Being part of Scotland's story under the Disability Convention - what the Convention means for mental health?

VOX UNCRPD Event summary report

On the 28th March 2012, VOX with the Equality and Human Rights Commission and the Scottish Human Rights Commission delivered a seminar to explore the United Nations Convention on the Rights for People with Disabilities (UN Disability Convention) and what it might mean for people with lived experience of mental health problems.

The United Nations Convention on the Rights of Persons with Disabilities (the Convention) is an international agreement that has been legally binding on the UK Government since 2009. It was drafted by and for people who have long-term physical, mental, learning or sensory impairments and who may face barriers to participating equally in society. The Equality and Human Rights Commission and the Scottish Human Rights Commission have been designated as the independent mechanism responsible for promoting, protecting and monitoring its implementation in Scotland. The Commissions are entirely separate and independent from Government.

The event

25 people attended the seminar; the seminar's aim was to give participants an opportunity to discuss what the UN Disability Convention means. The day began with an introduction to the Convention; the rights it promotes and protects, the role of Governments and the Commissions and the central importance of disabled people in making sure the right action is taken to implement the Convention.

There was also roundtable discussions about the issues facing people with lived experiences of mental health problems, with the aim of looking at the various ways the Convention can be used to help address these issues and how we can overcome any barriers to full enjoyment of the rights set out in the Convention.

The round table discussions

The discussion took on two separate forms some focusing on the questions provided on the day and other around people's own personal experiences of mental health service provision. All views were captured equally and the questions were not weighted, the comments below represent the views and experience of the people who attended the event, and took part in the discussions, and do not necessarily reflect the views of the wider VOX membership.
These are listed below in the two approaches;

Discussion responses in relation to the set questions

What are the key issues and barriers facing people with lived experience of mental health problems in Scotland?

- Healthcare professionals make assumptions when a patient is distressed that they don't have capacity to make decisions – it can be particularly difficult to get support for decision-making if you have no close family present. Mental healthcare professionals should treat patients with courtesy and regard them as customers.
- Better access to independent advocacy is needed. For example, more independent advocacy organisations should be permanently based within hospitals.
- The National Self Harm Network have 'crisis cards' – you can hand these over in triage situations without having to explain – but psychiatrists and other healthcare professionals don't seem to like them as they 'get in the way'
- ATOS assessors (welfare benefit assessment) are sometimes not adequately trained in mental health – they look only for physical disabilities and give mental health scant regard – the assessment process can feel humiliating
- "reasonable adjustment" can scare employers – disabled people are seen as a 'problem' and unreliable members of the workforce. The "pull your socks up" attitude still prevails.
- An example was given of an employer refusing to allow long-sleeved T-shirts to be worn to cover up self-harm scars in a café (and other menial labour work places) – sometimes people feel forced to lie about their health condition in order to get a job
- There is criticism of the 'See Me' national campaign for being directed too much at educated professionals and for being "too fluffy" – greater work to combat stigma and

prejudice is needed. By comparison, the 'HUG' campaign is seen by some as good for raising awareness amongst school children about stigma associated with mental health

- Some bus drivers misunderstand the bus pass 'plus one' cards and assume fraud because the mental health disability isn't visible. This was seen to be a particular issue in Glasgow and Edinburgh but not so much in Inverness.
- Disability hate crime remains a big problem and one that is not taken seriously enough by the police. There could be reporting centres for hate crime that serve as intelligence touch-points. MENCAP have some good examples here.
- Negative language surrounding mental health is "insidious" in society and there remains ignorance and acceptance around language such as "manic", "mad" or "schiz". People make assumptions and "put me in a box"… "…and this isolates me". By contrast, it wouldn't be socially acceptable to describe someone as "leukemic"
- Media portrayals of mental health can exacerbate hate crime by being sensationalist and making mental health patients seem "scary" or "stupid". Sometimes people even associate mental health and paedophilia.
- Some people shared experiences of GPs looking 'panicked' when they noticed mental health episodes in a patients' notes.
- There is a perceived dichotomy in hospital waiting times and referrals between physical and mental health conditions
- There was some criticism of the social model of disability used by the UN Disability Convention – mental illness is a medical condition and should be seen as such
- "Scotland has taken its eye of the ball in terms of being ahead of the legislation game"
- Mental health outcomes need to be patient focused
- There is an issue with people being detained in hospital being prevented from smoking. This can be problematic because the hospital is the de facto home of the person and not being able to smoke can make them frustrated and potentially unwell. Too many blanket policies and disproportionate interferences with the right to private and family life.

What Convention articles do you think could be sued to tackle the issues you have identified?

- Article 19 – independent living
- Article 20 – mobility
- Article 27 – work and employment
- Article 30 – participation in cultural life, recreation and sport

(All taken from the guide to using the Disability Convention)

How could we use the Convention to achieve change?

- Collective lobbying is needed
- Disabled people's organisations should work more closely together
- With the help of an independent lawyer, VOX could find a test case to take through the courts to raise awareness of systematic discrimination against mentally disabled people
- Mental health should receive greater coverage by politics. There was a suggestion that people who have experienced mental health problems could form their own political party because the issues would be relevant to so many people
- VOX could consider drafting a parallel report to the UN Committee of Experts on the Disability Convention. One of the Directors is going to raise this suggestion at the next VOX Board Meeting. SHRC and EHRC could support facilitation of such a report.

<u>Responses from personal experiences of mental health service provision</u>

Patient's records and information

- Information being held about patients/ patient record that is wrong or inaccurate and inability to get it corrected. Statements from health professionals that are untrue, but cannot get these changed.
- Discussion about all conversations with psychiatrists being recorded so that an independent person can verify the psychiatrists' conclusions, so it is not the patient's view versus the psychiatrists where the psychiatrist always seems to be believed, even if it is disputed. There was mixed views about recording, but there was much greater support for patients not being on their own in these sessions and being able to bring with them a friend or an advocate to be there only as a witness.
- Views of patients are secondary to views of mental health professionals (this was cited as a general concern throughout all the discussion).

Inhuman and degrading treatment of patients in acute mental health wards

- Conditions in wards can be barbaric
- Failure to take into account the long-term side effects of psychiatric medication and use of Electro-Convulsive Technology
- Involuntary medication
- Detaining people for much longer than they need to be.
- Patients are not getting an equal voice, let alone having their views taken into account.

People not being free from violence or abuse in hospital wards

- People feeling unsafe in acute mental health wards because of sharing living space with people who may have significantly different mental health needs and there was some

concern raised about whether people serving criminal convictions were being placed in acute wards?

Drug and alcohol use in wards

- There was concern that patients were able to take illegal drugs and alcohol while staying in hospital wards and that professionals are aware of these problems but not doing enough – despite knowing the potential side effects of taking drugs and alcohol while on psychiatric medication.

Professional standards of mental health professionals

- Failure to monitor and promote professional standards of mental health professionals, leading to examples where individuals feel strongly that psychiatrists and Community Psychiatric Nurses (CPN) have abused their positions with significant negative effect on others lives.
- Very sceptical about the professional abilities of mental health professionals and that they are acting in the best interests of patients.
- Don't believe that psychiatrists, in general, take into account views of patients or listen to them. Belief that many mental health professionals are making decisions on assumptions, not facts. If they are going to make decisions that have such fundamental impact on people's lives then at the least the circumstances should be checked to make sure that it's not based on hearsay or opinions, but facts that can be evidenced.
- Strong views that psychiatrists are making the wrong decisions because of a lack of rigour, professionalism and consideration of patient's views and circumstances and that this can lead to unfair or wrongful detention. A similar conclusion was raised about failings of psychiatrists but this was because they were failing to keep patients detained and treat the causes of psychiatric behaviours. Instead there was concern that psychiatrists medicate to keep the behaviours down, but the behaviours are still there and not being properly treated. This leads to the public, friends and family being at risk of physical harm. Reference was made to whether the police could make better use of their powers to issue Public Safety Orders in these circumstances.
- It was acknowledgement that there are good professionals out there and these people need to be appreciated and held up as upholding best practice professional standards and to encourage others to meet these standards too.
- There is a revolving door of treatment then detention (both voluntary and involuntary). The proper support and help is not being provided when people leave hospital and so they too frequently return to hospital. There is a lack of suitably qualified CPNs and mental health social workers to provide the support that is needed to prevent re-admission or detention.

Lack of advocacy

- There is limited availability of advocacy even through there is a duty to provide advocacy under the MHA 2003
- At the Mental Health Tribunal advocacy support / service is not available – it should be.
- There is a need for improved and more training for mental health advocates

Good practice

- Lothian Network Recovery, Sense of Belonging (although mixed views from the group) and Charlie Reid Centre 'Support in Mind' for families and friends of people with mental health problems and also for people aged 16+ with mental health problems . It offers drop in support, counselling, support for family and friends and community cafe.

Mental Welfare Commission Scotland

- There was a feeling that staff from the Mental Welfare Commission speak to professionals and not to people who have lived experiences of mental health problems. Seen to be for mental health service professionals, not service users.
- Concern about the time-bar that may prevent people from bringing complaints and cases.

The picture

The discussion about people's own experiences demonstrate some of the wide and varying issues affecting people with mental health problems that have still to be addressed in relation to the human rights of people with lived experience of mental health in Scotland.

Some key points that emerged in relation to the aims of the seminar;

- There is a lack of knowledge of the Convention, its existence and what it means for people with lived experience of mental health problems.
- A number of the articles were potentially problematic in specific mental health settings with regards to how they could be implemented etc.
- Knowing how the Mental Health Act (which has a significant impact on people within the mental health system) relates if at all to the Disability Convention would be widely welcomed and beneficial in both improving monitoring and accountability and in supporting people to access their human rights, not just when they are well but when they are unwell.
- There are still examples where individual advocacy is and has not worked, leading to people not being heard and feeling isolated and angry.

Way forward

Overall there was lots of interest in the Convention, in people taking time to read through it and digest it. The EHRC Guidance for disabled people "the orange book" while laid out well was fairly large and intense for people to be able to go through on the day.

A welcome resource for mental health service user organisations and for individuals may be a guide that adequately reflects and if/where possible compares or highlights where the mental health and the Convention meet.

Reporting to the UN Disability Committee some of the human rights issues facing people with mental health problems may also be a way forward for VOX, the EHRC and SHRC to consider.

VOX aims to explore ways of further raising awareness of the Convention amongst members, sharing evidence of members' experiences in regard to mental health care and treatment to the Commissions.