

Mind Our Rights! A report from the “Body Image, Human Rights and Mental Health” Event

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Context: Human Rights Legislation and mental health service provision in Scotland in 2019

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“The idea of dignity is fundamental to how we regard ourselves. It’s something that connects people from all kinds of cultures and beliefs, and which has ultimately led to the universal recognition that we need to protect and realise this dignity for each and every person. We do this through human rights.”¹

In March 2003, the Scottish Government passed new legislation, the **Mental Health (Care and Treatment) (Scotland) Act 2003**. Hailed at the time for the groundbreaking human rights based approach taken, the Act came into effect on October 2005.

The human rights approach embedded in this Scottish legislation is rooted in the **United Nations Conventions on Human Rights** and is incorporated into Scottish domestic law in the **Human Rights Act (UK) 1998** and the **Scotland Act (Scotland) 1998**. The rights for anyone with “protected characteristics”² are further protected and promoted under **Equality Act (UK) 2010** and the related **Public Sector Equality Duty (Scotland) 2011**. People with mental health issues have the same human rights as every other person in Scotland in relation to the rights to health protection, prevention and treatment.

Scotland also currently recognises and observes the **European Convention on Human Rights (ECHR)**, an international convention created to protect human rights and political freedoms in Europe following WWII. Drafted in 1959 by the then newly formed Council of Europe, the convention entered into force on 3 September 1953 with the British Government being the first to ratify the legislation.

On 8 June 2009 the British Government ratified a crucial piece of legislation for people with mental health issues, the **UN Convention on the Rights of People with Disabilities (UNCPRD)**, which takes the principles embedded throughout and across all human rights and shows how they apply directly and specifically to people with disabilities. The UNCPRD affords additional rights and protections to anyone whose illness or disability in some way significantly affects their life or their participation in daily life³. This is a wide-ranging definition and includes anyone with a mental health condition who meets the stated criteria.

It is vital that NHS Scotland, local authorities, Integration Joint Boards, GPs and service providers understand that, under the UNCPRD, disability is defined by on the impact on an individual’s life. This means that a person does not necessarily require a medical diagnosis in order to access the rights afforded to them under the Convention.

It has become clear, however, that there are tensions between domestic and international law, policy/policy ambition and the reality for people with mental health issues having their rights observed and upheld.

Since 2003, domestic law has provided the normalised legal benchmark under which the human rights of people with mental health issues have been considered. Under domestic law, for example, it is understood, that the right to liberty can be restricted if that restriction is considered to be lawful in order to protect the individual - or other individuals – and if understood to be a “proportionate means of achieving a legitimate aim”.

The UNCRPD, however, provides disabled people with specific rights under

Article 14: liberty and security of person and are not deprived of their liberty unlawfully or arbitrarily; the existence of a disability shall in no case justify a deprivation of liberty; and

Article 15: freedom from torture or cruel, inhuman or degrading treatment or punishment; all effective legislative, administrative, judicial or other measures must be taken to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment to be free from all non-consensual treatment.

while also stating that it “does not permit the imposition of coercive measures in the supposed ‘best interest’ of an adult person with a disability (such as guardianship, psychiatric detention and compulsory treatment)”⁴.

At the time of writing, significant pressure is being brought on the Scottish Government from academia, legal organisations and rights and advocacy organisations to include the UNCRPD into domestic law on mental health. The ongoing review of the Mental Health Act (Scotland) 2003 may result in legislation relating to the UNCRPD being introduced to the Scottish Parliament. This would be a powerful statement that Scotland supports human rights for people with mental health issues – and indeed, for all disabled people in Scotland under the Scottish Public Sector Equality Duty.

In January 2016, the Scottish Human Rights Commission and the Equality and Human Rights Commission delivered a joint response to Scottish Government Draft Delivery Plan for the UNCRPD. It is the intention of the Commissions to hold the Scottish Government to account so that the rights of all disabled people in Scotland are recognised, promoted and respected.⁵

The framework of human rights – as described above – means that, in Scotland, people with mental health issues should already be afforded the greatest levels of respect and dignity throughout their care and treatment (and in society). They should always be understood to have equal decision-making competency – and therefore should always have an equal say in regard to the care and treatment they are offered/receive. If a person is unable to articulate their choices in a way that is effective for others, all possible processes of supported decision-making should be utilised by the professionals providing care.

It has been apparent, however, throughout the 15 years since the original Mental Health Act (Scotland) came into effect in 2005, that there has been a significant disparity between the intentions stated in legislation and Scottish Government strategy and policy and the delivery of a genuine, consistent and coherent human rights approach within both statutory and third sector mental health service provision.

In their most recent Mental Health Strategy (2017 – 2027)⁶, the Scottish Government have (again) stated that human rights are of central importance to the Strategy and integral to the delivery of all Actions associated with the Strategy. The Scottish Government has also declared an intention for all mental health services to be designed and delivered with the PANEL principles (see below) at their heart and with a intention to effectively address all forms of stigma and discrimination, remove barriers that prevent people with a mental health illness or condition from reaching their full potential and treat people with genuine dignity and respect.

The Panel Principles

Participation: people should be involved in decisions that affect their rights.

Accountability: there should be monitoring of how people’s rights are being affected, as well as remedies when things go wrong.

Non-Discrimination and Equality: all forms of discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised.

Empowerment: everyone should understand their rights and be fully supported to take part in developing policy and practices which affect their lives.

Legality: Approaches should be grounded in the legal rights that are set out in domestic and international laws

In March 2019, the Minister for Mental Health, Clare Haughey, declared that the Scottish Government would put the voices of those with lived experience “front and centre” of a review of the Mental Health Act. As the Minister, she understood that it is necessary to examine these issues and ensure that Scottish law fully reflects the ambitions of Government and the needs of the people the legislation is intended to support including making recommendations that reflect people’s social, economic and cultural rights.⁷

Legislation may, however, not be enough to ensure that those rights are observed and upheld. Many of the support services for people with mental health issues are provided by small, local third sector organisations and grassroots projects that are under threat from funding shrinking local authority budgets and integrated joint board efficiency improvement measures and strategies⁸.

With sweeping reforms of local strategies and service provision taking place, it is more important than ever to ensure that the people making decisions about services and strategies understand that any and all changes to service provision in the mental health sector must meet the Scottish Government requirements on equalities and the human rights agenda of the Mental Health Act and the Mental Health Strategy (2017 – 2027) and other equalities-focused legislation.

In addition, it is essential that there is full recognition at local strategic level and in the design and delivery of services in regard to the importance of early support and the observation and upholding of the human rights of people engaging with and supported by mental health services. Every single person has mental health – and the human rights

agenda is there to ensure that we are all afforded the respect and dignity and rights we are all entitled to when we need it.

The organisations that provide mental health collective advocacy in the City of Edinburgh will contribute to the review of the Mental Health Act. The staff and people they support will be informed by a clear understanding that each and every individual should be enabled to fully appreciate that they have the right to be treated with consideration and integrity in relation to their individual physical and psychological needs and to be included in every step of decision making about the services they are supported by.

Every Scottish citizen is entitled to be treated with dignity and respect; people supported by mental health services are entitled to have their human rights acknowledged and upheld by every public and third sector organisation they come into contact with. This understanding of human rights is fundamental to the principles and practice of mental health advocacy.

Key legislation: essential elements

The key rights for people with mental health issues are encompassed in the United Nations Convention on the Rights of People with Disabilities (UNCRPD)¹, noting that mental health conditions are recognised as disabilities. All Articles of the UNCRPD are essential and relevant and relate to persons with on an equal basis with others. Articles particularly highlighted through discussions include

UNCRPD Article 5: Equality and non-discrimination in which all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law; also relates to **UNCHR: Article 14**: protection from discrimination

UNCRPD Article 12: Equal recognition before the law and to enjoy legal capacity on an equal basis with others in all aspects of life

UNCRPD Article 14: liberty and security of person and are not deprived of their liberty unlawfully or arbitrarily; the existence of a disability shall in no case justify a deprivation of liberty

UNCRPD Article 15: freedom from torture or cruel, inhuman or degrading treatment or punishment; all effective legislative, administrative, judicial or other measures must be taken to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment; also relates to **UNCHR: Article 2**: freedom from torture and unhuman or degrading treatment

UNCRPD Article 25: persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability; also relates to ICESCR 1966: the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; all appropriate measures should be taken to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation

UNCHR Article 8: the right to respect for private and family life; also relates to UNCRPD Articles 19: living independently and being included in the community; 21: freedom of expression and opinion and access to information; 22: respect for privacy; 23: respect for home and the family

Other relevant, current legislation (in 2020)

- all other Articles of the UN Convention on the Rights of People with Disabilities
- UN Conventions on Human Rights (UNCHR)
- Human Rights Act (UK) 1998
- Mental Health (Care and Treatment) (Scotland) Act 2003
- Scotland Act (Scotland) 1998
- Equality Act (UK) 2010 and related Public Sector Equality Duty (Scotland) 2011
- European Convention on Human Rights (ECHR)
- International Covenant on Economic, Social and Cultural Rights 1966 (ICESCR; 1966)

¹ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>

Mind Our Rights!

Background to the event: inspiration, design and delivery of the first Mind Our Rights! event

Please see Appendices 1-? for additional information

The inspiration: an informed discussion on rights-based care with Colin Beck of Edinburgh Health and Social Care Partnership resulted in Patricia Rodger (AdvoCard) and Simon Porter, Martin McAlpine and Mark Somerville (all of the Royal Edinburgh Hospital Patients Council). At the meeting it was decided that the best strategy would be to take a proactive approach and to organise a collective advocacy event based around mental health and human rights. We also decided to embrace the 2019 Mental Health Awareness Week (MHAW) theme of “Body Image” in order to explore a number of key issues around mental health and physicality.

Anne O'Donnell (CAPS Independent Advocacy | LEARN) became part of the collaborative group and we worked together to develop a strand of partnership work for organisations that provide both community and hospital based independent advocacy in Edinburgh; we chose to call this project Mind Our Rights!

The idea behind the Mind Our Rights! strand of work is to ensure that people with lived experience of mental health issues and those supported by services are treated with dignity, have their human rights understood and upheld and given the opportunity to participate in decision-making processes that should include

- all decisions about how their care and treatment is provided (including strategic development and planning)
- all decisions about and delivery of their personal care and treatment
- all people involved in the design, provision and delivery of mental health services, including those supported by mental health services, being made aware of the rights of people with mental health issues
- all people involved in the delivery of and participation in mental health services committing to upholding of the rights people with mental health issues as set out in Scottish Government legislation and strategies

The design: the steering group discussed how Mind Our Rights! could engage with Mental Health Awareness Week 2019 (MHAW19) and the theme of “body image” and identified six key topics for conversations at an event:

- mental health medication and side effects (with a focus on weight gain)
- mental health, gender and sexuality
- mental health and eating disorders / manipulating body image
- mental health and self-harm
- mental health, self-medication and self-modification
- “it’s all in your head” / diagnostic overshadowing in mental and physical health provision

Professionals and people with lived experience with appropriate knowledge and skills relating to each of the topics were invited to be facilitators for each of the groups on the day. We invited Mhairi Snowden of Human Rights Consortium Scotland and Michelle Howieson of the Lothian Bipolar Group to present at the event.

Mind Our Rights! was held on Wednesday 15 May between 1pm and 4.30pm at The Hive, a SAMH-run facility in the grounds of the Royal Edinburgh Hospital (REH). The choice of venue allowed us to utilise a space in which in-patients could participate but which also allowed us to bring service users, survivors and people with lived experience and mental health professionals to come together for the event.

Attendance on the day reached the Hive maximum limit of 50 people – however we were able to utilise the main space for the main presentation plus one other room within the building and adjoining outdoor space for the breakout groups.

Mhairi Snowden opened the event with a presentation on the broad issues of the rights of people with mental health issues in Scotland, highlighting the UN Convention on the Rights of People with Disabilities and the growing recognition of the need to uphold the rights, wills and preferences of people being treated in relation to mental health issues.

Michelle Howieson then presented on her very personal experience of being in a situation in which both physical health needs and mental health needs were required to be met and the rights issues that needed to have been considered and addressed.

The delivery: We used the Eventbrite⁹ booking system for the event; the online system allows organisers to be aware of the number of spaces booked and flags when the maximum has been reached or if there are cancellations. We held a waiting list to maximise opportunities for people to attend and went ahead at maximum capacity.

We were given superb support on the day by the SAMH team at the Hive. The Scottish Independent Advocacy Alliance (SIAA) supported us with tote bags, pens, notebooks and printed copies of the publication *Advocating for Human Rights*¹⁰ while the Edinburgh Health and Social Care Partnership provided a budget for food.

Each of the group discussions was all well attended; facilitators and/or participants recorded key elements of each discussion on flipchart paper and specific forms provided by the design and delivery team. The following sections outline the key findings and set out the full discussion notes and emerging themes from each discussion.

Key emerging themes

- **People with mental health issues are often understood/assumed to have different rights to those of the general population: training on Human Rights is essential for all professionals working in the arena of mental health.** People working in financial planning and strategic development roles should be trained to ensure that the delivery of Human Rights is built into the structures and systems of service design and delivery; training should also be provided for mental health service managers and practitioners in all services at every level
- **More information on Human Rights should be readily available and accessible for people with mental health issues; the focus should be on the UNCRPD** because the Convention sets out ways in which disabled people have specific protections
- **Key decision makers and influencers should be aware that “absolute rights”, such as the right not to be tortured or treated in an inhuman or degrading way, must never be limited or restricted in any way**
- **A public authority such as local or national government can never use lack of resources as a defence against an accusation that it, or any funded service it provides, has treated someone in an inhuman or degrading way or breached any other “absolute right”**
- **Decision-making about care and treatment should be a shared/supported process:** co-production is key to ensuring the person receiving the care and treatment feeling that they have some control and agency in their life. Their needs and wishes must be heard, acknowledged, and validated and incorporated into any documents relating to current and future care and treatment.
- **Barriers to the realisation of human rights for people with mental health issues must be removed:** people with mental health issues are not necessarily familiar with the full spectrum of rights that they have in relation to care and treatment; local and national government and providers of services must take the responsibility for ensuring that users of their service, whatever that service may be, are aware of their rights and responsibilities
- **parity of esteem between physical health and mental health is essential: diagnostic overshadowing must be eliminated:** physical health and mental health are connected - care and treatment must reflect that. Knowledge and understanding of mental health among GPs/in GP practices/health centres should improve to stop assumptions being made that for someone with a mental health issue, physical issues are “all in their head”; counsellor/peer worker in every GP practice

These identified themes and issues emerging from the discussion groups are genuinely concerning. They evidence a considerable gap between Scottish Government legislation on the rights of people with mental health issues, the ambitions of Scottish Government policy on mental health provision and the experience of people with mental health issues receiving care, treatment and support from services.

Discussion 1: medication, side effects and human rights (with a focus on weight gain and harmful stereotypes)

Identified achievable/aspirational action:

more involvement for patients in relation to the balancing of risk when it comes to medication decision-making; more information about medication and weight-gain

Headline:

"Would you take that drug yourself doctor?"

Key human rights: UNCRPD Article 25: persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability; **UNCRPD Article 5:** Equality and non-discrimination in which all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law; also relates to UNCHR: Article 14: protection from discrimination; **UNCRPD Article 12:** Equal recognition before the law and to enjoy legal capacity on an equal basis with others in all aspects of life

discussion bullet points

- weight-gain makes you want to come off medication
- prescribing information re: weight gain "[knowing side-effects] would you prescribe it to yourself, doctor?"
- "do you see any oversize mannequins?"
- changes whole life when overweight - average size is 16; 63% of people are considered to be overweight and 29% "obese" but media don't cover that; overweight people stereotyped and judged
- [being overweight can damage] self-esteem; also links to depression
- over-sedation and lethargy reduces the motivation to exercise and eat well
- long term health effects/capacity issues
- we are told "it's your fault - it's what you want"
- expense of fluctuating weight: 'ballooning' weight and new wardrobe costs as you gain/lose weight. Clothing allowance? Charity shops? Clothing bank/exchange?
- in the community there is no access to dietician who can help you plan diet specific to meds
- but also helpful diet and exercise - not really/fully available in hospital
- health good is expensive; using frozen food is not always the answer because not everyone has access to a freezer
- all the issues about weight apply to men too – diabetes is a big risk
- compulsory treatment order/in hospital: people can refuse physical health meds but not mental health – no involvement in decision making
- most restricted patients in hospital - only guaranteed 15 minutes passes; no control over diet and exercise - right to outside/fresh air only. Limited time - link to smoking
- all-round long-term health effects/capacity issues
- supported decision making + review of MH laws - best interests of patients and service users
- question risk management/question involvement in the assessment of risk re: medication

Key narrative themes

Participation, discussion and dignity: the group identified a need for the [general health and mental health] system to be adjusted to provide adequate opportunities and time for full and frank discussion between anyone prescribing medication and the person taking medication in relation to the effects and side effects of any medication prescribed. Members of the group stated that there needs to be more genuine “shared decision making” and consideration of the potential impact on the body/physical health of the person taking the mental health medication; and consideration of any negative impact on the social, economic and cultural rights of the person being expected to take the medication.

Stop the “blaming and shaming” around size and weight: the group felt that when people become overweight as a result of medication, this is not understood by the general public; also that being overweight is stigmatised in our society and there needs to be more done to make people aware that being overweight may be as a result of having to take particular medication/s. Addressing this stigma should be part of addressing the stigma of mental health. Nobody involved in design, delivery or provision of services should treat anyone with a mental health issue with anything other than absolute dignity, acceptance and compassion.

There was concern within the groups that people who are overweight are often told “it's your fault - it's what you eat” when in fact the weight-gain is related to the medication they are taking. Both the weight-gain itself and the stigma of being overweight makes people want to come off medication but if when someone is subject to compulsion such as a Community Treatment Order they have no choice, even when the mental health medication may be causing physical health issues. The group felt that the [health] system allows people a choice about taking medication for a physical health issue but does not afford people the same right in relation to mental health medication. The group concluded that there needs to be more consideration of the impact of mental health medication on the physical health of the person being expected to take the medication, with the full involvement of that individual; a key identified issues is the lack of risk management in relation to the best interests of the patient/person with mental health issues.

The group also considered that access to a dietician and the need for an eating plan specific to the medications being taken might be a good idea but it was also noted that, while diet and exercise are helpful in managing weight issues, this was not really/fully available in hospital. Members of the group highlighted that the most restricted patients in the Royal Edinburgh Hospital are only guaranteed 15 minutes passes [to be off the ward] which is not enough time to take the kind of walk that would improve health and/or generate weight loss. The felt that the Right to Health included a right for any individual to access being outside/in the fresh air for exercise.

Additional issues discussed

- need to flag the (invisible) physical risks that may impact over time, such as Type II diabetes, kidney damage and discuss those risks as it seems that there is no choice about taking the mental health medication that may cause weight-gain and therefore ultimately cause these conditions
- attitudes to smoking were also raised particularly in relation to medication causing weight-gain for some people who then choose to smoke as a way of managing their weight.

- socio-economic issues were flagged as problematic and contributory to dietary health included poverty relating to the fact that “health food” (and healthier foods) are relatively expensive
- healthy food prep and storage can be an issue as not everyone has access to a freezer and other kitchen items that many people take for granted
- ballooning weight also may relate to eating disorders: dramatic weight gain or weight loss can be traumatising in itself

Discussion 2: mental health, sexuality and gender and human rights

Identified achievable/aspirational action:

[more] education, training, knowledge, respect on rights and sexuality and gender identity for both health and social care professionals as well as for people with mental health conditions. [Our] human rights need to be explained to people working in health and social care (they are the same rights as every other person in our society!) There needs to be a full appreciation that we should be treated with dignity, acceptance and compassion. We have a right to a private life.

Headline:

"Need a king-size bed for more than my head"

Key human rights: UNCRPD Article 5: Equality and non-discrimination in which all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law; also relates to UNCHR: Article 14: protection from discrimination; **UNCRPD Article 12:** Equal recognition before the law and to enjoy legal capacity on an equal basis with others in all aspects of life; **UNCRPD Article 19:** living independently and being included in the community; **UNCRPD Article 21:** freedom of expression and opinion and access to information; **UNCRPD Article 22:** respect for privacy; **UNCRPD Article 23:** respect for home and the family

UNCHR Article 8: the right to respect for private and family life; **Article 10:** freedom of expression

Everyone living in supported accommodation has a single bed (240 supported accommodation beds in the City of Edinburgh) yet they have the same Right to a Private Life as every other person in Scotland. They are unable to access that right due to the limitations of the rooms/furniture and supported accommodation unit protocols. "Single beds? What's that about?! Why are there only single beds in supported housing? We all have the right to a private and family life, regardless of our gender/sexual identity and our mental health."

Discussion bullet points

- training needs to be face-to-face and involve patients/people with lived experience, not just computer course
- we are making a plea: don't make assumptions; not everyone is the same...not everyone is heterosexual; not everyone fits the male/female binary definitions
- gender identity issues are not necessarily related to mental health issues
- sex is not always about risk
- sexual function/functionality is important – never talked about (nor relation to meds)
- we are not just our heads/what goes on in our heads: my body is important even when I am mentally unwell (and I still have needs and wants)
- homophobia and transphobia still exist/are demonstrated by staff in hospital and community treatment/support settings.

- things have got better but there still needs to be more work done (towards equal rights in relation to mental health and sexuality and gender)
- working to educate in-patients at the hospital who are expressing prejudice towards LGBTQI+ people that it is not acceptable and that they are causing harm

Key narrative themes

The group felt that (at least some of) the training should be delivered by people who have lived experience of facing issues of prejudice and discrimination relating to their sexuality and/or gender identity; they emphasised the understanding that we are all human and we all have the right not to be discriminated against. Prejudice and discrimination against any individual or group for any reason is damaging both socially and to each individual. It can have a very damaging impact on the mental health of people.

Members of the group said that they knew, from their experience, that homophobia and transphobia still exist within staff providing health and social care in mental health settings, at all levels and both in the hospital and in the community services (NHS and third sector). The group acknowledged that there has been some improvement...but more work needs to be done. Some of the group had experience of prejudice and discrimination from other patients.

They expressed a need for people working in health and social care to have a wider understanding and acceptance in relation to gender and sexuality, appreciating that not everyone is the same in how they identify: not everyone is heterosexual...not everyone identifies as “male” or “female” (i.e. gender-fluid, non-binary)

They also felt that there needed to be a much greater understanding that gender issues and issues of sexuality/sexual identity are not the cause of poor mental health as such - but rather that individual and societal attitudes towards people who are “different” in terms of sexuality and gender create mental health issues for people who identify as being part of the LGBTQI+ community

One member of the group said “Sex is not always about risk...it is about love, relationships, human contact and so much more.” The group also felt that sexual function/functionality is important for everyone - including people with mental health issues and people who identify as part of the LGBTQI+ community. Concerns were raised that relationships that develop between patients in hospital are broken up because they are deemed to be inappropriate but that is a breach of human rights.

Further concerns were raised about particular side effects of medication that impact on sexual function (in a variety of ways) and some of those side effects can be lasting. They felt that these issues are never talked about in relation to medication - including when under compulsory treatment orders when it does not feel like a choice to take medication that impacts negatively on sexual functionality - but as one person in the groups said “I am not just a head (with mental health issues)...my body is important to me even when I am unwell. I still have wants and needs.”

And everyone has a right to a private life.

Discussion 3: mental health/physical health, diagnostic overshadowing and human rights

Identified achievable/aspirational action:

A mental health specialist and counsellor in every GP practice; sympathetic practitioners who listen to individuals and take a holistic approach

Headline:

“See me as a whole person - don’t make assumptions; treat me as a human being - don’t label me as a condition”

Key human rights: UNCRPD Article 25: persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability; **UNCRPD Article 5: Equality and non-discrimination** in which all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law; also relates to UNCHR: Article 14: protection from discrimination; **UNCRPD Article 12:** Equal recognition before the law and to enjoy legal capacity on an equal basis with others in all aspects of life; **UNCRPD Article 15:** freedom from torture or cruel, inhuman or degrading treatment or punishment; all effective legislative, administrative, judicial or other measures must be taken to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment; also relates to UNCHR Article 2: freedom from torture and inhuman or degrading treatment

discussion bullet points

- some people think that any physical health issues are all in your head; it is called diagnostic overshadowing and AdvoCard did a whole project on this
- practitioners need to recognise/accept that people know themselves best
- listen to the person, need a holistic and individual approach; no one size fits all
- [I would like to say] reasonable adjustments should be made in all settings
- more time for mental health in GP surgeries and health centres; mental health counsellor and specialist in all GP surgeries and health centres
- relationship [between person and practitioner] and continuity of that relationship is important; recognition/right to see the same person
- [if relationship with one practitioner is not good] a willingness to refer onto someone else and get 2nd opinion
- the right to access treatment and support services, including benefits, without diagnosis; the right to work with practitioners to establish an agreed diagnosis and for there to be a written confirmation of that agreed diagnosis signed by the patient
- physical and mental health are connected and should sometimes be considered together, sometimes not; a sympathetic practitioner will listen and take a holistic approach
- accuracy in reporting important; I don’t want someone to make/report generalities of a diagnosis that don't specifically apply to me
- practitioners see the label [provided by diagnosis] and not the person
- the assumed root cause is attributable to mental health rather than physical health for many practitioners

Key narrative themes

The group emphasised the need for people to be treated as a discrete individual and not seen as part of a homogenous group with a diagnostic label. This was related to the potential for misdiagnosis [for convenience; to know what drug to prescribe even when the individual felt that the diagnosis was not appropriate]. This was strongly understood to be a human rights issue.

Members of the group also felt that practitioners were liable to putting everything under a mental health diagnosis, including physical conditions which they could dismiss as “all in your head”. Conversely, some people felt that there was a correlation between mental health conditions, medications prescribed for those conditions and the development of some physical health conditions.

Whichever way that the bias lay, it often results in the individual not getting correct treatment for [both] physical and mental health.

Members of the group discussed inaccurate reporting or exchange of information between practitioners as being a key issue. They understood there to be a need for continuity – to see the same GP as much as possible and to be able to develop strong, positive relationships with and individual GP; the need for the GP to know them as people not just a diagnosis (echoing the need for mental health specialists to “see” them as human beings rather than a diagnostic “label”). There was also an expressed desire to know more about medication – being on a drug and then being admitted to (general) hospital for a physical health problem and the mental health drug being forgotten about.

Members of the group felt that there should be mental health nurses/practitioners/specialists within every GP surgery/Health Centre. Some also felt that people with mental health issues should get a double appointment by default as they would always want to include mental health in any discussion with their GP. One person suggested that this would equate to a “reasonable adjustment” (normally utilised in an employment context) as whatever the nature of the physical issue they were presenting with, the person would have a mental health reaction to it.

One member of the group reported that they waited a long time for weight loss treatment because they, personally, wanted to prioritise their mental health even though carrying the additional weight was impacting on their mental health.

Another member of the group reported that they had had to look after their own physical health while being on a mental health ward – but they felt that this worked well for them, giving them some control.

Discussion 4: mental health and self-medication / self-modification and human rights

Identified achievable/aspirational action:

“be given the information to feel in control”

Headline:

“our bodies, our choices”

Key human rights: UNCRPD Article 25: persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability; **UNCRPD Article 5:** Equality and non-discrimination in which all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law; also relates to UNCHR: Article 14: protection from discrimination; **UNCRPD Article 12:** Equal recognition before the law and to enjoy legal capacity on an equal basis with others in all aspects of life; **UNCRPD Article 15:** freedom from torture or cruel, inhuman or degrading treatment or punishment; all effective legislative, administrative, judicial or other measures must be taken to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment; also relates to UNCHR Article 2: freedom from torture and unhuman or degrading treatment

UNCHR: Article 8: respect for private and family life; **Article 10:** freedom of expression;

discussion bullet points

- people must be allowed to have fun – fun is so important; just to be happy
- embrace our differences and the differences of other people
- let patients/people supported by mental health services know that making an Advance Statement is an option
- in general, having choice and control for patients/people supported by mental health services is a good thing
- shared decision making important; this should be supported rather than substituted whenever possible
- knowledge and power dynamic has to change
- NB: although issues relating to self-expression through self-modification were briefly touched on, they were not a key part of the discussion on the day

Key narrative themes

Respecting individual integrity and dignity: the group felt that people [seeking help, treatment, care] wanted to be given all the information that they want/require to in order to have some authentic and confirmed control in their own lives. There is also a need for “fun” and freedom of expression and the ability to embrace their experience in their own way.

The group discussion included the need for all people

- who have experience of mental health issues

- who are supported by mental health services
- who are and/or have been in hospital as a result of their mental health

should be told about Advance Statements and how they can be used to state an individual's wills and preferences in relation to care and treatment if admitted to hospital.

The discussion in the group moved on the need for greater control and choice in relation to their own lives; one group member felt that "it is good for any patient in hospital and anyone supported by services in the community to have some say, some control"

This related to group members feeling that the knowledge/power dynamic has to change between patient or service user and practitioners; some people felt that practitioners could enjoy feeling that they had control over the patients, which is unhealthy

The group discussed concerns that the needs of patients/people being supported by services are not being met, that the system is [potentially] unfair and that as a result, people self-medicate or that people self-medicate because they are trying to control whatever they are feeling and thinking.

There was acknowledgement that use of available substances such as alcohol and/or other substances (and behaviours) as a response to poor mental health and/or as a way of managing their mental health. This was felt to be a coping mechanism through which people gravitate toward the substance that alleviates their symptoms most effectively.

Smoking tobacco was acknowledged as self-medication – but not just as the use of tobacco and nicotine, also as a ritual/habit of taking time out to roll a cigarette or just the need to have to leave an indoor space to go and smoke.

If the [mental health] system worked with people rather than imposing itself on people, the group felt that more could be achieved and that patients and practitioners working together would give patients the control they wanted and therefore be more effective.

Discussion 5: mental health, eating disorders, self-image and human rights

Identified achievable/aspirational action:

“services need to change: criteria should not be based on weight and weight should not be the focus because this means that the services only treat the symptoms not the cause and excludes a whole lot of people ”

Headline:

“Access to eating disorder services should not be based on and restricted to weight and BMI”

Key human rights: UNCRPD Article 25: persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability; **UNCRPD Article 5:** Equality and non-discrimination in which all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law; also relates to UNCHR: Article 14: protection from discrimination; **UNCRPD Article 12:** Equal recognition before the law and to enjoy legal capacity on an equal basis with others in all aspects of life; **UNCRPD Article 15:** freedom from torture or cruel, inhuman or degrading treatment or punishment; all effective legislative, administrative, judicial or other measures must be taken to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment; also relates to UNCHR Article 2: freedom from torture and unhuman or degrading treatment

discussion bullet points

- being weighed is humiliating and prompts distrust of [eating disorder] services
- [eating disorder] services should not be based on the medical model/physical symptoms
- people need options like Peer Support and Psychological Therapies
- it is extremely difficult for individuals to secure and defend their human rights: a lot of support and resources are needed
- society and the medical profession shames people with eating disorders; obese people are segregated and marginalised – they do not receive the same standard of care in physical and mental health services as other people
- psychological and emotional suffering is extremely important and often ignored
- eating disorder services are not inclusive of all people with eating disorders; there is a very narrow perception of what an eating disorder looks like; lots of people are ignored and treatment doesn't address their actual needs
- strategies can just be tick-box exercises; the funding for services is available but it isn't being allocated as it should - use participatory budgeting methods with patients
- eating disorders can be very isolating; peer groups and support from people with similar experiences can be vital
- treatment needs to be individualised; professionals need to engage with and discuss treatment with the service users.

Key narrative themes

The group discussed the need for significant and radical changes to the thinking in service provision: services for people with eating disorders should not be based on/focus on weight and BMI; when they are, this leads to the service only treating the physical symptoms and not the cause. Group members also felt that being weighed is humiliating and prompts distrust of services and linked this to the right to be treated with dignity and respect.

The group felt that services for people with eating disorders should not be based on the medical model and presenting physical symptoms as this discounts the psychological aspects of the conditions treating the patients only as bodies; the need for psychological services was overlooked.

Some members of the group expressed concerns about being discharged from a service when they reached a “healthy” weight as they felt that appearances could often give a false impression of a person’s state of mind. They also expressed concern that eating disorder services are not inclusive of all people with eating disorders, saying that there is a very narrow perception of what an eating disorder looks like – the stereotyping of anorexia, the ignoring of obesity as being the result of an eating disorder, the lack of understanding of bulimia; this led to a discussion about the fact that eating disorders can be very isolating – something they felt that peer groups and support from people with similar experiences could be very helpful with as peers have “walked in their shoes”.

Overall, they came to the conclusion that care and treatment needs to be based on the needs of the individual professionals need to engage with and deliver treatment with compassion and without judgement.

The group also felt that it is extremely difficult for individuals to secure and defend their human rights – a lot of effort and resources are needed despite the fact that their rights are enshrined in Scots law that states that those rights should be upheld. The discussion highlighted that patients and people supported by mental health services find that practitioners are often unaware that the rights of people with mental health issues have human rights...and that their human rights are the same universal rights that the practitioners themselves have.

Discussion 6: mental health, self-harm and human rights

Identified achievable/aspirational action:

"less judgement and stigma; more understanding and support"

Headline:

"recognition of the multiple forms that self-harm takes is essential; all forms to be accepted as symptoms rather than as "a disease" in itself."

Key human rights: UNCRPD Article 25: persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability; **UNCRPD Article 5:** Equality and non-discrimination in which all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law; also relates to UNCHR: Article 14: protection from discrimination; **UNCRPD Article 12:** Equal recognition before the law and to enjoy legal capacity on an equal basis with others in all aspects of life; **UNCRPD Article 15:** freedom from torture or cruel, inhuman or degrading treatment or punishment; all effective legislative, administrative, judicial or other measures must be taken to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment; also relates to UNCHR Article 2: freedom from torture and unhuman or degrading treatment

discussion bullet points

- we want greater awareness of the issues and a greater understanding of forms of self-harm
- there needs to be service to ensure greater awareness of self-harm and suicide
- professionals [think they] "know better"
- need for mental health nurses at Royal Infirmary Emergency Department
- mental health is far more complex than we know
- broad involvement of all psych-disciplines in conversations about self-harm and suicide/attempted suicide
- need to understand more about the gender differences in relation to self-harm and suicide

but people who need support for self harm/suicidal thoughts/suicide attempts need professionals to

- see the "bigger picture"/more than one perspective at any time
- hear from/listen to voices of experience about what helps
- [psychiatrists should] really listen to what is being said by the person
- be more direct: "What happened to you?" "What is going on in your life?"
- recognise wide scope/range of self-harm and suicide attempts and see them as a symptom of mental distress (rather than an attention-seeking behaviour)

Key narrative themes

The group were clear in their understanding that everyone has the right to caring, compassionate medical treatment. People who self-harm should receive the same level and

quality of care that a person presenting with an identical but accidental injury would receive but with additional mental health support. When a person presents at the emergency department with a self-inflicted injury or following a suicide attempt, they should be included in any discussion relating to any proposed psychological assessment.

The group also wanted the right to have feelings behind self-harming attempts to be understood to be valid and part of a bigger picture, a symptom rather than a diagnosis: self-injury does not occur in a vacuum. Anyone who self-harms in any way is externalising (in response to) distressing feelings. The individual has a right to disclose to whom they choose only what they choose. No professional practitioner should disclose to others that injuries are self-inflicted without obtaining the permission of the person involved unless in a team-based hospital setting.

It was felt that professional practitioners should listen to the individual and acknowledge their distress; the individual should not be shamed, admonished, or chastised for having self-harmed, whatever form that self-harm might present as. Self-injury and self-harm may be the only coping mechanism for that person. Any individual seeking treatment for or following self-harm should not automatically be considered a danger to themselves or others simply because they present with a self-inflicted injury nor should self-harm be understood to be an attempt to manipulate.

Some members of the group suggested that self-harm to be understood as a symptom of an underlying mental health issue that was most likely related to trauma that they were unable to express in any other way

Conclusion: where are we now...

...and what needs to happen to make rights real?

It is clear from the comments made in the various Mind Our Rights! discussion groups that there is a significant disparity between the intentions stated in Scottish Government legislation, policy and strategy on mental health and human rights and the experience of people with mental health issues in relation to the realisation of their human rights.

While the comments made at the event were in relation to personal experience, understanding of human rights, how rights could be fulfilled and rights-related issues remedied, similar issues are replicated and views expressed by people supported by services across the country every day.

In addition, over the last few years there has been a significant increase in knowledge and understanding of human rights among people with mental health issues, their carers, and organisations that seek to defend their rights.

The key issue is, therefore, the lack of sufficient and appropriate knowledge and understanding of human rights and associated good practice among professional practitioners, public bodies, public sector providers and third sector organisations that fulfil a public function, influencers, policy makers and purse-string holders in the arena of mental health to support the actual realisation of human rights.

Essential action: everyone involved in provision of mental health services - funders, policy makers, health and social care partnerships, staff delivering public services and the Boards, management and staff of third sector organisations - must all receive adequate and appropriate education and training in relation to the human rights of people with mental health issues and how, as service providers, they can meet their legal obligations.

In addition: people with current/previous lived experience of mental health issues should be fully involved in the design and delivery of this education and training.

The lack of knowledge, understanding and related strategic thinking described above means that when individuals or groups of people with mental health issues raise issues in relation to human rights, individuals and services involved in the design and provision of professional mental health services are unwilling and unable to provide the remedies that are legally required.

In this culture of unawareness of and resistance to human rights responsibilities, people with mental health issues must be supported to secure their lawfully held human rights.

It is vital that everyone involved in the provision of mental health services are trained in the required relevant knowledge and skills that will allow them to meet human rights legislation - without training, public bodies and service providers may feel under pressure because they are being challenged and shown to be wanting.

This is likely to lead to some providers becoming resentful and obstructive, unwilling to accept that they have a legal duty to uphold human rights as to do so changes both the dynamic and balance of power in favour of those who use the service rather than those who provide it. This may, in turn, lead to service providers perceiving service users who ask for their rights to be met and advocacy/human rights workers supporting the service user/s and defending their rights being perceived as “being a nuisance” or “causing trouble”; whereas the reality is that they are legitimately working to ensure that the issues faced by people with lived experience are recognised, acknowledged and met

Essential actions: everyone involved in mental health service provision should understand and respect the human rights of the people supported by services; they should also understand and respect the role of any and all workers acting as human rights defenders

In addition Employers, should also take measures to

- develop, nurture and sustain resilience within their team/s
- ensure they are aware of the human rights issues and what work to challenge individuals and organisations involved in the provision of mental health service may entail
- ensure they are aware of the potentially stressful nature of the work required to secure and/or defend human rights; people with mental health issues and the workers acting on their behalf may be placed under significant stress and employers should ensure that all parties are adequately and appropriately supported
- be prepared for complaints to be made against workers acting as human rights defenders - recognising that the complaint is not being made because the worker is at fault but because the worker is successfully fulfilling a key function of their role and supporting the worker to continue with their work

The Mind Our Rights! event and this associated report have demonstrated that there is a very genuine need to maximise the extent to which the rights of people with mental health conditions are understood - through education and training - so that public authorities, service providers and any organisation that fulfils a public function can meet their legal obligations in relation to human rights.

As a nation we can celebrate that on 1 September 2020, the United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill was introduced to the Scottish Parliament. This Bill will make Scotland the first country in the UK to directly incorporate the United Nations Convention on the Rights of the Child into domestic law and give some of the most vulnerable people in our society specific entitlements and protections under the law of the land.

This legislation will make it unlawful for public authorities to act incompatibly with the incorporated UNCRC requirements, giving children, young people and their representatives the power to go to court to enforce their rights.

The Scottish Government has stated that “Our vision is a Scotland where children’s human rights are embedded in all aspects of society. A Scotland where policy, law and decision

making takes account of children's rights and where all children have a voice and are empowered to be human rights defenders."¹

Essential actions: human rights organisations and advocacy providers must support and/or advocate on behalf of people with mental health issues and those who care for them to work to ensure that the incorporation of this rights-based legislation is a catalyst for the Scottish Government to legally afford similar specific entitlements and protections to physical and/or mental health disabilities.

Only by incorporating the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) into domestic law can the Scottish Government truly "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity...where persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

¹ <https://rightsinfo.org/what-is-dignity-and-what-does-it-have-to-do-with-our-rights>

² <https://www.equalityhumanrights.com/en/equality-act/protected-characteristics>

³ <http://www.scottishhumanrights.com/media/1677/crpdpartnershipreport.pdf>

⁴ Interim Report of the Special Rapporteur on Torture and other Cruel, Inhuman and Degrading Treatment or Punishment (SR Torture Interim Report), 28 July 2008, UN Doc A/63/175, at [44]; also see For further background to the CRPD, see T Minkowitz, 'Disability Convention Advocacy by the World Network of Users and Survivors of Psychiatry: The Emergence of a User/Survivor Perspective in Human Rights', in M Sabatello and M Schultze (eds) *Voices from Within – Civil Society's Involvement in the Drafting of the CRPD*

⁵ <http://www.scottishhumanrights.com/health-social-care/disability/>

⁶ <https://www.gov.scot/publications/mental-health-strategy-2017-2027/pages/8/>

⁷ <https://www.holyrood.com/articles/inside-politics/rights-mind-mental-health-reform-centred-humanrights>

⁸ <https://www.holyrood.com/articles/inside-politics/rights-mind-mental-health-reform-centred-humanrights>

⁹ <https://www.eventbrite.co.uk/>

¹⁰ Scottish Human Rights Commission & Scottish Independent Advocacy Alliance: *Advocating for Human Rights* https://www.siaa.org.uk/wp-content/uploads/2017/09/SIAA_Advocating_Human_Rights_Guide.pdf

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