****

**JFA Purple Orange Submission**

To the Senate Standing Committee on Community Affairs’ Inquiry on *The adequacy of existing residential care arrangements for young people with severe physical, mental or intellectual disabilities in Australia.*

**Submitter details**

JFA Purple Orange

104 Greenhill Road

Unley SA 5061 AUSTRALIA

Telephone: + 61 (8) 8373 8333

Fax: + 61 (8) 8373 8373

Email: admin@purpleorange.org.au

Website: www.purpleorange.org.au

Facebook: www.facebook.com/jfapurpleorange

**Contributors**

Geoff Barber, Chief Operating Officer

Ann-Marie Loebel, Policy Officer

JFA Purple Orange Policy & Initiatives team

**About the Submitter**

JFA Purple Orange is the social policy arm of the Julia Farr Association Inc. We are a non-government, social profit organisation that conducts research and engages in dialogue with people with lived experience of disability to develop policy and practice. Our work is anchored on the principles of Personhood and Citizenhood.

© February 2015 Julia Farr Association Inc.

Contents

[1. Summary 4](#_Toc412197778)

[2. Introduction 6](#_Toc412197779)

[2.1. JFA Purple Orange 6](#_Toc412197780)

[2.2. International and National Contexts 6](#_Toc412197781)

[2.2.1. The United Nations Convention on the Rights of Persons with Disabilities 6](#_Toc412197782)

[2.2.2. The National Disability Strategy 7](#_Toc412197783)

[2.3. Key Values 8](#_Toc412197784)

[3. Our Approach to this Submission 10](#_Toc412197785)

[3.1. Definitions 10](#_Toc412197786)

[3.2. TOR (d) The Appropriateness of the Aged Care System for Care of Young People with Disability 10](#_Toc412197787)

[3.2.1. Why are young people living with significant disability living in residential aged care facilities? 12](#_Toc412197788)

[3.3. TOR (f) the options, consequences and considerations of the de-institutionalisation of young people with disability. 15](#_Toc412197789)

[3.3.1. What type of system do we want? 15](#_Toc412197790)

[3.3.2. Principles and values 16](#_Toc412197791)

[3.3.3. Framework to navigate the system 17](#_Toc412197792)

[3.3.4. A range of options 19](#_Toc412197793)

[3.3.5. An example of contemporary community social housing 21](#_Toc412197794)

[3.3.6. Separation of accommodation and support 22](#_Toc412197795)

[4. Conclusion 24](#_Toc412197796)

[5. Recommendations 26](#_Toc412197797)

# Summary

JFA Purple Orange is an independent, non-government organisation based in South Australia that fosters innovation, shares useful information and promotes policy and practice that support and improve the life chances of people living with disability.

In preparing this response we interviewed a number of people with lived experience of disability who moved from, or were at risk of placement in, a residential aged care facility. The individuals interviewed highlighted the fundamental human need, and right, to have authorship over their own lives, and to make their own daily decisions about food, activities, and social contact – decisions most of us take for granted.

We have addressed the core issues, namely the inappropriateness of residential aged care facilities for young people living with significant disability, and have suggested a framework and options to inform future discussions.

Young people moving from, or at risk of placement in, residential aged care facilities need a range of creative and innovative housing solutions to enable participation and real choice. This should be the norm, and not an opportunity available to a lucky few.

JFA Purple Orange commends the Senate Standing Committee on Community Affairs and the heartfelt comments individuals made about the inadequacy of residential aged care facilities. The comments highlight the importance of living in the community which brings with it choice and control, valued roles in community life, and social connections bringing a sense of companionship, emotional support and belonging. In other words, no different from the aspirations an able-bodied young person would have.

We recommend the Senate Community Affairs Committee:

1. Adopt the basic premise that it is never acceptable for a young person to live in a Residential Aged Care Facility.
2. Develop a national program which addresses the systemic failures at key transition points which contribute to young people living with disability being placed in residential aged care. This program should:
   1. target transition points such as health (hospitals and rehabilitation services), crisis care, education and arrangements with ageing parents and
   2. include strategies which increase/release the capacity of people living with disability and their families to imagine a range of positive outcomes, plan and make informed choices.
3. Endorse a clear set of values and principles for government, young people living with disability and their families to guide the decision making process. Values may include:
   1. Articulating the importance of power, choice and control
   2. The preference for young people to live in, or return to, their family or community
   3. The importance of capacity building for individuals for informed decision making
   4. Providing an environment which is responsive and flexible to individuals
   5. The availability of flexible funding, support and assistance.
4. Consider the opportunities and options provided through a framework such as The *Model of Citizenhood Support*[[1]](#footnote-1), which employs strategies and actions to facilitate choice, participation and autonomy.
5. Explore pathways to contemporary models to enable individuals to have genuine choice in their housing. These might include:
   1. Living with family with appropriate building modifications
   2. Co-tenancy with friends or flat mates in private rental or affordable housing
   3. Living alone with support as required in private rental or affordable housing
   4. Home-share options where a person with disability shares accommodation with someone without disability (often a student) for reduced or no rent in exchange for support around the home
   5. Attendant care – individual dwellings dispersed within a suburb, where tenants use the same support agency/support agency staff
   6. Mini-cluster housing – two or three units on one site with support as required.

# Introduction

## JFA Purple Orange

JFA Purple Orange applauds the Senate Standing Committee on Community Affairs’ commitment to achieving appropriate and just outcomes for people living with disability, and appreciates the opportunity to provide a submission to the Inquiry on “the adequacy of existing residential care arrangements for young people with severe physical, mental or intellectual disabilities in Australia”.

JFA Purple Orange is the social policy agency of the Julia Farr group, a trio of social profit, non-government organisations based in South Australia, working to improve the life chances of people living with disability. The Julia Farr group (JFA Purple Orange, Julia Farr Housing Association, and the Julia Farr Trust and Julia Farr MS McLeod Benevolent Funds) and its predecessor organisations have been involved with the disability community, older people and other vulnerable groups for more than 130 years. We are an independent, non-government organisation that fosters innovation, shares useful information, and promotes policy and practice that support and improve the life chances of people living with disability.

JFA Purple Orange is not a service provider – we deliver research, evaluation and information services anchored upon the stories and experiences shared by people with a lived experience of disability and others in their lives.

## International and National Contexts

The matters outlined in the Senate Inquiry Terms of Reference highlight some of the key factors which may impede or assist younger people living with disability from experiencing the community inclusion and participation stipulated in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), ratified by the Australian Government and endorsed by the National Disability Strategy 2010-2020.

### The United Nations Convention on the Rights of Persons with Disabilities

There is national recognition, through the ratification of the UNCRPD by Australia in July 2008, that all people living with disability have the right to live in the community, with choices equal to others.

Article 19 [[2]](#footnote-2) of the Convention sets out clear responsibilities for signatory nations to:

… take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

1. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and;
2. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
3. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

### The National Disability Strategy

The National Disability Strategy 2010-2020 highlights issues relating to housing and support in three of its six key outcomes. Outcome 1 (Inclusive and Accessible Communities) promises the “improved provision of accessible and well-designed housing with choice for people with disability about where they live”; Outcome 3 (Economic Security) undertakes to “improve access to housing options that are affordable and provide security of tenure,” and Outcome 4 (Personal and Community Support) identifies the “continued development of innovative and flexible support models for people with high and complex needs as an area for future action”. [[3]](#footnote-3)

JFA Purple Orange’s submission to the Senate Standing Committee on Community Affairs endorses the UNCRPW and National Disability Strategy. We provide evidence below, based on the lived experiences of people with disability, to support the life-changing choices and chances afforded to younger people living with disability who move out of residential aged care.

## Key Values

The work of JFA Purple Orange is anchored on the principles of *Personhood* and *Citizenhood* and is guided by human rights values and social inclusion. Each of us seeks to build a good life for ourselves. A good life might be characterised by the presence of the following:

* Authorship of an individual’s own life (often described as control and choice)
* Having valued roles in community life and the economy (often described as inclusion).

As set out in our *Model of Citizenhood Support*[[4]](#footnote-4), a good life is characterised by such valued roles (termed Citizenhood) and by the decisions we make (termed Personhood). A good life largely depends on the availability of life chances – the assets and opportunities available to a person.

Unlike citizenship, Citizenhood is a dynamic experience: it can rise and fall depending on a person’s circumstances. The extent to which any person can naturally take up Personhood and Citizenhood is influenced by the presence of circumstances that can adversely impact on the person's capacity to build authorship of their own lives and the person's capacity to take up valued roles in community life and the economy.

As eloquently described in the South Australian Social Inclusion Board’s blueprint to enhance the life, and claim the rights of people living with disability:

Home is more than shelter; it is a place of identity and expression, sanctuary and safety, a place that fosters strength, wellbeing and revival. Home is intimately and inextricably connected to the person. People with disability need to have choice in the place and with whom they live rather than simply accepting an accommodation offer or not. Current accommodation offers rarely relate to social networks, location of family, recognition of culture, personal desires or ambition.[[5]](#footnote-5)

The importance of accommodation and appropriate individual supports for improving the life chances of people living with disability cannot be overstated. People living with significant disability can, and do, live as contributing and valued members of their local community regardless of the nature of their disability. A greater range of creative and innovative housing solutions must be established to facilitate choice and personal control, and enable an individual’s move into roles of Personhood and Citizenhood.

# Our Approach to this Submission

Our submission focuses on the values, matters of concern and experiences of JFA Purple Orange drawn from discussions with people living with disability.

The issues of primary interest to JFA Purple Orange are those outlined in two of the Inquiry’s Terms of Reference:

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

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

We interviewed a number of people with lived experience of disability who moved from, or were at risk of, placement in a residential aged care facility. We have included their reflections in our submission, along with suggested frameworks and recommendations for the Senate Community Affairs Committee to consider.

## Definitions

For the purpose of our submission, we have defined two of the Inquiry’s key phrases as follows:

* *Severe* – rather than severe we prefer the term *significant support needs* which includes “support in multiple areas of activities and participation, typically involving multiple service sectors.”[[6]](#footnote-6)
* *Young People* – less than 65 years old.

## TOR (d) The Appropriateness of the Aged Care System for Care of Young People with Disability

Placing young people living with disability in a residential aged care facility is **never** an acceptable option. The work of JFA Purple Orange highlights that individuals do not aspire to live in a residential aged care facility; regardless of age, people want to live in their own community where they have family, friends and connections.

One interviewee stated:

“Nursing homes do not provide adequate care or stimulation for a person with a young, agile mind. They don't provide any opportunity or encouragement to expand beyond the institutions walls to be a part of the greater community. It's inappropriate for a 20 year old to be housed solely with 80 and 90 year old people. Young people need to be involved with families and friends which provide warmth and love and life. All these things are essential for emotional stability.”[[7]](#footnote-7)

There are a number of core issues which highlight the inappropriateness of residential aged care for younger people with significant disability:

* **Institutional settings:** Institutions such as residential aged care facilities fundamentally segregate young people from the community. They provide an impoverished life for a young person, compared to the life of someone of a similar age without disability. An institutionalised lifestyle has an artificial structure and routine to the day; people generally experience a reduction in social contacts, particularly in interactions with people their own age; and have limited choice and control in their lives.
* **Age incongruence:** Young people are living in congregate care with people many years older. The number of permanent residents in Government-funded aged care facilities has increased by nearly one-quarter in ten years (23 per cent, or 31,028 residents between 2001 and 2011). Growth in the number of permanent residents aged 85 and over has been particularly significant, increasing by 39 per cent over this period, and residents aged 85 and over account for the largest proportion of all residents (57 per cent at 30 June 2011 compared with 50 per cent at 30 June 2001). [[8]](#footnote-8) The increasing age and frailty of aged care facility residents serves to amplify the inappropriateness of younger people living with disability in residential aged care facilities.
* **People living with disability being co-located:** It is more than the incompatibility of age groups that make residential care facilities inappropriate for young people. Young people don’t necessarily want to live with other young people living with disability in a residential care or group home setting; it may be a preference over living with people many years their senior, but is not an aspiration.

It is reasonable to argue that very few people living in group homes would choose to live in such a setting if they had a realistic choice. It is a compromise brought about by necessity, as they do not have enough support through funding for paid support, even augmented by their family and informal support networks, to live in their own home.[[9]](#footnote-9)

Research indicates internationally the situation is similar to that in Australia, in that younger people living with significant disability are placed into residential aged care facilities if no other options are available. In 2014, a Monash University researcher commented “Not enough accessible and affordable housing and support for people with disability is a worldwide issue.”[[10]](#footnote-10)

Monash University’s research indicates global data is scarce, but what is known is that in the USA, one in seven residents in residential aged care facilities is under 65, and since 2003 the population of younger residents in aged care facilities there has increased by 22 per cent. Canadian research has identified aged care facilities as an "inappropriate living environment" for people with acquired brain injury, but the research on which to model alternative arrangements is lacking. In the UK, recent research by a spinal injury charity says one in five people living with spinal injuries will end up in and aged care facility because there is nowhere else for them to go.[[11]](#footnote-11)

### Why are young people living with significant disability living in residential aged care facilities?

Across Australia, approximately 6500 young people live in residential aged care facilities. Nearly 700 of these people are under the age of 50; with some 5 per cent of that cohort under the age of 30. In South Australia in 2010, 473 people under the age of 65 lived in residential aged care facilities.[[12]](#footnote-12)

The work of JFA Purple Orange highlights there is a range of contributing factors which may trigger a change in living circumstances for a young person living with significant disability; often coinciding with a crisis point in their life.

Trigger points include:

* a traumatic accident or event
* declining general health
* carer’s age or ill health
* carer burn out
* the family home being unsuitable for modification or specialised equipment
* general cost of care.

These factors have a huge impact on the sustainability of housing for people living with disability. Currently, to receive the support they require, many younger people have no choice but to move into a residential aged care facility.

The work of JFA Purple Orange indicates the trigger points in isolation are not the causes of young people ending up in residential aged care. It is often the failure in the response to these transition points which result in residential aged care being the only or “best of a bad situation” solution.

From our experience there is often systemic failure at these key transition points, despite the efforts of hard-working practitioners. The disability sector needs to interconnect better with the health, rehabilitation, education and social welfare systems.

JFA Purple Orange observes people living with disability and families often have limited support to increase/release their capacity to imagine a range of positive outcomes, plan and make informed choices.

This often occurs at transition:

1. to independent living at early adulthood
2. post-hospitalisation and rehabilitation
3. due to the ageing, illness or death of a primary carer
4. due to a change in personal capacity of an individual or their service provision.

As the Productivity Commission Inquiry Report into Disability Care and Support (2011) noted:

The current disability support system is underfunded, unfair, fragmented, and inefficient. It gives people with a disability little choice, no certainty of access to appropriate supports and little scope to participate in the community. People with disabilities, their carers, service providers, workers in the industry and governments all want change.[[13]](#footnote-13)

Transition post-hospital is a known point at which a young person living with disability may enter aged care. Historically, the disability system has followed a common pathway to that of aged care, with discharge from hospital to a nursing home. One young person, living with Multiple Sclerosis, who spent a period of time in a nursing home for rehabilitation shared their experience:

“I couldn’t relate to anyone, and my friends didn’t want to visit because I was in a home, and the people there were 40 or 50 years older. Many [young people with disability] enter a home expecting to be there for a couple of weeks, but end up being there for a couple of years. This isn’t appropriate for young people. I want all young people to have a choice in their support and accommodation options.”

From our experience, the preferred pathway for people transitioning from hospital is to access community based rehabilitation within their own community, while adjusting to the home they will occupy post-rehabilitation (this may be their own home with modifications, or a new accommodation arrangement).

The following are comments from individuals who were at risk of moving into a residential aged care facility:

“I was scared at first [but then got a home in the community].”

“[Current housing] is a good system. I would hate to be this age [40s] in a nursing home – scary – living with people twice your age.”

“I don’t want to get stuck in one of those [residential aged care facility]. It may have to come to that though.”[if the individual’s health declines]. [[14]](#footnote-14)

## TOR (f) the options, consequences and considerations of the de-institutionalisation of young people with disability.

### What type of system do we want?

For many years, conventional disability support has tended to make a person living with disability a passive recipient of care instead of an active valued member of the wider community[[15]](#footnote-15) as “people with disabilities and their families are disempowered and have little choice.”[[16]](#footnote-16)

For young people living with significant disability, this system **must** change. Having authorship (choice and control) over our own lives is something most people take for granted. For people living with disability this is a right that often has to be fought for.

Few things are more fundamental than having somewhere to live. Having little or no

choice in where one lives has a profound impact on physical and mental health, and

the ability to participate in employment and community activities. Yet this is precisely the experience of many people living with disability.[[17]](#footnote-17)

Few Australians without disability can imagine what it would be like to have no say

in where they live or who they live with. The freedom to choose where and with whom one lives is a fundamental freedom, but it is one few people living with disability are able to exercise.[[18]](#footnote-18)

### Principles and values

In developing a more appropriate range of accommodation options for people living with significant disability, there are a number of principles and values to consider:

* **Supporting power, choice and control**: these are the essential expressions of Personhood. Individuals draw on their own Personal Capital (personal assets) such as potential, strengths, self-worth, vision, control and confidence to advance or uphold a good life. These values are critical when the person is making decisions, choices or taking actions. Supported-decision-making is an important process for some individuals to express their Personhood. [[19]](#footnote-19)
* **Facilitating younger people to live with or return to their community/family**: Young people living with disability have the same dreams and aspirations as others their age, and should have the same options available to them. Typically a young person would have the choice of living with family, sharing with one or more friends, a partner or flatmates or living alone. There are already young people living with significant disability in their community and we need to draw on their experiences and expertise.
* **Providing early investment to allow individuals and their families to plan:** Many younger people living with disability and their families are not aware of housing options available to them. Providing information early about funding and housing options will develop an individual’s capacity to make informed decisions. For example, conversations with young people living with disability living in community housing indicated that, although there is a structure and process in place, individuals generally viewed their placement in community housing as a result of luck, being in the right place at the right time, or having the right people backing them up. In effect people have little choice, and accept what is offered to them regardless of accommodation type or suburb, due to the shortage of appropriate housing and flexibility of personal support funding.
* **Develop an environment which enables, and is responsive and flexible to individuals’ situations rather than one that is fixed, predetermined and imposed:** Individuals should not have to “fit the system”. The system must be flexible enough to ‘fit’ them. This mandates a person-by-person approach, so that each individual determines what a good life looks like to them.
* **Funding flexibility and individualised self-directed support**: It is essential that there is a move from block funding which “locks” in the funding with a particular provider, and perpetuates a power imbalance between the provider and the individual, to a system of genuinely flexible and individualised funding.
* **Availability of funding, support and assistance:** People may need support and assistance to develop the awareness and capacity to be self-directing and self-manage their funding and no longer be constrained by service-provider’s systems.

### Framework to navigate the system

#### The Model of Citizenhood Support

The work of JFA Purple Orange is anchored on the principles of Personhood and Citizenhood, and how these might be advanced and upheld in the lives of people living with disability. The following information is taken from the *Model of Citizenhood Support*. [[20]](#footnote-20)

Citizenhood is a situation in which a person is actively involved as a valued member of their local community, contributing to community life. Citizenhood means people lead an active and fulfilling lifestyle informed by a set of personally defined lifestyle choices. They contribute and grow through their involvement in meaningful activities, and participate in a network of relationships characterised by acceptance, belonging and love.

The *Model of Citizenhood Support* is a framework for determining what kind of assistance might be most helpful to people in developing their Citizenhood. The Model carries the assumption that a good life is crafted by the decisions we make and the actions we take. However, our decisions and actions are facilitated or constrained by our life chances.

Having good life chances makes it easier for individuals to build a good life. Having fewer life chances makes it harder for people to build the life they want.

The *Model of Citizenhood Support* asserts that our life chances comprise four different, but interrelated, types of assets we can call upon, termed the Four Capitals. These are: Personal Capital, Knowledge Capital, Material Capital and Social Capital. The Model provides an opportunity for the person to reflect on how they are currently being supported and provides a similar opportunity for agencies or individuals (for example family or friends) to reflect on how they offer assistance to the person. Such reflection is important because the Model asserts decisions and actions taken by such agencies and agents will either grow Capital or diminish it; there is no decision or action that has a neutral effect on the Capitals. This is a critical point, because it illustrates the possibility that agencies or individuals involved in people’s lives may be making decisions or taking actions, however well-intentioned, that are diminishing the Capital available to the person.

Young people living in residential aged care experience a negative impact on their life chances, a reduction in their Four Capitals, and a decrease in Citizenhood. Upholding the Model of Citizenhood Support as a philosophical base will increase an individual’s life chances and should be the starting point for any conversation about housing options for younger people living with disability.

#### NDIS

In the NDIS landscape, the focus must be on the individual. The values of power, choice and control described earlier strongly align with the principles of the NDIS, and provide a context for:

“… a shift from block funding and a service-centred model to one in which people with disabilities and their carers would wield the greatest control, whether that be to cash out their package, or to have it met in flexible ways by providers.”[[21]](#footnote-21)

The NDIS website states the scheme:

“… gives you more choice and control over how, when and where your supports are provided, and gives you certainty you will receive the support you need over your lifetime.”[[22]](#footnote-22)

Given the context of the NDIS, no young person should have to live in a residential aged care facility.

### A range of options

Currently young people living with significant disability live in a range of accommodation from contemporary to traditional models, to those that could be considered more “historic”. Generally, there has been a sector-wide shift towards the contemporary models described below:

* Contemporary:
  + Living with family with appropriate building modifications
  + Co-tenancy with friends or flatmates in private rental or affordable housing
  + Living alone with support as required in private rental or affordable housing
  + Home-share options where a person living with disability shares accommodation with someone without disability (often a student) for reduced or no rent in exchange for support around the home
  + Attendant care – individual dwellings peppered with in a suburb who use the same support
  + Mini-cluster housing – two or three units on one site with support as required.
* Traditional:
  + Cluster-housing – one large central dwelling with multiple individual dwelling on same site with support as required
  + Small group homes - three or four individuals sharing one house
  + Large group homes - multiple dwellings on one site, each with a number of individuals sharing a house.
* Historic:
  + Boarding houses
  + Large congregate institutions.

From our experience we have noted the value of individual (rather than shared) tenancies. This ensures people living with disability are not obliged to live with three or four others in a group home setting, with people they may not know or have little in common with apart from living with disability.

The following comments were from interviews with social housing tenants and their families:

“You have your own unit, to do what you want. I couldn’t share with someone else.”

“[You have an] independent back yard, having your own things, family visiting. The family can sit in a casual setting, and you don’t get that in a nursing home – you have to go to a day area. There’s more time to sit - no time limits or restrictions. You can go to bed anytime you like. A better environment.”[[23]](#footnote-23)

JFA Purple Orange recommends that pathways to contemporary models are explored to enable individuals to have genuine choice in their housing, for both the 6500 younger people currently residing in residential aged care, and for those individual currently awaiting suitable accommodation options.

### 3.3.5. An example of contemporary community social housing

In preparing this submission, JFA Purple Orange interviewed a number of tenants in community social housing, where the building is owned and managed by a social landlord and personal support arrangements are provided independently.

The role of the social landlord involves much more than just providing an affordable "roof" over people’s heads or a bed to sleep in. Social landlords have a crucial role to play in promoting social inclusion and addressing barriers to accessible, life-enhancing housing; taking a person-centred approach and enabling tenants living with disability to have peace and comfort, security of tenure, safety and independence in their housing.[[24]](#footnote-24) [[25]](#footnote-25)

The tenants interviewed had all been part of the Younger People in Residential Aged Care (YPIRAC) program and had moved from, or had been at risk of admission into, a residential aged care facility. YPIRAC was a joint Commonwealth, State and Territory Government initiative implemented between 2006 and 2011, which aimed to reduce the number of young people living with disability living in residential aged care facilities throughout Australia.[[26]](#footnote-26) In South Australia, 50 younger people were supported to move from residential aged care under the YPIRAC program.

The tenants’ comments highlight the fundamental human need, and right, to have authorship over our own lives, to be able to exercise choice and control, and to make daily decisions about food, activities, and social contact that most of us take for granted.

These are some of their comments:

“My unit is only a street away from the main street. l drive my electric wheelchair there and access the whole town … Such choice, such exquisite freedom.”

“I have achieved many things since moving into my home – I access local transport, work one day a week; gaining self-control and independence.”

“I can have my grandson over to stay with me.”

“I’ve got my independence – with household tasks, shopping, volunteering three days a week locally.” [[27]](#footnote-27)

“You can come home later [at night]. Just organise it with staff. It’s flexible.”

“This place is free-running; it’s only a rental but feels like ownership. It’s very comfortable and staff are all pretty good (nobody could be perfect!)”

“I’m more relaxed knowing my family can be around all the time.”

“I have increased confidence.”

“Living in a supported unit has given me my only opportunity to ever have my own home with my limited abilities and financial constraints. It's given me the room necessary to grow outwards towards a fuller life should my health allow that. It's given me hope and an ultimate goal of independence to look forward to achieving. Without the hope of a better life I would find no point in continuing on.” [[28]](#footnote-28)

### 3.3.6. Separation of accommodation and support

A key principle to be considered for, and by, young people living with significant disability is the separation of accommodation and support. A building may be physically suitable, but without the right support, provided in the right way, at the right time, people living with significant disability cannot lead independent, fulfilling lives, where they are connected and involved in the community. The principle of separating housing from personal support arrangements allows people to change either their housing or personal support without affecting the other.

One of the tenants who had moved from a residential aged care facility into the community summed up the importance of having the right support staff:

**ME + STAFF = INDEPENDENCE**

Staffing is a vital support for people living with disability; however there are some risks to the support relationship if staff fail to respect the resident’s home as a home, not a workplace.

One tenant and family member commented:

“Staff all need to be on the same page. They need to understand that it’s the [tenants] unit, not just a unit for care – it’s the person’s home not a staff workplace.”

# Conclusion

Many of the elements of a good life involve a person taking up active roles which are meaningful to the individual and will be valued by other people; collectively these Citizenhood roles help an individual find their valued place in the community. Young people living with significant disability need a range of creative and innovative housing solutions to enable participation, real choice and a genuine place in the community.

The work of JFA Purple Orange highlights that young people living in residential aged care do not have these experiences which are common to other young people. We believe residential aged care facilities are inappropriate for young people living with disability due to institutionalisation, age incongruence and the co-location of people living with disability. This is exacerbated by systemic issues in the disability sector which have failed many individuals particularly at transition points in their lives.

However, living in the community does not automatically create community connections. Any housing model must be anchored on supporting the person to move into roles of Personhood and Citizenhood, which aims to facilitate choice, participation and autonomy.

Having accommodation of choice should be the norm, and not an opportunity available to a lucky few, as these interview comments attest:

“This [unit] is a good set up and it is very sad to see young people my age [30s] having to enter Nursing Homes. There should be more model units set up like this unit.”

“I should not be one of the few, I should be one of the many living in my own supported unit.”

“I was so lucky [after a period spent in respite] to get this unit as so many people are waiting for a placement.”

“There is much debate at this time about the inhumane treatment of asylum seekers living in detention centres. This debate needs to be moved urgently towards the hundreds (maybe thousands) of Australian citizens who by no fault of their own find themselves imprisoned in nursing homes. These people are some of the forgotten Australians. A nursing home is no place for young people.”[[29]](#footnote-29)

# Recommendations

We recommend the Senate Community Affairs Committee:

1. Adopt the basic premise that it is never acceptable for a younger person to live in a Residential Aged Care Facility.
2. Develop a national program which addresses the systemic failures at key transition points which contribute to young people living with disability being placed in residential aged care. This program should:
   1. Target transition points such as health (hospitals and rehabilitation services), crisis care, education and consider the situation of ageing parents; and
   2. Include strategies which increase/release the capacity of people living with disability and their families to imagine a range of positive outcomes, plan and make informed choices.
3. Endorse a clear set of values and principles for government, young people living with disability and their families to guide the decision making process. Values may include:
   1. Articulating the importance of power, choice and control
   2. The preference for young people to live or return to their family or community
   3. The importance of capacity building for individuals for informed decision making
   4. Providing an environment which is responsive and flexible to individuals
   5. The availability of flexible funding, support and assistance.
4. Consider the opportunities and options provided through a framework such as the *Model of Citizenhood Support*[[30]](#footnote-30), which employs strategies and actions to facilitate choice, participation and autonomy.
5. Explore pathways to contemporary models to enable individuals to have genuine choice in their housing. These might include:
   1. Living with family with appropriate building modifications
   2. Co-tenancy with friends or flat mates in private rental or affordable housing
   3. Living alone with support as required in private rental or affordable housing
   4. Home-share options where a person with disability shares accommodation with someone without disability (often a student) for reduced or no rent in exchange for support around the home
   5. Attendant care – individual dwellings dispersed within a suburb where tenants use the same support agency/support agency staff
   6. Mini-cluster housing – two or three units on one site with support as required.

JFA Purple Orange would be pleased to further discuss any aspect of this submission with the Senate Standing Committee on Community Affairs.

1. Williams, R. (2013), *Model of Citizenhood Support: 2nd edition,* Julia Farr Association Inc, Unley South Australia [↑](#footnote-ref-1)
2. United Nations, (2006), http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf [↑](#footnote-ref-2)
3. Commonwealth of Australia (2011), *National Disability Strategy 2010-2020* pp. 32, 44, 52. [↑](#footnote-ref-3)
4. Williams, R. (2013), *Model of Citizenhood Support: 2nd edition,* Julia Farr Association Inc, Unley South Australia [↑](#footnote-ref-4)
5. South Australian Social Inclusion Board, (2011), *Strong Voices. A Blueprint to Enhance Life and Claim*

   *the Rights of People with Disability in South Australia*, p. 68. [↑](#footnote-ref-5)
6. Centre for Disability Policy and Research (2014), *Cross-Sector Service Coordination for People with High and Complex Needs,* Policy Bulletin 2, p. 3., University of Sydney and Young people in Nursing Homes National Alliance [↑](#footnote-ref-6)
7. Julia Farr Housing Association tenants (2015) interview comments [↑](#footnote-ref-7)
8. AIHW (2013). Australia's Welfare (2013). Cat. no. AUS 174, 268. Canberra: AIHW, p.268 [↑](#footnote-ref-8)
9. National People with Disabilities and Carer Council (2009), *Shut Out: The Experience of People with Disabilities and their Families in Australia,* p. 27, Commonwealth of Australia. [↑](#footnote-ref-9)
10. Monash University, (2014), Monash Magazine on-line article *Too Young to be Forgotten* http://monash.edu/monashmag/ [↑](#footnote-ref-10)
11. Monash University, (2014), ibid. [↑](#footnote-ref-11)
12. Young people in Nursing Homes National Alliance (2015), http://www.ypinh.org.au/statistics [↑](#footnote-ref-12)
13. Productivity Commission (2011), Disability Care and Support: Executive Summary, Report no. 54, p.3, Canberra. [↑](#footnote-ref-13)
14. Julia Farr Housing Association tenants (2015) interview comments [↑](#footnote-ref-14)
15. Williams, R (2013), Model of Citizenhood Support Summary Reference Guide, p. 7, Julia Farr Association, Unley South Australia [↑](#footnote-ref-15)
16. Productivity Commission (2011), Disability Care and Support: Executive Summary, Report no. 54, p. 4, Canberra. [↑](#footnote-ref-16)
17. National People with Disabilities and Carer Council (2009), *Shut Out: The Experience of People with Disabilities and their Families in Australia,* p. 27, Commonwealth of Australia. [↑](#footnote-ref-17)
18. National People with Disabilities and Carer Council (2009), *Shut Out: The Experience of People with Disabilities and their Families in Australia,* p. 28, Commonwealth of Australia. [↑](#footnote-ref-18)
19. Williams, R (2013), Model of Citizenhood Support Summary Reference Guide, p. 7, Julia Farr Association, Unley South Australia [↑](#footnote-ref-19)
20. Williams, R. (2013), Model of Citizenhood Support: 2nd edition, Julia Farr Association Inc, Unley South Australia [↑](#footnote-ref-20)
21. Productivity Commission (2011), Disability care and Support: Executive Summary, Report no 54, p. 4 [↑](#footnote-ref-21)
22. NDIS (2015) *What is the NDIS,* http://www.ndis.gov.au/document/811 [↑](#footnote-ref-22)
23. Julia Farr Housing Association tenants (2015) interview comments [↑](#footnote-ref-23)
24. Julia Farr group (2015) http://www.jfm.org.au/jfa-general-distribution-fund/social-landlord/ [↑](#footnote-ref-24)
25. Centre for Housing, Urban and Regional Planning (2012), *Being a Social Landlord in the 21st Century:*

    *Insights from Tenant and International Experience,* p. 25*,* University of Adelaide. [↑](#footnote-ref-25)
26. Australian Government Department of Social Services (2015), https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/younger-people-with-disability-in-residential-aged-care-initiative [↑](#footnote-ref-26)
27. Julia Farr Housing Association (2008), Presentation to SA *Disability Conference: Shifting the Paradigms*. [↑](#footnote-ref-27)
28. Julia Farr Housing Association tenants (2015) interview comments [↑](#footnote-ref-28)
29. Julia Farr Housing Association tenants (2015) interview comments [↑](#footnote-ref-29)
30. Williams, R. (2013), *Model of Citizenhood Support: 2nd edition,* Julia Farr Association Inc, Unley South Australia [↑](#footnote-ref-30)