



INDEPENDENT LIVING
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Independent Living Movement Ireland submission on the review of the Mental Health Act 2001

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Introduction to Independent Living Movement Ireland

Independent Living Movement Ireland (ILMI) is a campaigning, national Disabled Person's Organisation (DPO) that promotes the philosophy of independent living and seeks to build an inclusive society. ILMI works with disabled people on a cross-impairment basis. Central to the way we work is to ensure that policy and legislative discourse and decisions that impact on the lives of disabled people have to be directly influenced by those whose lives are directly affected.

Our philosophy can be summed up as: 'Nothing about us without us!' and 'Rights Not Charity'. Our vision is an Ireland where disabled persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals.

Emotional Distress and the Medical Model of Disability

The medical / charity model individualises the term 'disability' to equate with an individual's proscribed impairment label and impairment. It encourages the idea that people are disabled by their impairments or perceived differences, including psychiatric "diagnostic" labels. The medical model constantly focuses on people's impairments from a western professional medical perspective. This medical model

paradigm of thinking proposes the person needs to be 'fixed', to be 'cured', to return them to an acceptable level of normality in mind and body. The medical model has sub-headings such as the Charity 'model', where disabled people are marketed as 'vulnerable' passive objects of 'care' that must be paid for by 'normal' duty-of-care fearful citizens and multi-billion euro private organisations.

Frequently, the medical / charity approach to impairment still looks at what is 'wrong' with the person and what in their 'best interest' and not what has happened to people that has caused emotional distress or what the person effectively requires to access pathways towards their individual lifecourse wishes and preferences.

It creates low expectations and leads to people losing independence, choice and control in their own lives. The medical / charity model never recognises the rights of disabled people and assumes that disabled people need to be 'looked after' or 'cared for'. The medical/charity model has many non-disabled dis-empowering professionals make decisions for disabled people without appropriate systems and structures for capacity built consultation or dialogue. People informed by the medical / charity model, being focused on disabled people's impairments, use the term 'people with disabilities', or in relation to emotional distress, "service users" or "clients".

Emotional distress is almost exclusively viewed in Ireland through the lens of the biopsychosocial model, which is a medical model of disability. The biopsychosocial model is predominantly an epidemiology (disease) model that looks at the interconnection between biology, psychology, and socio-environmental factors. Ultimately, as a medical model, it predominately looks at impairments relating to emotional distress as being something that is "wrong" with the individual that needs to be treated.

It states that people who have experienced distress are "broken" or "flawed" and that it is something "inherent" that needs to be "fixed". Extreme forms of this medical approach can lead to refusal to engage with people's lived experience and life history and can have medical professionals remove autonomy from people, including forced detention and denial of basic human rights.

Most discussions in Ireland around emotional distress use the term “mental health” in Ireland. A term that is assumed to be sensitive and neutral, “mental health” is actually a loaded statement. People who experience emotional distress are not sick and do not suffer from an illness. Taking a social model of disability we need to recognize that using terms like “mental health” medicalises and individualises people’s emotional responses to traumatic life events and societal pressures. Emotional trauma and distress is not an individual medical issue but a social issue and it cannot be “treated” as a medical condition.

From a social model of disability, ILMI believes we should move towards discussions around people who experiencing emotional distress as an understandable response to part or present traumas, grief or societal pressures and extreme challenges that people face. We need to move from systems that ask “what is wrong with you” to asking “what has happened to you” or “what do you need”.

Many instances where people emotional distress result from societal structures and pressures which are ultimately outside any individuals’ control, and cannot be “treated” medically or “cured” by pharmacology. These include issues relating to employment (meaningful work), poverty, Status and respect (including lack of status due to sexuality, gender, ethnicity, impairment, socioeconomic status), loss of identity and meaning, lack of meaningful connection with other people, a loss of future opportunities.

Many people have experienced extremely traumatic events in their lives. Supports for people who experience emotional distress is multifaceted, but by individualising the societal conditions that create distress by adopting a medical approach to mental health that can be “cured” needs to be challenged. If someone emotional distress due to the complex interaction between low-paid unfulfilling work, the challenges of trying to raise a family on minimum wage, the lack of social spaces for interaction based on an inaccessible environment or lack of PA hours, lack of meaningful relationships due to social isolation, or past emotional trauma, cannot be “cured” by medical, institutional or pharmacological approaches.

We need to provide an alternative analysis based on lived experience that recognises the pain people experience as real but recognising what causes emotional distress is located in what has happened to people and how people have responded to trauma and threats to their identity.

People in distress and in pain need supports that give them safety and it needs to be person-centred which meets specific needs (not a one size fits all medical / institutional approach) and should reflect their aspirations for life: a sense of being empowered, in control, with improved self-belief, with relationships that lead to fulfilment, with the opportunities in education, employment and socialising that lead to hope in the future for a life of possibilities.

Social model of disability

Ireland is due to make its first report to the UN under the Convention on the Rights of Disabled People (CRPD). The UNCRPD at its core is framed through an understanding of disability known as the social model of disability. From ILMI's perspective, it is vital that there is a clear and full understanding of what the social model of disability is and how it should inform future discussions on policy development and improvement and policy implementation, including a review of the Mental Health Act (2001). The social model looks at how society is structured and how it disables people. It is not based on a person's impairment, it is focussed on the barriers that exist in terms of attitudes, policy development, access or lack of supports that prevent people from participating in society as equals, with choice and control over their own lives. In this model it is society that disables people from achieving their hopes and dreams, not a person's impairment. The social model informs all aspects of the work of Independent Living Movement Ireland.

The social model is especially important in ensuring that any proposed legislative changes made to the Mental Health Act (2001) are consistent with the principles of the UNCRPD and ensure that mechanisms to include the voices of disabled people, specifically people who experience emotional distress.

Emotional Distress and the Social Model of Disability

Given the predominance of the medical / charity model of disability, many people assume that “disability” relates to physical, sensory or intellectual impairments. Many people who have had or do experience emotional distress view disability through a physical, sensory or intellectual (medical) impairment lens and thus do not view themselves as “disabled”. This is further exacerbated by the predominant medicalised, diagnostic ideology on emotional distress (“mental health”) which often means that many people who experience issues relating to emotional distress do not view themselves as being “disabled”.

Taking a social model of disability, the UNCRD recognises that it is how society is structured that disempowers and disables people. The medical approach assumes that professionals must “look after” people with impairment, (including people with psychiatric “diagnostic” labels) removing control over their lives. It labels and stigmatises disabled people based on their impairments. A collective social model analysis of disability has the potential to generate a new focus to connect disabled people on a cross impairment basis, including people who have or do experience emotional distress.

Embracing a social model of disability recognises that impairments are part of the human condition and that diversity of ways of being alive should be the norm throughout history, but it is how society is structured that disables people from living the lives of their choosing. The social model of disability recognises the pain and suffering that people experience as real,

The capacity to think, decide and act on the basis of your desires freely and to be in control of all aspects of your life are the core tenets of Independent Living. As a rights-based Disabled Person’s Organisation led by the social model of disability, these values are to the core of all aspects of our work.

Introduction

ILMI welcomes the long-overdue review of the Mental Health Act 2001. However, the short timeline imposed by the Department of Health (one month) gives no regard to the involvement of people with lived experience. A lack of formal engagement with DPOs and organisations representing the voices of lived experience of emotional distress and survivors of psychiatric systems is contrary to Article 4.3 of the UNCRPD and General Comment 7.

By imposing a short timeline, it prioritises medical health professionals and their organisations in having resources to respond and denies the primacy of the voice of lived experience, again contrary to the UNCRPD.

Changes to definitions in the Act

The language and definitions used in a new act need to reflect the social model of disability which reflect the values of the UNCRPD.

As such terms such as “mental illness” or “mental disorder” medicalise and pathologises pain and suffering. “Mental health” or “mental illness” presupposes that the emotional distress people experience can be “cured” by medical interventions.

Psychiatric diagnosis criteria (based on DSM or ICD) which impose “mental health diagnosis” impairment labels are extremely subjective and although are presented as the basis of the “biopsychosocial” model of psychiatry are not based rigorous scientific analysis ¹. They are subjective interpretation of distress which cannot be verified by medical tests as with physical diagnosis.

They are also linked to stigma and shame. Diagnostic impairment labels disable people by denying people access to healthcare on an equal basis with others. Diagnostic overshadowing impacts on people’s employment, education and participation in social life. It removes agency and choice and intersects with other

¹ “Cracked: Why psychiatry is doing more harm than good”, Davies. J. (2013)

forms of discrimination. For example, women with diagnostic impairment labels can lead to threats of child protection services and loss of children permanently.

Inclusion of guiding principles

Definitions:

A review of the Mental Health Act needs to move from the medical / diagnostic model of emotional distress which views people who have experienced distress are “broken” or “flawed” and that it is something “inherent” that needs to be “fixed”. We need to provide an alternative analysis based on lived experience that recognises the pain people experience as real but recognising what causes emotional distress is located in what has happened to people and how people have responded to trauma and threats to their identity.

Role of DPOs in all aspects of reviewing Mental Health Act 2001

The UNCRPD makes specific references to state party commitments to ensure disabled people are effectively involved in all policy forums which article 4.3 and 29. B of the convention state. Article 4 - General obligations 3 outlines that state parties shall closely consult with and actively involve disabled people, including disabled children.

Article 29. B outlines actively promoting an environment in which disabled people can “effectively and fully participate” in public affairs, without discrimination and on an equal basis with others. Article 29 B also states participation of disabled people in non-governmental organisations and associations concerned with the public and political life.

Most importantly article 29 B states disabled people should be involved in “forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels”. For far too long disabled people have been excluded from participation in decision making structures at all levels. Disabled people and specifically people who experience emotional distress need to be resourced to have their voices heard in any aspect of reform, drafting and implementation of a successor to the Mental Health Act 2001.

There is a loss of lived experience in mental health policy and roll back from *Vision for Change*'s commitment to participation and co-creation of policy / oversight implementation of policy of people with lived experience. *Vision for Change* also had commitments to enabling people with lived experience to participate in and deliver services. This is absent in the newer *Sharing the Vision* policy. There has been an according change in vocabulary which has moved towards a more medical approach.

In resourcing DPOs, it should be on a cross-impairment basis and resource and support the voices of lived experience of emotional distress and survivors of psychiatric systems to work collectively. Structured supports are needed to bring people together to facilitate authentic lived experience representation based on a collective voice which is free to critique functions of the State.

Changes to the criteria for detention

Article 14 of the UNCRPD ("Liberty and security of person") specifies the scope of the right to liberty and security of all disabled people, prohibiting all discrimination based on disability in its exercise. Specifically Article 14 1 (b) binds all State parties to ensure that disabled people "are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the *existence of a disability* shall in no case justify a deprivation of liberty".

Furthermore the Guidelines on article 14 of the UNCRPD Committee "has established that article 14 does not permit any exceptions whereby persons may be detained on the grounds of their actual or perceived impairment" ²

Ratification of the UNCRPD mandates States to move towards a social and human rights model of disability, which should include prioritising, funding and resourcing alternatives to the medical model and coercive practices which needs to be reflected in the review of the Mental Health Act 2001 and any future legislative change need to recognised Ireland's commitments under Article 14 of the UNCRPD.

² <https://www.ohchr.org/Documents/HRBodies/CRPD/14thsession/GuidelinesOnArticle14.doc>

Interdisciplinary approach to care and treatment

There needs to be recognition of the value of a wide range of holistic supports and real alternatives to coercion that support legal capacity and provide pathway away from coercive practices to ensure that individuals who experience crisis can exercise their legal capacity on an equal basis with others.

Changes to time limits

Currently, the Mental Health Act states that individual can be treated for 21 days without consent if deemed to lack capacity, before a tribunal is held to determine if tribunal meets criteria. From our consultations with people with lived experience and survivor testimony that “emergency” treatment is widely abused, and often where there is no immediate threat / risk to the individual life or another individual

Enhancing safeguards for individuals (including seclusion and restraint)

The Mental Health Act needs to be revised to prohibit seclusion and restraint (including chemical restraint). These coercive practices, in line with UNCRPD committee findings position that these practices are do not comply with the prohibition of torture, cruel, inhumane and degrading treatment or punishment.

Mental health tribunals

The Mental Health Act states that after 21 days of involuntary detention, Mental Health Tribunal reviews take place as policy. There is lack of data that this policy is being carried out in practice. There is a further policy and procedural silence that people with lived experience are encouraged to participate in all aspects of the role of the Mental Health Commission, including mandating that lived experience is a desirable attribute for lay members of mental health review boards.

There is a need to train all tribunal members with input from the voice of lived experience of coercive practices / neglect. The remit of tribunals should be expanded to consider other pertinent issues, including how the ‘will and preferences’ of the

individual has been upheld in decisions around the DOL, is the individual being treated in the 'least restrictive manner', compliance with rights under the Constitution, ECHR, International Human Rights instruments especially UNCRPD.

Individuals deprived of their liberty should be allowed and supported to get their own independent professional assessments / reports from outside the State if necessary, given the dominance of the medical model in Ireland. The tribunal psychiatrist needs to consult with range of other professionals from interdisciplinary backgrounds.

There needs to be access to trained, independent peer advocates as a right for anyone before a tribunal. Individuals should as a right have access to automatically obtain written report and recording of tribunal proceedings

Change of status from voluntary to involuntary

Involuntary Detention is contrary to equality and non-discrimination provisions under Article 5 of the UNCRPD and need to be removed from the new act. It also violates absolute ban on deprivation of liberty (Article 14 and Committee Guidelines on Article 14). Involuntary detention removes the agency and autonomy of people to make a whole range of decisions in respect of healthcare and treatment decisions, including the option to voluntarily avail of inpatient options.

Frequently patients entering inpatient facilities on a 'voluntary' basis are not informed of their rights including the provisions of section 23 which provide for regrading of status

What is not understood is that it is often a perfectly normal reaction for an individual who experiences human rights violations/neglect/harassment/abuse etc. in inpatient settings to wish to leave the facility. The Expert Group recommends that **all** patients must be fully informed of their rights when presenting for admittance to a residential unit

In consultation with people with lived experience, many people felt that a "change to 'involuntary' status is sometimes done as a punishment or reprisal, including for calling out abuse in in patient settings of the individual or other patients". People also identified other methods to ensure "complete compliance" and preventing even

‘voluntary’ patients in many cases leaving the facility often include taking clothes, shoes, mobile phones, keys, money etc.

Whilst the revised Vision for Change policy recommends that involuntary detention should not be used outside emergency situations, this leaves scope for further broadening out of the criteria to detain in so called emergency situations.

Capacity and advance healthcare directives

An international review has shown that AHD’s have reduced involuntary admissions by twenty-three percent ³. In addition, they are also associated with a reduced need for readmission to hospital ⁴ and improved recovery ⁵. Given sixty-five per cent of admissions to the Irish mental health system are readmissions ⁶, AHD’s would provide a useful mechanism to uphold the autonomy, dignity along with the will and preference of the individual when faced with a crisis situation.

At present there still exists a discriminatory provision in the Assisted Decision Making (Capacity) Act, that AHD’s (made when the individual is deemed to have mental capacity) are not legally binding and therefore can be set aside if the individual is subsequently allocated ‘involuntary’ status under the Mental Health Act. The State has not indicated when this discriminatory provision will be rectified, providing for AHD’s to be legally binding on an equal basis for all.

Capacity assessments are subjective, embedded in the medical model and typically focus on the perceived deficits of the individual in terms of decision-making skills and rubber stamping ‘mental disorder’ diagnosis are inherently problematic and not conducive to upholding human rights and equality standards. Rather the focus

³ [1]Mark de Jong and others, ‘Interventions to Reduce Compulsory Psychiatric Admissions: A Systematic Review and Meta-analysis’ (2016) 73 (7) JAMA Psychiatry 657.

⁴ [2] Claire Henderson and others, ‘Effect of Joint Crises Plans on Use of Compulsory Treatment in Psychiatry: Single Blind Randomised Controlled Trial’ (2004) 329 British Medical Journal 136; Chris Flood and others, ‘Joint Crisis Plans for People with Psychosis: Economic Evaluation of a Randomised Controlled Trial’ (2006) 333 British Medical Journal 729.

⁵ [3]Marvin Swartz and Jeffrey Swanson, ‘Commentary: Psychiatric Advance Directives and Recovery-Oriented Care’ (2007) 58 Psychiatric Services 1164.

⁶ Health Research Board 2019

should be in line with UNCRPD to provide the supports on an equal basis with others to support the individual's legal capacity. Legally binding Advance Healthcare Directives (AHD's) would help support the individual's capacity to make their own decisions in relation to treatment and support options, support 'recovery' and reduce the need for deprivation of liberty and coercive practices

Consent to treatment

The concept of consent and choice needs to be explored by direct consultation of people with lived experience of emotional distress to inform the review of the Mental Health Act. People often "consent" to "treatment" on the basis that there are no perceived choices. Real choice to a suite of holistic supports and therapies needs to be prioritised away from a medical system that denies control and choice.

In discussion with people with lived experience, there was an understanding that many individuals continue to "consent" to treatment as they know if they refuse, they will be given it anyway. It is simply easier to be seen to be "compliant" especially in inpatient settings, despite the detrimental effect this can have on the individual's psyche, self-worth and esteem and potential for what is often termed 'recovery'. Some individuals subjected to coercive regimes and neglect by psychiatric services continue to take their own lives, such is the impact of their experiences. Many others have to recover from services in addition to the distress and trauma which prompted them seeking support.

Informed consent also needs to include evidence-based discussions on the long-term negative impact of medication and whether medication has any real basis for addressing emotional distress caused by trauma, social isolation, poverty, gender based violence, racism etc.

The Mental Health Act consistently refers to "treatment" and provides no distinction between therapeutic and holistic supports and other interventions, including those provided at approved psychiatric settings.

All interventions and efforts toward care and support provided at psychiatric approved settings should not be placed to be placed under the term 'treatment'.

Treatment implies doing to, fixing, curing (of a biological nature with genetic underpinnings, based on a medical analysis of emotional distress).

Care and support need to be added to the Mental Health Act making distinctions between physical interventions, medical treatments and human-to-human care and support.

ECT

In 2015 the term 'unwilling' to consent with respect to ECT was removed from the Mental Health Act, 2001 (s. 59 (1) (b)), but the term 'unable' was retained. Therefore, individuals deemed by Psychiatry to lack mental capacity can still be administered ECT against their express wishes, even if they (and indeed their family) object, even if they have an Advance Healthcare Directive made with respect to treatment choices (when deemed to have capacity). This in effect means that any person can still be given ECT under without their informed consent once their treating psychiatrist and another psychiatrist deem that they are 'unable' to consent. In addition, some individuals including elderly women are consenting as there are no real alternatives provided and they are also aware that should they refuse, ECT can still be administered under coercion. It is easier to accept ECT in those circumstances, but this clearly does not constitute informed consent.

The Committee has been unequivocal in stating that States Parties should ensure that the provision of health services, including mental health services are based on free and informed consent ⁷.

⁷ General Comment No. 1: Equal Recognition Before the Law (article 12) (Geneva: UN Committee on the Rights of Persons with Disabilities, 11 April 2014). 34 Ibid at para 41