



Office of the Public Guardian  
(Queensland)

Submission to the Senate Community  
Affairs Reference Committee

*Inquiry into the Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*

## Background to the Public Guardian

On 1 July 2014 a new independent statutory body—the Office of the Public Guardian (OPG)—was established to protect the rights and wellbeing of vulnerable adults with impaired decision making capacity, and children and young people in out-of-home care (foster care, kinship care), residential care and youth detention.

The OPG combines the roles that were previously undertaken by the Adult Guardian and Child Guardian and has special responsibilities to support and protect the rights of children and young people in the child protection system. The OPG supports children in care through two specific programs; the community visitor program for children in care, which aims to ensure children and young people in the child protection system are safe and well and are being properly cared for, and the child advocacy program, which gives children in care an independent voice, ensuring their views are taken into consideration when decisions are made that affect them.

Children and young people in out-of-home care have particular needs that must be addressed in order to ensure their safety and improve their emotional, physical and psychological well-being.

The Charter of Rights for a child in care under the *Child Protection Act 1999*, section 74 and Schedule 1 describes the core rights that apply to every child and young person who is in the child protection system and includes the right to be provided with a safe and stable living environment and to be placed in care that best meets their needs and is culturally appropriate.

The OPG also works to protect the rights and interests of adults who have an impaired capacity to make their own decisions, recognizing that everyone should be treated equally, regardless of their state of mind or health.

Our charter with respect to adults with impaired capacity is to:

- Make personal and health decisions if we are their guardian or attorney
- Investigate allegations of abuse, neglect or exploitation
- Advocate and mediate for people with impaired capacity, and educate the public on the guardianship system.

The OPG also provides an important protective role in Queensland by administering a community visitor program to protect the rights and interests of the adult if they reside at a visitable site.

The *Public Guardian Act 2014* and *Guardianship and Administration Act 2000* set out our legislative functions and powers and the *Powers of Attorney Act 1998* regulates the authority for adults to appoint substitute decision-makers.

## Position of the Public Guardian

The Public Guardian welcomes the opportunity to respond to the Senate Standing Committee on Community Affairs inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.

Lack of appropriate accommodation is a significant barrier for OPG clients. The inability to find accommodation for clients with serious intellectual and cognitive disabilities and complex behavioural or health problems often means that the residence in an aged care facility is the only available option, regardless of its appropriateness to meet the disability and support needs of the client.

### Appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities

#### *Need for an appropriate model of care*

For the purpose of this inquiry, I have understood 'young people' as referring to persons under the age of 65 years. On this basis, the aged care system is by its very nature not designed to support and care for young people with disabilities. The model of service and care in an aged care facility is directed towards providing for the nursing and personal care of people as they age, and is focused upon persons aged 65 years and above.

The model of care in an aged care facility is more aligned to a health model of treatment and care, than a disability model designed to address barriers that a person with disability might face to full participation in society through provision of rehabilitation and habilitation programs, and other supports and services. Persons with all levels of intellectual, cognitive and mental disability need access to varying levels of rehabilitation and habilitation programs to enable integration into the community and development of independent living skills. Aged care facilities generally do not provide programs or facilities to develop or maintain these skills.

Aged care facilities are generally not 'home-like', but are more 'institutional' in their setting, with limited privacy, individual choice and decision-making (such as meal or bed times, or the ability to prepare one's own food). There is a risk that a person with disability may have a diminished social life through limited opportunities to develop relationships in the community with individuals of their own age. Therefore, appropriate accommodation for a person with disability provides choices of lifestyle and opportunities for participation in the community.

There is a significant risk that the longer a person with a disability resides in an aged care facility they will experience a corresponding decrease in their functional capacity. This in turn leads to the need for increased support needs over time. Without ongoing habilitation and rehabilitation support and proactive development of living skills, a person with disability may lose (or not attain) life skills needed for independent or community living. If the person is subsequently presented with the option of alternative accommodation outside of an aged care facility they may require substantial support to address the deterioration in significant life skills which has occurred while living in the aged care facility. In the experience of OPG clients, the longer that a person with disability stays in an aged care facility, it becomes less likely and more costly to transition that person to supported living in the community.

It is also important to note that the workforce in aged care facilities are generally experienced and trained in aged care, and is invariably not skilled or trained in best contemporary practice of disability service, support and care.

*Recommendation 1*

An appropriate system of care for a young person with serious and/or permanent mental or physical disability in a residential facility should, amongst other things, provide access to: the community, independent living, specialist disability supports, and schemes to learn and develop educational or vocational opportunities and be supported by a workforce trained and equipped to provide such care.

***Appropriate accommodation should meet complex needs and comorbidities***

Overall, the aged care system is not equipped to address the complex disability support needs of this cohort, particularly with respect to behavioural issues. Young people with severe mental or physical disabilities who have complex health and support needs are often placed in aged care facilities. This may be due to insufficient funding available to provide the substantial supports required to assist them to live in the community or prioritisation issues under the *Disability Services Act 2006* (Qld).<sup>1</sup>

While there is a dearth of available accommodation in the community, even finding an aged care facility that *will* accept a person with serious mental or physical disabilities and complex health needs can be a real challenge, as often the person's behaviours are too complex for the aged care facility to handle. In the experience of the OPG while it can be challenging to find accommodation for middle aged adults, it can be even more difficult to find appropriate accommodation for young adults, particularly clients with challenging behaviour, health issues, and an intellectual or cognitive disability.

Placement in an aged care facility can be compounded by the nature of the accommodation provided being inappropriate. There is limited ability of an aged care facility to tailor the residential environment to suit an individual person's needs. This often leaves only one of two options available: either an open ward, or closed/locked ward facilities. A person with behavioural issues linked to their disability may find themselves in either a 'locked' or 'dementia' ward due to the facility's inability to manage their behaviour in a less restrictive way. In these cases, people who have previously been managed under positive behaviour support<sup>2</sup> programs in disability services find their liberty and independence drastically diminished.

In other situations, an aged care facility may be the only accommodation option if a disability accommodation service is no longer able to cope with the dementia and associated behavioural issues. The OPG has had several cases involving clients under the age of 65 with intellectual disability who have developed early onset dementia. For these clients there is often no alternative other than to be placed in an aged care facility. There can be several contributing factors leading to this outcome. These factors may include the inability of the disability service provider to cope with the increase in disability support needs of the client, or the limited funding available for the increased funding and support package needed to meet the person's needs in the community. The problem is exacerbated by a shortage of

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<sup>1</sup> See section 8 of the *Disabilities Services Act 2006* and the provision of disability services in Queensland being subject to the state's finite resources and prioritisation

<sup>2</sup> Positive behaviour support refers to strategies and methods to assist a person to reduce challenging behaviour and increase the person's quality of life through teaching a person new skills and adjusting their environment to promote positive behaviour change.

purpose-built community-based accommodation that can provide disability services and support for mainstream clients, let alone for persons with complex and high support needs.

*Recommendation 2:*

Favourable consideration needs to be given to the provision of purpose-built community based accommodation that can provide dedicated disability and support services for young people with complex and high support needs on a respite or more permanent basis.

*Need for greater regulation of aversive or restrictive practices*

In Queensland, if an adult with a disability displays challenging behaviours that could cause harm to themselves or others, an application can be made to the Queensland Civil and Administrative Tribunal to have a guardian appointed with special responsibilities to help manage those behaviours. If a guardian is appointed, they need to consider the use of a positive behaviour support plan, which could include a range of 'restrictive practices' such as: containment and seclusion; chemical (medication), physical or mechanical restraint or restrictive access. There are also a number of other factors that restrictive practice guardians are required to consider, but these vary with each individual and include: appropriate assessments, seeking specialist medical advice, and compliance with legislation.

With respect to the use of aversive practices (such as physical, verbal or emotional abuse, or deprivation and punishment), there is a responsibility on disability service providers in Queensland to ensure that staff do not engage in such practices, through the provision of appropriate policies, procedures, training and supervision.

In Queensland there are legislative provisions and regulations providing safeguards with respect to such practices in disability and mental health services, including the independent OPG community visitor program. However, there are few equivalent safeguards in aged care facilities. There appears to be a lack of transparency in the use of aversive or restrictive practices with respect to young people with serious mental and physical disability residing in aged care facilities. Legislative regulation of such practices, particularly as they relate to the cohort in question would ensure that restrictive practices comply with best practice of behaviour management support and aversive practices are prohibited.

*Recommendation 3*

While aged care facilities continue to accommodate young people with severe physical, mental or intellectual disabilities, it is recommended that greater focus should be directed towards ensuring such practices are regulated and monitored, with safeguards that are commensurate with protections given to other vulnerable persons in Queensland.

*Recommendation 4*

It is also recommended that independent community visitor programs be funded for monitoring aged care facilities to ensure that the rights and interests of the residents, particularly resident young persons with disability, are protected.

## Alternative systems of care available in federal, state and territory jurisdictions for young people with serious and/or permanent mental, physical or intellectual disabilities

### *Need for investment in alternative systems of care*

Investment is needed to develop and fund alternative systems and care. Without innovation and alternatives, there is a risk of a return to institutionalism. Although there are alternative systems that have emerged for young people with serious disabilities, such as the Youngcare model and Endeavour Foundation residential accommodation services, these models are appropriate for some individuals, but not for all. Models of care are needed that can be individualised and adapted to each person's needs. Innovation in this area should have particular focus upon ensuring appropriate systems of care for persons with disability with high and complex support needs are developed and not placed in the 'too hard basket'.

#### *Recommendation 5*

It is recommended that an appropriate system of care should be developed that includes plans for care, rehabilitation and habilitation, holistic care and supports that enhance a person's autonomy and assist them in either living or transitioning to living in the community, either independently or with support, regardless of the complexity of the person's support needs.

### *Need for culturally appropriate systems of care*

A significant issue of concern for OPG clients is the lack of appropriate systems of care for Aboriginal and Torres Strait Islander young persons with disability. Every young person is entitled to placement in a care environment that not only meets their needs but is also culturally appropriate. In practical terms, with limited choice of facilities there may be no alternative other than to move a young person to an aged care facility located some distance from their cultural community. In addition, the person may find themselves placed in a culturally inappropriate and unduly restrictive environment due to their disability and behaviour.

#### *Recommendation 6*

Where Aboriginal and Torres Strait Islander young persons are only able to be placed in residential services outside of their community, it is essential that facilities provide appropriate cultural supports and less restrictive living environments as part of the effort to reduce intergenerational trauma and loss of connection to community.

### *Need for appropriate systems of care for children and young persons with disability*

Article 23 of the United Nations Convention on the Rights of the Child provides that children who have any kind of disability should receive special care and support so that they can live a full and independent life. The current residential models available for care for children and young people with disability in Queensland, particularly if they reside in age care facilities, risk falling short of this obligation.

Children and young people with a disability are especially vulnerable with respect to their safety. Placement in aged care facilities are not necessarily a safe option for children. Models of care are needed that are specifically designed for children to ensure their safety and well-being. Anecdotally, the OPG has observed incidences where young people with a disability have been harmed as a result of inadequate safety measures in the care environment, including within aged care facilities.



Following public concern over the increasing number of children and young people coming into care, the Queensland Child Protection Commission of Inquiry was established in July 2012 under the leadership of the Honourable Tim Carmody QC (the Carmody Inquiry). The Carmody Inquiry was charged with conducting a far reaching review of Queensland's child protection system to determine if the system was failing children and, if so, why and what should be done to fix it. The final report *Taking responsibility: A Roadmap for Queensland Child Protection* was released in July 2013 and concluded that the existing system was not ensuring the safety, wellbeing and best interests of children as well as it should.

In line with recommendation 12.8 of the Carmody Inquiry, the Community Visitor Program of the OPG for children was refocused to provide more help and support to the most vulnerable children and young people in out-of-home care, as well as children and young people in residential care, mental health facilities and young people in detention or prison. The Public Guardian, as part of recommendation 12.7 of the Carmody Inquiry, was also given special responsibilities to provide individual advocacy for children and young people in the child protection system, ensuring their views and wishes are taken into consideration when decisions are made about them and their care arrangements.

One of the issues examined under the Carmody Inquiry included the practice of a parent who is no longer able to care for a child with a disability being required to unwillingly relinquish their child to the child protection system, in order to obtain access to full-time services required. The Carmody Inquiry heard that the removal of a young person with a disability or high support needs from their family's care due to a lack of support to enable the family to continue to care for their own loved one is very traumatising for both the young person and their family. Subsequently, the Carmody Inquiry recommended at 4.12 that this practice of relinquishment cease and Disability Services allocate sufficient resources to families who have children with a disability to ensure that they are adequately supported to continue to care for their children. Every year approximately 14 children in Queensland are subject to relinquishment and cared for by Child Safety Services until their 18th birthday.<sup>3</sup> The Carmody Inquiry noted that these children require extreme levels of support in their home for more than 50 per cent of the time and cannot be provided with this support by Disability Services and that there is no available out-of-home placement for these children within the disability service system.<sup>4</sup>

It is inappropriate for these children to be unwillingly relinquished to Child Safety and placed in the child protection system. In determining whether a child is in need of protection Child Safety must determine the child is at risk of *significant harm* and does not have a parent able and willing to protect the child from significant harm.<sup>5</sup> The requirements of significant harm (most likely from neglect) and the lack of able and willing parents, would be satisfied by few of these cases, if any.

The Carmody Inquiry was also of the view that all residential care facilities for children should have a therapeutic framework focused upon the child's needs, within which to deliver their services, and recommended the government partner with peak agencies and non-government residential care service providers to develop a suitable framework. The inquiry

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<sup>3</sup> Queensland Child Protection Commission of Inquiry, *Taking Responsibility: A Roadmap for Queensland Child Protection*, June 2013 p.111

<sup>4</sup> *Ibid.*, p111

<sup>5</sup> See section 10 of the *Child Protection Act 1999* (Queensland), noting that the risk threshold for a child in need of protection was increased as at 19 January 2015 from 'harm' to 'significant harm'.

also explored options<sup>6</sup> for alternative out-of-home care placements, identifying options as worthy of further exploration, including the use of professional carers to assist in meeting the needs of children and young people with complex and extreme problems.

The risk in Queensland is that the number of these children with disability who cannot be provided with substantial support packages and/or out-of-home placement will continue to increase unless alternative care arrangements and supports are provided. However, in light of the pending transition of Queensland to the National Disability Insurance Scheme (NDIS) in 2016 there is a corresponding risk that resolution of this issue will be placed 'on hold' in the hope that the NDIS will provide the 'reasonable and necessary' supports and funding required to assist these children, effectively leaving these children in limbo.

#### *Recommendation 7*

Appropriate systems of care, and most importantly, appropriate out-of-home placements need to be developed to address the high level of support required to meet the increasing complexity of behaviour and needs of children with severe disability, particularly as they mature and age. Funding and prioritisation of these children's needs is required for appropriate accommodation and services to provide full time care for these children and ensure ongoing participation in care and decision making by parents and families of these children, untainted by any stigma or restrictions associated with the child protection system.

It is crucial that there is greater investment in developing alternative systems of care to address this issue, including supports and accommodation required to transition the child to independence when they reach the age of 18.

#### **Options, consequences, and considerations of the de-institutionalisation of young people with serious and/or permanent mental, physical or intellectual disabilities**

De-institutionalisation is dependent upon the availability of appropriate accommodation in the community, and supports, services and specialised staff to meet the varied and complex needs of this cohort. Insufficient and inappropriate supports can lead to negative outcomes, risking a return of the person to institutional living. Effective de-institutionalisation is individualised and places the person and their needs at the centre of services and support provided, optimising the person's social, physical, economic and emotional well-being.

Transitioning a person to live in the community requires funding and investment. Services are needed to develop and maintain the use of life skills that maximise the person's ability to integrate into the community and live independently either with, or without, supports.

Transition is not an easy process for a person with moderate disabilities. For OPG clients with serious disabilities and complex needs, the transitioning from an institutional environment to the community is a challenging path. Persons with dual diagnoses of intellectual or cognitive disability and mental illness, or those who exhibit 'challenging behaviours' are at higher risk of being left out of de-institutionalisation processes and placed in the 'too hard' basket as they require substantial (and therefore costly) support packages and comprehensive transition programs.

Once a person is transitioned to living in the community it is essential to ensure long and short term treatment and rehabilitation options are available. Community based rehabilitation

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<sup>6</sup> *Ibid.*, the Carmody Inquiry, p278-284



services are essential for those with serious acquired brain injuries in order to re-attain life skills and increase opportunities to re-develop their capacity to participate in community life.

*Recommendation 8*

Every young person is entitled to live a full life. In keeping with this entitlement, de-institutionalisation requires targeted funding and investment to develop a broad range of accommodation options and innovative service responses to enable young people with disability to live in the community in a way that supports their will, preferences and rights. Regardless of the severity or nature of disability, all people should have the opportunity to participate in community and decisions about their life, including being supported in their decision-making with respect to options for the future. For individuals with high and complex disabilities this may mean substantial support packages need to be provided.

*Recommendation 9*

People with disability also need to develop and maintain strong connections with the community and their families, with their families engaged in the ongoing care and support provided. In order to achieve effective de-institutionalisation particularly for OPG clients, support and service responses need to be holistic to address their multiple and complex needs. Delivery of human services across governments and non-government service providers need to address issues of co-ordination and case management to ensure a more strategic and targeted delivery of services that meets the specific and often complex needs of a young person with disability.

### Impact of the introduction of the National Disability Insurance Scheme (NDIS) on the ability of young people in aged care facilities to find more appropriate accommodation

Individuals with intellectual, cognitive or mental disability and complex needs require services and supports available from a range of health, housing, and specialist disability services. There is a high risk that many of these needs are unlikely to be resolved or provided through the NDIS, either by virtue of being outside the intended scope of disability support, or not deemed 'reasonable and necessary' supports. Without significant investment in funding and developing appropriate community accommodation, the impact of the NDIS on the ability of young people in aged care facilities to find more appropriate accommodation should not be overestimated.

The NDIS is intended to provide an individual with disability with more choice and control over how, when and where their supports are provided, emphasizing their social and economic participation to increase their independence and develop their capacity to actively take part in the community. However, 'choice' and 'control' is predicated on the basis that there is a real choice available. Anecdotally, the OPG has observed that the more complex the needs of the individual concerned, there is a correlating decrease in availability of choice of services, supports or accommodation. For many OPG clients in aged care facilities there are no other accommodation options available. There is anecdotal evidence that smaller services have struggled to compete in the market against larger, more established disability organisations. There is already very limited choices for the cohort with high and complex needs. When only one or two organisations dominate the disability accommodation market, there is effectively no real alternative or 'choice' other than residence in an aged care facility.

Persons with complex disability and support needs are just as entitled to real choice in accommodation service provision as those in the mainstream with moderate disability. Substantial investment in alternative accommodation is required to ensure that these individuals with complex needs are not the ‘last cabs off the rank’ or ‘left behind’. Without inter-governmental commitment to funding and cooperation between the Commonwealth, disability service providers, health and housing prior to full implementation of the NDIS, the impact of the NDIS on young people with complex disability support needs and their ability to find more appropriate accommodation is likely to be negligible.

It should also be noted that there are significant cost and income pressures on the non-government sector which threaten the viability, availability of choice and sustainability of services. These issues need to be addressed if the NDIS is to rely upon the non-government sector to deliver disability services and supports that provide real ‘choices’ to meet not only mainstream, but also the more complex (and therefore costly) disability support needs.

*Recommendation 10*

It is recommended that significant investment in infrastructure and workforce development be prioritised under the NDIS. Urgent funding and cooperation is required between governments and the non-government sector to address two of the greatest barriers to implementation of the NDIS, namely, lack of appropriate accommodation options and a skilled workforce to address the gaps that currently exist in the service delivery and support needs of this cohort.

### **Concluding Comment**

I am pleased to lend my support to the Committee as it progresses this inquiry in the interests of ensuring that future arrangements to address residential care arrangements for young people with severe physical, mental or intellectual disabilities meet the needs of the people that they are designed to support. I would be pleased to make myself available to the Committee should there be an opportunity to expand on the issues raised above.

**Kevin Martin**

**Public Guardian**