce capacity particularly a workforce with permanent positions.

QDN recommends that NDIS pricing for support workers’ pay scales also include a component for the provision for staff training and professional development. This would enhance worker interest to the sector, market interest in becoming an NDIS registered provider and also potentially contribute to better outcomes for participants through ensuring a skilled and developing workforce in disability sector.

NDIA administrative delays have also led to Queensland providers continuing to provide services and carrying debt while waiting for participant plans to be approved. This impacts provider viability and could lead to NDIS market failure in Queensland resulting in poorer outcomes for participants affected by thin markets.

QDN welcomes the release of changes to SDA Pricing and Payments Framework, to SDA Rules, the NDIS SDA Design Standards and the SDA Innovation Plan, and looks forward to these initiatives translating into better outcomes for participants needing SDA. However, again, the lack of real-time demand data, particularly around SDA mean that providers cannot make well-informed decisions about investing in SDA. QDN recommends NDIA routinely release of real-time data, particularly around the demand for SDA.

QDN welcomes efforts to improve NDIS governance arrangements and recommends a consensus model where agreement is required from the States and Territories and the Commonwealth on NDIS policy matters. Given States and Territories’ substantial investment in the scheme to ensure the best outcomes for people with disability who live in their jurisdictions, QDN is concerned that the NDIS amendment (Streamlined Governance) Bill 2019, currently in the Senate, could undermine the role of States and Territories in the scheme and will unduly centralise decision-making authority in the NDIS. QDN supports the January 2019 Productive Commission’s Report recommendations that the Australian, State and Territory Governments have a shared role in the NDIS and that this should be reflected in NDIS-related instruments including the NDIS Act.

QDN also welcomes the COAG’s agreed amendments from the NDIS 2015 Act Review at Attachment B of the Discussion Paper, however, QDN believes that an approach to strengthening of the Functions of the Agency under Chapter 6, Part 1 - NDIA Local Area Coordination and support coordination to support new entrants through the pre-access process, access, planning and implementation phases of the participant pathway are still not adequate in Queensland. It is critical that Local Area Coordinators and Support Coordinators have stronger knowledge of disability and the supports needs of participants in the execution of their roles and delivery of their services. Information, Linkages and Capacity Building (ILC) component of the NDIS is a critical piece to achieving the outcomes of this transformative change, and it is important that a strategic and considered approach to investment, as well as an increase in investment in this area is achieved, to ensure jurisdictional as well as national outcomes can be achieved. NDIA performance monitoring and management of the service providers who are delivering supports coordination also needs focus and attention.

In terms of making the participant experience with the NDIS better, QDN recommends a strategic approach in Queensland that engages community partners as well as internal resources and stronger role of the NDIA to include proactively identifying ‘new’ participants and supporting prospective participants through the access, pre-planning and planning process and for the NDIA to have a stronger role in market stewardship particularly in thin markets.

Queensland’s transition rate against bilateral estimates compares very unfavourably against other jurisdictions, with transition rates ranging between 60 per cent in the Northern Territory to 153 per cent in the Australian Capital Territory, indicating the need for more targeted strategies and NDIS investment in Queensland to support new entrants into the scheme.

Queensland’s geography and demographics are unique and include people with disability living in many rural, remote and very remote communities. These issues coupled with a transition rate of 57 per cent against bilateral estimates require the NDIA to bolster investment in strategies to build the capacity people with disability to support their access to the NDIS and to activate and implement their plans.

Some QDN members have reported disappointing experiences with the quality of supports coordination, in particular, poor communication with Supports Coordinators with delays of up to three months to get back to the participant; the lack of consistency in processes and procedures and inadequate time allocated to support the participant through all aspects of the pathway. QDN suggests the development of a Supports Coordination Framework in collaboration with people with disability, nationally consistent training of Supports Coordinators, use of nationally consistent templates for Supports Coordinators to guide participants through the NDIS pathway and NDIA performance monitoring of organisations commissioned to delivery supports coordination.

QDN is aware of gaps in services particularly in relation to Partners In Recovery (PIR) and the Queensland Community Support Scheme (QCSS). Sector allies confirm issues with transition stating there are still services, like Partners in Recovery, providing transitional services and the transition from these services to NDIS is not being adequately supported. Recently in Queensland the Queensland Community Care program was replaced by the QCSS. QDN was funded briefly to provide information and support to people during this transition. This also involved supporting people to check their eligibility for the NDIS. This was a time of change and uncertainty for these individuals and they needed support to negotiate arrangements with new providers and to navigate the NDIS.

QDN notes the average cost per person to support a person in the NDIS is $40,000 with the average investment per person in the Information, Linkages and Capacity Building (ILC) component of the NDIS at approximately $50. Given this, QDN recommends greater emphasis in the Legislative Framework on ILC to urgently provide adequate investment in social capital and to build the capacity of people with disability and their families for navigate the NDIS system. Information, Linkages and Capacity Building investment is also required for the nationally consistent training of Local Area Coordinators, so they have the knowledge, experience and skills to deliver nationally consistent support for people through the access, pre-planning, planning and implementation phases of the NDIS process. QDN suggests the use of nationally consistent LAC templates to support people’s journey through the NDIS pathway.

### Possible Principles for Service Standards

QDN agrees the possible Principles for the NDIA Service Standards of *Timely, Engaged, Expert, Connected, Valued, Decisions Made on Merit* and *Accessible,* noted in the Discussion Paper (pp. 5-6), and recommends strengthening of the suggested Service Standards related to these Principles to include QDN’s recommendations noted below and in Attachment A of this submission.

### Participant experiences with the NDIS

**Access Process**

QDN’s experience demonstrates significant challenges for people with disability to gather the documents to support their Access Requests and to provide evidence on the impact of their disability on their functional capacity. The NDIS pathway for people who are new to the scheme and those with complex needs, require a critical first step around NDIS pre-access that delivers targeted, tailored and user-friendly early engagement. QDN’s Getting-on-the-Grid and Peer-to-Peer Advocacy Projects demonstrated the importance of early engagement with the person to give them information about accessing the scheme and the hands-on support they need, and delivered positive outcomes for people with disability entering the NDIS.

QDN’s experience includes working with people with disability who were ‘new’ participants to the scheme including people who were hard-to-reach, often having complex interactions across multiple mainstream service systems.

QDN recommends that these hard-to-reach prospective participants and many other Queenslanders with disability need additional support and funding for the costs of assessments to evidence the functional impact of their disability and support to gather specific evidence for Access Request Form, and to help them complete the documentation needed to meet NDIA requirements. QDN also recommends that people are supported to attend appointments with their General Practitioners (GPs) and other health professionals so they can be provided with the information needed to accurately complete their Access Request Forms.

Further, 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. 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.

QDN believes the right to advocacy should be clearly articulated within the Act. It is vital that the role of advocacy in supporting a person to exercise choice and control with respect to the NDIS is acknowledged, respected and upheld.

At the pre-planning phase, QDN recommends that independent advocates support the person prepare for the planning conversation and to work through resources and processes to prepare the participant statement and help them identify goals to discuss with the NDIA planner and to identify the reasonable and necessary supports needed to reach their goals. At the planning phase, QDN recommends that the participant is provided support to communicate critical information about their disability and their support needs, goals and reasonable and necessary supports.

*Investment in NDIS Literacy***:** The goals of ILC are to promote individual capacity (ensuring that people with disability have to capacity to achieve their goals), and community inclusion. QDN’s experience indicates the need for ILC investment in NDIS literacy so that people with disability can operate in the new NDIS environment and have the capacity to obtain, process and understand basic NDIS information and the support needed to make appropriate NDIS decisions. NDIS literacy would help people with disability: (1) navigate the NDIS system, including filling out complex forms; (2) be able to share personal information about their disability and the impact of their disability with planners; (3) locate, choose and engage providers and services that suit their needs; (4) manage and implement their plans, and (5) understand the NDIS appeals’ processes.

**Planning Process**

QDN members report mixed feedback about the experience, expertise and qualifications of planners. Some members have had positive experiences saying they are “very happy” and have been “extremely fortunate as the planner was reasonably knowledgeable”. While other people reported: “the planner seemed good at the meeting but didn’t give me any information about where to get support and didn’t return my call for two weeks”.

*Planner training:* A consistent theme regarding planners is that the onus is on the individual to express their needs well: “if you are able to express your needs, you will do well. If you can’t do this, you may miss out on the essential supports you need. It all comes down to how well the person can tell their stories and explain their needs. You need to be able to express what your goals are and what supports you need to achieve your goals”.

Another QDN member responded: “The NDIS is incredibly complicated. If you are very organised, it can work very well. But if you’re not organised, or have difficulties organising yourself, it can be difficult. If the process was a little bit simpler it would be better”.

Further feedback from QDN members indicates that some people’s plans are being done by their services and that they have limited or no input in the development of the plans. QDN experience also indicated that participants do not routinely see a draft plan prior to plan approval, and that poorly crafted first plans are leading to the continuous roll over of poorly crafted subsequent plans that do not address the participants needs, goals or aspirations. QDN’s experience is that participants are often not provided with explanations about how planning decisions are made.

*Need for support in the planning process:* These member reflections highlight the need for people with disability and their families and supporters to have access to advocacy and peer support to navigate the NDIS planning process. As reported by a QDN member in regional Queensland: “I found it very easy due to peer support”. This was supported by another member who said: “I found the planners pretty good, providing the participants were able to relay the information in a way that planners would accept. It is better to have a person in the room with you”.

QDN’s experience of assisting people to navigate the NDIS indicates that planners need additional training to understand the diverse needs of people with disability. For example, if a person has previously had negative experiences with systems or authority and has difficulty articulating what they need, they may not be able to clearly give information about their needs and link them to goals and therefore not get their basic needs met in their plan. Feedback from QDN’s peer support workers also identifies that some people may give inaccurate information about the level of their support needs, “playing them down”, as generally, people with disability want to portray a positive, highly competent image of themselves to someone they perceive to be in a level of authority, perhaps resulting in the person not getting the funded support they need to have a good quality of life.

QDN observes, that in, general planners do not ask open-ended questions to elicit information from individuals. This can result in vital information about a person’s support needs being missed. Hence, the presence of an independent support person can help to draw these issues out further. Also, QDN feedback indicates there are instances where the Local Area Coordinator has led the planning process and where critical information about the individual has not been communicated to the NDIS planners who has the authority to sign-off on the participant’s plans.

Another theme from QDN members about their experience with planners, is the language that planners use. Many people with disability, particularly those with intellectual or cognitive impairment, report feelings of confusion regarding the language used by planners in planning meetings, many saying that planners need to ask simpler questions and to use simple language. The NDIS planning process needs to be accessible for all individuals accessing the scheme, and it is not appropriate for people to become disengaged as a result of an inaccessible process.

QDN is aware 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.

QDN concurs with our allies that 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.

*Supported Independent Living (SIL):* QDN’s work has highlighted challenges that participants and their families/decision makers/nominees are experiencing with regards to SIL. It is particularly important for planners to work with the participant to help them understand and fully explore what they need in relation to their SIL needs. Feedback to QDN indicates that some SIL providers are directly providing information to NDIA planners to be inputted into a participants plan without including the participant in pre-planning discussions or giving the participant or their family any information about what is in the quote, what is not in the quote and what this will mean for the person’s day to day supports. Feedback to QDN indicates that it is difficult to disaggregate shared versus individualised supports under SIL, in particular, the funding to assist the participant with social and community participation. Feedback to QDN indicates that participants are not being involved in discussions with their SIL provider prior to a quote being submitted despite this being a requirement. QDN believes that the SIL planning and quoting process is not reflective of the NDIA mandate to include the participant and their families in planning decision-making. The current processes in place also indicate that inadequate levels of support are being built into SIL quotes, leading to individuals having to ‘share supports’ to go in group of 3 to their individual allied health or doctor’s appointment, or being unable to go on a holiday as all the supports are ‘tied up’ in shared arrangements and can not be individually allocated for these essential day to day supports, leading to decreased choice and control for people with disability. For some participants previously funded under State Government disability supports, quotes have been provided without any consultation and people are transitioned into the same arrangements under the NDIS without any opportunity for choice or change. Where participants have been involved, feedback to QDN has included that the focus has been on maintaining what is in place without exploration of whether people want to change their accommodation arrangements, with whom they live and their supports. People have also reported that they have not been able to get a written copy of their individualised quote from their provider or the NDIA to be able to better understand what the individual, shared and flexible supports they have under the SIL. Similarly, the service agreements do not include a detailed breakdown of the annualised hours to identify the individual, shared and flexible supports.

Feedback to QDN also indicates that the options for management of their funding is limited within a SILs arrangement, and that they would like the option of plan management. Funding is tied directly to the SIL provider even when participants are requesting different options. Participants living in supported accommodation facilities are also being funded under SIL arrangements where this may not be the best mechanism to deliver the choice and control that people need to achieve their goals under the NDIS.

A robust, transparent and accountable mechanism for the provision of SIL quotes to the NDIA is essential to ensure that people with disability, requiring SIL arrangements, and their families can make informed decisions about their SIL arrangements and alternative options. The current practice indicates that some providers are submitting quotes directly to NDIA three months prior to planning meetings without any input engagement with the participant or their families to ensure they understand what is in and out, and what impacts this will have on the person’s day to day support and their options for services and support.

QDN believes that the current SIL processes don’t appear to be designed to support consumer driven market practices, as the direct relationship is between the service provider and the NDIA rather than the participant. QDN’s experience is that service providers are often not providing SDA and SIL to the participant, that the participant and their families are not included in SIL decision-making in the pre-planning phase and in SIL planning discussions with the NDIA. There is also limited information about what supports specifically sit under SIL, provided to the participant and their families by the NDIA and service providers.

Supported Independent Living is defined as including personal care and other assistance to enable a participant to live in a secure, independent environment in the community and incorporates assistance with and/or supervising tasks of daily life in a shared living environment. QDN notes there is no SIL Rule that participants must have only one provider to provide all the SIL supports.

With regards to Specialist Disability Accomodation (SDA), there is a reported lack of understanding by participants and their families about SDA and options. QDN considers that SDA and SIL services linked to one provider does not represent best practice, and this has implications where the SDA provider has already entered into an arrangement with a provider to be the SIL provider for that property. This limits choice and control, and can lead to support and whole-of-life services are provided by one provider that could have implications of market power. Potential conflicts of interest also arise when the provider is both the SDA and SIL provider, with one report to QDN that a participant was told it was not feasible to have more than one provider delivering the support in the household and they would have to find somewhere else to live.

QDN recommends urgent review of SIL and SDA policy and practice, in consultation with people with disability, and recommends the following as solutions for consideration:

**Prior to the planning meeting:**

* Provision of user-friendly information about SIL outlining what it covers and how costings have been determined provided in user friendly format accessible for all people with disability including an easy English version to be placed on NDIA website;
* SIL quotes include individualised funded supports to be built in for holidays, shopping and visits to health professionals so participants are not forced into ‘group support arrangements’ to be able to undertake their day to day activities like going to the physiotherapist.
* SIL providers be required to provide NDIA documentation signed by the participant and or their family member/substitute decision maker that the SILS arrangement has been discussed with them when the quote is submitted. This to also include that the provider has discussed the participant’s level of satisfaction with their current arrangement, and the quote is reflective of any changes/additions to the participants supports that would be seen as reasonable and necessary. Additionally this could include independent supports coordination to explore their options going forward. It is important that provider time for undertaking this work is built into funding arrangements.

**At the planning meeting:**

* Requirements are in place that during the NDIS plan review meeting, that the Planner reviews the SILS arrangement to ensure it aligns with the participants goals, including their current accommodation arrangements and that they are aware of the range of supports covered in their SILS arrangement.
* The NDIA has a requirement that the SIL provider must include a detailed breakdown of the range, frequency, and level of individual and shared supports, both regular and irregular in the participants Service Agreement. It is important that holidays, illness, hospitalisation are included in this.
* The Planner gives information about other options such as Independent Living Options to the participant as reasonable and necessary supports.

Broader systemic issues with regards to the practices and implementation of SILS are leading to limited choice and control for participants about who they live with and where they live leaving no real choice around housing and co-tenants, with group houses being the option provided rather than exploring more innovative and sustainable options.

QDN recommends the following to address broader systemic issues:

* Collaborative, strategic planning between State and Commonwealth Governments is undertaken as a priority to fund a range of accessible, affordable housing options to provide increased choice.
* Locally based ‘connection hubs’ that connect people with disability who are looking at shared living arrangements to assist people to find suitable co-tenants is also an option.
* Separation of SDA and SIL service provision
* Cease funding SIL arrangements for participants in supported accommodation facilities
* portable SIL funding to enable participants to seamlessly change their SIL provider
* NDIA exploration of providers of last resort, should arrangements break down.

*Planning grounded in the everyday experiences of the participant:* The complexity of analysing supports underlines the importance of the NDIS participant pathways such as the Complex Supports Needs Pathway. QDN’s work emphasises the importance of NDIA planner assessment grounded in the everyday circumstances of the participant in all aspects of their lives including their ability to access social and economic participation. QDN recommends NDIA consideration of collaboration between those involved in a person’s life and the provision of support, and holistic case management within the scheme. The NDIA needs to examine the possible benefits of targeted case management funding for participants with complex needs.

QDN has seen the tensions between the rigid use of reference packages, the adoption of Operational Guidelines and a transparent individualised planning process. Planners need to analyse the benefits of funding for supports rather than rely on a general decontextualized appraisal of the participant’s general capacity. Recent Administrative Appeals Tribunal (AAT) criticisms of the NDIS around the inclusion of generalised statements that funding of transport assistance is limited to those who cannot use public transport due to their disability, highlights this issue.

QDN experience is that planning is very challenging for the participants, in the context of a planning meeting, to identify and narrate all the elements of support they need. QDN advocates that participants need to be actively supported to do so by peer advocates, independent advocates, and other supports, and that Local Area Coordinators and NDIA staff have a clearly defined role in the planning development and approval processes. QDN urges that participant review of a draft plan is standard practice prior to final plan approval at both first plan and subsequent planning review meetings. A well-crafted and implemented plan is more likely to lead to good outcomes for the participant and is unlikely to trigger unscheduled reviews.

**Using and Reviewing Plans**

Supports coordination aims to assists participants active their plans in a timely manner, and successfully engage and negotiate with service providers. Queensland’s NDIS transition data shows only 41 per cent of participants had supports coordination in the plans, and that plan activation from initial plan approval to activation was often significantly delayed with 6 percent of participants, in Quarter 4 2018-2019, not activating their plans at all.

QDN’s members report their experience of inadequate supports coordination funding in participant plans and for some, supports coordination is removed after the first plan on the assumption that the participant has the capacity to coordinate their supports after one year, and that there is a variation in the quality of support provided by Support Coordinators. QDN recommends support coordination to be more routinely funded in participants’ plans, for this to be high quality, and be in place until the participant has built their capacity to successfully manage the coordination of their supports for themselves, acknowledging that some people may always require an element of supports coordination.

QDN also recommends the development of a Supports Coordination Framework, in collaboration with people with disability, that ensures the nationally consistent, high-quality supports coordination service provided to participants.

*Adequacy of the NDIS Market and workforce growth and plan underutilisation*: Another challenge for Queensland is the inadequate development of the NDIS market and workforce, particularly in rural and remote communities. Inadequate service availability in these communities is resulting in participants’ needs not being met. QDN looks forward to the outcomes of the Thin Markets Review and that the implementation of the Thin Markets Review recommendations ensuring that NDIS participants affected by thin markets have access to the supports they require. QDN experience is that the underutilisation of plans has resulted in people receiving fewer supports at plan review; the assumption being that the funding for supports is no longer required rather than it being the result of inadequate service availability or gaps in information on available services. QDN recommends NDIA leadership in collaboration with the Queensland government to urgently address the development of the NDIS market, and workforce demand.

*Plan review processes and self-management:* QDN is aware that some people who are self-managing their supports have had their plan reviews earlier than expected. This has lead to some invoices still being outstanding and being rolled over into next year’s funding. People who agree to earlier plan reviews should have their remaining plan funding available until their original plan expiry date and the administrative implications of this need to be addressed to ensure the burden is not placed on the person with disability who is self-managing because of the change of timeframe driven by the agency and the subsequent challenges experienced to billing, invoicing and plans.

*Review mechanisms:* QDN acknowledges that many people find the annual process of plan review to be very arduous. QDN gives in-principle support to plans being automatically rolled over on the proviso there is no change in the participant’s circumstance and the needs of the next year could be met with the same level of funding. In instances where the plan has been automatically rolled over and where the participant requests a plan review; this should be done in a timely manner.

A robust, transparent and accountable review mechanism provides an essential safety net for people who are affected by NDIA decision-making. This is particularly important where decision-making is complex, subjective or has a significant impact on the daily lives of affected people. In the NDIS, all three of these factors are often in play, making an efficient and responsive review system vital. QDN’s experience with NDIS review processes is that there are systemic issues such as gaps in communication about the review processes and outcomes. QDN’s experience is that Assistive Technology Reviews are taking up to nine months to complete with a substantial impact of the participant’s wellbeing. QDN’s experience is that, even to get a cushion for a member’s wheelchair took months with another member waiting 12 months for a new wheelchair. These delays are unacceptable and can lead to a significant impact on the person’s health and wellbeing.

QDN recommends consideration of efforts to improve the timelessness of the NDIA’s reviews and better communication with participants as there is a risk that participants’ right to review will be undermined and review processes will continue to lack fairness and transparency. In Queensland, the achievement of bilateral targets for access requests, plan approvals and scheduled plan reviews appear to have been prioritised over internal reviews and unscheduled plan reviews. It appears that participant-initiated reviews are considered ‘unplanned work’ and that the NDIA has put in place resourcing to handle a certain level of reviews, but the actual number has been far higher than anticipated.

**Plan Amendments**

Plan amendments are most commonly requested where there is an important change to the person’s circumstances. QDN experience indicates that the process involved in plan amendments is often disproportionate to the reason for the need for a plan amendment, and that the requests for plan amendments are not being conducted in a timely manner. QDN recommends timely responses to avoid the participant reaching the critical stage where supports are inadequate for their needs compromising their health and wellbeing.

QDN recommends a hierarchical approach to plan amendment requests, and timely responses to these requests. QDN recommends an approach to monitoring the status of the appeals process with the use of a system, such as the Australia Post tracking tool, so that participants can see the real-time status of their appeal.

### Appealing a decision by the NDIA

**General Comments**

QDN experience is that the process and information required for resolving disputes or disagreements is unclear. The NDIA rarely provides a contact name for appeals or a process that supports participants to escalate their concerns. These practices are not participant-friendly and actively discourage new entrants to the Scheme or funded participants to best advocate for their rights, and to enter a complex and bureaucratic dispute process. QDN experience and the experience of our allies shows that this process can be confusing and time consuming for families who are involved in an onerous amount of follow-up and that the review process is often taking months to resolve.

QDN recommends consistent information be provided to participants on the NDIS review process and about their rights to an internal review, and if necessary, to escalate this to the AAT. The NDIA should also provide consistent information about where people can access the support to appeal NDIS decisions.

**Access decision appeals**

The number of new entrants seeking access to the NDIS in Queensland is increasing. QDN’s experience is that new entrants who do not meet NDIS disability access requirements on their first attempt are succeeding on subsequent attempts.

QDN has successfully supported prospective participants on successive attempts to gain NDIS access by helping them identify the functional impacts of their disability and gather specific evidence to complete the Access Request Form, and to help them complete the documentation needed to meet NDIA requirements.

**Planning decision appeals**

QDN notes that, in terms of reviewing a participant’s plan, at Subsection 48 2A of the NDIS Act 2013, that the CEO must decide to conduct a review or not within 14 days after receiving a request, another 14 days to facilitate the review, and for the review to be completed *as soon as practicable.*

QDN recommends tighter time-frames as it is QDN’s experience that participants who have requested a plan review are being stuck in a lengthy internal review process while their support needs are not being met. The current process also adds substantial time where the participant decides to pursue an AAT review of an NDIA decision following an unsuccessful internal review. QDN’s experience suggests that the ability of the participant to monitor the status of the appeals process is an issue and suggests with the use of a system such as the Australia Post tracking tool.

### Legislative Framework

The notion of an ‘ordinary life’ captures the subjective nature of the right of people with disability to have an ordinary life. This is entrenched in the Objects and Guiding Principles of the NDIS Act. QDN’s view is that changes and amendments to the Act, and Rules under the Act, must be guided by the voices of people with disability, their families and carers. NDIS processes must reflect the application of the NDIS legislation to the person’s unique situation. The NDIA’s adherence to Operational Guidelines is at odds with the intent of the Act. QDN asserts the need for Rules and Operational Guidelines to be consistent with the intent of the legislation, that is, to support the independence and social and economic participation of people with disability.

QDN welcomes the agreed Council of Australian Governments’ amendments from the NDIS 2015 Act Review at Attachment B of the Discussion Paper, however, requests the governance structure of the NDIS include State and Territory partnership and collaboration with the Commonwealth to ensure the integration of State and Territory service systems with the NDIS. QDN welcomes more emphasis and stronger commitment to the ILC component of the NDIS and recommends expanding funding to enhance NDIS literacy, and to fund processes that provide quality support for people with disability though the pre-access, access, pre-planning, planning and implementation stages of the participant pathway.

QDN recommends updates to enhancements to the NDIS Participant Pathway including reporting on the implementation and outcomes of the NDIS Participant Service Guarantee as an ongoing standing item on the COAG Disability Reform Council agenda for 2020 - 2021.

QDN and our allies believe that there are intangible benefits from disability advocacy and that the reduction or absence of disability advocacy services imposes real costs on the wellbeing of people with disability, their families and the broader community. QDN notes that disability advocacy funding is separate from NDIS funding for several reasons including the need to ensure the independence of advocates, which is central to their effectiveness in helping people with disability to engage with the NDIS. QDN recommends that any reviews of the NDIS Act and Rules be conducted parallel with increased Commonwealth investment in disability advocacy so that prospective participants and funded participants are actively supported to navigate the NDIS participant pathway.

QDN supports our allies and believes the terms advocacy and disability should be clearly defined in the definitions section of the Act. The definition of “advocacy” must include the requirement that it is provided by advocacy organisations which are funded for this purpose and audited and accredited against state and/or federal standards. The definition of “disability” should be consistent with the understanding of disability articulated in the United Nations’ Convention on the Rights of Persons with Disability, 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). 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).

**Attachment A:** **QDN Recommendations on the Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing red tape**

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| **Issues** |
| **Possible Principles for NDIA Service Standards**  |
| **Principles and descriptions**  | **QDN Service Standards’ Recommendations**  |
| **Timely** The NDIS process will be easier to understand and use, enabling decisions about access, planning and review to happen promptly.  | The NDIA makes decisions in a timely and responsive manner: * Once the NDIA has appropriate information, Access request decisions are made in **14 days**.
* Participants are offered a planning meeting within **14 days** of receiving their *access met* decision.
* First plan approvals take less than **28 days** after their access decision
* Plans are approved within **14 days** of their final planning meeting, following the provision of necessary evidence.
* Plan amendments are considered within **5 days** of the request.
* Plans involving SDA or AT requests are made within **10 days** of the information being provided.
* Participants who request an internal review of a decision are contacted within **5 days** of the request.
* Include a timeframe for notification of revocation of access status by the CEO, which must give the Participant at least **3 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.
* A participant requesting a review of their plan within 3 months should not have to prove their circumstances have changed
* In regard to reviews, the words “as soon as reasonably practical” should be removed and reviews should be completed within **28 days**.
* 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. This needs to be amended to include the right to review this decision.
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| **Engaged**The NDIA engages with people with disability, their family, carers and other support persons when developing operating procedures and processes. | * QDN supports the suggested Service Standard for this Principle (at Attachment A), and recommends specific reference to *co-design* with people with disability as central to all policy and Participant Pathway design decisions to ensure these decisions best serve the needs of people with disability.
* QDN recommends that the NDIS complaints and feedback systems provide learning opportunities to inform continuous staff development and NDIA service delivery.
* QDN recommends the NDIA proactively identify and support ‘new’ entrants to submit high quality access requests; this includes targeting people from Aboriginal and Torres Strait Islander and CALD background, very remote and remote communities, people in Level 2 and Level 3 boarding houses, people in caravan parks, people in prisons and people who are homeless.
* Of importance to Queensland is the bilateral agreement target of 64,000 participants, with plans in place, by March 2020 - QDN recommends the NDIA focus substantial resources to engage with ‘new’ entrants so they can successfully access the Scheme.
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| **Expert**NDIA staff have a high level of disability training and understand the impact of particular disabilities have on people’s lives. They understand what supports are most effective for a person’s disability. | * QDN supports the suggested Service Standard for this Principle (in Attachment A), and requests NDIA assessor and planner recruitment preferentially appoint staff with allied health qualifications or experience in the disability sector; mandatory induction training in disability and the functional impact of disability on people’s lives; mandatory ongoing disability in-service training; timely roll-out of the staff training in the enhancements to the Participant Pathway and the implementation of these enhancements; and an emphasis of reflective practice processes which support continuous improvement in assessor and planner knowledge, skills and practice.
* QDN recommends that NDIA staff interactions with people with disability are underpinned by compassion and that the participant’s needs, goals and aspirations are central to planning decisions.
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| **Connected**The NDIA works well with governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services.  | * QDN supports the suggested Service Standard for this Principle (in Attachment A) for the NDIA to act collaborative with the broader service system and requests partnerships with State and Territory Governments to ensure the seamless transition of participants between service systems.
 |
| **Valued**Participants, their families, carers and other support persons feel valued in their interaction with the NDIS and know where to go if they need further assistance.  | * QDN supports the suggested Service Standard for this Principle (in Attachment A) and recommends NDIA staff have a profound understanding of disability, of the community and of the barriers that people with disability and their families face.
* QDN supports a greater emphasis on Information, Linkages and Capacity Building into the legislative framework under Chapter 2: subsection 14(a) of the NDIS Act 2013 (refer Attachment C) and looks forward the new definition expanding the NDIA’s funding power to fund persons and entities to provide information relating to disability and disability supports; and to provide assistance to build capacity amongst providers and people with disability and their families.
* QDN recommends ILC funding to specifically target NDIS literacy.
* QDN recommends key investment with community based organisations to assist people with disability to submit high quality NDIS Access Requests and to be support them in the pre-planning, planning and implementation phases of the participant pathway.
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| **Decisions made on merit**The NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made.  | * QDN supports the suggested Service Standard for this Principle (at Attachment A) for the NDIA to act in a transparent, informative and collaborative spirit, and requests the routine inclusion of participants in all NDIS decisions that impact their lives.
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| **Accessible** All people with disability can understand and use the NDIS, and the NDIS ensures its services are appropriate and sensitive for Aboriginal and Torres Strait Islander people, people from Culturally Linguistically Diverse (CALD) Backgrounds, LGBTQIA+ and other individuals.  | * QDN supports the suggested Service Standard for this Principle (at Attachment A) for the NDIA to provide information to meet the needs of specialised groups including CALD, LGBTQIA+ and Aboriginal and Torres Strait Islander people, to enable them to access the NDIS like any other citizen.
* QDN recommends that the NDIA routinely seeks and uses the input of people with disability and their families and carers to ensure access is fair, equal and transparent.
* QDN recommends the NDIA monitors and addresses potential barriers to accessing information and that information is communicated to each participant using language and a mode of communication and terms that the participant is most likely to understand.
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| **The NDIS Participant Experience: Participant Pathway** | **QDN’s Recommendations on improving the participant experience**  |
| Access Process  | **General Comment regarding the participant pathway:** QDN requests NDIA updates on enhancements to the NDIS Participant Pathway and reporting on the implementation and outcomes of the Participant Service Guarantee as an ongoing standing item on the COAG Disability Reform Council agenda for 2020 - 2021.QDN recommends:* The right to advocacy should be clearly articulated within the Act. It is vital that the role of advocacy in supporting a person to exercise choice and control with respect to the NDIS is acknowledged, respected and upheld.
* NDIA to have function to request and pay for additional assessments required to deliver evidence sought by NDIA for access pathway.

Participants to be engaged early in the NDIS pathway and are actively supported through the pre-access process with targeted, tailored and user-friendly information.* NDIA assessors to have experience and expertise in disability and to be appropriately trained.
* NDIS Access Request information is user-friendly and accessible.
* NDIA assessors understand the functional impact of disability rather than use a prescriptive list of conditions to inform the access decision.
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| Planning Process  | QDN recommends:* The NDIA support participants through the pre-planning and planning process with targeted, tailored and accessible information.
* Local Area Coordinators to have appropriate experience and expertise to be able to provide high quality participant support in the planning process and must ensure that all critical information about the individual is communicated to the NDIS planners prior to approval of participant plans.
* Planners to have appropriate experience and expertise in disability and the impact of disability on a person’s functional capacity.
* Planners to be appropriately trained and to be involved in continuous training in best practice.
* NDIA planner assessment must be grounded in the everyday circumstances of the participant in all aspects of their lives including their ability to access social and economic participation.
* Planners need to place participants at the centre of decision-making.
* Participants need access to independent support with pre-planning and planning processes
* Planning needs to be individualised with reasonable and necessary supports tailored to the participant’s goals and aspirations.
* NDIA decisions are responsive, transparent and timely.
* NDIA to consider collaboration between those involved in a person’s life and the provision of support, and holistic case management within the Scheme.
* Planners need to analyse the benefits of funding for supports rather than the inflexible adoption of Operational Guidelines and a transparent individualised planning process.
* Participant review of a draft plan is standard practice prior to final plan approval.

QDN recommends urgent review of SIL and SDA policy and practice, in consultation with people with disability, and recommends the following as solutions for consideration: **Prior to the planning meeting:** * Provision of user-friendly information about SIL outlining what it covers and how costings have been determined provided in user friendly format accessible for all people with disability including an easy English version to be placed on NDIA website;
* SIL quotes include individualised funded supports to be built in for holidays, shopping and visits to health professionals so participants are not forced into ‘group support arrangements’ to be able to undertake their day to day activities like going to the physiotherapist.
* SIL providers be required to provide NDIA documentation signed by the participant and or their family member/substitute decision maker that the SILS arrangement has been discussed with them when the quote is submitted. This to also include that the provider has discussed the participant’s level of satisfaction with their current arrangement, and the quote is reflective of any changes/additions to the participants supports that would be seen as reasonable and necessary. Additionally this could include independent supports coordination to explore their options going forward. It is important that provider time for undertaking this work is built into funding arrangements.

**At the planning meeting:** * Requirements are in place that during the NDIS plan review meeting, that the Planner reviews the SILS arrangement to ensure it aligns with the participants goals, including their current accommodation arrangements and that they are aware of the range of supports covered in their SILS arrangement.
* The NDIA has a requirement that the SIL provider must include a detailed breakdown of the range, frequency, and level of individual and shared supports, both regular and irregular in the participants Service Agreement. It is important that holidays, illness, hospitalisation are included in this.
* The Planner gives information about other options such as Independent Living Options to the participant as reasonable and necessary supports.

Broader systemic issues with regards to the practices and implementation of SILS are leading to limited choice and control for participants about who they live with and where they live leaving no real choice around housing and co-tenants, with group houses being the option provided rather than exploring more innovative and sustainable options. QDN recommends the following to address broader systemic issues: * Collaborative, strategic planning between State and Commonwealth Governments is undertaken as a priority to fund a range of accessible, affordable housing options to provide increased choice.
* Locally based ‘connection hubs’ that connect people with disability who are looking at shared living arrangements to assist people to find suitable co-tenants is also an option.
* Separation of SDA and SIL service provision
* Cease funding SIL arrangements for participants in supported accommodation facilities
* portable SIL funding to enable participants to seamlessly change their SIL provider
* NDIA exploration of providers of last resort, should arrangements break down.
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| Using and Reviewing Plans | QDN recommends:* The NDIA ensures supports coordination is adequately funded participant plans and is included in participant plans, particularly for participants with complex needs and those who have limited informal supports, for as long as required to build the participants capacity to manage their supports and services.
* The NDIA focus substantial resources and efforts to reduce waiting times at all points of the NDIS, especially plan approval, activation and review.
* The NDIA release a strategy to address thin markets as a matter of urgency.
* NDIA considers alternatives to fee-for-service funding, to ensure appropriate and quality services are delivered across all geographic locations.
* Participants being able to review draft plans prior to plans being approved as this will enable participants to have greater say in the development of their plans and foster greater understanding of why particular decisions have been made and may lead to less unscheduled reviews and appeals.
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| Plan Amendments  | QDN recommends:* NDIA plan amendment processes to be proportionate to the reason for the need for a plan amendment.
* The NDIA use a hierarchical approach to plan amendment requests, and to provide timely responses to these requests.
* The NDIA provide an approach to monitoring the status of the appeals process such as a tracking tool.
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| Appealing a Decision  | QDN recommends:* The NDIA routinely provide consistent information to new entrants and participants on NDIS review processes, including their rights to an internal review, and if necessary, to escalate this to the AAT.
* The NDIA to routinely provide consistent information about where people can access the support to appeal NDIS decisions.
* The NDIA to routinely provide a contact name for appeals, and the process that participants can use to escalate their concerns.
* The NDIA to provide consistent and timely review of decisions.
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| **The Legislative Framework**  | **QDN’s recommendations of the Legislative Framework**   |
| **Background:** The largely technical recommendations from the 2015 NDIA Act 2013 review endorsed by the Council of Australian Governments, have not yet been legislated. The current Review presents an opportunity to reconsider whether parts of the Act and Rules are working for people interacting with the NDIS. | **General comments:** QDN recommends:* People with disability and their families must lead NDIS policy discussions and be actively involved in the co-design of NDIS policy and processes.
* Changes and amendments to the NDIS Act and Rules under the ACT, must be guided by the voices of people with disability, their families and carers.
* NDIS processes must reflect the application of the NDIS legislation to the person with disability’s unique situation.
* More emphasis and stronger commitment to the ILC component of the NDIS including expanding funding to enhance NDIS literacy, and to fund processes that provide quality support for people with disability though the pre-access, access, pre-planning, planning and implementation stages of the participant pathway.
* The governance structure of the NDIS to include State and Territory partnership and collaboration with the Commonwealth to ensure the integration of State and Territory service systems with the NDIS.
* The Commonwealth adopt the January 2019 Productive Commission’s Report recommendations that the Commonwealth, State and Territory Governments have a shared role in the NDIS, rather than centralising decision-making authority in the NDIS, and that this should be reflected in NDIS-related instruments including the NDIS Act and that any legislative changes to NDIS governance arrangements be delayed pending the outcome of this review.
* The NDIA closely monitor and report on the performance of community partners delivering local area coordination and to urgently intervene where people with disability are not being adequately supported to navigate the participant pathway.
* Additional funding for disability advocacy organisations and Disabled Persons Organisations to support people with disability to navigate the NDIS Appeals Process and to support any complaints related to the Participant Service Guarantee.

**Access:** * Participants are supported through the pre-access process with targeted, tailored and user-friendly information.
* The NDIA uses an early engagement model to support peoples’ access to the NDIS.

**Assessment and Planning:** * Assessors and Planners have the appropriate skills and training in disability and the functional impact of disability and in engaging with people with disability.
* Participant involvement in pre-planning discussions to be standard practice.
* All planning discussions and face-to-face meetings include the participant or the participant’s nominee or guardian.
* Planning decisions be individualised and underpinned by the intent of the Act rather than rigid adherence to Operational Guidelines.
* Reasonable and necessary supports be individualised and support the person’s needs and their goals and aspirations.
* Participants review access plans prior to final approval.

**Review processes:** * The NDIA provide consistent information to participants about the NDIS review process of an NDIA decision and about their rights to an internal review, and if necessary, to escalate this to the AAT.
* The process and information required for resolving disputes or disagreements is user-friendly and clear.
* The NDIA to routinely provide a contact name for appeals, and the process to support participants to escalate their concerns.
* Reviews to be conducted in a timely way and participants should be able to track the review process using a NDIS review tracking tool.
 |