



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

Reshaping the Disability Services Act 2006

Submission by Queensland Advocacy Incorporated

to

**Department of Communities, Disability Services
and Seniors**

"I am neither an optimist nor pessimist, but a possibilist." - Max Lerner

"To give real service you must add something which cannot be bought or measured with money, and that is sincerity and integrity." Douglas Adams

"The best customer service is if the customer doesn't need to call you, doesn't need to talk to you. It just works." Jeff Bezos

Ph (07) 3844 4200 or 1300 130 582 Fax (07) 3844 4220 Email qai@qai.org.au Web 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

14 November, 2018

Strategic Policy and Legislation

Department of Communities, Disability Services and Seniors

GPO Box 806

Brisbane Qld 4001

By email:-

submissions@communities.qld.gov.au

Dear Department of Communities,

Reshaping the Disability Services Act 2006

Thank you for the opportunity to participate in the review of the Disability Services Act 2006 to ensure Queensland laws reflect how supports for people with disability are funded and delivered across Australia.

QAI commends the Minister and the Department for undertaking this timely review. Members of our staff have participated in two of the local consultations. It is our hope that this review will provide redress and reassurances to the majority of people with disability who will still require supports and services from the state government who are ineligible for the NDIS or for those participants of the Scheme but whose other supports fall outside the scope of that system.

Given the statement that Queensland Government's role in the disability sector is changing with a primary focus to champion accessibility and inclusion of people with disability within the community, we offer our submission in writing to ensure the best way to achieve those goals.

Yours sincerely,



Michelle O'Flynn

Director

About QAI

Queensland Advocacy Incorporated (QAI) is a member-driven and non-profit advocacy NGO 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.

Our Human Rights and Mental Health services offer legal advice and representation: the first, on guardianship and administration and the latter on mental health matters. Our Justice Support and NDIS Appeals programs provide non-legal advice and support to people with disability in the criminal justice system and to participants in NDIS Appeals. This individual advocacy informs our campaigns at state and federal levels for changes in attitudes, laws and policies, and it assists us to understand the challenges, needs and concerns of people who are the focus of this submission.

QAI's constitution holds that every person is unique and valuable, and that diversity is intrinsic to community. People with disability comprise the majority of our Board; their wisdom and lived experience of disability is our foundation and guide.

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Key Recommendations for the New Disability Services Act ('the Act')

- The Act should include a preface that places strong emphasis on the shared responsibility across agencies and the community to uphold the rights of people with a disability.
- The Act should require government departments and statutory bodies to align with the *Convention on the Rights of Persons with Disabilities* and uphold the rights of people with disability, for example, in developing disability inclusion action plans with measureable goals, KPIs and outcomes.
- Rather than state only high-level principles, the Act should set out guidelines and procedures that activate established principles.
- The Act must identify clearly the role and relationship between the state government particularly the Department of Communities and Disability Services and the National Disability Insurance Agency ('NDIA').
- The Act should promote a strong person-centred approach, such as that found in the Victorian *Disability Services Act 2006*; set out the responsibilities of departments and agencies to provide person-centred services; and, embed the rights of people with disability to have access to services and to be involved in service planning.
- The Act should set out best practice consultation and/or, co-design with people with disability.
- The Act should outline a mechanism to ensure accessible procurement by government agencies.
- The Act must stipulate ongoing data collection and analysis by all agencies with responsibilities under the Act.
- The Act should require that it first should be reviewed after three years, then every five years thereafter. Reports of these reviews should be tabled in State Parliament.
- The Act should appoint a Disability Commissioner, with key powers and responsibilities set out below at #10.
- The Disability Commissioner will adopt the disability-relevant functions and powers of the Public Advocate as set out in the *Guardianship and Administration Act 2000* (Qld), but with broader scope to promote and defend the rights of people with disability, particularly those who do not have NDIS Plans.

- The Act should include provision for people with cognitive impairment, providing recognition of their specific rights and needs, as does section 6 of Victoria's *Disability Act 2006*.
- The Act should mandate 'no card no start', except where people with disability are self-managing their supports and services. In that instance, sole traders and unregistered providers should be able to work while awaiting screening, but only if safeguards are implemented, including risk management plans and supervision by a screened NDIS worker.
- The roles and responsibilities of the Disability Advisory Councils should be reviewed and invigorated. The Act should outline the function, terms of recruitment, membership and the terms of review of the Councils OR
- The Disability Advisory Councils should be convened by and linked to an agency with expanded authority, such as the Disability Commissioner, as outlined below.
- The Act should establish a right to advocacy support and the state government should continue to fund it.

1. Rights Charter

QAI commends a Disability Rights Charter, but we note the potential for redundancy. Queenslanders with disabilities already have the nominal protection afforded by the principles set out in the *Convention on the Rights of Persons with Disabilities* ('CRPD') and the Optional Protocol to the Convention Against Torture. The National Disability Strategy sets out policy goals to implement the CRPD. Queensland's new human rights legislation too, if passed, will include some disability-relevant human rights principles that are in some measure enforceable. More important than another statement of principles is for the Act to link principles and action. The Act should include a Charter, and set-out mechanisms to enforce it.

The 2018 report by Human Rights Watch¹ on conditions for prisoners with disabilities, for example, revealed that some Queensland prisons use solitary confinement as a disciplinary measure. Effective mechanisms to ensure compliance with existing charters eventually would put an end to such practices, and to others such as the use of restrictive practices in schools, or the discounting of the decision-making capacity of people with mental illness who are subject to ECT.²

Rather than state only high-level principles, the Act could set out guidelines and procedures for putting established principles into effect. Whenever they begin a new major project or procure new infrastructure, and when the executive drafts new legislation, the Act could require state government departments and statutory agencies to commission Disability Impact Statements from third parties, rather like Regulation Impact Statements. Someone with disability and relevant expertise would develop the statement. The Act could require each department and

¹ "I Needed Help, Instead I Was Punished": Abuse and Neglect of Prisoners with Disabilities in Australia <https://www.hrw.org/report/2018/02/06/i-needed-help-instead-i-was-punished/abuse-and-neglect-prisoners-disabilities>

² Victoria Legal Aid was successful in the Court of Appeal for an appeal against the decision of VCAT in relation to involuntary ECT. The case was argued on both administrative law and human rights law grounds using the Victorian Human Rights Charter. The Guardian article is here: <https://www.theguardian.com/society/2018/nov/01/shock-therapy-court-upholds-appeal-by-patients-prescribed-ect-against-their-will> and the judgment here: <http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/vic/VSC//2018/564.html>. The standard applied by the tribunal to decide whether patients with a mental illness were capable of giving informed consent was higher than would be expected of a person who was not the subject of an involuntary treatment order, and was therefore discriminatory. Denying or diminishing the extent of illness was not uncommon in people both with mental illness and without mental illness, and applying it as a determining factor of the ability to give informed consent in this case would be discriminatory. 'A person does not lack the capacity to give informed consent simply by making a decision that others consider to be unwise according to their individual values and situation [...] To impose upon persons having mental illness a higher threshold of capacity, and to afford them less respect for personal autonomy and individual dignity, than people not having that illness, would be discriminatory'.

statutory agency to develop disability inclusion action plans with measureable goals, KPIs and outcomes.

The Act should promote a strong person-centred approach, such as that found in the *Victorian Disability Services Act 2006*, and should embed the rights of people with disability to have access to services and to be involved in service planning. It should set out the responsibilities of departments and agencies to provide person-centred services.

The Act should include provision for people with an intellectual disability, providing recognition of their specific rights and needs, as does section 6 of Victoria's *Disability Act 2006*.

- The Act should contain detailed descriptions of the rights, responsibilities and services that arise from the legislation.
- The Act should provide that people with disability should participate in the planning and operation of services, or have the choice to develop their own service model.
- The Act should provide that people with disability contribute to their Positive Behaviour Support Plans and to the strategies to reduce or eliminate the use of Restrictive Practices.
- The Act should provide that people who wish to exit co-tenant arrangements (i.e. 'group homes' or congregate care arrangements) should be fast-tracked to suitable housing of their choice.

We note the incongruence between rights provided by a disability charter and anti-discrimination provisions that may undermine those rights. 'Unjustifiable hardship' is an escape clause for departments, particularly Education Queensland, that will exclude students with diverse support needs rather than exhaust every means to include them. Unjustifiable hardship is based on an assessment of what is fair and reasonable in the circumstances, but the Act should promote adjustment over exclusion.

2. Clarify agency roles and responsibilities, including for collaboration

The service needs of people with a disability cross the jurisdictions of different government agencies, with clear implications for policy and service delivery. Acknowledging this in the legislation will provide strong leverage for interagency policy and service development. This will be especially relevant as individualised funding is implemented per the National Disability Insurance Scheme (NDIS), accentuating the need for clear service access pathways.

Clear stipulations for agencies in the new legislation would clarify the requirements, reduce ambiguity and increase the accountability of these agencies.

The National Disability Insurance Scheme (NDIS) Bill 2012, the Human Rights & Anti-Discrimination Bill 2012 and the UN Convention on the Rights of Persons with a Disability offer a positive framework against which to review the responsibilities of agencies

Currently, articulation of agency responsibilities for people with a disability are dispersed across different legislative frameworks, including the Mental Health Act 2016, the DSA and the Guardianship and Administration Act.

Interrelationship with other Legislation

The conflation of intellectual impairment and mental illness has historically and currently resulted in the inappropriate institutionalization of vulnerable people with disability in mental health facilities. This is exacerbated by the language used by government departments, legislation and policies. Section 216 of Queensland’s Criminal Code refers to people as having “impairment of the mind” conflating mental illness and intellectual impairment and discriminating against people based on impairment.

The Mental Health Court determines diversion to forensic facilities, and the law uses language such as “unsound mind” or “insanity defense”. This is reinforced by language such as “limited community treatment’ at the Forensic Disability Service – people with intellectual impairment who do not also have a mental illness do not require ‘treatment’ but do require education, habilitation and support. The Act should be a tool to assist in the education of and refinement of appropriate language across other legislations, policies and practices.

The Act should also outline the formal reporting arrangements to the Minister of Disability. The relationship between the Act and the Guardianship and Administration Act should be identified clearly within the Act. For example, the legislative framework should be articulated for persons with disability who require decision-making support. Presently this is unclear, and this is problematic in service delivery.

Queensland must move towards a ‘supported decision-making’ guardianship system rather than ‘substituted decision-making’. The former is consistent with the *Convention on the Rights of Persons with Disabilities* and reduces the degree of government intervention in people’s lives.

There are limited responses to breaches of the current Act. The Victorian Act has a maximum penalty of up to 240 PU or \$26,400, and this more appropriately reflects the seriousness of breaches of the rights of people with disability.

The legislation must require coordinated efforts across government in the provision of services for people with a disability. The Department of Communities must take a lead role with other government departments to redress the multiple layers of repression and ableist mechanisms that have historically been at the root of abuse and neglect. A number of government agencies will need to work together to remove forced co-tenancy, collaborate with DHPW to facilitate more appropriate and less clustered housing options, and more choices about who, where and how people with disability live. This will help alleviate the issues that give rise to the violence, abuse and neglect and use of RP.

We recommend that:

- A preface be included in the Act that places strong emphasis on the shared responsibility across agencies and the community to care for, support and uphold the rights of people with a disability;
- The Act must identify clearly the role and relationship between the state government particularly the Department of Communities and Disability Services and the National Disability Insurance Agency ('NDIA').
- There must be a mechanism that ensures that when a person with disability enters the National Disability Insurance Scheme ('NDIS') any state funded supports that are not to be funded by the NDIS do not cease.
- People who have never received any supports and who will not be eligible for NDIS will require state funded supports and services. There must be a user-friendly application process rather than having to apply for a Scheme (NDIS) in order to be rejected merely to apply for state services. The Act must articulate that provision of supports and services will continue for eligible Queenslanders with disability.
- The Act must outline clearly the roles and responsibilities of agencies with key links to the disability sector, including departments of health and housing, non-government service providers, Disability Advisory Councils, the Public Advocate, the Public Guardian, the Public Trustee and Community Visitors.
 - Legislative requirements and responsibilities of Official Community Visitors in relation to disability services should be provided in the Act, to enable greater recognition of their role and significance in disability support;
 - The relationship between the Act and the Guardianship Act should be articulated and address capacity for decision-making and decision support.
 - Stronger penalties must be imposed for breaches of rights of people with a disability.
 - The Act must define the meaning of 'inclusion' to ensure that there is no misunderstanding of the term.

3. Update the Regulatory Framework for Restrictive Practices (NDIS Quality and Safeguards)

Given the stated Service Delivery Principles that people with disability should participate in the planning and operation of services, including the services and premises where they are provided, it is essential that people with disability are included in the development of their Positive Behaviour Support Plans and the strategies by which Restrictive Practices (RPs) are reduced or eliminated.

QAI recommends that the Centre of Excellence:

- Provides training in the development of Positive Behaviour Support Plans and monitors their implementation to ensure that all Plans meet the standards
- Collects data on type, use, frequency and reduction (or not) of Restrictive Practices
- Monitors the strategies used for the reduction or elimination of the use of RPs
- Reports to the NDIS Quality and Safeguards Commission ('the Commission') on the use, type and frequency of RPs for people who reside at the Forensic Disability Service ('FDS') even though the FDS is not an NDIS-registered provider. (The Commission must have complete RP data).
- Mandates and delivers training for services that fail to reduce the use of RPs within the timeframe of the Approved Order. Where a service has failed to reduce the use of RPs within the review period for an approved order, the Centre of Excellence should consult with the person (and/or their informal or formal supporters) about whether the service is appropriate to their needs.
- Report on the data collected
- Report service providers' breaches of the rights any person with disability to the NDIS Quality and Safeguards Commission.

People who are subject to forensic orders and who live with RPs must have optimal Positive behaviour Support Plans.

4. Data Collection

Improving services requires evidence, and ongoing data collection is imperative. The Act should stipulate the routine collection and use of data in the provision and evaluation of services for people with disability. This is outlined in the National Disability Agreement and in the Victorian Act, section 8(1)(c).

5. Information about the Act

QAI recommends that the Act should provide that:

- Notices and other information related to the Act should be available in other languages.
- Government publications should be available in accessible format, such as Augmentative and Alternative Communication or Easy Read.
- People with disability should receive appropriate support to understand information about the Act (for example, as outlined in section 7 of the Victorian Act).

6. Review of Act

Rapid change in the landscape of disability service provision will have implications for carriage of the Act, making regular review imperative. The Act should require that it first should be reviewed after three years, then every five years thereafter. Reports of these reviews should be tabled in State Parliament.

7. Mandate State, Departmental and Agency Disability Inclusion Action plans

The Act should stipulate that each government department, statutory body and agency should devise a Disability Inclusion Action Plan, and that these plans should be reviewed every five years. A Disability Commissioner should model disability plans.

8. Disability Advisory Council

The efficacy of the Disability Advisory Councils ('the Councils') appears to be limited, but it is impossible to say so with any certainty because there is little accountability built into the Councils and little in the way of reporting structure. The Councils appear to be tokenistic and ineffective, but this is likely not a reflection on the membership of the Councils, but on the lack of accountable recruitment, the lack of broad reporting requirements, and the low priority government appears to give their advice.

Membership of the Councils should be advertised and promoted within the disability, family and advocacy sector to ensure equal opportunity for engagement. Advocates must represent people with disability who do not have capacity to engage and whose experiences are unique.

The Disability Advisory Councils should report to the wider public, and the remit of the Councils or any future equivalent should strongly reflect the rights of persons with a disability, including those with intellectual disability.

We recommend that either:

(a) The roles and responsibilities of the Councils be legislated to invigorate their authority and strengthen their relationship with the Minister for Disability Services. The Act should outline the function, terms of recruitment, membership and the terms of review of the Councils

OR

(b) Consider merging the Councils into an agency with expanded authority (the Disability Commissioner, as outlined below). Regardless, there must be a majority of people with disability with lived experience, their family members or advocates with authority and experience in the areas of responsibilities.

9. Worker Screening

QAI supports choice and control and recognizes the diversity of needs of people with disability. We support the limiting of screening to the scope required by the national policy for NDIS worker screening, allowing self-managing participants to request workers of unregistered providers to have a NDIS worker screening clearance but not requiring screening for unregistered providers.

However, we think that the weighting in screening should be heavily in the favour of protective, proactive action in this realm, having regard to:

- the particular vulnerability of many people with disability;
- the power imbalance between a person with disability and their support worker;
- the high rates of violence, abuse and neglect of people with disability;
- the low rates of conviction or disciplinary action against perpetrators of violence and abuse against people with disability; and
- the need for cultural change towards a zero tolerance approach to violence and abuse by those in positions of power towards people with disability.

QAI considers that the Department should show leadership by explicitly demonstrating that they will not be complicit in the perpetuation of the risk of abuse. For example, where one service provider knowingly employs a person in another sector (for example, from aged care to disabilities) with a history of inappropriate conduct, we recommend this should attract criminal sanctions.

We further propose that applicants should be required to disclose additional information, including,

- whether any complaints have been made against the applicant by or on behalf of a person with disability that relates to the applicant's fitness to work with people with disability.

QAI reiterates our concerns regarding unscrupulous hostel and boarding house owners. QAI is aware that an increasing number of hostels, boarding houses, nursing homes, and long-stay health facilities are now registered as providers for the NDIS. While there may have been some sort of oversight of the operations and staff of these and other congregate care settings in the past, we are unsure as to the type or intensity of checking on the owners and or managers of such facilities.

We are aware that it is not a difficult hurdle to overcome for some owners to register premises in the name of family members, to employ family members and other relatives or friends to avoid scrutiny of hidden but serious misconduct or criminal activity. Additionally we are

aware that people residing in such facilities have been subjected to coercion, threats, control, abuse and potential eviction for even voicing a complaint.

Regarding ability to start work, QAI generally supports 'no card no start', except where people with disability are self-managing their supports and services. In that instance, sole traders and unregistered providers should be able to work while awaiting screening provided that safeguards are implemented, including putting in place risk management plans and making sure the person is supervised by someone who has an NDIS worker screening clearance.

Finally, any worker (and/or complicit employer) found to pose an unacceptable risk of harm to people with disability must be deterred from seeking work in any care system.

10. Disability Commissioner

QAI proposes that the Disability Commissioner undertakes functions and powers similar to but in conjunction with the Public Advocate as set out in the *Guardianship and Administration Act 2000* (Qld), but with broader scope to promote and defend the rights of people with disability, particularly those who do not have NDIS Plans.

The Disability Commissioner, who would have statutory power to:

1. Promote, by education and publicity, respect for and observance of the rights of people with disability, and, in particular, to promote awareness among people with disability, Queensland government departments and statutory bodies, of the rights of people with disability, and of the means by which those rights may be enforced;
2. Make public statements and publish reports in relation to any matter affecting the rights of people with disability, including statements and reports that promote an understanding of, and compliance with, any potential Disability Charter or the provisions of the Act;
3. Review Disability Inclusion Action Plans, relevant legislation and policies to ensure compliance with the CRPD and the National Disability Strategy;
4. Review, approve or veto any procurement by any departments or statutory bodies that pertain to the accessibility and inclusion of people with disability;
5. Make recommendations to any appropriate person or authority in relation to the means by which complaints involving alleged breaches (of any potential Disability) Charter may be resolved and further breaches avoided;
6. Investigate complaints, determine merit and undertake resolution in conjunction with any potential Human Rights Commission should it be instigated with the new proposed Bill.
7. Make suggestions to any person in relation to any matter that concerns the need for, or desirability of, action by that person in the interests of the rights of people with disability;

8. Review any (potential) Disability Charter and make recommendations to the Minister³ about changes to the Charter;
9. Convene the standing Disability Advisory Councils and convene special councils or reference groups as need for co-design/consultation arises. The Disability Advisory Councils would report to the Commissioner, and the Commissioner to the Minister for Disability.
10. Report to the Minister on the need for, or desirability of, legislative, administrative or other action to give protection or better protection to the rights of people with disability;
11. Receive and invite representations from members of the public and from any other body, organisation or agency on matters relating to the rights of people with disability;
12. Gather information that in the Commissioner's opinion will assist in carrying out the Commissioner's functions under the Act;
13. Exercise and perform such other functions, powers and duties as are conferred or imposed on the Commissioner under the Act or by any other enactment;
14. Establish and maintain links with representatives of consumers, providers, and other bodies and organisations concerned with health or disability matters in performing his or her functions; and
15. Consult and co-operate with other agencies concerned with personal rights in performing his or her functions (eg: The NPM investigators for OPCAT)

Disability Commissioner and the Community Visitor Program

Part of a Disability Commissioner's functions should be systemic advocacy on behalf of the most disadvantaged people with disability. To do this well, the Commissioner would need special powers to access premises where people with disability live in congregate arrangements, like hostels and boarding houses, youth detention or adult correctional centres, disability services or mental health facilities.

The *Public Guardian Act 2014* sets out the powers of the Community Visitors working under the Public Guardian. In our view, the current arrangements can create a conflict of interest between the duty of the Public Guardian to be a decision-maker of last resort, and the Community Visitor's function to monitor and report on conditions in congregate residential arrangements like hostels and boarding houses. The Public Guardian is making decisions on behalf of people with disability *and* overseeing the program that monitors and reports on the potentially adverse consequences of those decisions.

Unique among Australian jurisdictions, Queensland recognized the potential for a conflict of interest between decision-making and reporting in our statutory separation of the Public

³ With the disability portfolio.

Guardian and Public Advocate. The creation of a separate office of the Public Advocate was a specific recommendation of the Queensland Law Reform Commission's ('QLRC') 1996 report on guardianship in Queensland.⁴ The Minister commissioned the QLRC report as a part of the government's response to the horrific revelations of the Ward 10B Inquiry and the investigation of the Basil Stafford Centre

In that 1996 report, the QLRC noted that the submissions received in response to its draft report strongly supported the separation of the systemic advocacy role from the role of decision-maker of last resort, and for three principal reasons:

1. The submissions emphasized the need to minimise potential conflict of interest, arguing that the decision-making role should be separated from the advocacy role.
2. There was a perceived need for focus and clarity of roles because the combination of two offices would inevitably lead to the subordination of one office's power to the other, and the dilution of each.
3. The QLRC noted that issues arising from the work of the Tribunal or from other functions proposed by the Commission should not be allowed to drive the work of the Public Advocate at the expense of broader systemic issues of importance to the interests of people with a decision-making disability in Queensland. The systemic problems facing people with intellectual disabilities coming into contact with the criminal justice system might not be directly raised through the work of the Tribunal or the Adult Guardian, but should come under the purview of the a Public Advocate.⁵

In our view, the Community Visitor Program should be reassigned to a Disability Commissioner, provided that the Commission is has investigative powers, or alternatively, a Disability Commissioner should have statutorily-mandated access to the reports of the Community Visitor Program.⁶ Through the Community Visitors, the Commissioner can make inquiries and lodge complaints on behalf of adults with disability and refer complaints to other bodies such as the NDIS Quality and Safeguards Commission.

Advocacy

Like any effective democratic political system, ours must have checks and balances mitigating the abuse of power and ensuring that rights are upheld. Well-funded advocacy is one of those checks and balances. The Act should establish a right to advocacy support and the state government should continue to fund it.

The Productivity Commission's *Disability Care and Support* (2011) acknowledged that "the Government makes clear that it does not intend for the scheme to address the care and support

⁴ Queensland Law Reform Commission, *Assisted and Substituted Decisions: Decision-making by and for people with a decision-making disability*, Report No 49 (1996)

⁵ Queensland Law Reform Commission. 2010. *A Review of Queensland's Guardianship Laws* Report Volume 4 Chapter 24.

⁶ Failing a Disability Commissioner, the Public Advocate needs statutory mandate to receive these reports as a matter of priority.

needs of all individuals, but rather should focus on those where needs are greatest”.⁷ Not everyone who wants one will qualify for an NDIS support package. It is important to be clear about what the NDIS is not. It will not be a panacea. No single program, even a generously funded one, will meet all the needs of all people with disabilities.

Even if everyone’s support needs were met, there would still be a demand for advocacy. The nature of disability changes with context, and it is clear that there still will be additional social barriers to full citizenship and participation that the NDIS cannot, in the short term, break down.

The original ‘Tier 1’ initiatives, for example, were intended to raise disability-related awareness, but prejudices and preconceptions about what is good or appropriate for people with disabilities will persist and passive discrimination will be hard to dislodge. The Commonwealth *Disability Discrimination Act 1992* has been in force for more than twenty-five years now, yet disability-related complaints are still the most common.

Market forces will still create barriers regardless of attitudinal changes or the amount of support any one individual is given. Take, for example, the ‘two wheel chairs per flight’ policy on many Australian domestic flights. It is difficult for people with mobility-related disabilities to travel in groups, and this often means delayed travel arrangements. Then again, there is a paucity of fully accessible residential accommodation and that severely limits housing options and has profound flow-on effects for people’s care choices. Lack of accessibility affects where people live, where they work and where they socialise. It is a barrier to independence, is linked to secondary disease and illness in the home, particularly for carers, and affects decisions about viable long-term care resources.

‘Appropriate housing’ says Stone⁸ ‘is the “where” in long-term care decisions’ and a key factor in determining people’s choices. Creating more accessible houses and improving visitability maximises independence and may prevent secondary disease and illness in the home. Accessible housing provides a viable long-term care resource because appropriate housing is the ‘where’ in long-term care decisions. It can be the difference between living in an institution and living in community, yet even *with* a national commitment to Universal Housing Design people with disabilities’ housing choices will continue to be limited for decades to come, regardless of individual resourcing.

Educational neglect is the root of adult issues:

Educational barriers persists for children with disabilities. Schools have not been more accommodating of children with intellectual disabilities, or autism, or many other disabilities just because we have an NDIS. Australia-wide, more than 70 per cent of students with disabilities have had their enrolment discouraged by principals of mainstream schools.⁹ In Queensland,

⁷ Page 165.

⁸ Stone, R. (2000). Long-term care for the elderly with disabilities: Current policy, emerging trends, and implications for the twenty-first century. New York: Milbank Memorial Fund.

Wolbring, Gregor. 2012. ‘Leg-ism leaves some Paralympic stars out on a limb’

in <http://theconversation.edu.au/leg-ism-leaves-some-paralympic-stars-out-on-a-limb-9008>

⁹ Kathy Cologon and Robert Jackson. 2017. Gatekeeping and restrictive practices with students with disability:

14.3 percent of students with disabilities attend special schools,¹⁰ and the rate of student number growth in these schools is alarming: approximately 5 percent per annum over 2011 to 2016, compared to an average 6 percent growth in numbers of students who do not have disabilities.

While there has been a modest drop in the proportion of students with disability in special schools, enrolment in special schools still outstrips general population growth. Further to this, there is an expectation and commitment to filling positions in segregated settings just as the archaic practices of institutionalization of people with disabilities: if you build it, then you must fill it.

Issues are compounding almost daily and it is hardly surprising when the leadership roles within some schools fail to ensure that all students are welcomed and valued. Gatekeeping, tokenistic concessional attendances and the high rate of suspension or exclusion of students with disability conveys this message to community and our organisation is often dealing with adults with disability who experienced educational neglect and marginalisation. The issues that have begun in school are the cause of much of the social disadvantage that leads to people with disability experiencing high rates of unemployment, living in institutional settings with shared support arrangements where high incidents of physical, sexual and financial abuse are perpetrated. Our clients are engaged in the criminal justice system as offenders (although often they have been victims of crime themselves), live in forensic facilities and are subject to restrictive practices with very little control or autonomy over their lives. It can be a bleak future for students with disability who are appropriated supported, included and educated with their peers.

QAI has long recognised the dearth of advocacy assistance to students with disability and their families in Queensland.

In the absence of formalised advocacy support for students with disabilities and their families, QAI has endeavoured over the past 6 years to provide information, advice and or referral to parents on a range of issues for students with disabilities including enrolment, the use of restrictive practices, bullying and victimisation, lack of support within schools and for schools, segregation and rejection by schools and teachers including principals, physical abuse by teachers and or principals, accommodations and learning support, inclusive child care and kindergarten, bureaucratic buck-passing, and funding for local OSHC. However, this is not sustainable without a concerted and multi-level advocacy strategy.

Nor have jobs magically appeared, post-NDIS, for the 50 percent of people with disability who are not in the workforce, compared to 20 percent of people with no disability.¹¹ It is widely acknowledged that the workforce participation rates of people with disability are too low, whether compared against the relative rates of employment of people without disability or

results of an Australian survey: Paper delivered at the Inclusive Education Summit, Adelaide.

¹⁰ 2016 figures.

¹¹ Australian Bureau of Statistics.

against international benchmarks.¹² The already dismal statistics on employment participation rates of people with disability are even worse when one considers the amalgamation of people with disability in sheltered workshops, or Australian Disability Enterprises (ADEs) and further disguises the significantly lower rates of appropriate and meaningful employment.

While sorely needed the NDIS has solved neither all disability-related challenges or extinguished the demand for individual and systemic disability advocacy because:

- There is already considerable unmet demand for advocacy;
- Demand for advocacy will likely increase during transition under an NDIS;
- Support for advocacy is central to the current National Disability Strategy; and
- The Commonwealth is signatory to international human rights covenants that promote and encourage advocacy for people with disability.

There is already unmet need for advocacy

Existing advocacy services do not provide adequate coverage for the disability sector. There are large geographic areas of Queensland without practical access to advocacy services, and that there are insufficient advocacy services for those most vulnerable, including people with reduced mental capacity and those needing communication supports. Evidence of advocacy needs includes the following:

- Disability-related complaints are more common than any other human rights complaints handled by the Australian Human Rights Commission, representing roughly 44 per cent of all complaints and the majority of complaints lodged under the *Disability Discrimination Act 1992* for the past five reporting periods, yet advocacy support for discrimination complaints is almost non-existent.
- QAI runs one of the only mental health legal services providing accredited legal advocacy before Queensland's Mental Health Review Tribunal. There is huge unmet need for representation, yet these hearings determine whether the Tribunal places a person on a Treatment Authority that may require medication, confinement, or Electro-Convulsive Therapy ('ECT').
- People with disabilities make up a disproportionate number of victims of crime, and offenders. Approximately 10 percent of people in corrective facilities have intellectual disability, and another 28.6 percent are in the 'borderline' intellectual disability range. Lack of support, including advocacy support, when people exit prison is a determining factor for the high recidivism of this population.

¹² Only 53.4% of Australians with disability are in the workforce, compared to 83.2% of people with no disability, with only 25% of people with a profound or severe core activity limitation active labour market participants. Similarly, in the National Disability Employment Framework – Issues Paper, it was noted that in 2012, only 52.9% of Australians with disability of working age were in the workforce or actively seeking work, as compared with 82.5% of the same demographic group without disability. This is concerning because the trend is stable and the rate of employment of people with disability is low by international standards.

- Queensland Parents of People with Disability was defunded in 2014. There is no funded group providing information and support to the thousands of parents of school-age children with disability.

Demand for advocacy has increased

The NDIS has brought unprecedented opportunities to people with disabilities, providing people with the means to participate more fully in community life and the means to do many of the things most of us take for granted, but post-NDIS demand for advocacy support has not decreased. Even those who are successful in getting NDIS packages have unmet needs, or have new needs generated by the nature of the support itself and the transaction costs in acquiring it. 'Transaction costs', the Productivity Commission notes, "largely reflect the central role of government in the disability system. Most of these costs are not measured and fall on some of the most vulnerable people in Australia".¹³

Consider, for example, that many people receiving self-directed support place the management of that support in the hands of a service provider. How does a person with an intellectual disability negotiate a management contract? How do they know they are getting a fair deal, and what mechanism will there be to ensure transparency, accountability and proper consent? Not everyone has a family member, friend, or guardian to help with the details of getting, and keeping, support. NDIS Appeals advocates only assist with review or appeal of reviewable decisions.

Who will assist people to make a complaint when they are unhappy about the service provided? Families and other supporters will usually have that role, but when there is no family and no other supporter a person with a cognitive or intellectual disability may need someone in their corner, and that someone will need to have minimal conflicts of interest, and remain loyal, accountable, emphatic and vigorous. That person will be an advocate. Indeed, the fact that there is *more* money in the system available for support means that there is *more* risk to manage, more chance of being ripped off, *more* need for watch-dogs that will act in the person's interest.

Deinstitutionalisation has been going on for a number of decades, but there are still many people who would rather live in the community than in institutions like the Baillie Henderson hospital in Toowoomba, or the Jacana slow-stream rehabilitation facility for people with acquired brain injuries in Brisbane. The NDIS is making it possible for people in these institutions to move in with their families, or into the community, but that presents a new set of challenges, many requiring advocacy.

Advocacy is central to the current National Disability Strategy

¹³ *Disability Care and Support*, 2011: 479.

The second of the six Major Policy Areas of the Commonwealth's *National Disability Strategy 2010-20* is 'Rights Protection, justice and legislation—statutory protections such as anti-discrimination measures, complaints mechanisms, advocacy, the electoral and justice systems'. The Outcome measure for this Policy Area is that 'people with disability have their rights promoted, upheld and protected', and this often must be done through advocacy.

The Commonwealth is signatory to international human rights covenants that promote and encourage advocacy for people with disability

The *Convention on the Rights of Persons with Disabilities* is a recent step in a political battle to establish such rights, and the Commonwealth is a signatory, but the problem is realizing such rights and turning wonderful aspirations into better lives. Every Australian nominally 'owns' such human rights, but rights have practical effect only if they are legally conferred and enforceable. We do not yet have a human rights statute backed by a strong complaint mechanism and enforceable penalties, but rights still have a symbolic and aspirational effect beyond their practical implementation by encouraging institutions to make structural changes that will allow institutions to accommodate *everyone* and *all abilities*.

Disability advocacy should be funded outside the NDIS, as the Productivity Commission recommends, because both individual and systemic advocacy should as far as possible be free of conflicts of interest. It is essential that systems advocates continue to work directly on-site with individual advocacy teams so that systems advocates have a clear hands-on picture of the experiences of people with disabilities.

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