



The Australasian Society for Intellectual Disability, (ASID) welcomes the Commissions draft report on Disability Care and Support and in particular the recommendation for the introduction of a National Disability Insurance Scheme (NDIS).

ASID's mission is to enhance the skills, knowledge and commitment of its members and to facilitate a supportive network in order to enhance the quality of life of people living with an intellectual or developmental disability.

Members of ASID include:

- Academics
- Service providers
- Developmental Educators
- Management staff
- Clinicians, therapists and case managers
- People living with intellectual disability
- Intellectual disability organisations
- Families, carers and advocates
- Teachers and educators
- Disability support workers
- Policy makers
- Medical practitioners
- Government departments and staff
- Accommodation, support and community services
- Employment services

The goals of ASID are to :

- Promote the research and understanding of intellectual disability
- Bring together people with an interest in the field of intellectual disability
- Promote high standards of practice in the field of intellectual disability

With such a diverse membership committed to enhancing the lives of individuals with an intellectual disability and a philosophy of research to practice, ASID believes that we have the skills and knowledge to comment on the report from the perspective of individuals with an intellectual disability and their families. As many members of ASID are part of other organisations and networks, we expect that a number of our members will be making contributions to other submissions including supporting individuals with an intellectual disability to make their own submissions.

## **1 Commission's recognition of the issue/complexity of individuals with an Intellectual Disability**

The Commission is to be commended for including coverage for those with an intellectual disability who are not easily covered by the definitions, i.e. *Intellectual disability not already included (50 000)*.

Such individuals are very vulnerable and their inclusion is recognition that they have particular needs that if left unmet will result in such individuals being homeless and open to abuse and neglect, particularly for those individuals who have no one independent of the service system to assist and guide them.

ASID has concerns that other groups will attempt to have the definitions expanded rather than a specific category for this group and therefore jeopardise the inclusion of this very vulnerable group. We understand that the Commission will not wish to expand the definitions as it greatly increases the coverage and leaves a possible loop hole for many others to enter tier three undermining the scheme. We implore you to retain this very important inclusion.

## **2 Vulnerability of individuals with an Intellectual Disability**

Many individuals living with an intellectual disability have someone in their lives independent of the service system to assist and guide with decision making and when required make decisions for them. However, there remain a large number of individuals who do not have an independent person to assist and they are very much reliant on the empathy and compassion of service providers to “do the right thing”. It will be very important that such individuals receive support to ensure that service outcomes and decisions are in the best interest of the individual. This may require the support of an independent advocate and ASID notes that advocacy is a service which can be purchased if required.

Those living with an intellectual disability have extra vulnerabilities related to their disability and research indicates individuals are far more likely to be the victims of abuse including financial and sexual abuse. It will be important that there are sufficient safeguards to protect those with an intellectual disability and the system does not unwittingly leave individuals more vulnerable. For example, no training benchmarks will leave individuals with an intellectual disability very vulnerable. It is imperative that sector wide independent safeguards are established and maintained such as the Community Visitors Scheme operating in Victoria. For those that cannot easily speak up and represent themselves, such safeguards are critical particularly in a service system which may become deregulated.

ASID notes that for many people with physical and sensory disabilities, such safeguards will not be necessary and such individuals wish to get on with their lives with a guarantee of individual funding over which they have maximum control and autonomy. That fact that this large group will not require the safeguards must not preclude this very vulnerable group from having access to them.

## **3 Training**

ASID agree with the Commission that a good relationship is the primary requirement of staff supporting a person with a disability and essential skills such as empathy and the capacity to listen are intangible and not easily created by training. However empathy and the ability to listen may only be part of the skills required to support a person with an intellectual disability. Although agreeing with the Commission regarding relationships and empathy being key components of the skills required, ASID is concerned about the lack of training benchmarks. The scheme will bring about a significant increase in individual support resulting in unsupervised workers and the vulnerability of those with an intellectual disability is considerable.

For example a young person who has a diagnosis of severe Autism may display violent tendencies as a result of their disability and will consequently need a support worker who is well trained and supported. Research indicates that those with behaviours of concern are highly likely to be subjected to restrictive practices and have their human rights violated if support staff are ill informed and do not understand the person's disability.

Once again ASID is aware that other groups will argue against training benchmarks as they wish to train and guide their own staff which is highly appropriate for those that are able to do so. It is important to note that in other areas such as childcare and aged care, there has been a significant increase in training benchmarks over the past five years due to consumer vulnerability. Where individuals are vulnerable, training benchmarks are imperative.

An example of good practice in this area is in South Australia where for individuals with high and complex health needs, there is a key government policy and guidelines in place regarding risk management including training of staff. This policy and guideline is particularly important for those with an intellectual disability who are totally dependent on the worker to meet their needs. The guidelines allow for exemptions. For example a person with an intellectual disability that lives in a group home who receives nutrition via a gastrostomy, and has a compromised respiratory system that requires a specific plan, will need a specifically trained support worker to meet their needs, otherwise there is the distinct possibility the person might die. A person with the same health issues with no intellectual disability who is able to train and direct their staff, would be exempt from the training at the request of the person who can take responsibility for their own health.

Currently a typical 'Disability Support Agency' which supports individuals who predominately have an intellectual disability will require staff to have a minimum of Certificate III Disability, preferably a Certificate IV. In addition there will be regular updates and training in a number of areas including:

- Nonviolent crises Intervention
- First Aid
- Medication administration and general health training such as epilepsy and standard precautions
- OHS&W
- Positive Behaviour Support
- Manual Handling
- Mealtime Management- completed by a Speech Pathologist to ensure staff feed someone appropriately who is at risk of choking such as someone with cerebral palsy. A person with an intellectual disability and a physical disability such as cerebral palsy is statistically at much higher risk of choking.
- Child Safe and vulnerable adult safe environments.
- Food handling
- Nutrition and healthy eating
- Specific disability type training. For example staff supporting someone with Prader-Willi Syndrome will need to have a good understanding of the disability in order to keep the person safe and respond to their highly specialised needs.

Given the recruitment issues most agencies meet the cost of Certificate III & IV training in addition to the areas above.

It is possible to have a 'win-win' situation in the area of training and ASID implores you to consider training benchmarks with the flexibility of exemptions.

#### **4 Benchmark pricing and supervision, mentoring and coaching of staff**

As outlined above, those living with an intellectual disability are extremely vulnerable and often require skilled staff that are well supported. A well trained support worker who is supporting someone with very complex needs will need a solid support infrastructure in order to be successful. They need ongoing training, 'drop-in' support, mentoring, support from a clinician such as a psychologist and emergency back-up. Pricing frameworks will need to take account of such costs.

#### **5 Whole of government/society responsibility for disability**

ASID commends the Commission for keeping a clear separation between income support, health and education etc. and a NDIS. It will be important to be vigilant and ensure that those areas of support that are available to any other community member are accessible to those with a disability. If you have a major health issue and an intellectual disability you should have access to the same health services and support as other members of the community.

ASID has one concern and that is the link to housing and support. For many years there has been a concerted effort to separate direct support to live in the community with the provision of housing for individuals with an intellectual disability. Who you rent your home from should be irrelevant and separate to the direct support you receive. Individuals may be at risk of losing their home if they have conflict with the direct service provider who may also be the landlord.

#### **6 Research and development**

The Commission's draft report notes that research capacity will be necessary, to collect and analyse data about service utilisation, service costs, and outcomes for people with disability. The report poses questions such as, *what is the role of research and innovation in a national disability scheme; how could it be promoted, and who would do it?*

ASID applauds the Commission's recognition of the importance of research, and of its integral role in the development of any NDIS. Embedding evidence-based practice in disability services will not only be critical to the success of any NDIS, but its inclusion will reinforce the vital role research has to play in the development of disability support services more generally. While the health sector has embraced evidence-based policy and practice, the disability sector is seriously lagging behind. Including consideration of research in this pivotal report will provide a much needed catalyst to placing the support of people with disability on a much needed robust scientific basis.

ASID takes the position that research, and the appropriate funding of research, should not be limited to the evaluation of existing services and service outcomes. Research funding and infrastructure should be supported to the extent that innovation and the systematic trial of such innovation is possible. Australian's with disability are often the recipients of service models from overseas. The effect of this is that such models are not always culturally appropriate without adaptation, and come with some considerable delay. Individualised funding models, already available in the UK, the USA and Canada are one such example. Appropriately funded research would serve to alleviate some of these problems which perpetuate disadvantage among Australian's with disability.

Currently, what little research is conducted in Australia is generally driven by short-term agendas of state and territory jurisdictions, with a focus on evaluating existing services. Access to commonwealth funding, and funding which allows for the proposal, development and trial of new and innovative approaches is limited by virtue of the position of disability research relative to other competing national priorities.

ASID requests the Commission recommend that issues pertinent to the support of people with disability be recognised as integral to our national wellbeing, and appropriately listed among those areas of research priority for funding by both the Australian Research Council (ARC) and the National Health and Medical Research Council of Australia (NHMRC). Furthermore, ASID would support the establishment of a national research fund focusing on innovation in disability services, so long as this fund was appropriately resourced, open to submission by researchers with respect to the subject matter of the research projects, and subject to scientific peer review. It could be that such a fund was administered within the existing infrastructure of the ARC or NHMRC, capitalising on their existing research funding expertise and avoiding the need to replicate the infrastructure required to administer such a scheme. Also, ASID would draw to the Commission's attention models of research funding already trialed in the UK, whereby funding arrangements encourage and reward active partnerships between researchers and people with disability, both in the development of research proposals and the implementation of research activities.

Further to our reference earlier in the current submission concerning the importance of workforce training and the benchmarking of qualifications, ASID would submit that if the benefits of evidence-based policy and practice to people with disability, and those who support them, are to be realised, it is imperative that the disability support workforce is scientifically literate. To this end, ASID would request the Commission make a recommendation that bodies responsible for workforce training and development, such as the Community Services & Health Industry Skills Council, include reference to evidence-based practice and the scientific method in their training standards and curriculum. Furthermore, that provision is made for the support of disability-related study in programmes of undergraduate and post-graduate education in the university sector, in addition to the current focus on generic medical and allied health practitioner training. This could take the form of both targeted scholarships (especially at a PhD level) and funding the development of courses, in much the same way that national priorities have been identified for higher education in areas such as indigenous health, teacher training and nursing, etc. In developing any such recommendations, it should be noted that internationally recognised good practice in support of people with disability includes, but goes beyond the provision of health services, and will include an emphasis on multi-disciplinary practice.

## **6 Quality & Standards**

The Commission recommends a market driven system with an underlying assumption that such a system will lead to quality services. ASID is concerned that a market driven system will result in the most vulnerable and disenfranchised such as those with an intellectual disability and complex behaviour support needs being left with few, if any, agencies willing to support them due to the economic drivers of such a system.

Although benchmarks and quality services are mentioned in the report, it is unclear the extent to which benchmarks and quality systems will be implemented. ASID supports an overarching national framework including standards, expected outcomes, accountability measures and governance. An overarching set of standards and outcomes however should be structured in such a way that they can be implemented locally taking into account the unique circumstances of the region/situation. For example the structure of implementation in rural and remote areas will be different from a metropolitan area.