

NSW DISABILITY NETWORK FORUM

Introduction

The NSW Disability Network Forum (DNF) thanks the Community Affairs Reference Committee for the opportunity to provide a response to the Inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.

About the NSW Disability Network Forum

Initiated in June 2011, the NSW Disability Network Forum comprises non-government, non-provider peak representative, advocacy and information groups whose primary aim is to promote the interests of people with disability. The aim of the NSW Disability Network Forum (DNF) is to build capacity within and across all organisations and groups so that the interests of people with disability are advanced through policy and systemic advocacy. The Council of Social Service of NSW (NCOSS) provides secretariat support to the DNF.

NSW Disability Network Forum Member Organisations:

Aboriginal Disability Network NSW	Multicultural Disability Advocacy Association of NSW
Association of Blind Citizens of NSW	NSW Consumer Advisory Group - Mental Health
Brain Injury Association NSW	NSW Council for Intellectual Disability
Deaf Australia NSW	NSW Disability Advocacy Network
Deaf Society of NSW	People with Disability Australia
DeafBlind Association NSW	Physical Disability Council of NSW
Deafness Council (NSW)	Positive Life NSW
Information on Disability and Education Awareness Services (IDEAS) NSW	Self Advocacy Sydney
Institute For Family Advocacy	Side By Side Advocacy Incorporated
Intellectual Disability Rights Service	Council of Social Service of NSW

The DNF welcomes this Inquiry and believes it presents a real opportunity to find ways to meet the residential care and support needs of young people with severe physical, mental or intellectual disabilities (complex needs). One of the principles guiding the National Disability Insurance Scheme (NDIS) is:

Reasonable and necessary supports for people with disability should:

- (a) support people with disability to pursue their goals and maximise their independence; and*
- (b) support people with disability to live independently and to be included in the community as fully participating citizens; and*
- (c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the community and in employment.¹*

The DNF does not support institutionalised care of young people. The DNF believes that the creative and person-centred approaches that are arising in NDIS launch sites and more broadly as

¹ Disability Insurance Scheme Act 2013 (Cth) pt 2, s 4, sub s (11)a-c.

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Governments prepare for the transition should be accessible to young people and focused on supporting them to live in accordance with their vision and goals.

While it is clear that aged care facilities do not meet the social and cultural needs of young people, the DNF does not believe specialised facilities for young people or separate wings of aged care facilities for young people are the answer. These are still institutions and do not foster community inclusion and participation.

Enlivening the principles of the NDIS to support people to live independently, be part of the community and to exercise choice and control will require a harnessing of creative approaches and the tackling of systemic issues. The DNF offers the following comment against a selection of the Inquiry's Terms of Reference to promote the need for action so young people with complex needs have greater access to accommodation and support that works for them and recognises their capabilities.

d. the appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities;

The DNF does not support housing people with disability in institutions—whether they are aged care or other types of facilities. Aged care institutions are not appropriate for young people for several reasons. Young people in residential care have reported negative impacts of these environments.² These impacts include:

- mental ill health;
- a lack of access to community/social isolation;
- inability to exercise choice and control;
- a loss or reduction of life-skills;
- no appropriate mechanisms for sexual expression;
- distance from family and friends;
- isolation from their peers;
- regular exposure to death of fellow residents; and
- Distance from culture and country.

The Case Study overleaf demonstrates some of these impacts in an everyday situation.

² See, Brain Injury Association of NSW, MS Society, Multicultural Disability Advocacy Association of NSW, NCOSS, Physical Disability Council of NSW, People with Disabilities and The NSW Council for Intellectual Disability, *Younger People with Disability out of nursing homes: A Discussion Paper, 2002 and The Summer Foundation, The Victorian Younger People in Residential Aged Care Initiative: Evaluation of quality of life outcomes for participants, 2012.*

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Case Study

A man in his thirties with a significant physical and developmental disability became hospitalised due to health issues. He spent nine months in hospital as an appropriate solution to help him exit the hospital system could not be found. Prior to entering hospital, he had resided with his ageing mother who was experiencing the early symptoms of dementia. A support service had been in place in this home environment however due to multiple reasons, primarily the inability for the support service to look at this gentleman holistically, this had broken down.

He was exited from hospital and placed in a residential aged care facility. A local service advocated strongly for him to acquire accommodation through Housing NSW and after three months the man moved out of the residential aged care facility and into a purpose- built home to accommodate his complex physical needs. Due to the complexity of the gentleman's support needs, Ageing Disability and Home Care (NSW) pushed for him to move into a purpose built YPIRAC residential service. This process took a further 18 months to 2 years.

While in the residential aged care facility, the gentleman experienced a steep decline in both his emotional wellbeing and his physical wellbeing. Due to his communication barriers and the lack of appropriate training of nursing home staff, his needs were not being met. Due to the very lengthy hospitalisation followed by the nursing home stay he had virtually lost most of his skills in everyday living as there was little or no emphasis on maintaining this area of his life. As discussed, his emotional wellbeing experienced a dramatic decline and he was very concerned that this would be the place that he would end up dying. Residents within the nursing home showed very little understanding of his disability and he found himself isolated within this context. Due to his high level of anxiety in this setting he experienced negative relationships with the nursing staff.

Cultural Issues

Living in a residential aged care facility far from their own land, their home ground and their people can increase feelings of isolation for many younger Aboriginal and/or Torres Strait Islander people with disability. Where families face difficulties meeting the cost of travel to visit, living arrangements and separation from family can exacerbate the person's sense of desolation and marginalisation.

People with disability from Culturally and Linguistically Diverse (CALD) communities can be affected by the perception that highly bureaucratic systems (such as residential aged care facilities) provide better care and support than families and non-institutionalised systems. In some cultures, a view that professionals know best can contribute to a reduction in contact between the younger person with disability and their family.

The lack of extended family support systems (including difficulties in obtaining carer's visas for family members overseas) and the overall lower socio economic status of migrant families adds to the limited ability of families to support people with disability.

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The DNF believes that supported accommodation located within communities provides better opportunities to maintain cultural, family and social connections than institutional settings. The positive effect these connections have on people's wellbeing should not be underestimated.

Recommendations about the provision of accommodation are included below.

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

Consumer issues

Institutionalisation of young people is never optimal. Many people become so institutionalised that they have never learnt, or have forgotten how to exist within the community. This leads to deeply ingrained assumptions that people in these situations do not hold the capacity to live in the community. This is quite simply not the case.

There are various examples of where successful transitions out of residential care have occurred. In these cases, support services often hold a deep understanding of the established impacts of institutionalisation and work to assist the person and build their supports to accommodate community living. While some services do amazing work in this area, there is a real lack of this knowledge within the service systems and some decision-makers about the type and level of resources needed to assist people make this transition or avoid entering residential care. At times, this lack of knowledge sees both groups resort to the historical approach of large residential services and institutions. This dynamic can also extend to family members and supporters of the person with a disability. The consequences of institutionalisation are quite simply devastating for the person who has been subjected to this approach and in short it is a life lost.

Individual Support Plans can articulate a person's vision and goals for their life and articulate the supports needed for a person to transition out of, or avoid entering, residential care. It is important that young people with complex needs already residing in residential care facilities have access to planners, who are independent of the service system, to do this work with them.

The NSW Government has contracted five disability community organisations that are independent of service provision, to work with people to develop individualised support plans. This program was established to help people move to individualised, person-centred support as NSW transitions to the NDIS. People are referred to these organisations by Families and Community Services NSW (FaCS).

The development of plans by support planners who are independent of the service system resolves conflict of interest issues but more importantly it fosters a non-service system approach that begins with what a person wants to achieve, rather than applying or repeating a narrow, historical view of what is available to assist people because that is how it has always been. It is important to maintain a move away from historical approaches and provide people in residential care with all of the opportunities that individualised funding and new creative, innovative approaches can provide.

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There is a need to manage the paradigm shift from a time when residential aged care was seen as the only option for young people with complex needs. Training to promote alternative options and widely available information resources (as recommended above) will help to ensure this option does not continue to be put forward without offering alternative options that align with people's goals.

It is also important that young people with complex needs who are residing in, or at risk of entering residential care are given access to planners who can develop an individual support plan as a matter of priority. This group must not be left out or behind of the change process as the transition to NDIS gets underway.

The DNF suggests that FaCS could make young people in residential care a priority group for referrals to support planning services. The Committee may wish to explore options for similar prioritisation in other jurisdictions as part of this Inquiry.

Recommendation 1

FaCS makes young people in residential care a priority group to receive support planning services.

Recommendation 2

The Committee investigates how young people residing in residential aged care can be given priority access to support planning services (or the equivalent) in non-NSW jurisdictions.

Systemic issues

Often people are placed in residential care because of a lack of alternative options. This care may be seen as safe and a site where 24-hour medical care is available. Helping young people to leave residential aged care will require the provision of alternatives.

Housing

The lack of secure, accessible and affordable housing is a systemic issue that must be tackled in order to provide viable, person-centred living options for young people with complex needs. This must occur as a matter of priority, with targets set and properties quarantined for this purpose.

It is important to understand that this issue will not be solved through existing Social Housing provision or the private rental market. Social Housing in NSW is under extreme pressure, with 'priority' applicants waiting an average of ten months for housing while general applicants face an average wait time of four years.³ The private rental market in NSW has a very small supply of affordable housing. For example, only 1 per cent of rental property in the NSW North Coast and 5 per cent of properties in the Riverina were both accessible and affordable for a single person receiving the Disability Support Pension.⁴

Access to affordable, accessible housing that is developed using universal design can provide young people with complex needs a basis from which other supports, including medical care and rehabilitation, can be provided.

³ NSW Government Social Housing Discussion Paper Section 3.1.2.

⁴ Anglicare Australia, *Rental Affordability Snapshot*, Canberra, April 2014, 31 & 41 available at: http://www.anglicare.asn.au/site/rental_affordability_snapshot.php last accessed 10/02/15.

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Access to peers and community is an important factor in ensuring that young people with complex needs are included and can participate in community. For this reason, the DNF believes that housing that offers tenancies to a diverse range of people is important. The design should focus on reducing segregation and encouraging interaction between all tenants/owners rather than clustering (or segregating) people with complex needs onto one floor or area. Some grouping may be required to provide access to equipment or care, however small groups or clusters would be the goal.

The DNF recognises the economic pressure at all levels of Government makes further investment in housing infrastructure a challenging prospect. However, we believe that there are opportunities to work in collaboration with State and Federal Government, Community Housing Providers, Disability peaks, Community Sector peaks and private interests such as the peaks in the Urban Development space to explore opportunities to incentivise the building of accessible, affordable housing stock that includes accommodation suitable for young people with complex needs.

The National Rental Affordability Scheme incentivised the building of properties that included rental accommodation offered to low and middle income households at rates 20 per cent below the market rate.⁵ Although active funding rounds for NRAS no longer exist, the Scheme serves as an example of how collaboration between a range of interested parties can produce solutions to infrastructure challenges that Government alone cannot solve.

Recommendation 3

The Department of Social Services deliver a consultative process to explore opportunities to incentivise the building of housing stock for diverse tenant and owner groups that includes accessible, affordable, universally designed accommodation with a proportion quarantined for young people with severe physical, mental or intellectual disabilities. The process should all levels of government and peak bodies from disability, community housing, the community sector and urban development.

With NRAS no longer funded, the five-year Young People in Residential Aged Care (YPIRAC) Initiative coming to an end in 2011 and Social Housing at jurisdictional levels under enormous pressure, the DNF believes there is a need for a long-term strategy to make appropriate accommodation available for young people with complex needs. As noted above, the DNF acknowledges that this strategy will need to be enlivened by joint efforts. Nevertheless, the ongoing unmet need and the fact that accommodation facilitates all other support services highlights the need for innovative strategies and the setting of targets to ensure young people in residential aged care benefit from the principles of inclusion and participation enshrined in the *Disability Insurance Scheme Act*.

⁵ Australian Government, Department of Social Services, *National Rental Affordability Scheme*, website, available at <https://www.dss.gov.au/our-responsibilities/housing-support/programmes-services/national-rental-affordability-scheme> last accessed 10/2/15.

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Recommendation 4

The Department of Social Services produce a Discussion Paper and consultative process as an initial step towards the development of a long term accommodation strategy for people with disability who have complex needs.

Access to assistive technology and home modifications

The availability of more flexible supports under NDIS and access to home modifications and assistive technology can help people with complex needs avoid or move out of residential aged care. Lack of timely access to assistive technology or home modifications is an issue facing many people with disability. For people with complex needs, long waiting periods may prolong stays in residential aged care that could be avoided altogether or shortened with more timely access.

Recommendation 5

Timelines should be set for the provision of assistive technology and home modifications that standardise maximum waiting periods. Data on delivery against these timelines should be collected and inform regular reviews of the need for funding injections to meet need.

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;

Multiplying the benefit of creative approaches

The NDIS is changing the face of service provision for people with disabilities. Capacity to individualise funding packages and exercise choice and control are providing people with person-centred, rather than service system focused options.

Recently, Price Waterhouse Coopers (PwC) worked with the Summer Foundation to produce demographic projections of young people in residential aged care in the NDIS launch sites and investigate the resource implications within these sites over a four year period from 2013.⁶ This work projected that the majority of young people in residential care (65%) are likely prefer to leave residential care.⁷

The NDIS is encouraging creative approaches that may not have previously been available to people. Given a whole new system is in place, it will be important to learn from the experiences of young people in NDIS launch areas who transition out of residential care to understand what factors are enabling these move and what gaps may prolong their stay. Young people in residential care, their families and supporters would benefit from access to information about creative options that have helped others to transition out of residential care. They may also benefit from understanding others'

⁶ Winkler, D., Callaway, L., & Guthrie, S. (2013) *National Disability Insurance Scheme launch sites: Projection of the number of young people in residential aged care*. Sydney, NSW & Melbourne Victoria: PwC & Summer Foundation Ltd.

⁷ Ibid, 31.

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experiences of the transition process so they have knowledge to assist them with what may be a challenging and complex process.

An evaluation of the NSW Younger People in Residential Aged Care (YPIRAC) Program recently found that people did not understand what was available or how to navigate the system.⁸ The introduction of Ability Linkers is a recent innovation that will help people navigate formal and informal support systems. However, there is a particular need to create an up to date evidence base and accessible resources to inform people about innovative and creative approaches that are helping young people move out of residential aged care.

Recommendation 6

The National Disability Insurance Agency (NDIA) make targeted research and capacity building grants available to explore the experiences of young people transitioning out of residential care to create an evidence base on facilitators and barriers within the NDIS launch site areas.

Recommendation 7

These grants should also facilitate the development of information resources for young people wanting to exit residential aged care, their families, supporters and the sector (including Ability Linkers). Grants should be available to Aboriginal and CALD organisations to produce culturally appropriate resources that are accessible to diverse audiences.

⁸ NSW Department of Human Services, Evaluation of the NSW Younger People in Residential Aged Care (YPIRAC) Program: Final Report-March 2011, 4.