

Youth Disability Advocacy Service (YDAS) submission to the Productivity Commission on the draft report on a National Disability Insurance Scheme

The Youth Disability Advocacy Service (YDAS) is a Victoria wide advocacy service of the Youth Affairs Council of Victoria, funded by the Victorian Government to provide individual and systemic advocacy for young people with disabilities between 12 and 25 years of age.

In preparing this submission, YDAS discussed the findings of the draft report with young people with disabilities. Overall, young people with disabilities are extremely pleased with the report. Not only does the report provide a clear and accurate summary of the problems in the current disability support system, but it sets out recommendations for a new system that, if implemented, will lay the foundations for a much brighter future for people with disabilities in Australia.

We strongly support the following recommendations that are made in the report:

- **Recommendation 7.5** that the entitlement to reasonable supports is enshrined in legislation. Further to this, the right to self-directed support should also be included in the legislation as it has been in the UK, with the Direct Payments Act.
- **Recommendation 6.1** that people eligible for funding under the NDIS can choose the level of control that they have over their funding including the option for direct payments. YDAS strongly supports the range of options provided under this recommendation for maximising choice. We also support recommendations 6.2 & 6.3 and how they describe the implementation of self-directed funding. We believe that these recommendations strike a fair and reasonable balance between flexibility, and accountability and community expectations about the reasonable use of public funds.
- **Recommendation 6.4** that people have the option to employ their own support workers. YDAS has heard from many young people who want to be able to do this so that they can exercise more control over their lives and have a stronger say on how their supports are delivered and who provides this support. Directly employing support workers will not be everybody's choice, but we believe that it is an important option that has already been trialed successfully in Victoria.
- **Recommendation 6.10** is essential to ensure that people remain eligible for necessary social security benefits and are not forced to pay tax on their direct payments.
- **Recommendation 6.6** is important because without the necessary support and information, the number of people undertaking self-directed approaches will be limited. We need more information, training and peer support groups to assist people to make choices and take more control. Overall, the key principle here is that the NDIS should include an investment in information provision and programs that empower people with disabilities to have more control over their lives. To ensure that this

- information is objective, comprehensive, and unbiased, YDAS strongly believes that investment should be directed towards *user-led* organisations rather than funding service providers to take on this role who may be biased towards promoting their own services.
- **Chapter 4.6** describes an innovative approach to disability housing. The recommendation that people eligible for this kind of accommodation can cash out the cost of providing this combination so that they can have more choice and flexibility about where they live is strongly supported by YDAS. If this recommendation is implemented, it will allow more people to move out of group homes and have more control about where and with whom they live. This will allow them to be more connected with informal supports and with their communities. It will also increase employment opportunities and quality of life for people needing accommodation support. Furthermore, it will enable young people with disabilities to have greater choice about their housing and is likely to support them to move into more independent living arrangements earlier in life.
 - That the NDIS should not be means tested nor include any assets tests.
 - **Chapter 4.22** says that the NDIS should consider the need and cost of taxi transport as part of the assessment. In response to The Commission's requests for guidance on what would be reasonable, it is recommended that the assessment considers the amount of travel that the individual requires to undertake activities of their choosing and a budget line in the individual support package be developed according to this.
 - We support a whole of government approach to supporting the needs of young people with disability and therefore support the recommendation by the commission that education and employment supports still remain the responsibility of the relevant departments. However, we believe that a Memorandum of Understanding (MoU) should be developed between the National Disability Insurance Agency and the relevant departments to ensure that all government departments understand and accept their responsibility for providing reasonable supports to people with disabilities. The MoU should include commitments to ensure that services are consistent with self-directed supports and individualised funding models. This will be necessary to ensure that service provision, regardless of where the funding comes from is seamless and consistent.

We would like to provide the following feedback about other sections of the report:

- While the report does acknowledge that Australia is a signatory to the UN Convention on the Rights of Persons with Disabilities (UN CRPD), it is critical that the final report and the operation of the NDIS & NIIS are compliant with UN CRPD. We believe that entitlement to adequate support (including housing), the timely implementation of the support and the option to undertake self-directed approaches are essential for compliance.

- The existence of two schemes, the NDIS and NIIS, raises concerns about how equity is maintained between both schemes. It is essential that there are equitable outcomes under both schemes, so it is essential that the same assessment procedures are followed and that regular audits take place to ensure that people with disabilities are not disadvantaged if they happen to fall under a particular scheme.
- Page 23 of the overview document says that "some people have disabilities so severe that they could not realistically ever work". YDAS believes that all young people with disabilities have the potential to engage in meaningful employment, if the right supports are put in place. We also believe that the NDIS provides an opportunity for many more people with disabilities to enter employment by: covering the additional costs that people with disabilities experience when trying to participate in the labour market (for example transport costs, work-based disability support, training, additional personal care needs). YDAS strongly recommends the funding of work-related supports to reduce the current barriers and disincentives to employment currently experienced by people with disabilities.
- Box 4.1 describes the range of supports that would be funded. YDAS believes that it is important to be flexible and innovative with regard to the kind of supports that would be funded under the scheme. In the Victorian model of self-directed support, people with disabilities can decide for themselves what kind of support is most appropriate for the goal and outcome that they are wishing to achieve. For example, if the person experiences chronic pain as a result of their disability, they may find a certain form of massage is the best treatment for them, and therefore funding for this should be available under the scheme.
- Chapter 5.8 discusses how assessment should take into account informal supports. A vital issue that is missing here, is the importance of considering the person with a disability's preference for formal or informal supports. Any assessment must consider this and recognise that some people with disabilities undergoing assessment may be happy to continue receiving informal support from family members but others may wish to become independent from their families and not rely on them for their support.
- Chapter 5.9 says that the assessor should determine the suitability for self directed funding. YDAS believes that everyone should have the right to undertake self-directed approaches and that the decision should be up to the person and, if appropriate, their family. Some people may require additional supports to take on self-directed funding and the assessment should consider what these reports might look like if the person chooses to do so.
- Assessment should also include consideration for the realistic and lawful implementation of supports. For example, an assessment may reveal that a person only requires one hour of assistance in the morning, however, the relevant award may stipulate a minimum three hour shift. If the person

is only funded for one hour, there will be a funding shortfall that will need to be addressed to implement that support. Another example is a situation where a person may need assistance every hour for a task that only takes 15 minutes. The assessment would be misguided if it calculated all of the 15 minutes assistance intervals and did not recognise that this person, in reality, would need 24-hour support.

- Self-assessment should be included in the model of assessment. YDAS believes that people with disabilities themselves are best placed to decide what kind of support is necessary for them. While we understand the Productivity Commission's concerns that people will overestimate their needs, we believe that self-assessment is critical in order to pick up on the self identified needs and other nuances that other forms of assessment may miss.
- Chapter 7 assigns the title of "case managers" to staff from the National Disability Insurance Agency (NDIA) that will work directly with people with disabilities, overseeing the interaction between the agency and people with disabilities requiring support. YDAS believes that the term case management is disempowering of people with disabilities. People with disability are not "cases", and the new system is not about "management" of a suite of disconnected services. Also, for those people with disability who interact with the health system, the practice of case management is still common and having the same position in twin systems would cause confusion. We believe that the term "support facilitators" is more suitable.
- YDAS believes that in addition to expertise in finance and insurance, the NDIA Board include strong disability advocacy representation. We also support the recommendation that there be an advisory group made up of people with disabilities to inform the NDIA board. However, it is important that this group is not tokenistic and that it has a real influence. For this reason, we strongly recommend that a minimum of two members of this group are also represented on the board to ensure that the voices of people with disabilities are heard at the highest level. Furthermore, we believe that it is important that advisory group members have personal experience of using supports and a thorough understanding of issues faced by consumers of disability support services.
- The complaint process described in Chapter 7 is not adequate. An independent complaints and appeals handling body, entirely separate to the NDIA should be established to investigate complaints about the NDIA and disability services funded through the NDIA that cannot be resolved internally. This role could be similar to the Victorian Disability Services Commissioner, but should have the authority to hear complaints from people who have not been approved for funding or services.
- We believe that the final report should include reference to the importance of advocacy for people with disabilities and that advocacy should sit outside of the NDIS and be funded separately from individual support packages. The reason for this are that:
 - people may need advocacy in their dealings with the NDIS,

- advocacy agencies need to have the capacity to take on systemic issues separate to individual client work and
- advocacy services need to provide advocacy to people who fall outside of the individualised funding scope of the NDIS.