Policy briefing

#MyRightsMyMind

The case for a human rights-based approach to mental health

September 2019

MAKE OUR RIGHTS REALITY

Mental health is the topic of our time. The mental health 'crisis"[1] - in particular the massive barriers faced by young people in accessing appropriate, timely support - has led to both social outrage and a much-needed political drive for change.

But is this so-called crisis more than an issue of mental health? Are we also facing a human rights crisis and can looking to international law help us to fix it?

This briefing argues that, in the face of such massive systemic challenges, anything less than transformational change to the mental health system risks failing yet another generation of young people.

It thus explores the case for employing a human rights framework to tackle the specific challenges faced by young people in accessing mental health support.

This briefing is for politicians, commissioners and stakeholders in the mental health system, as well as service providers who value the rights of young people using their services.

Is there a right to mental health?

Health is a human right. This right is laid out in numerous international agreements which, alongside the majority of the world's states, the United Kingdom has ratified.

The International Covenant on Economic, Social and Cultural Rights (ICESCR) entered into force in January 1976.[2] Along with subsequent commentary by United Nations (UN) bodies[3] and special rapporteurs,[4] this legally binding agreement provides the blueprint for how states must behave when it comes to protecting and fulfilling the right of everybody to "*the highest attainable standard of physical and mental health*".[5]

While it is recognised that people may be unwell at different periods in their life, human rights law spells out the right of everybody to access care and treatment to support them to live as healthy a life as is possible. Crucially, the ICESCR values physical and mental health equally.

More recently, the UK signed the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007. This agreement is foundational to the modern-day application of human rights in healthcare; emphasising the need for a fundamental shift in perceptions of people with mental illness – moving away from biomedical approaches which favour diagnosis, medication and institutionalisation and moving instead towards an asset-based approach; treating the individual, the people and communities involved in their care as knowledgeable and equitable players in decisions affecting them.[6]

A human rights-based approach, therefore, should focus on progressing person-centred care and inclusive methods of co-production and participation in the system at large.

Key documents on the right to health

- International Covenant on Economic, Social and Cultural Rights (ICESCR)
- UN Convention on the Rights of Persons with Disabilities (UNCRPD)
- UN Convention on the Rights of the Child (UNCRC)
- NHS Constitution

"The service is designed to improve, prevent, diagnose and treat both physical and mental health problems with equal regard. It has a duty to each and every individual that it serves and must respect their human rights."[11]

Progressive realisation

It is recognised that fulfilment of the right to health may be a progressive process, adapted to the specific needs and resources available within a country.[7] The ICESCR, however, is absolutely clear that each state party is duty-bound to use '*the maximum of its available resources*' in order to achieve '*full realization*' of the rights outlined in the agreement, '*by all appropriate means*'.[8]

Moreover, the ICESCR imposes the requirement of expediency and forward progress. Governments must not drag their feet on realising the right to health, nor can they deliberately overturn or row back on advances in mental health provision according to political whim.[9]

This raises serious questions about the (lack of) support available to young people in the UK – currently the worst served age group by the mental health system.[10] Through a human rights lens, it is clear that progressive mental health policies cannot just be paraded for political capital or cut back when the going gets tough. They form part of the most basic provision of care that all human beings, without discrimination, are entitled to access, according to international law.

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Principles of the right to health & young people's experiences

The right to health in all its forms and at all levels contains the following elements or principles, which are interrelated and essential. Fulfilment of one relies on fulfilment of the others - none can be given higher regard over another or restricted without detracting from the rest.[12]

Here, we outline how these principles of *availability, accessibility, acceptability* and *quality* correspond to the prevailing situation in the youth mental health sector in England.

Availability

"Functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity."[13]

What it means

Adequate mental health services (and the staff to deliver them) must be available to everybody.

This doesn't just mean more hospital beds for when people reach crisis point – human rights conventions are clear on the need for governments to work towards providing more diverse, integrated services which work across health promotion, prevention, treatment, rehabilitation, care and recovery for every section of the population.

What young people actually experience

- A postcode lottery of waiting times, ranging from 14 days to over a year.[14]
- Nearly two in three young adults with diagnosable conditions go without necessary support, more than any other age group.[15]
- No universally-defined criteria for which children and young people meet the threshold for mental health care in the UK.[16] Often service providers are entitled to set thresholds for care upon the basis of resource (or lack thereof) of the local system, rather than on the patient's need.[17]
- Cuts to community-based youth services which focus on promotion, prevention and early intervention.[18]

> **I was diagnosed with anorexia, but because I was still a 'healthy' weight, I couldn't access support... In the end I was forced to pay for private treatment. I spent thousands of pounds of my own money and travelled hundreds of miles because what I needed just wasn't available where I live.** - Amber, 21

Accessibility

"Health facilities, goods and services have to be accessible to everyone without discrimination."[19]

What it means

Services, as well as the underlying determinants of positive mental health should be:

- Physically accessible for all sections of the population. For young people this often translates as local community-based services with good public transport connections.
- Economically accessible, ie affordable - especially for poorer households.
- Non-discriminatory. This might mean offering different types of service to ensure equitable access, especially for marginalised groups.

Information about mental health, treatments and services must also be readily available to all sections of the population in terms of distribution, the use of appropriate language etc.

> **I was diagnosed with Borderline Personality Disorder at 17, however was told that I was not able to access [specialist support] until I was 18, yet despite the diagnosis I was discharged from the local adult team as I was too old for CAMHS and left with no support.** - H, 23

What young people actually experience

- Imbalance in spending - fifteen times more is spent on adult mental health services than children's.[20]
- Disproportionately poorer access and quality of support for young adults, particularly as they transition from children's to adults' services.[21]
- Young people from lower socio-economic groups and BAME backgrounds are less likely to access mental health services, and young men are less likely to seek or receive help than young women.[22]
- Young people are forced to access services far from home,[23] with rural communities particularly poorly served.[24]
- Lack of clear, accessible communication about treatment options.[25]
- Inflexibility in the system, eg fixed appointment times which don't work around caring responsibilities or other commitments.[26]

Acceptability

"All health facilities, goods and services must be respectful of medical ethics and culturally appropriate"[27]

What it means

Mental health services respect medical ethics and human rights, as well as meeting the needs of different cultures, genders, disability and, vitally, different age groups.

Young people have distinct preferences and face complex psychosocial challenges specific to their life phase[28] (leaving education; leaving care; entering employment; financial independence, etc) - and yet the current system caters only for children or adults - drawing a line between the two at age 18.[29]

Services should also be designed to respect confidentiality and empower individuals to control their own health and wellbeing. This is especially important for young people, who, for various reasons, may not want to involve their parents in their mental healthcare.

What young people actually experience

- Currently no statutory provision designed specifically for young adults or ringfenced funding for such services.[30]
- Many young people report feeling that professionals don't take them seriously or don't understand them.[31]
- Current policy emphasis on increasing support in schools or through CAMHS[32] risks further marginalising young people who fall outside of mainstream provision or who don't feel comfortable in those settings.

> **The [staff] are patronising and I personally don't feel very comfortable talking to them. I like having my Mum with me for reassurance... but I always feel awkward about this because of them. This seems to be because I'm a young adult and they're not sure how to interact with me - they either patronise or expect too much so this really needs to change.** – R, 22

Quality

"Health facilities, goods and services must...be scientifically and medically appropriate and of good quality."[33]

What it means

As well as ensuring the use of evidence-based practices, human rights conventions emphasise the need to shift away from over-medicalisation and institutionalisation of people with mental illness; looking instead to psychosocial models which see the individual as a whole person, with the right to live in their community.

This means working across both the medical and community/voluntary sectors, employing person-centred approaches and diverse methods of participation and co-production which appreciate the individual and their support networks as experts by their own experiences, and thus, as essential participants in decision-making at all levels.

What young people actually experience

- Poor quality care over the critical transition period between children's and adult's services - as few as 4% make a 'successful' transition into adult services.[34]
- Targets for local provision based on outputs (eg number of counselling sessions delivered), rather than outcomes for young people or their experiences of care.[35]
- A perceived power imbalance; young people report feeling cut out of decisions about their own care and the shape of the system.[35]

> **[The student counsellor] signed me up to a group anxiety management course - I could not imagine something more anxiety-provoking. I explained to her how I would not make it there, ironically due to anxiety problems and that it would be unlikely that I'd even make it out of the house nevermind get to the building, she just persisted that it would help and kept telling me to go. Obviously, I didn't go.** T, 21

The importance of underlying social determinants

Rights are like a jenga tower: they are '*indivisible*', '*interdependent*' and '*interrelated*'.[36] They rely on one another - so taking one away risks them all falling over. For example, if your right to good housing wasn't being met, and you were living with damp or even homeless, it's likely your mental health would suffer too. Having access to a great mental health service might help in the short term, but likely not for long.

A rights-based approach to mental health should reflect and respond to the different social issues which can be a risk to mental health. Cuts to local youth services, low-wage jobs, discrimination, disability, addiction... Mental health cannot be siloed off from the issues that impact upon it and are impacted by it. Any rights-based approach must reach across diverse policy areas and seek to tackle retrogressive measures which threaten the right to mental health.

Opportunities

Recent political impetus has paved the way to some exciting opportunities to drive transformational change in the mental health sector.

NHS Long Term Plan

Setting ambitious targets matched with £2.3 billion a year funding for mental health, the NHS Long Term Plan[37] presents a potentially once-in-a-lifetime opportunity to work towards the realisation of young people's rights when it comes to mental health.

A vital and pioneering element of the Plan requires every local health system to roll out a comprehensive offer of mental health support for children and young people aged from nought right up to 25, from 2021.

While the Plan makes clear that local health systems should seek to collaborate with and capitalise on the infrastructure and expertise held by the voluntary sector, there are as yet no quality assurances to make sure this is upheld at local level. This runs the risk of voluntary sector providers - many of which are already delivering quality, community-based services which meet the needs of 'transition age' young people[38] - being cut out of planning, commissioning and delivery of services.

Driving quality through collaboration: The Youth Access Altogether Better Charter

Through the Youth Access Altogether Better Charter scheme, hundreds of young people helped shape seven key principles, outlining how services designed to support their mental health and wellbeing should be run.[39]

Now, young people trained as 'Charter Ambassadors' analyse feedback from an online survey and regular youth-led focus groups to drive service improvement.

Social rights legislation

Despite the Human Rights Act (HRA)[40] and the Equalities Act[41] forming the bedrock of human rights law in the UK, neither explicitly reference the right to health. Since the UK has ratified the ICESCR, the UNCRPD and the UNCRC, it is bound by international law to enshrine these in domestic legislation. Without this, we face a disconnect between what our rights say we are entitled to and what we actually receive, and crucially, what can be enforced in the courts at national level.

Good practice in Scotland and Wales: In 2004, the Welsh government formally adopted the UN Convention on the Rights of the Child, meaning ministers must give it due regard when developing or reviewing legislation and policy relating to children and young people. In 2019, Nicola Sturgeon committed the Scottish government to incorporating the Convention into Scottish law within two years, making it binding in Scottish law and enforceable in Scottish courts.[42]

Engage young people

The people who have the greatest stake in any conversation concerning their rights are those affected by decisions and reliant on systems. A rights-based approach must prioritise the development of inclusive systems of participation which put young voices at the centre of decision-making and are accessible to young people from all walks of life.

Young people's call: Stand up for #MyRightsMyMind

Through the Our Minds Our Future campaign,[43] young 'Rights Advocates' are calling on politicians, commissioners and service providers to take the **#MyRightsMyMind** pledge[44] – promising to take a rights-based approach to improving mental health provision, starting by working with local young people to set the agenda. Their priorities for a rights-based action plan are:

- **Age-appropriate care** as we move into adulthood – not just services for children or older adults
- **Early identification and support** – not long waiting lists or only getting help at crisis point
- **Support we can access in our communities** – places we feel comfortable, not just in schools and hospitals
- **Clear options and decisions we understand** – not just being told what we can and can't access, with no alternatives
- **A seat at the table in decisions** about our own care, as well as what the wider system looks like

Put rights front and centre

To promote a rights-based approach in decision-making at all levels, rights should be explicitly referenced in health strategies, organisational policies and values statements.

Good practice in Northern Ireland - In 2018, Northern Ireland's Commissioner for Children and Young people conducted a 'rights-based' review - looking at a broad range of services against a range of rights-based standards.[45]

Politicians at national and local level, commissioners and diverse stakeholders can push for rights-based approaches by opening up discussions with colleagues and constituents, working on internal policy and seeking to pass motions and even legislation to hold systems to account.

At such a pivotal moment, it is vital that people of influence at all levels in the mental health system are reminded of their role not just as decision-makers, but as duty-bearers, with a fundamental role in upholding and realising the rights of all young people.

Politicians, commissioners and stakeholders in the mental health sector can make a start today: Join the #MyRightsMyMind community at bit.ly/myrights-community

References and detailed reading can be found in the 'Rights reading' insert or on our website at makeourrightsreality.org.uk/rights-briefing

YOUTH ACCESS
Championing advice and counselling

MAKE OUR RIGHTS REALITY

Make Our Rights Reality is a movement of young people demanding their rights. Coordinated by Youth Access, MORR helps young people to build the knowledge, skills and confidence to tackle injuctices head-on.

Youth Access exists to make sure all young people have somewhere local to turn to whenever they need to talk. We work with both young people and our membership of Youth Information Advice and Counselling Services (YIACS) to ensure that young people in every community can access great quality support as they move into adulthood.