



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

November 2017

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to seniorclerk.committees.sen@aph.gov.au

Committee Secretary
Joint Standing Committee on the NDIS
PO Box 6100
Parliament House
CANBERRA ACT 2600
AUSTRALIA
Phone: +61 2 6277 3083
Fax: +61 2 6277 5829
ndis.sen@aph.gov.au

Dear Committee

re General issues around the implementation and performance of the NDIS

We thank you for this opportunity to make a submission in relation to General issues around the implementation and performance of the NDIS.

Yours sincerely

Michelle O'Flynn
Director
07 38444200

Ph: (07) 3844 4200 or 1300 130 582 **Fax:** (07) 3844 4220 **Email:** qai@qai.org.au **Website:** www.qai.org.au

2nd Floor, South Central, 43 Peel Street, STH BRISBANE QLD 4101

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

For more than 30 years, QAI has campaigned at state and national levels for changes in attitudes, laws and policies. For the last nine years, our Human Rights Legal Service and Mental Health Legal Service have offered legal advocacy. Our Justice Support Program has advocated for people with disability in the criminal justice system. This work has assisted us to understand the challenges, needs and concerns of people who are the focus of this submission. More recently QAI is funded to provide non-legal advocacy support for participants for NDIS Appeals.

QAI constitution holds that every person is unique and of intrinsic value, and that difference and diversity are intrinsic to community. Attention to language and discourse is fundamental to the rights, dignity and status of people with disability. In all aspects of our work QAI will not perpetuate use of language that stereotypes or make projections based on a particular feature or attribute of a person or detracts from the worth and status of a person with disability. We consider that the use of appropriate language and discourse is fundamental to protecting the rights and dignity, and elevating the status, of people with disability.

People with disability comprise the majority of our Board. Their wisdom and lived experience is our foundation and guide.

Recommendations

- The NDIA should provide funding for translation services for CALD participants in planning and to engage with support coordination services.
- The NDIA must undertake intensive training for Planners and Plan reviewers to ensure that the Scheme is implemented as it was envisioned and not as a savings exercise. This training must also encompass respectful engagement with participants and plan nominees to overcome the fear and distrust that is being experienced as a result of bullying by Planners.
- The NDIA must randomly audit plans developed by NDIA Planners to determine consistency of content and supports.
- A person who needs decision-making support and who has no informal supporters is better served by an advocate or another non-statutory supporter to assist them through the planning process and help them to exercise their choice and control. An advocate's support through NDIS access, planning and review is a human right, offering rights promotion not decision substitution.
- Support the expansion of Community Visitors. Expansion of Community Visitor's schemes emerged as a key recommendation¹ of the Senate Community Affairs References Committee's recommendations in its 2015 inquiry and report into Violence, abuse and neglect against people with disability in institutional and residential settings.²
- Change the SIL pricing better reflect the meaning of '*supported independent living*' to allow people to move to a home of their own choosing. Currently, many participants have little choice or are coerced to agree to shared-care arrangements. It has been recognised that congregate settings or a lack of choice about living arrangements has contributed to the horrific stories of abuse and neglect in residential settings.
- Service providers have a vested interest in the application of restrictive practices because:
 - group homes place extra pressure on people with high and complex needs. The more restrictive the space, the greater the likelihood of push-back and frustration from the person subject to it

¹ Recommendation #9: 'The committee recommends the Australian Government work with state and territory governments on a nationally consistent approach to existing state and territory disability oversight mechanisms, to include: [...]

- increased funding for community visitor schemes, with consideration these schemes be professionalised in all jurisdictions and with a mandatory reporting requirement for suspected violence, abuse or neglect.'

² The Senate Community Affairs References Committee. 2015. *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability.*

- lack of resources for families who wish to self-manage/self-direct a person's supports and services particularly when required to provide complex and detailed assessments and positive behaviour support plans
 - lack of resources for positive behaviour management and multi-disciplinary interventions to 'challenging behaviours',³
 - ongoing application requires extra staff, extra surveillance, and consequently, bigger support packages.
 - Lack of incentive to reduce or eliminate the use of restrictive practices
- Review the unit prices for specialist behavioural intervention support, development of behaviour management plans and training in behaviour management skills. These exceed by far the unit prices for non-specialist support. While these prices currently reflect the extra investment required for upskilling, they also encourage services to implement restrictive practices and to keep them in place..
- The NDIA should do more to coordinate transitions from custodial settings to community, and from courts to community-based supports rather than prisons or forensic facilities. With good support, people with intellectual impairments would avoid imprisonment in the first place.
- The NDIA must implement the NDIS Standing Committee's recommendations
 - to clarify what approved supports are available to NDIS participants in custody and how it monitors and ensures NDIS participants access the supports they are entitled to while in custody.
 - To establish a unit specialising in the interaction of the Scheme with the criminal justice system.⁴
- The NDIA must take extraordinary measures to overcome the barriers to NDIS service delivery for Aboriginal and Torres Strait Islander people including:
 - using existing networks and service provision in health and aged care
 - block funding suitable providers where services would not otherwise exist or would be inadequate
 - fostering smaller and consultative community-based services that engage local staff particularly with pre-planning activities.
- The NDIA must collect and publish CALD participant data.
- Understanding and knowledge of the NDIS is poor among Aboriginal and Torres Strait Islander people, particularly in remote communities. 'Disability' has no equivalent

³ Paul Ramcharan et al, 'Experiences of Restrictive Practices: A View from People with Disabilities and Family Carers' (Research Report, Office of the Senior Practitioner, 2009).

⁴ Recommendations 22 & 23 in NDIS Standing Committee, 2017. Report on Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.

in many Aboriginal languages. The notion that support can come from a person outside one's family or kinship group is foreign, and Aboriginal people are less likely to engage with the NDIS. Word of mouth is key, and familial or tribal connection will generate more success in engagement.

- Face to face conversation with peers who have a lived experience of disability is an effective way to share the NDIS message.
- Continue 'block-funding' of peer support focussed mental health services.

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1. Access

1.1 For Participants Who Have No Prior Contact with Disability Services

There is no systemic mechanism that triggers contact between the NDIA and people who are unaware of their eligibility and no history of accessing external service providers. Potential participants miss out because they are:

- information poor
- remotely located
- unwilling to ask for help
- isolated by their disability
- not literate
- not online
- incarcerated
- subject to control and coercion by service providers and hostel/boarding house managers.

1.2 For Culturally and Linguistically Diverse ('CALD') Participants

The current NDIS pathway presents obstacles for CALD participants and their families.

- Providing evidence of disability is difficult when many people, particularly those from refugee backgrounds, do not have formal diagnosis of their condition or impairment.
- Obtaining a diagnosis of disability or impairment is costly and challenging, often requiring specialist appointments, formal assessments and tests that can be expensive in the private system and slow to access in the public.
- There is no referral pathway to link people from CALD backgrounds to clinicians that can offer culturally appropriate assessments, often using interpreters.
- Timely and affordable assessments are challenging.
 - There are lengthy delays in accessing Queensland's public health system.
 - Families cannot afford assessments.
 - It is difficult to access interpreters for allied health professionals who would like to conduct these assessments.
- Access to credentialed interpreters and the provision of translated and easy English information ensures that people are able to:
 - understand important information
 - communicate their needs
 - make informed decisions
 - exercise choice and control.

In 2016, interpreting was no longer available as a line-item on plans. It was removed before the NDIA had developed an alternative process. Participants could not implement their

plans. In September 2017, the NDIA released a process for NDIS participants with approved plans to access interpreters.

The process, however, is inconsistent with good practice in the provision of language services and contravenes the federal government's multicultural language service guidelines. It encourages LACs and support coordinators to engage informal community or family members rather than professional interpreters, contrary to federal government policy and to Queensland Language Services Policy guidelines that state that friends and family members should not be interpreters. Children and young relatives are not appropriate interpreters in any context.

The NDIA has refused participant requests for plan translation. Some NDIA staff are not aware of their obligations under the *National Disability Insurance Scheme Act 2013* (Cth). Education and training is required urgently. Participants have asked settlement services to provide interpreters, but this is not their role. Participants have been forced to rely on family and informal supports which can be culturally inappropriate for family dynamics and the roles within families..

Participants are not familiar with appropriate supports and services, and they often do not know what information to share. Inexperience limits their expectations. They do not know what a 'good life' for people with disability in the Australian context can look like, and intensive pre-planning support to create a vision for a good but ordinary life is part of that development. It is difficult to have complex and lengthy planning discussions *via* interpreter.

The NDIA has not reported CALD participant data. The National Ethnic Disability Alliance estimates that approximately 13.7% of participants of the NDIS in Queensland could be from a CALD background.⁵ Queensland's figures for the first NDIS June 2016 Quarter shows that 2.5% of participants classified as CALD have approved plans.

The failure by the agency to collect data will diminish the agency's ability to monitor participation rates, develop policy and the workforce, and engage with diverse communities. Lacks of data means Queensland services are ill-prepared for CALD participants.

2. Planning

The NDIA should randomly audit the manner in which plans are developed by NDIA staff to determine consistency of content and supports.

- Supports that participants and nominees discuss and agree to at planning meetings do not always end up in the plan.
- Plans for people with similar situations and needs are not consistent.

⁵ National Ethnic Disability Alliance (NEDA) (March 2016). Unpublished data. NEDA

In one instance, NDIA staff reluctantly provided copies of an assessment they undertook during the plan meeting or review. A participant made an FOI application in order to access their assessment. For the NDIS to truly deliver on choice and control no information about a participant should be denied them, particularly the assessment details or outcomes. Rather, participants should be asked to submit a self-assessment which should be incorporated into the process.

2.1 NDIS v Mainstream Supports

Participants who require health care, small home modifications or other supports to meet disability support needs have experienced 'cost-shifting' as the NDIA and mainstream services fine-tune responsibility for funding certain supports. While the state of Queensland has made a commitment to reinstate services that had been ceased upon the approval of a Plan, there is no mechanism currently in place to ensure that those supports or services are not ceased upon Plan approval.

- Better communication between existing state services that will not be funded by the NDIS must occur before the Plan is activated.
- LAC's must take a more proactive role in engagement with state funded services. This is especially critical for people who may be ineligible for the scheme but have disability support needs that can be met by state funded services, but who have not yet accessed them.

2.2 People with Complex Needs

Some participants have received services and supports in the state system and now have NDIS plans approved for the same number of support hours. Contrary to the 'no-one worse off' principle, the NDIA has advised them to seek less expensive services.

Example

Angie is living with cerebral palsy. Her parents ordinarily provide support for daily living, but now her mother is recovering from heart surgery and her step-dad is paralysed on one side. With the help of two support workers, Angie can place weight on her legs and access her home via a step.

Angie's NDIS plan includes \$2500 for home modifications, but in Angie's region, rumour has it, there are 200+ other participants who need ramps. The NDIA advised her to use core supports for access, but this is not a long term solution.

In some instances the services do not have staff with skills to meet their needs. Regarding nursing care and some specialised therapies, some people with complex support needs require specialist supports that cost more than what is stipulated in the price guide.

Of great concern to QAI is that some people with high and or complex support needs who have been self-managing and self-directing their supports and services for several years under Your Life Your Choice, are now having their rights to self-determination revoked as the NDIS rolls closer. We are aware of several participants who have demonstrated the benefits and advantages of self-management, the development of 'right relationships' with their support workers, have complied diligently with Queensland regulations for reporting and data collection regarding the use of Restrictive Practices. These participants (and potential participants) have demonstrated that when autonomy and support for decision making is

respected and enabled, the use of Restrictive Practices are not only reduced but are often eliminated.

2.3 SDA and SIL

Participants residing in their parents' homes who want to live independently have received plans structured around Supported Independent Living ('SIL'). The supports have been priced accordingly. They have little choice but to agree to shared-care arrangements or to continue living in the homes of their aging parents. Access to "Specialist Disability Accommodation" (a label that QAI finds disturbing and entrenched in archaic midset about disability, lifestyle and housing), is more than purpose-built environs for physical access or people with a history of extreme measure of control and restriction. People with disability want a home of their own and for some, this will require measure that the SDA can provide but must be made available to all who require it and not merely an exercise steeped in tired and failed measures of congregate shared care.⁶

2.4 NDIA Planners, LAC's, Support Coordination and Plan Management

Participants have experienced bullying tactics and disparate information from various NDIA staff, who ask questions from a checklist that is not dissimilar to anachronistic deficit models. NDIA staff have refused participants who seek to review or even to see plans before they are submitted. When some participants have contacted planners to discuss discrepancies in plans or areas of disagreement they have been told that this is seeking a review, and have threatened that plans will be reduced at each successive review. Other Planners have returned plans to participants with no changes or only minor ones. Participants have not got the plans to which they believed they had agreed.

Local Area Coordinators (LAC's) are often either writing plans or reviewing plans rather than supporting people to access disability and generic supports and services. Neither Planners or LAC's are actively encouraging self-management and appear not to understand the differences between self-management, plan management and Agency managed. Participants who have clearly articulated that they wish to self-manage (often because this what they have been doing before intake to the NDIS) have had plans returned stating that the Plan will be managed by either the Agency or a Plan Manager. This is extremely distressing when they have existing support staff and services in place. LAC's does not understand self-management and how funds may be used creatively and have given mis-information about excluding funds to pay for support in self-management, either with bookkeeper, payroll support or support such as what some support coordination services offer.

⁶ QAI Position Paper on the right to a "Home of One's Own".
<http://www.hpw.qld.gov.au/SiteCollectionDocuments/QueenslandAdvocacyIncorporatedSubmission.pdf>

2.5 People with Psycho-social Disabilities

Many do not have anyone to help them to pre-plan or to navigate the complexities of the NDIS, particularly people who have no previous mental health service engagement. Neither LACs nor the NDIA provide that assistance. Some service providers do not support clients to prepare or apply, and in many instances this would be inappropriate. People who are labelled with this term are among the most vulnerable yet may have the most to gain from such opportunities that the NDIS could offer. It is important that the NDIA provide equitable opportunity for the rights-based approach to supports rather than a homogenous approach that the NDIS is becoming – a reversion

Case example: Despite an overall increase in funding, Narelle's NDIS allocation for independent travel is not enough for someone who uses a power wheelchair, and Narelle has lost her independence. She has no access to core funding for independent transport. She relies on carers to transport and push her around in a manual wheelchair, and this is more expensive.

Prohibiting the use of core funding for taxi services is counter-productive and costs the tax-payer more. NDIA staff told Narelle that carers can drive her in their own cars but none has a certified power wheelchair accessible car. Narelle cannot use core funding to hire a wheelchair accessible van unless it is for a 'day program' or a professional appointment. Communication with the NDIA is not fully accessible. The NDIA decision-maker seemed not to understand that power chairs do not fit in a 'normal' car, or that people sit in their electric wheelchairs when being transported.

Narelle cannot speak, and the NDIA is not set up to allow Skype or conference calls with clients, so her parents and other family members have to speak for her.

Example: Communication

Misleading correspondence from the NDIA has caused frustration and disappointment. XXXX was already receiving disability supports and the NDIA advised her of her imminent transition.

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.

In January 2017, the NDIA notified XXXX that it had declined her participant request because she did not meet the access criteria.

to the old system that failed most people.

Targetted and tailored pre-planning supports that may be best delivered by the advocates who work with this group of people may be the only way to ensure that the NDIS is a fair and equitable approach to supports as envisioned by the Productivity Commission in 2012. It is also for many people who are marginalised with such labels and often ill-deserved reputations to shirk some of the disadvantage they have experienced for much of their lives due to a lack of appropriate supports, education and habilitation.

3. Communication

The initial contact that participants receive from the NDIA offer hope and assurances of a smooth transition from one system to another without any warning or clear information about the eligibility requirements or what preparations may be needed, and many people are left bewildered and excluded as a result.

In correspondence, the NDIA appears to make no concession to people who have intellectual impairments, learning disabilities or other impairments that affect literacy: significant proportion of all NDIS participants. Complex grammar and long words are not 'easy read' to people with intellectual impairments. Some participants cannot speak (see example) and the NDIA is not set up to allow Skype or

conference-calls with clients, so advocates, parents and other family members have to speak for them.

4. Safeguards

4.1 Decision-making Support and Advocacy

At full roll-out, about 70 percent of participants will have cognitive impairment. Most are capable of making decisions about their plans, and many may need some decision support, but there are widespread prejudices and misconceptions about capacity and liabilities. Service providers, tribunal members and bureaucrats are still reverting to control over participants by pressuring them to defer to formally-appointed decision-makers for NDIS planning.

Guardianship should always be a 'last resort', but a guardian who is appointed for the purpose of NDIS planning often becomes the decision-maker for many areas of another person's life. A person who needs decision-making support is better served by an advocate or another non-statutory supporter to assist them through the planning process and help them to exercise their choice and control. An advocate's support through planning and review is a human right, offering rights promotion not decision substitution.

According to the Queensland Public Guardian, there were 94 applications for guardianship in Townsville at the beginning of NDIS rollout. About half were dismissed because there was someone in the person's life who could and would advocate to support the participant. Of the remaining applicants, 36 engaged advocates instead. In regional and remote Queensland and, in particular, there remains a huge deficit in culturally appropriate advocates to sit with Aboriginal and Torres Strait Islander people through the planning process.

Block-funded advocacy is effective for persons with disabilities and is cost effective. QAI's Justice Support Program, for example, provides court support to people with cognitive or psycho-social impairments in or at risk of the criminal justice system in Queensland. More than 10 percent of defendants in local courts have intellectual or cognitive disabilities.⁷ By providing advocacy and support this program:

- Arranges criminal defence
- Ensures court attendance
- Arranges supporting evidence such as evidence of impairment for the court
- Provides general support and advocacy assistance to redress the social disadvantage that impacts upon the person and contributed to the offending behaviours and prevents further offences:-

⁷ NSW Law Reform Commission. 2010. *People with cognitive and mental health impairments in the criminal justice system: an overview*.

- housing, personal assistance, counselling
- to comply with Court orders i.e. attend appointments

Most of the clients will not qualify for NDIS packages because they do not have such high support needs, but they will benefit from ILC-funded services.

4.2 Oversight

The Quality and Safeguards Framework ('the Framework') is still under construction, but whatever its final shape it is clear that there must be coordinated grassroots mechanisms to prevent and address neglect, mistreatment and abuse, and to identify, investigate, remedy and record service-delivery oversights and mis-management. The Framework does not include 'eyes on the ground' in group homes, hostels, and boarding houses, or in health, aged care and nursing home facilities where many persons with disabilities live. In aged care facilities alone there were 6240 people under 65 years in June 2016.⁸

The Framework will have no mandate to address individual or systemic issues outside of the NDIS. When interfacing or using other service systems, the majority of people with disability as well as NDIS participants will have protection only through existing regulatory and policy frameworks. Those frameworks provide inadequate protection (see textbox Case Example: Unauthorised Restrictive Practices, Neglect and Abuse in Disability Accommodation).

4.3 Community Visitors

The adult Community Visitor is a program under the mandate of the *Guardianship and Administration Act 2000* (Qld) for the oversight of all disability-funded accommodation services, whether government funded, NDIS funded or government administered. The program identifies problems that would not otherwise be picked up. In the last financial year community visitors made more than 5000 visits to adult visitable sites and identified 1,931 issues, a significant proportion of which related to personal safety and security, including complaints of abuse or assault. Expansion of Community Visitor's schemes emerged as a key recommendation⁹ of the Senate Community Affairs References Committee's recommendations in its 2015 inquiry and report into Violence, abuse and neglect against people with disability in institutional and residential settings.¹⁰

There is no nationally consistent approach. And across all jurisdictions, the roles and responsibilities of community visitor schemes differ widely. Some jurisdictions have community visitor programs responsible for inspecting residential facilities for people with disability. Other jurisdictions have community visitors for mental health services only. In

⁸ Hansard, 20 October 2016, Senate Community Affairs References Committee. Ms Glanville.

⁹ Recommendation #9: 'The committee recommends the Australian Government work with state and territory governments on a nationally consistent approach to existing state and territory disability oversight mechanisms, to include: [...]

- increased funding for community visitor schemes, with consideration these schemes be professionalised in all jurisdictions and with a mandatory reporting requirement for suspected violence, abuse or neglect.'

¹⁰ The Senate Community Affairs References Committee. 2015. *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability.*

Victoria, volunteer Community Visitors provide an important protection at a minimal cost, and actively foster the social inclusion of people with disability in the community.

In Queensland, community visitors are called upon by the Queensland Civil and Administrative Tribunal to write reports on inappropriate or unauthorised use of restrictive practices against a person with disability. Unauthorised restrictive practices, however, are not uncommon, and some escape the community visitors.¹¹

Where individuals enter individual agreements with service providers they may need advice, including legal advice. People with disabilities who are non-verbal, for example, and those who have limited ability to self-advocate will have few opportunities to access the new complaints commission. QAI asserts that people with disabilities should be supported to develop their own agreements to offer to service providers and that Plans should include funds to obtain legal advice for this particularly for vulnerable people who may have difficulty accessing appropriate supports and services.

4.4 Safeguards – Reducing and Eliminating Restrictive Practices

In Queensland, restrictive practices currently are regulated under the *Disability Services Act 2006* (Qld) and they include mechanical, physical and chemical restraint, containment and seclusion. Restrictive practices are used in circumstances to protect the person with disability or others from harm, but such practices are also imposed as a 'means of coercion, discipline, convenience, or retaliation by service providers (often in relation to understaffing and cost cutting) staff, family members or others providing support'.¹²

Since March 2014, a coalition of advocates, services and government has moved for consistency and standardisation in the regulation of restrictive practices in the form of the National Framework which is intended to work within existing legislative arrangements to establish minimum standards. State-based regulation will soon merge with the National Quality and Safeguards Framework for Reducing and Eliminating the Use of Restrictive Practices.

It embodies the agreement by all jurisdictions that, by 2018, all disability service providers with NDIS funding will implement six core strategies to reduce the use of restrictive practices. The six core strategies are: person-centred focus; leadership towards organisational change; use of data to inform practice; workforce development; use of restraint and seclusion reduction tools; and debriefing and practice review.¹³

The COAG Disability Reform Council indicated that these core strategies will guide governments in the development of national quality and safeguards system for the

¹¹ See Case Example Two in text box.

¹² Disability Rights Now, *Civil Society Report to the United Nations on the Rights of Persons with Disabilities* (2012) [241].

¹³ See further Australian Government, *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* (2014).

NDIS.¹⁴ Until such a system is developed, state and territory quality assurance and safeguards frameworks will apply.

Inappropriate or overuse of restrictive practice is endemic to disability services. In our advocacy experience, services have a vested interest in their application. A key explanation for the use of restrictive practices may be the lack of resources for positive behaviour management and multi-disciplinary interventions to 'challenging behaviours',¹⁵ but the opposite is also true: services have sought to apply Restrictive Practices, unnecessarily, in our view, because they know that ongoing application requires extra staff, extra surveillance, and consequently, bigger support packages.

A social model recognises disability as a product of impairment and environment.¹⁶ Understanding behaviour means understanding the whole of the environment in which the person (with impairment) lives. So-called 'challenging-behaviours' may be better understood as a 'legitimate response to difficult environments and situations' or 'adaptive behaviours to maladaptive environments'.¹⁷

A restrictive environment is a self-fulfilling prophecy. The more restricted the environment and the practices used within that environment the more it dehumanises the people in it, people with disabilities and support people alike. A greater sense of frustration and disempowerment, despair and anger, hurt, humiliation, resentment, sorrow, mental anguish is a predictable outcome.

QAI has advocated for several years that the NDIS must enable people who live with restrictive practices the same opportunities and rights as other NDIS participants to exercise their autonomy and control in their lives. This restoration of respect and self-determination has already empowered the few who have taken advantage of this prospect and are living the life that the advent of the NDIS had promised for so many. It would be a cruel and hazardous assault to revoke this right from

Case Example: Unauthorised Restrictive Practices, Neglect and Abuse in Disability Accommodation.

Leah Floyd* died from sepsis associated with a necrotic sacral pressure wound. Ms Floyd was a tetraplegic and vulnerable to pressure sores. She received supported accommodation and care at a non-government disability service provider, with assistance in wound care by Blue Care nurses.

The disability service provider was responsible for implementing strategies in wound care prevention/ There was a lapse in September 2016 when Ms Floyd's sacral wound degraded from a stage 2 to stage 4. Although Ms Floyd became unwell she was reluctant to be admitted to hospital [largely because of her] mistrust of the disability service provider and her GP who had unreasonably against her will required her admission for a mental health assessment. Management at the disability service provider wrongfully endeavoured to impose restrictive practices on her and against her human rights. Ms Floyd finally agreed to be admitted to hospital immediately after having seen her children. By this time she was rapidly deteriorating and she died within a number of days.

*Inquest into the death of Leah Elizabeth Floyd
Coroners Court Maroochydore 8 December 2016

¹⁴ COAG Disability Reform Council, *Meeting Communiqué*, 21 March 2014.

¹⁵ Paul Ramcharan et al, 'Experiences of Restrictive Practices: A View from People with Disabilities and Family Carers' (Research Report, Office of the Senior Practitioner, 2009).

¹⁶ World Health Organization. 2011. *World Report*, page 4. http://www.who.int/disabilities/world_report/2011/chapter1.pdf?ua=1

¹⁷ Paul Ramcharan et al, 'Experiences of Restrictive Practices: A View from People with Disabilities and Family Carers' (Research Report, Office of the Senior Practitioner, 2009) 2.

people who have so much to gain, and who would otherwise be subjected to an increase in the use of practices that amount to drugging, imprisonment, restraint that is tantamount to bondage and or solitary confinement.

There is a danger that the NDIS pricing model will perpetuate and even exacerbate the use of Restrictive Practices by attracting service providers that seek to implement them in order to obtain the lucrative packages that some participants; plans will contain, than providing incentives for services that seek to reduce or eliminate them. The unit prices for specialist behavioural intervention support, development of behaviour management plans and training in behaviour management skills exceed by far the unit prices for non-specialist support. While the expertise required for understanding the unique communication that is employed by people who have no other alternative than to demonstrate this through their behaviour, it is not often aligned with the skills associated with behaviour support – that is more often experience in applying restrictive practices.

While training in alternative approaches that do not resort to restraint and seclusion are more costly, in the long run they can save money by creating a safer home/workplace and without the long term costs to the quality of life for the participant. In addition to training, the price guide must provide for ongoing supervision of staff to ensure that they consistently implement positive behaviour support plans (PBSPs). Reduction of restrictive practices is linked to the quality of plans and the quality of their implementation. Without supervision (and organisational leadership¹⁸ and cultural change¹⁹) support staff will not properly implement a plan.

We do not dispute that it costs more to develop a plan and train support workers to implement it, than it does to provide ordinary access support. However, there appear to be no financial incentives to create quality living environments or support approaches that would reduce the use of restrictive practices.

By quality living environment we mean living spaces that people can consider their *own* rather than shared with 1 or 2 or even 7 or more other people. The pricing structure for group living has the reverse effect, incentivising group living by offering little proportionate decrease in weekly unit funding as the number of people sharing a space increases. This pricing may motivate providers to under staff and divert the money saved to cover other costs, particularly for administration.

¹⁸ Huckshorn, K.A. (2005). Six Core Strategies to Reduce the Use of Seclusion and Restraint Planning Tool. Alexandria, VA: National Technical Assistance Centre.

¹⁹ Williams, D.E., & Grossett, D.L. (2011). Reduction of restraint of people with intellectual disabilities: An organizational behavior management (OBM) approach Research in Developmental Disabilities 32, 2336–2339.

Support Item	Support Item Ref No.	Description	UOM	Quote Required	Price
Specialist behavioural intervention support	11_022_0110_7_3	Highly specialised intensive support interventions to address significantly harmful or persistent behaviours of concern. Development of behaviour support plans that temporarily use restrictive practices, with intention to minimise use of these practices.	Hour	N	\$196.45
Behaviour management plan, training in behaviour management strategies	11_023_0110_7_3	Training for carers and others in behaviour management strategies required due the persons disability.	Hour	N	\$178.98
Individual social skills development	11_024_0117_7_3	Social skills development with an individual, for participation in community and social activities.	Hour	N	\$56.14

High Intensity needs

Support Item	Support Item Ref No.	Description	UOM	Quote Required	Price
Assistance to access community, social/rec acts - individual higher intensity - weekdays	04_101_0104_6_1	Individual participation support by a support worker with additional qualifications and experience relevant to the participant's complex needs during the week.	Hour	N	\$47.20
Assistance to access community, social/rec acts - individual higher intensity - weekday evening	04_098_0104_6_1	Individual participation support by a support worker with additional qualifications and experience relevant to the participant's complex needs during the weekday evening.	Hour	N	\$51.76
Assistance to access community, social/rec acts - individual - higher intensity - Saturday	04_099_0104_6_1	Individual participation support by a support worker with additional qualifications and experience relevant to the participant's complex needs on a Saturday.	Hour	N	\$65.48
Assistance to access community, social/rec acts - individual higher intensity - Sundays	04_100_0104_6_1	Individual participation support by a support worker with additional qualifications and experience relevant to the participant's complex needs on a Sunday.	Hour	N	\$83.78
Assistance to access community, social/rec acts - individual higher intensity - public holiday	04_097_0104_6_1	Individual participation support by a support worker with additional qualifications and experience relevant to the participant's complex needs on a public holiday.	Hour	N	\$102.08

Support Item	Support Item Ref No.	Description	UOM	Quote Required	Price
Specialist behavioural intervention support	11_022_0110_7_3	Highly specialised intensive support interventions to address significantly harmful or persistent behaviours of concern. Development of behaviour support plans that temporarily use restrictive practices, with intention to minimise use of these practices.	Hour	N	\$196.45
Behaviour management plan, training in behaviour management strategies	11_023_0110_7_3	Training for carers and others in behaviour management strategies required due the persons disability.	Hour	N	\$178.98
Individual social skills development	11_024_0117_7_3	Social skills development with an individual, for participation in community and social activities.	Hour	N	\$56.14

5. NDIA & persons with disabilities in the criminal justice system

5.1 Justice support

The Principles To Determine The Responsibilities Of The NDIS And Other Service Systems state that the NDIS will fund specialised supports to assist people with disability to live independently in the community, including supports delivered in custodial settings (including remand) aimed at improving transitions from custodial settings to the community, where these supports are required due to the impact of the person's impairment/s on their functional capacity and are additional to reasonable adjustment.²⁰

²⁰ Applied Principle #5 – 'Justice' from Council of Australian Governments: Principles To Determine The Responsibilities Of The NDIS And Other Service Systems.

QAI observes no coordinated effort by the NDIA to implement this principle. For example, there is yet no attempt to liaise with the Queensland Chief Magistrate to ensure a referral pathway to the NDIA from the lower courts.

From March 2017, Queensland Magistrates-

- a) will have the power to dismiss complaints (criminal charges) if satisfied on the balance of probabilities that the defendant was of unsound mind or is unfit for trial²¹
- b) may refer defendants who are unfit for trial to a 'appropriate agency', including the National Disability Insurance Scheme²² or the Transition Agency established under the *National Disability Insurance Scheme Act 2013* (Cth) or the department in which the *Disability Services Act* (Qld) is administered,²³ and if 'a)' above applies, and the person has or may have a mental illness
- c) may make an examination order for clinical determination of need for treatment.²⁴

NDIA Local Area Coordinators must take the initiative and approach the Chief Magistrate and Court Liaison Officers to explore possibilities for diversion and support.

There are ILC opportunities for court support. Approximately one in three people appearing as defendants in Queensland's criminal courts have cognitive impairment and may have considerable difficulty understanding court proceedings. They may not seek assistance or explanation because of fear or longstanding habit.

People with cognitive impairment may have some strong functional and survival skills that mask their real difficulties. They may not understand their court obligations or the consequences of failing to meet them.

5.2 Indictable Matters

The Mental Health Court ('MHC')²⁵ presides where a person is charged with an indictable offence and capacity is at issue, whether in relation to 'fitness for trial' or 'unsoundness of mind'. The MHC sits at the top of the 'forensic system' and makes dispositions in relation to people who are unfit for trial or who are of unsound mind, or sends matters back to the regular courts where capacity is not at issue.

MHC dispositions ('forensic orders') send people to secure mental health facilities or place people on community supervision. A small proportion goes to the Forensic

'Robert' - summary offences, no diversion.

A man walked to the primary school he had once attended. A teacher called the Toombul police, and they apprehended, charged and released Robert. Police later arrested him for an exposure offence at a different location. The Magistrate said he believed this was a case of 'complete lack of capacity' but the system did not allow him to recognise it as such. The Magistrate did not want to issue any kind of punitive or custodial sentence but nor did he feel in a position to simply ignore the offences. Since March 2017, Queensland's new *Mental Health Act 2016* has given Magistrates an option to refer defendants like Robert to the NDIA for 'appropriate care' (s 174 (2)).

²¹ *Mental Health Act 2016* (Qld) section 172.

²² Or to Queensland Health

²³ *Mental Health Act 2016* (Qld) section 174.

²⁴ *Mental Health Act 2016* (Qld) section 177.

²⁵ The Mental Health Court is a division of the Supreme Court

Disability Service at Wacol, near Brisbane, a purpose-built facility for the indefinite detention of people who have cognitive impairments. There is only one such facility in the state, and inmates are sometimes held a great distance (up to ~ 2200 km) from home. Only one or two inmates have yet transitioned from the Forensic Disability Service, despite parliament's intention that it be a transitional facility. While there is only one such facility, QAI asserts that it has not been effective in its purpose and in fact it is our experience from working with individuals detained there, that it has been detrimental to most. The service has a chequered history and the former Chief Psychiatrist deemed it was 'unfit for human habitation', and the current director's submission to the Senate Inquiry revealed inadequacies in the service's performance.²⁶

The purpose of a forensic order is treatment or training and habilitation of the person and the protection of others; the system's ultimate goal is to reintegrate the person into the community. Properly implemented, a forensic order can have many benefits for an individual with complex needs. Those benefits must be weighed, however, against the restrictions imposed by forensic orders, restrictions that for many QAI clients have lasted for many years more than a criminal sentence in relation to a similar fact scenario.

The forensic system, although nominally less punitive, creates a new set of barriers that slow or indefinitely defer a person's transition to community. Whether detained in a secure mental health facility or in the Forensic Disability Service, one of the primary reasons for prolonged detention is the lack of accommodation or supports needed for transition into community. The kinds of supports needed are not always available through mainstream services, but do fall squarely into the reasonable and necessary supports the NDIS can provide.

If people with intellectual impairments had been appropriately supported in the first instance, most would not have contact with the criminal justice system, or avoid prison in the first place. Given a suitable range of options, the courts would divert them from prisons, which are expensive to run and promote recidivism. Effective prevention and diversion programs for persons with disability either do not yet exist or are rudimentary and lack appropriate levels of funding. In this chapter we canvas some of the strategies employed in other Australian jurisdictions.

A prisoner, whether remanded, sentenced or in police custody, should have timely referral and access to specialist mental health services when appropriate. Persons attending court who appear to be mentally ill, or about whom there is concern exists that mental health issues exist, should have access to assessment by an appropriately trained mental health clinician.

5.3 Prison Transition

The work of the Prisoners' Legal Service, the Catholic Prison Ministry and the Queensland Centre for Intellectual and Developmental Disability demonstrates that ex-prisoners are most likely to reoffend in the first difficult weeks out of jail. Ex-prisoners often have nowhere to live, little money, few friends or supporters and meagre employment prospects. For some, a return to prison is an alternative to poverty, loneliness and homelessness.

²⁶ Indefinite detention of people with cognitive and psychiatric impairment in Australia Submission 69

Piecemeal changes are not enough: the NDIA's first step is to promote a coordinated cross-government approach to post-release services to ex-offenders with disabilities so that they are better equipped to reintegrate and live fulfilling lives.

In custody or in transition to community, plan reviews need to be regular and plans must be reflexive. People's needs fluctuate. The only available support for review of plans in the Queensland launch site is one advocacy agency. The NDIA must focus more on process.

The key decision-maker, apart from the person and the Mental Health Review Tribunal, is a person's treating team. If the treating team is not aware of supports that are available, or may be possible, they will go with a conservative estimate of supports.

Example: A man in a rehabilitation unit had to make his own application to the NDIA. He had no support, and consequently, his plan lacked elements that he would otherwise have had.

The NDIA must implement the NDIS Standing Committee's recommendations

- to clarify what approved supports are available to NDIS participants in custody and how it monitors and ensures NDIS participants access the supports they are entitled to while in custody.
- To establish a unit specialising in the interaction of the Scheme with the criminal justice system.²⁷

The NDIS and the justice system will work closely together at the local level to plan and coordinate streamlined services for individuals requiring both justice and disability services recognising that both inputs may be required at the same time or through a smooth transition from one to the other.

6. People with a Lived Experience of a Mental Health Condition

QAI is one of only two services in Brisbane that provide legal advice and representation to people who appear before the Mental Health Review Tribunal in relation to Treatment Orders pursuant to the *Mental Health Act 2016* (Qld). This service is not through the NDIA, but 'block-funded' funded through the Queensland Department of Justice. Through this service, we have extensive contact with people who move between community, prisons and acute-care institutions and have an understanding of people's support needs.

Many other services for people with a lived experience are still block funded, among them, Partners in Recovery (mental health peer support) and the Personal Helpers and Mentors Scheme (PHaMS). PHaMS provides opportunities for recovery for people who are severely affected by mental illness, helping them to overcome social isolation and increase their connections to the community. People are supported through a recovery-focused and

²⁷ Recommendations 22 & 23 in NDIS Standing Committee, 2017. Report on Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.

strengths-based approach that recognises recovery as a personal journey driven by the participant.

PHaMs workers provide practical assistance to help people to achieve personal goals, develop better relationships and manage everyday tasks, helping people to access services and participate economically and socially in the community and increasing their opportunities for recovery. These services will cease at full NDIS roll-out, leaving many of our clients with nothing else between them and an acute care facility where they may be subject to physical or chemical restraints, containment or seclusion. Many block-funded mental health services will not survive the roll-out because intermittent and informal 'drop-in' contact with their members/constituents/clients is the foundation of their business model.

As the principal provider of mental health *legal* services in Brisbane, we have many clients who have chronic and/or acute mental health issues. Some of our clients have the 'significant and enduring psychiatric disability' described by the Productivity Commission as the trigger for NDIS participant packages:²⁸

Many people with significant and enduring psychiatric disabilities have the same day-to-day or weekly support needs as people with an intellectual disability or acquired brain injury. These can include assistance with planning, decision making, scheduling, personal hygiene and some communication tasks. Regular support and, in some cases, supported accommodation, allows such people to live successfully in the community.²⁹

The Commission estimated that there would be 57 000 people with enduring and significant psychiatric disabilities who would meet the eligibility criteria. However, few of our clients who are not in acute care, however, need around the clock support or the kind of time-tabled support that people with physical, intellectual or sensory disabilities require, and around which the Productivity Commission designed the NDIS

Far from it; the majority needs on-call support that by its nature is unpredictable and un-budget-able: available at any time, but never all of the time and by its nature unquantifiable in advance.

The Productivity Commission took the view that only the community mental health system shared an NDIS philosophy and approach, and that community health tends to have a 'clinical needs' rather than 'community needs' orientation. There have long been community-based groups in Brisbane with just that 'community needs' approach - the Brook Red Centre, the Richmond Fellowship and the Stepping Stone Clubhouses have operated for decades.

Stepping Stone clubhouses, for example, offer participation in work units including Employment, Clerical, Administration and Training; Reception and Media or Hospitality, and members engage in a range activities designed to boost self-esteem and help prepare participants for other employment or education activities. Brook Red is managed and operated only by people who identify as having a lived-experience of recovery.

²⁸

²⁹ Productivity Commission. 2011. *Disability Care and Support*. Page 26.

None of these operates their core business through fee-for-service. They could do so, and cater exclusively to the approximately 10% of people who have severe and persistent mental illness who will qualify for NDIS packages, but they would not have sufficient operational 'fat' to cater to the other 90% who will not.

Nor is the ~\$150 million of ILC funding enough to block fund mental health supports, and as people are no longer able to access the support they have been using through the Personal Helpers and Mentors, Partners in Recovery or a Day to Day Living program there will be an increased risk of crisis. With none of these familiar services available, people must turn to health and emergency services and police.

7. Aboriginal and Torres Strait Islander Provision

Aboriginal and Torres Strait Islander Australians experience higher rates of disability than do other Australians. After taking into account age differences between the Indigenous and non-Indigenous populations, the rate of disability among Aboriginal and Torres Strait Islander Australians is almost twice as high as that among non-Indigenous people.

The experience of marginalised Aboriginal and Torres Strait Islander people with neurocognitive disabilities and brain injury is far removed from community norms and their disadvantage is extreme. Many experience complex disablement that is impacted by intergenerational physical and psychological trauma and poverty; lack of opportunity; domestic violence; substance abuse and recurrent involvement in the criminal justice system. Many are disengaged from existing services and from the NDIA, and there are limited culturally appropriate services available to respond to their needs.

In indigenous communities, knowledge of the NDIS and the roll-out is poor. One of the few indigenous participant readiness projects in south-east Queensland is Synapse's 'Murri DAN' Disability Advisory Network, which delivers information sessions and convenes yarning circles that spread NDIS information by word-of-mouth. In 2016, approximately 36 people living in South-east Queensland and 38 people in Brisbane attended Participant Readiness information sessions run through Murri DAN. This is a tiny proportion of potential participants.

People from Aboriginal and Torres Strait Islander backgrounds in rural, remote and regional Queensland have not been given information or advice about the NDIS – what it is, how to apply, or what they can achieve. Disability is an English term that has no equivalent in many Aboriginal languages. Word-of-mouth is an effective way to share the NDIS message.

Even if knowledge of the NDIS was much higher it might not be enough to ensure reasonable rates of participation. The notion that support can come from someone outside one's family or kinship group is a foreign one to many Aboriginal people, and this contributes to a cultural disconnect on disability issues. Face to face conversations with peers who have the lived experience of disability are the most effective way to share the NDIS message in Aboriginal communities.

The NDIA must take extraordinary measures to overcome the barriers to NDIS service delivery including:

- block funding suitable providers where services would not otherwise exist or would be inadequate
- using existing networks and service provision in health and aged care
- fostering smaller and consultative community-based services that engage local staff
- engaging support from larger experienced service providers to decentralise and engender local responsive smaller micro-services
- employing and developing Indigenous staff and developing the cultural competency of non-Indigenous staff
- working with state and territory governments, indigenous advocacy groups, specialist disability legal services, and other community groups to develop and refine funding strategies, understand local and systemic issues

Rather than duplicate or merely replicate tried and failed models, the NDIS will need to cooperate and coordinate with innovative and successful person-centred and person-controlled and operated models on wider measures that address Indigenous disadvantage, and exploit potentially novel participant pathways through:

- criminal justice institutions such as police, magistrates and higher courts, corrective services, prisons and post-prison services, and parole boards
- hospitals and other health services
- child protection services
- schools and other educational institutions.

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