



COMMUNITY SAFEGUARDS COALITION

SUBMISSION TO

COMMUNITY AFFAIRS REFERENCES COMMITTEE

“The adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.”

A HUMAN RIGHTS PERSPECTIVE

...rights are guaranteed, maintained and strengthened through being used. That requires awareness, knowledge and determination.

Don MacKay
Chair of the United Nations Ad Hoc Committee on
The Rights of Persons with Disabilities

Background

I am pleased to present this Submission on behalf of Community Safeguards Coalition (CSC), Queensland. CSC is a coalition of people with disabilities, families/allies, advocacy agencies and individuals from non-government disability services who agree to the mission and purpose of CSC.

CSC is not a funded or incorporated body and does not have paid staff: the Chairperson role is voluntary. CSC engages in systems advocacy and does not undertake individual advocacy.

Its Mission is *to promote people with disabilities having the equal right, together with appropriate support and resources, to the same range of lifestyles as other people by safeguarding against legislation, policies and practices that limit or deny their fundamental rights.*

Preamble

CSC believes that no existing residential care arrangement is appropriate for ‘young people with severe physical, mental or intellectual disabilities’. We believe that **all** people with disabilities have the right to live in a home and community of their choice and be part of the social network of that community. Therefore, it is not intended to address the Terms of Reference, but rather to encourage the Committee to look at the situation from a human rights perspective.

CSC believes that having a place to call home and having access to the appropriate social support is a fundamental human right. This has been acknowledged in the *Convention on the Rights of Persons with Disabilities (2006) (CRPD)* and other instruments including the Productivity Commission’s recommendations in the Report to government, the National Disability Insurance Scheme (NDIS) and the *Queensland Disability Services Act (2006)* and the Amendment *Your Life Your Choice*.

Australia has ratified the Convention which, under international law, means all State governments now accept three levels of obligation in relation to the realisation of human rights:

- We must *respect* human rights
- We must *protect* human rights
- We must *fulfil* human rights

It is clear from the principles of the *CRPD* that many systems in our society have violated these rights. For example, the concept of specialist housing, group homes or large residential facilities deprives people with disability of the right to live where they wish and with whom they wish and be included in their communities.

Definition

The *CRPD* will have very little meaning for those people with disabilities who are segregated in institutions and will continue to live there unless government progressively takes concrete action to implement the *CRPD*. CSC concurs with the broader definition of institutions that the European Coalition for Community Living (ECCL)¹ uses:

An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. It is also any place in which people do not have, or are

¹ ECCL Focus Report 2009

not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.

Introduction

CSC has been advocating passionately to the Queensland Government for many years to cease the practice of what CSC calls ‘forced co-tenancy’. CSC is **not** against people living together, sharing accommodation – the crucial factor in this is that this arrangement needs to be a genuine choice for those people. CSC defines the features of ‘forced co-tenancy’ as:

- A person is denied the fundamental right to choose where and with whom they live
- A vacancy in a group home is provided as the only option in order to receive support
- The only solution to any shortfall in funding provided by the service or government is that the person must share their house with another person with a disability so that support can be shared
- Any block funding arrangement is delivered in ways that give individuals very little choice except to live in group situations, making them ineligible to access individual funds to move out of the group situation.

Purpose

The purpose of this Submission is to highlight the human rights dimension on accommodation for people with disabilities with particular reference to Article 19 of the CRPD. The CRPD provides a clear vision for the future – a future that ensures that people with disabilities have a right to live and participate in their community with the support they need and to ensure that any assistance provided to them should be based on their own choices and aspirations. Specifically, Article 19 states that services for people with disabilities should *support living and inclusion in the community* and aim to *prevent isolation or segregation from the community*. This cannot be achieved in institutions.

Current Status of housing/support in Queensland

There is a strong push for the implementation of housing guidelines that adopt the liveable design approach. This arises, in part, from the realisation that our current housing stock is not easily adapted to the changing needs of citizens as they age. It also recognises that, for people living with a disability, housing designed with their requirements in mind is fundamental to living as part of (rather than apart from) a community. With NDIS supporting inclusion, community participation and citizens with disabilities being able to live ‘ordinary lives’ the push for reforms in the housing sector becomes more urgent than ever.

There is a subset of this push, however, that seems to have veered off at a tangent from the core idea of inclusion and an ordinary life. This discussion seems to have a primary focus on the group of citizens labelled as having **complex needs**, such as your Inquiry indicates: ‘young people with severe physical, mental or intellectual disabilities’. It is when this group is discussed that ideals of an ‘ordinary life’ and community inclusion seem to get subverted by a more dominant discussion where the theme is building ‘facilities’ to house them. The former approach assumes that all citizens, including those with disabilities, need accommodation and there should be housing options for people to rent or buy what is needed and that sharing your home with others is by choice. The latter approach assumes that there is a group of citizens for whom this aspiration is not possible and they require something different to what other citizens might desire.

There is a long tradition of this thinking here in Australia and the proliferation of residential aged care services is a testament to this. Most contemporary aged care thinking critiques this simple solution and has shifted focus to what can be done to maintain aging citizens in their own home. At the same time however, in Queensland, there would appear to be a predominate idea of building more congregate care facilities for people living with a disability in spite of the overwhelming evidence that this does not lead to good outcomes for the individuals involved.

The Queensland Government, through the Department of Communities, Child Safety and Disability Services (Disability Services) is playing an increasing role in facilitating the establishment of these congregate care facilities. The 'bricks and mortar' solutions being built around the State under the guise of shared accommodation, innovative support and housing and so-called 'positive futures' environments underscore this trend.

The most insidious of all the initiatives is the emergence of the 1.042 Group Home service outlet within the outputs based funding approach. (Refer to <http://www.communities.qld.gov.au/resources/disability/key-projects/documents/disability-services-outputs-and-output-measures.pdf> for a full description of this and other output codes.) Through the use of this code (which describes the service being provided to an individual) the home that this person lives in is regarded as a group home where they occupy a 'place'. The Group Home service type has been in existence since reporting about funded services provided under the National Minimum Data Set began, however many service providers have never used it. They have opted instead for the more generic Inhome Support (1.06) service type which allows for reporting a variety of very flexible supports as hours. During the outputs based funding negotiations it was made very clear by Disability Services that individuals who receive high levels of funded support, particularly those who have 'sleepover' support, were to be recorded as receiving the 1.042 Service Type (Group Home) support and that this was non-negotiable.

The significance of this information in the context of the housing debate is quite profound. This process redefines a home, supplied by the Department of Housing and allocated to a citizen or citizens in receipt of Disability Services funding where there is a sleepover component, as a residential facility or 'group home' (this can pertain to one person living by themselves). The people living in this situation occupy a 'place'. CSC has not been able to determine exactly what the residents are actually renting from the Department of Housing. It appears that they are only renting the bedroom they sleep in. Why they are therefore paying the same rent as other Housing tenants who get a house remains unanswered. In this way, public housing has become the vehicle for establishing and expanding the number of group homes across the state where individuals occupy a place and when they leave that facility a vacancy is created.

The combination of block funding together with public housing being redefined as a group home service outlet have become mechanisms for vacancy management across the State. By pre-purchasing places in group homes through the use of block funding and using public housing (or shared accommodation funding) to establish the bricks and mortar, Disability Services can effectively control where people with complex support needs live and who they live with.

To further consolidate this approach there is a strong move from Disability Services to shift individual funding to block funding where individuals residing in these 1.042 facilities have individualised accommodation support funding. The Department also says that if they have block funded one of these houses then it is a condition of any person wishing to join this household that

they relinquish their individual funding (if they have been lucky enough to secure it at another time). In this way Disability Services and Department of Housing are making access to public housing for people with disabilities (particularly those with higher support needs) subject to conditions that are not imposed on other tenants. This situation also reinforces the original hypothesis that underscored the establishment of the Community Safeguards Coalition, that is: The dominant support model promoted by Disability Services for people with 'complex' support needs is co-tenancy and the pursuit of this objective eventually leads to 'forced' co-tenancy at the expense of genuine choice, creative service design and any real opportunity for the residents in these facilities to live an ordinary life. In addition, a person is not able to leave one of these facilities unless a 'vacancy' exists in another facility or they receive support funding from another source.

The link between the Group Home scenario just mentioned and the housing forum and other discussions is that it is extremely difficult to have a serious discussion about the future of housing design, its relationship to people with disabilities and its place in an inclusive society when we are unable to critique and discuss the existence of a very big elephant in the room: That elephant that shall not be named is the ever increasing proliferation of group homes and congregate care facilities across the State under the auspice of Disability Services, with the endorsement at times of the non-government sector, and the appropriation of Department of Housing homes for this purpose. Without this debate the NDIS will simply serve to consolidate these group living situations rather than become a mechanism for real transformation in the way we understand the support of people experiencing disability.

CSC Policy Position

CSC policy is to continue our advocacy efforts to ensure that the government and non-government sector fulfil their fundamental obligations under the CRPD and, in particular, to begin to take steps to implement Article 19 which enunciates the rights of people with disabilities to live independently and be included and participate in their community. CSC will continue to advocate for the right of people with disability to take control over the direction of their lives.

There are at least two elements CSC puts forward on this matter:

1. The use of public funds

CSC is concerned that government funds are being used to perpetuate the practice of congregation of people with disability implementing more and more 'bricks and mortar' solutions rather than using the funds to develop community based alternatives. It is significant to note that Article 5 of the CRPD *Equality and Non-Discrimination* specifically prohibits segregation on the basis of disability because this is inherently unequal and detrimental treatment and is therefore discriminatory².

2. The abuse of rights

CSC argues that one of the most consistent abuses of human rights experienced by people with disabilities is their congregation and segregation from the community in institutional environments. Article 19 states, in part:

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 are not obliged to live in a particular living arrangement.

² From a submission to the Productivity Commission by P. French

CSC takes the position that the current government practice does not align with Article 19 of CRPD. As well, current practice does not align with the *Queensland Disability Services Act (2006)* which states in part³

...people with a disability have the right to.... *participate actively in decisions affecting their lives, including the development of disability policies, programs and services*

And

...the conditions of everyday life of people with a disability are... *the same as, or as close as possible to, the conditions of everyday life valued by the general community*⁴.

Living in a group home or a large residential facility cannot in any way be construed as being '*the same as...the conditions ...valued by the general community*'.

Key Concerns

CSC has several concerns. Each of these concerns is significant in its own right. Together they represent a pattern of the abuse of rights. The continuing practice of congregation does not allow people with disabilities to take control of their own life decisions, does not give them genuine or authentic choice nor does it give them and/or their families any authority over their support arrangements. This practice and the current funding structure do not make this possible.

CSC puts forward the following reasons why current practice does not comply with the CRPD, the NDIS and the *Act*:

1. There is consistent anecdotal evidence from individuals where they have been placed in group arrangements (see attached document "Journeys to a Better Life"). This includes stories from individuals who live in their own privately rented or privately owned homes where they have been under pressure to accept another person with a disability into their home in order to receive additional funding for their changing needs.
2. On-going financial support from government to build large residential facilities and group housing (even though the physical environment of such facilities may be of good 'quality') implies that there is no commitment to address the fact that segregation and congregation is unequal and detrimental to people with disabilities in that it does not represent the *conditions of everyday life valued by the general community*.
3. Funding the non-government sector to construct institutions and be both the landlord and service provider constitutes a potential risk of conflict of interest. There needs to be a separation of these functions, but one which would safeguard people's rights as tenants and give them security of tenure and enable them to call where they live their **home**.
4. The 'choice' for people to live *where and with whom* they wish and not be *obliged in live in a particular living arrangement* is the exact opposite of what is actually happening in practice.

³ Part 2 Division 1(2)(d)

⁴ Part 2 Division 2,23(a)

Government could just as easily provide funded services to people in the community and under Article 19 of the CRPD have a fundamental obligation to do so.

5. It is often said that people ‘choose’ to live in group settings. CSC challenges this statement on the basis of who is making this decision. People with disabilities have been, and continue to be, obliged to live in these settings in order to receive support services. CSC does not believe that this situation constitutes the choice of the individual; rather it is the government and non-government sector who persist with imposing segregated and congregated support options on people with disability. Families are frequently told that a vacancy in a group home is the only option available for their son/daughter with a disability in order to receive support. This does not align with Article 5 or Article 19 of the CRPD nor with the principles of the NDIS.
6. Government rhetoric would suggest that people do have choice about their living arrangements. However, no real options are presented – certainly no valued options that meet the principles of the CRPD and the NDIS. In practice, there is no attempt to provide real, genuine alternatives to this ‘model’.
7. There appears to be an assumption that all of the responses to people’s needs will be ‘paid’ responses sourced from disability services. This does not allow for creative ideas/flexibility and the linking to informal supports available in the community in designing support for people with disability. The linking to informal supports in the community is currently very superficial in that people may simply be referred to organisations in the community with no or little support or follow up. This is not an approach that encourages sustainability. Reliance on informal support being provided by the family, while usually given freely, is often not appropriate to a particular situation.
8. The structure of the funding for disability services puts the majority of the decision making in the hands of public servants rather than the recipients of support and beneficiaries of the funding. This is in direct contrast to the *Act* which states people with a disability have the right to.... *participate actively in decisions affecting their lives, including the development of disability policies, programs and services.*

Further, there is evidence that points to the harmful impacts of congregating and segregating people with disabilities. People with disabilities in these environments:

- i. Are less likely to have support that is individualised and so therefore are less likely to have their individual needs met
- ii. Spend more time waiting for assistance while staff attend to the needs of others
- iii. Are more likely to be exposed to negative role models than positive role models because they are grouped with others who also have impairments and lowered competencies.
- iv. Are less likely to develop skills because staff are more likely to target any support to ‘the lowest common denominator’ and so therefore operate with low expectations about what is possible in individual’s lives
- v. Are less likely to become independent as they live in a dependency-making environment where staff interpret their role as ‘caring’ for the ‘disabled’
- vi. Have less involvement with community life
- vii. Have less connection to their families
- viii. Have more paid people in their lives than unpaid people

- ix. Have more people who are in and out of their lives due to staff turnover and so develop difficulties with trust, security and stability
- x. Are more likely to be stigmatised as ‘belonging with their own kind’ and so not welcomed by their local neighbourhood

It can be seen that this shows that there are harmful impacts on the competence, status and reputation of people with disabilities who are subjected to congregated and segregated models.

Some steps towards implementation of the CRPD

Keeping in mind that governments are obliged to take steps towards making the transition to the Articles of the CRPD, CSC recommends the following:

- Place an immediate moratorium on all construction of buildings which congregate and segregate people with disability from the community
- Begin the process of planning for a future where people with disabilities have security of tenure and are able to call where they live their ‘home’. This would involve a gradual move away from situations where one agency is both landlord and service provider. In the interim clear safeguards/guidelines need to be developed so that of people’s rights are protected.
- Restore the policy and practice of individualised funding arrangements that are portable within state borders and across state borders
- Uphold the natural authority and right of people with disabilities and their families to influence the direction of their lives
- Any plan that is developed should be in conjunction with the person with a disability and meet the person’s needs, wishes and aspirations and be open to review and change over time
- Begin planning around the process of transition to community based living. This should be based on the general principles of the CRPD (Article 3) which includes ‘*respect for inherent dignity, the freedom to make one’s own choices, independence and full and effective participation and inclusion in society*’. The transition process should be monitored by the collection of data which indicates the rate of progress.
- Involve people with disability in all stages of policy development and the implementation process of Article 19
- Begin training of staff on the rights set out in the CRPD so that the assistance they provide aligns with those rights.

Conclusion

Past history and the current lived experience of people with disability and their families would show that the congregation and segregation of people from their communities is the path to the degradation of human dignity. All Australian governments have a very serious obligation to *respect, protect and fulfil* the rights of people with disability. Changing these models of care is a challenge for all

stakeholders involved. However, the status quo cannot be maintained. We must all rise to this challenge.

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