Public Submission to the
Productivity Commission
Inquiry into a
Lifelong Disability Care and Support Scheme

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Response to the Draft Report

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The Centre for Disability Studies (CDS) is a private, non-profit disability studies research centre, affiliated with the University of Sydney and the Royal Rehabilitation Centre Sydney. CDS hosts the NSW Developmental Disability Health Unit (DDHU). The Centre's recently revised mission statement is 'Empowerment through Research, Education and Practice'.

CDS supports the Productivity's Inquiry into a national lifelong disability support scheme and in particular recommendations for the introduction of a National Disability Insurance Scheme (NDIS) in which the needs of people with a disability and their carers would be assessed rigorously, leading to the provision of individualised support packages with increased choice and greater long term certainty.

In this submission CDS wishes to address several key issues. First, the development of support needs assessments, secondly the funding of research and specialist essential health services, thirdly options for safeguarding independence of planning and fourthly training of support staff.

The Development of Support Needs Assessments

The practice of support needs assessment, and particularly linking support needs assessment to resource allocation, is a somewhat controversial topic in the disability sector internationally. There is much confusion in the design and selection of support needs assessment. At face value it would seem easy to determine if one person needs more support, or a higher funding allocation, than another. In practice, this is more difficult and unsubstantiated claims in relation to support needs assessment are being made such as *over engineering*.

CDS would encourage the Productivity Commission to review the work and conceptualisation that has taken place around the Instrument for the Classification and Assessment of Support Needs (I-CAN) (Arnold et al., 2009) including the brief version and the CAN-U skills assessment tool. CDS believes the suite of I-CAN assessment tools is a preferred option in comparison to other available support needs assessment tools.

CDS supports the concepts and analysis presented in the draft report coming from the Productivity Commission. Given our expertise in the area of support needs assessment, we were pleased by the

analysis and proposal presented in Chapter 5 of the draft report. However, one particular 'desirable feature' of support needs assessments that requires greater consideration is that of the ideal support needs assessment being 'public domain' or 'open source'.

Whereas public domain and open source products are highly successful and widely used in the field of computer software, we are not sure if the same success would be found within the area of support needs assessments. Highly successful open source software, for example Mozilla Firefox, is often supported by advertising. Mozilla Firefox earns many millions of dollars each year from channelling its user's internet searches to Google. It is unlikely that a support needs assessment tool could fund its own development through advertising dollars. This raises the first of a series of questions regarding the supposed benefits of an open source tool:

1. **Who pays for its development?**
2. **Who provides training?**
3. **How are updates and refinements managed?**
4. **Does full open-source increase potential for gaming?**
5. **What evidence exists that open source assessments are better than privately licensed assessments?**

Each of these questions is explored below.

1. Who pays for its development?

As noted by the Productivity Commission's draft report, the development of an assessment tool can be "time-consuming and expensive" (p. 5.15). In the short and possibly long term, it may be more cost effective to pay for the license fees of an already existing commercially developed assessment with a proven track record rather than attempt to develop a new assessment tool, which may not be as effective. There would be considerable time and cost for the proposed National Disability insurance Agency (NDIA) to design and conduct field and psychometric testing of a new assessment tool. A primary reason given for the benefit of using a public domain assessment is cost.

2. Who provides training?

In the Productivity Commissions draft report, mention is made that "Assessors would be properly trained" (p. 5.21). If using a public domain assessment tool, who would provide and ensure proper training? Is it envisioned that the proposed NDIA encompasses a significant assessment development and assessor training department? Would the NDIA become a competitor in the small support needs assessment market, though a competitor who is both the major available source of funding as well as the largest provider, effectively monopolising the market? This could potentially kill any incentive for innovation or competition, as opposed to encouraging it.

3. How are updates and refinements managed?

One of the major strengths of open-source computer software is that it allows the thousands of people with computer programming skills to submit bug fixes and develop features of the software. There are well developed systems such as Concurrent Version Systems to manage multiple versions of source code being developed by multiple programmers. However this strength does not necessarily translate to assessment development. In computer software development, minor revisions can be brought out at any point with little to no change to the core functioning of the

program. For psychometric assessments, even minor changes to the wording of an item or the number of items involved brings into question whether all psychometrics need to be recalculated and any allocation algorithm redeveloped or at least recalibrated. A hypothetical example, if version 1.01 is released of the national assessment tool half way through the year, does that mean, for reasons of fairness, that all people assessed in the first half of the year need to be reassessed, and another round of reliability testing and algorithm development? In computer software development, there are many people who know how to program software, and to learn how to program can be as easy as typing "PHP Tutorial" into Google. People with the skills to develop and properly test assessments are not as numerous as computer programmers. Further, to properly test or develop an assessment tool generally requires several hundred participants, as opposed to computer software, which only requires a handful of good beta testers.

4. Does full open-source increase potential for gaming?

The majority of national and international jurisdictions do not make publically available the algorithm that is used to compute assessment scores into resource allocations. As much as greater transparency is required in the public arena regarding how resource allocations are made, if it is widely known how items in an assessment are weighted in a funding allocation algorithm, then potentially it is easier for people to inflate their scores to gain maximum funding in the required areas and it may/may not be detected that they are gaming on the assessment process. Although there are examples of people returning funding not required, it is also well known that other situations exist where persons or case managers have exaggerated support needs in order to receive higher funding when resources are scarce, and cases where everyone seeking services through particular service providers are scored in the high or very high brackets.

5. What evidence exists that open source assessments are better than privately licensed assessments?

As support needs assessment is a relatively young science, few to no studies exist that compare existing tools, with no published studies to our knowledge that compare open source assessment tools with privately licensed tools. The Productivity Commission's draft report cites Owen et al. (2005) as evidence of the value of an open-source assessment tool. However, the report by Owen et al. (2005) only makes one argument as to the value of an assessment tool that is in the public domain "that the instrument can be used by all service providers in Australia without the cost of licence fees" (p. 21), and otherwise cites no evidence as to the benefit of an open-source assessment tool. The other reference cited from UNESCO (2004) which supposedly supports the fact that "where tools are in the public domain, it facilitates transparency and further research and development" (p. 5.14) is actually a report about governmental public domain information and a search for the word 'assessment' returns no results.

Indeed, in psychometric testing, the area with the longest history and the longest amount of time for an open-source competitor to become available and widely used is that of Intelligence Quotient (IQ) testing. It is widely accepted that the gold-standard for IQ testing lies with the privately licensed Wechsler and Stanford-Binet scales. The few 'free intelligence tests' available online would not be considered adequate in any clinical setting or for application to disability supports assessment. There are several reasons for this. If an IQ test is freely available it makes it relatively easy to learn the correct responses and so inflate or decrease the score, depending on the desired outcome. Further, standard IQ tests are administered by a psychologist. Part of the role of the psychologist is to observe the participant, and potentially identify reasons why the participant is scoring poorly in some areas and identify possible strategies for intervention based on these observations.

Applying these principles to support needs assessment, if a support needs assessment is freely available, including its scoring algorithm, it becomes very easy to complete the test in a way to obtain the desired score and avoid detection of gaming. Also, if a support needs assessment is facilitated by a trained assessor, the assessor can potentially identify if the participant is under or over-reporting needs. The assessor can also identify if issues arise through the assessment process that require further investigation or support.

Although the support needs assessment desired by the proposed NDIA is likely to be the shortest possible assessment that still provides accurate data for resource allocation, support needs assessment tools such as the full I-CAN assessment were designed to additionally be used as a planning tool and a clinical tool that identifies areas where a person is in need of support and possibly not currently receiving adequate support. The I-CAN tools aim to identify what support the person needs in order to live a life of quality of their choosing. The full I-CAN also functions as a clinical database and outcomes measurement and monitoring tool, as well as on-going work with a commercial partner for the I-CAN to fulfil National Minimum Data Set reporting requirements.

Having addressed the reasons why we believe a public domain assessment tool may not be the preferred option, we would briefly like to address the questions posed by the draft report (p. 5.17) regarding assessment. We believe the I-CAN suite of assessment tools are suitable for the assessment processes outlined in the draft report. The I-CAN tools;

- are **practical**, having been field tested with people with a range of different types or combinations of disabilities (including autism, vision impairment, spinal cord injury, acquired brain injury, intellectual disability, mental illness etc.) and age ranges (children, youth, adults and older people), and across a variety of different settings, and have been well received in the vast majority of cases
- have **good psychometric** properties, with some research already published and on-going research soon to be published that further demonstrates good validity, reliability and practical utility (the most recent data on psychometric properties has not been reported in the draft report, and though not yet published, could be made available to interested parties on request)
- are completed in **collaboration** with the person with disability and their circle of support (key stakeholders)
- take into account the **person's aspirations** and identifies support needed to increase independence where applicable
- record the **frequency and intensity** of support needed
- cover all domains of the International Classification of Functioning, Disability and Health (**ICF**) (WHO, 2001)
- operationalise the concept of **person-environment interaction**, and can take into account differing needs such as in the current home environment versus potential future environment.
- capture the additional support required if a person has **episodic** needs, such as episodic mental health conditions, epilepsy etc..

The I-CAN Brief is designed to be as quick and non-intrusive as possible whilst still gathering comprehensive information for resource allocation purposes.

The only desirable trait that the I-CAN tools do not currently meet is having public domain licensing. Further, the I-CAN is not a carer needs assessment, nor is it an equipment or home modification needs assessment. Our understanding is that equipment or home modification needs assessment is generally completed by a suitably trained allied health professional and does not necessarily utilise a psychometric assessment tool. The area of carer needs assessment requires further consideration, though we believe that a thorough carer needs assessment may be a separate tool and process from

individual support needs assessment. Carer needs assessment, equipment and home modification assessment could be conceptualised as modules within an assessment toolkit that could be developed.

CDS again strongly supports the Productivity Commission's Inquiry into a Lifelong Disability Care and Support Scheme and the draft report released. Having direct understanding of the effort and costs involved in developing assessment tools, we have strong reservations regarding the supposed value of a public domain assessment tool that would fulfil the needs outlined in the draft report when none currently exists. Given that more work is required in the area of support needs assessment, CDS would be interested in being involved or collaborating in any assessment development, training or research project in this area. Some negotiations may need to occur in order to make collaboration a possibility. CDS could also be interested in making publically licensed the work completed to date on the I-CAN project if an acceptable commercial arrangement could be made.

Funding of Research and Specialised Essential Health Services

There is a need for the delivery of services to have appropriate research to identify the best models of service delivery and effective person centred approaches. The draft report makes reference to therapies which should only be funded if there is evidence as to their effectiveness. Due to a lack of funding, research in these areas is limited. CDS has completed research of this type and is currently undertaking several related research projects, but would welcome a transparent tender approach that promotes collaboration rather than competition. It is also recommended that findings of research are publically made available, as different to what is often current practice where funding agencies receive and approve research reports but do not publically release them for stakeholder consideration in the pursuit of best practice.

Apart from the promotion of transparent and accessible research approaches and outcomes it would be advantageous if the Productivity Commission's Inquiry into a Lifelong Disability Care and Support addressed the funding of (and current under-funding) of essential existing services. People with disabilities need to be in a position to not only plan through individualised funding but also to have access to a greater range of services and in the case of health and well being for people with intellectual disabilities, the option of referral to specialised health and counselling services. For example, CDS is a partner in a specialised health clinic, the NSW Developmental Disability Health Unit (DDHU) located at the Royal Rehabilitation Centre Sydney. The DDHU operates two days per week and is booked out for the rest of 2011. In 2010 it received 250 new referrals and did 850 reviews across both health assessment and counselling. Additional funding is required not only at DDHU but also for similar units to be developed throughout Australia. When congregate settings began closing it was hoped internationally that generic health services would serve the needs of people with intellectual disabilities. However the experience of the staff of the DDHU challenges this assumption. Clinical practice with people with intellectual disabilities reinforces the need for specialised health services that work in collaboration with both general practitioners and specialist medical practitioners. CDS is in full support of the position taken by the Australian Association of Developmental Disability Medicine (AADDM) and NSW Council for Intellectual Disability (NSW CID) that specialised health assessment and intervention services for people with developmental disabilities should be adequately funded.

Safeguarding Options for Planning

In relation the steps outlined on p. 31 of the draft report, outlining what is proposed to follow the NDIS assessment and budget allocation, a person can gain support in planning through either a Disability Service Organisation or go directly to a Service Provider. With reference to the second

option it would appear advisable to safeguard it for people who choose to return to an agency that they have long association with for planning. Safeguards need to be put in place to make sure that they have access to a diverse range of options that meet their dreams and aspirations. Third party involvement may need to be considered to ensure independence of planning, for those people who need support in decision making and do not have access to family connections and /or a personal advocate. An area worthy of research in the first pilot would be to compare and contrast the satisfaction of people across the two options if such options become part of the accepted protocol for the NDIS.

Training of carer support staff

On p. 39 of the draft report it reads that there should be "no minimum training requirement to work as a personal support worker". In full cognisance of the need to avoid over professionalization of personal support workers, the need to ensure however that support workers understand their role within the context of a person centred approach is essential. A values based person centred induction programme that could be credited to further qualifications would guarantee that people with disabilities would be able to choose from a range of potential support people who have had at least had an opportunity to examine their own values in relation to supporting people with a disability.

References

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