

Submission to the Review of the Guardianship Act 1987

Vanessa Browne

I want to draw the Commission attention to the perennial struggle that people with moderate to profound intellectual and communication disability and their families face in gaining acceptance and respect for the expert and sincere representation that families provide in all settings, everywhere and every day.

A chasm exists in relation to the rights of people with moderate to profound intellectual and communication disability. They have been overlooked by the movers and shakers in the human rights circles because they must necessarily rely on others to be their voice, to champion their rights and to make the running on their behalf.

People with moderate to profound intellectual and communication disability are overlooked and disregarded because they literally cannot speak, cannot get in touch with the mainstream media, start a change.org petition or otherwise protest about the infringement of their basic human rights. Some don't know they have human rights, they don't understand what they are or how to claim them.

Their plight has been lost on everyone except their parents and families and now we must mobilise because the NDIS is coming, and the lack of formal representation for our children is endemic and systemic.

This naturally brings me to the issue of guardianship. There is no denying the fact that in Australia there quite possibly several hundreds of thousands of people who are overlooked in relation to representation for the reasons set out above. They are deemed to be in need of guardianship and financial management but have neither. The majority are living at home with ageing parents who love them, are devoted to them and who have always supported them for their entire lives. They have been completely overlooked as they carry on at home in the loving care of their family.

The law has forgotten them.

On page 4 of the NSW Ageing Disability and Home Care Policy document on Decision-making and Consent it says:

Policy and Principles

The Policy and Principles contained in Part 1 are mandatory for both ADHC operated and funded non-government services

1.1 Purpose

The policy is to inform service providers and care workers who need to obtain consent either directly from a client or from a legally appointed guardian.

Then on page 7 in relation to Decision-making and Consent it says:

If there is no legally appointed guardian, staff should contact the Guardianship Tribunal on 1800 463 928 or 9556 7600 for advice about applying for the appointment of a guardian.

If staff are concerned that decisions being made by the family or a guardian are not in the best interests of the client, they should refer the matter to the line manager who will assess the need for a review by the Guardianship Tribunal.

This applies in all situations where the person with disability who has decision-making incapacity is over the age of 18 years.

Furthermore a goodly number of applications for Guardianship are made by Service Providers and with the NDIS being implemented in most regions of NSW this year the matter of Guardianship must be resolved. Under the Australian Constitution guardianship is a state issue and legislation must be passed by the States. However if the States decide that that power can be vested in the Commonwealth then the States can agree to surrender that power to the Commonwealth which is what they did with income tax back in the 1940s and disability services which they did in 2012/2013 with the National Disability Insurance Scheme.

With respect to people with moderate to profound intellectual and communication disability, guardianship can be applied for either through the Guardianship Tribunal or through the Supreme Court.

I am aware of a great many unbalanced, unfair and extremely distressing guardianship matters and these stories cause me to believe the process should be undertaken by the

operation of a law passed to make application for guardianship and financial management simpler, easier and more timely and less emotionally and psychologically damaging.

A law is required as an adjunct to the current law as it stands and should be applied and administered by the Supreme Court for one very important reason.

The rules of evidence apply in the Supreme Court; whereas, in the Guardianship Tribunal the rules of evidence do not apply.

Where there is no dispute there should be the operation of a law that permits an ex parte application by summons (this is an application which does not need to have the parties present) supported by affidavit evidence meeting criteria set out in legislation, along the lines of when applying for probate e.g. evidence from medical and allied health and disability professionals, lawyers and others who can attest to the situation and the need for guardianship; at the end of the process a Grant is ordered by the Registrar of the Equity Division using the court's full *parens patriae* protective power.

The current situation is a clear case of discrimination against our children with moderate to profound intellectual and communication disability.

We are whole persons with physical and intellectual capacity, we have legal agency by virtue of our capacities and we have

it every day of our lives, it is not intermittent, nor is it bestowed or withdrawn by fiat, nor is it episodic.

Until our children with moderate to profound intellectual and communication disability turn 18 years of age, they are whole and complete people, because the deficits in their intellectual capacity are covered by assistance and representation by their families.

However, on turning 18 they essentially suffer a civil death because they cannot make decisions about the more difficult complex issues in their life. They continue to need assistance with just about every aspect of life and their families continue to provide that assistance even though they currently have absolutely no legal standing.

According to the current laws our children remain civilly dead until someone becomes their legal guardian and financial manager.

Civil death is the loss of all or almost all civil rights by a person due to the conviction for a felony or due to the action **or inaction** by the government of a country that results in the loss of civil rights.

Please compare the situation described above to that of a young person born with physical disability but otherwise intellectually competent. This young person has always been provided with the physical aids which best enable mobility and inclusion and development into a wonderful young

person intelligent, well-educated, confident, eminently employable. On turning 18 life just goes on.

What do you think would happen if upon turning 18 the law says those physical aids that enable mobility and inclusion must be removed until the young person goes before a special court hearing to win the right to have those aids returned/restored/provided? Would the community be as accepting of this situation as it is of the stripping of the rights of a person with moderate to profound intellectual and communication disability to continue to be represented by their loving and expert families?

Our children with moderate to profound intellectual and communication disability are victims of chronology. While chronologically they may be 18, 21, 25, 45 years old, developmentally and intellectually they may not have attained the capacity for decision-making or financial management because of their disability.

Where are the reasonable adjustments and accommodations at law for them our children, which the UN Convention on the Rights of Persons with Disabilities, to which Australia is a signatory, calls for?

Yet Australian law and society justifies inaction on this point by equivocating, lest the United Nations Convention on the Rights of Persons with Disabilities be infringed; inaction is justified by claiming their human rights are infringed by making decisions for them; when, in reality it infringes their human rights for society NOT to intervene to provide those

decision-makers and financial managers who will make them complete in the eyes of the law and in the eyes of society; where they themselves are represented and their rights affirmed, validated and championed through the agency of their guardians; usually their parents, family members and/or significant others.

We demand a new law which will provide for the guardian and financial manager to be appointed by a legal process which is simple, timely and seamless and can be prepared for while the young person is still under the age of 18 so that it comes into effect at the age of 18.

Our children in need of such assistance cannot live by a fiction that says that everyone is deemed to have capacity, because for them it is just that, a fiction; their lives should not be based by a fiction, they need and deserve to be a whole person; not a civilly dead non-person.

Thank you.

Yours Sincerely,

Vanessa Browne