Queensland Advocacy Incorporated

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

Systems and Legal Advocacy for vulnerable people with Disability

10 August 2017

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Submissions should be received by 10 August

Email your submission to the committee secretariat or
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re Transitional arrangements for the NDIS

Dear Committee

We thank you for this opportunity to make a submission in relation to the Inquiry into Transitional Arrangements for the NDIS.

Yours sincerely

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Director

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QAI endorses the objectives, and promotes the principles, of the Convention on the Rights of Persons with Disabilities.
Patron: His Excellency The Honorable Paul de Jersey AC

About QAI

Queensland Advocacy Incorporated (QAI) is a not-for-profit, member-driven systems and individual advocacy organisation and community legal service for people with disability. Our mission is to promote, protect and defend, through systems and individual advocacy the fundamental needs, rights and lives of the most vulnerable people with disability in Queensland. QAI does this through campaigns directed to attitudinal, law and policy change and by a range of advocacy initiatives in this state and on a national scale.

QAI has an exemplary track record of effective systems advocacy, with thirty years' experience advocating for systems change, through campaigns directed to attitudinal, law and policy reform and by supporting the development of a range of advocacy initiatives in this state. We have provided, for almost a decade, highly in-demand individual advocacy through our three individual advocacy services – the Human Rights Legal Service, the Mental Health Legal Service and the Justice Support Program. Our expertise in providing legal and advocacy services and support for individuals within these programs has provided us with a wealth of knowledge and understanding about the challenges, issues, needs and concerns of individuals who are the focus of this inquiry.

QAI believes that all people are equally important, unique and of intrinsic value and that all communities should embrace difference and diversity. QAI avoids language that relies on stereotypes or labels based on personal features or attributes or that demeans any person with disability. Attention to language and discourse is fundamental to the rights, dignity and status of people with disability. QAI's constitution mandates that the Board of Management is comprised of a majority of people with disability. Their wisdom and lived experience is the foundation that guides us.

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1. Issues to be Addressed & Recommendations

- Knowledge of NDIS itself and the roll-out is poor among Aboriginal and Torres Strait Islander people and in remote indigenous communities. Disability has no equivalent term in many Aboriginal languages, and the notion that support can come from someone outside one's family or kinship group is foreign to many Aboriginal people, contributing to a cultural disconnect on disability issues.
- **Face to face conversation and preferably with peers who have the lived experience is the most effective way to share the NDIS message in Aboriginal communities.**
- The messages conveyed in community about the NDIS are hopeful, yet the experiences of many people are indicative of great distress and distrust. NDIA Planner correspondence to participants on occasion is misleading. **The NDIA must be careful not to raise participants' expectations and then to disabuse them.**
- NDIA correspondence is not accessible to many of the people addressed. **When appropriate to the participant the NDIA must use easy to read language.**
- Privacy issues have emerged with Participants Plans sent to incorrect addresses, even interstate. This has caused delays in Participants receiving Plans or notifications on decisions and escalated concerns about the security of their personal information. **QAI recommends a double checking system to ensure NDIA confidential information is remitted to the correct Participant**.
- Commonwealth and state governments have not resolved issues regarding smooth transitions when Participants are accepted into the Scheme with state services being discontinued. **QAI recommends that the NDIA and the State departments must confer regarding Participants who receive state services from sources other than the Disability Ministry (eg. Health Department services) to ensure that services are not ceased merely at the approval of a Plan**.
- General practitioners are not resourced adequately to support people with disability to get appropriate eligibility documentation, and this is leading to people not meeting the NDIS access criteria. **QAI recommends that clear information about eligibility is made available to practitioners including a relevant questionnaire to guide the conversations with their patients.**

1. Introduction

Queensland Advocacy Incorporated has been granted funding to perform NDIS Appeals support. Many of the examples cited here are de-identified experiences of real people.

The NDIA must reassess the way communications are delivered with participants.[1] Complex grammar and long words are not 'easy read' to people with intellectual impairments.

The NDIA should attend to the accuracy of its correspondence. The rapidity of the roll-out and NDIA under-resourcing means that planners cut corners by communicating over the telephone and by letter when face-to-face may be more effective and reduce the possibility of misinterpretation. Face-to-face creates certainty that participants will be treated as persons, sometimes 'in a crisis situation'[2] rather than a set of conditions, symptoms, support needs or as 'a bunch of letters on a piece of paper'.[3]

A participant shared with us correspondence from the NDIA that promises her an NDIS Plan on the basis that she is already in receipt of disability supports. Correspondence with XXXX in September 2016 said, ve*rbatim*:

> *We are writing to you to begin your transition to the NDIS. [..] we expect that you will be able to receive support under the NDIS [..].*
>
> *An NDIS rep will meet you to discuss the next steps. Your current support arrangements will continue until a NDIS plan is in place.*

The NDIA subsequently made the decision that this person does not meet the access criteria. On 16 Jan 2017 the NDIA notified XXXX that the NDIA had declined her request to become a participant. Of course, not all applicants will meet the access or early intervention criteria, so many requests will be declined immediately. The NDIA's fault is to raise people's expectations and then disappoint them.

It is unreasonable for the NDIA to raise what later prove to be false expectations, particularly when, from the applicant's point of view, the same organisation and even the same 'faceless bureaucrat'[4] is responsible for initially raising their expectations, and then their ultimate disappointment.

For many prospective participants there is much at stake. To meet the section 24 or 25 conditions an applicant must provide documentation - often considerable documentation - that demonstrates a permanent disability that results in substantially reduced functional capacity etc. *or* the early intervention requirements. It may not always be so, but for some this can be a frustrating and demeaning process and one that can damage the self-esteem of the applicant or their relevant person.

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[1] In this submission, 'participants' may include prospective and rejected participants.
[2] Queensland Advocacy Incorporated client.
[3] Queensland Advocacy Incorporated client.
[4] This was the term was used by a complainant who Queensland Advocacy Incorporated represents to describe an NDIA decision-maker.

The President of Queensland Advocacy Incorporated is an Aboriginal man. He reports that knowledge of the NDIS is poor in his family's community in Cherbourg in South-western Queensland. He notes that disability has no equivalent term in many Aboriginal languages, and the notion that support can come from someone outside one's family or kinship group is foreign to many Aboriginal people, contributing to a cultural disconnect on disability issues. An advocate in north-west Queensland reports that NDIS-awareness in gulf and western communities is also poor. Face to face conversations, ideally with peers who have the lived experience, is the most effective way to share the NDIS message in Aboriginal communities.

NDIA Planners

1. Participants (and or their plan nominees) have had their plans sent to the wrong addresses. When this has happened they have been told that they have had access to other's personal details and that they are to destroy the information but they have not actually been to the person's house to retrieve the documents so there is no guarantee that the participants have not had their identity and records taken by another person. Further to this it has created delays in plan approvals.

2. When participants have their (mostly) phone interviews they have been asked questions from a checklist not dissimilar to the deficit models used in the past, and yet the participant is never asked to review the plan before it is submitted. When the participants have received the plan in the mail, they have contacted the planners to discuss discrepancies or areas that have been omitted or some areas of disagreement. Sometimes the plans have been sent back with no changes and others with minor changes, but mostly never with what the participants feel was what they had agreed to. When the participants have called again, Planners have told them that they can ask for a plan review, but they have been told YOUR PLAN FUNDING WILL BE REDUCED IF YOU SEEK A PLAN REVIEW. None of the planners have put this in writing but several participants have received plans with less money each time.

3. Participants from CALD backgrounds have been told that they should talk to their support coordinators but the NDIA will not fund interpreter services. It is impossible to negotiate the system without them but even worse trying to have their supports and services implemented without crucial communication supports.

2. Responses to Terms of Reference

a. The boundaries and interface of NDIS service provision, and other non-NDIS service provision, with particular reference to health, education and transport services;

Some state-funded services appear to take the position that the establishment of a person's NDIS plan will be a panacea that justifies the cessation of those state-funded services regardless of whether the person's NDIS plan is approved, or whether it includes provision to replace those services. The health management needs of people with a disability particularly are a concern, as the NDIA does not appear to allow wound care and some continence

supports in plans. These were traditional areas of service under the 'Community Care' program. In one case, a person's NDIA plan has not included provision for clinical services for the treatment of a health condition in order to improve the health status of the participant.

Queensland's Community Care program is undergoing a progressive reduction in program size and funding as more areas transition to the NDIS. However, although numbers of Community Care clients will reduce dramatically with NDIS uptake not all people will be eligible participants of the NDIS.

Some of the challenges are:

- The old 'block funding' approach does not always require services to distinguish support needs that are particular to each service recipient, so currently it is unclear who is or is not eligible for 'reasonable and necessary' supports. The NDIA has informed some block funding recipients that they likely will receive an NDIS package. At a later date, the NDIA has written to say that the person will not receive support because they do not meet the access requirements.

- The uptake of clients to the NDIS has been slower than expected compared to the rate at which Community Care providers are required to reduce funding in each region.

- General practitioners are not resourced adequately to support people with disability to get appropriate eligibility documentation, and this is leading to people not meeting the NDIS access criteria.

Health example 1:

In this example, a person's NDIS plan does not include support for wound care, skin checks and catheter changing. The participant received these services under the community care program.

- Before her largely successful application to become an NDIS participant, Njila had the in-home services of a registered nurse provided through ****Care, a community-based subsidiary funded through grants from Queensland's Department of Communities, Child Safety and Disability Services. The nurse provided catheter maintenance skin condition checks and wound maintenance.

  On application, the NDIA planner refused to include these services in the Plan because the participant identified that these services needed to be provided by a registered nurse. NDIA correspondence in relation to internal review of the NDIA decision not to fund the services said that:

  > *The NDIS should not fund clinical nursing supports for treatment of a health condition (including ongoing and chronic health conditions) or preventative care with the aim to improve the health status of a participant (NDIS Su[ports for Participants Rules 2013)*

The NDIS *would* fund provision of care, training and supervision of a delegated worker to respond to the complex care needs of a participant where that care is not the usual responsibility of the Health System, and where the person is medically stable and clinical care of a RN is not a requirement for the safe management of the client. ****Care took the view that 'once she has a [NDIS] plan she will no longer need our supports'.

Health example 2:

A woman in North Queensland has an NDIS Plan that includes personal supports. After admission to hospital for medical treatment the hospital has insisted that she continues to rely on her personal supports.[5]

Example 3:

In June 2017 our client Jessica contacted MASS to order some incontinence aids for her Participant daughter, only to be advised by MASS that Jane's (her daughter's) funding ceased in Jan/Feb 2017, as the client had received an 'interim' order pending the roll out of the NDIS. MASS advised Jessica to get back in touch with the NDIS.

MASS also gave Jessica the CAPS number, as Jane may be eligible for some funding. However, they too advised that this matter needed to be referred back to the NDIS. When Jessica spoke with the NDIS in June she asked where her daughter stood with regards to ordering incontinence aids.

The NDIA representative advised that until the plan is approved it was business as usual e.g. *via* MASS. However, it appears that this was not the case, and Janine's daughter is 'Out of Pocket'. NDIS assessments are taking 1-3 months in Toowoomba.

Transport example:

- Transport that was previously funded as a community care service is no longer viable for some organisations as funding reduces. The impact of this following the cessation of the TSS scheme and mobility allowance is causing disadvantage and access issues for people with disability. Some people can get support from the NDIS but they cannot get to services or activities as this is not in their NDIS plan.

b. The consistency of NDIS plans and delivery of NDIS and other services for people with disabilities across Australia;

[5] Applied Principles: Health #4. The NDIS will be responsible for supports required due to the impact of a person's impairment/son their functional capacity and their ability to undertake activities of daily living. This includes "maintenance" supports delivered or supervised by clinically trained or qualified health professionals (where the person has reached a point of stability in regard to functional capacity, prior to hospital discharge (or equivalent for other healthcare settings) and integrally linked to the care and support a person requires to live in the community and participate in education and employment.

Queensland Advocacy Incorporated is funded to provide participants with support, advice and representation for NDIS Appeals. Since beginning this service in May 2017 QAI has been approached by nearly 60 clients. We have identified a number of complaint 'themes', including poor communication from NDIA staff, nevertheless, the breadth of our experience is not sufficient to allow us to make like-to-like plan comparisons. We can, however, make some broad comparisons about planning processes, and the inequities generated by them. Two case examples illustrate this point.

Case example one:

Adrian entered a nursing home when he acquired a brain injury as a teen. AS an adult, a few years ago he moved into a nursing home in an area of Queensland that now has the NDIS to be closer to his family. Adrian's NDIS plan was written 4-5 months ago during and after a 45 minute phone call. Adrian cannot communicate by phone, so the conversation about his needs took place between a planner and Adrian's mother, who is his relevant person.

According to Adrian's mother, the Plan has not included any reference to his need for a wheelchair. Adrian has an uncomfortable and unsuitable wheelchair for around the home, but nothing for outside. Unless the need is exceptional he cannot access a maxi taxi because the nearest one is many kilometres away. The Plan made no mention of his need for incontinence supports, or his desire to move out into a home of his own.

Case example two:

Neroli is the teenage daughter of two well-known local identities. Neroli has a physical impairment and needs supports to help her prepare for her transition from school to tertiary education. Her parents have both worked in the disability sector for decades. They organised a face-to-face planning meeting, at which they clearly articulated Neroli's goals, wishes and aspirations. By clearly articulating a comprehensive set of goals and linking these to support needs, Neroli and her family got everything they wanted (and considerably more) by way of supports.

Education example: A school principal is fed up with NDIS Plan-related OTs and allied health professionals coming in and disrupting classrooms by doing assessments. S/he bans them from entering the school.

Complex Needs:

Some participants who have received services and supports in the state system that recognised the need for more specialist supports have had plans approved for the same number of hours (eg. respite) but are being told to seek less expensive services. In some instances the services do not have the staff with requisite skills to adequately meet the needs of the individuals.

Home modifications:

A young female Participant (we will call her Sally) who is living with a physical impairment, remains mobile with the assistance of a wheel chair. Her parents provide the majority of her support in her daily living. However, her father has a physical impairment as a result of a

stroke, while her mother had major surgery and is subject to bed rest during her many weeks recovery.

Their home has a step at the main entrance that Sally cannot access without being removed from her wheel chair. With assistance from two support workers and some weight bearing, Sally can just manage this. Otherwise she must crawl up the step. Sally has an approved NDIS plan. She also has plan management. This plan does have funding in Capital and includes $2500 for home modifications. A quote is required to have a ramp approved.

The participant's mother spoke to a worker at NDIA and was given the message that the ramp is not a priority. This planner has told the mother to continue to access her core supports to assist the participant in and out of the house. This is not a long term solution and is severely impacting on her independence. Rumour is that there are at least 200 applications in to for ramps to be installed**.**

SDA and SIL

Participants who have been living in their own homes without sharing are (without consultation) receiving plans with SIL (Supported Independent Living) on the plan and the plan is being priced according to this. The SIL is being used to coerce people into shared care and shared living arrangement with their supports and services in the plan based on a shared model.

Principle of No Disadvantage

From the NDIS FACT SHEET November 2014

Governments made a commitment – through the Intergovernmental Agreement for the NDIS Launch (IGA) – that if you were receiving supports before becoming a participant in the NDIS you should not be disadvantaged by your transition to the NDIS.

The commitment is that people who become participants in the NDIS should be able to achieve at least the same outcomes under the NDIS.

This does not mean that you will always have the same level of funding or supports provided in the same way. You will have access to reasonable and necessary supports consistent with the National Disability Insurance Scheme Act 2013.

Where the NDIS does not fund a support you previously received under another program, the Agency will seek to identify alternative supports or refer you to other systems with a view to ensuring you are able to achieve substantially the same outcomes as a participant in the NDIS.

Given the case examples outlined above, QAI is aware of the extreme duress and frustration that many Participants are experiencing especially in relation to a reduction in supports and service. **QAI urges the NDIA to instigate measures to ensure that no person is without adequate support or services during the transition and that NDIA employees improve behaviour and communication techniques to alleviate some of the stresses that are directly related to their interactions**.