



SUBMISSION

DEPARTMENT OF SOCIAL SERVICES

NATIONAL DISABILITY INSURANCE SCHEME QUALITY AND SAFEGUARDING FRAMEWORK

"The goals of our public welfare program must be positive and constructive. [The welfare program] must stress the integrity and preservation of the family unit. It must contribute to the attack on dependency, juvenile delinquency, family breakdown, illegitimacy, ill health, and disability. It must reduce the incidence of these problems, prevent their occurrence and recurrence, and strengthen and protect the vulnerable in a highly competitive world."

John Fitzgerald Kennedy

About QAI – Our Values and Beliefs

Queensland Advocacy Incorporated (QAI) is an independent community-based advocacy organisation that has for over twenty-five years campaigned for the rights of vulnerable people with disability in Queensland. With a focus on the fundamental needs of the most vulnerable people in our community, QAI has a history of avant-garde advocacy for people with disability to have supports to live an inclusive life in the community.

At QAI, we believe that all human beings are equally important, unique and of intrinsic value. Everyone should be seen and valued as a whole person, first and foremost. The human condition is such that societies tend to devalue those who do not fit within their models of perfection. These groups, including people with disability, are socially marginalised. As an organisation we seek to bring about a common vision where all human beings are equally valued.

Our organisation has been immersed for decades in advancing the agenda for people with disability to have support to live in a home in a community of their choice and with whom they wish to live. We believe that the spirit and intent of the NDIS is supportive and congruent with our vision and mission.

Culture

There is a dire need to address the cultural mindset shift required from both the National Disability Insurance Agency and the service sector. This is necessary to deliver envisaged quality and ensure safeguards that reflect the 'choice and control' intended by the inception of the NDIS, while creating safeguards that ensure people are not disadvantaged or harmed. It has become apparent in the journey of the NDIS to date that there is still a lot more development required given that at advocacy consultations conducted recently, the focus was about service providers and not the correct emphasis on people with disability. People with disability should be driving this process and are still somewhat being regarded and portrayed as passive recipients.

There is a tendency for many service providers to view the NDIS as a threat to their viability rather than an opportunity to change and be more responsive to need. We have witnessed this in interstate trial sites with service providers speaking about 'offering programs to new clients' and 'merging and amalgamating' to remain viable. This approach entrenches the monopoly that existing large service providers already have on the sector and will result in small innovative services struggling if they are not recognised for their excellent support in enabling people's autonomy.

Smaller responsive and innovative service models need to be supported and promoted as being geographically ideal and person centred. There is only one known service provider that is attempting to break down its large top heavy service model into smaller geographically located services. This seems an issue of particular importance in Queensland, given that it is documented that 80% of providers have an annual turnover of less than \$2 million and many operate in rural and remote areas. We need to support small responsive and individual targeted services, rather than increasing the power and coverage of the 20% who are wielding significant power and funds.

Some service providers are not reporting abuse – deeming it to be ‘normal behaviour of siblings’ even though this is hitting, punching, etc. This indicates a lack of understanding or valuing of people with disability.

The Myth And Aberration Of Choice, Control? – AUTONOMY

The terminology of “Choice and Control” is bandied about as if it is a commodity rather than promotion of the intention to increase autonomy, and what important safeguards are obligatory to give effect to these words. It is imperative to recognise that people are transitioning from having no choice or control to having opportunities to ‘choose and control’.

Some individuals who are self-directing will still surrender their funds to large providers of support.

Of course the word “choice” is a key and now popular catchphrase used by the same service sector that unconsciously at times does everything to eliminate the autonomy that choice should lead to. Family members too can sometimes supersede the wants and wishes of the person with disability as they too have competing interests.

Advocacy that is independent of these conflicts is important to ensure that the person is not left to make choices from rotten apples. It is not appropriate to ask a person who has always lived in a nursing home, or a group home if they would like to stay, or if they would like to share with another of their ‘co-tenants’. Rather it is important that in the pre-planning stages people are encouraged to create a vision for how they would like to live. This may require that people are supported to meet other people with disabilities who are living in the community with adequate supports in a variety of living arrangements that are consistent with ordinary community expectations and situations.

QAI is concerned that people with impaired capacity who have not had opportunity to exercise basic choices, particularly in rural and regional localities or who live under restrictive or institutional situations, are the most vulnerable. It is essential that those who have not experienced such opportunities are extended extra supports for decision making, trialling different opportunities and even the chance to make and learn from small mistakes.

Certainly families and supporters should be consulted, but it is long overdue that the individuals themselves are encouraged and supported to communicate in whatever means, their choices about their future. This will require considerable concerted and detailed efforts to allow residents to explore opportunities and options that they may (in some cases) never have experienced in their lifetimes

People will be experiencing a new system and they will need encouragement and supports in the beginning phases to learn the new system and at differing levels and duration of assistance.

It is critical that the NDIS does not replicate what already exists.

The importance of relationships cannot be underestimated in the development and creation of a positive culture.

Advocacy

The National Disability Insurance Scheme (NDIS) will improve the lives of many people with disability. It will also mean an increase in demand for advocacy. The NDIS will provide more support, more opportunity and more economic and social participation. People with disability will engage more broadly with the world. The Productivity Commission has predicted, for example, that workforce participation¹ by people with disability will increase once the NDIS is operating nationally.

That participation and engagement in the workforce, in education, in recreation, tourism and in community life generally will not always be welcomed, or run smoothly. Many people with disability will manage those transitional challenges themselves but many others will need advocacy to secure the rights the Commonwealth has endorsed.

People with disabilities face extra barriers in finding employment, accessing services, education and suitable housing, health and social care services. People with disabilities have been expected to fit into support services, rather than services personalised to promote independence and extend opportunity.

People with disability often receive both support and accommodation from the same organisation. These arrangements may be cost-efficient for the organisation but present major conflicts of interest and add an extra layer of exposure to people with disability. They are vulnerable to eviction both for breaches of the tenancy agreement and when there is a dispute over support provision. The advent of the NDIS will not immediately address this conflict, although it must do so as soon as possible. Advocacy seeks to ensure that people with disability are not threatened and will advance the agenda for service providers to divest themselves of much of the control and ownership over a person's life.

Restrictive Practices are forms of physical and chemical restraint, containment and seclusion regulated pursuant to the Disability Services Act 2006 (Qld) and the Guardianship and Administration Act 2000 (Qld). These practices often involve a serious infringement of the liberties of people who lack legal capacity, and who are therefore unable to represent themselves in the Queensland Civil and Administrative Tribunal. In October 2013 the South Australian Public Advocate noted that many of the Restrictive Practices around this country are likely to be a breach of the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, a convention this country has yet to ratify.

Guardians, in our experience, do not always act in the interests of their clients. QAI advocates have been denied access/right to represent clients by guardians who are unwilling to appoint them. People with capacity

The importance of advocacy is recognised but the need and requisite urgency for advocacy is largely underestimated.

There will be predictably an increased need for individual advocacy as people with disability gain confidence encounter new and different experiences by exercising autonomy in their

¹ 1 See Chapter 20- Productivity Commission. 2011. *Disability Care and Support*.

lives. It is highly probable that for a time there will be an increased demand for legal representation for people with disability whether due to civil matters or representation before Guardianship and other Tribunals.

Systems Advocacy:

However, it is perhaps not so widely acknowledged that much of the reform that will be required will be changes to our legislation, policies and practices that eventuate due to the significance of systems advocacy. Indeed, the revolutionary impact of the NDIS is largely due to the vigorous and emphatic systems advocacy efforts of so many individuals, collectives, and allies with over 10,000 people now trialling and testing the scheme. The outstanding improvements our nation has enjoyed because of the vigorous and unswerving endeavours of systems advocacy take considerable time to achieve, thus requiring fidelity and perseverance to the cause.

Some of the most important systems endeavours by QAI include the following:-

The Convention on the Rights of Persons with Disabilities is an example of systems advocacy at the highest order, and the Civil Society in Australia has made a subsequent 'shadow report' - "**Disability Rights Now**" - reporting how Australia is performing in bringing this document to life in every aspect in every avenue of Australian life for people with disabilities. QAI was one of the contributors to this work.

Queensland Advocacy Incorporated has expert knowledge of some of the most serious threats that bring harm and demean vulnerable people with disabilities. However the state of Queensland also has developed the most stringent and controlling legislation regarding the use of heinous **restrictive practices**. QAI's systemic work in this area is highly valued and as a result of this was successful in attending the **United Nations Convention Against Torture** last year as part of the NGO delegation with the focus of restrictive practices and involuntary treatment of people with mental illness. Our Human Rights Lawyer has been referred cases for reviews of restrictive practice orders because of the systemic work and expertise of QAI.

The **deinstitutionalisation** of people with disability has been a perennial agenda item for QAI. We extend our efforts to promote the long term benefits to individuals, their families, neighbours, friends, and local communities when all people are included in the fabric of local life. As people have moved from the harsh and often listless existence of institutional or congregate care arrangements into homes of their own, they contribute to the richness of their communities by being neighbours, employees, employers, and customers. These ordinary but important roles are not often available to people who are secluded from the rest of our society.

Our state has the most progressive **guardianship** legislation with excellent principles recognising the value of supports for decision making (yet unfortunately is rarely practiced by those very statutory bodies entrusted to ensure this.) The mechanism of 'support for decision making' will be especially important with the impending NDIS rollout, and more broadly has the potential to free people from unnecessary guardianship orders, enable people to exercise autonomy with support and release our administration tribunals from an overburden of

hearings, saving valuable fiscal resources. QAI has written on this subject and held a forum in the last two years to promote support for decision making on the disability agenda.

I draw your attention to the **National Disability Advocacy Framework** (2008) areas that specifically apply to the need for vigorous systemic advocacy.

Principle (c) Disability advocacy seeks to influence positive systemic changes in legislation, policy and service practice and works towards promoting inclusive communities and awareness of disability issues;

Objective: People with disability have access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling full community participation.

Outcomes (a) people with disability are accorded the rights and freedoms described in the United Nations Convention on the Rights of People with Disabilities and other relevant United Nations Rights Treaties;

(b) Disability advocacy that is informed by an evidence base and is provided in an accountable and transparent manner;

(c) Disability advocacy that is planned and delivered in a coordinated manner and supports communication between disability advocacy support, disability services, mainstream services and governments;

(d) Disability advocacy that promotes community education and awareness of disability issues and rights;

(e) Systemic advocacy that positively contributes to legislation, policy and practice that will support the agreed outcomes.

(a) Reform and Policy Directions (f) Improving coordination and communication between the disability advocacy, mainstream sector and governments to develop the overall capacity of the sector, including promoting linkages between individual and systemic advocacy.

As systems advocates QAI's works to promote, protect and defend the needs, and rights and lives of people with disability, while also promoting positive images of people with disability as valued contributors to our society. Part of this work can also entail the systems advocacy directed to services, the community in general and such areas as employment.

Organisations such as QAI can advocate to Retailers' Associations, Small Business Associations, and Chambers of Commerce etcetera. It is clear that systems advocacy is as important as ever and that much of this work is important to shape and develop our communities towards a civil society.

Individual and Citizen Advocacy:

The safeguards framework developed from this consultation will likely incorporate systems that exist to support all people, such as complaints systems. There are concerns that some

people with impaired decision-making capacity can't access these safeguards and that other people who are vulnerable to their supports services will not access these systems.

Far too many people with a disability have nobody in their lives with the exception of those paid to be there – ie, doctors, professionals and support workers who may not prioritise their interests. If people don't have a trusted person in their lives, they will need someone apart from the service system to be there for them. This is a great opportunity to expand Citizen Advocacy. The potential for such relationships to be both informal supports and enduring relationships is both a momentous advantage and a worthwhile opportunity. Citizen Advocacy programs would need expansion in every neighbourhood and advocates would need to training to work within the principles of citizen advocacy.

Independence of Advocacy

When advocacy is independent it is free to promote the rights and welfare of people with disability without conflict of interest. Social institutions that have the potential to inflict harm on vulnerable people ought not to have a say in whether advocates can act to challenge them. Any organisation that already provides a service to people with disability - accommodation, support, legal services - must not also be responsible for advocating on their behalf. Inevitably there will be conflict between service needs and those of people with disability. The police should not police themselves, and nor should service systems, government or insurance schemes. The National Disability Insurance Agency must not fund disability advocacy. Funding should remain separately funded under the National Disability Advocacy Program.

Neither advocacy, nor individual advocacy is well-suited to a user pays system. Systemic advocacy has characteristics of a public good (in some ways similar to research and development), meaning it would be under-provided in the absence of dedicated public funding. In the case of individual advocacy, it is problematic attempting to predict individual need for it during assessment processes. Relying on individual's capacity to privately pay for advocacy is likely to render it unobtainable to those who need it most. For these reasons, it is important that advocacy should continue to be block funded.

In doing so, genuine independence from the NDIS will be a critical determinant of the effectiveness of advocacy. The NDIA should not directly fund advocacy. The role of allocating funding for advocacy should continue under the National Disability Advocacy Program administered by the Department of Social Services as well as from state and territory governments. There may be merit in the NDIA or the Federal Attorney General contributing additional funds to this program (though with no associated directive as to how they should be used).

The delivery of advocacy support to people with disabilities must be provided by agencies that are able to demonstrate independence from all actual, potential or perceived conflicting interests. To establish independence, an agency needs to have advocacy as its core business and not to be a provider of any of the following services: employment, accommodation support, personal care support, independent living support, respite, vocational training, brokerage, change agency, mediation or case management.

Independence of advocacy is crucial to ensure the minimisation of conflict of interest. Since the trial of the NDIS began, there has been a number of new support services develop that advertise 'programs' and services that span a lifetime – from cradle to grave and include fees for services such as advocacy and support for decision making. While it could be interpreted as a desire to offer all things to all people, this type of approach leads to ownership of a person with unprecedented control upon that person. Fees for such fundamental protections and supports as advocacy and or support for decision making should never be applied. Indeed, that service providers promote themselves in this way is major cause for concern for advocacy organisations and the conflict this presents is indefensible.

Access to Advocacy and Advocacy Development

In conjunction with the other points made within this submission regarding intentional actions to enable increased autonomy for vulnerable people with disability, it is a supreme imperative that there are alert points for the appointment of independent individual advocate. This must also be directed at the service level as well as the systems level, and systems advocacy organisations have a crucial role to play in this matter.

There is likely to be an increased need for legal advocacy and systems advocacy will play an important role in the oversight of how the legislation and policy and practices are impacting or improving the lives of people with disability.

With an increase demand for advocacy services it is vital that new or expanded services are instigated in local communities, particularly for people with heightened vulnerabilities. Relationships developed by advocates with people who require their support must have fidelity and longevity – Citizen Advocacy is a prime example of the benefits of genuine commitment to the person and the longstanding benefits this type of advocacy relationship can bring.

The capacity building of individuals and support for decision making that advocates cannot be underestimated. Advocates must work within the principles of advocacy.

Lack Of Vision In The Culture Of The System And Service Sector

There is an urgent and dire imperative for change in culture and mindsets by systems and services including the National Disability Insurance Agency. People with disability including those with impaired capacity can be supported to make decisions and exercise autonomy and control in their own lives. The focus of consultations has been about the service sector and less about enabling people to take control.

The Productivity Commission did not envisage the proliferation of group homes. Has the NDIS lost sight of the intention of the Productivity Commission? Where is corporate memory of the Productivity Commission and how does that fit within those who work within the National Disability Insurance Agency?

The Convention on the Rights of Persons with Disabilities is mentioned briefly in the NDIS Quality and Safeguards Framework document, but should be incorporated to a much more significant extent; in guiding framework for support for choice and control and what providers

can offer (eg a 10-bed residential doesn't fit with principles of CPRD). The NDIA should be leading by example and make more use of CRPD principles to guide development.

There still prevails a risk practice management and risk adverse policy - procedures can overrun rights and freedoms of individuals to exercise their own decision-making capacity of choice and control.

It appears that people are still being viewed as helpless and that they must be managed - who determines what is a genuine decision? A greater emphasis on support for decision-making via trusted advocates and supports can alleviate the restriction and impositions on people with disability that can occur from the risk adverse mindset.

No Additional Bureaucracy In The Lives Of People With Disability

Participants in the NDIS will be enabled to enjoy newly discovered freedoms and a broader range of opportunities and in particular those who take up self-direction and self-management of their supports and services.

However, there is a tendency to over-protect and therefore restrict people by layering overly burdensome bureaucratic processes and procedures. The process of review needs to be least restrictive and least intrusive. Why should people who are having a good life need to 'pass the test' over and over?

Again QAI cannot reiterate strongly enough that the NDIA must not replicate the status quo, or it will defeat the purpose of this strategy.

Building Capacity

People with disabilities have the same right as other people to make decisions about their own lives.

Some people may have difficulty making choices, formulating decisions and communicating their preferences, but that must never be held as or/made a barrier to them making positive choices and decisions which further their personal development, relationships and participation in their communities².

Under no circumstances should any person with a disability be considered completely unable to make decisions simply because of their disability. The legal right of people with disabilities to make their own decisions should only ever be interrupted in extraordinary circumstances.

Any person with impaired decision making should be provided with supports to enable them to exercise capacity like any other.

The great majority of Australians who have impaired decision making already have supporters who help them in the decision making process. Some people have misunderstood what supported decision-making is and have seen it as another bureaucratic attempt to interfere with these informal arrangements. Our vision for supported decision-making is a

² Queensland Advocacy Incorporated acknowledges here the Montreal Declaration made by Michael Bach of the Canadian Association for Community Living.

means to reduce the level of unnecessary systemic or service interference in people's lives and return authority, authenticity, control and dignity to the person.

Supported decision-making is about encouraging people with disability and their informal supporters so that-

- guardianship and administration orders are in some cases no longer necessary, and
- informal supporters conduct their support with morality that respects the dignity of risk, and allows people with disability to make mistakes, to learn, and to truly make their own decisions.

However valid decision making support means enabling the person with disability to take control and be the decision maker.

Supported decision making occurs in any aspect of a person's life. It is when another individual, known to and trusted by the person making the decision, supports and enables them to make more decisions in their daily life. And like most people, this begins for people with disability when afforded simple choice making during childhood.

Practice in daily life provides the opportunity to develop skills, starting with small decisions, building to more complex decisions with time.

This support for decision making must be employed in the planning process. However, people build capacity by trying new experiences, making mistakes and learning from those experiences and plans should not be used as acquittal tools, or be held to strict accountability. Most people are not held to account for not reaching their desired goals within a specified time frame and it is unreasonable to expect people with disability to achieve articulated aspirational goals in order to maintain NDIS funds.

People must be allowed flexibility to change their minds, and to trial options without retribution, and to have those decisions respected and not over-ridden by contractual clauses or dominant factors.

Planning should be done by independent organisations and not direct support providers. Planning takes time and is done with the person and, for people with impaired capacity, with those who know them best. Plans should not be reviewed by the service but the independent planner. There must be fidelity to the vision of the person with disability to ensure that the plan has quality and durability.

Safeguards For Participants Who Manage Their Own Plans

Participants who enter into agreements with workers will need some support and training in contractual knowledge, employment roles and responsibilities and acquittal processes. Queenslanders who self-direct have had the benefit of host-provider support and this is often a benefit before proceeding to manage funds entirely. Some participants have used minimal support from host providers while others have taken advantage of extensive supports such as payroll etc.

However, QAI does not believe that this should be proscribed as many people will wish to manage on their own at the outset.

It should be acknowledged that self-directed service delivery operates on a continuum of 'managed well' and 'not managed well' and that, like capacity building, this may take time and the learning process is a valid and valuable as the NDIS itself.

There is a need to safeguard people who self-direct and self-manage their funds from the misconception that they are operating small businesses and should be exempt from vexatious complaints. Some people are using contracted workers, while others are employing permanent employees and operating under the PAYG taxation laws, and therefore are being deemed as small businesses.

These people are potentially at risk of litigation and or vexatious claims.

Some host providers in Queensland have offered training for people who self-direct, self-manage their funds and this is a good example to others. Most people will not have sufficient ongoing funding to manage the continuous training and development of staff and the coordination of their workers. The NDIS should offer ongoing funds to support participants to train their own staff and for coordination of staff.

Safeguards

The NDIS Participant Readiness Schemes will not outreach to all who are eligible for the scheme. It is important for all people with disability to be made aware of their rights to personal integrity, dignity, safety, privacy, respect, and to be free from harassment, abuse or neglect and funded advocacy can assist people to be given deeper understanding of what this means to them at a personal level.

Some of the information should be incorporated within NDIS Participant Readiness Workshops and disseminated via Centrelink communication to recipients of the Disability Support Pension.

People with impaired capacity will have much more difficulty in accessing and navigating the NDIS and intentional funded supports such as services that specialised in planning such as independent from direct support provision host provider services (such as currently available in Queensland and individual advocacy can deliver this much needed advice and guidance.

In building capacity for participants, people with disability need to have contractual knowledge about what they are agreeing to with any service provider. Participants should be encouraged to compose their own agreements or at least make amendments to contracts as they see fit, and have knowledge about pitfalls of terms of contracts.

Service Providers that are in control of the contractual arrangement rather than the participant may impose unreasonable penalties or fees for 'notice' to quit an arrangement (ie withhold funds, not deliver a service). To date the limited scope of NDIS Participant Readiness initiatives have not been able to outreach the population of potential participants who would therefore be unaware of these conceivable risks. The NDIA and The Department should have some clear guidelines and supports regarding contractual obligations and fairness.

It is equally important that the NDIA answers concerns regarding the arrangements where contracts are signed by Nominees or if a person signs who has impaired capacity? Will service providers honour such agreements if there are disagreements? Will such arrangements prompt applications for more guardianship orders and what position does the NDIA have on ensuring this does not occur?

Intentionally Created Informal Supports

The building of natural network and informal supports is a foundation for ordinary but good life. It is extremely valuable to inject funding until such time as the natural network is developed and strengthened.

Volunteer Friendship Program was a noteworthy endeavour in the past and it is timely that such programs be revisited and promoted within community, with the development of skills and training, but it is and perhaps most appropriate if this is developed more along the lines of citizen advocacy guidelines to ensure that friendships are lasting, honestly engaged and reciprocal. Any attempts however to formally bureaucratise such relationships by insisting that volunteers are screened for criminal history is likely to thwart such endeavours.

Monitoring And Oversight

While the NDIA will monitor the scheme and the progress made over time, and provide oversight on the system. Monitoring of individual services will be most likely be performed by service users, or self-managing participants employing their own staff, and not according to compliance with service standards.

Much of the time issues will be discussed and resolutions will be negotiated, but at times, there will be complaints that will not be managed at the local level. The determination of quality is not merely the provision of direct personal support but relates to the ability of service providers to respond to a wide range of requests. It will not suffice to have too many specialist service providers that will inevitably seek to exclude those who don't fit.

Under the proposed suggestions that people who live under restrictive practices will remain in the status quo, in order for the protection of monitoring and reporting of the use of such practices, please see the section on Restrictive Practices.

The analysis of complaints data will inform and educate and raise awareness of the kinds of issues – It is a necessary safeguard that systems advocacy informs policy and lawmakers about the required adjustments for continual improvement.

While QAI would assert that congregate and shared care or work arrangements (not of the individuals' own designs) should by necessity be phased out of existence, it is acknowledged that for a significant number of people with disability this reality will prevail for some time. Therefore the role of community visitors must continue as a safeguard until the transition to fully inclusive lifestyle is achieved.

While community visitors' schemes that are well-resourced and well-trained are useful, it is important that their role is not intrusive or unwelcome especially in people's homes.

How Do Participants Get Information?

Under the Information Linkages and Capacity Building (tier 2) Local Area Coordinators (LACs) will play a very important role especially for people who don't have families, but they cannot and should not be seen as advocates, and indeed, LAC's should have an obligation that they ensure that vulnerable participants (particularly those with intellectual or cognitive impairments) without families or informal supports are connected with an advocate.

There will also be a need for education regarding generic services.

People with disability are often not given the same access to information as service provider or families. It is incongruent that the people who should be driving the agenda for reform are often still seen as passive service recipients and receive information about what will happen rather than being the creators of their own schemes. This can be a challenge for service providers who work with people who lack a supportive familial/friendship network is to build their capacity.

Information is not easily accessible not is it universally inclusive of people from culturally and linguistically diverse backgrounds, indigenous people with disabilities, and those who use diverse communication methods.

Peer support should be provided by people who have directed their own supports - "This is what my life was and this is what it is now". Some participants and their families may need to meet others who have experienced the change in their lives, overcoming adversity and now living a good life - some may need to be shown that change is possible.

It is important to recognise that participants will not necessarily respond immediately, but should be afforded opportunities for personal development.

Quality

It is highly probable that many stakeholders will have differing views on what makes "quality" service. While providers of support may view themselves as "excellent" in what they provide, it is to be determined by those who use the service or purchase the supports. These decisions by participants may be supported by families and advocates.

However, for participants looking to purchase supports and services it is more likely that people with disability be reassured when they hear anecdotes from others' experiences with that service. This is not merely about service providers but also about the contrast the quality of people's lives especially if they self-direct or self-manage their own funds.

Providers of support need to be focused on being the best and compete for the best reputation (just in the same way as retail stores compete for this reputation).

There is an expectation of providers of support to change and adapt to what people need and want in their neighbourhoods rather than a centrally but distant location – however, there is a role for providers to have specialised niche services to supply on demand.

In many instances, individuals may have their funds managed by the service so the service system may not be very different from the way it is now. The risk is that things will stay the same.

Providers of support may use independent persons to rate their service and publish this rating (e.g. Trip Advisor or as RACQ with insurance) but as any practices consumer will attest, this is not reliable.

Quality assurance and compliance has proven to be a failure to determine quality of service as advocate will indicate. – see Bribie Care and Yooralla examples. People with disability and their families will not want to have auditors intruding into their homes.

The following statements regarding Levels and standards of provider registration have bearing on what is quality in support services.

Levels And Standards Of Provider Registration

There are concerns regarding the emergence of the rogue support service (entrepreneurship). There will be no monitoring of that and we will see the impact of power over people. The person with a disability is often so reliant on their support worker who can dictate terms of support, service that are offering everything from support for decision making for a fee, to making wills and trusts and management of funds. The NDIA has a tremendous role of oversight to ensure that this kind of service is outlawed.

If there are to be introduced standards they must be of quality rather than compliance – eg:- Outstanding leadership in cultural change – mandated Social Role Valorisation training for all staff that is clearly demonstrated in their service delivery which need to be accredited by participants and their families.

National Disability Insurance Agency Provider Registration

What are the requisites for a service provider to be registered? What if anything excludes a service provider from approval for registration? If the service provider has various or many complaints laid against those complaints could be fully investigated to the satisfaction of the person making those complaints. Currently complaints are addressed from quality assurance perspective. This has little or nothing to do with the issues raised by the complainant and is unsatisfactory.

Service Provider Practices

The following issues are common practices that must desist under the new scheme. QAI asserts that complaints on these issues should be resolved before a service provider can obtain registration.

- Inappropriate co-tenancy resulting in restrictive practices and or assaults
- The process of new tenants being introduced (there is currently supposed to be a trial period but this is not always the case)

- People being forced to move because the Service Provider or the Department is selling their homes.
- People have to 'share' their support because a person moves in and doesn't have a funding package
- Service providers who do not report instances of abuse by co-tenants.
- Service providers who relinquish care when a complaint is made about not delivering a service or not reporting abuse.
- Service Providers who relinquish care and are also the landlord of the accommodation.

Systems For Handling Complaints

The safeguards framework will incorporate existing systems that exist to support all people, such as complaints systems. There are some concerns that some people with impaired decision-making capacity can't access these safeguards.

There are assumptions that people with a disability can access many of those mechanisms and therefore advocacy is critical to ensure that people are supported to make their claims particularly as sometimes people don't recognise that they have a complaint to make.

- **There is a need for someone to help individuals walk through the complaints system – especially vulnerable people.**
 - **Least Restrictive – we need minimal limitations and should be able to rely on informal arrangements. Need to look at the Guardianship and Administration Act 2000 (Qld) and the general principles including the principle about least restrictive.**
 - **Staff made complaints regarding people with a disability – they were explained away by senior staff. The allegations were explained away in a very sophisticated way. If there are substantial numbers of complaints within an organisation, this situation needs to be identified and the organisation needs to be investigated before allowing registration.**

importance of review to ensure measures are working.

Also, need to recognise abuse that occurs, such as **psychological abuse** that is constant and gives insight into how system is working. **Calling this type of abuse 'complaint' is problematic** – concern about terminology. Also, concerned not to designate these issues simply as HR/IR issues.

- (Response: even at lowest tier, would be code of conduct.) **Might need advocate to help through process. Process is complex; complexity increases as you go through different levels. (flagged by LAC or Community Visitor)**

QAI is grateful for the opportunity to comment on the complaints management systems for adults with impaired capacity given the long term and entrenched problems arising from the processes that have been used to date.

The complaints mechanism currently does not provide timely or satisfactory responses when people are being abused in any form or not receiving their service for which they have paid. Issues or complaints against a service provider are taken by the Department that determines if the service provider has breached or not complied with service standards. QAI asserts that these complaints should be investigated by an independent authority with due regard given to the complainants rather than merely ensuring the Service Provider has been compliant with Quality Assurance.

The current status of service providers is that provided they are “approved” by the Department they will be deemed as suitable under the NDIS. QAI is aware of a number of service providers with significant unresolved serious complaints against them.

QAI acknowledges the Queensland Public Advocate’s project which has a stated objective to identify and articulate what may constitute best practice in complaints management for the systems that adults with impaired capacity may interact with.

To this end, the following core elements have been identified:

- accessibility
- fairness
- customer focus
- efficiency
- systems improvement

We agree that these are all important components of a complaints management system for adults with impaired capacity. We wish to briefly note the following points that we consider integral with respect to each:

1. Accessibility

The onus should not be on the person to know or recognise what avenues for complaints are available. For any service or system that prides itself on excellence this should be offered at any reasonable expression of dissatisfaction.

If a person is experiencing dissatisfaction with either a service or system this should automatically generate a prompt to the internal complaints system and once this is exhausted or rejected for whatever reason is escalated to the independent mechanism.

- It is important to ensure any complaints handling process is easily accessible to both complainants and respondents – i.e. it must be available in a simple-to-use format, in a number of forms, and not overly bureaucratic. For people with disability, this can be particularly challenging to ensure. Flexibility as to form is required – there should be

no requirement that a complaint from a person with impaired capacity be in a prescribed form or meet certain requirements to be actioned.

- The onus must be on the service provider to investigate informal complaints as well. This will obviously require the introduction of safeguards to ensure that complaints are reported and actioned appropriately.
- An important component in accessibility for people with impaired capacity is ensuring that they have the support – this includes support to feel empowered to make the complaint, support to provide adequate detail to enable the complaint to be investigated, support to respond to any questions regarding the complaint. To this end, it is integral that their support people are proactively involved from the earliest opportunity.
- Further, it is important that proactive mechanisms are put in place to ensure that, to the greatest extent possible, potential problems are detected. It is inappropriate to place the full onus of understanding, identifying, communicating and pursuing a complaint on a person with impaired capacity. In many instances, there are indicators of a problem that are apparent to relevant observers. Protocols must be put in place to aid the identification and reporting of any indications of sub-optimal service delivery.
- It is important to ensure that the system does not rest on assumptions such as that complainants will have access to and the ability to effectively use the internet, the telephone, etc., both as a means of accessing information relevant to making a complaint and to communicate the complaint.
- It is vitally important to consider the power imbalance that can exist between a person with impaired capacity and a service provider. People with impaired capacity are often in a very vulnerable situation and may fear reprisal for making a complaint. It is essential that they feel supported to voice any complaints without concern about retribution or cessation/reduction of the service. It is important that the NDIS vision of having people with disability empowered as consumers within a disability services market translates into empowerment for people with impaired capacity to feel they have options and can therefore voice dissatisfaction with unsatisfactory service and have autonomy to exercise choice and seek change.

2. Fairness

People with impaired capacity are not always treated fairly. Fairness can be improved by ensuring the person has support for decision making, and referrals to an advocacy organisation should be offered where no informal supports are available or effective. However, this can only be managed with a well-resourced and vibrant advocacy sector, which is very scant and in some areas non-existent

- The complaints process should clearly defined and communicated, open and accountable to both staff and consumers.

- Outcomes of the complaints system must be clearly outlined and communicated to all relevant people. This must be counterbalanced with the need to ensure privacy and confidentiality so that people feel confident making complaints without fear of reprisal.

3. Customer focus

Everything in the investigations of a complaint is answerable to the person with disability and or their supporter making the complaint. By this we mean that all the concerns are addressed, that the investigations and processes are timely, and that the person is included in the processes. All processes are transparent and the investigating body is accountable to the person making the complaint but also engages all parties and ensures all communications are clear, open and honest.

- Complaints must be treated seriously. This has important implications not only for ensuring the complaint itself is appropriately addressed but also in empowering people with capacity impairment to articulate their concerns in a supportive environment. This is particularly appropriate given that the vision of the NDIS is to support people with disability to be consumers in the service marketplace, rather than passive service recipients. It should follow that this will also have the effect of elevating the importance of service satisfaction for people with impaired capacity.
- There is the potential role for the development/use of a tool to assess seriousness of the complaint that will dictate how it is directed and the urgency with which it is prioritised (e.g. 'Seriousness Assessment Matrix' used by Department of Health in Victoria). The use of such a tool must obviously be based on the differing needs and capacity of people with impaired capacity while the use of such a tool is not used to dismiss or exclude complaints that are unusual.
- It is important to ensure there is a procedure in place to ensure all complaints are followed-up to ensure the complaint has been properly resolved and has not recurred.
- It is important to ensure that people with impaired capacity have all the relevant support they need to understand when conduct or service is suboptimal and should appropriately give rise to a complaint, when and how a complaint should be made, what they can expect to happen, and to be supported in making the complaint.
- The investigations show due diligence, must address the complaint and not merely look at governance or compliance of standards. This Mechanism must be funded as a statutory or Parliamentary body. All recommendations or orders are binding. If for whatever reason the person's complaint is not within the scope of the investigation or is deemed to be not completely relevant there should be redirection to mediation until some satisfaction or compromise is reached.

4. Efficiency

- We consider that it is important to differentiate between internal and external responses and have clear guidelines stipulating what must happen in each situation, having regard to the seriousness of the complaint and the stage at which it is at.

- It is important that there is an emphasis on an expeditious timeframe for dealing with complaints. To ensure complaints are dealt with in an appropriate timeframe, the protocol for addressing complaints must be very specific and detailed about relevant timeframes.
- However, it is also important that the specific needs of the complainant are considered, including their need for support in making a complaint and therefore that expediency is not prioritised over meeting the needs of the complainant in a personalised way.

5. Systems improvement

- The complaint handling system should ultimately be a means of obtaining critical information that can promote positive change in the organisation.
- While part of the role of any complaints protocol is addressing grievances, a significant part should also be to educate the service and relevant staff in better practice. Receiving and responding to complaints can help the service and staff to learn and to shape a better practice model.
- The complaints system can be integrated into the whole service, such that complaints relevant to systemic issues are used to identify gaps in service quality, develop collaboration in investigating and responding to complaints and sharing information among management teams.
- Creating an environment where complaints are readily received and actioned without animosity also encourages the giving of all types of feedback, including positive feedback, and supports staff to feel confident to report any adverse events.
- There should be penalties for any retribution against a person making a complaint - after all the complaint should be seen as an opportunity for quality improvement.

Ensuring Staff Are Safe To Work With Participants

People who experience abuse of all kinds should not merely be seen as complainants. Abuse is not a complaint of service quality. Abuse comes in all forms and is not restricted to physical sexual or financial. Abuse can be coercion silencing the person or even deliberate withholding of information or skewing what information is available or how it is provided. Who can support a person with a disability to make a complaint? How can this be done for people without family or friends? Clearly advocacy has an important role. Systemic issues will be identified and should be acted upon. Who will identify these systemic issues?

Some people with disability may use mainstream safeguards such as the police – however police are reluctant to take on reported issues regarding people with disability or older people particularly when allegations are made against support workers or co-tenants with impaired capacity.

Reducing And Eliminating Restrictive Practices In NDIS Funded Supports

What supports are available under restrictive practices? Positive behaviour support plans are non-negotiable. Posted restrictive practices must be the last resort. People who live under restrictive practices should not be stuck with the status quo and should be entitled to choose their own supports, their own workers, how they are supported, when, where and how. The status quo will realise no change in the lives of vulnerable people in rural and regional areas where there is only one service provider. It is discriminatory to deny people who live under restrictive practices the same access to the same rights as other people with disability under the scheme.

- All Australian governments committed to reducing and eliminating RPs
- National Framework for reducing RPs in disability sector
- Focussing on process, rather than content:
 1. Who should be able to make a decision?
 2. How should use of RP be reported and monitored?
 3. What we would like to see under NDIS system?

They should not definitely be any voluntary code of practice and nor should there be a panel of skilled employees of the service provider. No Way!!!

There is a need for greater advocacy services and access including Citizen advocacy especially in support of the decision-making so that people with disability can drive their own version of the NDIS.

People who are under the imposition of Restrictive Practices are excluded from being able to employ their own staff and self-direct or self-manage their supports and/or funding. While we recognise that this is currently the national position for the NDIA, QAI maintains that this discrimination is unfair and imposes severe limitations in the choice and control available to the most vulnerable people who are eligible for the NDIS supports. Furthermore, the legislation for the use of Restrictive Practices in Queensland is the most robust and longstanding yet it has been amended several times, with each amendment imposing more constraints on individuals while affording more ease for service providers. This would suggest that Queensland's Department of Disability Services and the service sector have not developed the mindset or embraced the culture to be ready for the NDIS.

We understand the need to safeguard people from inexperienced workers or those who may abuse or take advantage of vulnerable people. However, the current system does not safeguard people from the same happening within traditional service responses. Excluding these people from the same opportunities as others is discriminatory and will exacerbate the denial of autonomy and control for this vulnerable group.

An alternative measure is to support people who live under Restrictive Practices to train or direct their own staff (with their informal supporters as and when required) or to have their

own selected staff be trained at the Centre of Excellence. QAI believes that a significant number of people who are supported to move towards this level of autonomy will then be enabled to emerge from under Restrictive Practices.

People who live under the imposition of Restrictive Practices are currently confined to the few choices of Service Providers available that are perceived by The Department to have expertise and knowledge of Positive Behaviour Support Plans and how to use Restrictive Practices. This is certainly exacerbated in rural and remote areas of Queensland with few if any choices of services. We point to the model of Kalpana – a small person-centred service geographically located and specifically designed to support 10 individuals deemed ‘too difficult’ for all other Service Providers. Those people no longer live under Restrictive Practices and self-direct their own supports. The service operates with a coordinator and a governance model.

The Department’s own service provider AS&RS has expertise that need not be lost. People who wish could and should be able to hire AS&RS staff as independent contractors as they can any other staff. Clinging to the notion of department owned and run service providers is not conducive to the NDIS and not necessarily enhancing the lives of people with disability.

Strengthening safeguards for all people with disability

A Human Rights Act would inform everyday Australians, as well as those with power to make and shape the law, about their rights and responsibilities, creating a culture of understanding and respect for human rights. We are particularly concerned about protecting the rights of vulnerable people who are liable to be treated in a discriminatory way and who are not able to advocate for themselves to assert and defend their basic rights.

QAI considers that it is vital for people to understand that human rights are for everyone – the right to liberty, to a fair trial, to appropriate housing and to fair working conditions, along with the right to make basic choices such as who we lawfully associate with, are fundamental to basic freedom and democracy.

Victoria has a Charter of Human Rights and the ACT has a Bill of Rights.

QAI asserts that the introduction of a Human Rights Act would mean that vulnerable people with disabilities would have a robust and primary legal framework providing remedies and protections, instead of relying on secondary sources such treaties to ensure they are less likely to face indefinite detention, restrictions and breaches of human rights that most of us take for granted.

Access To Justice

Consider the issues working with generic services. QPS, for instance, won’t touch issues where one person with a disability has assaulted another person with a disability in the home. If we are going to encourage accessing generic services, there is work that needs to be done within mainstream systems

- Criminal justice. If a person with a disability is incarcerated, they cannot get parole without an address, and later can’t get a job.

- QPS – it is difficult for people with impaired decision-making capacity to get heard. It is even more difficult getting an issue to progress to court.
- People wouldn't make a complaint against the people living with them even in cases of aggression. Justice
- The QPS advises that people with impaired decision-making capacity will not make good witnesses and the issue won't progress. You can, however, go to the QPS website to record an incident which provides people with an opportunity to at least voice what happened without dispute.
 - Victim Support Service, saw a lack of reporting.
 - Commonwealth Centrelink Assistance
 - Concerns were raised about the Disability Support Pension (DSP) and potential cuts to the DSP for people with a mental illness who are involuntarily detained in facilities (e.g. Queensland Health Hospital, Forensic Disability Service and Prison).
 - Queensland Corrective Services (QCS), Queensland Health, Disability Services Queensland (DSQ) and PTQ are key stakeholders in relation to this issue.
 - Suggestion was made that Queensland Health and DSQ should be meeting with the Commonwealth about this issue – it was advised that this has occurred.

Forensic Detention

The NDIA has deemed that people who are incarcerated will not be supported by the NDIS. This means that people who are in detention at forensic disability facilities and/or people who are held in psychiatric facilities such as The Park will be excluded from the supports of the NDIS. There will be no habilitation, recovery and no way out for many people without adequate funded and tailored supports. We are aware that current state funding for "Limited Community Treatment" (LCT) is inadequate and that some people are therefore denied the LCT that is part of their planned rehabilitation. The Forensic Disability Service Unit has been in existence for 5 years and no-one has moved out.

There is uncertainty whether the newly released Federal funding will support people with mental illness who reside in community care units or other psychiatric facilities that are transitional placements.

QAI has grave concerns that people held in forensic detention in psychiatric or disability support facilities will be denied the Disability Support Pension that is vital to the habilitation and/or recovery of these people before returning to community.

Employment

It is thought that if employers have to pay open employment pay rates, some people with a disability may lose their jobs. There is a need to consider if the workplace is really that or if it is indeed a day service.

Employers who operate in the open market and whose products compete in the open market should pay equal rates. People with disability who are employed in sheltered workshops should eventually progress to open employment.

The issue is consistency of opportunity. Jodie talked about a young man with intellectual impairment employed locally. He appeared to be respected by his co-workers. The current system is inconsistent – similar opportunities aren't available to all. This should be considered under an NDIS as its purpose is to facilitate social and economic participation. If we don't eliminate the barriers, people will hit brick walls. So how do we 'market' people with a disability as being able and capable?

We need to look at the business sector to promote inclusion of people with a disability. Such as the Council of Businesses Australia, Council of Small Businesses Australia, Chambers of Commerce, Retailers' Associations. The NDIS needs to ensure that the community is educated - systems advocacy can play an important role in promotion and community education

Continuity Of Quality

Self-directed funding provides opportunities for people to be in community, but how will we maintain community living over a long period of time (say 20 years)? Many carers are older people who say they are never going to be able to retire. Is this a risk for people with a disability? It identifies the need for succession planning.

More adult brothers and sisters are coming to CRU about succession planning. We can understand how carers want to have someone to hand the caring role to.

We can't assume that carers' sons and daughters will take over this role.

Success planning and advocacy can ensure a trusted person in their lives, they will need someone apart from the service system to be there for them. This is a great opportunity to expand citizen advocacy. They would need to work within the principles of citizen advocacy and be trained.

Congregation

The sharing of accommodation is fraught with the issues of forced co-tenancies, lack of choice and control about one's life and where and with whom one lives, but the sharing of care is just as (if not more) problematic. Whether one resides in a 'duplex' or cluster housing, a person will be dependent upon the timing of delivery of supports and services to another or others. It is incongruent to believe that anyone can live independently while having to share care.

As the recent expose of Yooralla and many other institutions will attest, congregate care and control is not only dysfunctional but also lends itself to the propagation of abuse and neglect, learned helplessness and loss of capacity.

QAI has made submission³ to the *Community Affairs References Committee on the Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*. Our submission gives detailed position of the pitfalls of congregate settings as below:-

'It is important that whatever the alternative means of accommodation from congregate care, we do not merely devise a replacement model in cluster or groups.

Family members of people residing in long stay health facilities had opted for their family members with disability to remain with the status quo because of fewer choices, little information about suitable alternatives and the less desirable option of group homes.

Young (2006)³, in another comparison of two matched groups each of 30 individuals moving from Challinor to (a) small, dispersed community residences versus (b) a cluster of group residences found that both groups improved after the move from the institution; however, those who moved to the dispersed homes did significantly better.⁴

The congregation of people with disabilities according to their 'support needs' offers no choice or control as intended by the advent of the National Disability Insurance Scheme. It is flagrant disregard to Article 19 of the Convention on the Rights of Persons with Disabilities to which Australia committed in 2008.

This is not a simple matter of merely accommodating people and ensuring support needs. The perpetuation of forced co-tenancy is a symptom of an archaic mindset that has not recognised its failures or the damage to human lives, families, communities or acknowledges the false economy and increased indirect costs.

However, there remains a significant disparity between the preferences and reality of accommodation for many people with an intellectual or cognitive impairment. For many people with disability, their choice is not to be accommodated in a group home, but rather to live in an ordinary home in the community, either alone or with housemates chosen by them, in the manner that most Australians are able to choose their accommodation arrangements. Recent Australian research has recognised the desirability of taking an individualistic approach to housing for people with a disability.⁵

People will need the Community Visitor and advocacy representatives - We have concerns about rural areas: people may have fewer options. And disability services are just going to be rolled over: "How is my life going to be any different?"

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http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_ag_ed_care/Submissions

⁴ "Community and cluster centre residential services for adults with intellectual disability: long-term results from an Australian-matched sample" *Journal of Intellectual Disability Research* L. Young, 2006

⁵ Lesley Chenoweth, Natalie Clements and School of Human Services and Social Work, *Funding and service options for people with disabilities: Final Report, Griffith University, June 2009, reporting on the 2008 meta-analysis by Parmenter and Arnold for the Victorian Department of Human Services*

We also need to be aware that service providers may simply carry across the same structures using different means, such as moving people from institutions into three-bedroom homes where they are still sharing with people who are not of their choosing.

Housing

Private rentals may register as providers of support. If people cannot access public housing then people should be helped financially to enter into private rentals. There is a lack of housing options that could be addressed if people were subsidised to enter private rentals at the same costs as public housing.