



THE AUSTRALIAN NATIONAL UNIVERSITY

# Rights, Respect & Dignity For People with Disability in Healthcare

David Heckendorf Ph.D. Candidate

College of Law, Australian National University, ACT.

**Emerging Health Policy Research Conference**

University of Sydney

Wednesday, 19 August 2009

## Recent history of the UN Convention on the Rights of Persons with Disabilities

13 December 2006 – adopted by the UN's General Assembly

30 March 2007 – opened for signature by countries in N.Y.

17 July 2008 – Australia ratified

16 August 2008 – Australia became internationally legally bound

30 July 2009 – the U.S.A. signed (indicating its intention to ratify)

6 August 2009 – 64 countries had ratified & 142 signed

## So, why have such a Convention?

Ratification is an international signal to the rest of the world that Australia will not act inconsistently with the human rights set out in the Convention.

The Convention gives a document in which human rights are consolidated to empower the disempowered.

It establishes an international monitoring mechanism to monitor compliance improvements over time (Articles 34 to 36).

Through the Optional Protocol, it establishes a final forum of appeal.

It sets international standards by articulating universally applicable human rights as they may apply to people with disability.

It promotes dialogue, discussion, education, and the development of jurisprudence at that international, national and local levels.

## So, what does this new Convention say?

The Convention identifies approximately 26 human rights:

Article 5 - Equality and non-discrimination

Article 6 - Women with disabilities

Article 7 - Children with disabilities

Article 8 - Awareness-raising

Article 9 - Accessibility

**Article 10- Right to life**

Article 11 - Situations of risk and humanitarian emergencies

Article 12 - Equal recognition before the law

Article 13 - Access to justice

Article 14 - Liberty and security of person

**Article 15 - Freedom of torture or cruel, inhuman or degrading treatment or punishment**

Article 16 - Freedom from exploitation, violence and abuse

**Article 17 - Protecting the integrity of the person**

Article 18 - Liberty of movement and nationality

Article 19 - Living independently and being included in the community

Article 20 - Personal mobility

Article 21 - Freedom of expression and opinion, and access to information

Article 22 - Respect for privacy

Article 23 - Respect for home and the family

Article 24 - Education

**Article 25 - Health**

Article 26 - Habilitation and rehabilitation

Article 27 - Work and employment

Article 28 - Adequate standard of living and social protection

Article 29 - Participation in political and public life

Article 30 - Participation in cultural life, recreation, leisure and sport

## Article 25 - Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

...

- d) **Require health professionals to provide care of the same quality** to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, **dignity**, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

...

## Article 3 – General Principles

The principles of the present Convention shall be:

- Respect for **inherent dignity**, individual autonomy including the freedom to make one's own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Equality between men and women;
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

## What is the dictionary meaning of “dignity”

1. *a composed or serious manner or style*
2. *the state of being **worthy** of honour or respect*
3. ***worthiness**, excellence.*

(The Australian Concise Oxford Dictionary, 3rd Edition)

## Why do we value some people over others?

Beauty or looks, health & youthfulness

Wealth, security & independence

Fame, personality & charisma

Education, qualifications or professional occupations

etc

## Social Role Valorisation: what is it?

First developed in the late 1960s as the theory of “Normalisation”, Wolf Wolfensberger renamed it in the 1980s to avoid the misconception that the theory requires people to be made “normal”.

SRV suggests that the life situation of a devalued person can be improved by the person assuming a position role.

While SRV has theoretical shortcomings, it suggests that the devaluation of people has three likely consequences:

(Wolfensberger 1983:44)

# 1. Devalued people will be treated badly.

Devalued people are apt to be rejected, even persecuted, and treated in ways, which tend to diminish their **dignity**, adjustments, growth, competence, **health**, wealth, lifespan, etc.

2. The (bad) treatment accorded to devalued persons will take on forms that largely express the devalued societal role in which they are perceived.

For instance, if a person with a disability is (unconsciously) viewed as less than human, i.e. as animals, then:

- they may be segregated into settings that resemble animal shelters;
- their group-homes may be positioned away from residential areas of the city and their daytime activities may be medial and repetitive;
- their care may be provided poorly by underpaid, under-trained and overworked staff.

3. How a person is perceived and treated by others will in turn strongly determine how that person behaves.

Therefore, the more consistently a person is perceived and treated as being deviant, the more likely it is that s/he will conform to that expectation and will behave in ways that are socially expected of him/her.

## News article 1 – Indonesia asks disabled pedestrians to wear sign

JAKARTA, May 26, 2009 (AFP) - Disabled pedestrians in Indonesia are required to wear signs identifying them as handicapped under new traffic regulations passed unanimously by parliament on Tuesday.

Amendments to the Traffic and Transport Law state "handicapped pedestrians must wear special and clear signs which can be easily recognised by other road users."

The lawmaker in charge of the committee which drafted the amendments, Ahmad Muqowam of the Islam-based United Development Party, said they were designed to protect disabled people from road accidents.

"This is a humanistic act. It's for their safety on the streets," he told AFP.

## News article 2 – Care worker slept in disabled woman's bed

A carer kicked a severely disabled woman out of bed and left her to walk around a group home unattended in the middle of the night while the carer changed into her own pyjamas, climbed into the woman's bed and went to sleep.

(The Sydney Morning Herald 16/3/09 page 3)

## News article 3 - Disabled abuse in homes doubles

COMPLAINTS against welfare workers in New South Wales have jumped dramatically, with a total of 380 incidents reported including neglect, abuse and theft from the disabled in government-run homes.

Despite twice as many alleged offences by staff in the past year, just one in 10 of the investigations has been finalised, and hundreds more have not been investigated at all.

(The Daily Telegraph, 20 October 2008)

## Examples of reports that discusses the low status of people with a disability

- National People with a disability and Carer Council (NPWDACC) 2009, *Shut Out: Experiences of People with Disabilities and Their Families in Australia* (National Disability Strategy Consultation Report).
- Joint Standing Committee on Treaties (2008), 'Convention on the Rights of Persons with Disabilities', *Report 95: Review into treaties tabled on 4 June, 17 June, 25 June and 26 August 2008*, Chapter 2.
- Senate Community Affairs Committee (2008), *Funding and operation of the Commonwealth State/Territory Disability Agreement*
- Senate Community Affairs Committee (2008), *Cost of living pressures on older Australians*.
- Australian Law Reform Commission (1996), *Making Rights Count: Services for People with a Disability*. A review of the *Disability Services Act 1986 (Cth)*.
- New South Wales Department of Women (1996), *Reclaiming Our Rights*. Looks at violence against women with disabilities or who are hearing impaired. See, in particular, page 17 on which Chenoweth is cited as saying that women with disabilities are four times more likely to be sexually assaulted.

## How can the health system better protect the dignity of people with disability?

Suggestions for improving the accessibility of the health system for people with disability:

- 1. Awareness raising** of the issues that confront people with disability in the medical and nursing schools as well as the ongoing training in journals and courses attended by health professionals. (see Articles 8 & 25(d))
- 2. Adoption of policies and procedures** for accommodating and caring for people who are at special risk in the hospitals (see Article 4(1)(a) & 25(b)). For instance, these measures might include assigning senior or regular nurses on wards to nurse particular individuals rather than using the usual rotation of staff and agency nurses. It may also include communication tools to assist with patients with hearing impairments (see Article 21).
- 3. Inclusion of patient-consultants** to advise boards of management and ward managers on disability related issues (see Articles 4(3) & 29(b)(ii)).
- 4. Integrate measures**, which are adopted to increase the accessibility of health services, throughout the health care system (see Article 4(a), (b) & (c)).
- 5. Monitoring, evaluation and reporting** must be regularly.

*THE trouble with disabilities is that most Australians think they happen to someone else. Recently I was talking to a man whose partner was disabled by a recent accident and he told me: "I just didn't realise how bad things were for people with a disability - until it happened to us."*

(Dr Rhonda Galbally, 10-August-2009)

Thank you

David Heckendorf

David.Heckendorf@gmail.com

<http://www.david.heckendorf.name>