



SUBMISSION TO
IMPROVING
THE NDIS EXPERIENCE:
ESTABLISHING A PARTICIPANT SERVICE
GUARANTEE AND REMOVING
LEGISLATIVE RED TAPE

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About Darwin Community Legal Service

Darwin Community Legal Service (DCLS) is a multi-disciplinary service serving the communities of the Northern Territory (NT) Top End. Our specialised Seniors and Disability Rights Service provides advocacy support and empowers people in Darwin, Palmerston, Katherine and remote communities in the areas of disability and ageing.

DCLS also provides a general legal service and a tenancy service which, together, enable us to provide wrap-around support. We work to promote understanding of laws, create awareness and empower our community, to support access to services and rights, and to advocate for change that promotes fairness and justice.

In July 2018, the National Disability Insurance Scheme (NDIS) commenced full implementation in the NT. Since then, DCLS has supported 82 participants (with 95 different issues) to understand, access, and improve their outcomes under the NDIS. We have had to turn away many more potential clients because of our limited capacity. Sadly, we have barely touched the surface in remote areas where an intensive outreach approach is required. In addition, DCLS has also responded to 109 general inquiries about NDIS, and provided input in 47 education sessions about NDIS. On average each case takes six months to resolve – half a year that disability support for a vulnerable individual is inadequate or simply unavailable. Where children are concerned these delays can have serious consequences for their development and impact their life prospects.

Key Issues and Recommendations

The NDIS is a complex system, rolled out without the necessary supports and services in place. The result is that there are now pockets of people who are worse off than they were before the NDIS. A review of the Act should not occur in isolation: the objectives of the Act will not be realised without understanding how it is implemented and what happens on the ground.

Lack of services is a critical issue in the NT. Inflexibility and lack of understanding and expertise in responding to this fundamental flaw will continue to hinder the operation of the Act and scheme until the long-overdue safety net is implemented.

The onus of proof weighs heavily on the person with disability, who struggles with information asymmetry and is frustrated by delays and bureaucratic barriers. The obligations and burden should instead be on the scheme, with its bundles of unspent and unallocated resource and its army of workers and consultants, to ensure front line services and supports.

Access to the NDIS will be improved by:

- Providing NDIS resources that are accessible, appropriate and contain enough guidance to support a successful application.
- Providing quality information for participants - and medical/technical experts - about the requirements of s24 of the Act and the decision-making approach adopted by the NDIA.
- Ending the practice of rejecting applications for insufficient information. NDIA should refer back to the applicant with specific guidance about what's missing and how to obtain that information.
- Streamlining access for participants with significant impairments that have obvious functional restrictions related to their disability. For example, participants with complete blindness or deafness should not be required to submit specific evidence about impacts on their functional capacity for access purposes.
- Providing access to specialist services for assessment in areas where these services are not available.
- Providing clear and unequivocal timelines - and default provision of support if timelines are not met.
- Establishing less restrictive interpretation of requirements for NDIS access, and a more pro-active role for LACs and NDIA staff to assist applicants to establish eligibility, thereby shifting some of the burden from the applicant.
- Providing more support for the development of expertise and recruitment of relevant skill sets in the NDIA and its partners and of the resourcing of independent advocacy services for those who need them.



The planning process will be improved by:

- Including an offer of Coordination of Supports funding to participants at every plan development.
- Developing NDIS planners and placing a stronger recruitment focus on candidates with expertise in disability.
- Demystifying plans so participants are clear about what supports are available and how they might be secured.
- Basing performance measures for NDIA and NDIS Community Partners on acceptance at first submission and within time frames and on the comprehensiveness of plans, and
- Providing advocacy support to ensure that vulnerable participants understand how to best address their needs through the planning process.

The Review process will be improved by:

- Focusing on getting plans right in the first place.
- Acknowledging that circumstances change, and facilitating review processes in a timely and accessible way.
- Establishing legislated timeframes for delegates to deliver decisions in relation to s48 and s100 plan reviews.
- Considering the introduction of a plan amendment process to deal with minor amendments and adjustments.

Services should be guaranteed:

- A Participant Service Guarantee (PSG) should guarantee services, plain and simple.
- Guaranteeing services would mean guaranteeing access to services, e.g. by providing sufficient funding for travel to enable participants to access services, or by guaranteeing services will be available, no matter where participants live.
- NDIA must deliver on the promised “provider of last resort” as a matter of urgency.
- The PSG should guarantee appropriate support for applicants and participants, including expertise of delivery staff, standards of communication and information, and adequate resourcing of independent advocacy.

1. The Northern Territory context

The NDIS is one of the most significant social changes of this generation and we laud its objectives of:

- supporting the independence and social and economic participation of people with disability,
- providing reasonable and necessary supports, including early intervention supports, for participants,
- enabling people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports,
- facilitating the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability, and
- promoting the provision of high quality and innovative supports to people with disability.

However, in the implementation of a “nationally consistent approach” the scheme does not support tailored solutions according to need, nor does it support equitable access. Our experience indicates that the rhetoric of ‘national consistency’ is often used to justify ‘cookie-cutter’ decisions made without local context or understanding. Conversely, arbitrary decisions seem to be made without clear explanation or consistency. While regulation is often seen as a dirty word in the current environment, transparent guidance for decision-making is critical to ensure that the system is fair and effective. In its absence, there is a lingering perception that access to a plan, and support under the plan, is a lottery.

The NT faces unique challenges in service delivery stemming significantly from the tyranny of distance: the lack of infrastructure, high costs relative to other jurisdictions, and the lack of economies of scale. Over 26% of the NT population identifies as Aboriginal or Torres Strait Islander, (79% in remote NT) compared with the second highest figure of 4.6% in the jurisdiction of Tasmania.¹

Aboriginal people form a significant part of the DCLS clientele (as they do for all mainstream services in the NT) and have the most complex and immediate needs. Nationally, Aboriginal and Torres Strait Islander people are 1.7 times more likely than non-Indigenous people to be living with disability. Aboriginal and Torres Strait Islander children aged under 14 are more than twice as likely as non-Indigenous children to have a disability.² Therefore, part of this submission focuses on the challenges for Aboriginal people and those living in remote and regional areas of NT in accessing the NDIS and disability services. If those most in need are unable to access support, then the NDIS is not delivering.

¹ ABS Census 2016

² Aboriginal and Islander People with a Disability, 2012 <https://www.abs.gov.au/ausstats/abs@.nsf/mf/4433.0.55.005>.



NDIS implementation in the NT

At the commencement of the scheme, it was estimated that there were 4,933 potential NDIS participants in the NT. This figure is likely to be significantly understated because of a large Aboriginal population, mainly in remote locations, who either don't use the descriptor 'disabled', or don't access services where disability may be identified. Despite this, take up in the NT is at only half the estimated figure.³ This can be explained partly by the complexities in accessing the scheme, and partly because of the lack of market services to support individual plans.

People with disability are entitled to an equitable standard of services that meets their needs, no matter where they live. A scheme based on 'competition and choice' in locations where there is no competition nor choice further disadvantages those who are already significantly disadvantaged. Investment in services needs to be refocused on needs rather than on markets. The introduction of the NDIS has seen state services withdrawn in the transfer of resource and responsibility to NDIS, with no realistic support put in their place.

The NDIS have focused on developing markets and have neglected to provide the promised safety-net for those who have no access to a market. Of the 848 service providers registered in the NT, only 170 are active⁴, yet applications for packages to include travel to enable access to services are rejected.

Large financial packages for disability support services are widely publicised, but the reality is that the money is not being spent in the NT because there are no services. These funds are subsequently lost to the NT and re-allocated elsewhere.

³ COAG Disability Reform Council, Quarterly Report, 30 June 2019 <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

⁴ Ibid.

2. Access and eligibility

The four key barriers to NDIS access for participants in the Territory are:

- Lack of information;
- Difficulties in evidence gathering;
- Delays in decision-making; and
- Lack of support for applicants.

Lack of information

Getting clear and practical information about how to access the NDIS is an ongoing battle for people with disabilities in the NT. The time commitment, persistence and emotional resilience required to pursue an application is huge amongst a population with high disadvantage and many existing barriers to accessing basic services. Many people simply cannot access the scheme without support from an advocate. Some of the major obstacles are:

- Lack of guidance about how to document the s 24 criteria of diagnosed impairment, permanency, and impacts on functional capacity.
- Failure of NDIS to request missing information – with the consequence that many access requests are rejected on this ground alone.
- Over-reliance on technical jargon. NDIS should provide all information in plain English to enable participants to make informed decisions. NDIS explanatory documents have been translated into at least ten different languages including Arabic, Greek, Italian, Vietnamese and Chinese. However, NDIS documents are not produced in Aboriginal language and there is little involvement of Aboriginal interpreters in supporting access to NDIS.
- Insufficient use of Indigenous cultural understandings of disability to explain the functions of the scheme and what difference it may make to the life of a person. Residents of remote NT communities in some instances were fearful of the 'purple shirts' visiting their communities. NDIA outreach is often limited to 'meet and greet' community barbeques which don't offer explanation of the scheme and its benefits or detailed advice on how to access it.
- Communication modes are unsuitable. Letters are posted to individuals who don't understand them and discard them, or letters sit at a community office uncollected.

Difficulties in evidence gathering

The evidence requirements for NDIS access are complex, inflexible and often hidden from view. There are unstated rules and guidelines or specific words or language that need to be used to unlock access.

Evidence requirements are hard to satisfy because:

- accessing historical records is difficult and slow (an FOI request in the NT takes one month to process and complete),
- access to assessments from health professionals is hampered by long delays and waitlists,



- assessments by health professionals are expensive,
- some assessments can only be made interstate, adding to expense and delay,
- the NDIS access requirements discriminate against those who live in remote areas, are Indigenous, or do not speak English as their first language.

There is not enough training and information for medical practitioners to assist them in documenting the s24 criteria, and address functional capacity for all six domains on the Access Request Form. DCLS delivers information sessions to medical practitioners about how to effectively complete access request forms and draft supporting letters that meet the criteria. This ensures there will not be large numbers of rejections simply because the right wording is was not used. (See the “Cheat Sheet” developed at Attachment A)

The NDIA does not access relevant disability records already held by government (particularly records that prove eligibility for the Disability Support Pension, which require similar eligibility criteria), even when consent is provided in the access request. Instead the NDIA is making participants lodge additional Freedom of Information requests to obtain this information, or seek new assessments and reports.

Participation in the NDIS is inhibited for those in remote areas because evidence from allied health professionals is often required to meet the access criteria. Specialist medical services are limited, creating issues for participants needing medical evidence to support applications.

DCLS is aware of many clients on waiting lists of twelve months or more to receive services from neurologists, rheumatologists, ear nose and throat surgeons, and other specialists. As of September 2019, there was a ten-week wait time to see an occupational therapist. Specialised allied health services are also largely unavailable in the Territory, forcing participants to travel interstate at significant personal cost or wait it out on long public health waitlists with no access to supports in the interim.

Examples of difficulties sourcing evidence in the NT

- Two current clients with visual impairments have to fund their own travel to access specialist occupational therapists, as there are no specialist providers in the NT.
- A 37-year-old man with a neurological disability had his initial access request rejected due to lack of information about functional capacity. He has been placed on the public allied health wait list and will be waiting at least four months for an appointment.
- A 35-year-old woman with an intellectual impairment needs to see a neurologist to obtain evidence of her diagnosis. She has been placed on the public waitlist to see a specialist and has no timeframe for her appointment. Anecdotal evidence suggests that the waitlist for public neurology services exceeds 12 months in the Territory.
- A 59-year-old man with debilitating arthritis needs to see a rheumatologist to obtain a report with evidence of his diagnosis for access. It is expected that he will be waiting up to a year to receive an appointment with limited supports in the interim.
- Two brothers, aged 8 and 9 years old, are waiting for a paediatric report to provide evidence in support of their access requests. The paediatrician who previously saw one of the siblings is now at capacity with a 5-month waiting list, and not taking new clients. The mother of both boys is currently attempting to negotiate services for her children with this paediatrician.
- A 36-year-old woman with a hearing impairment and a learning delay is on a 12 month wait list for an Ear Nose and Throat Specialist. She requires evidence that her hearing impairment is permanent and has recently resorted to an appointment with a private specialist at significant personal financial cost given her reliance on the Disability Support Pension for income. She also requires an adult cognitive assessment for her learning delay. This is not accessible through the public health system in the NT and the price of a privately obtained assessment cannot be met on her income. After seven months, she is still waiting for access and has required substantial assistance from an advocate to progress her request. Given the high cost of assessments, access for this client remains very uncertain.
- A 20-year-old Aboriginal man with a cognitive impairment has been waiting four months to access an occupational therapy assessment through the public health system for evidence of functional capacity. He cannot afford the cost of a report from private providers as the DSP is his only source of income. He has been heavily reliant on advocacy support owing to his lack of informal supports and is still waiting for access.
- A 24-year-old man with dyslexia and a learning disability applied for NDIS Access and was asked to provide further supporting documentation. It took three months for him to obtain a report from a psychologist which has now been submitted to the NDIA. The participant is mainly seeking support to keep his current job and is very fearful that he will lose employment if he does not receive supports soon.

Delays in decision-making

DCLS is aware of few cases where the NDIA has complied with the 21-day access timeframe for deciding requests under s 20 of the Act. Since January 2018, the majority of our clients have waited more than the prescribed 21 days to receive a decision on their access requests, with most waiting 30 days or more.

The NDIA frequently uses s26(1) to request further information to extend timeframes, even when that information has already been provided. It is not unusual for NDIA staff to contact a participant around 12-16 days after lodgement to confirm already documented details such as address or date of birth. This is viewed by the NDIA as a s26(1) request for additional information and under s26(2) is used to lengthen the decision timeframe by a further 14 days.

There is often inconsistent advice from NDIA about when the timeframe commences for an access decision. We have variously been advised that there is an additional 5 day administration period added to the access timeframe, or that the timeframe does not commence until documents are uploaded into the NDIA system.

Examples of difficulties arising from delayed NDIS decision making

- A 54-year-old client with fibromyalgia was initially rejected due to lack of evidence showing her disability was permanent under section 24(1)(b). An Occupational Therapy assessment was completed and a report submitted as further evidence. She was again rejected access but not formally advised of this until two months after the date of the decision. The participant is now waiting on a specialist appointment for further evidence and continues to live without adequate supports.
- A 47-year-old woman with an intellectual disability physically submitted an Access Request Form to an NDIA staff member in her remote community in July 2019. She was required to leave the community a few months later for safety reasons. DCLS enquired about progress with her access decision and was advised in September 2019 that the NDIA had lost this access request and a new one would have to be lodged on behalf of the participant. A new access request was lodged and a decision has still not been made at the time of writing.

Lack of appropriate support for applicants

Local Area Coordinators (LACs) are engaged to help a participant to “understand and access the NDIS via workshops or individual discussions” about the NDIS. However, in our experience LACs are not providing this individualised support. Their advice is frequently limited to running workshops and handing over access request forms - with only limited instruction about the nature of the evidence required. Potential participants are often referred to the NDIS website for further information.

Access assistance should include individual face-to-face support by trained, knowledgeable NDIS staff and LAC staff. Investment at this early stage will reduce problems, delays and unwarranted rejections in later stages. However, there is a limit to the support that can be provided by LACs and NDIA staff in representing the best interests of the applicant, as they are not independent and are subject to the performance requirements and interests of the NDIA.

At present, limited independent advocacy support is available for NT participants but demand is very high. DCLS's service is beyond full capacity with new clients currently being placed on a six-week waiting list or offered interim advice for self-advocacy. Advocates play a critical role in explaining what the NDIS can do for a person with a disability, translating access requirements, and helping collect evidence relevant to the access criteria. Without additional advocacy services, access will continue to be a challenge for people with disabilities in the NT.

Recommendations – Creating Easier Access to the NDIS

Access to the NDIS will be improved by:

- Providing NDIS resources that are accessible, appropriate and contain enough guidance to support a successful application.
- Providing quality information for participants - and medical/technical experts - about the requirements of s24 of the Act and the decision-making approach adopted by the NDIA.
- Ending the practice of rejecting applications for insufficient information. NDIA should refer back to the applicant with specific guidance about what's missing and how to obtain that information.
- Streamlining access for participants with significant impairments that have obvious functional restrictions related to their disability. For example, participants with complete blindness or deafness should not be required to submit specific evidence about impacts on their functional capacity for access purposes.
- Providing access to specialist services for assessment in areas where these services are not available.
- Providing clear and unequivocal timelines - and default provision of support if timelines are not met.
- Establishing less restrictive interpretation of requirements for NDIS access, and a more pro-active role for LACs and NDIA staff to assist applicants to establish eligibility, thereby shifting some of the burden from the applicant.
- Providing more support for the development of expertise and recruitment of relevant skill sets in the NDIA and its partners and of the resourcing of independent advocacy services for those who need them.

"NDIS Navigators" as potential solutions

- One way of achieving quicker and easier access would be to establish NDIS Navigators, a role similar to the Aged Care System Navigators which are currently being trialled across Australia.
- Aged Care System Navigators operate under Department of Social Services (DSS) funding to provide face-to-face, phone and online assistance to seniors and their families with navigating the complexities of government supported aged care programs. Navigators are employed by advocacy organisations in receipt of this funding.
- NDIS Navigators could provide similar assistance with understanding the practicalities of access and reaching out to those facing language, cultural and geographical barriers. An independent support role such as an NDIS Navigator would allow for individualised support to navigate a complex system.

3. Developing a plan

Major challenges in the planning process are:

- Participants not equipped to tailor their own plan
- Excessive reliance on informal supports
- Poor quality service from NDIA partners

Participants not equipped to tailor their own plan

Participants continue to be confused by the planning process. They have rarely been asked what they want before, and they often lack understanding about what they need. They also lack information about the kind of evidence that has to be put forward to get the supports they need. The limited availability of skilled health professionals – needed to identify appropriate support and therapy to be included in plans - and the lack of advocacy support results in inadequate or inappropriate plans.

Complex NDIS language impedes understanding and participants' capacity for self-advocacy in planning meetings. For example, participants often ask for 'respite', but this word does not exist in the NDIS lexicon. Participants are generally told this is not funded by the NDIS. If participants reword this as a request for 'short-term accommodation' they are more likely to be met with a positive response.

Housing access delayed in NT by lack of assessment services to provide evidence

- A 25-year-old woman with an intellectual impairment has been waiting for three months for an occupational therapist (OT) assessment report to obtain Supported Independent Living (SIL) accommodation supports. A service provider has reserved a place for her in their accommodation but there are concerns that this place will be taken if SIL funding is not approved soon. In addition to the wait for an appointment, the OT report is likely to take some time to complete – further increasing the risk of losing accommodation.
- A 47-year-old woman with physical and psycho-social disabilities was waiting for a SIL assessment report to be prepared around her preferred accommodation with a specific provider. By the time of report completion, the preferred accommodation was no longer available. She is now looking at other accommodation options and another SIL report will need to be prepared in relation to the next property that she chooses, meaning a further delay. The participant has now been in hospital for 18 months waiting on suitable accommodation arrangements to enable safe discharge.
- A 28-year-old man with autism and a severe intellectual impairment is seeking funding for Specialist Disability Accommodation (SDA). The NDIS Rules and processes around eligibility for SDA funding are rigorous and it has taken eight months to complete the relevant assessments in the settings of his family home, day program and prospective accommodation. At the time of writing, the participant has received an extensive 40-page SDA assessment report but is still waiting for approval for SDA funding and is likely to face challenges using this funding because there are few SDA properties in the NT.

Excessive reliance on informal supports

Informal supports are critical in assisting people with disabilities in the NT, because formal mechanisms comprehensively fail to meet the need. In Aboriginal communities in particular, informal support is a cultural expectation, and in remote communities it might be the only support available. One in four Aboriginal and Torres Strait Islander people aged 15 years and over provided care for a person with a disability, a long-term health condition, or old age. In the general population this figure is less than one in ten. The provision of care increases with remoteness (34% providing care).⁵

However, informal supports should not be seen as a substitute where no formal services exist, or as a justification for failing to provide formal support.

In our experience, the NDIA over-emphasises the capacity of informal supports, omitting Coordination of Supports (CoS) funding in plans. Participants rarely understand the role of a CoS – which is critical in areas with a minimal services.

In locations where no services exist (including no CoS services) the role of community and family members in providing support should be formally recognised by the NDIA, with investment in capacity-building, and provision of resources, remuneration and respite. Instead, family and community carers take responsibility. They are often disadvantaged because:

- they play a vital role in supporting people with disabilities, but are not considered 'active carers' and are not recognised for the purposes of a carer's payment.
- they are subject to penalties, such as termination of Community Development Program payments because they are 'unavailable' for work, despite the valuable role that they play.
- they do not receive respite under the NDIS.

Poor quality services from NDIA partners

Lack of expertise and training of NDIS Community Partners is hampering planning for participants. This results in plans that are poorly researched, poorly written, underfunded, and inappropriate to a participant's needs.

Frequent planning difficulties arising from NDIS Community Partners include:

- Participants receiving plans with details of their daily life and plan goals that do not reflect information provided during planning meetings.
- Plan goals that have minimised participant's disabilities and the level of support they require.
- Participants receiving plans that have clearly been 'cut and pasted' from other participants plans, which consequently cite incorrect participant names and genders in the plan goals.

The most important part of the plan – the amount of funding available and its authorised uses – is needlessly complex. Plan funding is grouped under terms such as 'core', 'capacity building' and 'capital' supports - which have limited meaning for a layperson. Participants are entitled to answers to basic queries such as (i) how much money there is for therapies, (ii) whether they can purchase communication devices, (iii) where the money is for community access, and (iv) how they are going to

⁵ ABS, *National Aboriginal and Torres Strait Islander Social Survey 2014-15 and Disability, Ageing and Carers Australia: Summary of Findings, 2015*



pay for their transport in the community. The answers to these questions are hidden behind vague terminology that is not explained by planners.

Recommendations - Making the planning process easier and more effective

The planning process will be improved by:

- Including an offer of Coordination of Supports funding to participants at every plan development.
- Developing NDIS planners and placing a stronger recruitment focus on candidates with expertise in disability.
- Demystifying plans so participants are clear about what supports are available and how they might be secured.
- Basing performance measures for NDIA and NDIS Community Partners on acceptance at first submission and within time frames and on the comprehensiveness of plans, and
- Providing advocacy support to ensure that vulnerable participants understand how to best address their needs through the planning process.

Example #1 - planning difficulties

Julia is a young woman with severe cerebral palsy, epilepsy, an intellectual disability and incontinence, who lives with her mother in an urban area. She uses a manual wheelchair and is fully dependent on her mother for all activities of daily living and PEG feeding. Julia's mother manually lifts her at home for all transfers as a hoist will not fit into their bathroom and bedroom. Julia's mother has minimal outside support and suffers from carer fatigue and physical injuries. Her only respite is her daughter's attendance at a disability day program. The equipment used in their home is old and needs repairing or replacing and home modifications are also required for the safety of both mother and daughter.

Julia's plan had the following major deficiencies caused by poor consultation during the initial planning meeting:

- Funding was insufficient for the home modifications required to safely transfer Julia within her home environment and prevent injuries to herself and her mother.
- There was no funding for Julia to attend her day program so her mother could work.
- No Coordination of Supports funding was included in the plan (her mother and sister named as informal supports).
- The wording of Julia's goals minimized the severity of her disability and supports required. For example, "I will maintain my mobility to become independent". Her disability is such that she will remain fully dependent for all activities of daily living and will not be able to achieve independence.
- The format of the plan budget was confusing and complex to family members.
- Budget details in the plan made limited sense. For example, "[Client's] mobility/strength & stamina/speech and skill development in improving your daily routines and assistive technology."

Julia's mother requested DCLS assistance with a plan review.

- DCLS contacted the NDIS Community Partner to request a meeting for a plan review discussion and helped to arrange an additional occupational therapy assessment of supports required.
- DCLS followed up with the Partner's staff on progress and later discovered that their staff had escalated the s48 plan review to a s100 internal review with no consultation with Julie or her mother.
- DCLS requested a withdrawal of the internal review and requested a face to face meeting with NDIS representatives to address plan deficiencies.
- The requested Coordination of Supports funding, assistive technology and home modifications (ceiling hoist and structural alterations) were subsequently approved by a NDIS Senior Planner at a face to face meeting.
- These issues took six months of advocacy work to resolve.

Example #2 - planning difficulties

Tanya is a 49-year-old woman who has limited mobility, chronic pain, and a psychosocial disability. She uses a walking frame for mobility and lives in a separate section of her parent's house.

Tanya's plan had the following major deficiencies caused by poor consultation during the initial planning meeting:

- Tanya felt her plan was patronising. One goal stated; "My parents will encourage me to keep my home clean" despite her being capable of this herself.
- Tanya felt the plan did not reflect the discussion she had with the NDIS Community Partner planner about her goals and supports. The goals were simplistic and did not meet her aspirations.
- Tanya was not asked about Coordination of Support (CoS) hours at the planning meeting and did not know that was an option.
- Her plan was implemented with no consultation regarding the draft goals and statement, which meant Tanya had no opportunity to rectify inappropriate goals drafted by the planner. The first time the participant saw the goals was when her plan arrived in the post..

Tanya was referred to DCLS by a service provider, as she did not understand her plan.

- She had attempted to contact the NDIS Community Partner to discuss her plan for over 4 weeks with no response.
- DCLS met with the NDIS Community Partner to discuss changing Tanya's statement and goals and including CoS hours.
- After a lengthy investigation, the NDIS Community Partner Manager admitted that staff had not appropriately addressed Tanya's goals or provided information about CoS support.. The NDIS Community Partner Manager sought approval from the NDIA delegate to rewrite Tanya's plan to include the statement and goals she had drafted. Tanya requested a new planner as she had lost all confidence in her previous planner.
- This issue took two months of advocacy work to resolve.

Example #3 - planning difficulties

John is a 41-year-old man who has profound deafness in one ear and uses a high powered hearing aid in the other. He is a single father of two small children living in his own home and works full time.

John's plan had the following major deficiencies:

- John had difficulties getting funding released for his hearing aid.
- He was told to pay for it out of own money (minimum \$7000), and then had to return it when the NDIS Community Partner couldn't reimburse him from his plan. This was eventually paid for by NDIS but created unnecessary stress for John.
- John received email approval from the NDIS Community Partner to order Assistive Technology for CCTV and intercom to support his plan goal to have a safe home environment. He ordered these and they arrived from interstate.
- Subsequent to this he received an email determination from the NDIA that the items were declined under section 34(1) as not "reasonable and necessary", because home security is considered a day to day living cost and will not increase independence. John then had to arrange for return of the items which incurred a return fee as they were from interstate.
- The NDIS planner suggested that John wear hearing aids during high frequency visiting times of the day when people are likely to be calling, and schedule visits to occur at prearranged times. Someone without a disability would not be told to pre-schedule visits to their home.
- The Community Partner LAC stated to John that they had no background, nor training in hearing impairment and were unable to help him. The LAC made several comments in emails directed to or copied to John about their confusion in regard to hearing impairment supports.

John contacted DCLS in relation to the difficulty in drawing down from his plan for items he was told he could purchase.

- John provided DCLS a series of some 30 emails attempting to get assistance from the NDIS Community Partner LAC and gain some clarity over what he could draw down from his NDIS plan.
- DCLS contacted a Senior Planner at NDIS directly with these issues. All items were subsequently approved, including reimbursement of the return fee for ordered goods.
- This issue took one month of intensive advocacy work to resolve.

Example #4 - planning difficulties

Kara is an 8-year-old girl with Level 3 Autism and a history of complex childhood trauma. She has an Indigenous background and is from a remote community. She is living with foster parents in an urban location under the guardianship of Territory Families.

- NDIS were engaged as a LAC for Kara and assisted to build her plan.
- Kara's foster parents had to chase up progress on her plan. It had been approved but was 'sitting on someone's desk' for nearly 3 months until it was forwarded to her foster parents. The plan approval date and covering letter date differed by 3 months. Kara was therefore unable to commence with crucial supports for 3 months, which makes a significant difference in childhood intervention.
- Paediatric OT, Psychology and behaviour support reports for Kara indicated that intensive therapy, behaviour management and OT sessions were required, yet only 67 therapy hours were funded over a 12-month period.
- Kara has complex needs, with additional levels of coordination being required due to her foster care arrangements, yet only 48 Coordination of Supports hours were funded over a 12-month period.

DCLS was contacted by Kara's Coordinator of Supports regarding significant underfunding in her plan.

- DCLS met with Kara's foster parents, Coordinator of Supports, Territory Families and NDIS to discuss her needs, which included:
 - intensive therapy for emotional regulation strategies and social interaction skills;
 - psychotherapeutic support to process complex trauma;
 - behaviour management therapy to manage triggers and consequences of aggressive behaviours;
 - tutoring to counter the effect of autism on schooling;
 - activities and family visits to maintain connection to country; and
 - an increase in coordination of supports hours due to Kara's complex needs.
- Negotiation between DCLS advocates and a NDIS senior planner resulted in an increase in plan funding from approximately \$17000 to over \$44000, a reflection of the level at which the plan should have been funded in the first instance, including an increase of coordination of support hours to 80 hours over 12 months.
- These issues took two months of advocacy work to resolve.

4. Plan Reviews and Appeals

Effective use of NDIS plans is impeded by the following:

- Understanding the review process
- Delays in the process

Understanding the review process

Many participants do not know that they have the option of changing their plan if it is not suitable. Nor do they understand how to lodge a review, or the different types of review options available.

Advocates are therefore critical in this area.

Almost all DCLS clients seeking review assistance advise that no-one has explained the review process to them beforehand. Information about reviews on the NDIS website is oversimplified, fails to distinguish between the different review options, and makes no reference to expected timeframes, whether legislated or not. DCLS has assisted nine participants who have had plan reviews triggered without their consent.

Delays in the process

Where there are problems with an approved plan, there has been a tendency to go to a s48 unscheduled review. Minor amendments require a lengthy and complex plan-review process, even if the correction is required because of an error by the NDIS Planner.

We are aware that both NDIA and Community Partners have an internal policy to escalate a s48 review to a s100 internal review where a decision has not been made on the initial review for a three-week period. This action denies the participant a step in the review process and fast forwarding their application to the last 'port of call' before an Administrative Appeals Tribunal (AAT) application.

DCLS example of the impact of delays in NDIA decision making regarding reviews

DCLS was engaged by a client with vision impairments to help progress a plan review lodged by the Community Partner LAC for more funding for maintenance of his guide dog and some assistive technology.

- A section 48 review was prepared by DCLS and submitted to the LAC in June 2019 and the NDIA subsequently failed to notify whether they would conduct the review within the required 14-day period under section 48(2) of the Act.
- One month later DCLS made a written request to the participant's Community Partner LAC seeking notification about whether a review would be conducted. The written correspondence also specifically requested that the Community Partner refrain from escalating this matter to a section 100 internal review.
- On the same day, the Community Partner forwarded this request to the NDIA National Review Team and triggered a section 100 review, contrary to our instructions on behalf of the participant.
- DCLS and the participant had now lost control of the review process and faced an unsuccessful outcome from the review because we did not have enough time to gather and submit required evidence for the supports.
- DCLS provided additional evidence to the National Review Team over the next few months.
- The review remains unresolved at the time of writing.

Inappropriate plan review actions

A 25-year-old woman with an intellectual impairment wanted her plan changed to include Supported Independent Living (SIL) funding, behaviour support therapies and coordination of supports.

- She was initially told her that this could be addressed through a 'light touch review', despite the breadth of the additional supports being sought.
- A plan review under s100 was then requested without consulting with her or her legal guardians.
- DCLS was then advised that the appeal would not succeed because the NDIA would require substantial evidence from allied health professionals to support the requests for Supported Independent Living and behaviour support funding.
- DCLS were eventually able to withdraw the appeal on the client's behalf and she is now collecting evidence to support a section 48 review in the near future.

The family of a three-year-old child with severe Autism, sensory processing disorder and speech delays was being supported through a NDIA Early Childhood Early Intervention (ECEI) Partner.

- The ECEI Partner lodged a review seeking the additional therapy hours required because of a new diagnosis. The participant's mother received limited information about the review process at the time of lodgement.
- Despite repeated attempts at contact over two months the Participant's mother received no further updates from the ECEI Partner about progress.
- It was later discovered that a section 100 review had been lodged on behalf of the participant and this was withdrawn by DCLS at the mother's request. The process has now been restarted with a section 48 application.
- In the interim, the child has regressed severely and exhibited self-harming behaviours due to lack of funding for required therapies.
- At the time of writing, our service is urgently requesting a plan review with the NDIA.

Recommendations – streamlining the review process

The Review process will be improved by:

- Focusing on getting plans right in the first place.
- Acknowledging that circumstances change, and facilitating review processes in a timely and accessible way.
- Establishing legislated timeframes for delegates to deliver decisions in relation to s48 and s100 plan reviews.
- Considering the introduction of a plan amendment process to deal with minor amendments and adjustments.

DCLS see benefits in using a plan amendment avenue to 'complete' plans that are missing specialist supports for which substantial evidence is required, for example home modifications, complex assistive technologies, Supported Independent Living (SIL) and Specialist Disability Accommodation (SDA) funding. This approach would ensure continuity and certainty for the participant and their support providers about the types and funding for agreed supports, while substantial evidence is gathered for specific support types.

It would also benefit participants who want to change the way that their plan is managed, for example those wanting to access unregistered providers by changing from NDIA-managed to plan-managed. Participants often don't fully understand the implications when they first choose the way their plan is managed, and only some months later decide it is better managed another way.

Example #1 of the impact of delays in NDIA decision making regarding reviews

SP is a six-year-old with a primary diagnosis of Attention Deficit Hyperactivity Disorder (ADHD), as well as Oppositional Defiant Disorder and Specific Learning Disorder.

- SP's parents lodged an access request on behalf of their child in **August 2018**.
- The NDIA rejected access on the basis that a report from his paediatrician excluded one sentence stating that his impairment was permanent. The NDIA rather than seeking further information from SP or his parents or requesting the paediatrician amend the report to include one sentence to confirm compliance with section 24(1)(b) chose to reject his application for access thus giving him no option other than to seek an Internal Review. But for one sentence, the access request would have been accepted.
- In **December 2018** DCLS assisted SP and his parents to lodge a s100 internal review. Part of the Internal Review Application included an amended paediatrician report, which now included the sentence to satisfy s 24(1)(b).
- In **February 2019** our service contacted the NDIA Internal Review Team and asked why the NDIA had not reached a decision after 77 days. An email response from a senior staff member contained the following advice: "The agency also have a priority register, unfortunately due to the high volume of reviews there is a 6-8 week wait depending on the level of priority." There was no explanation as to where a six-year-old with an identified need for "optimal early management" sat within this priority register.
- Over this period SP's condition deteriorated due to lack of supports with significant impacts on his education, development and relationships with family and peers. SP's parents reported that his anxiety and frustration gave rise to more difficult behaviour at school and at home. He was frequently locked in a classroom to manage his behaviour and eventually suspended from school for extended periods.
- At home, SP would run away when upset and inflict significant property damage due to behaviours arising from his various impairments. His parents began to notice that his behaviours were pushing other children away from him which affected his self-esteem and caused him to further retreat.
- In **March 2019** the NDIA finally handed down its decision to uphold the original access rejection. DCLS filed an appeal in the Administrative Appeals Tribunal in **April 2019**, and in **August 2019** submitted additional evidence from medical professionals and ADHD experts.
- Following meetings with NDIA legal representatives and further exchange of information, terms of agreement were reached allowing SP access to the scheme.
- On **24 September 2019**, SP was finally granted access to the NDIS – over 12 months after his initial access request was lodged. That period of time in the life of a six-year-old and the loss of early intervention is unmeasurable in relation to the long-term effects on his development.

Example #2 of the impact of delays in NDIA decision making regarding reviews

DCLS was engaged by a client with vision impairments to help progress a plan review lodged by the Community Partner LAC for more funding for maintenance of his guide dog and some assistive technology.

- A section 48 review was prepared by DCLS and submitted to the LAC in June 2019 and the NDIA subsequently failed to notify whether they would conduct the review within the required 14-day period under section 48(2) of the Act.
- One month later DCLS made a written request to the participant's Community Partner LAC seeking notification about whether a review would be conducted. The written correspondence also specifically requested that the Community Partner refrain from escalating this matter to a section 100 internal review.
- On the same day, the Community Partner forwarded this request to the NDIA National Review Team and triggered a section 100 review, contrary to our instructions on behalf of the participant.
- DCLS and the participant had now lost control of the review process and faced an unsuccessful outcome from the review because we did not have enough time to gather and submit required evidence for the supports.
- DCLS provided additional evidence to the National Review Team over the next few months.
- The review remains unresolved at the time of writing.

5. Guaranteeing appropriate and accessible services

DCLS broadly supports the principles suggested in the Participant Service Guarantee (PSG) Standards, however we remain concerned about its efficacy in the NT context.

Even where NDIS access, planning and review processes are streamlined, this will not improve the circumstances of most NT participants who have limited support options. Addressing regulatory issues and applying broad service principles will not change the state of a non-existent market.

Proposed principles

- Expert Principle – this principle must apply to NDIA LAC Community Partners and ECEI Partners in Community as well. They are gatekeepers to the NDIS and its processes. DCLS regularly see the negative impacts of limited disability expertise and knowledge amongst their staff.
- Connected Principle – Advocates should be specifically mentioned in this principle. We are an important support link between participants and the NDIS.

Measuring delivery on each of the PSG principles will be challenging. It should include drawing information from advocacy services about their caseloads for NDIS clients (and waitlists), wait times for decisions, and progress towards improving accessibility for Indigenous and CALD clients, and other disadvantaged groups.

Lack of services and failure to deliver a provider of last resort.

Limited access to support services is a huge problem for NDIS participants in the Northern Territory. DCLS frequently meets participants with large plans but no services on which to spend their funding. Increasingly, we observe funds are being withdrawn from plans because services don't exist, rather than efforts being made to ensure services are secured.

The report on the roll-out of the Barkly Region Trial in NT identified the 'competition and choice' model as ineffective. Specifically, the Barkly trial evaluation found that providers were being discouraged from entering remote markets because of (i) poor infrastructure for service delivery, (ii) inadequate pricing structures set by NDIA, (iii) small numbers of NT participants and (iv) problems with staff recruitment and retention. The report highlighted the considerable difficulties experienced by Aboriginal people negotiating the very real barriers to access.⁶ NDIS was, however, rolled out without regard to the model's serious limitations for application to remote areas and continues to operate to discriminate against those in remote areas.

Limited services in high demand results in high prices, depleting packages quickly and effectively restricting access to necessary supports. It also has a flow on impact on non-NDIS disability services and aged care services.

Urgent work is required to establish alternatives to the individualised fee-for-service model in remote and rural areas where markets are non-existent and to deliver on the promised safety net. While some small changes have been introduced to assist clients in crisis, including the recent establishment of a Complex Special Needs Pathway team across NT NDIA offices, this will only address some of the needs of a few complex participants in crisis situations or with significant complex support requirements.

⁶ National Institute of Labour Studies, *Evaluation of the NDIS, Final Report*, February 2018.

Examples of difficulties accessing supports in remote NT

B is a client from Ngukurr (635 km from Darwin) who has severe stage Machado-Joseph Disease (MJD).

- B initially received a large amount of funding in her plan which was directed at purchasing supports to allow her to stay living in her community.
- When her plan was reviewed recently, the NDIA reduced her core support funding by 45%. In an email explaining this decision, the NDIA advised that her core funding was reduced because of “under-utilisation and thin markets”, and this had been explained to the participant’s representative at the initial planning meeting.
- A further nine NDIS participants in Ngukurr incurred similar funding decreases during plan reviews because the services they so desperately need are not available where they live.
- Participants on nearby Groote Eylandt are suffering similar reduction, with their plans being cut by an average 31% largely due to lack of services.* ‘Fund cuts hit NDIS remote customers’, *The Australian*, Amos Aikman, 22 March 2019.

No support for travel to access services

The refusal to include travel in plans effectively reinforces isolation and deprivation of those with disabilities in remote. Common sense dictates that if needed services are not available where you live then a scheme that provides resources for support should fund travel to enable access to these services. Failure to do so just reinforces the postcode lottery. However it appears that people from remote communities can be flown to Melbourne to attend a football match. It seems the priorities are seriously askew.

Travel funding denied

- A two-year-old diagnosed with Autism Spectrum Disorder (ASD) severity level 3 requires interventions of speech and language therapy, occupational therapy and physiotherapy. There is only one speech therapist in the whole of NT, limited occupational therapy and physiotherapy, and no substantive language therapy. None of these services apart from physiotherapy is available in Nhulunbuy where the client lives.

Travel funding to enable flights to Queensland – where he was able to access intensive therapy sessions with all providers – have not been approved by the NDIA, who maintained that the cost should be met by his parents.

- A man who is non-verbal and severely disabled, sought assistance to fly from Maningrida (very remote NT) to attend a review meeting of his plan in Darwin. He was refused because travel is not allowed under a plan. Previously DCLS had arranged for him to attend in Darwin for plan meetings by combining the visit with respite, but respite (short term accommodation) is no longer allowable under his plan.
- In an outreach visit to Nhulunbuy in August 2019, DCLS accepted five new clients requiring plan reviews, all children needing therapy supports which do not exist locally nor visit Nhulunbuy regularly enough. Parents report that even when therapists visit Nhulunbuy there is no consistency. A different Occupational Therapist or Speech Therapist may attend each visit (from the same organisation) meaning that parents have to reiterate their child's story and needs every appointment. This wastes time and money as re-explaining decreased the amount of time spent on actual therapy in the session.

Recommendations - Guaranteeing services

Services should be guaranteed:

- A Participant Service Guarantee (PSG) should guarantee services, plain and simple.
- Guaranteeing services would mean guaranteeing access to services, e.g. by providing sufficient funding for travel to enable participants to access services, or by guaranteeing services will be available, no matter where participants live.
- NDIA must deliver on the promised “provider of last resort” as a matter of urgency.
- The PSG should guarantee appropriate support for applicants and participants, including expertise of delivery staff, standards of communication and information, and adequate resourcing of independent advocacy.

Appendix A: DCLS 'NDIA Cheat Sheet' for Medical Practitioners

Guide to Completing The NDIS Access Request Form

The NDIS Access Request Form when submitted by the applicant is accompanied by an NDIS Access Request – Supporting Evidence Form. The NDIA use the information contained in the form to determine if a person meets the requirements to become a participant in the National Disability Insurance Scheme. **A request for access can be refused solely on the lack of medical information contained in the Access Request – Supporting Evidence Form.**

Sections 2 and 3 of the Access Request – Supporting Evidence Form must be completed by a health or education professional.

The relevant section in relation to “**disability requirements**” is section 24 of the National Disability Insurance Scheme Act 2013.

When completing the Access Request – Supporting Evidence Form it must be shown that the person has a disability that is attributable to one or more of the following –

- Intellectual
- Cognitive
- Neurological
- Sensory
- Physical

Or

- To one or more impairments attributable to a psychiatric condition.

And

- The impairments or impairments are, or are likely to be permanent.

And

The impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities –

- **Communication** – being understood in spoken, written or sign language, understanding others and express needs and wants by gesture, speech or context appropriate for age. **Does the person require assistance to communicate effectively because of their disability?**
- **Social interaction**- making and keeping friends, interacting with the community (or playing with other children), coping with feelings and emotions. **Does the person require assistance to interact socially because of their disability?**



- **Learning** – understanding and remembering information, learning new things, practicing and using new skills. **Does the person require assistance to learn effectively because of their disability?**
- **Mobility** – mobility/motor skills moving around the home, getting in or out of bed or a chair, leaving home and moving about in the community. **Does the person require assistance because of their disability?**
- **Self-care** – (not for children under 2) showering, bathing, dressing, eating, toileting, caring for own health. Assistance required does not include commonly used items such as slip mats, bathroom grab rails and stairway rails. **Does the person require assistance with self-care because of their disability?**
- Self management – doing daily jobs, making decisions, handling money (not for children under 8). **Does the person require assistance with self-management because of their disability?**

And

- The impairment or impairments affect the person's capacity for social or economic participation

And

- The person is likely to require support under the National Disability Insurance Scheme for the person's lifetime.