Interim report on See Me’s Engagement work on the review of the Mental Health Act

Background

The Scottish Government announced in April 2019 that they are conducting a review of the Mental Health Act, and have appointed John Scott QC to lead the review. The Mental Health Act means a person can receive care and treatment against their will, if they are seriously mentally unwell. The motivations for the review are changes in international and rights law since the Act came into place in 2003; a marked increase in the use of compulsory powers over the last decade and the need to examine crossover between the Mental Health Act and the Adults with Incapacity (Scotland) Act 2000. This review means there is an opportunity to change the law relating to compulsory treatment, and make suggestions for changes needed to prevent people being detained under the Mental Health Act and support those that are to realise their rights. For this reason, See Me has engaged with its cohort of champions and people with lived experience to hear what changes they want to see made to the Act.

Up until December 2019, See Me has conducted a consultation event with Youth Champions and one-to-one interviews with five people with lived experience of the Mental Health Act, either from having themselves been detained or from caring for a person who has been detained under the Act. See Me is supporting one of our Youth Champions to sit on the Communications and Engagement Group, that advises the Executive Group of the Review on how to engage with people with lived experience. See Me has also been engaging with a number of organisations and individuals on this topic, including co-hosting an event with the ALLIANCE on how to ensure the voice of lived experience are involved throughout the review, and facilitating at one of VoX’s consultation events.

This interim report outlines the emerging findings See Me’s consultation work and outlines some key themes that will form the basis of See Me’s position on the Mental Health Act and eventual response to the review. It also draws on previous engagement work done by See Me and partners on embedding a human rights-based approach into Scottish policy and legislation – the Rights for Life agenda. Summarising the themes and taking stock at this stage will allow See Me to identify any potential gaps in knowledge and better inform upcoming engagement work. See Me is especially concerned with current tensions between mental health legislation, upholding human rights and autonomy and the discriminatory nature of the current legislation. Ultimately See Me will take a position on the Mental Health Act that focuses on reforming the Act in a way that ensures it is free from stigma and discrimination and upholds people’s rights.

Key emerging themes

i. Lack of knowledge about severe and enduring mental health conditions

“People have no idea what it’s like to live with my condition.”

A theme coming out strongly in the consultation work is that there is a lack of understanding of what it’s like to live with a severe and enduring mental health problem. This applies for the person themselves, the staff they come into contact with and the general public. People with severe and enduring mental health problems are not being properly informed how to manage their conditions, due to a culture of silence around severe and enduring mental health problems. This makes it harder to seek help and a fear of being admitted to hospital prevents people from speaking out. For example, one participant highlighted that patients who are becoming unwell may try to conceal their illness from Community Psychiatric Nurse (CPN) for fear of being admitted to hospital. Another highlighted how self-stigma meant they wanted to retreat from the world when they realised they were becoming unwell. This means they did not receive the help they needed at an earlier stage which culminated in them being detained under the Mental Health Act.

There is also sense that staff do not appreciate the impact of severe and enduring mental health problems. For example, they may think a person is being ‘difficult’, without appreciating the implications of their mental health condition. Furthermore, the general public have very little appreciation of the impact of mental health problems, and this means they are unable to support people in need or avoid the person.

Emerging recommendations:

- There needs to be a greater focus on how people know about their mental health condition and helping make people aware of warning signs. People need support identifying factors that lead to poor mental health for them.
- There should be more openness about severe and enduring mental health problem. Not addressing this leads to a culture of silence and people not receiving help. This could be done through extramural classes in the community led by people with lived experience of severe and enduring mental health conditions, making use of information stalls in libraries and training targeted directly at health practitioners.
- Openness about mental health, coping strategies, and what impacts on a person’s mental health should be taught to people from an early age.

Recommendations drawn from Rights for Life:

- Mental health education should be promoted across the life-span with a particular emphasis to support children and young people’s understanding of mental health, reduce stigma and discrimination and encourage timely and effective help-seeking.
- Engagement activity with civic society to promote understanding of people’s rights and experience of living with severe and enduring mental health conditions.

ii. Upholding rights

“Where do I find out what my human rights are around mental health?”

One theme coming out clearly was that people do not know what their rights are under the Mental Health Act. People are not being informed of their rights before, during or after their detention and this means they do not know what safeguards are in place to uphold their rights or where to go if they want redress. These rights include the right to advocacy, which treatments are and are not allowed without further approval under the Mental Health Act, provisions for named persons, and respect for advance statements. Several interviewees highlighted that all these points would be better secured if people were made aware of advance statements and how they are intended to uphold a person’s rights. The interviewees also felt that people should be informed of their rights when they were detained and during any time spent in hospital.

Emerging recommendations:

- Take proactive steps to inform people of their rights, including information campaigns, being read a ‘letter of rights’ upon detention, having a person’s rights on clear display in a hospital ward, informing Mental Health Officer, CPN, and other key healthcare professionals of these rights.

Recommendations drawn from Rights for Life:

- Ask people with lived experience what the barriers to understanding rights are.
- Create a national discourse actively encouraging the empowerment of people with lived experience.
- Create Tip Sheets on how to claim right within different settings (similar to 5 Choosing Wisely Questions from Realistic Medicine) and what information people need to know to claim their rights.
- Review (and if needs refresh) and disseminate existing information on rights specific to mental health to ensure it is accessible and create new accessible material as needed co-produced with people with lived experience.
- Create clear and accessible information for duty bearers, supported by training and ongoing CPD.
- Highlight positive stories.

iii. Advanced statements and advance planning

“Advanced statements act a guarantor for all other rights.”

Related to the above key theme, the importance of advance statements was emphasised by several interviewees. An advance statement sets out how a person wishes to be treated when they are seriously unwell. CPNs should have a key role in promoting the existence of advance statements, to open a conversation about what matters to a person when their mental health deteriorates, and how they would wish to be treated. People need better support to make these plans, alongside personal statements –which provide more context on the person - and management plans – which set out how the person’s plans for managing their condition. Currently advance statements may be overturned because they contain material incompatible with treatment in hospital – e.g. “I want to be able to smoke” – however, if people were supported by a healthcare professional to frame what is important to them, it could act as a strong legal guarantor of how people should be treated.

Emerging recommendations:

- Given the importance of advance statements, there should be key trigger points for completing or updating an advance statement with the person. For example, after a person has had their first mental health crisis and at the point of being discharged from hospital. As soon as the person is well enough, they should be encouraged and supported to write advance statements.
- Proactive steps must be taken to ensure that advance statements are available and accessible to all parts of the service, especially psychiatric wards. It should be automatic for a psychiatric ward to enquire with the Mental Welfare Commission whether a person has an advance statement upon admission.
- Communities, schools and universities should have information on advance statements.

- The Government should fund initiatives to raise the knowledge of advance statements, create a bank of example advance statements and set out clear guidelines for completing these.

Recommendations drawn from Rights for Life:

- Promote and support uptake of advance statements, and enhance their use in clinical settings through embedding in policy, practice and legislative reform. Provide national guidance and support to facilitate this and reinforce systems of independent monitoring and accountability.

iv. Raising status of Mental Health Officer as a career

“It’s no wonder they (Mental Health Officers) burn out.”

Mental Health Officers (MHOs) have a particular place in the Mental Health Act because a person’s MHO must be consulted before that person is detained under the Mental Health Act. However, all too often this does not happen. There was a repeated theme from interviewees that MHOs are overstretched, underfunded and not supported to fulfil their important role of promoting people’s interests and supporting their mental health. MHOs need to be recognised as a respected group of professionals, with better training, higher salaries and greater experience requirements to recognise the important difference they can make in a person’s life.

At the moment the supply of MHOs is sporadic across Scotland, and on occasion other professionals are redefined as MHOs without requisite training or experience. Formalised training of MHOs must include information on signposting to community services, the role of advance statements, upholding rights and how to support a person before, during and after detention under the Mental Health Act.

Emerging recommendations:

- There must be a concerted effort to increase in status of Mental Health Officers, to improve recruitment, morale and recognition of the importance of their role.
- There needs to be a greater focus on how to ensure there is consistency of service across Scotland.
- An MHO should always be consulted before a person is detained under the Mental Health Act.

Recommendations drawn from Rights for Life:

- Modernising training within key job groups relevant to mental health where human rights are core.
- Review and consolidate existing training against the WHO Quality Rights Toolkit, the human rights framework, and with reference to the Convention of the Rights of Persons with Disabilities.
- Providing training around how to uphold and how to claim rights in day to day practice.
- Peer-to-peer support for rights holders and duty bearers.
- Encourage Royal Colleges and other bodies to embed rights within training programmes, alongside the contribution of lived experience to course development and delivery.

v. Challenges facing community services

"How ill do you need to be before you get help?"

A key theme emerging from interviews and the focus group with Youth Champions was that there is not enough support in communities and that this impacts on people's mental health. "It's all about early intervention" said one interviewee, highlighting that people do not have services to go to, or the waiting times are too long. This can mean a person's mental health deteriorates to the point of crisis. Another interviewee argued that only those people who know what is available to them are able to say they want to be signposted to that service. The interviewee added that people who may need services were excluded because they did not know what was 'out there' or what support they are entitled to from public services.

Emerging recommendations:

- A reduction in waiting times to mental health services. "Ask for help once, get help fast."
- There need to be better provisions for signposting and greater awareness of what third sector services are available in an area. This would mean greater use of link workers, not just to signpost people, but to support people to attend services. It also means highlighting signposting resources to healthcare professionals (e.g. ALISS and other local databases).
- Services should be adapted to suit all age groups, and be mindful of the impact that stigma has on preventing people from accessing services in the first place.

Recommendations drawn from Rights for Life:

- A lack of funding is a barrier to implementing rights-based approaches and therefore there is a distinct need to change the emphasis towards it being core, not additional.
- There is a strong need for a root and branch review of what people with mental health conditions say they require through their life stages, what provision would best accommodate their needs and what resource allocation is required for delivery. A coordinated and integrated approach needs to be taken to the review of provision, focused on the whole person and incorporating health, social care and protection, employment, education, housing and transport.

vi. Better support around transitions

"My CPN visits just stopped."

One theme emerging strongly from the consultations was a lack of support around transitions; for example, when a person moves from CAMHS to adult services or from adult services to older people's services. An interviewee reported that after turning 65, visits from CPNs were cut down and the support she was offered was geared towards dementia and not her specific mental health condition. Furthermore, there needs to be greater attention paid to when a person transitions from CAMHS to adult services. Too often people are not followed up properly and left isolated, leading to worse mental health outcomes.

Emerging recommendations:

- Greater focus on supporting people during transitions between services, communicating with the person and ensuring that the level of support they are currently receiving is maintained.

vii. Stigma and labelling

“I am already judging myself, so how is it supposed to make me feel when I’m judged by my CPN?”

Another theme that emerged strongly was the stigma and discrimination experienced by people with severe and enduring mental health problems. This included judgemental responses from GPs, CPNs, psychiatrists and others meaning the person was less likely to wish to engage with these services in the future and might enter into an adversarial relationship with them.

Stigma associated with specific diagnoses was also highlighted. For example, one interviewee with a diagnosis of schizophrenia said he had called emergency services after attempting to take his own life, and instead of healthcare professionals, four police officers were sent. In spite of having no criminal record, the explanation given for this was “He’s got a marker on him.” In general, the language of the Act is unconstructive and should be reformed alongside people with lived experience and professionals, e.g. mental disorder, detained.

Emerging recommendations:

- Changing the terminology of the Act in consultation with patient groups. For example, moving away from ‘mental disorder’ and ‘detention’, which have highly stigmatising connotations.
- Drawing on evidence of how to reduce stigma and discrimination, especially around severe and enduring mental health conditions

Recommendations drawn from Rights for Life:

- Include measures to address the stigma and discrimination of those affected by mental health problems; re-framing this work in the context of equalities and human rights.

viii. Compulsion and hospitalisation

“How do you get well in that environment?”

The participants agreed that compulsion was sometimes appropriate, but only under very particular circumstances, for example, imminent risk to the person or other people. There was, however, a strong feeling that a person must only be under compulsion for the shortest period possible, and that the focus must always be on supporting the person’s decision making. Detentions are currently too lengthy, and need to be geared towards de-escalation of detention quickly. Another point that emerged was that capacity is not total and that it may be worth exploring categories of capacity, rather than just incapacity or capacity. For example, as soon as the person gains the some capacity the emphasis must always be on supporting them to be a part of decisions about them.

There was broad agreement that at the moment treatment in hospital is too focused on medicalisation. Some of the interviewees said one only sees nurses when receiving medication and that other patients became the most important source of support when in hospital. One interviewee highlighted that a nurse followed her around without speaking to her, this added to feelings of isolation and hopelessness.

Several interviewees said that there need to be a greater focus on talking therapies and other therapeutic approaches to help recovery. For example, the benefits of peer support, group work, relaxation methods and talking therapies were highlighted by all interviewees, but all said there had been none of this during their experience of hospitalisation.

Emerging recommendations:

- Gradations in capacity should be explored.
- Detention currently means that a person is fully under compulsion. There should be a focus on what the person can do and what they would like to develop.
- There should be a retrospective debrief between a nurse and a patient after detention to explain what has happened and why it happened. This would allow for greater focus on de-escalation and promoting recovery of the person.
- Mobile phones should be banned from wards. Interviewees reported that nurses may be texting during duty time and ignoring their patients. Patients should have access to their mobile phone as a matter of practice as it allows them to feel less isolated and in touch with the outside.

Recommendations drawn from Rights for Life:

- A shift in policy and practice towards supported decision-making in all circumstances.
- A legal basis for positive obligations on duty bearers to respect, protect and fulfil economic and social rights, as well as civil and political rights.

ix. Advocacy

Individual advocacy is where a person receives one-to-one support to help them make a fully informed decision. Collective advocacy is where people who are all facing a common problem and have had a similar experience get together to work on specific issues and have their voices heard. The group as a whole may campaign on an issue that affects them. The theme of advocacy did not emerge as strongly as was expected from the interviews conducted, however, See Me’s previous engagement work has shown that it is of critical importance in the context of the Mental Health Act. People are entitled to advocacy through the Act, but too often they do not receive it, meaning they are unaware of their rights and are not empowered to claim them.

Recommendations drawn from Rights for Life:

- Improved access to independent advocacy in different forms for people with mental ill health and carers across all services to help people make decisions.
- Policy level support around the role of independent advocacy (individual and collective) is urgently needed, in light of serious pressures on advocacy services and provision.
- Improved understanding of independent advocacy for people with lived experience and unpaid carers, as well as service providers.
- Independent advocacy is core to supported decision making and is a core element of service experience.

x. Accountability

Accountability came up in only one interview with an individual who had had particular experience of the Mental Health Tribunal system. He expressed concern that the Tribunals are too geared towards the professional viewpoint, and that the role of advocacy was not fully understood by the Tribunal. His advocate had been told they could not speak, but this goes counter to the role of being an independent advocate and is based on a misunderstanding of the current legislation. See Me's previous engagement has also shown people who do not know their rights are poorly placed to hold the system to account.

Emerging recommendations:

- Ensure there are clear guidelines and examples of good practice for members of any Mental Health Tribunal and for those attending a Tribunal.

Recommendations drawn from Rights for Life:

- Establish accountability arrangement for scrutiny of human rights policy and practice; empowering rights holders to hold duty bearers (including public services and employers) to account
- Ensure lived experience is intrinsic to commissioning, procurement, delivery and regulation processes.
- Stronger accountability mechanism. This should include clarification of standards of care and what people should expect from services, more accessible and effective complaints systems and the routine proactive gathering of view and experiences from people in receipt of services that are reviewed and acted upon.

Themes for further exploration

In addition to the themes above there are a number of themes that emerged in one or two interviews that are clearly of great importance to the review of the Mental Health Act, but need further research and consultation to better understand and shape recommendations around.

xi. The support in place for family and carers

xii. Provisions for named persons

xiii. Follow up after detention – what support is in place after a person is discharged from hospital

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If you have any questions or would like more information on this interim report, please get in touch:

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