Queensland Advocacy Incorporated

Systems and Legal Advocacy for vulnerable people with Disability

Queensland Advocacy Incorporated
Submission in relation to the
Productivity Commission Draft Report
April 2011

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About QAI

QAI is an independent, community-based, systems and individual legal advocacy organisation that has more than twenty-three years of experience conducting strong independent systems advocacy in Queensland for people with disabilities. Its mission is to promote and protect the fundamental rights of these people. Our commitment extends beyond defending the civil and political rights of people with disability. We are just as determined to ensure the rights that often lack a legal foundation. These are the rights to self-respect and respectful treatment, which are embodied in the simple quality of human dignity.

QAI ensures accountability to the most vulnerable people with disability by fully incorporating qualified people with disability in key board positions and other areas of function. QAI's Management Committee members have experience in advocacy, institutional living, community legal service, private legal practice, legal aid, accountancy and community work. QAI is a member of the National Disability Advocacy Network of Australia (DANA) and Combined Advocacy Groups Qld (CAGQ).

As well as its traditional systems advocacy QAI has, for the past two years, provided individual legal advocacy to people with a disability who are at risk of human rights abuses particularly around guardianship and restrictive practice matters. In the same period QAI has also assisted people experiencing mental illnesses who appear before the Mental Health Review Tribunal. QAI also provides non-legal individual advocacy to people with disability at risk from the criminal justice system by marshalling legal and community services to help the person with a disability remain in the community.

QAI acknowledge our comments in this submission were developed collaboratively with a number of advocacy organisations and people with disability organisations around Australia.

(For more information about QAI's knowledge and experience, please see Attachment 1).

Introduction

People with disability are among the most vulnerable, disadvantaged and easily exploited groups in society. Indeed, virtually every Australian with disability encounters human rights violations at some points in their life, and very many experience it every day of their lives (QAI Submission to the Productivity Commission Disability Care and Support Inquiry, 2010, p. 4). It has been this way ever since the first time a child born with disability was exposed on a hillside to die.

People with disability continue to be marginalised and discriminated against because prejudice continues. This is because there are still many people who fail to acknowledge the humanity in someone with a disability. They therefore disregard the needs and feelings of that person. They see someone who should be content with less – less money, less advantage, less opportunity, and less control over their lives – than people without disability are accustomed, or prepared, to expect.. Unfortunately, these attitudes are entrenched in the community and they fight vigorously and stubbornly for their survival.

It is in this context QAI welcomes the release of the Productivity Commission's Disability Care and Support Draft Report dated 28th February 2011.

NDIS Draft Report

QAI is encouraged by the cultural shift evident in the overview of the Draft Report for Australia to move from a welfare model of support based on crisis initiated funding responses to one of entitlement based on a social model of disability, inclusion and human rights. This is a significant shift for the Australian community, governments, individuals, legislators, policy makers, and organisations that provide service to people with disability.

QAI commends the Commission for proposing a scheme that:

- is portable
- is based on need rather than diagnosis or impairment
- includes a high degree of self-determination built into the scheme
- is committed to empowerment of people with disability
- shifts decision-making to people with disability
- is responsive to changing circumstances
- is person focused rather than service focused
- effectively doubles current support funding , and
- takes into consideration key transition stages of life and focuses on support over a persons' lifetime rather than focusing on supporting the service provider

Generously the Commission has acknowledged that the Draft Report is a work in progress capable of refinement and improvement. Humbly but firmly QAI advises improvement can and must be made to the Draft Report's treatment of advocacy.

Disadvantage, disempowerment and discrimination are everyday experiences for people with disability. Strong independent advocacy is an indispensable safeguard of their rights. QAI argued this strongly at the Commission's recent Public Hearings in Brisbane. The attending Commissioner was receptive to the argument. The Commissioner's receptivity had been primed by an earlier submission by a person who described their inability under the current system to obtain the necessary support for their basic hygiene needs.

After QAI's formal presentation, the Commissioner posed a question to QAI. Why, the Commissioner asked, with the United Nations Convention on the Rights of Persons with Disability (CRPD), and advocacy organisations such as QAI, was this person unable to obtain such basic but essential supports?

QAI explained that while the Australian government has ratified the CRPD, it has not been enacted into domestic law. Consequently a remedy cannot be found in domestic law. The CRPD has at best persuasive force. Recourse may be had to the United Nations Treaty Body for the CRPD, but again the Treaty Body's rulings have only persuasive effect. They are not enforceable.

As for advocacy? QAI explained that funding for advocacy is only a tiny fraction of one percent of the funding provided for disability support. Relative to the need for advocacy services, this funds a bare handful of advocacy workers nationwide. Consequently, much desperate and deserving need, remains unmet because the demand for advocacy services grossly outstrips current supply.

The new system of disability support based on need, which the Commission proposes, must itself be supported by appropriate mechanisms to ensure the equity and propriety of the scheme and its administration. Strong independent advocacy is an indispensable part of those mechanisms. It is vital that the Commission understands this. For this reason QAI has devoted its entire submission to this subject. Areas that will be covered include;

- the definition of advocacy and a description of the major types of advocacy
- the importance of advocacy
- the role of advocacy in the NDIS
- the independence of advocacy, and
- funding for advocacy

What is Advocacy?

The agreed definition of advocacy by Combined Advocacy Groups Queensland (CAGQ) is:

> ***"speaking, acting and writing, with minimal conflict of interest, on behalf of the sincerely perceived interests of a disadvantaged person or group to promote, protect and defend their welfare and justice by being solely on their side, concerned primarily with their fundamental needs and remaining loyal and accountable to them in a way which is emphatic and vigorous and which is, or is likely to be, costly to the advocate or advocacy group"***

Advocacy organisations nationally play an important role in the prevention of abuse and neglect of persons with disabilities. They also work diligently on the protection and promotion of human rights of persons with disabilities. They work closely with persons with disabilities and know intimately the barriers faced by persons with disability when attempting to access a range of services and supports. These organisations also work systemically to identify and influence change to the structures and systems that impact on persons with disabilities.

Advocacy is underpinned by principles that have been developed over time. Advocacy principles provide the ethical underpinnings and provide a basis for advocacy practice. (For a full list of advocacy principles that inform advocacy practice see attachment 1).

Advocacy takes many forms in Queensland and offers persons with disability free access to a range of funded advocacy services. In order for persons who most need these services to access them, these services are delivered free to all who require them. This does not mean that everyone who requires advocacy support currently receives support. Advocacy resources nationally are often stretched and until recently some areas of Queensland remained unfunded and therefore many persons with disability received no advocacy support to meet their needs.

This clearly demonstrates that even though Australia has ratified the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol strong independent advocacy supports to ensure that all persons are able to realize and access these rights and the mechanisms that support the protection of these rights are vital.

It follows then that a shift toward models of self directed supports for persons with disabilities will also require a move toward an adequately resourced and supported independent advocacy support along with an adequate independent complaints system.

Advocacy types

There are many different types of advocacy that exist in Australia. They have been developed over time and include:

- Individual advocacy
- Citizen advocacy
- Systems advocacy
- Self-advocacy, and
- Family advocacy

Individual Advocacy

Here the advocate concentrates their efforts on one or two people only. There are two common forms of individual advocacy:

Informal Advocacy

Parents, brothers and sisters, relatives, friends who take on advocacy roles are all examples of informal individual advocacy.

Many different people, with a range of relationships to people with disability, have spoken out and persistently advocated for those who are vulnerable. What often goes unrecognised and unseen, are the efforts of individual people who may struggle with the injustices with little or no support. Such individual efforts have been termed informal advocacy. These individual advocacy efforts can and do last many years, often in significant isolation.

Individual advocacy organisations

Another form of individual advocacy is voluntary community based organisations that pay staff to advocate for individuals. Individual advocacy organisations exist to uphold the rights and perceived interests of people with all types of disability. They address discrimination, abuse, neglect, and support people to obtain the necessary supports they require to live with dignity. This type of advocacy (as demonstrated in the following case studies included in this submission) demonstrate the long term nature of advocacy and the complex nature of the issues vulnerable persons with disability often encounter in their everyday interactions with various systems.

In Queensland, organisations that operate in this way are Speaking Up for You (SUFY), Gold Coast Advocacy Group and Independent Advocacy in the Tropics (IAT).

Citizen Advocacy

Citizen advocacy is a community based movement that aims to recognise, promote and defend the rights, well-being and interests of people with intellectual and/or multiple disabilities. It does so by finding and supporting caring, responsible citizens who make

long-term voluntary commitment to make a positive difference in the life of a person who may be lonely, face difficult challenges, or be in “at risk” situations.

Each Citizen Advocacy relationship is unique. The citizen advocate may for example, offer his or her protégé friendship, new experiences and opportunities, spokesman-ship and protection from abuse.

The Citizen Advocacy office carefully matches protégés and citizen advocates to ensure there is a good match between the interests and needs of the protégé and the abilities, resources and commitment of the citizen advocate. Citizen advocates are orientated, assisted to gain further knowledge and resources, supported and recruited by the Citizen Advocacy office.

Sunshine Coast Citizen Advocacy organisation is an example of a citizen advocacy organisation.

Systems Advocacy

This form of advocacy is primarily concerned with influencing and changing the system (legislation, policy and practices) in ways that will benefit people with a disability as a group within society. Systems advocates will encourage changes to the law, government and service policies and community attitudes. Usually systems advocacy do not do individual advocacy. To do so can cause conflict around the use of resources, focus and purpose. Organisations that operate on a systemic level are Queensland Advocacy Inc (QAI) and Queensland Parents for People with Disability (QPPD).

Self-Advocacy

Self-advocacy is undertaken by a person or group who share the same characteristics or interests on behalf of the same person or group. The difficulty with this form of advocacy is that sometimes those undertaking advocacy and speaking up for themselves are likely to be further exposed and be more vulnerable to abuse, discrimination and ridicule as a result of speaking up for themselves.

These solo efforts can isolate individual advocates from their communities by the very nature of their efforts, particularly where the issue is controversial or perceived as detrimental to the wider system/environment in which the issue is placed.

For example, a parent’s efforts to seek enrolment of a child with disability in a regular school in a local community may stir enmities, conflicting interests and test established friendships.

These advocacy efforts by individual people for valued lives need to be supported, nurtured and protected. Individual people may want to be connected to others doing advocacy - to share the effort, to seek support, or to develop a collective response.

Family advocacy

Family advocates work with families and allies to enable them to act as advocates with and on behalf of a family member with disability. Family advocates work within the fundamental principle that the rights and interests of a person with disability are upheld at all the time. Families and allies are provided with advice and support, the person with disability is assisted via the family member being directly supported by the agency to advocate on their behalf. Queensland Parents for People with a Disability perform family advocacy throughout the state, and in New South Wales, Family Advocacy conduct this type of advocacy.

The Importance of advocacy

Advocacy is vital to assist the most vulnerable members of our society to express their rights and interests and have their needs and wants met. Many persons with disability however rely on other people to meet many of their basic needs every day. This makes them vulnerable to the actions and wishes of other people, some of whom have little regard for their wishes, interests and capacities.

The Shut Out report noted that people with disability in Australia daily experience segregation, exclusion and are ignored. The report said the following with respect to the social exclusion experienced by people with disability:

> ***"negative attitudes are both powerful and entrenched and, as a result, exclusion is both systematic and systemic. Widespread misconceptions and ignorance about people with disabilities are still informing the attitudes and behaviour of government, service providers, businesses and individuals in the community. People with disabilities, and their families, friends and carers, reported daily instances of being segregated, excluded and ignored".***

A well resourced advocacy program is necessary to meet Australia's obligations to protect people who are marginalised and vulnerable. The involvement of advocates to support people with disability to re-dress the power imbalance created by vulnerabilities is vital.

When advocacy support is unavailable or restricted by resource demands or simply unavailable in a particular region, the voice of persons with disabilities may be largely excluded and unheard. Their rights may be violated, denied or not respected.

As outlined by French in the Disabled Justice Report (2007), these persons would rather put up with a fractured system than receive no supports at all.

French explains:

> *"Many persons with disability have a high level of physical and psychological reliance upon services such as personal care and supported accommodation services. In many cases this assistance is fragile in that it stems from budget-capped, discretionary programs, block grants to services, and is provided in the context of great, unmet demand for such assistance. This level of dependency and anxiety about the continued availability of assistance means that persons with disability and their associates will tend to* ***tolerate abuse and exploitation*** *rather than* ***risk the collapse of their support system*** *by reporting it" (French, 2007, p. 23).*

The following case study illustrates the risks that can attend complaints about unsatisfactory service and why fear about making such reports remains so deeply entrenched.

Case Study

Approximately 20 years ago, Jack was involved in a car accident and, following a lengthy stay in hospital, was eventually able to move into his own home in the community with appropriate social supports. At that time, public policy supported persons with disability like Jack to become as independent as possible and resume a life in the community. Jack was provided with approximately 25 hours of support per week to assist him with personal care, cleaning and community access. Although his support was administered through a non-government block funded service provider, Jack felt that he had some control over his life as his workers were employed specifically for him. Jack made decisions about who was employed and when they worked. This gave Jack the opportunity to have a private and social life and to pursue his interests and hobbies.

Over the years, Jack found that he required more support as his health deteriorated due to a serious illness along with the fact that he was aging. Unfortunately, Jack's funding allocation was reduced, first to the equivalent of 20 hours, then to 19 hours and finally to 15 hours of support per week. The support service found it difficult to find workers and on many occasions Jack was left with agency staff who did not know how to provide him with the support he required. His service became inflexible and his privacy was compromised. Jack raised concerns with the support service. The support service terminated its services to Jack in response. As his support was 'block-funded', Jack could not withdraw his funding allocation from the service, and he had to apply for short-term crisis non-recurrent funding in order to survive. Due to the uncertainty in the continuation of this funding, Jack had found it difficult to obtain support from another provider.

Jack must now wait for a new allocation of government funding to meet the costs of his support services. There are many applications for such funding and it is not certain that Jack will be successful in his application. Even if he is, it is likely that he will only receive a sufficient allocation to live in a group or congregate environment.

Jack's story illustrates not only that an individuals' lifestyle can be dictated by the needs of the service system, but also that their right to live in the community with the necessary supports may not be met and further, they may have no effective remedy available to them in relation to the violation of their human rights.

Jack's story demonstrates that without strong, independent advocacy his life will be determined by the needs and expectations of the service system, rather than by his own identity, preferences and aspirations. He does not have somebody solely on his side protecting and defending his rights. No one is concerned primarily with his fundamental needs, which include his safety and wellbeing.

Essentially, Jack must rely on the bureaucratic processes to exercise their discretion and restore his fundamental entitlement to support. He must therefore try to seek re-dress from the very system that created the injustices that have adversely affected him. This created a disempowering situation for Jack, who, when he complained about the amount and quality of services he received swiftly had his support service terminated. By attempting to self-advocate without the appropriate and independent supports he needed for that effort Jack found himself in a vulnerable situation.

The role of Advocacy and the NDIS

The role of advocacy is poorly defined within the proposed NDIS. The Draft Report contains no detailed discussion of advocacy arrangements under the new system, nor does it provide any recommendation committing to continued support and resourcing for advocacy. Similarly, there is no discussion of resourcing the obligation to consult people with disability through their representative Disabled Persons Organisations.

Advocacy is briefly treated at various points through the PC Report, although at times the messages on the role of advocacy within the NDIS appear contradictory or out of step with current understandings (see for example p 10, p31, p4.1, p4.4, p4.5, p76.19, p7.14, p8.5, p8.76, p8.7, p8.9, p8.12, p9.17, and p17.6).

Given the Draft Report's strong emphasis on facilitating informed choice, and the need for individuals and families to:

- be aware of entitlements
- know how to deal with service brokers
- know how to navigate complex self directed funding arrangements
- be cognizant of available supports
- and be able to engage with complaint mechanisms

A role for advocacy would be in line with the obligations imposed by the CRPD, particularly at Article 21 – Freedom of Expression and Opinion and Right to Information.

There is a need for systemic advocacy, not only in relation to ensuring that people with disability are represented and have a voice (as per Article 4.3 CRPD) but also to ensure effective monitoring of progress against Convention obligations (as per Article 33.3 CRPD).

Advocacy support should be available to people with disabilities when confronting issues negatively impacting on their enjoyment of human rights and fundamental freedoms wherever they occur across the spectrum of civil, political, economic, social and cultural spheres.

In the context of a new approach to funding disability support, independent advocacy would:

- assist people with disability so they can be informed about the support choices available to them, assist them through the decision-making and implementation processes and assist them to effectively communicate their decisions and wishes to service providers and governments
- assist people with limited decision-making capacity to participate in decisions relating to their supports to the fullest extent possible
- where required, directly represent the interests of the person with disability to protect and promote their rights and/or empower and support those family members, friends and others that act for and with them for this purpose
- assist service providers (and system-level decision-makers such as funding agencies) to better understand the needs of consumers

- identify issues of common concern to people with disability and seek reform to address the issues (DANA Submission to the Productivity Commission Inquiry in to Disability Care and Support, 2010, p. 10).

Independence of Advocacy

Advocacy is a fundamental safeguard against the prejudice that threatens the rights and fundamental freedoms of people with disability. To be effective, it must function independently of the entities which are likely to create issues that will be the subject of advocacy.

Advocacy organisations have played a major role in bringing to the attention of the Australian governments the abuse, neglect and institutional harm perpetrated against significant numbers of people with disability. This has resulted in the closure of many large institutions and the development of more appropriate accommodation and support services. Much of their success has come from their unconditional allegiance to the person or group for whom they are advocating as they are not bound by another set of service or government imperatives.

This independent advocacy will be critical to the success of any future model of disability support, both during the transition phase and when it is completely implemented because it will enable a disability support system to work effectively and ensure that the interests and needs of people with a disability are protected and upheld.

QAI's original submission to the Productivity Commission recommended a

> ***"strong independent advocacy support program which is separately funded to support and protect the rights and interests of people with disabilities eligible under the scheme"*** (QAI Submission to the Productivity Commission Disability Care and Support Injury, p. 6).

Similarly, the Joint Submissions to the Productivity Commission supported the position that

> ***"people with disabilities and their families will need access to a strong independent advocacy program that provides a range of advocacy approaches, both individual and systemic, to ensure that there is an effective capacity to protect and promote rights and well-being in a new disability support scheme. This program should be funded such that both administration and delivery of advocacy support are independent of disability support program funding" (***Joint Submission to the Productivity Commission Inquiry into Disability Care and Support, 2010, p.4).

The Draft Report , however, proposes that intermediaries that will act as brokers and advisors to people with disabilities on the types of support services available to them could also advocate on behalf of these people, especially in relation to complaints or disputes with support providers (Productivity Commission's Disability Care and Support Draft Report, p. 7.14). The Report is therefore proposing that brokerage and other intermediary services, which will be provided from within the scheme, should also deliver advocacy services.

The problem here is plain; incorporating advocacy services into the entities which are likely to be the subject of their scrutiny creates a glaring conflict of interest, which would jeopardise the principle of strict partiality to the individual’s interests discussed earlier. This is because the advocate would not be placing themselves fundamentally on the side of the person with a disability. Such a conflict of interest would inevitably be resolved in the entities favour.

A well-resourced, well managed independent advocacy program plays an important role in meeting Australian governments’ obligations to protect its more disadvantaged and vulnerable citizens. Community managed advocacy agencies, connected to local and regional communities are an effective and efficient mechanism for governments to meet this responsibility.

Funding for disability advocacy services in Australia

In 2007-08 the National Disability Advocacy Program (NDAP) received $11 780 376 (excluding GST). This represents 0.2% of total government expenditure on CSTDA services ($5.7 billion in the 2007-08 financial year) in Australia. (Report of Government Services 2009, p. 14.11; Research of the Models of Advocacy funded under the National Disability Advocacy Program Final Report, 2009, p.14).

In 2008 Queensland had 14 State funded advocacy services operating (Review of DSQ Funded Advocacy Services, 2008, p. 28, 31). At first glance this number seems not insignificant. The reality is otherwise. The number of advocates funding from all sources supports is grossly inadequate relative to demand for their services. Further, many advocates are employed only part time, and are underpaid relative to their skills. Until recently the Wide Bay region received no funded advocacy services, while Moreton, Central Qld, and Sunshine Coast receive very little advocacy funding (Review of DSQ Funded Advocacy Services, 2008, p. 28, 31).

Advocacy agencies recognise that the most vulnerable and marginalised persons are those who experience the most difficulties accessing advocacy supports. Some persons may be unable to articulate their need for an advocate or to understand that advocacy support exists to support them. Advocacy agencies often face this barrier to accessing these persons, along with significant resource issues that impact on the number of persons they can assist and the outreach they can provide to identify and support vulnerable and marginalised persons.

The case studies provided in this submission serve to highlight the importance of a comprehensive independent advocacy support system that includes self advocacy, citizen advocacy, family advocacy, legal advocacy, and systems advocacy. Each type of advocacy plays a complementary role in the empowerment of persons with disabilities in Australia.

Systemic Advocacy

Of the types of advocacy described, systems advocacy may be the least understood because of its focus on identifying and resolving the structural issues that affect human rights. Yet, by focussing on system-wide change rather than change to the circumstances of an individual, it has the potential to improve the lives of entire groups or classes of people.

A recent example of systemic advocacy in which QAI was engaged involved the establishment of the Forensic Disability Service (the Service) in Queensland. The service found its genesis in the recommendations contained in ‘Challenging Behaviour and Disability: A targeted Response, the Hon Justice William Carter’s report about the use of restrictive practices on people with intellectual or cognitive disability in Queensland.

One of the most objectionable practices Justice Carter identified was the detention in mental health services of people with intellectual disability on forensic orders. The practice is objectionable because mental illness and intellectual disability are entirely different conditions requiring very different forms of support. The medical model used in mental health is entirely inappropriate for people with intellectual disability. Justice Carter recommended the establishment of a new service completely divorced from the Mental Health Service and its attendant culture and practices to provide for the support needs of people with intellectual disability on forensic orders. A practice model founded on the principles of person-centred positive behaviour support was the most vital element for the new Service.

Draft legislation to support the new Service was prepared and released for comment. QAI was shocked to find that the Bill proposed a regulatory framework that mirrored in almost every detail the framework prescribed in the Mental Health Act. QAI pointed this out in two forceful submissions and recommended sweeping change to the Bill to bring it into line with the principles outlined in Justice Carter's report.

To the Government's immense credit, the Bill was quickly withdrawn and substantially remodelled. If not for strong independent systemic advocacy, the Bill may have been passed in its original form and provided to the people whose lives it regulated, little of the positive support its drafters intended.

Restrictive Practices

This was not the first time QAI advocated around restrictive practices. QAI has advocated systemically and legally for years about this matter, and will continue to do so for years to come. The matter is highly relevant to this submission for two reasons. Firstly, restrictive practices are too often abused or, at the least, used inappropriately. Secondly, the Commission has in its Draft Report signalled the continued use of restrictive practices under the NDIS. At p8.30-1 the Draft Report says;

> *For people with severe intellectual disabilities who exhibit challenging behaviours (such as harming themselves or others), at times it will be in their best interest (and the interest of their carer and others around them) for restrictive practices to be used. These practices include: containment (preventing free exit from a service provider premises) seclusion (solitary physical confinement), chemical restraint (involving the prescription of a pharmaceutical for reasons other than a medical condition) mechanical restraint (any device that restricts movement) and physical restraint. While these practices may be unavoidable in certain circumstances, the recognition that, by definition, they impinge upon basic human freedoms, implies a strong need for clear guidelines and regular scrutiny and reporting (p8.30-1)*

It is important for the Commission to understand that the restrictive practices proposed for use under the NDIS either violate or conflict with at least seven articles of the CRPD, including 13, 14, 15, 16, 17 and 25.Indeed, it is the view of the UN Special Rapporteur on torture that in particular circumstances restrictive practices may even constitute torture (Proposed National Disability Insurance Scheme Human Rights Analysis April 2011 p. 98-100).

The following case study illustrates how quickly and easily restrictive practices can become the dominant and inappropriate response to behavioural issues that are poorly diagnosed and improperly understood. It also demonstrates how dramatically the intervention of an effective advocate can restore quality of life to a vulnerable individual reduced by circumstances to a life of hopeless confinement.

Case Study

Mark is a young man 34 years of age who lived in the Redlands area after moving out of home in his 20's. Mark moved out of home with very few hours of paid support to assist him to live independently as a young man in the community. As Mark's support arrangements broke down over time Mark ended up in an emergency transition unit supported by the Department of Disability Services Queensland.

Mark had epilepsy but his service providers also believed he was autistic. He exhibited signs of disruptive behaviour which lead to his institutionalisation at a major Disability Services facility in South-East of Queensland. (Mark lived alone in his unit at the facility and had no support and was secluded for 4 years.)

Initially this emergency accommodation within a major Disability Services facility was to be for 3 months until his transition back into a community placement with more appropriate levels of support. But whilst at the facility, Mark's behaviour was often escalated. The service provider increasingly used seclusion to manage Mark's outbursts which steadily became more frequent and more harmful to others and to himself. Disability Services' clinicians working with the service provider decided that Mark could not be resettled into the community until his behaviour issues were resolved. So Mark continued to reside within the DSQ facility.

After about three years, DSQ and the service provider were required by law to apply to QCAT for approval to use seclusion to manage Mark's behaviour. In their first application they sought and were given approval to seclude Mark up to 90 minutes at a time when his behaviour became escalated.

But Mark's behaviour further deteriorated and six months later DSQ and the service provider sought approval of the tribunal to seclude Mark for periods of up to 24 hours per day and also use physical restraint on Mark. By this time the service provider was secluding Mark several times a day and on occasion Mark was secluded in his room most of the week. Mark's parents and guardians disagreed with the use of seclusion to this extent but the service provider said the seclusion was required to keep Mark safe and his support workers safe as well. But conflict steadily rose between the parents, the service provider and DSQ.

At this point Mark's guardian instructed a QAI legal advocate to represent Mark at the Queensland Civil and Administrative Tribunal (QCAT) hearing. Acting on behalf of Mark, the legal advocate convened a meeting between the service provider, DSQ and Mark's parents and guardians. This conference of the stakeholders served to ease the mounting conflict and refocus all players toward working together to resolve Mark's crisis situation.

At the QCAT hearing Mark's legal advocate argued that the use of seclusion, particularly for periods of up to 24 hours, was not treatment but amounted to a failure of proper treatment. The legal advocate made submissions to the Tribunal that secluding Mark for 24 hours amounted to unlawful violation of his human rights. However QCAT approved the use of seclusion for up to 24 hours and encouraged all stakeholders to continue to work together to improve Mark’s life.

Several months later DSQ and the service provider reapplied to QCAT for approval to seclude Mark for continuous periods more than 24 hours. They were then secluding Mark for more than a day at a time after regular behavioural escalations. In fact, Mark was being held in seclusion most days and often for continuous periods for more than 24 hours.

Mark’s legal advocate made stronger submissions at this QCAT hearing, referring to the CRPD and the Convention Against Torture. The legal advocate made submissions that secluding Mark for more than 24 hours amounted to torture and that the state could not lawfully approve secluding Mark in this fashion.

But the Tribunal again approved seclusion and physical restraint of Mark but qualified its approval by making it conditional on monthly reporting of the using of seclusion, joint reports of stakeholders regarding their collaborative efforts to formulating a new behavioural support plan for Mark, regular reporting about implementing positive behavioural programs for Mark and the commissioning of a full mental health assessment for Mark.

As a result of these conditions imposed by the Tribunal, DSQ appointed a psychologist to the clinical team working with the service provider and a speech pathologist undertook a communications assessment of Mark. The clinical team also undertook extensive consultation with Mark’s parents and essentially the whole approach to working with Mark was reframed and a truly person-centred plan was formulated.

As a result of this renewed collaboration work Mark was found to have a communication disorder that had not been previously recognised. Indeed the clinicians found that rather than secluding Mark when his behaviour escalated, it was more effective for his support workers and clinicians to positively engage him in communication to assist him to work through the cause of his distress. Indeed, it was established that secluding Mark only served to exacerbate his distress and that seclusion had in fact been compounding “his behavioural issues”.

As a result of this “reframing” of approach by the clinicians and the service provider, Mark made remarkable progress. Within two months the use of seclusion by the service provider had been reduced to nil.

When the approval for restrictive practices came back before QCAT for periodic review (6 months after approval for more than 24 hours seclusion and physical restraint) DSQ and the service provider made no application whatsoever for approval to seclude or physically restrain Mark.

With the support of DSQ clinicians and Mark’s parents/guardians, Mark’s service provider staff now have a better understanding of Mark’s situation and now see things from his point of view when treating him. Because of the progress he has made, there are now plans for Mark to return to the community and live near his family and friends. This turnaround occurred within months of the legal advocate becoming involved. Without the legal advocate’s efforts, Mark would have remained voiceless and the conflicts among the parties would have continued, making his remarkable turnaround unlikely.

Australia’s current arrangements, which allow for the use of restrictive practices and compulsory treatment for some people with disability, are at odds with the obligations imposed by international human rights instruments (see for example French, Dardel, & Price-Kelly. 2009). Substantial policy, legal, and administrative reforms are necessary to ensure that Australia complies with the obligations imposed by CRPD and other international instruments with respect to restrictive practices.

Complaints mechanisms

Many persons with disability are isolated from the very access to complaint mechanisms that enable them to complain about the adequacy, quality and frequency of supports they receive. If they are living in supported arrangements they are more likely to report crimes to disability support workers. However French in Disabled Justice (2007) notes that these complaints are more likely to be solved internally within the agency without external agencies becoming involved. One reason may be the agencies’ fear of reputation damage, access to other funding sources or an attempt to minimize external scrutiny (French, 2007, p. 24).

Australia has a number of existing complaint mechanisms established under disability and other legislation. In Queensland for example, the Australian Government Attorney General’s department in meeting their obligations to women and children with disability (Article 16 freedom from exploitation, violence and abuse) point to the Adult Guardian as a protection mechanism. The Adult Guardian has legislated powers to both investigate allegations that are made by any person or organisation of abuse, neglect or exploitation against an adult with impaired capacity and to take protective action if the allegations are substantiated and the adult is at risk of further abuse. The Office of the Adult Guardian despite powers to investigate and take protective action is limited by available resources in order to fulfil its mandate.

Further, concerns have been raised about the relationships that can develop between representatives from service providers and representatives from the Office of the Adult Guardian. This is no sinister plot, but merely the natural development of intimacies that occurs through regular association. This carries with it the potential for service providers to exercise unusual influence over representatives of the Adult Guardian relative to the influence that can be exerted by parents or other intimates of the individual who the Office of the Adult Guardian barely knows. This can lead to biased decisions favouring the service provider and a preference for the Office of the Adult Guardian to be awarded guardianship when there is a contest about such matters.

There are also concerns that guardians from the Office of the Adult Guardian are frequently rotated and may be making decisions for someone they have never met. This regular rotation encourages overworked officers to rely more heavily on advice from service providers who they know well and with whom they have long-standing relationships. Because the Office of the Adult Guardian has many clients substantial numbers of who receive support from service providers, the Office of the Adult Guardian has a strong interest in maintaining good relations with service providers. This could pressure officers from the Office of the Adult Guardian to compromise their decisions about individuals in order to preserve the status of other clients who receive support from the same service provider. All of this means that the Office of the Adult Guardian may not always be the vigorous guardian of people’s rights that Government generally considers it to be.

Inn Queensland a further complication is soon to be added. Currently Queensland is the only state that has separate statutory offices of the Adult Guardian and Public Advocate. The Queensland Law Reform Commission recommended this separation when it conducted its 1996 review of Queensland's Guardianship laws. It recommended separate offices because of the clear conflict of interest it envisaged in a combined office. The conflict would arise if ever the Public Advocate was required to turn the glare of its scrutiny on to the actions of the office of the Adult Guardian. The Queensland Law Reform Commission affirmed this stance when it conducted a separate review of Queensland's guardianship laws in 2007-2010. Despite this the Queensland Government has decided to amalgamate the two Offices. This will concentrate power in the Office of the Adult Guardian, while at the same time reducing the independence and potentially the effectiveness of advocacy in Queensland.

The following case study illustrates how thoroughly values and actions, and therefore the outcomes for a vulnerable person, can differ between an officer from the Community Visitor and an independent community advocate. In Queensland the Community Visitor sits within the Office of the Adult Guardian.

Case Study

Jane is 37 years of age and had cerebral palsy, intellectual disability and osteoporosis. Jane spent her child hood in institutional care and when the institution closed was relocated to live in the community with a person who Disability Services felt was an appropriate co-tenant.

Jane has no verbal communication and her only form of mobility is to bottom shuffle on the floor. Jane enjoys the company of her support workers and likes to follow them around the house using this form of mobility.

Jane's mother contacted an advocacy organisation on Jane's behalf when she noticed that Jane's support service was not meeting her needs. Jane's mother wanted an increase in her funding and also wanted the advocacy organisation to investigate an injury that Jane had received while in the care of the service. Jane's mother wanted an organisation that was independent from Jane's service provider to assist her to investigate issues of suspected assault and neglect as she had lost confidence in the service provider.

While Jane's independent advocate was visiting Jane she noticed that she was tied to the kitchen chair for long periods of time. Further investigation showed that Jane was restrained on a daily basis for up to eight hours a day. The reason given by the service provider was that Jane could not be safely supported to get up from the floor as the service has a no lift policy and a suitable hoist had not been identified. The advocate felt that this situation needed to be addressed as a matter of urgency as medical tests showed that Jane's osteoporosis was becoming more pronounced.

The advocate contacted the Community Visitor as she believed that restraining Jane was a breach of her human rights. The Community Visitor, after visiting Jane reported that the practice was acceptable. Jane's advocate did not agree with the Community Visitor's decision and felt that more had to be done to ensure that a positive and fundamental change occur in Jane's life. Independent advocacy is about doing much more than what is done routinely and sometimes this means upping the ante if things are not addressed.

The advocate influenced the service provider to investigate other lifting devices and eventually a hoist was identified as being suitable to safely lift Jane from the floor. The service provider however then stated that they would not use the hoist in Jane's home as the co-tenant had a fascination with wheels and would tip the hoist, thus making it unsafe. Consequently Jane would remain tied to the kitchen chair for most of the day.

The advocate than contacted a lawyer who's advice suggested that 'Jane was being discriminated against under the DDA, that under article 20 of the CRPD Jane's personal mobility was being violated, and that unlawful mechanical restraint was being used on Jane which was a criminal act and needed to be investigated by the police.

Jane's life has been a constant struggle and she will require an advocate over the long term to ensure these issues are appropriately addressed, and that she is not again placed in a situation where she is isolated and that the only people in her life are paid workers who appear to have total control over her life.

Case study provided by Speaking Up For You (SUFY), 2011, Brisbane: Australia

Jane's story clearly illustrates that even when the Community Visitor Program undertakes investigations into human rights breaches these investigations do not in every case result in remedies that rectify such breaches and further legal and individual advocacy was required in order to make Jane safe. In Jane's case, the independent advocate was able to with minimal conflict of interest demonstrate that Jane's human rights were clearly being violated, and continued to advocate on behalf of Jane until changes were made to stop Janes' human rights being violated. Independent advocacy is about going beyond what is done customarily, standing alongside the person as long as they are needed.

Recommendations:

- A strong independent advocacy support program which is separately funded and administered must constitute a fundamental component of the mechanisms established to protect the rights of people who are receiving support, or who are the subject of decisions made , under the NDIS
- The establishment of such mechanisms must be an integral and ineluctable purpose of the NDIS
- An Appropriate independent review process must be available for people who are the subject of decisions made, under the NDIS. Individuals must be provided with the information and support they need to make use of that process. That support must be independent of the NDIS and totally allied to the interests of the individual to minimise the potential for conflict of interest.
- Enhance capacity for effective participation in decision making by people with disabilities, including through support for and recognition of the roles of advocacy and representative organisations must be supported under the NDIS.

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Attachment 1

QAI's knowledge and experience

QAI has been involved in numerous systemic enquiries, reforms, and campaigns including the:

- development of the Queensland Guardianship and Administration Act,
- the closure of Maryborough Hospital disabled persons ward,
- represented the residents' interests in the Criminal Justice Commission (CJC) enquiry into Basil Stafford Centre,
- exposure of multiple human rights violations of vulnerable people living in for profit hostels (which resulted in two pieces of legislation being developed to protect the tenancy rights and accommodation rights of people with disability)
- 70 submissions into government enquiries over a 23 year period,
- Ratification of the Convention on the Rights of Persons with Disability and it's Optional Protocol,
- Disabled Justice report that examined the experience of persons with disability with the Queensland criminal justice system, comprehensively stated the case for reform and to outline the various dimensions of the reforms required,
- development of a national peak body for advocacy organisations (DANA)
- the Wasted Lives campaign advocating for over 1000 forgotten people with intellectual, physical, acquired brain injury (ABI) left in health institutions in QLD. This is now in contravention of Article 19 of the CRPD.

Attachment 2

Principles of Advocacy

Strict partiality

This means the advocate must place themselves fundamentally on the side of the person with a disability. It does not mean that an advocate is required to be aggressive or confrontational although some situations may warrant that. It simply means clearly, consistently, and firmly acting and speaking on behalf of one person or group of people.

Minimal conflict of interest

This issue lies at the core of advocacy because it supports the principle of strict partiality. In any situation, there will be more than one person or groups' interests that will conflict the interest of a person with a disability.

The advocate must identify any interests and needs that may conflict with those of the person for whom they are advocating. As an advocate, they must attempt to reduce conflicts of interest or, at least, be prepared to acknowledge these conflicts and therefore the limitations of the advocacy.

Emphasis on fundamental needs and issues

Strong advocacy requires giving priority to a person's fundamental needs. For example, a person's need for a home of their own, strong and enduring relationships, be free from abuse, healthy and safe may take priority over encouraging a person to attend personal development courses or finding employment.

Vigorous action

Strong advocacy requires fervour and depth of feeling in advancing the cause or interest of another. An advocate must take the lead and act out of a sense of urgency. It requires putting in the extra mile and bending over backwards to achieve even the smallest gain. Instead of writing a letter to the editor, the strong advocate may also ring their local politician; instead of complaining once about an unacceptable situation, they will complain weekly.

Costs of advocacy to the advocate and the person receiving advocacy

The advocate must consider all the effects their advocacy may have on their personal life.

These considerations include the advocate's time and resources, the highly emotional nature of advocacy, the possibility of social rejection or ridicule, the possible compromise of financial security or livelihood, safety and/or health of the advocate.

The advocate must also consider the costs to the person for whom they are advocating. They need to determine whether their advocacy will do more harm than good and any outcomes that would occur if the advocate did not act. If there is a potential cost to the person with a disability, the advocate must warn them of it.

For example, advocating for a person to have visitors when they wish requires the advocate to consider how their actions could negatively affect the person. If it is likely the person could be penalised in small ways, such as being served last at dinner, the advocate may decide to continue with their advocacy. However, if the person will be singled out by staff, ridiculed and humiliated, the cost may be too great. However, if the advocate was complaining to a service because of suspected physical and sexual abuse, stopping the abuse will outweigh the costs of any humiliation or ridicule the person may experience from staff.

Fidelity

Advocacy involves being there for the long run. This may involve making a commitment to be in someone's life for a long time or making a commitment to see a particular situation through to its end. Some people with a disability, particularly those who are dependent on services, have little continuous contact with people. Residential care officers, mental health workers, social workers, case managers often come and go.

Being mindful of the most vulnerable person

Sometimes the advocate must consider the needs of other parties other than the person for whom they are advocating. For example, the children of parents who lack competence are more vulnerable than those parents. Advocates for the parents must bear in mind the needs of the vulnerable children and at least arrange for independent advocacy for the children.