

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY  
THE DEPARTMENT OF AGEING, DISABILITY AND  
HOME CARE**

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# Submission

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**People with Disability Australia Incorporated**

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# **1. People with Disability Australia (PWD)**

## **1.1 About us**

PWD is a national disability rights and advocacy organisation. We work within a human rights framework to provide a number of activities, which include individual, group and systemic advocacy, information, education and training, and complaints handling.

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 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.

## **1.2 Our expertise**

This submission is primarily based on the information, knowledge and expertise PWD has gained from our members, the people with disability we work with in providing individual advocacy and through conducting our systemic advocacy work:

- PWD is the largest provider of individual advocacy programs for persons with disability in Australia. We have operated a state-wide program in NSW for over 20 years. We currently work from a central office in Sydney, an office in the Sutherland Shire, an office for the Queanbeyan region and one for the Southern Highlands and Southern Tablelands regions. We also have 5 regional offices in Queensland. As well as providing direct assistance to people with disability, these programs also provide advice, information and advocacy mentoring support to family members and carers of people with disability. PWD currently provides more than 1500 instances of individual advocacy assistance to persons with disability and their associates a year. Our individual advocacy is funded by the

Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

- PWD also provides, and has done so for the past 8 years targeted support to residents of NSW licensed residential centres (boarding houses). PWD's Boarding House Advocacy Project is funded by Ageing Disability and Home Care (ADHC), and has developed from 2002 into a state-wide service. It provides regular outreach to all residents on the basis of an annual schedule of regular monitoring visits to all licensed residential centres across NSW.
- PWD is funded as a NSW peak disability organisation by ADHC. As a peak, we represent the views of our members on many NSW government and non-government committees and during meetings with Ministers, MPs and senior government officials. We also work collaboratively with the NSW and national disability sector on a range of issues aimed at improving the lives of people with disability. Many of the systemic issues that arise from our individual advocacy program become the focus of our systemic project work. We also receive funding from other government and non-government agencies to conduct specific projects.

As a consequence of our work, PWD has detailed, specialist understanding and knowledge of the service system in NSW, and the legislative and administrative arrangements that underpin this system.

### **1.3 Context of our Submission**

PWD strongly believes that the Terms of Reference of this Inquiry need to be understood and addressed in a broad human rights context, and with specific reference to the United Nations' Convention on the Rights of Persons with Disabilities (CRPD). This Convention was ratified by Australia in July 2008, and on 16 August 2008 it entered into force in Australia.

The Australian, State and Territory governments now have an obligation to implement CRPD. We suggest that the Social Issues Committee use its Inquiry as an opportunity to assess ADHC's performance against CRPD, so as to make recommendations that will ensure ADHC is able to move towards CRPD compliance. Such compliance will create meaningful reform to enable people with disability to achieve full and equal inclusion in all aspects of community life in NSW.

This submission makes reference to CRPD in its responses to the Terms of Reference and provides broad recommendations that reflect the rights contained in CRPD.

## 2. Response to Inquiry Terms of Reference

**1. That the Standing Committee on Social Issues inquire into and report on the quality, effectiveness and delivery of services provided or funded by the Department of Ageing, Disability and Home Care (ADHC), and in particular:**

**(a) the historical and current level of funding and extent of unmet need:**

Over the past 15 years, there has been considerable change in the administrative structure for the provision of disability services in NSW. This period has involved the creation of a stand-alone Ageing and Disability Department (ADD), which initially only provided funding for services and policy development; and the creation of the Department of Ageing, Disability and Home Care (DADHC), which incorporated disability service funding and delivery and the provision of Home Care services through the implementation of a regional structure. In 2009, the Department of Human Services was created, which includes a range of human service delivery agencies, including Ageing, Disability and Home Care (ADHC).

While successive changes aimed to enhance disability service delivery, considerable resources were used to consolidate administrative arrangements. Small and irregular growth funding meant that services were crisis-driven, reform was piecemeal and limited by resource constraints and service demand was growing.

With the release of *Stronger Together* in 2006, NSW had a ten year plan that included five year growth funding allocations and program and funding targets. This provided a welcome change, in that *Stronger Together* provided a commitment to ongoing growth funding for the provision and delivery of enhanced disability services aimed at addressing key areas of unmet need. It also required public reporting on measures to meet these targets. The NSW Government is currently conducting a five year review of *Stronger Together* with the aim of ensuring funding, service delivery and priorities build upon the first five years.

In PWD's submission to the *Stronger Together* five year review (see <http://www.pwd.org.au/submissions.html#mainstart>), we congratulated the NSW Government on the significant injection of funding that enabled significant improvements and service developments that were long overdue in the disability service system. We recognise the developments in intensive family supports for families, in flexible respite packages, in the expansion of attendant care packages and in post-school and day programs for people with disability.

However, PWD is aware of considerable unmet need for disability services in NSW. We regularly assist people with disability and their families who have been waiting for long periods of time for services, who are in crisis due to lack of services or failures in the service system, who cannot control the supports they need, who fall between service system gaps or who cannot obtain a service unless they are in crisis. We provide examples of this throughout this submission.



This is evidence of a system that is still crisis-driven, of largely poor quality, unable to respond quickly and flexibly and unable to meet the growing demand for disability services in NSW. Despite increasing funding and service developments over the last five years, *Stronger Together* is only the first step in addressing a system that prior to 2006 had been neglected for many years. *Stronger Together 2* will also require significant growth funding and service development and enhancement to continue reforms in NSW.

However, growth funding and service development and enhancement will only be meaningful if *Stronger Together 2* aims at achieving the human rights of people with disability as outlined in CRPD. Using the CRPD as a framework would provide surety that the NSW Government was meeting its human rights obligations in the provision of disability specialist services and supports, and would enable consistency with the draft National Disability Strategy (NDS) and the proposed National Disability Insurance Scheme (NDIS). It would also provide a means to evaluate and report on performance in achieving human rights outcomes for people with disability in NSW.

Both the NDS and the NDIS claim to be underpinned by CRPD. The NDS takes a whole of government approach to achieving social inclusion and human rights for people with disability. The NDIS is a proposal for community responsibility for individualised funding supports for people with disability. The development of *Stronger Together 2* provides an opportunity for NSW to make the transition to a system that has CRPD as its framework and that is in line with the development of an NDIS or similar scheme.

ADHC does not have sole responsibility for achieving CRPD rights in NSW, and the NSW Government policy, *Better Together* provides a plan for other NSW government agencies to provide services to people with disability. No reports have been provided on policy actions nor has it been reviewed. Without this, it is difficult to assess its effectiveness, however it would be timely to review *Better Together* and revise it in line with CRPD.

There is significant research and views currently being canvassed by disability representative and advocacy organisations to respond to the Productivity Commission Inquiry into disability care and support, which includes the proposed NDIS. The various submissions are likely to provide invaluable information in relation to eligibility, assessment, governance, individualised funding, monitoring etc that would provide invaluable guidance for developing *Stronger Together 2* that is consistent with future directions in Australia (see PWD's preliminary submission at <http://www.pwd.org.au/documents/pubs/SB10-PCEnquiryDCS.doc> ).

#### **Recommendations:**

PWD recommends that:

- CRPD be the overarching framework for *Stronger Together 2*;



- *Better Together* be reviewed and revised with CRPD being the overarching framework for *Better Together 2*, given the interconnection between this policy and *Stronger Together*.
- *Stronger Together 2* and *Better Together 2* ensure a transition for NSW to become consistent with national approaches to the provision of disability supports in line with CRPD.

**(b) variations in service delivery, waiting lists and program quality between:**

**(i) services provided, or funded, by ADHC:**

PWD is concerned that many people with disability who require assistance and support are unable to obtain this support, or can only do so in very limited ways. We draw the Committee's attention to the following examples that arise frequently in our Individual Advocacy program:

- **People with autism who are assessed as 'higher functioning' are not eligible for ADHC direct services**, and are highly unlikely to find an available ADHC funded service to provide day to day support. This often results in the person being without a service or relying on their family for support.
- **People with intellectual disability who are assessed as having 'low to moderate support needs' are unlikely to receive any ADHC operated services** unless they are in crisis, such as at risk of homelessness. There are also very few ADHC funded services that are available to provide support to this group of people.
- **People who acquire disability after 17 years, 9 months and 30 days are not eligible for ADHC operated services**, such as supported accommodation or case-management; they are only eligible for ADHC funded group home placements and other services, which limits their ability to obtain any service. This largely affects people with acquired brain injury.
- **People who acquire a disability between 50 and 60 years old, such as a stroke or brain injury, are often unable to obtain an ADHC provided or funded service** as there is usually no availability in the service system. ADHC often tell people that by the time something becomes available, they will have reached the age, or be closer to the age where they can have an aged care assessment (ACAT). This often results in the person being cared for by their family, or being placed in a nursing home.
- **People who have dual or multiple impairments will only be eligible for ADHC provided or funded services if the person's 'primary' impairment is a developmental disability; or if their 'primary' impairment is a physical impairment and the person is eligible for an Attendant Care Package.** Where this is not the case, the person will be referred to another service system, such as the health system for a person with psychosocial disability and intellectual disability, where the person's 'primary' disability is considered to be psychosocial disability. This often results in a person being referred back and forth between service systems without receiving any or very limited supports.

- **Families with children with complex and multiple needs often do not get the support they need through short-term intensive family support.** They may need longer term assistance and support options that are not available in the service system. This is particularly the case where families who are in crisis may want voluntary out-of-home care support that is more intensive than respite, such as a shared cared arrangement, a host family arrangement, or another family-like environment. These options are not always readily available, nor does ADHC always accept these options even when PWD has found such an option for the family, with the result that the family moves further into crisis, and is often forced to make a decision to relinquish their child to the Department of Community Services (DOCS).
- **People with multiple or complex needs are often deemed ineligible for Home Care,** as there is a view that more specialist supports are required or that there is an Occupational Health and Safety (OH&S) issue for Home Care.
- **People with disability who receive a service from the spectrum of ADHC provided and funded day programs, such as community participation, post-school options, transition to work or other day programs are subject to different funding arrangements and levels as well as program objectives.** This is the result of piecemeal reform in this area over the last ten years, where funding and service objectives for people in various programs depends on the date they entered the program. Some people with disability are in programs that are block-funded, while others can have self-managed options. Funding levels for individuals are also inequitable across the programs.
- **People with disability who are part of the Young People in Residential Aged Care Program (YPIRAC) are often only provided with in-reach support from ADHC funded services due to the lack of accommodation and support options in the service system.** This means that people may be able to participate in social activities or outings but are not able to obtain a group home vacancy, or NSW Housing states that the person needs support to sustain a public housing placement. Such support is often not available from crisis-driven ADHC services, who view the person as a low priority as they already have 'a roof over their head'.
- **People with disability living in Licensed Residential Centres (LRCs), or licensed Boarding Houses do not have tenancy rights or protections, experience numerous human rights violations, and do not receive the same quality of care that is required in ADHC provided and funded services under the *Disability Services Act 1993* (NSW), associated Disability Service Standards, or ADHC service policies and guidelines.** The legislation governing licensed Boarding Houses is the Youth and Community Services Act (YACS Act), and ADHC performs a licensing and monitoring role. PWD is aware of the sub-standard living conditions and breaches of rights that are faced by people with disability in Boarding Houses. Reform of the YACS Act has been stagnating for over 10 years, while licensing conditions remain outdated and unenforceable by ADHC. The recent Regulation to the YACS ACT has provided enforceability to outdated licensing conditions and this Regulation is currently under review. PWD has

provided a detailed submission to the Review process outlining our concerns (see <http://www.pwd.org.au/submissions.html#mainstart> ).

### Recommendations:

PWD recommends that:

- ADHC review eligibility and assessment for services so that procedures are based on a robust, internationally valid framework, such as the World Health Organisation's (WHO) International Classification of Disability Functioning and Health (ICF-10), which determines eligibility and assesses need according to a sophisticated classification that takes account of the functional limitations of a person, and their level of disadvantage relative to the social, economic and environmental context in which they live;
- *Stronger Together 2* focus on providing funding directly to people with disability who are currently deemed 'higher functioning', low priority or who have complex needs, so they can obtain, control and direct the supports they need without going into crisis;
- ADHC undertake major reform of its day program spectrum to ensure coherence and equity of funding and individualised, flexible and portable supports;
- *Stronger Together 2* includes an appropriate strategy for residents of licensed boarding house for ensuring their human rights are respected, protected and fulfilled along with their peers in the disability service system;
- the NSW Government's Interdepartmental Committee on Reform of the Private Residential Service Sector (IDC) immediately provide an action plan on its directions for sector reform and the review of the YACS Act;
- the NSW Government undertake an evaluation of ADHC's Boarding House Reform Program, its objectives and the success of its outcomes for achieving positive systemic reform within the licensed boarding house sector.

### (ii) ADHC Regional Areas:

Different ADHC regions can vary in the way services are delivered depending on the availability of service types and the interpretation of service and funding guidelines. For example:

- It is extremely **difficult to receive Home Care** services anywhere in NSW but particularly in metropolitan regions. People who request Home Care services are often told that Home Care is at capacity and that they will need to call back. There are no waiting lists and many people do not call back assuming that they are unable to receive a service.
- Services in **different regions may interpret funding or program guidelines differently** resulting in different services being offered. For example, some respite services include transport in their service while others do not; some enable children with disability to be taken on activities outside the home and others do not.

- The Integrated Services Program (NSW Health, Housing NSW and ADHC) provides a service to people with complex needs in the Metro North region. Many other **regions are not aware of what this Program is or whether they can refer people to it.**
- In many rural areas, there can be a **small pool of staff for a number of services**, such as Home Care and disability support programs. If a person with disability has difficulty with a particular staff person, they may not have the choice to change as there are no other staff. They may have to accept the same staff member for more than one service.
- Both the Metro North and Metro South regions are very large. **People with disability within these regions can be offered group home placements a great distance away from their local support services and family and friends.** For example, someone in the Sutherland shire may be offered a placement in Campbelltown, or someone from Parramatta may be offered a placement in the Northern Beaches. As the placement is still within the region, ADHC argue that these offers are reasonable, but such placements can place additional pressure and costs on families in visiting their adult children and on the person with disability who becomes disconnected from their community networks.
- **People with disability who are unable to obtain a service in one region because of lack of availability in that region, are not able to get the available service in another region** even if they live in close proximity to the service. For example, a person who lives in Bowral comes under Metro South, but is unable to obtain the service they need because it is in Goulburn in the Southern Highlands region.
- **People with disability and their families who move from one ADHC regional area to another are unable to receive the same services that they had.** They must go on a waiting list in the new region. This can often lead to significant stress and family breakdown which then can result in intensive family support services being provided. Crisis is the factor that leads to service delivery, rather than receiving services that would prevent crisis in the first place.

### **Recommendations:**

PWD recommends that:

- people with disability decide which supports and service locations are suitable for their individual circumstances;
- *Stronger Together 2* focus on providing funding directly to people with disability, so they can obtain, control and direct the supports they need without going into crisis;
- Home Care develop a Waiting List system to ensure that processes are in place for people to be contacted when a service is available;
- ADHC develop protocols between its regions to ensure that people with disability are able to access the most convenient supports and are not disadvantaged when moving to another region.

**(c) flexibility in client funding arrangements and client focused service delivery:**

Currently, individualised funding and self-directed supports are not widely available for people with disability in NSW. There are some programs that provide individualised funding with varying levels of control by the person receiving the funding, but generally, people with disability are reliant on what the service system provides, what support they are eligible for, and the type of support that is available.

Individualised funding and self-directed supports is centred on a commitment to enhance self-determination of people with disability by being flexible and responsive to the culture, values and preferences of each person and, where appropriate, their family. The shift towards individualised funding and self-directed supports is more likely to achieve client focused and flexible service delivery as the person with disability genuinely controls and directs supports. It is more likely to achieve CRPD rights.

PWD is keenly aware of the disadvantage many people with disability face because the service system controls the supports despite the specific circumstances and choices of the person with disability. Many of the examples provided in our responses above demonstrate the inflexibility of client funding arrangements and client focused service delivery in ADHC provided and funded services. Other examples include:

- **People with disability who move into NSW from other States where they had individualised funding packages are often unable to find the support they need from ADHC provided and funded services.** They either are a low priority for funding because their needs do not fit the funding requirements in NSW, or their needs are classed as 'low'. Even where States work with NSW to continue support for a period of time, ADHC may still have difficulty finding and providing support in the allotted timeframe, which results in stress for the person with disability.
- **People with disability are subject to providing many duplicate service forms and paperwork within ADHC provided and funded services** to receive different services. Often a GP is required to provide the same information over and over again on multiple forms.
- **People with disability can be disadvantaged when a tender process results in another service provider managing a service.** It can mean that the service is costed differently so that a person with disability could have a reduction in service hours and quality. Some parts of the service may no longer be included, such as travel and social activities and these costs may be deducted from service funding, or charged to the person. It can also mean that long standing relationships between a person with disability and a support worker is not maintained, all of which can have negative effects on the person with disability. In some cases, ADHC has tried to resolve this by brokering the previous support worker at greater cost. While the previous service may have been much more cost effective, flexible and of higher quality, the person with disability has no control of the service or the supports they receive.

- **Many people with disability with multiple or complex needs or dual or multiple diagnosis need support from more than one agency**, such as ADHC and NSW Health or the Housing NSW. ADHC may categorise a person according to a 'primary' diagnosis and therefore not provide the support they need regardless of whether it is available or not from the office they are referred to. Despite Memorandums of Understanding (MOUs) between agencies, many people in this situation are often referred from one Office to another without receiving any supports or receiving very little supports.
- **Parents with disability may require intensive support to assist their parenting capacity and build parenting skills.** While there are some supports provided by the Department of Community Services, these are often piecemeal and uncommon with varying expertise. A common response is a child protection one where the parent is seen as a 'risk' to the child. This issue is not addressed by the MOU between ADHC and DOCS, but should prompt an appropriate coordinated response between these agencies.

#### **Recommendations:**

PWD recommends that:

- ADHC focus on developing individualised funding and self-directed support options in partnership with people with disability, and their families to respond to the needs of people with disability who currently fall through the gaps in the service systems.
- ADHC work with interstate disability departments to ensure service equity and portability of funding for people with disability moving into NSW;
- ADHC work towards reducing red tape in the provision of its provided and funding services so that people with disability don't need to duplicate the same information multiple times.
- *Stronger Together 2* focus on providing funding directly to people with disability, so they can obtain, control and direct the supports they need and not have to accept services from a provider not of their choice.

#### **(d) compliance with Disability Service Standards:**

- **An end to institutional accommodation**

Along with many disability representative and advocacy organisations, people with disability, parents and families, PWD is extremely concerned about the commitment in *Stronger Together* to redevelop institutions. *Stronger Together* refers specifically to the redevelopment of the Grosvenor Centre, Peat Island and the Lachlan Centre, which had been earmarked for closure by the NSW Government in 1998. We are also equally concerned about the general regressive move back to congregate supported accommodation facilities. This has been evident in tender processes, planning frameworks and service announcements that directly refer to accommodation options, such as cluster housing, villas, specific purpose facilities, that congregate and segregate people with disability.



PWD and many other organisations are publicly opposed to institutional environments for people with disability, as they do not comply with the DSA or the CRPD. The situation in NSW and our arguments against this are outlined in PWD's February 2009 E-bulletin (see <http://www.pwd.org.au/documents/pubs/EB50.html#pec> ).

The redevelopments of institutional accommodation and other related developments represent the most regressive disability policy to emerge in Australia in 30 years. PWD spent many months of unsuccessful attempts to persuade successive Ministers for Disability Services that these developments represent a violation of the human rights of persons with disability, and that they are contrary to the requirements of the DSA. Unfortunately, and as a last resort, we reluctantly filed an application with the NSW Administrative Decisions Tribunal (ADT) seeking a review of the Minister's decision to continue to operate Grosvenor, Lachlan and Peat Island Centres, contrary to the DSA. This action is still ongoing.

In our response to the *Stronger Together* five year review, we outlined the obligations of governments under CRPD Article 19, *Living independently and being included in the community* and repeat it in this submission:

**CRPD Obligations:** CRPD Article 19 enunciates the right of people with disability to live independently and be included in the community. Article 19 applies the traditional civil and political rights of liberty and security of the person, and freedom of movement, to one of the most pervasive human rights abuses experienced by persons with disability; their segregation and isolation from the community in institutional environments. Civil and political rights are to be immediately complied with. Given Article 19 is a civil and political right, it must be immediately complied with.

CRPD Article 28 guarantees the right to an adequate standard of living, including the right to adequate housing and support services. Article 28 applies the traditional economic, social and cultural right of an adequate standard of living. Economic, social and cultural rights must be realised progressively. This means that Article 28 can be continuously achieved over time.

In essence, Article 19 guarantees the rights to liberty and freedom of movement of persons with disability by requiring housing and support services to be structured and provided in ways that enable independence, autonomy, participation and inclusion in the community. Article 28 guarantees the right to an adequate standard of living, including the right to adequate housing and support services. While the NSW Government can pursue the right to adequate housing and the right to adequate social services progressively, they must do so in a way that immediately complies with the right of persons with disability to live in and be a part of the community.

It is therefore not open to governments to claim, for example, that institutional accommodation and support services are a justifiable stage of achievement in progress towards the full realisation of the right to adequate housing and the right to adequate social services for persons with disability. Still less can governments claim

that institutional accommodation support services fully realise the rights of persons with disability to adequate housing and support services. The CRPD is clear that institutional accommodation and support services are an explicit violation of human rights, and one that the NSW Government has an immediate responsibility to prevent and remedy.

**Choice:** Sometimes it is argued that persons with disability 'choose' to live in segregated accommodation options, and that Governments must give effect to this 'choice' on the basis that the right to personal autonomy overrides all other values. However, human dignity is the ultimate source of all human rights, and it might also be conceptualised as the end goal of all human rights. Right bearers (people with disability) as well as duty bearers (governments) have a fundamental responsibility to act in ways that respect, protect and fulfil human dignity. This has important implications for resolving the clash of constituent or subordinate human right values. Whatever the cause or motivation, the suppression of autonomy and personality of the individual by segregated, institutional models of housing and support is offensive to human dignity. Governments are under a clear obligation to protect and preserve human dignity. To do otherwise would degrade the dignity of all persons with disability, and our society as a whole, by creating or preserving social institutions that perpetuate a belief in the social inferiority of persons with disability.

**Same for all:** It is also sometimes argued that housing and housing and support options that congregate persons with disability together in significant numbers are justifiable because other people in the community choose to live this way. The most often cited example of 'typical' congregate accommodation options are residential services for older and elderly persons. This argument ignores or distorts very important facts.

First, the CRPD provides a very specific human rights related prohibition on the delivery of housing and housing and support services in ways that result in the segregation of persons with disability from their non-disabled peers and in the isolation from the community. The CRPD is clear that arrangements of this nature are human rights violations. All Australian Governments have a solemn obligation to recognise, respect, protect and fulfil CRPD rights. It is therefore not open to Governments to act in violation of these rights no matter what conditions may prevail with respect to other population groups within the community.

Second, the claim that older and elderly persons 'prefer' to live in institutional accommodation services is seriously misstated. In fact, in many cases, older and elderly persons are obliged or compelled to live in these environments in the same way that persons with disability have been historically. These environments have all of the same problems that institutional environments for persons with disability have had, and continue to have. If the necessary supports were provided that would enable older and elderly persons to age in their own homes safely and with dignity, the vast majority would do so. To a significant extent aged care policy now recognises this in its emphasis on the development and delivery of supports that will allow older people to 'age in place;' that is, in their own homes and communities, rather than in specialist aged care facilities.

Third, the 'contemporary' institutional housing and support options, such as villas, cluster housing and specific purpose facilities are actually segregated simulations of the larger group style accommodation they take as their precedents. Subject to other human rights considerations being satisfied, if persons with disability were to choose to live in larger group environments with a range of other persons of their choice, there may be no objection to such arrangements. However, that is not what the proposed 'contemporary' institutional models of accommodation involve. They segregate persons with disability from their non-disabled peers. In those circumstances where these facilities simulate services for older and elderly persons, they also typically violate age-related norms. Non-disabled 'younger' adults do not choose to live in residential aged care facilities.

Finally, it might be observed that there is a significant qualitative difference between a frail elderly person nearing the end of their life being accommodated in a residential facility, and a young person with disability with many years of life to lead being accommodated in such a facility. Such accommodation is not preferable for either group but it is more intensely inappropriate for younger persons with disability.

Most governments in Australia and internationally have moved away or are moving away from institutional accommodation options. In many cases, individualised funding and self-directed support options are being provided to enable people with disability and their families to genuinely live in the community.

#### **Recommendation:**

PWD recommends that the NSW Government fulfill its CRPD obligations by ensuring that *Stronger Together 2* reverses the shift to institutional accommodation options, and take the lead in developing housing and support options that enable genuine community living that protects and preserves human dignity.

#### **▪ NSW Government abuse and neglect prevention framework**

Considerable evidence and research finds that people with disability experience abuse, neglect and violence at much higher rates than the general population. Disability Service Standard 10, *Rights and Freedom from Abuse* requires ADHC provided and funded agencies to "ensure the legal and human rights of people with a disability are upheld in relation to the prevention of sexual, physical and emotional abuse within the service." CRPD Article 16, Freedom from Abuse

PWD is aware of people with disability who experience abuse and neglect in ADHC provided and funded services. While ADHC has abuse and neglect policies and child protection and reporting policies for its direct and funded services, these policies do not apply in licensed Boarding Houses making residents of these services particularly vulnerable to abuse and neglect.

**Recommendation:**

PWD recommends that ADHC take the lead in developing a NSW Government abuse and neglect prevention framework to address abuse and neglect of people with disability. This framework would include measures to safeguard people with disability in the disability service system as well as in other service systems and the community, and would identify specific actions for a range of government agencies, such as NSW Police, Office for Women, ADHC, DOCS, the NSW Trustee and Guardian, and the judiciary. The Framework would be developed with people with disability and their representative organisations.

**▪ Protection from abusive behaviour management practices**

Behaviour management practices should result in positive behaviour change for people with disability. Many people with disability in ADHC provided and funded services are subject to behaviour management practices to address 'challenging behaviours'. These practices include chemical, mechanical and physical restraints, detention, seclusion, and exclusionary time out. They may cause physical pain and discomfort, deprivation of liberty, prevent freedom of movement, alter thought and thought processes, and deprive persons of their property and access to their children. They may constitute humiliation and punishment.

In PWD's joint submission with the Mental Health Coordinating Council to the Social Issues Committee Inquiry into Substitute decision-making for people lacking capacity, we argued that some restrictive practices should be unlawful in all circumstances. Other restrictive practices may be justifiable in very specific circumstances where they are necessary to prevent serious harm to the person or others. However, any such use must be subject to the principle of the 'least restrictive alternative,' and the active promotion of positive alternatives. They should also be subject to rigorous approval and to ongoing monitoring and review by an independent authority. Such an authority would be one measure under an abuse and neglect prevention framework discussed in the previous section.

ADHC has established an Office of the Senior Practitioner to oversee behaviour management practices, but this Office is contained within ADHC without a legislative framework or powers. This significantly weakens the role such an Office could play in regulating behaviour management practices and safeguarding people with disability who are subjected to these practices by ADHC provided and funded services.

**Recommendations:**

PWD recommends that:

- specific NSW legislation be enacted to regulate the use of restrictive practices. This legislation should apply in all situations (that is, in situations of informal support (such as a family context), in the specialist mental health, brain injury and disability service systems (including acute mental health services), and in the

commercial disability service sector (in particular, licensed residential centres or boarding houses);

- The legislation would establish an independent, statutory Office of the Senior Practitioner and would provide that certain restrictive practices are entirely prohibited. These ought to include the following practices:
  - Practices that are experimental;
  - Practices that cause pain or discomfort;
  - Practices that are cruel, inhuman, degrading, or humiliating;
  - Practices that result in emotional or psychological deprivation or other harm;
  - Physical restraint; and
  - Seclusion;
- The Senior Practitioner would regulate the use of restrictive practices and have the explicit role of protecting and promoting the human rights of people with disability subject to, or at risk of, restrictive practices. The Office ought to have at least the power to:
  - Declare a restrictive practice prohibited (both at large and in relation to a specific individual);
  - Authorise, or refuse to authorise, a restrictive practice (both at large and in relation to a specific individual);
  - Impose mandatory conditions on the use of restrictive practices (both at large and in relation to a specific individual);
  - Give compulsory directions to service providers in relation to the use of restrictive practices;
  - Enter any premises upon reasonable notice, interview any personnel, and examine and copy any document about or relating to the use, or suspected use, of a restrictive practice.
- The Senior Practitioner would have the following functions:
  - Developing standards and guidelines in relation to the use of restrictive practices;
  - Developing and delivering professional education in relation to restrictive practices and positive alternatives to restrictive practices;
  - Research and development in relation to restrictive practices, and in particular, to positive alternatives to the use of restrictive practices;
  - Evaluating and monitoring the use of restrictive practices, including by collecting and publishing data in relation to the use of restrictive practices;
  - Developing policy recommendations to government and other relevant bodies about any matter relating to the use of restrictive practices;
  - Publication of comprehensive periodic reports detailing the type and incidence of restrictive practices used in NSW.

**(e) adequacy of complaint handling, grievance mechanisms and ADHC funded advocacy services:**

▪ **Reviewable decisions under the DSA**

Under section 20 of the DSA, a number of decisions related to the funding of disability services can be reviewed by the ADT if a service user or anyone with a genuine concern appeals the decision if they believe it does not meet the requirements of the DSA.

In the submission to this Inquiry made by the NSW Disability Discrimination Legal Centre (DDLC), there is comprehensive information provided about the Minister's and / or ADHC's failure to conform to the requirements of Part 2, Division 2 of the DSA in the allocation of financial assistance to its direct services. This means that the ADT may hold the view that an appeal to the ADT can not be dealt with, as the ADT does not have the necessary basis to be able to deal with the matter. This was the recent decision taken by the ADT in PWD's appeal in relation to the funding of disability services.

As the DDLC point out, funding related decisions about ADHC's direct services are not able to be subject to merits review by the ADT under this view. If this view is correct, then it "necessarily follows that all ADHC funding for its direct services is being administered *ultra vires* the DSA" (DDLC, page 7).

▪ **ADHC funded advocacy services**

The NSW Advocacy and Information Services Review has been in progress for several years with ADHC moving towards an outcome in the near future. The Review has been frustrated by administrative changes and delayed to coincide with the Commonwealth National Disability Advocacy Program Review (also delayed over a number of years). The constant delays and various consultations conducted at each administrative change have created significant uncertainty and flux in the NSW Advocacy sector.

Advocacy is vital to assisting people with disability to achieve their human, legal and service user rights. However, there is no recognition of the need to increase and resource independent advocacy programs in *Stronger Together*. Through the provision of advocacy, PWD is very well aware of the unmet demand for advocacy within NSW. Some areas of NSW have little access to advocacy support, such as in the far West of NSW, some people with specific impairments, such as those with psychosocial disability have limited advocacy support, and some population groups, such as Indigenous people with disability have little to no advocacy.

**Recommendation:**

PWD recommends that *Stronger Together 2* include growth funding for increased independent advocacy, initially targeting areas of greatest need in NSW and focusing on groups that currently have limited or no access to advocacy support.



**(f) internal and external program evaluation including program auditing and achievement of program performance indicators review:**

The Integrated Monitoring Framework (IMF) provides ADHC with a means of evaluating disability funded services. It involves a self-assessment by the service provider staff, a desk audit by regional ADHC staff followed by an on-site review. An action plan for service improvement is agreed by both ADHC and the service provider if this is required as an outcome of the evaluation.

The IMF is deficient in providing any evidence of outcomes for people with disability. It is largely a policy and administrative review of the service provider, with no evaluation of whether the services being delivered are achieving quality outcomes for people with disability. ADHC is required by the DSA to review disability services, and given the rights-based objectives of the DSA, and the human rights outlined in the CRPD, it is critical that ADHC evaluate whether its provided and funded services are achieving human rights outcomes.

In reviewing ADHC provided services, it is critical to avoid conflicts of interests by establishing an independent body to accredit and monitor specialist disability services. PWD supports the recommendation made by the NSW Law Reform Commission following its review of the DSA in 1999, and suggests that the proposal contained in the recommendation replace the IMF. Recommendation 7.20 and 7.21 in the Commission's Report from its review, stated:

- "...the establishment of a new and independent body... to administer the quality assurance process, and to monitor quality. The Commission has referred to that body throughout this Report as the Disability Services Quality Assurance Council ("DisQAC").
- The functions of DisQAC should be developed in consultation with all stakeholders in the disability sector.... As a general guide, the functions could include:
  - establishing the quality assurance scheme;
  - assessing and certifying Stage 1 and Stage 2 transition services;
  - assessing and certifying new services as conforming with the DSA;
  - providing advice and support to services about quality service provision;
  - monitoring whether services meet targets set in Stage 1 and Stage 2 transition plans;
  - monitoring whether services are achieving continuous quality improvement;
  - identifying and registering services of "concern", where closer monitoring may be necessary;
  - notifying the Minister if a service fails to comply with the requirements of the quality assurance process; and
  - recommending to the Minister that sanctions be imposed on services that fail to comply with the objects, principles and applications of principles."

**Recommendation:**

PWD recommends that the NSW Government establish a 'Disability Services Quality Assurance Council' to accredit, monitor and review the disability service system (as outlined in the NSW Law Reform Commission Report from its review of the DSA); and that this body replace the current IMF.

**(g) any other matters:**

▪ **Audit of laws, policy and programs**

CRPD was ratified in 2008, and as a recent international law it is highly likely that many laws, policies and programs in NSW will either not conformed or only will only partially conform to CRPD.

CRPD Article 4, *General Obligations* requires that action is taken to ensure that all laws, policies and programs meet the human rights obligations set out in the CRPD. It is critical that an audit of NSW law, policy and programs be undertaken so that non-compliant areas can be identified and addressed. This will not only ensure that NSW is in line with CRPD, such a review would result in the reinvigoration of, and recommitment to, a disability rights agenda across all sectors of the community, following an extended period of stagnation and regression.

**Recommendation:**

PWD recommends that an audit of NSW laws. Policy and programs is undertaken by the NSW Government to ensure that NSW is in line with CRPD.

▪ **People with disability must be involved in decision-making**

CRPD Article 4 (3) *General Obligations* requires governments to "closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations" in all matters affecting their lives. This means that people with disability and their representative organisations must be active and equal participants in the development, monitoring and review of laws, policies and programs and any other initiative that affects their lives.

**Recommendation:**

PWD recommends that *Stronger Together 2* and a revised *Better Together* must ensure there are mechanisms for enabling people with disability and their representative organisations can actively and equally participate in development, monitoring and review of laws, policies and programs and any other initiative that affects their lives.