

# **An New Era in Disability Rights**

**A new Human Rights Charter plus a new UN Convention.**

**Human Rights Conference  
Victorian Equal Opportunity and Human Rights Commission  
27 February 2007**

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## **Abstract:**

For advocates of disability rights, it seems fortuitous that the new Human Rights Charter for Victoria comes into effect just as a new UN Convention on the Rights of People with Disabilities has been adopted by the United Nations. This fortunate coincidence gives Victoria a golden opportunity to include in its review of all state legislation the new international standards for disability human rights. The focus of this presentation will be to highlight some of the key principles in the UN Convention, with particular emphasis on the substantial impact it will - or should - have on advancing the rights of people with psychosocial disability.

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## **Context – a new UN Convention and a new Victorian Charter on human rights**

When the UN General Assembly adopted its latest human rights Convention on December 13 last year, Kofi Annan hailed it as the “dawn of a new era” for the rights of people with disabilities. After five years of negotiations, the Convention on the Rights of Persons with Disabilities (CRPD) became the eighth UN human rights convention since the Universal Declaration of Human Rights in 1948. It follows other similar conventions, such as those on the rights of women and children, in recognising that more general treaties had failed to protect the rights of particular populations. As Kofi Annan observed on December 13, “On paper, they [people with disabilities] have enjoyed the same rights as others; in real life they have often been relegated to the margins and denied the opportunities that others take for granted.”<sup>1</sup>

Coincidentally, 2006 also saw the Charter of Human Rights and Responsibilities Act passed by the Victorian parliament. Although the Charter came into effect on January 1, 2007, it allows twelve months for current Victorian legislation to be reviewed – and amended if required – before coming into full effect on January 1, 2008. The Charter defines human rights “civil and political rights” (Part 1, Section 3), indicating its emphasis on these rights based on the International Covenant on Civil and Political Rights (ICCPR) of 1966. The Act includes a review of the Charter after four years that will include consideration of “additional rights”, and specifically mentions the International Convention on Economic, Social and Cultural Rights (ICESCR, 1966), the Convention on the Elimination of Discrimination against Women (CEDAW, 1979), and the Convention on the Rights of the Child (CROC, 1989). Presumably this review after four years would now also include the CRPD of 2006.

This does not, however, mean that the civil and political rights of people with disabilities can also

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<sup>1</sup> <http://www.un.org/News/Press/docs/2006/sgsm10797.doc.htm>

be postponed in Victoria for four years. Many of the human rights protected under the Convention are civil and political rights. Indeed, the Convention does not create any new rights for people with disabilities but only reinforces existing rights, such as the civil and political rights under the ICCPR, as they apply to people with disabilities.

### **Civil and political rights for people with psychosocial disability**

This paper highlights some of the civil and political rights in both the Charter and the Convention, with particular reference to their significance for people who experience psychosocial disability. One of the outstanding achievements of the Convention was the extensive participation and cooperation of representatives from all sectors of the disability community in the negotiations for the Convention. Although there are variations in the human rights priorities among different sectors of the disability community, the underlying principle throughout the Convention is that it *prohibits any discrimination based on a person's disability*. With this overarching principle in mind, the focus of this paper now shifts to the most urgent human rights issue for people who experience psychosocial disability, which is involuntary psychiatric treatment.

Section 10 of Part 2 of the Charter on the “Protection from torture and cruel, inhuman and degrading treatment”, states that:

“A person must not be:

- a) subjected to torture; or
- b) treated or punished in a cruel, inhuman or degrading way; or
- c) subjected to medical or scientific experimentation or treatment without his or her full, free and informed consent”

There are strong arguments that involuntary psychiatric treatment meets all the internationally recognised standards for the definition of torture<sup>2</sup>. There is also overwhelming anecdotal evidence from people who have experienced involuntary psychiatric treatment that they experience it as cruel, inhuman and/or degrading, and that it is often imposed on them for reasons other than treatment, typically to control the person's behaviour but also often as punishment. The discussion that follows, however, focuses on the critical issue of full, free and informed consent, or part (c) of the above section of the Charter.

### **Protection from medical experimentation without consent – a non-derogable right**

First of all, it is claimed by some that the right to be protected against medical *treatment* without consent is not an 'inviolable' or 'non-derogable' human right in the way that, say, freedom from torture is. It is argued that, unlike torture, there are rare exceptions when involuntary medical treatment is justified. Before addressing this claim though, let's first look at the prohibition of medical *experimentation* without consent, which is generally regarded as a non-derogable civil and political right similar to the prohibition on torture.

One clearcut example of medical experimentation without consent is probably a daily occurrence on psychiatric wards throughout Australia. An involuntary patient (whose identity I must be careful not to disclose) is receiving more than double the maximum recommended dose of an anti-psychotic drug without his consent. That is, more than double the maximum dose recommended by the manufacturer of the drug, which means that the drug has not been tested – or approved – for use at this dose. Without even looking at the known hazards of this family of drugs (which can be

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<sup>2</sup> See, for instance, Minkowitz, T. (2006) *No-Force Advocacy by Users and Survivors of Psychiatry*. Wellington: Mental Health Commission.

extreme, including permanent brain damage, even at approved doses), such use of them constitutes medical experimentation without consent and should simply *never* occur any more than torture.

An even more common example of medical experimentation without consent on psychiatric wards is the extensive use of multiple psychiatric medications being used simultaneously on involuntary patients. Very few of these drugs have been scientifically tested in combination, with the only evidence to support such complex and potentially dangerous 'polypharmacy' being the anecdotal evidence of treating doctors who might claim that these drug combinations "seem to work" ... sometimes ... for some people ... Without the scientific evidence of properly undertaken drug trials, the use of such combinations of drugs without consent also constitutes medical experimentation without consent, and should also *never* occur.

One particularly disturbing example of medical experimentation without consent in psychiatry is the not uncommon use of electroconvulsive therapy (ECT, also known as 'shock treatment') on involuntary psychiatric patients. Again, only anecdotal evidence is offered to justify this practice by the treating doctors, who freely admit that they have no scientific explanation for why "it seems to work". At a conference in Milan in 2005, the Director of Mental Health and Substance Abuse at the World Health Organisation, Benedetto Saraceno, compared involuntary ECT to the barbaric practice of ECT without anaesthesia, which still occurs in many countries, though not Australia:

*WHO believes that even if ECT is considered by many psychiatrists an acceptable treatment, nevertheless, due to the great debate surrounding this practice this should be at least considered controversial. WHO would like to stress that involuntary ECT or ECT without anaesthesia should be considered unacceptable*<sup>3</sup>

Let's be very clear, though, at what the real issue is here. Medical experimentation *with* full, free and informed consent is not the issue. In fact I suspect most of us have at some time agreed to a medical procedure or treatment that the doctor admits to being experimental but which, in his considered, professional opinion, is worth the risk for the medical condition we might be having problems with. Done properly, with *full, free and informed consent* (and the trust and respect that we can reasonably expect from our doctors) this is not a human rights issue but rather good medical practice. The human rights issue is that *without* the full, free and informed consent of the patient, such medical experimentation should *never* occur. Contrast this to the reality on psychiatric wards around the country where the status quo is just the opposite with medical experimentation routinely imposed on very many – thousands – of involuntary patients every day without consent.

### **A reality check – the excessive use of psychiatric treatment without consent**

Are there times when medical *treatment* – as opposed to experimentation – can be justified without the consent of the individual receiving the treatment?

One proponent of medical treatment without consent is Graeme Innes, Australia's Human Rights Commissioner at the Human Rights and Equal Opportunity Commission (HREOC), who was part of the Australian delegation to the UN for the Convention negotiations. Graeme argued at the Convention negotiations, and again at a forum in Melbourne last year hosted by the Victorian Mental Health Legal Centre<sup>4</sup>, that there are "rare and extreme" occasions when medical treatment

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<sup>3</sup> Benedetto Saraceno, Director of Mental Health and Substance Abuse, World Health Organisation, '*Psychiatric services users: the WHO perspective*', presented at conference of World Association of Psychosocial Rehabilitation, Milan Italy, June 2005

<sup>4</sup> Graeme Innes, keynote address at a Forum on Advance Directives, Mental Health Legal Centre, Melbourne July 22, 2006

without consent is necessary, giving the examples of a person in a coma or someone with severe brain damage.

Before looking at such “rare and extreme” cases, another reality check of current psychiatric practice in Australia is necessary. Rather than rare and extreme, involuntary treatment is widespread and common, and not at all comparable to the comatose or severely brain damaged examples that advocates of forced treatment like to cite.

It is probably a daily occurrence on psychiatric wards in Melbourne that a person says to the treating doctor – quite clearly and unequivocally – that they do not want to take the drug being prescribed. Often, the person has taken the drug previously and knows that it does not help them and/or that they find its side-effects unacceptable. But regardless of their reasons, they are clearly saying “No”. Under any other circumstances such clear and unequivocal withholding of consent is considered the legitimate exercise of a fundamental human right. But with the help of some quite peculiar circular logic, our current mental health laws regard the refusal to consent to treatment as a symptom of mental illness, which then becomes the justification for imposing the forced treatment without consent. “No” somehow no longer means no. It is hardly surprising then that so many people who have experienced forced psychiatric treatment compare it to rape.

Anyone who has spent time on a public psychiatric ward knows that involuntary treatment is an ever-present threat and an intrinsic feature of the culture of the ward. Even voluntary patients learn of this threat quickly. Following the peculiar circular logic of our mental health laws again, it is a cliché on these wards that “if you don’t take your pills then we’ll have to make you involuntary”.

Stepping outside the hospital wards, Community Treatment Orders (CTOs) represent an even more widespread use of psychiatric treatment without consent. Under the guise of “community based rehabilitation”, a CTO is a legal requirement under mental health laws to impose and enforce involuntary psychiatric treatment on people, in their homes, whether they like it or not. Rather than “rare and extreme”, CTOs represent the massive reinstitutionalisation of the mad, except the bricks and mortar of the old loony bins have been replaced by a psychopharmacological ball and chain.

There are more people in Victoria on CTOs than there are in its prisons. There may in fact be twice as many people on CTOS as there are in our 5 prisons (roughly 2,500) but, unlike the Department of Justice, the Department of Human Services is not very forthcoming about the CTO numbers. We can continue this comparison and see that there are far greater human rights protections in our criminal justice system than there are in our mental health system. In particular, a properly constituted court of law, including all the protections that come with it, is required in our criminal justice system for society to deprive a person of their civil and political rights. But not so in our mental health system, whether on a hospital ward or through a CTO, which only requires the signatures of a couple of doctors.

People on CTOs are not only denied access to a proper court of law when they are first deprived of the right to refuse treatment. Should they wish to appeal against the CTO, they must do so through a tribunal, the Mental Health Review Board (MHRB), which is not a properly constituted legal court. The MHRB is notorious among those who have experienced its power as a rubber stamp – or kangaroo court – for the psychiatrists who invariably insist that the person must remain on the CTO. To illustrate the poor human rights practiced at the MHRB, the single most frequent argument used to keep someone on a CTO is that they “lack insight” into their mental illness. But such an arbitrary, subjective and poorly defined concept as “insight” would not stand up to scrutiny in a proper court of law as sufficient grounds to deprive a person of a very basic human right<sup>5</sup>.

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<sup>5</sup> See Diesfeld, Kate, & McKenna, Brian. (2005). *Insight and Other Puzzles: Undefined terms in the New Zealand Mental Health Review Tribunal*. Wellington, Mental Health Commission

My colleagues in countries that Australia might compare itself with, such as the UK and the US, are horrified when they hear of our CTOs. The UK is currently trying to introduce involuntary outpatient treatment (i.e. CTOs) against strong opposition, not only from those who have experienced forced psychiatric treatment on hospital wards but also many others concerned about psychiatric human rights. In the US, not all states have involuntary outpatient treatment and those that do, such as New York, require a court order, not just a doctor's signature. Needless to say, in states like New York where people's rights are protected by a proper court rather than a kangaroo court like the MHRB, involuntary outpatient treatment orders are imposed far less frequently than they are here in Victoria.

The gross misuse of involuntary psychiatric treatment on hospital wards and the thousands of people in Victoria on CTOs cannot possibly qualify as the "rare and extreme" cases that Graeme Innes is referring to as occasions when medical treatment without consent can be justified. Even a conservative reading of Victoria's new Human Rights Charter, now reinforced by the UN Convention, requires that the involuntary psychiatric treatment described above be recognised as a violation of fundamental civil and political rights, which must now be prohibited, beginning with the immediate abolition of Community Treatment Orders.

### **Human rights principles for "rare and extreme" cases of medical treatment without consent**

But are there genuine "rare and extreme" cases where medical treatment without consent is justified? This question takes us to the very heart of the UN Convention on the Rights of People with Disabilities and the civil and political rights of people with disabilities that the Victorian Human Rights Charter must take into consideration.

Recall that the underlying principle of the Convention is that it prohibits any discrimination based on a person's disability. Note also that the purpose of Victoria's Mental Health Act is discrimination in the form of limiting a person's human rights based on their disability. That is, the primary function of the Mental Health Act is to deprive a person of some very basic human rights – i.e. civil and political rights recognised in both the ICCPR and Victoria's Human Rights Charter – on the basis of a medical diagnosis, or psychiatric disability. Although the Charter does not specifically mention disability rights, the civil and political rights it asserts for all people are consistent with the Convention and therefore in serious conflict with Victoria's Mental Health Act.

Central to this underlying principle of the Convention is one of the core civil and political rights recognised in both the Convention and the Charter. In the Convention, this is Article 12 on Equal Recognition Before the Law. In the Charter, it is Section 8 of Part 2 on Recognition and Equality Before the Law. Both the Convention and the Charter assert that all people have the human right to be recognised as a person before the law, without any discrimination and on an equal basis with all other persons. In particular, in the words of the Charter (Section 8-3), "every person is equal before the law and is entitled to equal protection of the law without discrimination and has the right to equal and effective protections against discrimination".

Without explicitly mentioning disability, this section of the Charter effectively prohibits discrimination on the basis of disability, making it consistent with the Convention. This section is also sufficient, by itself, to require either the repeal of the Mental Health Act or at the very least major amendments to it. First of all, as noted above, the Mental Health Act discriminates against a person to deprive them of human rights on the basis of a psychiatric diagnosis, or psychiatric disability. Furthermore, when it deprives a person of a human right without the legal processes of a

properly constituted court, including the protections that come with this, then it is violating fundamental civil and political rights recognised in both the Charter (Part 2, Section 8) and the Convention (Articles 5 and 12). This applies equally to both inpatient and outpatient involuntary treatment orders, and also the inadequate and improper appeal process for people on CTOs through the Mental Health Review Board.

### **The “new era” as a paradigm shift – legal capacity and supported decision-making**

One of the breakthroughs of the Convention is that it clarifies the right to equal recognition before the law when it states in Article 12-2 “that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”. By recognising legal capacity as fundamental to equal recognition as a person before the law, and that people with disabilities are entitled to enjoy legal capacity on an equal basis with others, it makes clear that all people, without exception, are entitled to exercise their legal rights on an equal basis with others. Anything less is discrimination and a violation of a fundamental civil and political right, and therefore prohibited under both the Convention and the Charter.

For people who experience psychosocial disability this means that they are entitled to the full recognition as a person before the law, including the right to exercise their legal capacity on an equal basis with others, regardless of their mental health status. It also means that all five of the criteria under the Mental Health Act for imposing involuntary treatment on a person (whether inpatient or outpatient) violate one of the most fundamental civil and political rights according to both the UN Convention and Victoria’s Charter. Another way of saying this is that human rights are a legal issue, not a medical one. Or yet another way of saying it is that when someone refuses medical treatment, whatever the circumstances, “No” means no.

Equal recognition as a person before the law, legal capacity, the prohibitions on discrimination based on disability and on medical treatment without consent, along with the other rights now enshrined in the Convention represent, in Kofi Annan’s words, “the dawn of a new era” for the rights of people with disabilities. Others describe the Convention as a ‘paradigm shift’ that recognises disability as a social, not a medical, issue and that human rights is the social factor that is always present, and must always be considered, in the development of all policies affecting people with disabilities.

Part of this paradigm shift is a transition from a *substituted* to a *supported* decision-making model for people who do need assistance making decisions that affect their lives and their wellbeing. Which brings us, finally, to Graeme Innes’ “rare and extreme” cases. Substituted decision-making is the traditional guardianship model where the state appoints a person (or persons) to make decisions on behalf of a person deemed unable to make decisions on their own behalf. The supported decision-making model, on the other hand, says that when decision-making assistance is required for a person, every effort must be made to ascertain what that person’s wishes are and that these wishes are to always be respected and honoured. The supported decision-making model is consistent with the UN Convention, the substituted decision-making model is not.

Substituted decision-making has a long history of abuses and human rights violations against people with disabilities. Indeed this history was one of the primary motivations for a UN Convention by people with disabilities who wanted to reclaim their right to self-determination. Substitute decision-makers typically make decisions based on *their* judgements of what is in the best interest of the person concerned. But when these decisions conflict with the person’s own wishes, substituted decision-making becomes disempowering, disabling and susceptible to human rights abuses. Substituted decision-making is inherently in conflict with the human rights principles now enshrined in the Convention, making it an obsolete approach that requires a shift to the new

paradigm of supported decision-making.

The (very) rare and extreme cases that Graeme Innes and others refer to are those where a person is incapable of articulating their wishes, but supported decision-making can also be applied in these cases. A notable, recent example of this in Victoria was the tragic case of a woman in a coma where the Public Advocate, Julian Gardner, had to decide whether to turn off her life support systems<sup>6</sup>. On this occasion, he consulted widely with the woman's friends, family and others to try and ascertain, as best he could, what her wishes would have been if she had found herself in the situation that she was now in. Despite pressure from family and others, Julian Gardner came to the conclusion that she would not have chosen to be kept alive in a coma and so ordered that the life support be switched off. Although this represents a classic example of supported decision-making for which Julian Gardner is to be commended, the Public Advocate in Victoria is not legally obliged to adopt and enforce this model.

Problems arise when a person *is* able to articulate their wishes but they do not seem to be in the person's best interest, at least in the eyes of some people. Perhaps the most common and/or most serious examples of this arise when a person refuses medical treatment that others see as necessary for that person, possibly even life-saving. Again, the Convention is quite clear in this regard. If society wishes to limit a person's human rights, for whatever purpose, then it must be based on the human rights principles of legal capacity and equal recognition as a person before the law that is the same for all people. When the human rights that society might seek to limit in these situations are fundamental civil and political rights, then this is also an issue for Victoria's Human Rights Charter – right now, not in four years time.

### **Conclusions – human rights are a legal, not a medical, issue**

To say this another way, and at the risk of being repetitive, human rights are a legal issue, not a medical one. If there truly are rare and extreme cases where medical treatment without consent is necessary – which I and many others dispute – then this must be justified on legal, not medical, grounds, taking into consideration the human rights principles found not only in the Convention on the Rights of People with Disabilities, but all other relevant human rights instruments. Here in Victoria, this now includes the new Human Rights Charter.

Before concluding, it is necessary to highlight that this paper has deliberately *not* examined the validity – or otherwise – of the psychiatric diagnostic system used in Victoria to deny a person the right to refuse medical treatment. This is a controversial and complex topic that is beyond the scope of this paper. It is also irrelevant for the purposes of this paper or this forum. I repeat again – human rights are a legal, not a medical, issue. In particular, it is inappropriate and improper for medical professionals to be making decisions to deprive a person of their human rights, regardless of the validity – or otherwise – of their medical assessment of that person. Again, this is clear in both the Convention and the Charter based on the human rights principles of legal capacity and equal recognition as a person before the law. It is time for Victoria to take away from the medical profession its inappropriate and improper power to deprive a person of their most fundamental human rights.

To conclude then, we have seen that the use of involuntary psychiatric treatment in Victoria is extreme and excessive and violates even the weakest human rights standards. We have seen that this widespread abuse of some of our most fundamental (civil and political) human rights occurs because of, rather than despite, Victoria's Mental Health Act. We have seen how this Act represents institutionalised discrimination against people with psychiatric disabilities in ways that

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<sup>6</sup> Julian Gardner, Public Advocate, *Protecting the rights of the dying*, Address to the Rationalists' Society, 30 November 2005

are in serious conflict with the UN Convention on the Rights of People with Disabilities that prohibits any discrimination based on disability. And we have seen that the rights that are so frequently violated under this regime are some of the most fundamental civil and political rights that Victoria's new Human Rights Charter is designed to protect.