



Queensland Advocacy Incorporated

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

Systems and Individual Advocacy for vulnerable People with Disability

SUBMISSION TO **DISABILITY ROYAL COMMISSION** **2020**

The Hon Ronald Sackville AO QC (Chair)

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GROUP HOMES

“Home is where the heart is.”

Gaius Plinius Secundus or Pliny the Elder

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QAI endorses the objectives, and promotes the principles, of the Convention on the Rights of Persons with Disabilities.

Patron: His Excellency The Honorable Paul de Jersey AC

About Queensland Advocacy Incorporated

Queensland Advocacy Incorporated (QAI) is an independent, community-based systems and individual advocacy organisation and a community legal service for people with disability. Our mission is to promote, protect and defend, through systems and individual advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

QAI has an exemplary track record of effective systems advocacy, with over thirty years' experience advocating for systems change, through campaigns directed to attitudinal, law policy and practice reform and by supporting the development of a range of advocacy initiatives in this state. We have provided, for over a decade, highly in-demand individual advocacy through our individual advocacy services – the Human Rights Legal Service, Mental Health Legal Service, Justice Support Program, National Disability Insurance Scheme Appeals Support Program, NDIS Decision Support Pilot Program and more recently the Disability Royal Commission Advocacy Service and the state-funded Education Advocacy Service.

QAI has historically raised issues and recommended reforms related to congregated living arrangements where people with disability with complex support needs have been placed. Many of those issues have been acknowledged by the Disability Royal Commission (DRC) and the inquiry and *Issues Paper – Group Homes* was released in November 2019. Moreover, a public hearing was held by the Commission in December 2019, where evidence was presented about violence, neglect, abuse and exploitation of people with disability inside congregated houses – not only regarding group homes, but housing issues in general (**Housing Public Hearing**).

Since the advent of *Residential Services (Accommodation) Act 2002 (Qld)* and the *Residential Services (Accreditation) Act 2002 (Qld)*, little has changed regarding the living and housing arrangements for people with disability who remain marginalised and segregated in Queensland. Although the *Disability Services Act 2006 (Qld)* sends a clear message regarding the separation of housing from service provision, the congregation of people with disability in substandard facilities with inadequate supports is still routine. The notion that people with disability belong in such places is still the predominant mindset that informs service provision and practice – the “us and them” mindset perpetuates, notwithstanding that it is incongruent with the State Government's laws and policies.

QAI has been funded to provide advocacy support for people seeking to engage with the Disability Royal Commission (DRC). Our organisation has been contacted by a number of particularly vulnerable clients experiencing violence, abuse, neglect and exploitation in their current housing arrangements and in other aspects of their daily lives. In order to address a predictably huge demand for change of housing circumstances for those individuals, QAI is progressing advocacy along two lines: the presentation of this submission to the DRC in order to gather information around the housing matter and garnering support for the development of a Memorandum of Understanding (MOU) between advocacy groups, housing providers, government and non-government entities in order to build a concerted effective strategy.



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Introduction

This submission focuses on the experiences of vulnerable people with disability who do not have the opportunity or voice to express their own wants and wishes directly. Many of the people are often forgotten in places that do not feel like a home, are unsuitable for them and give rise to a series of physical, emotional, and/or sexual abuses that infringe or remove basic human rights. The passage of the *Human Rights Act 2019* (Qld), which commenced operation from 1 January 2020, provides, for the first time in Queensland, a means of enforcing the entitlement of all human beings to equal and inalienable rights.

While the *Disability Services Act 2006* (Qld) falls short of protecting any rights, it does uphold the principles of human rights, with s 18 establishing the principle that people with disability have the same human rights as others and s 22 stating that services should be designed and implemented “to ensure that the conditions of everyday life of people with a disability are:

- a) the same as, or as close as possible to, the conditions of everyday life valued by the general community; and
- b) appropriate to their chronological age.¹

Importantly, s 28 states that no single service provider is to exercise control over all or most aspects of the life of the person with disability. This is particularly relevant to our point that no support service providers should also be the provider of housing and vice versa.

The housing situation is but one of the many issues that the DRC will examine regarding the challenges that people with disability face. However, the support and living arrangements are often at the centre of many other related issues that impact on the lives of vulnerable people with disability.

QAI welcomes the DRC's focus on the living arrangements of people with disability, especially *group homes* that accommodate around 17,000 people with disability in Australia and where, in many instances, violence, abuse, neglect and exploitation flourish. It is important to note that congregated style of living is not limited to group homes, there are many long-stay health facilities, residential complexes, hostels and boarding houses that still accommodate large numbers of people who are required to share so much of their lives from the living space, communal areas, sometimes communal bathrooms, eating areas, and their personal supports. The deinstitutionalisation movement is still not a reality for many people with a disability.² Conversely, any residence may be institutionalised where the choice of support service, or the requirement to share support with another is not the decision of the person with disability.

¹ 'Disability Services Act (2006) Qld Division 2 Section 22.

² Movement on Shifting Sands: Deinstitutionalisation and People with Intellectual Disability in Australia, 1974–2014



Removing the right to live how, where, and with whom a person chooses exacerbates the power imbalance and inequitable life of a vulnerable person with disability.

Queensland had undergone numerous investigations, reports and reviews of places where people with disability have endured cruel, inhuman and degrading treatment, abuse, neglect and death. Maryborough Disabled Persons Ward, Cootharinga Nursing Home Townsville, Halwyn Centre, Basil Stafford and Challinor Centre, Baillee Henderson Hospital, Casuarina Lodge, Birribi Nursing Home and Respite Centre and Jacana Rehabilitation Hospital are all places that have been at the centre of an inquiry because of inadequacies of this model of support and housing. These are recognised institutions, but several group homes, hostels boarding houses and other residential facilities where people are ‘crated’ and share care have come under similar scrutiny albeit without as much public attention.³

The issues, concerns and examples that were presented during the Housing Public Hearing related to *group homes*, although mainly examples from New South Wales, resonate with cases in Queensland – and no doubt they are replicated across Australia. It is an inalienable, compounding systemic situation and will remain so while decision-makers continue to equate human life, dignity and rights with a costs efficiency plan. The new language aimed at increasing the appeal of group homes has not altered the reality of group homes. ‘Supported Independent Living’ and ‘Specialist Disability Accommodation’ is new terminology designed to positively rebrand institutionalised living arrangements. Yet the fresh labelling has not heralded a new approach to shared living arrangements, in which practices of abuse, exploitation and neglect, in addition to denial of choice and control, have perpetuated. This is the case notwithstanding the stated vision of the NDIS to return choice and control to people with disability, and the (predominantly retrospective) oversight provided by the NDIS Quality and Safeguards Commission.

QAI acknowledges the valuable work of other organisations that seek to bring about positive changes to ensure every person with a disability is supported to live in a home how, where and with whom they choose, that is culturally appropriate, accessible and secure.

The concept of equality is articulated clearly in the Convention on the Rights of Persons with Disabilities (CRPD) in Article 19⁴, which was quoted numerous during the Housing Public Hearing. On the 5th day of the hearing, the concept of **substantive equality** was presented by the Senior Counsel Assisting (Ms K. Eastman) as ‘*different treatment to achieve same outcomes or to achieve an outcome of equal basis*’. In other words, equals should be treated in measures that are equals, and unequal insofar as they are unequal.

³ <https://www.youtube.com/watch?v=D8DdZN3aEq8>
<https://www.youtube.com/watch?v=LQZ0F3GGdwU>
<https://www.youtube.com/watch?v=FGyWHfjnCR4>
<https://www.youtube.com/watch?v=fG27H1UJjaU>
<https://www.youtube.com/watch?v=pTEhtn-C-vY>

⁴ Article 19 – States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that: (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement; – 14 – (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.



The housing arrangements available for people with disability initially appears to be a very complex matter yet not when one considers the starting point as the basic rights that people without disability enjoy. People with disability waited too long to be seen, to be listened to and to express their wishes. The Disability Royal Commission offers the opportunity to enlighten a situation that has been dark for many individuals for far too long. Instead of attempting to convert a system that is clearly dysfunctional, or to re-shape what arrangements are currently in place, it is time to consider what should NOT be done. Two very simple starting points:

- We should not force people to share their supports in order to have a home.
- We should not force people to live together in order to have support.

What makes a home?

As a systemic and individual advocacy organisation and specialist community legal centre, working with and for people with disability and mental health issues, we hear from people about their housing wants and wishes. And people with disability want to live in homes like anyone else, and unfortunately there has been a failure in delivering that right.

The section 19 of the *Human Right Act 2019* (Qld) states: '*Every person lawfully within Queensland has the right to move freely within Queensland and to enter and leave it and **has the freedom to choose where to live***'. The word 'where' might mean city, neighbourhood, street, house, type of house and its features. Yet the right of choice is denied to many people with disability. Mostly this is applied by government, clinicians and service providers to people who are labelled as having high complex needs. However, usually the complexities are imposed upon people who are not well understood or well supported. It is the failure of systems and people with power that unfairly portray people and create undeserved reputations as "complex" or "challenging" rather than admitting to a less effective or appropriate supports to the person.

The Position Paper on the Right to A Home of One's Own (Attachment A) addressed, among other, the aspects that constitute adequate housing. Considerations encompassed include:

- Legal security of tenure;
- Availability of services, materials, facilities and infrastructure;
- Affordability;
- Habitability;
- Accessibility;
- Location; and
- Cultural adequacy.

It is reasonable to assume that a "home" is comfortable, loving, welcoming, situated in a location of one's choice, and that the occupant or occupants have chosen to live there, either alone by their own design or with people of their choice. However, common practices remove this decision from many people with disability, and others deem that a person's level of support needs should be the determining factor of where or how a person should live.

The Roman philosopher Pliny the Elder said: "Home is where the heart is", meaning home is a place we can never see with a stranger's eyes for more than a moment. Too many people with disability must feel like strangers in their own "home" - a place shared with strangers, unfamiliar faces, without the love and the coziness that a home should have. It's acceptable



that people feel displaced or like strangers when travelling, or when they need to stay for short periods of time in their relative's house, but soon enough they will be back to their so called "home". For people with disability, congregated places are not a temporary house. Living in those facilities can only offer them the unending feeling of being a stranger.

Colin Hiscoe, President of the organisation Reinforce Self Advocacy⁵ and one of the witnesses in the Housing Public Hearing, made his point by saying: "I've been told I've got human rights. I've been told I can do this, this and this. Now, you're telling me I can't. Please explain to me. And then just sit down and explain why."

Thus, we might see there are two main reasons why people with disability, in a practical way, do not have the same rights as everyone else:

- I. Although there are conventions and acts protecting human rights, the information doesn't always get to the people that matter – people with disability, and there are limits on the enforceability of many of these rights.
- II. When information is provided to them, often there is little opportunity to exercise those rights or to have them upheld or to defend those rights without well-funded and resourced independent advocacy support.

Information regarding the human rights that people with disability are entitled to and ways that they can exercise those rights must be provided in accessible format and conveyed to the broader community to ensure that those rights are respected.

People who may have impaired decision-making capacity are more vulnerable to misrepresentation and defamation as government and protection agencies are reliant on identification by others and have little capacity to see and understand what happens on a day-to-day basis.

A person with intellectual disability may experience conceptual issues with language, reading, writing, sequencing, or practical issues such as personal care and safety or have difficulties interpreting social cues, understanding sarcasm or irony, or be suggestible and susceptible to manipulation.

People who have intellectual impairment may therefore struggle to understand that some actions constitute a breach or breaches of their rights. For example, if a person with disability who has difficulty with the concept of time, may not be able to explain the duration or repeated acts of violence that may have been perpetuated against them for a specific or prolonged period.

For too long many people have either languished in congregate care arrangements such as institutions, group homes, hostels and boarding houses, quite often far removed from their families, informal supports and natural networks. Sometimes they have merely existed while experiencing abuse, neglect, violence, fear, humiliation, degradation and other forms of violation of the human rights.

Long waiting lists for public housing, unaffordable private rentals, and a lack of appropriate individualised support has forced people to accept untenable offerings. In Queensland (North Brisbane area) there is a house that accommodates about 60 people, but the site is not suitable for many residents as it is not designed for disability accommodation (e.g. there are no hand railings). We question whether it is the choice of any resident to live in that house – there existence there is a reflection of their lack of say and lack of appropriate alternative.

A home is every person's refuge, haven and domain. To limit a person's right to choose where, how and with whom they live, based on the person's perceived support needs, seriously erodes the person's rights as an ordinary citizen. Support to live in a home of one's own, in the location

⁵ <https://reinforce.org.au/>



of choice, with whom they wish is no extraordinary dream but has been unattainable for many individuals with disability.

In order to consider the immediate support needs of an individual it is vital that they are engaged in discussions about what they want, they have the right to exercise their freedom to choose where to live. Certainly, families and supporters should be consulted but it is long overdue that the people 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.

“A Home of One’s Own” (Attachment A) articulates the issues confronting people with disability who are ‘tertiary homeless’ when residing in boarding houses, hostels and other ‘packaged living’ situations. The paper also provides recommendations for equitable, accessible (to all) and affordable housing.

What is not a Home of One’s Own?

For clarity, QAI refers to group or congregated housing as any place where the person is forced to share their care, whether this is in a large residential facility, a small group home, boarding house, hostel, Supported Independent Living (or SIL – a new term under the NDIS which we consider a misnomer as any vision of independence in SIL living arrangements has not been actualised) or cluster homes even if they live in an individual unit. The notion of shared care is what creates institutionalised responses.

At the end of the first quarter of 2019 there were 3,220 NDIS Participants living in SIL in Qld.

As outlined in the QAI submission to the Joint Standing Committee Inquiry into Supported Independent Living (Attachment G), QAI asserts that:

- SIL has become the mechanism for the proliferation of the archaic block funded group home. Rather than enabling a person to live ‘independently in their home’, it is in reality shared care in a congregated setting, often not of the person’s choosing but instead organised, negotiated, and created by the NDIS system and the service providers.
- A dearth of truthful information about the inflexibility of SIL has reinforced the misconception that a person with high and/or complex support needs must therefore enter into a SIL arrangement.

Issues that pertain to hostels, boarding houses, cluster homes and residential facilities also apply to SIL and unfortunately the NDIS is part of the problem, promoting this as the Agency’s preferred model.

Issues pertinent to why living in a Hostel, Boarding House, SIL arrangement or Group Home is not a Home of One’s Own

The housing issues raised by many advocacy organisations and individuals with disability have been on record for decades. In 2003 QAI offered the *Legislation and Life* report (Attachment B) with recommendations to the Queensland Government calling for the following actions:



- a stop to the placement and use of supported accommodation hostels and boarding houses for people with disability with complex support needs.
- identification of existing residents with disability who are inappropriately placed in private residential services.
- provision for planning to identify decent and sustainable futures for each of these individuals.
- commitment of resources, as an election promise, for alternative housing and support for at least 100 people with disability in each of the next three years.
- maintaining demographic data centrally and monitoring changes and developments in the private residential services industries; and
- regulating the industry to avoid the segregation, congregation and abuse of vulnerable Queenslanders with disability.

In the nearly two decades that have elapsed since that submission, there has been little improvement regarding the number of people with disability living in congregated houses⁶ or the support provided to those vulnerable residents. While this current inquiry of the DRC is specific to group homes, there still exists in Queensland a proliferation of hostels, boarding houses and congregate residential settings to accommodate many people with disability – some houses have 60-80 people living together. Thus, the deinstitutionalisation that occurred in the 1970's, 80's and 90's did not extinguish the congregated living arrangements imposed upon many people with disability. If systemic changes brought following the DRC Inquiry does not prompt sweeping reform, we are committed to forever marking time and repeating the same mistakes.

In 2018, there were 4.4 million people with disability in Australia, and 4.3% were living in congregated houses (hostels, boarding houses, shared accommodation, care accommodation), which means 189,000 people with disability with complex support needs⁷ across the country still live in congregated houses, with potentially many others, as comprehensive records are not kept.

Coercion and Control

Many of hostels are members of the Supported Accommodation Providers Association (SAPA) and since 2015 SAPA openly has been gearing-up for the NDIS. SAPA [posts the names of members who are NDIS providers](#) on their website. The conflict of interest (i.e. provision of both housing and support) has always been built into the business plans of Level 2 and 3 hostels which, by definition, provide housing and supports, which is incongruent with the DSA (2006) Qld, but apparently no government department seeks to redress. This is despite the recommendations made by one of the governments' own Ministers for Disability Services to

⁶ In 2003, 175,700 people with disability were living in shared accommodation (4.4% of the population back then). <https://www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/3319EC785921CFFCCA2577FA0011C3C8?opendocument>

⁷ <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features152018?OpenDocument>



cease referring individuals with complex support needs and challenging behaviour to private residential facilities for long-term placements⁸

A key issue is choice and control: Residents must be free to choose who they want to provide their support and services, but practices utilised in many of these premises are strategies used to exert control, and/or coercion to prevent this. Many hostel and boarding house operators consider the residents to be 'theirs'.

The following non-exhaustive list of anecdotal examples have been provided to QAI by service providers, Local Area Coordinators and some former residents who do not wish to be identified:

- A hostel provider's direct relative has become an NDIS Registered Provider of Supports (RPS) and residents wanting to go with another RPS have been threatened with eviction.
- Another hostel provider's direct relative has become a Support Coordinator for those same residents.
- Hostel providers stand over residents while negotiating NDIS support agreements.
- Providers restrict entry to residents' guests, including to independent support coordinators.
- Provider sought Guardianship order, to override disadvantageous resident decision.
- Provider yelling, abuse, coercion, threats to get compliance.
- Manager controls which activities residents do with support workers.
- One hostel owner/manager has four houses – 2 are in good condition the other 2 are extremely filthy. If someone is to visit, the residents are moved to a cleaner home for the meeting. They are registered to provide Level 3 accommodation.
- Daily meals are not cooked for residents by staff, despite that this is included in the accommodation fee. Shopping is delivered to the home; the higher functioning residents cook the meals.
- Hostel Manager stated that the participant's psychiatrist does not listen to her or share what is happening with the participant. Manager wants to force the participant to see public mental health in another location as all her other residents attend this location and the clinician shares information with her.
- NDIS plans were opened by manager/owner and not given to the residents. This was common knowledge. One participant did not see her plan till a Support Coordinator arrived to speak about her plan. The resident did not even know she had an active plan but this time months had passed. This has since happened with several other

⁸ University of New South Wales Consortium April 2005 "Review of Disability Services Queensland Referral Processes to Private Residential Facilities"



residents who knew nothing of having a plan, yet hostel staff had opened the mail and uploaded the plans onto the persons' files, without the participant's knowledge or consent.

- Control of residents' own money. In one instance the Public Trustee was depositing \$80 per fortnight to a person's account but the hostel management would only allow the person to access \$2 per day and \$10 on Fridays.
- Residents are rarely able to visit their own GP, and instead a visiting GP treats all the residents, denying them choice with respect to their healthcare provision.
- One resident was on a waitlist for 6 years to have cataract surgery, but this was not followed up by the hostel owner and the resident has lost most of her vision. She then broke her right knee and left ankle when slipping over.
- The GP that visits (on an arrangement with hostel) diagnosed a resident with allergies. A concerned NGO staff took her to an external GP, and she was diagnosed with stage 4 cancer and passed away within a couple of weeks of this.

Issues of raising complaints and concerns to government and statutory bodies are fraught with siloed responses

The Community Visitor Program of the Office of the Public Guardian (**CVP**) is designed to safeguard the rights and interests of vulnerable adults, by providing external oversight. The Community Visitors can report on what they see or are told. For less serious complaints a visit report is sent to the provider with priorities to be remedied by the return visit. Community Visitors assess risks to residents of visitable sites yet can be limited in their recourse – a follow-up visit might be the only action, or some different issues may require more advocacy from the CVP. If an issue is urgent and is actioned on that basis, it still may take a matter of weeks before a report is tendered. If the site provider (hostel/boarding house) does not agree with the report, and more information is required for the Office of the Public Guardian to act, it may take longer. The Community Visitor has no enforcement power and can only enter and request information.

Complaints to Department of Housing and Public Works about dubious and unethical behaviour of hostel and/or boarding house operators does not constitute an infringement of their accreditation as a provider of accommodation. While complaints about hostels and boarding houses as it relates to NDIS registered support service provision may now be taken to the NDIS Quality and Safeguards Commission, there is no equivalent pathway for complaints about unregistered providers. It appears they are unfettered, unscrutinised and, while complaints may be progressed to the Queensland Human Rights Commission, complaints must be undertaken by a resident or an advocate with the consent of a resident who is without fear of reprisals or eviction.

Lack of attention to health needs and appropriate health care

People with disability often have multiple and complex health needs and a high mortality rate. Yet they also face significant barriers to accessing appropriate health care, and experience poorer quality of health due to poverty and social exclusion. This alone provides compelling



reasons for the provision of individualised funding, proper support according to their particular needs and equitable choices for social housing.

In 2016, the Queensland Public Advocate published a report⁹ with details about 73 cases of people who died in care between 2009-2014 (Attachment C). The results of the study were shocking. The median age at death for males was 53 years, which is approximately 25 years less than the median age of death for the general population. The median age for women was 49 years, which was approximately 36 years less than the general population. And the most astonishing conclusion: **67% of the deaths were potentially avoidable.**

The related Deaths in Care - Expert Review panel report for the Coroners Court of Queensland is provided for the DRC (Attachment D). This horrific reality is not exclusive to this state but duplicated in different states across the country. A witness at the Housing Public Hearing, the Victorian Disability Service Commissioner, Mr Arthur Rogers, offered testimony of an investigation in 2017 and findings of potentially avoidable deaths of people with disability and the failure to manage some key risks. In the reports and coronial findings to which we refer here, people with cognitive disabilities have a significantly lower life expectancy because their health needs are poorly monitored, or not at all. Many people in congregate supported accommodation do not get adequate attention paid to their health needs because their service providers, many of whom operate on a for-profit basis, do not run their businesses with appropriate checks and balances or with a positive health model.

Level three accredited hostels, for example, provide accommodation and personal services including distribution of medication to clients who typically require some level of supports. Often, the residents have complex medical, psychiatric, and social conditions which place them at a disadvantage. The hostels typically provide facilities that can only be described as modest.

Few operate with an appropriate ratio of residents to staff, or an appropriate level of training of staff and procedures. Many do not properly document the medication they distribute to residents, and to our knowledge, none is audited independently to ensure medication is dispensed in correct dosages or at the correct frequencies.

One of the primary reasons that we know what we do about these hostels in Queensland is that the mandatory reporting of deaths occurring in level three accredited hostels was introduced by amendments to the Coroners Act 2003 (Qld). These reports have shone a light on the lives and deaths of people who lived in what can only be described as Dickensian conditions - but in a first world country.

QAI is aware of one large hostel where the health care in 2009 was provided by the registered owner of the building. The local GP owned the accommodation, managed the upkeep of the lodge, provided the primary health care, and, when residents died, issued their death certificates - a clear conflict of interest. You can read about these arrangements in the Queensland Coroner's report on the death, from heat exposure, of Mr Leon Streader, one of the residents¹⁰.

⁹ https://www.justice.qld.gov.au/_data/assets/pdf_file/0008/460088/final-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf

¹⁰ Office Of The State Coroner: Findings of Inquest into the death of Leon Streader. Coroner's Court Brisbane FILE NO(s): COR 573/04(3) https://www.courts.qld.gov.au/_data/assets/pdf_file/0004/86782/cif-streader-l-20091001.pdf



Recently, the case of Ann-Marie Smith's death came to light in Adelaide – SA¹¹. Ann-Marie had an NDIS plan and was living in the community. She died as a result of the most heinous neglect. The case shows a “distressing and disturbing picture” that not only Ann-Marie has suffered, but many Australians still experience every day. Three lives lost to appalling neglect and shocking treatment in three weeks. All preventable.

The callous disregard shown in such instances is a terrible reflection of how people with disability are viewed by government, by service providers, and/or by individual support workers. A commonality for people who live in congregated housing is the lack of value for the person and the lack of care, training, and ‘right relationship’ between the person providing support and the person with disability. Unless people with disability have control over their lives, their supports and where and with whom they live, our society will continue to inflict the same pain, abuses and horrors upon vulnerable people, while the community, now inured to such stories, is complicit and idle.

Restrictive Practices

QAI will offer a separate submission to the DRC given the recent publication of the relevant Issues Paper. However, it would be remiss not to point out in this context that the use of Restrictive Practices (RP) most frequently appears to be utilised by paid service providers in places where people with disability are forced to co-habit with other people with disability. The numbers of unauthorised uses of RP has been reported in the NDIS Quality and Safeguards Commission (Q & S C) Annual Report. It must be remembered that the following statistics apply to only two states – New South Wales and South Australia where the Commission operated for its first year.

The Q & S C received 4,537 notifications of reportable incidents, including 1,618 notifications of unauthorised use of RPs (‘other’ reportable incidents). 353 were deaths, 641 were known serious injury (including accidents) and 1,925 were alleged abuse and neglect (physical and other). Of the 1,925 alleged abuse and neglect (physical and other) reportable incidents, 9% were alleged sexual misconduct, 28% were allegations of unlawful physical/sexual contact and 63% were alleged abuse and neglect.

Only 47 per cent of 1,422 complaints received by the Q & S C were handled within six weeks of lodgment and a further 50 per cent were handled within six months. Others took more than 6 months. The report does not indicate whether those complaints were resolved – just handled.

QAI's recently offered a submission to the DRC's Emergency Planning and Response Inquiry. Our organisation is opposed to the use of RPs as they currently exist. It is an appalling state of affairs when the Commission established under a scheme meant to provide ‘choice and control’ for people with disability does not ensure quality, does not safeguard, and the participants have little control. We direct your attention to the Fact sheet: Coronavirus (COVID-19) – Behaviour support and restrictive practices, published by the NDIS Q&S Commission and intended to guide NDIS Service Providers on supporting people with restrictions on community movement in force due to COVID19.

¹¹ <https://www.abc.net.au/radionational/programs/breakfast/horrific-death-of-adelaide-woman-in-care-not-unique:-steele-john/12262476>



Congregate and shared care living arrangements are often the source of many sanctioned and unauthorised applications of RPs. They are also the places where instances of abuse, sexual violence, assault and discrimination occur. It is not unreasonable to expect that a Commission (costing tax payers over \$16 million per annum) would be proactive in monitoring and reducing the uses of cruel inhuman and degrading treatment and would exercise its authority to proactively safeguard people with disability (as its core function) by discerning with due diligence the registration and approval for providers of service.

Improperly trained and unskilled workforce in thin markets

One of the many reasons why the current system continues to fail people with disability was presented during the Housing Public Hearing. It is presumed that the casualisation of the workforce, with the resulting lack of appropriate training of staff, is a key problem. This is a complex and contentious issue.

Some workers seeking employment with a disability support service are required to hold a Certificate 111 or IV in Disability. Some courses are available in online formats¹². A requirement of the course is to fulfil a work placement, but this is completely inadequate and inappropriate to properly understand the role or to be prepared for it. It is far more appropriate for workers to take their direction and training from the person they are to support or from their closest supporters (family or care givers). This may be provided along with competent and appropriate supervisory support (buddy shifts).

Many people with disability and their families find that the courses offered to qualify support workers are not directed at the most important factors. The courses available do not convey any attention to Human Rights or to the CRPD. Human Rights training should be mandatory and accompanied by suitable components such as trauma-informed practice, vulnerability and conscious and conscious actions that lead to forms of coercion, control, discrimination, neglect and abuse.

Service providers recruit and train their support staff according to the needs of the organisation. The focus on having Certificate III or IV qualifications is about understanding some basic principles and various workplace expectations. While casual staff often appear to have fewer qualifications and or experience, many university students studying allied health professions, social work and or social justice areas often have more respect and understanding about their roles and relationship with the people they are hired to support. It is, however, inevitable that graduates will progress to their chosen field and while their absence creates a void, no doubt their experiences as disability support workers enhance their professional knowledge in their future endeavours.

As noted in QAI's submission to the Department of Social Services Thin Markets Project (Attachment E) there are many factors impacting on the workforce and the scarcity of quality support workers is central to this. People with disability and their families cannot recruit and retain loyal support staff willing to be hired as employees. A vast number of workers are sole traders – many completely new to the sector lured by the promise of flexible working hours and high charge-out rates (many workers charge and encourage others to charge the maximum rates prescribed by the NDIS Price Guide). Disability support service providers are constantly

¹² <https://training.gov.au/Training/Details/CHC43115>



seeking staff who may be underpaid considering the importance of their roles, with the result that many leave to set up their own businesses or operate as contracted sole traders.

For self-managing Participants in the Scheme there is little recourse but for them to pay overinflated prices given the paucity of skilled support workers. Not only does this impact on the viability of Participants' funding in their NDIS Plan, but also drives up the cost of the Scheme.

With the combination of a thin market, the transience of sole trading support workers, and the reallocation of staff by providers to cope with minimal staff numbers, the quality and consistency of support to vulnerable people with disability is severely compromised. It is a natural consequence then that workers do not understand or know the people for whom they provide support, creating unhealthy and disrespectful relationships amidst power imbalances, and causing a lack of trust and an escalation of fear for the person with disability.

Since the implementation of the NDIS in 2016 the number of people accessing funded disability supports increased, which has represented a significant life improvement for many Queenslanders who require support. Yet many people with disability struggle to receive funding related to living arrangements.

Every person with disability with significant complexities in their lives, and who requires a high level of quality support should have a NDIS plan adequately funded for housing and living arrangements of their choosing. While this has not yet been tested, it is anticipated that the initial investment would offset the high costs incurred by the Department of Health every year created by having people with disability admitted and readmitted to hospitals; the costs for the Department of Justice resulting from the incarceration of people with disability; the costs of funding advocates, organisations and many other mainstream services that are in the front line of responding to all types of marginalisation, segregation, neglect, abuse and violence. This is in addition to the incalculable cost of human lives and fractured families, for to attribute any amount would add further insult and cheapen the cost of human life.

QAI's Submission to the Joint Standing Committee on the NDIS Workforce Inquiry (Attachment F), provides recommendations regarding the interagency relationships that must have holistic and integrated approaches to upskill their workforce in order to support people with disability. People who require supports and services from cross government agencies are inadequately understood and are often unsupported in health and aged care sectors.

Recently, the story of David Harris who died from neglect was reported by the media. He had purportedly "stopped answering phone calls and, it appears, his provider had not bothered to find out why — he was dead."¹³

Congregate life and shared support do not engender opportunities to build capacity in people with disability. They are not encouraged to have goals or to look forward to having their own independent lives, with jobs and a family, thereby increasing dependency on an overloaded system, maintaining the misconception that people with disability rely on supports for every aspect of their whole of life. This can be mitigated with tailored support.

Section 28 of the *Disability Service Act 2006* (Qld) requires that 'Services should be designed and implemented to ensure that no single service provider exercises control over all or most

¹³ <https://www.crikey.com.au/2020/05/22/health-system-mental-illness-david-harris/>



aspects of the life of a person with a disability'. Yet many businesses are providing care and housing to groups of people, homogenising their delivery of supports and failing to deliver a tailored service that provides tools for people to build their trust, independence, and self-confidence. It is a poor model, yet one that is associated with significant profit. A number of hostels that accommodate people with disability in Queensland have a General Practitioner as their manager and/or owner, thus the same person controls the rules of the house, the health management, their leisure and choices, etc. It is a totalitarian method of control.

Last, but not least, the personal costs are most obvious and are often reflected not only in the lives of people with disability, but also in the lives of their families and others close to them. The emotional, physical, sexual and financial abuse lead to high losses – dislocation from family, friends and ordinary life, the loss of relationships, the loss of opportunities, the loss of skills, and the loss of personal control, with the resultant helplessness and hopelessness of living a wasted, routine existence and a life apart. In some extremely bad situations this can, and does, as we have seen, result in loss of life.

While the reality doesn't change and vulnerable people continue to live (and die) in congregated places, where they need to share their space, their food, their leisure time, their care and their toiletries, it is essential that immediate actions are taken in order to deliver an adequate and standard of living, including adequate food, clothing, and housing. Now, with the advent of the *Human Rights Act 2019* (Qld), all parties must continue to strive for the improvement of living conditions and take appropriate steps to safeguard and promote the realisation of the fundamental human rights of all Queenslanders without discrimination on the basis of disability.

The absence of good practices in congregated houses

As explored before, there are many key issues that surround not only group homes, but any other type of clustered or congregated houses, that are primarily populated so people must pool their funds, resources and share their care. It is not possible for this model - large or small, with many people or only a few - to be an exemplar of good practice. This is not equitable to where people choose to live together as family, friends, or even housemates sharing the rent as young single Australians will often do. If and when a person chooses to live in shared accommodation it is only equitable if the person chooses where, how and with whom they live; the daily routine of the resident is according to his/her choice; their supports and services are chosen by him/her; the physical arrangements (wall colours, carpet type, bed style, etc) are all according to his/her choice. However, there is no such model within group, supported accommodation, cluster homes, SIL or any other and therefore, no model of good practice.

The housing system crisis is no excuse to continue to impose a failed model that was already rejected in the Convention on the Rights of Persons with Disability. Article 19 clearly states:

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:



(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.

Searching for isolated areas of good practice is like giving crumbs to people, and people with disability with high complex needs had enough of small favours, little choice, social crumbs. To quote the well-known proverb, there is small choice in rotten apples. The Policy Manager for the Summer Foundation, Dr Taleporos, one of the witnesses that gave evidence at the Housing Public Hearing, made clear in his final statement that is not satisfactory to omit information, rights and choices from people with disability:

I am up here speaking now. There's a lot of people who can't speak but we want access to advocacy, independent advocacy, well-funded independent advocacy for people who can't speak for themselves. We need that principle of choice and control that's in the NDIS Act. It's in the Act. It's written there. But it needs to be upheld. We need Article 19 of the UNCRPD recognised, upheld. I can't stress the importance of the right to choose where you live, who you live with and how you are supported. We must also take action to free people who are captive of providers. Even though we have the NDIS we have providers who effectively provide everything for that person.

They don't tell them about their options, and that fact with that provider. And that's not okay. All of these things are critical so that people with disabilities can understand their rights, advocate their rights, take action where their rights are abused, so we can all have a good life in the community. And that is what will address abuse and neglect: people having the ability to speak up, understand their rights, and have providers that respect us.

Searching for redemption in cases where crisis occurs in a service would communicate to people with disability that the system will once again turn away from what has been echoes for decades by people with disability and their families. There is no redemption for what transpired in Yooralla (or indeed so many institutions, group homes, boarding houses and hostels). The incidents and sexual crimes were exposed by the Victorian Court in 2013, yet the CEO of Yooralla showed the unpreparedness of the institution towards the residents who were the victims of such crimes. There was no support for any of the survivors to have legal advice regarding eventual criminal compensation; there was inequity between the survivors while some had compensation and others had not; one of the victims was maintained in the same room where the abuse took place and was only removed because there was 'a series of refurbishments' occurring.

The statement from Dr Sherene Devanesen, the CEO of Yooralla, is indicative of wrap around supports and services provided to their 'customers', many of whom would eat, sleep, work, rest and play under the same roof with the same co-tenants, day in and day out, often with the same support workers. Dr Devanesen's account of the vast array of services to thousands of people with disability and the respective numbers of support staff, service manager, group managers, senior managers, executive directors, etc. clearly demonstrated how far removed the management of Yooralla was from personal connection with 'customers' of that service, and undoubtedly the care and support provided to them by their own staff.



All the qualifications and expertise of the executive directors responsible for everything from recreation and employment to behaviour support and allied health did not safeguard or protect or adequately care for their ‘customers’. The structure of the Board with its various subcommittees had nothing in place to review day-to-day affairs of the residents in the group or congregate settings...just the entire Board.

The transcript of Dr Devanesen’s testimony describes the process that residents of the group homes engage with Committees – it appears that the YCPAC is the only opportunity but there is no representative on that Committee. In fact, the method of feeding back to that committee is via meetings within the group homes with families and workers. It is clear that many residents are not widely informed about other opportunities outside of congregate lifestyles and few have experience of anything other than congregation.

The highly professional and skilled CEO of that organisation did not offer survivors of criminal sexual assault any support to attend police, seek legal support and or compensation, obtain trauma counselling or even offer an apology. That Dr Devanesen did not perceive any conflict of interest in meeting with a survivor in the place where the abuse took place to discuss how the person might appear as a witness at the DRC, belies her perceived professionalism, skills and suitability for her role.

If the survivors of crimes reported in the media, and discussed as examples at the Housing Public Hearing, still did not receive independent supports and services after such exposure, we can only imagine the trauma and harm occasioned upon anonymous people in every and each group home across Australia.

QAI acknowledges the valuable work of some services providers that seek to bring about positive change to support self-determination for every person with a disability supported to live in a home how, where and with whom they choose, and that is culturally appropriate, accessible and secure.

Concerns regarding the Covid-19 pandemic

The wellbeing of people with disability living within closed residential facilities becomes a greater concern during situations of crises – like the current Covid-19 pandemic. QAI understands that measures to “lockdown” some facilities and/or restrict access to them may be necessary in certain circumstances to reduce the risk and spread of infection. However, such measures may also have the unintended consequence of reduction of formal oversight mechanisms and informal oversight provided by family, friends, supporters, and advocates. With the decrease of oversight comes an increase in the risk of violence, abuse, neglect, and exploitation that have already been experienced for many of those segregated in such living arrangements.

There are reports from Community Visitors regarding the way that residents have treated by hostel owners and/or managers since restrictions government rules and restrictions were introduced. Some houses have unnecessarily banned visitors, support services and advocates, and restricted movement of residents from exiting the building or grounds. This is in direct discord to the statement by the Prime Minister Scott Morrison:¹⁴ *“But more broadly,*

¹⁴ <https://www.abc.net.au/news/2020-04-24/coronavirus-aged-care-facilities-urged-to-follow-visitor-rules/12181408>



having people stuck in their rooms, not being able to be visited by their loved ones and carers and other support people, that's not okay."

Undoubtedly there may be cases where some residents or support staff exhibit symptoms, giving rise to an urgent need to isolate that person from other residents living in the same house. It may require a reduction of visitors to the infected resident temporarily until that person is tested and, eventually, treated. However, many people with disability residing in congregated settings are even more isolated than they were before and may have been more at risk of infection from residential staff. Residents have been restricted from going outside for exercise or to the supermarket, or to attend appointments. Such arbitrary removal of the person's right to see their advocates and have their own support workers take them out for such activities is untenable. The decision to impose such restrictions should not be at the discretion of the landlord and should incur severe penalties.

Concerns about hygiene and disinfection and ensuring people actively keep spatial distance is difficult in crowded housing arrangements. It is the excuse of service providers and residential owners that residents are unable to follow the directions and do not understand what is required of them. This is unlikely as all people with disability can learn and is a poor excuse for the lowest quality of support. Unfortunately, an overcrowded and congregated house is the reality of many people with disability and the risk of contracting the virus becomes greater to them.

In addition, it appears that accurate and honest information about Covid-19 and managing risk hasn't been reaching residents in closed and congregated care settings. This is a typical experience however, given that many residents do not have their privacy respected. It is a common occurrence for managers to open mail and screen phone calls, or where conversations either in person or by phone are always conducted with the manager present. This is an inappropriate restriction of their right to privacy. Moreover, it is essential that residents' human rights are not violated in procedures to manage the potential spread of the virus, nor in any other aspect of their lives.

Considering that a significant percentage of people with disability have complex health needs, it is critical they are fast-tracked for testing where Covid-19 symptoms have presented, there is a high risk of contracting the virus, or they have regular interactions with a high rotation of support workers.

Recommendations

As mentioned previously, QAI's report "Legislation and Life" 2003, presented not only the issues and problems that people with disability have to face in their daily life when living in a group home, but recommendations to ensure that people with disability can enable their right of choice and control. We present them again to this Commission, noting our regret at the lack of progress in these areas despite the significant passage of time since that report, and add additional recommendations:

- **Do not force people to share their supports in order to have a home.**
- **Do not force people to live together in order to have support.**



- Stop the placement and use of supported accommodation hostels and boarding houses for people with disability.
- Identify existing residents with disability who are inappropriately placed in private residential services.
- Provide for planning to identify decent and sustainable futures for each of these individuals: Encourage the government to review the educational system regarding the recruitment and training of staff/support workers.
- Regulate the industry to avoid the segregation, congregation, and abuse of vulnerable people with disability.
- Introduce penalties for breaches of human rights.
- Invest in raising the consciousness of the general public about the human rights of people with disability. Ensure these rights and the expectation of them to be respected and upheld is highly visible, and that there is no tolerance of abuse, coercion, neglect or violence.
- Ensure people with disability are supported to voice their rights, to speak up in regular schools alongside their peers, to choose where and how and with whom they live and to direct and train their supports staff as they wish.

Investment in individualised supports, services and housing for people with disability - it is an investment in humanity and community.

The advent of a Royal Commission to address and redress issues impacting people with disability has been long overdue.

People with disabilities, their families, friends, advocates, and supporters have stood in the front line of the daily battle against segregation, ableism, neglect, abuse and violence.

We have seen successive generations of reinvented language and rhetoric used to apply a cosmetic appeal to poor practice and devalued status. It is time to stop using bargain basement approaches to housing vulnerable people with disability, impervious disregard for human rights, complaints systems that only respond to catastrophic events like a 'clean-up crew' in aisle 6.

Now the time has come to take courage, to do right and make right.

