3 July 2017


To whom it may concern,

I am writing to you as the Research and Policy Officer at the Youth Disability Advocacy Service (YDAS) in response to your request for feedback on the National Disability Insurance Scheme (NDIS) costs paper (distributed in June 2017).

YDAS represents young people with disability and assists them in the protection and realisation of their rights under the United Nations Convention on the Rights of Persons with Disabilities. The work of YDAS is guided by a steering committee. This steering committee is composed of young people with disability, who give feedback about the experiences of young people with disability. YDAS currently receives funding to prepare young people for the NDIS, through the Transition Support Packages provided by the Victorian Government.

YDAS is a core agency of the Youth Affairs Council Victoria (YACVic), the state’s youth peak body. The work of YDAS and YACVic focuses on young people aged between 12 and 25. Any recommendations made within this submission will be specific to the needs of young people. Through our work engaging young people
with the NDIS, YDAS has determined that there are potential concerns across a number of key areas covered by the position paper. These include:

- Eligibility (learning and social interaction)
- Scheme supports
- Interfaces (housing, education & employment)
- Readiness (participants)

YDAS does not support slowing down the NDIS rollout. YDAS acknowledges that since the disability support sector began transitioning to the NDIS many individuals have been left waiting for adequate services. We believe that the urgency of need for support outweighs a need to slow down roll out. YDAS broadly recommends continued investment in supports for young people and a continued focus on maximising the ‘lifetime return’ of the scheme. This is achieved most effectively through a continued focus on capacity building for the NDIS and all associated frameworks.

**Eligibility (learning and social interaction)**

Inclusion of ‘learning and social interaction’ within the eligibility criteria is consistent with the broadening of the classic definition of ‘disability’ from a strictly medical definition to encompass functional and social models of disability. This evolution is in line with the principles enumerated in the United Nations Convention on the Rights of Persons with Disabilities, which are core to the legislative and moral drivers for the NDIS. (UNCRPD 2006)

Utilising the NDIS to provide supports to individuals with these disabilities has the potential to provide greater economic return in the long run. Addressing social interaction will prevent social exclusion, which will in turn lead to greater social and economic participation. Initial employment for young people without a disability is often achieved through informal social networks. Social development is key in bridging the gap between the experiences of young people with and without disability; allowing them to achieve the same outcomes.
The inclusion of learning and social interaction within the NDIS is likely to benefit all young people with disability. It will also account for unique support and development needs of children and young people with autism spectrum disorder. Children and young people with autism spectrum disorder have been shown to have extreme difficulties and unique challenges associated with socialisation. (Rogers 2000) This can often lead to difficulties in classroom environments. Combining learning and social interaction with early intervention will greatly advance the independence of young people from long term supports.

**Scheme Supports**

In relation to scheme supports, YDAS agrees broadly with the recommendations of the Productivity Commission.

However, further restriction of what is considered to be ‘reasonable and necessary’ would ultimately hinder the broader productivity of the scheme as well as the ability of the scheme to adapt to the goals of individual participants. This is consistent with reports reviewing the UK individual funding system, where critics noted that increasing the rigidity and formality of funding structures greatly reduced the potential return in the long run. (Duffy & Williams 2012)

YDAS is opposed to the use of phone planning as a default. While the Productivity Commission has recommended a review of phone planning procedures, YDAS would recommend that phone planning is only used upon request of the individual participant. The planning process can be quite extensive and include complex questioning. It is the position of YDAS that phone planning places undue burden on the participant; losing much of the insight that would have been gained through face-to-face planning. (Warr et. Al. 2017)

Educated and specialised planners would greatly reduce the burden on individual participants, with reduced capacity or desire to provide detailed explanations of the specifics of their disability. YDAS currently runs NDIS readiness workshops for young people with disability, where we find that many young people do not
want to identify as disabled. Specialist planners should be trained to conduct meetings in a fashion that is not ‘impairment or disability-centric’ to make sure that young people coming to terms with their identity are able to fully participate in the planning process.

General Principal 8 of the NDIS states people with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity. (NDIS Act 2013) YDAS is unique because it is directed by the young person with disability themselves and through this inclusion we continually undertake systemic advocacy and work on policy issues that are important to young people with disability such as housing, independent living, employment and education. We work to ensure that the interests of young people with disability are heard by government and other decision-makers. We work directly with the young person to help them achieve the outcomes they want.

**Recommendation:** YDAS would encourage the NDIS to continue to work towards a person centred model where the person with disability is the ultimate decision maker in their own lives; exercising all possible choice and control.

YDAS recognises the discussions involving mental health and family instability can be difficult for young people to take part in.

**Interfaces, education, employment, health and housing (ILC)**

Access to an appropriate NDIS plan can significantly improve the development of a young person with disability. For young people, an appropriate plan has to take into account some of the complexities related to interface arrangements. Young people living ordinary lives undergo major life transitions: school to work, home to independent living. This can cause a range of issues such as a need for
adaptive supports, consideration of changing mental health and assistance with skills development or capacity building.

Effective use of ILC supports is also key, as a lack of economic inclusion is a primary factor in continued reliance on welfare and supports. According to the 2012 report; *Social Inclusion in Australia – How is Australia faireing?* The presence of disability is often an indicator of low economic resources and financial stress. (ASIB 2012) While little is known regarding predictors to employment for people with disability there is at the very least a need for greater accessibility of mainstream systems. (Lindsay 2015 & Honey 2014) A recent review of Disability Employment Services revealed that the system continues to lack a long term impact. Our reading of the recent DES outcome data would suggest that as few as 1 out of 10 people maintain employment after six months when utilising Disability Employment Services. (DSS 2016) This data is further evidence of the need for people with disability to have greater choice and be given the opportunity to interface with mainstream systems. Segregation, whether of employment, education or housing only slows the progression towards normalisation and acceptance of people with disability in addition to the social and economic benefit they provide.

**Recommendation:** YDAS advocates for the setting of a consistent standard of inclusion across all ILC; negotiated between the NDIA and mainstream service providers.

The NDIS should continue to be cognisant of the long term economic benefit of a scheme that maintains a focus on capacity building from the earliest possible point as well as the inclusion of employment supports within NDIS plans.

**Readiness (participants)**

The NDIS trials have clearly shown that a successful NDIS requires the continued support of individual and systemic advocacy.

**RECOMMENDATION:** YDAS recommends that advocacy remain an important cornerstone to the matrix of services available to people with disability within the community and this should continue to be funded by Commonwealth, State and
Territory Governments in order to support participant readiness and a smooth transition to the full scheme.

Through our NDIS readiness workshops, we have found that many young people are still not aware of the existence of the NDIS. Furthermore, advocacy cases related to the NDIS have indicated that the majority of information provided by the NDIA is largely generic and should be adapted to the specific needs of young people. The planning process remains largely inaccessible, as there is a required understanding of complex language to ensure maximum benefit from an NDIS plan.

**RECOMMENDATION:** YDAS recommends strong investment in a communications strategy for the NDIS that is both co-designed by people with disability as well as targeted to the unique communication needs of young people with disability.

Young people often don’t want to identify as having a disability. The NDIA needs to implement mechanisms for accessing the scheme that are friendly to young people and respectful of the individual’s relationship with their impairment.

NDIS plans are structured around central goals. These plans are intended to go beyond day-to-day support needs and can include things such as travel, a transition to independent living or the seeking of employment. While conducting NDIS readiness workshops, YDAS has discovered that many young people misunderstand the purpose and potential scope of a ‘goal’. This is in large part due to many young people with disability being provided direction by their parents.

YDAS understands that this often results in many young people with disability having diminished self-esteem and low expectations of themselves. Parents should be encouraged to balance their instinct to protect or shelter their children with the potential benefits of involvement in the planning process. Young people with disability should be afforded the same ‘dignity of risk’ as their peers. This has been the experience of a number of the YDAS steering committee. YDAS works to empower young people to seize more choice and control over their own lives.
If you would like to discuss any of these recommendations further please do not hesitate to contact me.

Sincerely,

Ewen Rawet

YDAS Policy and Research Officer

Appendix

Australian Social Inclusion Broad 2012, ‘Social Inclusion in Australia – How is Australia Faring?’ Department of Prime Minister and Cabinet
<http://library.bsl.org.au/jspui/bitstream/1/3170/1/Social%20inclusion%20in%20Australia%20how%20Australia%20is%20faring2012.pdf>

Commonwealth Department of Social Services 2016,'DES Outcomes by Disability Type', Published December 2016.

Duffy, S, Williams, R 2012,' The Road to NDIS:Lessons from England about Assessment and Planning',Purple Orange, Published October 2012.


Lindsay, S, & DePape, A 2015,'Exploring Differences in the Content of Job Interviews between Youth with and without a Physical Disability', PLoS ONE, vol. 10, no. 3, pp. 1-16,

National Disability Insurance Scheme Act 2013

