



Submission No. 17

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Victorian Law Reform Commission
Review of Victoria's guardianship and administration laws
Level 3
333 Queen Street
Melbourne Victoria 3000 Australia

13 May 2011

Dear Commissioners,

We thank you for the opportunity to provide a submission to the review of Victoria's guardianship and administration laws.

About Inclusion Melbourne

Inclusion Melbourne is a not-for-profit organisation that provides services to people with an intellectual disability, helping them to create more enjoyable and rewarding lives and participate fully in the community.

Our vision at Inclusion Melbourne is for people with intellectual disability to live in an inclusive community, where everyone has the same opportunities to participate in community life and to take their place in society as respected citizens.

We believe our role as a disability support provider, is to encourage and enable people with disabilities to achieve and maintain a valued quality of life. We achieve this by supporting people to create highly personalised and flexible lifestyles based on their needs and desires. To achieve this we encourage people to participate in activities and develop relationships with people within their local community.

Our response

Inclusion Melbourne welcomes the Victorian Law Reform Commission's report into Victoria's guardianship laws to ensure they reflect modern standards and that Victorian guardianship laws respond to the current and future needs of people with impaired decision-making capacity and promotes their rights.

It is our position that the current system of guardianship and administration, in principle, is the best way to ensure the needs of vulnerable people are met and their rights protected. However we believe that there are better ways that this system can work in practice and that improvements can be made to incorporate new models of supported and joint decision making.

At present the system is complex, heavily reliant on process and paperwork, and not generally well understood and known of by the general public. It is our view that the system should be streamlined to reduce bureaucratic complexity.

Areas of concern

An area where we see room for improvement on the current system is the difficulty in obtaining guardianship for occasional decisions (such as undertaking an activity where a service providers

seeks a signed consent form – eg: horse riding, or a joy flight) We suggest that less restrictive options be enshrined in legislation in line with the principles of the Disability Act, recognising greater independence for the person with a disability, and the Charter of Human Rights.

Inclusion Melbourne also appreciates that there is a gap in the provision of information to families about the termination of a parent's right to legally oversee their child's affairs upon reaching the age of majority. Families are justifiably shocked at this discovery and a greater effort must be made to inform both people with a disability and their families of this - distribution via schools would be an obvious approach for the dissemination of information.

Inclusion Melbourne believes that providing parents with no option rather than limited guardianship for specific purposes demeans the special bond, relationship and role carried out by parents in caring for their children. When combined with the burden and stress of caring due to a service system recently described by the Productivity Commission as '*underfunded, unfair, fragmented, and inefficient*', it serves only to compound the stresses and anxieties experienced by carers. Finally, we are concerned that a greater emphasis is placed by VCAT on a person's need for a guardian rather than the suitability of the guardian. We believe strongly that there should be on-going scrutiny, or at least a process for scrutinising, an appointed guardian.

Community awareness, education and support for guardians

It is the experience of Inclusion Melbourne that the general public has little knowledge of the existing guardianship and administration protections, and so is therefore unable to support friends, family members or neighbours during periods of high stress and anxiety when a loved one either temporarily or permanently loses the capacity to make informed decision for him/herself. Further, given the complexities of powers of attorney (medical treatments), general practitioners and other medical staff are often not well informed about the differences that exist between powers of attorney and guardianship and administration. Consequently, we suggest that any new system be accompanied by community wide educational strategy. To be effective, we would also recommend that easily accessible information and timely provision of advice would also form part of such a strategy.

People who are appointed as guardians currently have little support for carrying out an extremely sensitive and challenging role. We therefore recommend that any changes to the Act are accompanied by a review of the systems that operationalize the legislation, and that these systems would include the establishment of a unit that can provide training programs and generic advice to guardians. Such a scheme could operate within the Office of The Public Advocate, or be tendered out to the community sector and could easily be accommodated by an existing advocacy, training or community support organisation either at a regional or state-wide level. Such a scheme could be funded via a combination of government and user pays (eg: establishing paid course to educate community workers about guardianship and its application)

We are of the view that a substitute decision maker must be equipped with the skills to perform these duties to a high standard. This necessarily requires significant time, appropriate skills and insight to understand the views of a person with a disability. We would therefore support the development of legislation that enables activist tribunals, in so far that they can question and investigate alternative people to act as a guardian, recognising that the next of kin may be a person

with whom the individual has had limited or no contact with for extended periods of time. In these circumstances we believe the tribunal should seek information from a community support provider where that provider has played a significant role for a number of years.

Education for guardians should reflect the Charter of Human Rights and a social model of disability, as it is our experience that guardians make cautious decisions, rather than utilising their powers to reflect a person's desire to engage in risk, whether this be through questing the movement from supported accommodation into the private rental market, seeking employment in the open market rather than remaining within an Australian Disability Enterprise, or seeking personal relationships (eg: accessing funds to visit a legal brothel).

Best Interests

We believe that it is essential that every effort is made to identify a represented person's wishes and follow these where possible. In working with people with intellectual disability, we recognise that there is usually not any written evidence of lifelong dreams and desires, and that family members often quash discussion of 'living in a place of my own' or 'moving to live by the beach' as drivel, rather than an expression in exercising choice and self-determination. In working with people with intellectual disability, we believe processes should exist to encourage the attainment of a person's wishes on a wide range of matters, including health, employment, education and accommodation and any future plans that the person may have when their existing arrangements change (eg: death of parent forcing relocation to a group home in another suburb). We believe strongly that a represented person should be respected in their ability to contribute. An example we experienced was where a person we worked with was relocated away from his community, even though he was very clear that it was his wish to remain in the local area, but a guardian approved a move to a supported accommodation services approximately 25 kilometres away, uprooting him from his local connections and services. In every decision, we believe some weighting should be given towards the expressed wishes of the people with a disability.

In terms of capacity versus disability, Inclusion Melbourne are of the view that the issue of capacity to make an informed decision regarding a particular matter is more relevant than a particular label regarding disability. Our experience is that many people with intellectual disability should not automatically be perceived in law to have no ability to consider or reach an informed decision. Therefore, we recommend that the Commission consider alternative models of joint and assisted decision making, with appropriate safeguards to ensure that the needs of the individual are being listened to, and adequately represented. Therefore, a new system of guardianship and administration must consider how best to provide assistance to people to make decisions, and to deal with conflict that may exist around particular viewpoints. Such a system must recognise that the best person to support this process may not always be an immediate family member, particularly when the decision of the person lacking capacity may impact upon the family member (eg: moving out of home means that the parents are no longer able to afford the rental on the property as it was being subsidised by the person in question).

Microboards: a potentially less restrictive option for assisted decision making

A Microboard is a small group of committed family and friends who join with a person who has a disability to create a community board. The Microboard supports the person to plan for a good life and to achieve their goals, dreams and wishes. Each Microboard supports one person. The

Microboard also helps the wider community to have a relationship with the person, and to benefit from their contribution.

The majority of people with a lifelong disability in Victoria continue to live at home with their parents well into middle-age. The increased life expectancy of people with disabilities means that as they reach middle age and beyond they will be living with their older parents whom they are more likely than in previous generations to outlive. The question *"Who will take care of our son or daughter when we are gone?"* is real and pressing for many older carers in Victoria. The Coalition for Disability Rights estimated that in 2008 in Victoria there were 3000 ageing parent carers which they estimate would increase to over 4000 by 2013. Similarly, they estimate more than 1300 people with disabilities are on urgent list for accommodation and support.

Preparation and planning for the future is essential to avoid future crisis and the unplanned transition of adults with a disability to inappropriate accommodation and dislocation from their local community. Future planning is not only about finances and accommodation but retention of family support from siblings, nephews and nieces and replacing less explicit parental 'caring about' roles which involve negotiation with formal services, advocacy and monitoring quality of care.

Microboards offer a practical approach to involve people alongside ageing parents in this support, advocacy and futures planning for someone with a disability. This approach provides greater control and choice for people with a disability and their families, increased access to informal supports, and increased options for a person's future.

Microboards were initially used in Canada by Planned Lifetime Advocacy Network (www.plan.ca), where a small group of parents acknowledged that one day they would need to pass on the responsibility for the care of their son or daughter to someone else.

In the past decade organisations in around the world have begun to explore the Microboard concept, but to date the development of microboards has relied on the initiative of well-resourced families. The potential application of microboards to the Victorian context & people with disabilities from a wider range of socio- economic backgrounds is not known. Further, little is known about the skills, strategies or resources necessary to establish and maintain viable microboards.

Adaptation of Microboards for Victorian circumstances could provide a powerful tool for increased power and choice by people with a disability and their families. The Australian Government's Productivity Commission draft report (Feb 2011) recommends that people should be given much greater power and choice in a new disability support system, with the objective of giving people greater flexibility and control over their lives — with the ultimate goal being greater wellbeing. There are strong rationales for a consumer choice approach. As people know their needs better than others, it can increase pressures on suppliers to perform, and people value choice in its own right. Given the proposed direction for the National Disability Insurance Scheme to exercise consumer choice, it is clear that people with a disability who are provided with an individualised package and expected to manage it at the micro level (self-directed funding) will require appropriate models of shared or joint guardianship and decision making responsibilities for managing these support packages. It should be noted that support packages that will increase in size as the support needs increase, resulting in a person with profound disability to be in control of a support package in excess of \$100,000 per annum. One potential of Microboards is to provide a way people with limited intellectual and decision making capacity to be empowered to make these choices, alongside family members, friends and neighbours, supporting not only the person with the disability but his or her

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parents as well, thereby reducing the burden of caring experienced by ageing parents who feel that they are 'doing it alone'.

Evidence from Europe and North America has already highlighted a number of benefits of Microboards and individualised support arrangements. These include:

- A wide range of positive wellbeing outcomes from self-directed funding for people with disabilities and their carers, including higher satisfaction with life, more independent living, better continuity of care and lower levels of abuse and neglect.
- Self-directed funding appears to cost no more than traditional models of care, and may well cost less.
- Support for ageing parents.
- Greater community connections.
- Decreased reliance on paid support systems

As you would be aware, these outcomes are in line with those that are sought by the recently released National Disability Strategy. Therefore, as a process that encourages participation, the Microboard concept, along with laws that enable shared or collaborative decision making, may offer additional options to people where it is clear that we require a greater continuum of choices in order to best meet the needs of unique circumstances.

Yours sincerely,

Daniel Leighton
Chief Executive Officer

