



Submission to
The Productivity Commission
Disability Care and Support
Public Inquiry

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Introduction to Youngcare

More than 6,500 young Australians (under the age of 65) with 24/7 care needs are living in aged care simply because there are very few alternatives.¹ There are more than 700,000 young Australians with a severe or profound core activity limitation², many of whom are being cared for at home by family and friends.

Due to advances in medical technology and the high standard of Australia's health system, the number of people with high care support needs is increasing. People are surviving accidents but living with acquired disabilities with long term care and support. In addition, Australians who suffer from a degenerative disease are now able to receive medical assistance and support to prolong life.

However, while these advances are prolonging life these people are falling through the cracks in the Australian health care system.

Over the last five years, Youngcare has been committed to raising awareness of the issue across the nation so that we can drive change and create real choices for young Australians and their families.

Youngcare focuses on providing choice in care and accommodation options for young Australians with full-time care needs.

In 2010, Youngcare's focus will remain on raising awareness through marketing and fundraising, as well as lobbying government for policy change. We will also focus on three key programs including Youngcare Connect, At Home Care Grants and developing a range of accommodation.

For many Australians with high care needs, aged care can often be the only option available to receive the level of care they require. It is simply inappropriate that young people with full-time care needs are limited to this option.

While some families and friends are able to care for their children and loved ones at home, other people simply don't have the support networks and are faced with the prospect of putting their loved one into aged care. An even more concerning trend is the crisis occurring for those Australian families who are being housed in hospital wards or cared for at home with little funding support and medical assistance. Youngcare works with people who have been stuck in hospital wards for excessive periods of time, in some cases costing \$5,000 a day simply because they cannot get funding to be cared for at home.

People with high care needs have complex and long term issues that need to be addressed in a much more holistic manner rather than simply as a disability issue. Unless the housing, aged care and most

¹ The Senate Community Affairs Reference Committee Quality and equity in aged care 2005.

² *Australian Institute of Health and Welfare 2007. Current and future demand for specialist disability services. Disability series. Cat no. DIS 50. Canberra: AIHW*

importantly, health systems work together with the disability sector, we are not going to find sustainable and meaningful answers.

Youngcare believes that every young person deserves a young life.

Young people are living in aged care facilities around the nation because they have had a catastrophic injury or illness, like Motor Neurones, MS, Huntington's disease or an Acquired Brain Injury, that has left them requiring full-time care.

For those young people living in aged care, statistics³ suggest that:

- 44% will receive a visit from friends less than once a year
- 34% will almost never participate in community based activities such as shopping
- 21% will go outside the home less than once a month

In 2007, the first ever Youngcare Apartments were opened at Sinnamon Park, west of Brisbane. It is now home to 17 residents with 24/7 care needs who are funded through the Young People in Residential Aged Care Program (YPIRAC).

But there is so much more that needs to be done which is why Youngcare has expanded nationally to offer a range of activity and programs such as:

- a. Working to **raise awareness** of the issue
- b. **Lobbying Government** to drive policy change and systems reform

With key programs including;

- c. The **Youngcare Connect** Support and advice hotline
- d. An **At Home Care Grants program** designed to top-up the care funding for those young people wishing to reside at home with loved ones
- e. And continuing to build more **Youngcare Accommodation** on the Gold Coast; followed by Sydney and then Melbourne

With the combined support of the community, government and business, Youngcare can help address this enormous gap in the health and disability system. Youngcare exists to connect people with the issue, government with people, and business with the community

Youngcare believes this issue is solvable in our lifetime - **because every young person deserves a young life, regardless of their care needs.**

3 Di Winkler et al Winkler, D., L. Farnworth, et al. (2006). Australian Health Review

Youngcare's Response to the Productivity Commissions Issues Paper No. 1

Youngcare supports a National Disability Insurance Scheme (NDIS) that would provide people with high care needs with an individualised and lifetime approach to care and support. We believe that an NDIS has the potential to provide choice in care and accommodation options for young Australians with full-time care needs.

It is only through the introduction of the NDIS, and the possibility of funding for lifetime care, that young Australians with complex support can have what they need. That is;

- choice about where they live and how they are supported
- funding and support options that are client focused rather than provider focused
- ready access to relevant information about programs, services and funding that will help them in a range of aspects of their lives
- access to comprehensive and individualised service planning
- care that is provided by a skilled and competent workforce

Youngcare has responded to four questions within the Issues Paper.

Question:

Who should be eligible: What groups have the highest need or have been most disadvantaged by current arrangements?

Australians with high care needs are currently disadvantaged and in crisis with aged care often the only option available to receive the care they need to live a dignified life. It is simply inappropriate that young people with high care needs are limited to this option.

The Senate Standing Committee: Quality and equity in aged care (2005)⁴ found:

That residential aged care is, in most cases, an inappropriate setting because it does not address the social, financial, emotional, medical and rehabilitative needs of younger people.

There are more than 700,000 young Australians with a severe or profound core activity limitation⁵, many of whom are being cared for at home by family and friends. Some families choose to undertake this important and vital role but other people simply don't have the support networks and are faced with the prospect of placement into aged care. An even more concerning trend is the crisis occurring for those Australians families who are being housed in hospital wards or cared for at home with little funding support and medical assistance.

⁴ Senate Standing Committee: Quality and equity in aged care (2005)

⁵ Australian Institute of Health and Welfare 2007. *Current and future demand for specialist disability services. Disability series. Cat no. DIS 50. Canberra: AIHW*

Clearly this is inappropriate.

Currently the health, aged care and disability sectors are not talking to each other about this group of people. Through no fault of their own, all three sectors are struggling to care for people with high care needs. There must be a coordinated and comprehensive approach to understand this group and address their medical, social, financial and emotional needs.

Recommendation: An NDIS must address the needs of people with high care needs in the community - who do not fit neatly into health or disability models of care – and are currently falling through the cracks.

Recommendation: That the Productivity Commission recommend that there be a coordinated and comprehensive approach by the Federal and State Government to address the medical, social, financial and emotional needs of people with high care needs.

Question:

The nature of services: Are there any services not provided now that should be part of a national disability insurance scheme?

Over the next 40 years in Australia, the number of people with severe or profound disability is projected to grow from 1.4 million to 2.9 million. Recent trends indicate growth in demand for specialist disability services of 7.5 per cent per annum in real terms⁶.

The National Disability Insurance Scheme must contribute to meeting the requirements of people with high care needs and both in terms of care and housing.

Housing is a major issue for people with a disability - 60% of callers to the Youngcare Connect⁷ hotline call in relation to accommodation or housing. Youngcare believes one of the core areas to meet the growing demand for disability services must be in disability housing. The need to provide more housing for people with disability was recognised by the Disability Investment Group with two key recommendations – namely the introduction of better town planning regulations to meet disability requirements and the amendment of the National Rental Affordability Scheme to include people with a disability.

⁶ *The Way Forward*, Disability Investment Group

⁷ **Youngcare Connect** is a dedicated information, advice and referral line run by Youngcare as a single point of contact for appropriate information and referral pathways about relevant services for young people with full-time care needs.

The Australian Institute of Health and Welfare⁸ found that;

Almost two thirds of people who are funded under the Young People in Residential Aged Care program lived in residential aged care. Of these, nearly 2 in 5 reported that their main reason for living there was because appropriate accommodation was not available.

Fifty years ago, people with disabilities were housed in large institutions and kept isolated from their families, friends and their communities. Within the past couple of decades, the pendulum has swung the opposite way, with institutions closed and people with disabilities moved in to the community in settings such as individual homes, group homes and cluster properties. However, appropriate accommodation is scarcely available with limited availability and choice coupled with an increase in the unmet need.

Whether a person with high care needs wants to live in a group home, their own unit, with their family or within a congregate model, they should have the right and the choice to do so.

The United Nations Convention of the Rights of Persons with a Disability recognises the importance of people with a disability to have the right to autonomy, independence and freedom to make their own choices, including the active participation and involvement in decision-making regarding their health and wellbeing.

The Disability Investment Group⁹ found that:

“Most people with disability face significant challenges securing private housing. This is because the disability housing sector is not sufficiently profitable to attract purely commercial investment. People with disability usually have to rely on the capabilities, resources and determination of their own families or groups of parents to develop solutions.

In order to support people with a high care needs, Youngcare believes there needs to be a range of options and choices regarding accommodation, housing and support options to cater for and meet the diverse care needs of all people with disabilities, especially those with severe or profound core limitations.

Fundamentally, we believe that disability housing must be considered as an important part of the care mix when providing care and support for people with high care needs. Disability housing must be part of the broader conversation on social housing. We strongly support the Disability Investment Groups statement;

An alternative approach is to provide more choice, by separating the care and support from the physical infrastructure or dwelling. This recognises that preferred suppliers of accommodation and care and support to people with disability may not be the same

⁸ Younger People with Disability in Residential Aged Care program: report on the 2008-2009 minimum data set, Australian Institute of Health and Welfare, 2010, Page vii,

⁹ *The Way Forward*, Disability Investment Group pg 40

organisation. In this alternative framework, providing housing should form part of an affordable housing strategy because disability is just one among many possible causes of poverty. However, the housing must be accessible¹⁰.

There needs to be the development of a financial support structure that will enable the building of appropriate capital works, including group homes, cluster properties and congregate models, and allowing for the provision of home modifications to support those able to live at home with family members.

Questions include:

- Is it appropriate to have private investment in disability housing?
- How much would it cost to build appropriate and affordable disability accommodation?
- Some benchmarks of cost to build a range of disability housing i.e. group homes, congregate models, cluster settings and at home with supported care options?
- How do we get private investment into disability housing? With the possibility of investigating models for example such as childcare, aged care and affordable housing.
- What are the financial models that would encourage investment?
- How can the National Rental Affordability Scheme be amended to include disability housing?
- How can building regulations be amended to included mandatories for universal design?

With the introduction of an NDIS also comes an income stream which could enable the development of a disability housing market and private investment options.

Recommendation: Youngcare believes that further investigation needs to be undertaken to meet the growing demand in disability housing and also to establish *how private sector involvement and the government can work together to build more disability housing that is affordable and replicable as part of the NDIS.*

Question:

What is the magnitude of funding needed for a national disability insurance scheme?

Every Australian needs to take responsibility for their fellow Australians, including those with a disability as we are no longer talking about a small, unheard of, minority group – there are 20% of Australians with a disability.¹¹

¹⁰ *The Way Forward*, Disability Investment Group p41

¹¹ Australian Bureau of Statistics (ABS) 2003 Disability, Ageing and Carers: Summary of Findings, cat. No. 4430.0, ABS, Canberra

As the number of people with a disability increases, so too will the number of people with high care needs.

The number of people aged 0–64 years with severe or profound core activity limitations is projected to grow substantially between 2006 and 2010.

The Australian Institute of Health and Welfare estimates an increase of 4.8 per cent to 752,100 people. The Institute also suggests that increases over recent decades in the prevalence of some long-term health conditions, particularly related to disability, may result in further increases in the size of this population.¹²

Youngcare was a critical player in pushing for awareness and policy change for people with high care needs and was instrumental in the introduction of the Council of Australian Government's \$244 million initiative, the Young People in Residential Aged Care (YPIRAC) program, the first step in addressing this important issue.

The program has three main objectives¹³:

- to move younger people with disability currently living in residential aged care into appropriate disability supported accommodation, where it can be made available and if that is the client's choice;
- to divert younger people with disability who are at risk of admission to residential aged care into more appropriate forms of accommodation; and
- to enhance the delivery of specialist disability services to those younger people with disability who choose to remain in residential aged care or for whom residential aged care remains the only available suitable supported accommodation option he YPIRAC target group is people with disability aged under 65 years who live in, or are at risk of entering.

Youngcare is a strong supporter of the YPIRAC initiative. The 16 residents who live at the Youngcare Apartments at Sinnamon Park are currently funded under the YPIRAC initiative at approximately \$120,000 per annum (funding is provided to Wesley Mission Brisbane). In addition, the Queensland State Government has committed \$3 million over three years in recurrent funding to Wesley Mission Brisbane for the 7 residents who will live at the new Gold Coast residence.

The recent Australian Institute of Health and Welfare Report indicates that in the first three years of the program, over 90 people were moved out of nursing homes, 300 people were provided with improved services within aged care, and 150 were diverted from inappropriate admissions to aged care.¹⁴

¹² The Way Forward, p11

¹³ Disability Services Queensland Factsheet, What is the Younger People with a Disability in Residential Aged Care Initiative? October 2006

However, statistically the program is not going to meet the needs of all young people in Australia with high care needs, particularly as the population increases. In addition, the program tends to focus on those people who are in an aged care home or at risk of entering one. A concerning trend is the crisis occurring for those Australian families who are being housed in hospital wards or cared for at home with little funding support and medical assistance.

Families who often do not want to put their loved ones into aged care or say “they are at risk” undertake the required care in the home environment but are struggling to be granted funding assistance to meet the high cost of the medical care required.

Currently, the welfare sector struggles to provide the practical support desperately needed by people with high care needs and their families – home modifications, specialist equipment, respite care, allied health support – while ensuring a helpful range of social supports are available, such as counseling and support groups.

There must be a focus on providing funding of appropriate levels of care to meet the needs of people with severe or profound core activity limitation. Appropriate levels of care must include access to medical, respite, rehabilitation services and social care support options such as counseling.

Recommendation: Funding must be provided to individuals to provide appropriate levels of care to meet the needs of people with severe or profound core including medical, respite, rehabilitation services and social care support options such as counseling.

Question:

How would stakeholders be given a say in a national disability scheme? Who should be represented?

Since 2005, Youngcare has focused on giving a voice to people who were not being heard. Awareness of the fact thousands of young people are living in aged care is an integral part of the work Youngcare undertakes.

Youngcare raises awareness through a national advertising campaign; a targeted media relations strategy; national Thong Day; advocacy; speaking engagements and through several key partnerships including Suncorp. Youngcare has also recently joined forces with Channel 9, signing a three year partnership agreement that will provide Youngcare with another platform to spread the word nationally.

It is this type of activity that the Productivity Commission must investigate as part of its work on an NDIS.

¹⁴ Australian Institute of Health & Welfare, *Younger People with Disability in Residential Aged Care Program* May 2010 p51

Over the last twelve months, the disability sector has spent much time discussing the pros and cons of the proposed NDIS, what it could look like and how far could it go?

But a key stakeholder that we must now turn to is the Australian public.

Before the Australian public recognises the urgent need for a better system that can provide lifetime care for Australians with a disability, they must recognise the rights of people with a disability. They must see that there are people with a disability that can contribute and participate in Australian society.

We believe that to ensure the success of the Australian public's acceptance of the introduction of an NDIS, a national marketing campaign must be undertaken by the Federal Government. The campaign needs to be a joint campaign with the backing of the disability sector. While one in five Australians have a disability, the general public's knowledge of what this means and how it impacts people's lives is limited.

It is basic Australian value that all Australians deserve a fair go and currently, this is not the case for Australians living with a disability. The fact that "it could happen to me or someone I know" creates relevance and empathy. Most Australians don't know anyone with a disability, so we need to tell the stories of those who are disabled before discussing an insurance scheme.

The campaign messages need to focus on the fact that the NDIS is working to improve the dignity and relevance of the care environment, and to provide CHOICE for ALL people with a disability, not just those with certain medical conditions.

The campaign would raise awareness of the issue of disability and pave the way for Australians to open to the idea of funding a scheme such as the NDIS.

Recommendation: That a national marketing campaign be undertaken by the Federal Government, with the backing of the disability sector, to ensure awareness of the issue of disability. The campaign would then pave the way for Australians to open to the idea of funding a scheme such as the NDIS.

For further information regarding Youngcare's Submission to the Productivity Commission into Disability Care & Support please contact Youngcare on 07 3041 3400.