

Apparently we have human rights to health? Health and human rights frameworks of people with disabilities in Victoria

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Study Background:

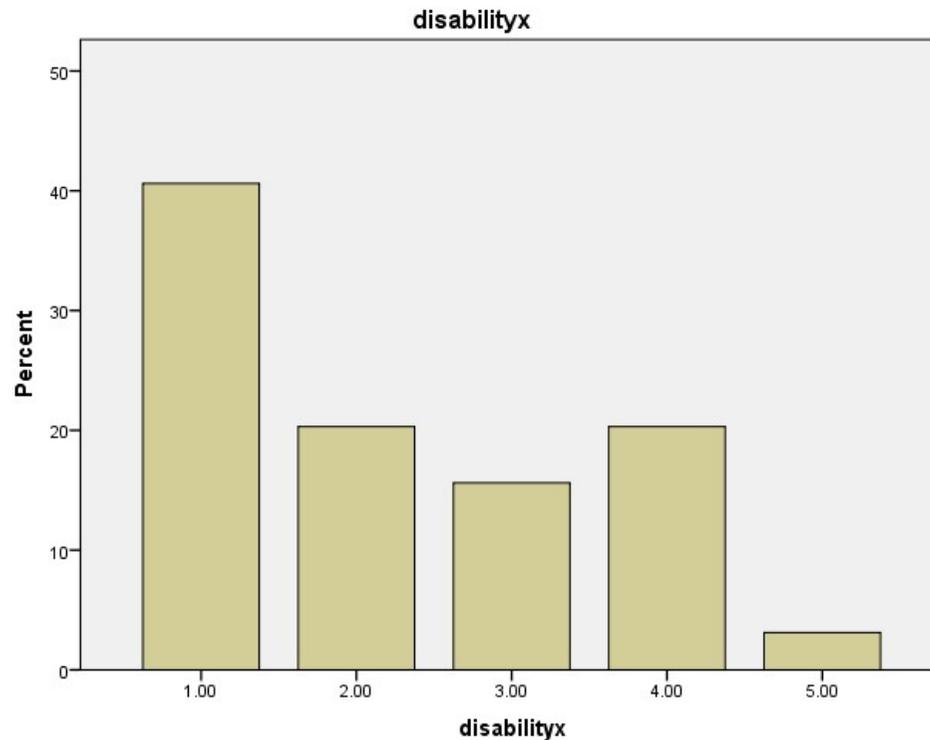
- Human rights monitoring project part of an ARC Linkage Project – Auditing the Victorian Charter of Human Rights and Responsibilities 2006 (Vic)
- Affiliated with the international disability rights monitoring project Disability Rights Promotion International (DRPI)
- looking at international and domestic human rights instruments as points of reference:
 - Convention on the Rights of Persons with Disabilities (CRPD)
 - International Bill of Human Rights (UDHR, ICCPR, ICESCR)
 - Victorian Charter of Human Rights and Responsibilities 2006 (Vic)
- Participants from Victoria only

Focus of this paper

- the principles of human rights, inequality and discrimination are the focus of this paper
- the data utilised related specifically to participant interaction with the healthcare system
- this paper firstly maps the human rights frameworks related to health (from a Vic perspective) and then considers the role of human rights in addressing experiences of inequality and discrimination

Summary of methodology

- all health data obtained from Part 1 of study – open-ended discussion
- number of participants in part 1: 75 - (7 people unable to contribute in an interview situation and 4 sound files corrupt)
- 30-90 min interviews
- variety of disabilities



Key:

1. Intellectual disability
2. Physical disability/mobility
3. Acquired brain injury
4. Psychiatric
5. Sensory impairment

Mapping the human rights frameworks of disability and health

- International human rights frameworks
 - International Bill of Human Rights (UDHR, ICCPR, ICESCR)
 - Article 25 - Convention on the Rights of Persons with Disabilities (CRPD)
 - World Health Organisation

CRPD – 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:

a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

c) Provide these health services as close as possible to people's own communities, including in rural areas;

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;

e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Mapping the human rights frameworks of disability and health

- National human rights framework
 - Disability Discrimination Act (DDA)
 - Australian Human Rights Commission (AHRC)
 - Australian Charter of Healthcare Rights - Australian Commission on Safety and Quality in Health Care -policy
 - The Standards for General Practices (4th edition) (2010) - the Royal Australian College of General Practitioners (RACGP) -policy

Mapping the human rights frameworks of disability and health

- Victorian human rights framework
 - Vic Charter of Human Rights and Responsibilities (Political and Civil rights only - no Economic, Social, Cultural rights)
 - Vic Equal Opportunity Human Rights Commission (VEOHRC)
 - Office of the Health Services Commissioner (HSC)
 - Mental Health Complaints Commissioner (MHCC)
 - Office of Public Advocate (OPA)
 - hospitals display various brochures and posters - policy

General Findings

- range of discrimination and inequality in accessing healthcare for many participants across hospitals, mental health facilities, GPs, OTs, dental facilities
- breaches privacy, lack of quality, unwanted treatments, informal carers providing care in the hospital, attitudinal discrimination from healthcare staff, disagreements on medication, uncertain diagnosis, questionable ethical practice, resistance of complaints systems

Findings related to Human Rights Framework

- participants only engaged with the human rights framework to a minimal extent in responding to a breach of human rights
- the minimal level of human rights protections offered by the legislative framework in Victoria did not appear to be visible or actively safeguarding the healthcare interactions of participants
- on few occasions where participant engaged the legislative framework, the resolution or mitigation of human rights infringements appeared stressful, was often drawn-out and impacted on life quality of the participant
- complexity of accessing human rights framework - what is jurisdiction of each agency and gaps in HR framework:
 - CRPD aspirational - lack of progressive realisation
 - no ESC in Vic Charter

Utilisation of human rights frameworks in relation to Ramcharan's 3 dispositions:

Bourdieu (1993) argues that power is culturally and symbolically created in the interplay of agency and structure - concept of habitus

- first category - no knowledge of their human rights or of any human rights mechanism. - did not link the bad treatment to any breach of human rights or standards; normalised the negative experience as just how things were in life for a person with a disability, and although describing being angered or upset by the incident, did not appear aware of paths for redress or complaint paths. Responses included avoidance, emotion or telling others of the negative experience only
- second category - those with knowledge of human rights mechanisms, but chose not to utilise them; often identified and acknowledged the breach of their human rights and understood that they 'should' do something and take further action, but seemed to view further action as too complex, burdensome, tiresome or too difficult from their particular living situation (advocate or peer support sometimes used)
- third category - had knowledge of and utilised the human rights mechanisms in response to breaches of their human rights; small group of participants actively engaged with the human rights framework, human rights organisations and frequently referenced the specific anti-discrimination acts and CRPD

Human Rights protections within the healthcare setting

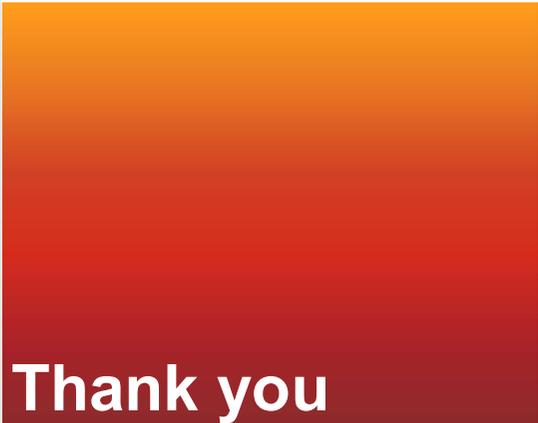
- significant amount discrimination and inequality based on attitudinal barriers with healthcare staff
- human rights needed to begin with participants and healthcare workers understanding their rights and obligations
- abuse and trauma of past experience often dominated the internal narrative of healthcare for participants
- often at the heart of the interactions were the unjust power relations experienced in the healthcare settings between healthcare staff and participants; patient views were often dismissed as a result -this disparity can be exponentially greater for patients with a disability who may be more vulnerable due to communication difficulties, non-typical behaviours, physical impairment and/or intellectual disability
- evolving notions of human rights are required to develop a more comprehensive context in which to recognise how people with disabilities are impacted by power structures in the healthcare interaction

Improvement ideas?

- improve access to frameworks for pwd - portals, advocates visible, an individual advocate assigned to each individual, education
- fix gaps in current Vic framework - expansion of Vic Charter of Human Rights and Responsibilities to include ESC human rights
- something stronger than conciliation to resolve poor outcomes
- DDA healthcare standards (similar to education standards)
- specific disability healthcare medical centres (SA) - financial incentives? while continuing to educate/improve clinical practices mainstream healthcare workers
- wider powers for VEOHRC to audit healthcare facilities

Ongoing

- We are now using the model to explore in what ways new organisational and support to change structures to accomplish human rights as an everyday social practice.
- To accomplish human rights as an everyday social practice, legal solutions, complaints procedures to VEOHRC and HSC need to be supplemented by new forms of advocacy that promote human rights as an everyday social practice
- As Leaning (2001) identifies - 'good intentions in the healthcare setting are not enough'; evolving notions of human rights are required to develop a more comprehensive context in which to recognise how people, and in our case people with disabilities, are impacted by power structures in the healthcare interaction



Thank you

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