

# **Minda Incorporated**

## **Submission to the Productivity Commission**

### **1. INTRODUCTION**

This submission details what Minda Incorporated, a long established service provider to persons with intellectual disability currently 1,500 individuals, believes is required to build a good system of long term disability care and support.

### **2. BACKGROUND**

Minda Incorporated was established in 1898 after a group of children, specifically those with intellectual disabilities, were deemed not to be suitable for the services provided by the Blind, Deaf and Dumb Institute. Many of these children found themselves in the Parkside Lunatic Asylum where was witnessed “the pitiable sight of children of weak intellect walking through the wards of a lunatic asylum”. Interestingly, the group of civic minded citizens who saw the need for a new approach clearly understood that any new service should provide an education to these children. Their request for government to “subsidise, pound-for-pound, money to be subscribed by the public for the purpose of erecting and maintaining a home and special school suitable for weak minded children then in the Parkside lunatic asylum” was eventually agreed.

Josiah Symon, the initial President, said at the opening ceremony that the great object of the institution “was that such intelligence as the little ones had might be fanned by gentleness and care into brightness and the promise of a useful life”. Minda therefore embarked on its century plus of support to people with intellectual disabilities with a developmental focus, recognising the capacity of these previously abandoned children to learn and contribute to the South Australian community. This is an important point and one to which this submission will return later on.

Initially supporting all of its endeavours through public subscription, more recently Minda has been supported by a combination of State and Commonwealth funding. In the 112 years of its existence, Minda has seen many changes and developments. It has had a special school on its site; developed work opportunities both at the Brighton and Craighburn sites; developed a training program that was accredited by the Nurses Board of South Australia and grown to the point where it now accommodates 258 clients at its Brighton site and 253 clients in community accommodation. It also provides respite, vacation care, day options, supported and assistance with open employment, aged care and family support services.

In 2009 the Minda Board agreed that the United Nations Convention on the Rights of People with Disabilities would guide its service developments and is now working to ensure that the principles of the Convention underpins all

service delivery. This is supported by its vision statement which is “to maximise choice and inclusion of people living with intellectual disability to achieve their aspirations”. Minda sees its mission as creating “the environment for individuals to pursue opportunities to lead valued and meaningful lives in supported communities”. The key values underpinning its Vision and Mission are respect – being valued by other people as an individual; inclusion – taking part in ordinary activities with other people in the community; and choice – autonomy of the individual.

In 2010 the Minda Board also agreed to a blueprint for the future which would see personal choice underpin the creation of new community living options and improved individualised accommodation on the Brighton site. A pilot program titled “Real Lives, Real Places” based on person centred planning and active support has been funded by the Board to demonstrate how a personal approach to the needs of people with intellectual disabilities can be translated into service options. Again this submission will return to this point later on. The Board envisages that its blueprint would see significant organisational funds directed into providing the additional support required to ensure that people were more in control of their own lives.

### **3. THE NATURE OF INTELLECTUAL DISABILITY**

It is essential that the Commission understands the nature of intellectual disability and its effects on the individual and the family. Traditionally intellectual disability has been defined by three components:

- a sub average level of intellectual capacity;
- one or more functional deficits;
- the occurrence of these phenomena in the developmental period, i.e., up to 18.

However, under this very broad definition lies a wide range of levels of disabilities and capacities. Some people will have a mild intellectual disability such that they are able to live relatively normal lives perhaps with occasional support in areas where complicated issues or decisions are involved. At the other end of the spectrum will be people with profound intellectual disabilities or multiple disabilities which might make the individual almost totally dependent on support for even the most basic of daily activities. Between these two extremes are people with a wide variety of disabilities and capacities.

The importance of this point cannot be overstressed. That decision makers were not aware of the profound levels of disabilities has never been more dramatically demonstrated than in the demonstration projects that were developed as a result of the then new Disability Services Act in the mid-1980s. One funding program was based on people with severe disabilities living in the community with 28 hours support a week. Families and advocates of people with these more severe levels of disabilities were rightly shocked by the ignorance of decision-makers, aware that many of these individuals required many hours of support per day, sometimes by two staff, and 24 hours a day monitoring. The credibility of this program was essentially destroyed because

people making decisions were driven more by ideology than a real knowledge of individuals and their needs.

It is also important to understand that there are significant differences between the needs of people with intellectual disabilities and those with other disabilities. This is often not understood by decision makers who have tended to adopt a “one size fits all” approach.

#### **4. THE UNITED NATIONS CONVENTION**

Key to the Convention is its principles (Article 3):

- Respect for everyone’s inherent dignity, freedom to make choices and independence.
- Non-discrimination (treating everyone fairly).
- Full participation and inclusion in society (being included in your community).
- Respect for differences and accepting people with disabilities as a part of human diversity.
- Equal opportunity.
- Accessibility (having access to transportation, places and information, and not being refused access because you have a disability).
- Equality between men and women (having the same opportunities whether you are a girl or a boy).
- Respect for the evolving capacity of children with disabilities and their right to preserve their identity (being respected for your abilities and proud of who you are).

The Australian Government has adopted the Convention, however, there has not been a co-ordinated nation-wide approach on how the Convention will be operationalised. In the absence of government leadership, the Minda Board has recently commenced work on how the Convention will affect service outcomes and how these outcomes can be measured and monitored. An audit of our performance against the Convention has been completed giving our Board an action plan for further improvement.

#### **5. PREVIOUS SERVICE RESPONSES**

If Minda had a progressive attitude to the support of people with intellectual disabilities in the 1890s, this was certainly not replicated for other people with intellectual disabilities who traditionally found themselves in the back wards of psychiatric hospitals. This has been dramatically described by Professor Bill Cramond in a short paper called “From Darkness to Light”. It demonstrated the scant regard in which people with severe disabilities were held and the unspeakable conditions in which they were treated.

Characteristic of these approaches were:

- an obvious disregard of the human worth of these individuals;
- an emphasis on congregate care in crowded and unhygienic settings;
- the use of restrictive practices, including medication, to control behaviour;
- a complete abandonment of the human rights that other members of the community would take for granted;

- a belief that professionals were in the best place to make decisions for individuals;
- no opportunities for skill development, and
- no participation in the affairs of the South Australian community.

If these blots on our community were eradicated in the 70s, 80s and 90s, many of the underlying attitudes persisted and many of the services provided to people even up until the present time were more about warehousing than providing support to people who are perceived to be valued citizens. The unstated but obvious message was that people with intellectual disabilities were “problems to be solved”. Furthermore, the underlying government policy seems to be that the care of people with disabilities, particularly those with intellectual disabilities, can be left to parents and / or carers.

## **6. THE LEVEL OF SUPPORT NEEDED TO MAKE THE CONVENTION A REALITY**

There are still large residential settings in Australia where the level of service provision does not support the human rights envisaged in the United Nations Convention. In the absence of appropriate levels of funding from government, many organisations provide a level of service which does not take into account the wishes and needs of the people that they serve. For example, it has often been the case that everyone eats at the same time, that everyone goes on the same excursions and that everyone fits in to the organisation’s ways of doing things given its capacity which in turn depends on its level of funding. An individualised approach requires increased staffing which in turn affects efficiency.

Inherent in the Convention’s intent is the need to ensure that services are provided in a way that ensures that people's rights are being met. There are two key components that significantly contribute to a person's ability to enjoy their rights as a human being. The first of these is the acquisition of skills so that people are able to make the lifestyle choices that are important to them. The second is an environment within which real choices are supported and encouraged. Minda supports both of these components and these are reflected in its vision and mission statements and its recent investment in the “Real Lives, Real Places” program – a person-centred approach.

To make this a reality around Australia there will need to be an additional level of funding to ensure that some of the programs that support skill development and choice can be implemented. Within Minda there is a commitment to active support, that is support which is based on individuals gaining skills and choice through using a person centred approach. That organisations around Australia have not adopted a rights-based approach is not because they are inherently bad or uncaring, but largely because they have not been funded by successive governments to provide this level of support.

Minda understands that it would be very difficult for any government to commit to a level of funding that would give individuals total choice over where they might live. For example, to support a person with severe and multiple disabilities

to live by themselves could cost of the order of \$300,000 to \$400,000 per annum. There is an acceptance that some group living will always be a part of the service mix in the future. However, it is important that the level of funding provided in the future recognises that Australia has adopted the Convention and that in so doing it will incur additional costs if this adoption is to be anything other than a political exercise.

## **7. UNMET NEED**

One of the key issues in the provision of disability services is the level of unmet need. Whilst Minda is not in possession of all the information to report on this in great detail, there are a large number of people registered for its services who are seeking services that are currently not available in South Australia. In particular, residential services and respite are severely rationed and it is our understanding that there are over 100 people in South Australia who are on the Category 1 waiting list for accommodation services. This means that these individuals are at immediate risk of harm to themselves or of harming others. Around South Australia, ad hoc and piecemeal solutions are adopted (often at great cost) to respond to the crises this approach regularly delivers.

The support of many people with disabilities falls largely on the shoulders of parents and other family members. In the past this has often occurred without any support from the service system and indeed an “all or nothing” approach has operated, that is you either look after your son or daughter without support or they are totally supported within their accommodation service. Although a large range of services have been painted into the service spectrum in recent years there is no doubt that the responsibility for caring for people with intellectual disabilities falls disproportionately on families. This is an issue that must be addressed in the Productivity Commission's deliberations.

## **8. AN ENTITLEMENT PROGRAM**

It is difficult to see how any future system that is based on equity and fairness can be anything other than an entitlement program, that is if you meet particular criteria that you will be provided with the level of support that will meet your needs. There are emerging trends around Australia that such support should be expressed in dollar terms that are made available to the individual or family for them to choose the services that make sense to them.

Anything other than an entitlement program will continue to see a competition between various groups and individuals within groups for the scarce resources that governments have traditionally made available. This is certainly not what is envisaged in the United Nations Convention.

## **9. CONCLUSION AND SUGGESTIONS**

Minda welcomes the Productivity Commission's investigation of a fairer and more transparent mechanism for funding disability services across Australia. It is appropriate that this is an issue that should be addressed at the national level and the insurance proposal is one of a number of funding mechanisms that

would ensure that people with disabilities were able to enjoy the rights envisaged within the United Nations Convention to which the Australian government is a signatory.

In supporting the work of the Commission, Minda would make the following suggestions:

- When looking at the level of funding that is required to support people with disabilities, particularly those in residential settings, there should be a commitment to a level of service that enhances skill development and provides an environment within which people are able to be in control of their own lives to the maximum extent possible.
- Any future system should not permit a continuation of the competition for resources between different disability groups or between individuals in the same group. It would be a disgrace if any future system did not stop the need for families and individuals to get the services they require by having to bring their plight into the public domain through negative media stories.
- There is a need for government leadership so that the principles of the United Nations Convention are made a reality. This would require the Commonwealth and State governments to enact legislation and reporting mechanisms that ensured that organisations were doing the things necessary to continually enhance the rights of the people they support.
- There is a need for government leadership so that the rights of people with disabilities and their place in the Australian community are enhanced, that their contribution to the Australian community is maximised, and that their inherent dignity and worth are recognised and celebrated.