

12 July 2017

Submission to the National Disability Insurance Scheme (NDIS) Costs study

Productivity Commission GPO Box 1428 BARTON ACT 2600

Dear Commissioners,

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Australia has a severe shortage of appropriate housing for people with high care needs. There are currently over 700,000 people living in, or at serious risk of entering inappropriate housing. Youngcare Ltd (herein referred to as "Youngcare") is a not-for profit organisation and registered charity established in 2005, working to liberate young people by providing options in appropriate housing and care. Our focus is on enhancing choice and control for young people with disabilities, promoting independence and dignity - and empowering them to lead the lives we all deserve.

Youngcare supports the introduction of the National Disability Insurance Scheme (NDIS), and appreciates the opportunity to provide feedback on the Productivity Commission's NDIS Costs position paper. Given the enormous scale of this reform, we understand that it is important to strike the right balance between the wellbeing of people with disabilities and long-term financial sustainability (including costs to the wider community). We also recognise that this is a complex and challenging task, which will be ongoing as the scheme reaches full rollout. This submission will outline some risks that we foresee and how these might be mitigated, especially with respect to supported housing for those with high care needs. As well, we will specifically address some issues raised by the Commission for feedback.

We wish to commend the scheme on its progress towards delivering better outcomes for people with disabilities across the life course, as reflected in the report. Specifically, we highlight the fact that 71% of participants and 61% of carers are currently satisfied. Many participants are gaining access to high-quality and flexible support services, some for the first time. The research leaves no doubt that the availability of support has brought benefits such as greater independence, enhanced health and well-being, and increased social participation. In particular, improved participation in activities outside the home indicates that people are exercising more choice and control over their lives. This aligns with the broader aims of the NDIS, and allows people with disabilities to lead fulfilling and meaningful lives.

As the sector shifts its focus from a system of rationing support, it is vitally important that people receive the types and amount of support they need for as long as they need it. The recent 10% decrease in participant satisfaction shows that some people are not experiencing the stated objectives of the NDIS, and this must be addressed. There is also a need to ensure continuity of adequate support for people who are not eligible for the scheme.¹

Underutilization rates of support (and poorer outcomes) can be due to insufficient supply to meet the demand, or an inability to properly navigate the system. Although it will depend on the type of support, Youngcare agrees that the inability to access supports will result in a substantial decline in wellbeing and will ultimately incur higher costs over the long term.² One example is the lack of infrastructure and services available to support people with high care needs who require immediate crisis care or accommodation, which place them at great risk; however even if their safety is not in jeopardy; no one should be prevented from leading a meaningful life. The effectiveness of the scheme needs to continually improve, particularly for anyone who finds it difficult to advocate for themselves.

Since many participants need help to access resources and information in an NDIS climate. Youngcare is committed to providing it. Based on research and best practice guidelines developed with Griffith University, we have created a practical and accessible guide as to what participants can expect from their service providers.³ It has been created for and by people with disabilities, with a major emphasis on lived experience. We believe it will be an invaluable tool not only for participants to know how to get what they need, but also for service providers to ensure they are offering truly person-centred care.

Housing is only briefly mentioned in this report. The NDIS needs to make good on its objective to give people with high care needs appropriate housing options and reduce the need for hospital stays beyond what is medically necessary. The report states there is currently no provision for emergencies. We are cautious that people with urgent and/or complex needs who do not receive adequate support may fall through the cracks, even those who might have been better served under the state. From the lived experience of our service users, we know that the burden of this extra support often falls to family members or carers who are already overstretched. Not only will this increase the risk of individuals being placed in inappropriate housing, it will encourage more people to try and enter the scheme to resolve a crisis. This poses a major risk to the scheme, as safeguarding eligibility is crucial to financial sustainability.⁴

Access to appropriate housing options improves outcomes in every domain of life. Although there is limited discussion of Shared Supported Accommodation (SSA), there is little if any discussion about the impact of Specialist Disability Accommodation (SDA). The prospect of SDA is favourable to Youngcare because it allows for a greater range and diversity of housing models, which will provide an unprecedented level of choice and control over housing. Assistive and adaptive technologies can also be very effective in building

¹ Every Australian Counts 2017, NDIS Report Card, Sydney

² Productivity Commission 2017, National Disability Insurance Scheme (NDIS) Costs, Position Paper, Canberra.

³ Youngcare Australia, 2016 'Knowledge Partnership', Available at: https://www.youngcare.com.au/our-work/knowledge-partnership/.

Productivity Commission 2017, National Disability Insurance Scheme (NDIS) Costs, Position Paper, Canberra.

independence and capacity, particularly for those with high support needs in supported housing⁵

The option for people with high care needs to live independently in their own home represents another significant philosophical shift - from crisis management to equitable opportunities. We reaffirm our support for a separation between the provision of housing and care arrangements. We see this as absolutely essential for maximising the choice and control that participants have, and especially security in situations where they are not satisfied.

The National Disability Strategy must be strengthened and adhered to as an underlying framework. It needs clear commitments and targets, particularly in terms of addressing barriers to supported housing and community infrastructure that promotes inclusion.

While we acknowledge that the hugely ambitious timeline of the scheme rollout has compromised the planning process and undermined participant engagement, Youngcare's position is that the time for slowing it down has passed. In regions where it has not yet been implemented, expectations of the NDIS are now far too high and it cannot be delayed. The NDIA must instead turn its attention to managing expectations and working effectively within the current timeframes, which includes the need for skilled and impartial planners.

With regard to the question of whether the fundamental concept "reasonable and necessary" should be better defined in the legislation, Youngcare believes that there is perhaps scope for more clarity. However, we remain cognizant of the fact that even people with similar needs may require vastly different supports. The NDIS must be able to respond flexibly to individual support needs and requirements, which must be assessed on a case by case basis.

Youngcare strongly supports the continual maintenance of "List A", so that people with certain conditions are automatically eligible for the NDIS. This is very beneficial for the people we service, who by definition often have a stable medical diagnosis. List A offers a significant reduction in administrative burden (and costs) for participants and the NDIA.

While the success of the NDIS seems to be broadly on track, Youngcare hopes for further improvements in its effectiveness so that more people with disabilities can get the support they need. In light of the Commission's emphasis on long-term financial sustainability, it is worth noting that the failure to properly cater for individual support needs and subsequent fall in wellbeing will create significantly higher costs. We also contend that participants of the scheme need support to better understand and negotiate their relationships with service providers. Specifically with regard to the issue of supported housing for people with high care needs, we have identified some concerns that need to be redressed. The absence of emergency care and support will force more people onto the scheme, posing another major risk to its financial sustainability. There needs to be a variety of housing options that allow people with disabilities to live independently, and a strong underlying framework to support this. We have also addressed a number of questions from the Commission - on issues such

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⁵ ibid

as the speed of the rollout, "reasonable and necessary" supports, and the maintenance of "List A" for stable conditions.

Overall, Youngcare strongly supports the NDIS and is very supportive of the Productivity Commission's outcomes. However, the time to slow down the roll out in order to review the NDIS supports being provided has passed. The people of Australia expect to see the NDIS being provided to those in the community who need the support the most. Youngcare also believes that the real cost of the Specialist Disability Framework needs to be discussed and considered in a realistic and timely manner; providing to those who need accommodation that is appropriate providing them the freedom of choice and control.

Thank you for the opportunity to submit feedback on behalf of Youngcare, should you wish to discuss this further please don't hesitate to contact me.

Yours sincerely

Anthony Ryan
Chief Executive Officer