

Submission

**SENATE COMMUNITY AFFAIRS REFERENCE
COMMITTEE:**

**Inquiry into planning options and services for
people ageing with a disability**

May 2010



people with disability

People with Disability Australia Incorporated

This submission has been compiled with the assistance of Zoe Brissett who undertook a student placement at PWD for the completion of a professional placement subject as part of a Bachelor of Arts in Communication (Social Inquiry) at the University of Technology Sydney.

Contact details:

Sonya Price-Kelly
Advocacy Project Manager
People with Disability Australia Incorporated (PWD)
PO Box 666 Strawberry Hills NSW 2012
Tel: 02 9370 3100
Fax: 02 9318 1372

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1. People with Disability Australia (PWD)

1.1 *About us*

PWD is a national disability rights and advocacy organisation. We operate from an international human rights framework and provide a number of activities, which include individual, group and systemic advocacy, consumer protection, information, education and training.

Individuals with disability and organisations of people with disability are our primary voting membership. We also have a large associate membership of people and organisations committed to the disability rights movement.

We were founded in 1980, in the lead up to the International Year of Disabled Persons (1981), to provide people with disability with a voice of our own. We have a fundamental commitment to self-help and self-representation for people with disability, by people with disability.

We have a cross-disability focus – membership is open to people with all types of disability. Our services are also available to people with all types of disability and their associates.

We are governed by a board of directors, drawn from across Australia, all of whom are people with disability. We employ a professional staff to manage the organisation and operate our various projects. A majority of our staff are also people with disability.

We are part of an international network of disabled peoples' organisations through Disabled Peoples International.

We have a vision of a socially just, accessible, and inclusive community, in which the human rights, citizenship, contribution, potential and diversity of all people with disability are recognised, respected and celebrated.

We believe that people with disability, irrespective of our age, gender, cultural or linguistic background, religious beliefs, geographic location, sexuality, or the nature, origin, or degree of our disability:

- Have a right to life, and to bodily integrity
- Are entitled to a decent standard of living, an adequate income, and to lead active and satisfying lives
- Are people first, with human, legal, and service user rights that must be recognised and respected

- Are entitled to the full enjoyment of our citizenship rights and responsibilities
- Are entitled to live free from prejudice, discrimination and vilification
- Are entitled to social support and adjustments as a right, and not as the result of pity, charity or the exercise of social control
- Contribute substantially to the intellectual, cultural, economic and social diversity and well-being of our community
- Possess many skills and abilities, and have enormous potential for life-long growth and development
- Are entitled to live in, and be a part of, the diversity of the community
- Have the right to participate in the formulation of those policies and programs that affect our lives
- Must be empowered to exercise our rights and responsibilities, without fear of retribution.
- Have the right to define the policies and programs that affect our lives
- Ought to be empowered to exercise our rights and responsibilities, without fear of retribution

1.2 Our human rights expertise¹

PWD has extensive human rights expertise, particularly in relation to people with disability. Our work – advocacy, training, information and consumer protection – is all underpinned by human rights. We recognise people with disability as right-bearers and interpret their needs and concerns in terms of human rights. This affects the work we do as well as how we do our work.

PWD has Special Consultative Status with the Economic and Social Council of the United Nations (UN), and participates in many UN Intergovernmental meetings and non-government forums at both the Asia Pacific and international levels.

PWD has extensive knowledge and understanding of the UN Convention on the Rights of Persons with Disabilities (CRPD). During the CRPD's development, PWD participated in several of the UN Ad Hoc Committee meetings, and undertook two consultative processes with people with disability throughout Australia on the CRPD. PWD made over 32 interventions to the Ad Hoc Committee including the last meeting where

¹ PWD 2009 *Submission: National Human Rights Consultation*, p.6-7

the draft text was agreed. The final text of CRPD, in many aspects reflects the content of the consultation reports and interventions of PWD.

The involvement of PWD, along with other disabled peoples organisations from around the world, marked an important shift in the development of United Nations instruments. This was the first time that the people directly affected were instrumental in drafting a thematic convention. We believe that this leadership role by people with disability must continue throughout the implementation of CRPD rights.

We acknowledge and fully support the Australia Government's ratification of the CRPD and all endeavors to ensure its implementation.

1.3 About this submission

This submission reflects the lived experience of people with disability. Using a range of case studies compiled by PWD, we identify current systemic issues that inhibit the rights of people with disability to access planning and funding options and services, which ensure their continued quality of life as they age.

This submission is provided from the perspectives of people with disability and aims to reflect their unique experiences of the disability services system. We provide this information with the view to informing the Australian Government's Senate Inquiry of gaps and barriers in planning and funding options, and service, for all people with disability, not just those living at home with ageing parents or carers.

PWD believes people with disability must be afforded the opportunity to make choices about the services and supports they require and not limited to being prioritized once they reach a crisis point. Nor should these opportunities be limited to the one time a person with disability leaves their family home, but rather provided on an ongoing basis as their needs, circumstances and lives evolve.

It is also important from a planning perspective that people with disability and their families are not left in a situation of being forced or obliged to accept a service simply on account of there being no other choice available. The continuing unmet need for appropriate housing and support, and the lack of alternative options available, can often be masked by the equally strong need of people with disability and their families to resolve a crisis situation. An effective planning and service system is one which is not crisis driven but respects, protects and fulfills the human rights of people with disability.

2. Snapshot of Australian People with Disability

- Some form of disability affects about one in five Australians, this represents almost 20 per cent or 3.96 million Australians. This number is increasing, particularly as the population ages².
- People with a disability are less likely to have completed a higher educational qualification than those without a disability³.
- Fewer people with disability participate in the workforce than those without disability. More people with disability are unemployed than those without disability⁴. When employed, people with disability earn lower wages, on average, than workers without disability⁵.
- People with disability have higher rates of health problems. For example, health problems experienced by people with intellectual disability are often not diagnosed or appropriately treated. Life expectancy is reduced by up to 20 years⁶.
- As a group, women with disability in Australia experience many of the now recognised markers of social exclusion – socio-economic disadvantage, social isolation, multiple forms of discrimination, poor access to services, poor housing, inadequate health care, and denial of opportunities to contribute to and participate actively in society.⁷
- People with disability are three times more likely to be a victim of violent crime. Fifty to ninety percent of women with intellectual disability are likely to be sexually assaulted in their lifetime. There are high rates of assault of people with disability by service providers. The sexual assault of a person with disability is less likely acted on⁸.
- Recent World Bank estimates indicate that people with disability may account for as many as one in five of the world's poorest people⁹.

² Australian Bureau of Statistics (ABS) (2003) *Disability, Ageing and Carers Summary of Findings*. Another 20 per cent of Australians (4.15 million) have a long-term health condition that does not restrict their everyday activities.

³ ABS, 2003, *Disability, Ageing and Carers Summary of Findings*

⁴ ABS, 2003, *Disability, Ageing and Carers Summary of Findings*

⁵ ABS, 2003, *Disability, Ageing and Carers Summary of Findings*

⁶ National and NSW Council for Intellectual Disability and Australian Association of Developmental Disability Medicine (2009), *Position Statement on the health of people with intellectual disabilities*.

⁷ Women with Disability Australia (WWDA) (2009) *Submission to the National Human Rights Consultation*.

⁸ Sexual Assault in Disability and Aged Care (SADA) (2007), *Sexual Assault in Disability and Aged Care, Prevention and Response for Residential Services. National and Regional Consultations. Findings and Recommendations* www.sadaproject.org.au

⁹ Ann Elwan (1999) *Poverty and Disability; a background paper for the World Development Report*, World Bank, October 1999. www.addc.org.au

- Parents with disability, particularly those with intellectual disability and psychosocial disability are significantly over represented in the child protection system¹⁰.
- Life expectancy for people with disability living in residential care is 54 years¹¹. This on average is 27 years less than the average Australian.

¹⁰ Legislative Council Standing Committee on Social Issues, (December 2002) *Care and Support – Final Report on Child Protection Services*, p. 144; Legislative Council Standing Committee on Social Issues, (November 2002) *Making it Happen – Final Report on Disability Services*, p. 126

¹¹ NSW Ombudsman 2007, *Report of Reviewable Deaths 2007: Volume 1 Deaths of people with disabilities in care*, p 6. at www.ombo.nsw.gov.au

3. Human Rights Framework

3.1 *What are human rights*¹²

Human rights are fundamental rights and freedoms that are intrinsic to every person by virtue of their status as a human being. In this sense, human rights are said to be 'inalienable' because they can neither be given to a person, nor can they be taken away from them.

Human rights are universal norms in the sense that they are recognised by the international community as intrinsic to every person irrespective of their national, cultural, political, geographic, social, religious or temporal context, and any other personal characteristics, such as gender, race, sexuality, age, or disability. They are norms applicable to all persons, at all times, in all societies.

The ultimate source of all human rights is the dignity of the person. Human dignity refers to the inherent worth, uniqueness, equality and autonomy of all human beings, and our ability to realize our potential. Dignity might also be conceptualised as the end goal of human rights. Human rights express the conditions necessary for human dignity to be fully realised.

3.2 *Human Rights in the context of this Inquiry*

In the context of this Inquiry, PWD uses a human rights framework which reflects the CRPD. Given the Australian Government's ratification of, and therefore commitment to, the implementation of the CRPD, it is relevant to each of the issues surrounding this Inquiry. Analysis of key issues reveal gross human rights violations that underpin systemic inadequacies that inhibit a person with disability's right to planning options and services.

'More and more people with disability are increasingly living in the community and not in institutions and are more likely to outlive their parents'¹³. Yet many people with disability live in a state of poverty in every aspect of their lives, because Governments and bureaucracies fail to ensure their rights are respected, protected and fulfilled.

The CRPD was developed in an effort to overcome the 'invisibility' of persons with disability in international human rights law and practice. Although major human rights covenants apply to persons with disability on an equal basis with others, these treaties have done little in practice to protect, promote and fulfil the rights of persons with disability. In part, this is because these treaties, both in their formulation and in their

¹² PWD 2009 *Submission: Human Rights Consultation*, p.13-18

implementation, have not penetrated to many of the specific forms of human rights violation persons with disability experience.

Human rights in their traditional formulation have often failed to penetrate to those human right violations most likely to be, or uniquely, experienced by persons with disability. It was for this reason that the CRPD was developed and is therefore, an essential supplement and interpretative aid for this Inquiry and all recommendations arising from it.

¹³ Boyce, Sue 2007 *Inaugural Speech*, Parliament of Australia: Senate, Canberra 12th June 2007

4. Key Issues for the Inquiry

4.1 Abuse and Neglect:

Licensed boarding houses in NSW are private for profit accommodation facilities, usually operating as institutional congregate models of accommodation. They are regulated under the NSW *Youth and Community Services Act 1973* (similar entities also referred to as rooming houses exist in other States).

In 2006, the NSW Ombudsman observed¹⁴:

The residents of licensed boarding houses are an extremely vulnerable group of people. They usually live in these facilities because they have no real alternatives. They often rely solely on a pension for income, which can be completely spent paying the boarding house proprietor for their board and lodging. Many have physical and/or intellectual disabilities with a proportion also suffering mental illness. Many are elderly.

The provision of decent accommodation and appropriate services is not always an easy job. The needs among a group of residents can be highly complex and varied. What is true for the majority is that they are dependent on the support and advocacy, if not of family members, of community or departmental workers to ensure their best interests are served.

... in this situation, it is absolutely essential that appropriate standards are set governing the care provided and that those standards are monitored and enforced effectively'

In NSW, some 830 people with disability currently live in licensed boarding houses with most residents aged over 42 years (86 per cent)¹⁵. It is one of the few accommodation service options, where vacancies exist, for people with disability who require supervision and support as they age¹⁶. It is however, as a result of a lack of other suitable, and better, alternative options for accommodation that many people with disability end up living in licensed boarding houses.

The following case study outlines the dire circumstances of a man with disability who was a resident of a licensed boarding house in NSW.

A man with a disability is admitted to hospital for treatment of pneumonia in 2008. Hospital staff raised concerns about his hygiene and nutrition.

¹⁴ NSW Ombudsman (2006), *DADHC: Monitoring Standards in boarding houses. A special report to Parliament under s 31 of the Ombudsman Act 1974*, pg 12.

¹⁵ Edwards. R & Fisher K (2010) *Active Linking Initiative (ALI) Evaluation Final Report*, Social Policy Research Centre, UNSW.

¹⁶ The NSW Licensed Boarding House Sector provides 930 beds with an occupancy rate of 89% - Edwards et al (2010)

They noted that the man is at a high risk of malnutrition. They had to use peroxide solution to remove the dirt from his skin and nails.

Following his discharge from hospital, we understand that this man returned to the same licensed boarding house responsible for his care and presentation to hospital.

Three months later, the man was found dead in his room by a staff member at the boarding house. He had been dead for at least twelve hours and had blood stains on his fingers, head and clothes. There was also evidence of blood stains on the walls and body tissue was found on two exposed nails on the back of the door to the room. The police officers who attended the scene reported that the man's bedclothes were covered with cobwebs and dust, faeces and used toilet paper were strewn around the room. There were also several unopened sandwich packages in the room.

When an independent monitoring body raised these issues with the then Department of Ageing, Disability and Home Care (DADHC and now known as Human Services, Ageing Disability and Home Care (ADHC)) responsible for the regulations and monitoring of licensed boarding houses, their advice was:

- that initiatives were in place to improve the support provided to residents at the boarding house to monitor compliance with the license condition¹⁷;*
- that they were seeking legal advice in relation to the boarding house's ongoing failure to comply with many of the conditions of their licence;*
- that they received legal advice that they did not have the power to enforce the licence conditions that apply to the health, wellbeing and cleanliness of residents and the facility;*
- that they were considering their options including prosecution and/or revocation of the licence, but given the unenforceability of conditions relevant to the man's death, any action taken with regard to prosecution or revocation of the licence had to focus on enforceable requirements such as the licensee's failure to comply with a fire safety order issued by the local council (NSW Ombudsman New South Wales Ombudsman Annual Report 2008-2009)*

¹⁷ Neither the Independent monitoring body, nor DADHC, specified what these initiatives were.

Relevance to Inquiry:

This case study demonstrates significant breaches of CRPD. It exemplifies the ongoing individual and systemic abuse (failure to recognise, provide or attempt to provide adequate or appropriate services, including services that are appropriate to that person's age, gender, culture, needs or preferences¹⁸) and neglect of people with disability residing in licensed boarding houses. Whilst this is a particularly brutal example, it is a well documented fact that people with disability experience abuse and violence at a greater rate than their non-disabled peers. For example:

- At least 85% of women with disability experience domestic violence in comparison to 25-50% of the general population.¹⁹
- 50-90% of women with intellectual disability are likely to be assaulted in their lifetime.²⁰

Furthermore, particular kinds of accommodation settings increase a person's vulnerability²¹:

- 'residents [of licensed boarding houses] are at a significant increased risk of abuse at the hands of staff and co-residents as a result of social isolation, inadequate monitoring systems and a lack of tenancy and other rights afforded them'.
- Violence against persons with cognitive impairment is reported to be particularly associated with institutional and other congregate supported living environments, including group homes. Institutions are characterised by an extreme power imbalance between staff and residents. Staff have access to residents' personal space, their body, and have the potential to control every aspect of their lives, including their sexuality, how and when they sleep, eat, wash, communicate, exercise, and rest.

¹⁸ Australian Government Department of Families, Housing, Community Services and Indigenous Affairs National Disability, Abuse and Neglect Hotline Website accessed at http://www.disabilityhotline.org/abuse.html#systemic_abuse

¹⁹ Waxman, B (1991) *Protecting reproductive health and choice*. Western Journal of Medicine, Rehabilitation Medicine – Adding Life to Years, Special Issue 154, p.629

²⁰ Blyth, J and Kelly, L. responding to sexual assault in disability and aged care settings: the SADA project. Presentation at the 2nd National ACROD Ageing and Disability Conference, Hobart, 19-20 July 2005.

²¹ French, Dardel and Price-Kelly (2009) Unpublished *Rights Denied: Towards a national policy agenda out abuse, neglect and exploitation of persons with cognitive impairment*, UNSW Disability Studies and Research Institute

This case study conveys clear evidence of human rights violations. As this man was discharged from hospital back to the licensed boarding house responsible for his initial presentation, there was foreseeable risk of further abuse and neglect, yet it is unclear whether any attempts were made to avoid this situation. This clearly diminished this man's universal right to live in freedom from violence, abuse and exploitation let alone his right to services and supports which promote his quality of life.

The case study highlights the inadequate provision of care and support for people with disability living in licensed boarding houses in NSW, especially in relation to the hospital discharge planning, case management and options for alternative accommodation and support services.

Current planning options for relocation of residents from licensed boarding houses are completely inadequate. The most common scenario that triggers relocation options for people with disability in boarding houses is when the operator gives notice of the intended closure of the boarding house. In many of these cases the planning and transition processes for people with disability to permanent alternative accommodation has been long and drawn out. Occasionally, it arises from a change in the person's needs and recognition that these can no longer be met in the licensed boarding house. However, as is clear from the case study above this is not always guaranteed. Even more rarely is such a process triggered by individual choice. Even in such a case, under current guidelines, individual choice would not be sufficient to prioritise a person's access to planning options for alternative accommodation and support.

The case study also demonstrates the inadequate regulations and monitoring mechanisms in place within the licensed sector to ensure quality of life outcomes for people with disability. The NSW Government's complicit involvement in supporting a sector which places people with disability at foreseeable risk of harm is unacceptable and must be questioned.

PWD has a long history in advocating for improved standards and regulation of licensed boarding houses, closure of institutions generally and seeking individualised models of funding and support for all people with disability. This advocacy is based on a number of key factors:

- congregate models of accommodation such as those provided by licensed boarding houses promote 'dependency through their institutional approaches to care by limiting all opportunities for

residents to self direct their daily routines and activities'²². There are few opportunities and facilities for resident privacy and dignity. Residents lack any legal rights of tenancy, leaving them with no safe mechanisms by which they can seek redress or make complaints without fear of retribution and homelessness. There is limited staff supervision, particularly at night. Staff lack the training and qualifications needed to care for people with disability and few opportunities exist for their professional development.

PWD strongly advocates that all people with disability have the right to a quality of life which is commensurate with their non-disabled peers and that is supported by individualised funding mechanisms which facilitate choice and control over their lives.

- People with disability living in licensed boarding houses are amongst the most marginalised and disempowered groups of people in our community. They lack an awareness of rights and self advocacy skills. Many have experienced lifelong institutionalisation through disability services or as a consumer of mental health services where their rights may have been considered secondary to considerations of treatment and 'their own good'.

People with disability must be educated in their rights as well as service system mechanisms such as planning options, to ensure they are afforded the opportunity to make decisions about their lives.

- Regulation and standards of care in licensed boarding houses in NSW do not reflect contemporary disability service practice or human rights standards.

The NSW Ombudsman's Inquiry into DADHC's capacity to monitor and enforce licence conditions (2006) highlights that DADHC have been aware of legal advice since 1999, suggesting that licence conditions imposed on licensed boarding houses may be beyond the power of the relevant legislation to enforce. It also highlighted DADHC's failure to implement and activate an effective monitoring system, which aimed to ensure that contemporary, individual care was provided to residents. The result of this is that DADHC is at a loss to enforce acceptable standards or seek redress for the person with disability, as highlighted in the case study above, leaving many residents in an unstable and unsafe living environment.

²² Epstein-Frisch, Belinda (2009) *Deinstitutionalisation: A Review of Literature*, Family Advocacy: Australia, p.8-9

On May 14th 2010, the NSW Government published the *Youth and Community Services Amendment (Obligation of Licensees) Regulation 2010*. PWD had hoped that this would address the long term problems regarding enforceability of licence conditions and create lasting systemic change across the licensed boarding house sector. However, as a result of the overarching *Youth and Community Services Regulation 2005*, which has been amended to include the *Obligation of Licensees*, being due for automatic repeal under the *Subordinate Legislation Act 1989* on 1st of September 2010, the net result of this action is 12 weeks of guaranteed enforceability and protection for people with disability living in licensed boarding houses.

What occurs after this time is only speculative and will be determined by a regulatory impact statement and consultation process that is yet to be held²³. Clearly though, people with disability in licensed boarding houses must once again fight for the recognition of their basic human rights.

Finally and perhaps the most frustrating issue highlighted by this case study is that the death of this man was preventable. Had there been higher standards of care, improved monitoring and the enforceability of licence conditions relevant to promoting the health, safety and wellbeing of people with disabilities and better planning and service co-ordination to ensure the relocation of residents at risk of abuse, in crisis or simply as a matter of choice, this man may have lived to experience a far better quality of life than the one he had prior to his death.

4.2 Inflexible Service Systems

The following case study outlines the circumstances of a man with paraplegia who resided in an institutionalised rehabilitation centre in NSW. It is provided with the intention of showing the inconsistency with which planning options for people with disability seeking alternative accommodation are applied and how inflexible service systems can limit their quality of life.

After finishing rehabilitation, a man with disability applied for ADHC's Attendant Care Package so that he may have a flexible and individualised package of support to assist him in his activities of daily living.

ADHC notified him of their approval of his application however as he was in transition at the rehabilitation centre and thus had no other

²³ ADHC Licensed Boarding House Operators Fact Sheet – Changes to Boarding House Regulation, May 2010.

accommodation, he was not in a position to immediately take up the Attendant Care Package.

Once he had found accommodation he notified ADHC that he was now ready to use his individualised package of support, only to be advised that there were no longer sufficient funds in the Attendant Care Program to meet his application.

As an alternative, they offered him services from a different program known as the High Needs Pool, a service provided by Home Care Service of NSW.

In using the High Needs Pool program however, this man would no longer receive important set up funds which he intended to use for the purchase of white goods, equipment, and some forms of home modification required in his new accommodation. He also lost the choice and control over choosing the agency and staff he would have assist him in this daily living.

He would now have to pay a fee for the services he would receive through the High Needs Pool and would have to fight to receive the level of care that he would otherwise be receiving with the Attendant Care Package as Home Care were known to continually push clients to reduce their hours of care due to high service demands and limited resources.

Relevance to the Inquiry

This case study highlights how poor program co-ordination, funding limitations and inflexible service systems can adversely affect people with disability's human rights, including the right to individual autonomy and independence, full and effective participation and to not be obliged to accept services that are not of their choice.

PWD understands that this case study is not an uncommon experience. But certainly an experience which leaves people with disability frustrated and in receipt of services which are unable to meet their needs as they age. Whilst it is understood that where there is limited funding, systems of prioritization will occur, it is inconceivable that people with disability may be accepted into a program but later declined due to a lack of funds. This case study is a clear example of service planning and program co-ordination failure.

The case study also highlights how inflexible service systems can unnecessarily limit both the capacity of people with disability and their quality of life. Whilst the Attendant Care Package (ACP) and High Needs Pool (HNP) are two programs that are similar in that they provide funding

for in-home personal care services for people with physical disability, they are distinctly different in their service delivery methods.

The most important distinction is that the ACP provides a portable, flexible and individualised package of support for people with physical disability who need personal help to complete activities of daily living, giving them control over the service they receive. The HNP on the other hand does not. It operates from a perspective that the person with disability is a 'client' or 'service recipient' who must fit within the pre-defined program of care provided.

The ACP is one of the few examples of individualized funding within NSW, due to the funding models it offers, including²⁴:

- *Employer Model* - Funds are paid to an approved service provider who employs the attendant carers and is accountable to DADHC for expenditure and service quality. Clients can be involved in the selection, rostering and management of attendant carers to different degrees;
- *Cooperative Model* - Funds are paid to an approved service provider who manages the funds, provides administrative support and is accountable to DADHC for expenditure and service quality. Clients are the employers of attendant carers and are responsible for managing them; and
- *Direct Funding Model* - Funds are paid directly to the client who is responsible for purchasing approved services and managing their care. Clients take on the full employer/service provider responsibility and are accountable to DADHC for expenditure and service quality under a Funding Agreement.

PWD supports the ACP funding models, as they allow a person with disability the capacity for freedom and choice when it comes to planning and directing the services they require. This is one of the key reasons for its high demand by people with physical disability.

Greater flexibility in the use of funding resources to designated client groups and, a focus on the individual needs as opposed to predefined program guidelines, would help to avoid situations such as this one, especially when resources are so limited.

Trends in disability service funding highlighted in a recent Productivity

²⁴ DADHC 2010 *Attendant Care Package*, viewed May 2010 at <http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Attendant+Care.htm>

Commission Research Paper in preparation for its public inquiry into a long-term disability care and support scheme also clearly show that greater funding needs to be allocated toward meeting the needs of all people with disability. It also, and perhaps most importantly, highlights changes required to the way need is assessed.

Statistics show that in 2006-07, governments spent \$4.3 billion in disability services, with 74.2% of the spending originating from State and Territory governments and 25.8 % from the Commonwealth²⁵. States provide the majority of funding and services such as accommodation, however, only 29% of the estimated potential population of people with disability (profound or severe) accessed them²⁶.

Arguably, where funding mechanisms are limited to people who have severe or profound disability, the significant needs of the remaining 71% of Australian's with disability is overlooked. PWD strongly advocates that definitions of 'severe' or 'profound' no longer hold legitimacy or real meaning. As it is now ten years since the International Classification of Functioning, Disability and Health (ICF) was produced, an understanding of disability for the purposes of eligibility and entitlement must surely take account of a person's activity limitations, participation restrictions, and the particular environmental factors that in total lead to an understanding of what supports need to be put in place. The lack of reference to the ICF in the NDIS framework or in funding and program framework determining the access that people with disability have to the critical supports they require to assist them, is astonishing, and needs redress.²⁷

4.3 No Individual Options:

The following case study outlines the circumstances of a 19 year old woman with intellectual disability and cerebral palsy who resides in respite care within NSW.

The reasons for the inclusion of this case study are to two fold. Firstly, to demonstrate to the Inquiry that there are many reasons why people with disability need access to effective planning options for alternative accommodation and supports when leaving the family home, many of which, have little to do with ageing. Secondly, to reiterate the point that people with disability must be afforded the opportunity to make choices

²⁵ Productivity Commission 2008, *Trends in Aged Care Services: Some Implications*, Productivity Commission Research Paper

²⁶ Productivity Commission 2008, *Trends in Aged Care Services: Some Implications*, Productivity Commission Research Paper

²⁷ Bleasdale M (2010) NDIS: In support of an inclusive campaign, *Link Disability Magazine*, Volume 10, Issue 2 (forthcoming)

about the services and supports they require and not limited to being prioritized once they reach a crisis point. Nor should these opportunities be limited to the one time a person with disability leaves their family home, but rather provided on an ongoing basis as their needs, circumstances and lives evolve.

A young woman with disability went to into respite care for a short term stay. When her respite placement was over she refused to return home to her mother's care because she was being physically abused there.

Following this she was repeatedly moved from one respite centre to another. This occurred three times over a period of five months. The frequent changes in her living arrangements have caused unneeded stress and anxiety as her environment, co-residents and staff were always changing. Staff were not always been trained in how to attend to her individual needs. This has resulted in unsafe practices and put her at further risk of harm.

The disability service provider responsible for her care eventually found her a permanent place to live however she did not have any say in this process even though she is able to communicate her needs, wants and preferences through the use of a communication aid.

Relevance to Inquiry:

This case study highlights the difficulties experienced by people with disability in having a say in the services and supports that they require and in having the same right as their non-disabled peers to have control over their lives. Practices in disability services which perpetuate these difficulties fail to recognise strong messages and evidence of the capability, diversity and contribution of people with disability.

It also represents a violation of CRPD:

- General obligations (Article 4) - to ensure all human rights and fundamental freedoms of persons with disability are promoted, protected and fulfilled by laws, policies and programs.
- Accessibility (Article 9) - necessary assistance is available to persons with disability to ensure their access to information, that barriers and obstacles to accessibility of services, processes and procedures are identified and eliminated, and standards and guidelines are in place and enforced to ensure the accessibility of such.

- Equal recognition before the law (Article 12) - persons with disability must receive any support they may require to exercise their legal capacity and express their will, needs and desires.
- Living independently and being included in the community (Article 19) - persons with disability are able to choose their own residence on an equal basis with others and are not obliged to live in any particular living arrangement.
- Freedom of expression and opinion and access to information (Article 21) - Persons with disability enjoy freedom of expression, opinion, to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice.

PWD strongly advocates that people with disability should have control and direction over how they are supported to live their lives. Opportunities should be afforded to ensure their personal aspirations as well as meaningful engagement in the social, cultural, political and economic life of their communities.

With the aim to achieve this PWD fully supports the introduction of a NDIS as currently being considered by the Australian Government²⁸. PWD recommends that an NDIS, which delivers individualised funding options is relevant to this Inquiry, as it is a way for people with disability to have control over planning and services, ensures their individual needs are met and affords a continued quality of life regardless of age and changing circumstances. PWD believes the NDIS should model the CRPD throughout its implementation and therefore be open to all people with disability as an entitlement.

PWD believes that funding generally, but specifically in regard to the NDIS, be directly allocated to the individual (or their nominated representative) so that people with disability are able to purchase supports and services of their choice. This enables people with disability to determine how supports can best be delivered to meet their individual needs. PWD strongly supports services that are purchased to provide support, and encourages service providers to be flexible and responsive in their provision of services.

As highlighted by a number of the case studies provided in this submission, individualised funding options ensure the dynamics of power between service providers and service recipients are repositioned. This

²⁸ PWD 2010 Campaign for National Disability Insurance Scheme gathers momentum, *E-Bulletin 60* April 2010

helps to avoid barriers which currently inhibit the choice and needs of people with disability.

4.4 Unmet Need and Compromise of Services

The Australian Institute of Health and Welfare²⁹ reported that in 2006-07, there were 6,613 residents aged less than 65 years accommodated in aged care services nationally. This represents 4% of all residents in aged care services. This pattern was similar across the States and Territories, with the exception of the Northern Territory, where the proportion of residents aged less than 65 years was considerably higher at 13%.

The following case study outlines the circumstances of a middle aged woman with Down Syndrome who resides in an aged care facility within NSW.

At the age of 28 this young woman moved into a nursing home because her mother, who was her primary caregiver, required nursing home care on account of her own failing health. The young woman herself did not require support for any medically related needs, but her mother did. When the mother passed away this woman remained living in the nursing home.

After living in this aged care nursing home for seventeen years, the woman (now aged 45) was put forward for the Young Person in Residential Aged Care (YPIRAC) program. A program introduced by the Commonwealth Government to address the issue of younger people with a disability inappropriately living in, or at risk of entering, residential aged care.

On assessment, she was deemed ineligible for YPIRAC funding because of her disability type, and so she was referred back to ADHC generally because she was 'their responsibility'. She continues to receive advocacy support to resolve the situation of her inappropriate placement in an aged care nursing home. This, includes being referred to a regional accommodation vacancy waiting list however, alternative suitable accommodation has yet to be found.

Relevance to Inquiry:

As background, the YPIRAC program is managed by ADHC, under the terms of a Bilateral Agreement with the Commonwealth Government.³⁰

²⁹ Australian Institute of Health and Welfare 2008. *Residential aged care in Australia 2006–07: a statistical overview*. Aged care statistics series 26. Cat. no. AGE 56. Canberra: AIHW

³⁰ DADHC 2010 *NSW Younger People in Residential Aged Care Program*, viewed 19th May at <http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/NSW+Younger+People+in+Residential+Aged+Care+Program.htm>

This initiative is a central strategy of *Stronger Together: A new direction for disability services in NSW 2006 - 2016*, the 10 year plan to provide greater assistance and long term practical solutions for people with a disability.³¹

This program aims to:

- provide alternative accommodation and support services for some younger people with a disability who are inappropriately living in, or at risk of entering, residential aged care; and
- provide support to better meet the needs of some of the younger people with a disability who remain living in residential aged care.³²

Priority is given to people aged under 50 years who are most inappropriately housed in residential aged care and those people under 50 years most at risk of inappropriately entering residential aged care³³.

This case study clearly demonstrates a similar range of human rights violations as outlined previously in the case studies within this submission. It also illustrates a far too common problem in a service system unable to respond to the needs of people with disability, including those who have remained living with their parents until they are no longer able to provide support and care for their son or daughter.

Disability advocates³⁴ believe that younger people with disability end up living in residential aged care facilities for a range of reasons including:

- a lack of other accommodation and support alternatives;
- ageing carers bringing along a family member with a disability when moving into the nursing home;
- Residential aged care facilities being perceived by many as the only secure option;
- Residential aged care facilities being known to people while other alternatives are not generally well known and understood;
- a Residential aged care facility may be the only facility close to family members;

³¹ DADHC 2010 NSW Younger People in Residential Aged Care Program, , viewed 19th May at <http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/NSW+Younger+People+in+Residential+Aged+Care+Program.htm>

³² DADHC 2010 NSW Younger People in Residential Aged Care Program, viewed 19th May at <http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/NSW+Younger+People+in+Residential+Aged+Care+Program.htm>

³³ DADHC 2010 NSW Younger People in Residential Aged Care Program, , viewed 19th May at <http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/NSW+Younger+People+in+Residential+Aged+Care+Program.htm>

³⁴ Brain Injury Association of NSW Inc et al (2002) Younger people with disability out of nursing homes. A discussion paper. Accessed at http://www.ncoss.org.au/bookshelf/disability/submissions/0209_yp_dis_nh_dp.pdf

- expectations of high quality medical/ nursing care in residential aged care facilities; and
- Residential aged care facilities are seen as a final alternative for people with high medical/nursing care needs.

We believe this case study clearly demonstrates a situation where this family had no other options available or because these options were not sought and explored. The fact that this woman with disability continues to reside in a nursing home some seventeen years later, suggests this is still the case.

It also highlights yet again how classifications of disability type used as eligibility criteria can work against a person with disability with a demonstrated level of need. As mentioned above, Governments and disability programs must introduce an understanding of disability for the purposes of eligibility and entitlement that takes into account a person's activity limitations, participation restrictions, and the particular environmental factors that in total lead to an understanding of what supports need to be put in place. The current system which promotes arbitrary cut off points continues to leave people, such as the woman in this case study, falling through the gaps. The shifting of responsibility for the needs of targeted groups or types of disability between different programs and government departments, also continue to leave people vulnerable to long term systemic neglect.

Given that nursing homes are institutional models of care there is also sufficient evidence to suggest that this woman's opportunity to achieve outcomes associated with the provision of smaller, community based residential services such as increased service user engagement, increased use of facilities, increased adaptive behaviour and skills, increased opportunities for choice and increased contact with family and friends have also been limited by this accommodation placement³⁵. We are outraged by the thought that had this woman been appropriately offered an individualised service or even one based on a community living model, she would have been afforded a better chance to achieve her maximum potential. Instead her right to experience her young adult years in a way commensurate to her peers has been, and continues to be, marred by the confines of a nursing home, where she must live alongside frail, aged and dying residents who have reached the final stages of their life.

³⁵ Emerson and Hatton 1997 Listening to adolescents and adults with intellectual disabilities from South Asian communities, *Journal of Applied Research in Intellectual Disabilities*, 10:3, pp. 250-63

Australia has a robust social security system which entitles all citizens to health services and income support based on individual needs and circumstances. However, for Australians with disability, there is no equivalent entitlement to disability care and support services. The Australian system of formal support is failing many people with disability, their families and carers, as highlighted through this case study. The high levels of unmet need for disability services impact heavily on people with disability but also on their families and informal carers.

Whilst all levels of government have increased funding for disability services in recent years, no government has committed to meeting all the essential needs of people with disability. This case study highlights the severity of this problem.

Governments fund a range of services, but people with disability and their families have no certainty and no guaranteed access to a system of core support. The reliance on informal carers has enabled the effective allocation of resources to those in or on the verge of crisis. A major drawback of current disability services is that the client is not at its centre. There is little opportunity for life course planning for individuals, which involves their families, helps them meet their aspirations, and prepares them for key transitions. The current system is under considerable stress and marginal change or add-on services will only lock in models that will continue to fail to meet the needs of people with disability, their families and carers.

One final point we would like to emphasize to this Inquiry is the arguments commonly used to justify the establishment of aged care facilities specifically for people with disability who are ageing. This includes the Specialist, 100-bed, aged care facility for people with an intellectual disability built by the NSW government in its re-development of Peat Island on the Central Coast of NSW.

It is commonly argued that persons without disability live in congregate settings such as retirement villages, intentional communities, cluster housing, housing co-operatives and communes, so therefore people with disability can do the same. We however believe this argument is based on false logic.

There would be no objection to people with disability living with their non-disabled peers in accommodation options of their choice. BUT that is not what these accommodation options involve. They involve a segregated simulation of the accommodation choices available to persons without disability, which violates norms and patterns of living among peer groups

(for example, non-disabled young people do not live in residential aged care facilities or retirement villages).

The NSW Government argues persons with complex needs such as challenging behaviour, high level medical needs or who are ageing need to live in segregated settings in order to receive specialist services and supports. This argument is also based on false logic. The only reason the specialist services and supports are available to persons with disability in segregated settings is because ADHC chooses to provide these services in this way. These services could be just as readily provided in community-based settings.

5. Concluding comments and recommendations

Over the past two years, it has become clear to PWD that there is no will, and no capacity, within the NSW Government to develop an innovative and responsive disability supported accommodation system that will enable persons with disability to live with dignity in the community. We have, and will continue to, make vigorous representations to our NSW Parliamentarians, and to NSW disability officials, about broad disability policy as well as the specific issues outlined in this submission.

However, we also believe it is necessary to focus our attention on representations to the Commonwealth Government. There are several reasons for this and these form our submission's broad recommendations:

The Commonwealth is a major funder of supported accommodation services being developed by the States and Territories. This includes Commonwealth initiatives such as the Home and Community Care Program, Disability Assistance Package and Young People in Aged Care Program.

1. We strongly recommend that the Commonwealth must insist that these funding initiatives are applied in a way that is consistent with Australia's international human rights obligations, and that they otherwise support persons with disability to live in and be a part of the community.

The Commonwealth has a major role in determining national disability policy, including through the National Disability Agreement and the National Disability Strategy, which is currently being developed.

2. It must use this policy setting role to ensure that the disability support and accommodation systems provided by all Australian States and Territories comply with international human rights obligations, and that they otherwise support persons with disability to live in and be a part of the community, as required by the Commonwealth Disability Services Act.

The Commonwealth Government is ultimately responsible for the implementation and monitoring of the CRPD in Australia. In 2011 it must present a comprehensive baseline report to the United Nations that sets out Australia's compliance with the CRPD. This report will then be examined by the Committee on the Rights of Persons with Disabilities. It is highly likely that the NSW Government's disability accommodation policies will be a key issue of contention in that report, and result in criticism of the Australian Government for its non-compliance with Article 19.

3. We therefore urge the Commonwealth's intervention in State and Territory government disability policy to bring accommodation services into conformity with CRPD obligations. The introduction of specific Commonwealth legislation in the area would be one step.

Australia has acceded to the Optional Protocol to the CRPD. Under the Optional Protocol, persons with disability can complain to the Committee on the Rights of Persons with Disabilities about violations of CRPD rights (provided they have first exhausted domestic remedies). NSW's accommodation policies, and residential institutions, are highly likely to be the subject of such complaints. If these complaints result in the Committee finding violations of the CRPD, it will be up to the Commonwealth government to remedy the situation.

4. That the Commonwealth intervene in NSW government disability policy, and other non-complying State and Territory disability policy, and require it to bring its accommodation services into conformity with CRPD obligations.

Our specific recommendations based on the key issues presented by way of our case studies include the following:

5. That the Senate Community Reference Committee's final report on its inquiry into planning options and services for people ageing with a disability are make reference to, and ensure the following:

- 5.1. Completion of the review the Youth and Community Services (YACS) Act 1973 to ensure the amendment of, or alternative legislation is created to ensure contemporary standards of care and accommodation are provided by licensed operators of boarding houses and that the right of residents are protected, promoted and fulfilled.

- 5.2. Referral pathways and planning options for all people with disability, regardless of the program or service type they access, or seek to access, are strengthened to ensure:

- there are appropriate transition processes in place;
- a range of options are considered and presented to people with disability and their families; and
- people with disability are given the control over decision-making which affects their lives.

- 5.3. Individualised funding arrangements are promoted as the key mechanism to ensure people with disability receive the necessary supports and services they require.
- 5.4. The Australian Government introduce a National Disability Insurance Scheme (NDIS) which ensures a mechanism for guaranteed funding of services required to meet the individual needs of all people with disability.
- 5.5. The Commonwealth Government increase funds to programs such the Young Person in Residential Aged Care (YPIRAC) program to ensure the immediate relocation of younger people with a disability who are inappropriately placed in residential aged care, and provision of supports to those at risk of entering.

6. Appendix

6.1 *Terms of Reference*

- Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age
- Identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability.

6.2 *Important Acronyms*

ADHC/DADHC – NSW Human Services - Ageing, Disability and Home Care, also referred to as its previous name the Department of Ageing, Disability and Home Care and acronym DADHC

PWD – People with Disability Australia Incorporated

CRPD – United Nations Convention on the Rights of Persons with a Disability

YACS – *Youth and Community Services Act (1973)*

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