

**AUSTRALIAN SENATE INQUIRY INTO THE ADEQUACY OF
EXISTING RESIDENTIAL CARE ARRANGEMENTS AVAILABLE
FOR YOUNG PEOPLE WITH SEVERE PHYSICAL, MENTAL OR
INTELLECTUAL DISABILITIES IN AUSTRALIA**



**A JOINT SUBMISSION BY
DEVELOPMENTAL DISABILITY WA
AND PEOPLE WITH DISABILITIES WA**



people with
disabilities
western
australia

About Developmental Disability WA

Developmental Disability WA (DDWA) has been the peak organisation for people with intellectual and other developmental disabilities and their families and carers since 1986. DDWA has a state-wide membership of approximately 1,300 people with disabilities and their families and 34 disability organisations. We are the Western Australian representative organisation of Inclusion Australia, the national peak for intellectual disability. DDWA is funded by the State government for systemic advocacy. Our model for systemic sees DDWA create lasting positive change by supporting people with developmental disability and their families to have a strong voice; partnering with others to develop more connected and inclusive communities, and influencing government and other decision makers.

About People With disabilities WA

Since 1981, PWdWA has been the peak disability consumer organisation representing the rights, needs, and equity of all Western Australians with a physical, intellectual, psychosocial, or sensory disability via individual and systemic advocacy. We provide access to information, and independent individual and systemic advocacy with a focus on those who are most vulnerable. PWdWA is run by and for people with disabilities and aims to empower the voices of all people with disabilities in Western Australia.

Introduction

On 3rd December 2014, International Day of People with Disabilities, the Senate referred the above matter to the Community Affairs References Committee for inquiry and report by 30 June 2015. On 17th February 2015 DDWA and PWdWA gave evidence to a hearing on this matter held in Perth. A number of people with disabilities also attended the hearing and shared their personal experiences of living in residential care facilities which did not provide the kind of choice and control necessary for them to live the kinds of lives that they wish to. The personal impact of this restriction on their individual agency was very clear to all who attended that hearing. Their accounts clearly demonstrated how people's quality of life is impacted when their ability to exercise choice and control over day-to-day aspects of their lives is restricted, and they are denied the opportunity to fulfil important valued roles that contribute to their identity and bringing meaning to life.

In our evidence to the hearing and in preparing this written submission, DDWA and PWdWA have given consideration to some definitional issues within the terms of reference. For example, in this submission we will refer to appropriateness as distinct from adequacy. The evidence provided by DDWA and PWdWA highlighted that some young people with severe physical, mental or intellectual disabilities are at particular risk of being placed into *inappropriate* residential care arrangements. We have deliberately used the term 'appropriateness' rather than 'adequacy' because we believe it better reflects the need to match care and support to individual aspirations and needs and is more aligned with the principles and intent of the National Disability Insurance Scheme (NDIS). We would contend that a residential care arrangement could be seen to be 'adequate' in that it meets a person's basic needs for shelter and personal care and yet be entirely 'inappropriate' in supporting people to live with a high

quality of life, choice and control.

While there appears at times to be a particular interest in the experiences of people being inappropriately placed in aged care settings, we have considered 'existing care arrangements' in its broadest terms to refer to any disability specific or mainstream care and support system where a young person with a severe disability is residing either on an ongoing or a temporary basis.

Another aspect of the terms of reference which benefits from further clarification is the use of the term 'severe'. We have taken it to embrace those people whose functional level of disability might not be high but whose need for support might be great because they have complex needs. There is a long held debate in the disability sector about the value of functional terms such as severe and profound because of their failure to capture the social nature of disability and the fact that two people with the same functional level of disability can have profoundly different care and support needs as a result of the social context in which they live. The notion of 'severe' disability, for example, hides the experiences of people with complex needs who might also be at great risk of being placed in inadequate and inappropriate care arrangements.

With these issues in mind, this submission draws attention to the needs of a number of particular populations of people with a disability who can be at risk of inappropriate placement in residential care settings as a consequence of the functional impact of their disability and/or the particular social and economic factors impacting on the life of the person with a disability and their family.

Young people with severe physical disabilities who are placed in aged care facilities or other nursing home or hospital residential care facilities, usually as a result of catastrophic injury or neurodegenerative disease, are one of the key groups of people with disabilities who face this dilemma. The evidence shared by people with disabilities at the hearing clearly reiterated evidence which has been provided across the country - that these types of facilities significantly constrain people's choice and control and make it harder to live the kind of lives which people want to live. A critical systemic tension for this group appears to be whether or not certain care needs are seen as 'health' or 'disability' and therefore which system should take responsibility for those needs. Unsurprisingly, that systemic tension has contributed to delays in decision making and resource allocation to enable people to make a better transition out of the health system and into suitable ongoing care and support arrangements with a specific intent of supporting people to live in the community.

People with intellectual disabilities or with complex diagnoses can also face the risk of inappropriate placement and poorly supported transitions into formal care, with many people making unplanned transitions from informal family support into formal residential care arrangements. For example, young people with challenging behaviours often experience an escalation in behaviours as a result of the onset of adolescence and puberty. People with intellectual disabilities or autism who also have diagnosable mental health issues are another group at risk of inappropriate placement. Mental health services often struggle to diagnose mental health issues successfully in this population, and people are often shifted between mental health and disability service systems in the absence of effective diagnosis and management,

with mental health issues often being misdiagnosed as challenging behaviour. With mental illness not being diagnosed and treated successfully and it can be difficult to support people effectively.

Another group who can be at risk of finding themselves in inappropriate residential care arrangements are people who are sometimes referred to as people 'at the margins' - people with intellectual disability who face additional challenges such as mental illness, poverty, homelessness, family dysfunction, and criminalised behaviour. This group are often people who have a mild to moderate level of intellectual disability who have fallen through the cracks of the system throughout their life. While their functional impact might not be 'severe' their level of disability as a consequence of the interaction between their functional impairment and other challenges have a severe impact on their lives and their interaction with mainstream service systems which are ill equipped to support them.

In our responses to the terms of reference we will share the real experiences of people who have a lived experience of inappropriate residential care, and we will also highlight the needs of some other experiences of disability. We will also endeavour to share what we know of work that is currently being undertaken in the Western Australian disability services sector to progress some of these issues, because we believe that local, targeted sector and community development to support the community, disability services and mainstream services alike to respond to the needs of young people with severe and complex disabilities is critical to reducing the risk of inappropriate placement.

The adequacy of existing residential care arrangements for young people with severe disabilities is a critical question as we prepare for the transition to a National Disability Insurance Scheme (NDIS). It speaks to where young people with severe and complex disabilities and their families are starting, what they hope for and require from the NDIS, and how successful the NDIS is in repairing the present cracks in our disability support systems and their interaction with mainstream services. It is the experiences of people with severe and complex disabilities which most challenge our current systems, and it is for this reason that DDWA and PWDWA have decided to make a joint submission to this inquiry focussing on people who are at risk of inappropriate placement in residential care facilities.

We believe that the evidence of this inquiry is of significant value to Senators who are also part of the Joint Parliamentary Committee on the NDIS, and there are a number of key issues that will be critical to the NDIS's success in responding to these experiences:

- Whether or not people with disabilities will have access to housing;
- Whether or not the NDIS pricing reflects the organisational capacity to support people with complex needs;
- The nature of the interface between the NDIS and mainstream systems;
- The availability of case management type supports to assist in coordinating the multiple supports and service systems often required by young people with complex and severe disabilities;
- The delivery of local, targeted community and service sector development to assist improve the responsiveness to young people with complex and severe disabilities.

Terms of Reference

A. The estimated number and distribution of young people in care in the aged system in Australia; and the number of young people who require care but are not currently receiving care.

While the first part of this term of reference can be answered with direct reference to some specific data sources, the second part of it is difficult for people with disabilities and their families to determine. Published data sources are either too broad, or government data sources informed by management information data are not accessible to the public beyond superficial information. Furthermore, most of these data sources are quantitative in nature and don't address some of the contextual questions required to inform levels of unmet need in our community¹.

Information from the Australian Institute of Health and Welfare at 30 June 2013 showed that 3.7% of all residents in residential aged care (permanent and respite), or 6,376 people, were aged less than 65². They also state that there was consistency with age distribution across states and territories, apart from the Northern Territory, so it would be fair to say that approximately 3.7% of people in residential aged care in Western Australia are under 65. This figure does not include people with disabilities who are in nursing home style accommodation that is disability specific. For example the Quadriplegic Centre is funded by the Department of Health in WA as a rehabilitation facility and it has a number of long term residents as well as residents who are waiting for funding to move into the community. It has a built environment similar to a 100 bed nursing home. Rocky Bay and The Centre for Cerebral Palsy have also had nursing home style accommodation which has recently been upgraded to provide a nicer home environment for the residents. However, for some people this is still isolated, congregate living that does not work for them. There are only small numbers of people in these situations, however, they are predominantly people with high medical support needs who would otherwise be in aged nursing home style accommodation.

In terms of intellectual disability, no data sources are referenced in this submission but it is possible that some data is available. The anecdotal evidence would suggest that the presence of young people in aged care would suggest numbers are low and that most commonly occurs as a result of early onset of ageing or age related illnesses such as dementia, or because a person who has always lived with their parents transitions with them into an aged care setting. This would require further examination. Anecdotally, we understand that disability services try to support people to age-in-place if they are already in residential care, rather than transition them to aged

¹ Developmental Disability WA, 2014; Submission to the Legislative Assembly Community Development and Justice Standing Committee; Inquiry into Accommodation and Intensive Family Support Funding for People with Disabilities.

² Australian Institute of Health and Welfare, 2013; Residential aged care and aged care packages in the community 2011–12.

care facilities. People with intellectual disability can be susceptible to early onset of aging or age-related disabilities or illnesses³. For example, people with Down Syndrome have a genetic vulnerability to Alzheimers disease⁴. This would suggest that effective planning for transition from informal to formal residential care needs to take this into account and disability support services supported to respond to an ageing population of people with disabilities. It also suggests that any funding system must be able to quickly respond to changing needs, and must be able to respond to the various care and support needs for someone who has more complex needs.

Definitive information about unmet need (the number of people who require care but are not currently receiving care) is difficult for people with disabilities and their families to source. One of the failings of previous systems approaches to meeting disability needs has been the problem of accurately identifying the extent and the nature of needs broadly across the community. We consider that the Disability Services Commission has a good understanding of the level of fully met, partially met, and unmet need of people with disabilities in WA. For example, it has been indicated that in the NDIS launch site in Perth Hills and the My Way sites the number of people with disabilities and their broad circumstances are known to the WA and Commonwealth Governments, and that this will permit effective planning. By contrast the Disability Support Funding Bulletin (a brief report of the outcomes of each Combined Application Process funding round) appears to serve only to confuse and concern. It is not helpful in understanding the extent of the unmet need across the State or in identifying any demographic hotspots of priority need, or systemic failings. The Bulletin does not provide data on how many applicants are people with severe and profound disabilities and what their current living situation might be, or how many received funding. We are familiar with the data that is available through the National Minimum Data Set (NMDS), and the Australian Bureau of Statistics' Disability, Ageing and Carers, Australia survey, last conducted in 2012. Whilst these are publically available, neither provides any useful quantitative information about levels of unmet need for services. This would suggest that the data available to the DSC comes from other sources, which are not publicly available.

When trying to measure the level of unmet need amongst people with severe and complex disabilities a number of definitional issues need to be addressed. Most obviously is the question of how we seek to define 'young people'. For the purposes of collecting data in relation to young people with physical disabilities in aged care or nursing home type care, 'young' has been used in a very broad term to refer to anyone who would not usually expect by virtue of their age to be placed in this type of setting. But in the broader context, greater clarity would be needed to determine how we would seek to define young people and for what purpose we are specifically seeking to collect the information. There is also the question of what we mean by 'care'. In this context, we are obviously referring to residential type care which in the disability context tends to refer to 'accommodation support' either to live independently or in a

³ Australian Institute of Health and Welfare, 2000; Disability and ageing – Australian population patterns and implications.

⁴ Alzheimers Australia, Centre for Developmental Disability Health Victoria, & Down Syndrome Association of Victoria; Down syndrome and alzheimers disease

group home or other formal care arrangement. Unpacking whether or not a young person requires care is a very individualised question. It is based significantly on what the expectations of that young person about the kind of life they want to live, and also on the expectations of family and carers about how much support they are able to provide. Importantly, it is a question on which the interpretation of 'reasonable and necessary' rests. For example, do we determine that a young person with a severe or complex disability requires care because it is a normative expectation that a young person should be expected to be able to leave the family home when they wish to or at a certain age? Do we determine that a young person with a severe or complex disability requires care because their family or carer determines that they are no longer able to provide informal care and wish to support their son or daughter to make a planned transition into an alternative care arrangement? And if so, what is a reasonable and necessary residential care arrangement? For example, if a person with challenging behaviours is transitioning into formal care will they be offered the option of transitioning to an individualised support living option, or are they more likely to be offered a place in a group home? How are decisions such as these being weighed in terms of reasonable and necessary support now and into the future?

What is a 'reasonable and necessary' expectation of when a young person with a severe or complex disability requires care because informal supports should reasonably be expected to be replaced by formal supports?

B. Short- and Long-Term Trends in Relation to the Number of Young People Being Cared for Within the Aged Care System

DDWA and PWDWA are not able to address this specific term of reference.

C. The Health and Support Pathways Available to Young People with Complex Needs

By the very nature of their needs, young people with complex needs are more likely to be at the interface between the disability support system and mainstream supports and services⁵. Pathways between human service systems are inherently difficult to navigate. Each service system is effectively designed to 'gate keep' access to it and each system is primarily focussed on addressing the needs that specifically relate to its particular focus and trying to distinguish between different needs within the same individual person. This is profoundly obvious in the experience of young people with disabilities who have complex needs who by the nature of their needs tend to need to access multiple service systems and who as a consequence of their complex needs tend to experience significant challenges in navigating these systems independently.

There are a number of support pathways critical to people with complex needs.

⁵ The needs of people with complex needs and the interface between disability and other support systems is the focus of a sector development grant by the Disability Services Commission to support the WA My Way NDIS Trial.

Education, health, mental health, housing, criminal justice, corrective services, and child protection are key mainstream services which people with complex needs often interact with. For some people with significant disabilities which have a significant impact across multiple forms of functioning, the support pathways are often within the disability services system itself and demonstrate the variety of supports and services that disability service providers have to be able to deliver to successfully support people.

The effect on health services treating people who became disabled as a result of catastrophic injury is a clear example of how the interface and pathways between disability and health operate. At the time of their injury, these people require access to a series of timely medical treatments and processes. The systems that have been developed to manage the complex treatment and rehabilitation processes are staged. The person's experience may be very lengthy and they will be served by medical and health professionals from many fields including intensive care, medical, trauma services, psychological and physical rehabilitation. This investment to catastrophically injured patients contributes to her or his survival, and ultimately serves to return that person to a community life that permits maximum independence. PWdWA is aware of many people who have worked through long, painful recovery and rehabilitation processes only to become stuck inappropriately and unnecessarily in an expensive medical/rehabilitation resource due to the inability to achieve funding through the current state funding process. These people often describe their situations as hopeless and say that they have resigned themselves to permanently residing with groups of other similarly affected people in health funded institutionalised care. There are other groups who are also living in inappropriate settings. There are people with disabilities who also have psychosocial disabilities living isolated existences in private hostels similar to boarding houses. There are young people residing in nursing homes designed for the care of an elderly frail population.

Inadequate, inappropriate and lack of services has a compound effect, leaving people who are in the situations for long periods of time often needing more support and having psychological damage that will cost the system more over time.

A person can apply for funding through the current state system using service providers, a social worker in a hospital, a Local Area Coordinator (LAC) or a range of other methods to find out where funding can be sourced or to help write applications. It does seem however, that where people are already in some type of accommodation that provides support, whether that be an aged care setting or a disability specific institution, there is generally a lower likelihood of getting an individual funding package through the current state funding system. It is also unclear at this time whether packages under the NDIS will provide enough support for people with high medical support needs to reside in the community.

In Western Australia there is an interesting example which shows part of the problem in this area. There is a program that is provided by the Department of Health called the Ventilator Dependent Quadriplegic Community Care Program. The aim of this program is to provide the training and support for people who are ventilator dependent to move back and live in the community. What this does is leave a situation where there are people with extremely high support needs because of being ventilator

dependent who do get support to go back and live in the community, whilst there are other people who are quadriplegics that do not need ventilator support who are on waiting lists for funding and residing in the rehabilitation hospital environment for 12 months or longer, with some who have lived there for over 10 years putting in applications to move out.

The quality of the application for funding also seems to make a difference with anecdotal evidence suggesting that those very experienced in writing funding applications doing better at getting funding.

Another significant interface and pathway is that between the mental health and disability systems. People with intellectual disability and/or autism face an increased risk of mental illness⁶. Diagnosis and effective treatment of mental illness in this population can be challenging. People with an intellectual disability and/or autism presenting with mental illness are often misdiagnosed as having challenging behaviours, and vice versa. Mental illnesses often go untreated, or alternatively they are misdiagnosed and are poorly treated. Improving mental health and support pathways has been a priority both nationally and here in Western Australia⁷. Here in Western Australia, the Mental Health Commission's ten year plan for mental health services includes plans to establish a "specialised service to meet the needs of people with co-occurring mental illness and intellectual and developmental disability, including autism spectrum"⁸. To inform better support pathways for people with an intellectual disability who also have mental illness, the University of New South Wales have developed a guide for accessible mental health services for people with an intellectual disability (see footnote 8). Here in Western Australia, the Mental Health Commission funded the WA Council of Social Services to develop a core capability framework and professional development training to support improved practice for people working with this target group and their families and carers.

Another group of people with disabilities who have complex needs and significant interfaces with mainstream service systems and who require effective support pathways are those people who are sometimes referred to as people 'at the margins'. whose experiences have been described previously. Here in Western Australia, this group is the specific focus of an initiative known as People with Exceptionally Complex

⁶ Department of Developmental Disability Neuropsychiatry, 2014; The Guide – Accessible Mental Health Services for People with an Intellectual Disability.

⁷ In 2013, the Australian Government Department of Health and Ageing convened a national roundtable of governments and clinicians to examine the issue. It identified eight key elements of an effective mental health care system for people with intellectual disability. In November 2014, the NSW Council on Intellectual Disability conducted an audit of progress across the jurisdictions in progressing improvements to their mental health care systems to better respond to the needs of people with intellectual disability – "Some Steps up the Mountain". It found that there had been recognition of necessary change by jurisdictions at the systemic level. It also identified localised training initiatives to improve the skills of practitioners in recognising, diagnosing and treating mental illness in people with intellectual disability.

⁸ Government of Western Australia, Mental Health Commission 2014; THE WESTERN AUSTRALIAN MENTAL HEALTH, ALCOHOL AND OTHER DRUG SERVICES Plan 2015–2025

Needs (PECN), and the new Young People with Exceptionally Complex Needs (YPECN) which specifically targets young people. Established in 2007, the PECN project targets people who are identified as having exceptionally complex needs by virtue of meeting two or more of a set of screening criteria including mental illness, and/or intellectual or cognitive disability; significant and problematic substance use; significant risk of harm to self or others; requiring intensive support, and capacity to benefit from coordinated services; and 'for whom the existing system is not working'⁹. This group tend to access a range of mainstream services including health, disability, drug and alcohol, housing, police and corrective services. They tend to be the kind of people who fall through the cracks, because of poor interfaces between systems. The PECN model facilitates inter-agency collaboration and coordinated use of the resources available to the person by providing case coordination and inter-agency decision making. A single person-centred integrated support plan is agreed by all agencies that have a role in the person's life. A key factor in the success of the model is that its inter-agency governance model ensures that people who have decision making authority are involved in the initiative. This ensures that critical resources become available at the right time in a person's support pathway such as, for example, where an offender with an intellectual or a cognitive disability might be leaving the prison system after serving a sentence.

There are many people whose complex needs are a result of disabilities which have a significant impact across multiple forms of functioning, and these people often need clear support pathways within the disability services system. One such group is people with intellectual disability and/or autism who have challenging behaviour¹⁰. Most often, these people have significant impairments in their communication and behaviour becomes a mechanism for communicating things like discomfort in an environment, pain or other physical distress, or sensory or emotional distress.

People with challenging behaviour are highly vulnerable to forms of restrictive practice in order to manage their behaviour both in informal, familial care and formal care. For many people who have behaviour which can be challenging, the transition from childhood into youth and adulthood can be a particularly difficult time. The onset of puberty can trigger dramatic escalation or changes in behaviour, and families often find that they strategies which they use to cope with their child's behaviour are less effective, particularly if those strategies have relied on physical restraint. For some people, this can be a time when informal care by a family can become unsustainable, and this can be a time when people make unplanned transitions into residential care arrangements which might or might not be appropriate and best suited to the person's individual needs. Often this occurs because families have not had good support to understand and successfully respond to their son or daughter's behaviour, or to be able to effectively communicate with their son or daughter. If a residential care

⁹ http://www.mentalhealth.wa.gov.au/mentalhealth_changes/complex_needs.aspx

¹⁰ Challenging behaviour is defined as: "Behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities"
<http://www.cddh.monash.org/assets/fs-challengbev.pdf>

arrangement is not appropriate to a person's needs, then this is likely to further exacerbate a person's challenging behaviour, therefore increasing the risk that they are subject to restrictive practices to manage that behaviour.

The need to provide better support pathways for people with challenging behaviours is the focus of a partnership between the Western Australian state government and the disability services sector to implement positive behaviour support in this State's disability services system¹¹. Two initiatives implemented to support this Positive Behaviour Support strategy include key aspects of this initiative are a capacity building and peer-support initiative to assist families to better understand and respond to their sons' and daughters' challenging behaviour, Side by Side, and an expansion of the Positive Behaviour Support team model - a highly targeted, intense, multi-disciplinary intervention to support individuals and families where challenging behaviour has become highly complex.

Side-by-Side is a peer support approach specifically targeted to support the families of young people who have 'challenging behaviour'.¹² It acknowledges the particular challenges and isolation that can impact on these families and seeks to support family resilience and hopefulness and ability to provide support to their son or daughter. It is hoped that Side-by-Side will reduce the likelihood that young people with 'challenging behaviours' make unplanned transitions to residential care.

The complex nature of challenging behaviour requires highly responsive and highly skilled support. It can require significant clinical expertise across a range of disciplines. It also requires sophisticated and highly individualised service design and support. The disability services that are supporting these people are very often also supporting the family of the person. Some families, for example, have multiple children with disabilities and might have one or more children with challenging behaviour. Those families often also need support for their own well-being if they are to support their sons or daughters successfully and so avoid inappropriate residential care placements. For disability service providers to provide high quality and sustainable supports to people with challenging behaviours, this range of skills and supports need to be embedded in the organisation's infrastructure. In order to ensure that the sector continues to provide quality services to this group, ongoing sector and staff development is also critical. This all has a significant impact on the cost of service delivery, and some concern has been expressed by the sector that the pricing of the National Disability Insurance Scheme does not adequately reflect the cost of providing services for people with such complex needs.

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<http://www.disability.wa.gov.au/disability-service-providers-/for-disability-service-providers/services-for-disability-sector-organisations/positive-behaviour-strategy/>

¹² <http://ddc.org.au/side-by-side/>

D The appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities

Carolyn Reedy:

Carolyn has Spinal Cerebellar Ataxia. It is a disease that is slowly progressive. (She also has bi-polar which is currently stable). Her speech is limited to a few words. Carolyn is fully cognisant and she uses a walking aid to move about. She gets very tired and is reliant upon others for her daily care needs.

Carolyn was forced to give up her Homeswest Home, managed by Southern Cross Housing, when her physical condition deteriorated more than a year ago as she could not obtain funding through the Disability Services Commission to enable her to remain in her own home. Services that could be provided through the Home and Community Care Programme would not have been adequate to meet her needs. Carolyn is living in McDougal Park Aged Care Home in Como where she has now lived for over a year. Most of the other residents in the aged care home have varying degrees of dementia and are all decades older than Carolyn.

Carolyn has an 11 year old son who lives with his father. Although there is a Court Order stipulating that Carolyn may see her son once a month the father is not proactive in arranging visits. The son lives in the north metropolitan area as do all of Carolyn's friends. Carolyn is now dependent upon her brother to support her in organising monthly visits with her son. Carolyn's friends are not able to visit her regularly as her nursing home is situated south of the river so Carolyn has been losing her community supports at a time when she needs them the most. Carolyn does get some limited funding through the Mental Health Commission which provides her with funded psycho-social support through Perth Home Care Services, enabling her to have limited community access twice weekly.

Carolyn does not wish to be in an aged care home. Since her admission there has been a noticeable deterioration in Carolyn's basic capacity to do things. For example, I understand she used to be able to keep track of all her appointments but now has difficulty with this. Decisions are made around/for her and, whilst Carolyn initially challenged this, she no longer has the strength to do so and is not asserting her needs but accepting that choices are being taken away from her. Carolyn had hoped to return to live in her Homeswest House and so was paying rent for this home for a prolonged period which caused financial issues over a period of time as she was also responsible for her nursing home fees. This went unnoticed because of the lack of one person/agency acting in a "case management capacity" which led to a complete breakdown in communication between Perth Home Care Services, Southern Cross Housing, Mental Health Commission, Disability Services Commission Local Area Coordination and the Nursing Home. From the observations of the PWdWA Advocate who only became aware of the situation shortly after PHCS referred Carolyn to PWdWA in late 2014, it appears that no one agency was prepared to "step outside their perceived boundaries of their role" which was necessary in this case. The nursing home put in an application to the State Administrative Tribunal and, in January 2015, an Administration Order was granted to be reviewed after three months. During this period, Carolyn will also undergo an assessment at the Memory Clinic in regard to her decision-making capacity. Carolyn has indicated she would have welcomed an

assessment prior to entering the aged care home so that a comparison could have been made. She is sure that any deterioration in her ability to function mentally and physically would have been less had she been able to remain in her home in the community.

Carolyn communicates using text on her mobile or by indicating yes or no with the shake of her head. She has had minimal speech therapy since entering the nursing home as there is only a part-time speech therapist across several nursing homes. Although Carolyn was assessed some months ago as potentially benefiting from having the use of an electronic communication device, she has yet to receive the device. An issue for many young people in aged care homes is that they are not eligible for some services/grants once they enter an aged care home and this often leads to difficulties in obtaining the disability aids they require as a necessity, not a luxury, unless they have financial means of their own. It is also difficult for them to attend medical appointments outside the nursing home unless they have family or friends able to support them with this which Carolyn does not.

Privacy was a major issue for Carolyn when she was first admitted to the nursing home as she had to share a room with three other ladies in their nineties. Although Carolyn has her own room now she still has to share toilet facilities and, because there is no ensuite bathroom, this can cause issues for her when she needs the toilet urgently. Privacy remains an issue. Other residents may wander into Carolyn's room and not all staff respect Carolyn's privacy.

Carolyn tries to remain optimistic that she will eventually be able to relocate back into a home of her own in the community. She has now decided that, if that is unattainable, due to lack of funding, she wishes to relocate to a nursing home in the north metropolitan area so that her friends are able to visit her more frequently and so that she is closer to her son. However, she may still have a lengthy wait even for a transfer to a single room in a nursing home in the north metropolitan area.

Denis

Denis lives in Tranby Aged Care today. He is now aged 67, but he was 62 and his wife 61 (died 2014) when they both moved into "low care" aged care because they could not get the support they needed to enable them to remain in their own Department of Housing property. Denis has a "mild" intellectual disability. He and his wife moved to WA some years ago from NSW and were not deemed eligible for registration with the Disability Services Commission.

People afraid to give evidence

PWDWA is also aware of people who have chosen not to give evidence because they are afraid that any input they give to this inquiry may impact negatively upon their prospects of obtaining funding.

E Alternative systems of Care in Federal, State and Territory Jurisdictions for Young People with Serious and/or Permanent Mental, Physical or Intellectual Disabilities

This term of reference appears to be asking what alternative systems of care might be available for young people with severe or complex disabilities if the disability services

system is unable to meet their needs, or because of complicating issues.

This submission has already referred to young people being inappropriately placed in aged care facilities, but disability specific nursing homes are also inappropriate in different ways, as demonstrated in the following case studies.

Robyn Keyte:

Robyn sustained C5/6 incomplete quadriplegia as the result of a motor vehicle accident in 1986. She was not eligible for any compensation for her injuries. Since acquiring her disability in 1986 aged 32 years, she has been totally reliant upon others for her daily care needs and activities of daily living.

Robyn was forced to separate from her family and live in a hospital setting. In the years following her accident Robyn's marriage broke down and, as a consequence, she missed out on being a mother to her children. From Nov. 1994 until Oct. 2007 she finally obtained some (CAP) funding through the Disability Services Commission and was able to live alone in the community with support. Robyn thrived in the community although the area she lived in was not optimal.

Unfortunately, when Robyn was hospitalised for surgery in 2007, her Homeswest rental was burgled and totally trashed. Robyn lost everything. It was unsafe for her to return to that property so she had no choice but to move back "temporarily" into the Quadriplegic Centre. This resulted in her losing her CAP funding and she have been stuck in the restrictive environment of the Quadriplegic Centre since late 2007 as her repeated attempts to obtain (CAP) funding to enable her to be able to purchase the care she needs in a community setting have all been unsuccessful.

Robyn feels angry and upset that although she had proved over 13 years that she was able to live successfully, with her disability, in the community and she has now been stuck in an institution again for another seven years. Robyn feels strongly that she should not be living in a hospital and that she should not be punished for matters beyond her control. Each time her CAP application is knocked back she becomes increasingly depressed. Robyn wants her life back and time is not on her side as she is now sixty years of age. The only way for Robyn to gain some personal autonomy is for her to obtain funding for support to live in the community.

Norman de Wet

My name is Norman de Wet and I was born in 1961. I was diagnosed with Motor Neurone Disease in 1995 at which time I was given 3-5 years to live.

The disease progressed rapidly and by December 1996 I was in a powered wheelchair and had lost the ability to communicate verbally. I resigned from work as a Bank Admin Manager for Banque Nationale de Paris in Perth in July 1997. My specialist gave me 18 months to live in 1997. 2015 is my 20th year living with Motor Neurone Disease.

I moved to Rocky Bay residence in 2006 due to issues at home. I was very angry when I arrived as I didn't want to be at Rocky Bay or at any institution. After nine years the major issues still are freedom of choice and competent care. Residents are not given control over their own lives. Management want total control of residents' lives. Complaint system is flawed. Feedback is welcomed but at the same time outspokenness is frowned upon. I have tried to be in total control of my life but finding

it impossible to do so in an institution.

People afraid to give evidence

PWDWA has had contact from people who do not wish to be named or participate because they “fear retribution” if their accommodation provider were to find out they had given input to the Senate Inquiry. Their key concern is that they are treated as “a cog in a wheel” not as an individual and that they are seen as a troublemaker when they try to assert their needs or make complaints about any unacceptable practises. Privacy or rather lack of privacy is another issue that concerns them – even such things as making a telephone call in private. Also support to attend appointments outside of the home is another issue.

We are very cautious around any housing models where there is not access to the community or integration with the community, and where a person has no say on the support they receive. People currently in accessible accommodation in congregate care want more control of the supports they get if this is where they must live.

Child Protection and Corrective Services as Alternate Systems of Care

While we do not have any case studies immediately at hand, we would like to raise in this submission that both the child protection and criminal justice systems also potentially serve as alternative systems of care for people with disabilities. We have not referenced have any data sources in relation to people with disabilities in the child protection system either as parents or as children, or people with disabilities in our prisons.

Here in Western Australia, one of the most topical issues recently in relation to alternative systems of care for people with disabilities has been in regard to accused offenders who are found to be mentally impaired under this state’s *Criminal Law (Mental Impaired Accused) Act 1996*. This includes people with a serious mental illness, a cognitive or intellectual disability. For some time there has been concern about the indefinite detention of such people in our prisons, which are not well designed to respond to their needs. There have been several recent case studies that have attracted public attention that have demonstrated that prisons have become alternative and inappropriate systems of care for several people with intellectual or cognitive disabilities who could be considered to be ‘at the margins’ or have complex needs. The inappropriateness of prisons for this population has long been recognised, and in 1996 the relevant legislation was amended to allow for the establishment of ‘declared places’ to support these offenders. No action was taken to implement ‘declared places’ for people with untreatable intellectual or cognitive disability until 2013, when the Western Australian state government announced that it would build two such facilities, to be known as a Disability Justice Service, to be administered by the Disability Services Commission. This was a significant and welcome development, because it ensured that the centres would be run with a focus on addressing the disability related support needs of these offenders and on models of support that specifically addressed the issues contributing to offending behaviour. The State Parliament passed legislation authorising the Disability Services Commission to operate ‘declared places’ in February 2015. The Service is expected to open in mid-2015 and is designed on a ‘flow-through’ model addressing people’s needs and supporting them to transition into the community. They are not intended to

become long-term alternative systems of care, and this is something that advocates will be closely following.

The *Criminal Law (Mental Impaired Accused) Act 1996* severely constrains the capacity of the criminal justice system to respond to the needs of this small population. It limits the choices available to judges, for example, and effectively drives people towards prison as an alternative system of care. These issues were highlighted in a joint submission by DDWA and the WA Association for Mental Health and other agencies to a current review of that legislation¹³. While the new Disability Justice Service is a welcome development, advocates are concerned that it will become the new alternative system of care to prison unless the legislation is significantly amended to enable judges to make non-custodial options for people that provide the kind of disability related supports necessary to successfully mitigate against the risk of reoffending.

F The options, consequences and considerations of the de-institutionalisation of young people with serious and/or permanent mental, physical or intellectual disabilities

This term of reference begs the question of what is understood by the term 'institution'. Institutions are widely understood either as a formal entity, or as a type of culture that prevails where the needs, choice and control of individual people come second to the management needs of a home, residence, facility, service or organisation. At different times there have been attempts to define institutions in terms of size, and while size is reasonably understood to contribute to the formation of institutional cultures it is not the defining feature. This debate often appears to be driven by an imperative to avoid defining various congregate models of care as institutions.

The terms of reference for this inquiry are very broad and seem to cover people with disability living in residential aged care, as well as those at risk of living in aged care. They also cover the pathways for receiving care and support and the alternatives to residential aged care. For people with high support needs and often medical support needs the options on where you can live and how you can get the right support are very limited. There are a range of factors which contribute, but one is the legacy of our built form.

Where congregate models of residential care have been built as hostels, or nursing home style environments, or even rows or villages of shared units, the experience of the people PWdWA support shows it is very difficult to provide flexible individualised support, particularly where the support and home are provided by the same entity. Whether it is one long building or a campus arrangement the set up is reliant on a majority of the rooms being occupied to provide the level of support needed and keep the whole viable. Therefore over time this built environment becomes self

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<http://waamh.org.au/assets/documents/systemic-advocacy/submissions-and-briefs/joint-clmia-submission-final-12.12.14.pdf>

perpetuating, and very difficult to change without a huge investment in capital. There are organisations, or people and families who may have started out wanting this type of support arrangement then when a person leaves or passes away someone must be found to fill the place or it becomes unviable, and so the perpetuation begins.

A couple of the organisations here in WA who have worked very hard to try and change the look and feel of that built environment but are still congregate accommodation settings, have still got some of the issues of being institutional our case studies show. We assert that part of the problem is that models of congregate care lend themselves to institutional practices and attitudes and not individualised and flexible supports. Therefore these are not and should not be alternatives.

In WA there were people with disability in aged care who were supported to leave using YPIRAC funding. They used the funding to get housing built as well as provide support. Without the housing they would not have been able to move even if they had the funding for support.

Here in Western Australia, the recent move by the State government to transition a substantial component of the accommodation services it currently provides to the non-government sector represented a significant opportunity to test how the options and consequences of de-institutionalisation are considered. While this opportunity has been welcomed by many advocates who have been concerned about institutional service delivery cultures in State government provided accommodation services, there has been significant concern that the process in place for managing this transition has not given due attention to the needs of people with disabilities and their families to give full consideration to the options and consequences. Specifically, the process has been criticized for not providing sufficient support to people to consider their options and for having limited options available. Until recently, there had not been a proactive strategy to connecting the people affected by this transition to independent individual advocacy if they were not satisfied with the options available to them and wished to take issue with the consequences of any decisions.

G What Australian jurisdictions are currently doing for young people with serious and/or permanent mental, physical or intellectual disabilities, and what they intend to do differently in the future

The broad and diverse needs of young people with serious and/or permanent disabilities as they make the transition from childhood into adolescence and adulthood are not the subject of a specific strategy as far as DDWA and PWDWA are aware. However, a WA My Way NDIS community development initiative funded by the Disability Services Commission and run by National Disability Service WA is currently underway with a focus on improving school-to-work transitions.

H The impact of the introduction of the National Disability Insurance Scheme on the ability of young people in aged care facilities to find more appropriate accommodation

The great hope for the NDIS is that by closing the gap between eligibility for disability support funding and access to disability support funding it will have a positive impact on the ability of all young people with disabilities to find appropriate accommodation.

For all young people, this will come down to a number of questions:

- whether or not the notion of ‘reasonable and necessary’ support will include the kind of transitions and pathways that are necessary for them to find the best accommodation option;
- whether or not the imperative to limit costs might define certain supports out of the NDIS, particularly where those supports relate to an interface with a mainstream support system; and,
- whether or not appropriate housing is available.

The provision and cost of health related support.

There is a concern that under the NDIS there will not be packages of a size which will be able to provide nursing care such as care for peg feeds, tracheostomies, catheters, et cetera. We are very concerned that people in residential care arrangements might find it harder to get the support they need to move out under the NDIS due to the lack of housing and the high medical and support costs that some people have. We are concerned that there may be an effort to push costs onto the health department who do not have an understanding of contemporary disability support, or the funding. The size of support packages are very high when nursing care is needed, and the emphasis on keeping average support packages low is detrimental to this group.

It is also a concern if aspects of care are considered to be covered by the health system and the health system don't take it up. In many cases there needs to be an overlap between health and disability.

Lack of affordable housing

The lack of affordable and accessible housing is a major issue for anyone wishing to move out of aged residential care or other forms of residential care. The main current mechanism for housing support is the Community Disability Housing Program (CDHP). The CDHP was established in 1996 and is a jointly administered program between the Disability Services Commission and the Department of Housing. The purpose of this program is to provide affordable rental housing for people with disability (with adequate support arrangements in place) to live independently in the community. The program is funded through the Commission, which transfers funding to the Department of Housing to either source existing or construct new properties. Applicants for the program need to be eligible for the community housing program, which has income and assets criteria. In addition, eligibility for the program requires sufficient support funding to be in place for sustainable provision of the required level of care for independent living.

People can't apply for housing until they have a support package. It could take up to two years then to get a house. The people we are supporting are all waiting for support funding and have missed out in previous rounds. A question must be will the Disability Services Commission in the future continue to pay for this housing? Under the NDIS housing is not included.