# Consultation on the Draft Initial State Report under the United Nations Convention on the Rights of Persons with Disabilities

**09 April 2021**

Mental Health Reform

Promoting Improved Mental Health Services

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# Submission

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## Introduction

Mental Health Reform (MHR) is Ireland's leading national coalition on mental health. Our vision is of an Ireland where everyone can access the support they need in their community, to achieve their best possible mental health. In line with this vision, we drive the progressive reform of mental health services and supports, through coordination and policy development, research and innovation, accountability and collective advocacy. With 75 member organisations and thousands of individual supporters, MHR provides a unified voice to Government, its agencies, the Oireachtas and the general public on mental health issues.

**Acknowledgements**
Mental Health Reform would like to thank all the participants who gave their valuable feedback as part of this consultation process.

**MHR's Work on the Convention on the Rights of Persons with Disabilities**
Mental Health Reform is a funded member of the newly established Disability Participation and Consultation Coalition (DPCN). As part of this membership MHR has played an active role in consulting with and building capacity amongst members of the public, on the implementation of the Convention on the Rights of Persons with Disabilities (CRDP). We have held two themed online public consultations and one online information session aimed at building understanding, awareness of, and capacity in navigating the CRPD.

The themes focused on in both sets of online engagements were identified during initial consultations with members of Mental Health Reform. They were:

1. Work and Employment (Article 27)
2. Education (Article 24)
3. Health (Article 25)
4. Access to Justice (Article 13)
5. Awareness Raising (Article 8)
6. Government Supports (Article 4)

The purpose of using these themes was to focus on the areas of greatest priority for the members consulted. Nevertheless, we acknowledge this is not a comprehensive list and urge that the content of this submission be seen as indicative of a wider trend rather than being limited solely to the content included here.

**Focus**
This submission is made in full recognition of the landmark shift that ratification of the CRPD represents with respect to the rights of persons with disabilities, and the obligations owed to them by the Irish State. MHR welcomes this and the advancements that have been made in developing progressive government policy in this area, for example *Sharing the Vision*, and reforming the legislative landscape via the current review of the *Mental Health Act, 2001.*

However, the evidence on the ground suggests that the effects of such policy and legislative advancements are yet to be felt on the ground among those living with

psychosocial disabilities. This evidence arises out of MHR's work as a member of the DPCN and other aspects of what we do, including;

1. Policy development and analysis
2. Advocacy work
3. Qualitative and quantitative research on mental health services in Ireland, and
4. Engagement with the 75 member organisations belonging to our coalition.

This submission relies on both the experience of those living with psychosocial disabilities, their friends, families, carers, and supporters, as well as those providing services to them.

Overall, our consultations have indicated that the state report would benefit and be strengthened by including information on implementation, as well as legislative and policy measures in place. Participants in both MHR and DPCN consultations have highlighted that the report needs to more accurately reflect the reality for persons with disabilities in Ireland.

## Mental Health Policy & Delivery

*Articles (5, 12, 13, 14, 15, 17, 18, 19, 21, 25)*

### Human Rights and Mental Health Law Reform

Changes in the law relating to mental health are needed to fulfill the vision set out in Ireland's mental health policy *Sharing the Vision* and to bring about compliance with several key human rights instruments, including the European Convention on Human Rights and the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

*The Mental Health Act, 2001* requires urgent reform to bring it into line with the CRPD on a range of grounds (see MHR submission on the review of the *Mental Health Act, 2001,* April 2021). In addition, several key pieces of legislation that have been enacted in recent years are either yet to be commenced, or require amendment to bring them into line with the Convention.[1]

The lack of priority that has been given to these vital aspects of rights vindication for people living with psychosocial disabilities is noteworthy. For example, review of the *Mental Health Act, 2001* began in 2011. However, the State has not yet published the General Scheme of the new legislation that is proposed to either amend or replace this Act. It is likely that, according to timelines indicated by the Department of Health (whose responsibility it is to produce this legislation), it may be 2022 by the time it is enacted by the Oireachtas. This means that Ireland has been operating an acute mental health care system that has been non-compliant with human rights standards under the European Convention on Human Rights since 2004, and non-compliant with the recently ratified CRPD since 2018. This is a cause of concern for MHR.

### Mental Health Policy

Published in June 2020, *Sharing the Vision* renews the government's mental health policy focus on the principle of partnership. This is intended to ensure that people using mental health services –and their family, friends, carers, advocates, and supporters – are key decision makers in their own recovery planning and play a central role in designing and developing services. It highlights the importance of mental health services adapting to meet the person's wishes and preferences, and recognises that self-determination is a vital part of successful treatment and recovery.

The progressive, partnership approach promoted throughout *Sharing the Vision* is a welcome addition to the Irish policy landscape, including as it does an aspiration to,

> Progress a 'zero restraint, zero seclusion' action plan, which should be developed in partnership with mental health services. Prioritise comprehensive legislation to reform the Mental Health Act in line with this policy and in line with international human rights law. In keeping with the evolving understanding of human rights, particularly the UN Convention on the Rights of Persons with Disabilities, ensure that involuntary detention is not used

[1] The *Assisted Decision Making (Capacity) Act 2015* falls short of the standards set out in the CRPD due to its continued use of substitute decision-making. Also, the decision-making assistance service provided for under this Act will not come into operation until 2022, a full 7 years after enactment of this legislation. The *Mental Health (Amendment) Act, 2018*provides additional safeguards for people in inpatient mental health care facilities.

except in a lifesaving emergency. Make available a range of advocacy supports including both peer and representative advocacy as a right for all individuals involved with the mental health services. A range of advocacy supports including both peer and representative advocacy should be available as a right for all individuals involved with the mental health. (pp. 110, recommendation 92)

MHR is, however, concerned that the structures are not yet in place to ensure delivery on these aspirations in an operational context. While the National Implementation and Monitoring Committee has been established to oversee the implementation of *Sharing the Vision*, it is imperative that the policy receives the funding and resourcing required to achieve its goals and aims.

**MHR Recommendations**
*Sections 175-178 and 333 of the State's Draft Report*

1. MHR recommends that reform of the Irish legislative framework on mental health service delivery set out in sections 175 – 178 of the State's Draft Report should strive to incorporate best practice established in other states, which have brought and continue to bring mental health service delivery into line with the standards set out in the CPRD and beyond. This is to ensure that we not only aspire to meet current human rights standards but anticipate the trajectory of these standards into the future, thereby enacting legislation that is fit for purpose and can stand the test of time. One of the most notable examples in this area is *India's Mental Healthcare Act, 2017,* which both enumerates a right to mental healthcare for that state's 1.3 billion citizens and brings its legal framework on mental health service delivery into line with the CRPD.[2]

2. Any new mental health legislation must have an embedded human rights focus, with the centrality of the person to the process being a fundamental principle and should progress the aspiration to move to a 'zero restraint, zero seclusion' model of delivery as set out in *Sharing the Vision* (Sections 175-178 and 333).

3. As set out in section 333 of the State's Draft Report, *Sharing the Vision* is a welcome progression of government policy governing mental health supports and services. MHR calls for a fully costed implementation plan to be developed to ensure this 10-year strategy is delivered in full.

[2] Duffy, R.M. and Kelly, B.D., 2020. Compliance of India's Mental Healthcare Act, 2017 with the United Nations' Convention on the Rights of Persons with Disabilities. In India's Mental Healthcare Act, 2017 (pp. 209-225). Springer, Singapore.

## Work and Employment

*Article 27*

> *The recent European Commission country Report for Ireland 2019 revealed that Ireland has one of the lowest employment rates for people with disabilities in the EU (26.2 % compared to 48.1 % in the EU in 2017). Ireland also has one of the highest gaps between people with and without disabilities (45.1 percentage points) in employment.*[3]

### Major Policy Initiatives

As it outlined in the State's Report there are clear commitments across national policy and law to ensure people with psychosocial disabilities are supported to both seek and sustain employment.

Of relevance to those living with psychosocial disabilities, the new mental health policy adopted by government in June 2020, *Sharing the Vision,* also promotes equality in employment and specifically recommends that,

> a sustainable funding stream should be developed to ensure agencies can work effectively together to get the best outcomes for the individual using the Individualised Placement Support model, which is an evidence-based, effective method of supporting people with complex mental health difficulties to achieve sustainable, competitive employment where they choose to do so (pp. 69, recommendation 71)

Despite strong frameworks, the reality is that such employment supports are relatively underdeveloped in Ireland. Historically, the system of employment supports for people with mental health disabilities throughout the country has failed to facilitate access to work. People with a mental health disability are nine times more likely to be out of the labour force than those of working age without a disability, the highest rate for any disability group in Ireland.[4] The Department of Employment Affairs and Social Protection's (DEASP) 2015 survey of Disability Allowance (DA) recipients found that 50% of participants reported mental health difficulties as the primary reason for being on Disability Allowance.[5] However, it further identified significant levels of interest among individuals on DA in taking up employment (including both part-time and full-time work). Among those who were not currently working, 35% expressed an interest in working part-time, while a further 8% expressed an interest in full-time employment, given the right supports.[6]

This was reflected in the contributions of participants to MHR's consultations as part of the DPCN. It was felt by contributors that the level of payments was too low to sustain an adequate and dignified quality of life, that these payments did not take account of the

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[3] Social Justice Ireland (2019). *Work and People with Disabilities*, https://www.socialjustice.ie/content/policy-issues/work-and-people-disabilities.

[4] Watson, D., Kingston, G. and McGinnity, F. (2012). *Disability in the Irish Labour Market: Evidence from the QNHS Equality Module,* Dublin: Equality Authority/Economic and Social Research Institute, p. 19.

[5] Judge, C., Rossi, E., Hardiman, S. and Oman, C. (2016). *Department of Social Protection Report on Disability Allowance Survey 2015,* Dublin: Department of Social Protection.

[6] Judge, C., Rossi, E., Hardiman, S. and Oman, C. (2016). Department of Social Protection report on. Disability Allowance Survey 2015. Dublin: Department of Social Protection

increased costs incurred by those living with disabilities.[7] It was also highlighted that inherent poverty traps and disincentives to working were embedded in the qualifying criteria for payments.[8]

**Protections for Workers**

As outlined in the State Report, equality legislation, employment law, and health and safety legislation does exist in Ireland to protect employees. However, research in the area and MHR's consultations, highlight that the practical barriers for those seeking to invoke such protections represent a chilling factor in accessing them. Accounts given during the MHR consultation on Work highlighted a range of issues connected with safeguarding legislation and this is reflect in existing research.

*Fear of discrimination*

People living with psychosocial disabilities experience lower level of workforce participation compared with the overall population (22% compared with 53%). Those who do report workforce participation are more likely to experience either discrimination or harmful effects from discrimination in occupational settings.[9] In a *See Change* public attitudes survey in 2010, 47 %of respondents agreed that a diagnosis of a mental health problem would have a negative effect on their job and career prospects. 37% said it would have a negative effect on their relationship with their work colleagues.[10] This is consistent with research conducted by the National Disability Authority into the disclosure of disabilities in workplace settings,[11] which found, *inter alia*, that the experience of those with 'invisible disabilities' was complex regarding whether to disclose a disability or not.

This emerged during the MHR CRPD consultations, where some workers or prospective workers living with psychosocial disabilities were reluctant to disclose the nature and existence of their psychosocial disability for fear of,

1. Being rejected in the applications process.
2. Being unable to link such rejection to the disclosure made at recruitment stage.
3. Having their role diminished under the pretext of 'duty of care' being exercised.
4. Being 'managed out' of a role by placement on extended leave etc.
5. Stigma relating to the ability to continue performing their role.

The consequences of this reluctance can be harmful in a range of ways, including that such persons cannot avail of supports and reasonable accommodations that may be due to them under Irish employment and equality law.[12]

*Alleged Breaches of Employment Law*

Some consultation participants also reported that they felt compelled to endure alleged breaches of employment law in exchange for remaining in employment, these included.

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[7] National Disability Authority of Ireland (2011) Indecon Report on the Cost of Disability. Dublin

[8] Social Justice Ireland, (2019). *Work and People with Disabilities*, https://www.socialjustice.ie/content/policy-issues/work-and-people-disabilities; https://www.independent.ie/irish-news/welfare-trap-is-stopping-people-from-taking-jobs-29529657.html

[9] Banks, J., Grotti, R., Fahey, E. and Watson, D., (2018). *Disability and Discrimination in Ireland,* pp. 5

[10] Millward Brown Lansdowne, *Public Attitudes towards Mental Illness: A Benchmark Study for See Change* (unpublished).

[11] ibid.

[12] National Disability Authority of Ireland (2009). *Disclosing Disability in the Workplace a Review of Literature and Practice in the Irish Public Sector. Dublin*

1. Being paid below minimum wage.
2. Having their role diminished in a form of *de facto* demotion.
3. Failure on the part of the employer to make reasonable accommodation for the needs of employees living with psychosocial disabilities.
4. Being forced out of their position through encouragement to take extended leave, with little effort being made to encourage or facilitate a return to working.

Finally, we received feedback that those who investigated their legal options to address breaches of employment law or equality legislation, found the process prohibitive. This related to a range of factors, including:

1. The prospect of being liable for costs in the event a claim was not upheld.
2. The length of time a claim would take to reach a tribunal or court setting.
3. The anxiety caused by engagement with such an adversarial process.
4. A feeling that statutes of limitations were too restrictive for those struggling to manage a psychosocial disability. There is a requirement that complaints be lodged within 6 months of an alleged breach being committed, and an extension of this was cited as necessary to accommodate the needs of some.

**Affirmative and Effective Action Measures**

The DEASP's Disability Allowance Survey also identified that people with psychosocial disabilities experience numerous barriers to employment and that a range of supports are required to help achieve employment ambitions and goals. This includes in areas such as supportive work environments, access to transport, mental health supports, adaptation of job tasks, flexible hours, flexible work arrangements, and, most importantly, retention of the medical card and other social welfare payments upon taking up employment.[13]

This sentiment was echoed by participants of the MHR public consultation. It was highlighted that lack of information, guidance, and assistance in finding and securing employment were significant barriers in entering, re-entering, or remaining in the workforce.

While welcoming the fact that the Covid19 pandemic has forced a move towards flexible and remote working practices within many work settings, some participants highlighted that pre-Covid19 requests for such accommodations had been met with reluctance. A preference was also indicated for action to be taken by government to encourage and facilitate greater commitment to flexible working practices, which it was felt would accommodate those living with psychosocial disabilities in accessing and remaining within employment in the future.

As is outlined in the State Report, services do exist in Ireland. However, many are underfunded and do not have the capacity to meet demand and there is a lack of uniform access across the country.

[13] Judge, C., Rossi, E., Hardiman, S. and Oman, C. (2016). Department of Social Protection report on. Disability Allowance Survey 2015. Dublin: Department of Social Protection

**Employment, and Vocational Training and Supports**
There is compelling evidence that the internationally recognised approach to supported employment (Individual Placement and Support or IPS), is the most effective method of supporting individuals with severe and enduring mental health difficulties to achieve sustainable, competitive employment.[14] IPS has also been shown to be less costly than traditional vocational approaches.

Internationally, the principles of the evidence based supported employment approach have been strongly endorsed, particularly in countries such as England and the US. Furthermore, the benefits of IPS have long been recognised in the Irish context. As far back as 2006, the Expert Group on A Vision for Change reported that "a cost-effectiveness study of different employment models in England found that…individual placement and support (IPS) or 'place and train' projects were significantly more effective than other [traditional vocational] approaches in enabling people with mental health problems to find and keep open employment".[15]

MHR acknowledges the reference to the programme in the State Report and the Government's commitment to the Integrating Employment and Mental Health Support (IEMHS) project, which piloted the IPS approach in the Irish context.[16]The operation of the Social Reform Fund has provided an opportunity to roll out and implement the IPS model in all nine Community Healthcare Organisations (CHOs), and in the National Forensic Mental Health Service. The additional funding committed by the Department of Health through the HSE, is used to sustain the programme in 2021.

It is imperative, however, that the IPS approach be implemented and sustained at a national level, through ongoing secure funding and the participation of Employability Centres and National Learning Networks across the country.

**MHR Recommendations**
*Sections 389 - 395*

1. Clear funding commitments must be agreed between the Department of Employment Affairs and Social Protection, Department of Health, and the HSE to ensure the proper implementation of the IPS model discussed in section 395 of the State's Draft Report.

2. Ongoing guidance and training should be provided to all INTREO staff (in particular, case workers and including any new staff) to ensure that they can support individuals with mental health difficulties to access appropriate benefits and supports. Monitoring and evaluation of this training should be provided on an ongoing basis. This will ensure that all steps are taken to facilitate people living with psychosocial disabilities in every

[14] Sixteen randomised controlled trials have demonstrated that IPS achieves far superior outcomes across varying social, political, economic and welfare contexts. Studies have shown that 61% of people with serious mental health conditions can gain open competitive employment using Individual Placement and Support, compared with 23% for vocational rehabilitation. Randomised controlled trials in the United States have also shown that IPS participants have much better employment outcomes than people supported by more traditional approaches of providing vocational training and job preparation before undertaking the search for competitive employment.
[15] Department of Health document (2006), p. 38.
[16] The project was managed by MHR and developed with Genio and DEASP funding and delivered in partnership between the HSE Mental Health Division, DEASP and Employability companies.

way possible, in availing of both employment and labour market access supports detailed in the State Report at sections 389 – 395.

## Education

*Article 24*

At an international level, the World Health Organisation (WHO) has identified ample evidence that school-based programmes can influence positive mental health, reduce risk factors and reduce emotional and behavioural problems through social–emotional learning and ecological interventions. Several outcomes have been identified from existing school-based programmes, including "academic improvement, increased problem-solving skills and social competence as well as reductions in internalising and externalising problems such as depressive symptoms, anxiety, bullying, substance use and aggressive and delinquent behaviour".[17]

Irish education policy is reflective of the WHO's perspective. For example, the introduction of a compulsory subject on 'wellbeing' for students starting first year of secondary school in September 2017, under the junior cycle. Further examples that should be noted in the report are the publication of the national guidelines on mental health promotion and well-being for primary schools in 2015, post primary schools in 2013 and more recently for the junior cycle in 2017.

The Department of Education and Skills has also published the *Wellbeing Policy Statement and Framework for Practice 2018-2023*, which aims to ensure that by 2023:

1. "[T]he promotion of wellbeing will be at the core of the ethos of every school and centre for education.
2. All schools and centres for education will provide evidence-informed approaches and support, appropriate to need, to promote the wellbeing of all their children and young people.
3. Ireland will be recognised as a leader in this area.

The Department of Children and Youth Affairs (DCYA) 2028 launched a Whole-of-Government Strategy for Babies, Young Children, and their Families 2019–in November 2018. 8. Objective 6 of the strategy is that 'babies, young children and their parents enjoy positive mental health'. This objective aims to improve the early identification of mental health difficulties among babies, young children, and families, and to provide access to mental health supports and services that integrate into child-serving settings and the wider community.

While these policies and guidelines are welcome, there has been a lack of implementation. It is imperative that a whole school programme on mental health promotion and well being is rolled out nationally and is available to all children and young people in both primary and post primary schools. In the Mental Health report consultation, several participants highlighted the barrier represented by lack of understanding of their needs by teaching staff and others working within educational settings. Reports suggested this led vulnerable

[17] WHO. (2004). *Prevention of mental disorders: effective interventions and policy options*. Geneva: WHO.

young people and adults to take on the role of self-advocate whereby they were required to identify, express, and press for their needs to be met. This places an emotional, psychological, and logistical burden on those who are already contending with significant challenges. It also means the nature of their relationships with workers whose role it is to support students and scholars, differs from that of their peers.

Those detailing such experiences highlighted the need for practical education for staff within educational settings, on both psychosocial disabilities and the supports needed by those living with them. By ensuring adequate training is given to staff, the hope among participants was that the burden of advocating for supports and explaining the challenges they face, would be lifted. Such interventions at governmental level would significantly lift the emotional toll of self-advocacy and allow those living with psychosocial disabilities to put their energies towards their studies and other pursuits.

**Therapeutic Supports**

It is imperative that the State Report highlight the substantial waiting lists for children needing interventions and supports. Some examples of children's unmet mental and physical needs include:

1. Figures from October 2020 show that there 2,229 young people with serious mental health and behavioural difficulties, on a waiting list for an initial assessment by a specialist child and adolescent mental health services (CAMHS) team. A third of these children have been waiting for longer than 6 months.
2. A report published by HSE mental health division, found that staffing levels at the end of 2019 in our Child and Adolescent Mental Health Services were just 57.5% of the levels recommended in *A Vision for Change*. In addition, 15% (approx.) of Child and Adolescent Psychiatry posts are unfilled, while a further 20% are filled on a temporary basis.
3. Children with special needs awaiting Speech and Language Therapy.
    a. 2019: 7,586 (1,035 waiting >52weeks)[18]
    b. 2020: 10,946 (4,243 >52weeks)[19]
4. Children with special needs awaiting Speech and Language Therapy Assessment.
    a. 2019: 12,760 (1,077)
    b. 2020: 19,864 (3,651)
5. Children with special needs awaiting Occupational Therapy.
    a. 2019: 33,434 (9,296 > 52 weeks)[20]
    b. 2020: 34, 658 (13,491 > 52 weeks)[21]
    c. 6,335 people are awaiting a first-time assessment for occupational therapy – including 20,996 children, more than half of whom have been waiting for more than a year.[22]

[18] HSE. (2019). Performance Profile July – September 2019: Quarterly Report. Retrieved from https://www.hse.ie/eng/services/publications/performancereports/july-to-september-quarterly-report.pdf.
[19] HSE. (2020). Performance Profile July – September 2019: Quarterly Report. Retrieved from https://www.hse.ie/eng/services/publications/performancereports/july-to-september-quarterly-report.pdf.
[20] HSE. (2019). Performance Profile July – September 2019: Quarterly Report. Retrieved from https://www.hse.ie/eng/services/publications/performancereports/july-to-september-quarterly-report.pdf.
[21] HSE. (2020). Performance Profile July – September 2019: Quarterly Report. Retrieved from https://www.hse.ie/eng/services/publications/performancereports/july-to-september-quarterly-report.pdf.

6. Children with special needs awaiting Aural/Audiology treatment
    a. 2019: 16,791 (2,617 > 52 weeks)
    b. 2020: 17,661 (6,756 > 52 weeks)
7. The National Educational Psychology Service (NEPS) currently has 199 posts filled. As there are 932,186 children and adolescents enrolled as students as of September 2020[23] (553,003 primary and 379,183 post-primary), the ratio is 1:4684.4 at the current staffing level. This ratio does not offer a service easily accessible to those children in need.

The above figures offer a snapshot of how health and education services are failing to meet children's needs, particularly those living with psychosocial disabilities. This lack of access to time-critical interventions has a detrimental impact on the wellbeing of these children and impacts their development into adulthood. While difficult to evaluate, the knock-on effects of living with the pain and stress of unmet physical and mental needs during childhood, is clearly a phenomenon as yet unquantified.

Access to developmental and educational supports at the point of need does not yet exist in Ireland. This is a particular barrier for those who do not have the resources to pay for private services, such as Speech and Language Therapy or Occupational Therapy. The result is added pressure on mental health and other services down the line, and a lost opportunity to provide for people living with psychosocial disabilities to attain their best possible mental health.

Difficulties accessing relevant supports can cause disengagement with education and result in less-than-optimal achievement and attainment within the education system. A lack of comprehensive and accessible information means lack of signposting for adults needing assistance, as well as parents and guardians seeking supports for their children.

**Support for Part-time / Flexible Education**

Means-tested grants are accessible for those meeting specified criteria and wishing to attend approved higher education institutions. However, this is only the case for those in full-time education, which proves incredibly limiting for people living with disabilities.

Part-time education can be a preferred and necessary choice for many reasons, including accommodating,

a. Healthcare needs.
b. Caring duties and family commitments.
c. Work commitments.
d. Financial situation.

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[22] HSE data obtained by TD Michael Moynihan. See Irish Examiner. "Long wait for therapy assessments". 2nd February, 2021.

[23] Department of Education (2020). Statistical Bulletin Enrolments September 2020 – Preliminary Results. Retrieved from https://www.education.ie/en/Publications/Statistics/Data-on-Individual-Schools/enrolments/statistical-bulletin-enrolments-september-2020-preliminary-results.pdf

By failing to support part-time educational access on a par with full-time access, the State has placed a significant barrier in front of people living with disabilities who wish to take up higher and further educational opportunities. This was reflected in the contributions made by many who attended the MHR consultations in relation to the CRPD.

**MHR Recommendations**
*Sections 45 – 51, 322 – 326*

1. In light of the ongoing waiting lists and difficulties in accessing therapeutic and educational supports, a full appraisal is needed of the State's fulfilment of commitments made to children and young people under the strategies set out between sections 45 – 51 of the State's Draft Report.

2. Sections 322 – 326 of the State's Draft Report, provide details of initiatives undertaken to support people living with disabilities in accessing tertiary and further education. However, no mention is made of the significant financial barriers faced by those seeking to access part-time and flexible learning, in further or higher education settings. This is due to lack of supports equivalent to those made available to full-time students. This significant barrier for people living with psychosocial disabilities must be reflected in the State's understanding of how people with disabilities are provided for, with respect to tertiary and further education.

3. Sections 322 – 326 of the State's Draft Report also fail to set out the support arrangements made available by the State for people living with psychosocial disabilities within tertiary and further education. A key barrier for students seeking to access GP led treatment, is the centre of permanent residence requirement that often bars those studying away from home from accessing mental health supports while attending a learning institution.

## Health
*Article 25*

### Access to Healthcare

The WHO states that universal health care is the optimal way to improve health outcomes, however, Ireland remains an outlier in its complex mix of public and private provision. Various reports show how the two-tier structure in the Irish health system results in poorer access and outcomes for those who rely on the public health system.

MHR notes that 2019 was the first full year of the *Sláintecare Implementation Plan* and that 112 of the 138 projects across its four work streams were on target by the end of that year. However, project 2.4 to review the current framework and develop a policy proposal and roadmap for universal eligibility, was one of only two projects that encountered a significant challenge that year. That delay is disappointing, as it is a critical component to improve access and reduce inequality barriers to mental health services for the many people who do not have the means to private health care. The deep pressures under which the health service is now operating due to the global Covid-19 pandemic, has also slowed progress on *Sláintecare* funding.

While MHR supports the ambition, scale, and breadth of the Sláintecare reforms to deliver universal access to health in the right place by the right team at low or no cost, we are concerned that mental health is a peripheral element. We acknowledge the complexity of the challenges, in particular the unwinding of private health care from public health care. However, we want to see a more explicit and cohesive approach to addressing the social determinants of mental health, and the negative role they can play in the lives of citizens who experience mental health difficulties.

Access, entitlement, and eligibility to the various elements of the public health system, and to the various schemes, is complex and difficult to navigate. This theme of how access to mental health services is hindered by access, affordability and entitlement emerged in our CRPD consultations. People described it as:

1. Paying for treatment is the only way to get treatment when it is needed.
2. Having to go to another state is mandated to access specialist services, for example psychological services for deaf people.
3. People needing to choose between physical and mental health where there is an upper limit on the amount of care that will be paid for by private insurers.
4. Waiting lists for specialist services mean treatment is not accessible when needed.[24]

### Advance Healthcare Directives

The fact that Advance Healthcare Directives (AHD) are not binding for psychosocial disabilities, whereas they are binding in relation to physical health, was raised in our consultations.

[24] Maresa Fagan (2020) *More than 2,000 children waiting to access mental health services*. Cork. The Irish Examiner

AHD provide a way for people to articulate their will and preferences for a later date when their views may become unclear or unknown. However, under the Assisted Decision Making (Capacity) Act 2015 people who are detained in hospital for mental health treatment are specifically excluded from these legally binding directives. They have no legal right to have their advance wishes respected, even though they had capacity to make decisions about their mental health care and treatment at the time of making their directive.

There is no other group of individuals who are specifically excluded from this legal right, a shortfall which is clearly contrary to international human rights standards, including the CRPD. To make a blanket denial of a person's preferences and concerns when such a directives become most important, is simply unjust. It is essential that advance directives apply equally to people with psychosocial disabilities, as to others, to ensure respect for treatment preferences. They should apply equally to people who are voluntarily admitted, those who are involuntarily detained, and individuals engaged with forensic mental health services.

**Trauma Oriented / Culturally Sensitive Services**

Participants felt there was a general lack of trauma-oriented service delivery, particularly in non-mental health-focused settings. This had the consequence of triggering traumatic responses to run-of-the mill healthcare procedures, which some participants felt limited their comfort in and ability to access healthcare.

Barriers were also reported in relation to form filling and administration when accessing services. For example, the reliance on paper-based appointment letters and lack of online and electronic appointment systems, meant that vital appointments were missed due to late postal delivery. Also, lack of adequate provision for literacy issues was raised in relation to applying for and accessing services.

This was particularly emphasised as a barrier for members of the Roma and Travelling Communities. On a related point, it was noted that no ethnic identifiers are recorded within the context of the healthcare journey. Participants highlighted a feeling that culturally sensitive treatment could not be forthcoming until this issue was addressed at a systemic level.

**Multi-disciplinary Approach**

Participants relayed a range of experiences that suggest a silo approach tends to be taken by some service providers, whereby alternative or complementary therapies and interventions are not signposted for the service user. One participant highlighted that after having attended a psychiatrist for over 10 years, they had only recently been made aware that talk therapy was available to them within the centre in question, and that this may provide a beneficial addition to their treatment programme.

**Information & Sources of Service Provision**

Fragmentation within the healthcare system as it relates to people with psychosocial disabilities poses a significant barrier to accessing effective treatment. Many participants felt they did not know where to begin seeking out help. It was felt that this was exacerbated

by the State's reliance on the non-profit sector to provide specialist services to people living with disabilities.

It was also felt that this approach to healthcare provision fostered stigma and othering given that those seeking services were being referred away from mainstream, State-provided care. Some participants highlighted circumstances where referral to a non-profit service meant they were removed from the public waiting list. This caused difficulty when these individuals needed to transfer back to the public system, when non-profit led services were discontinued due to budget cuts.

Lack of government accountability was also raised within the context of this form of outsourced care, as responsibility for service delivery rests solely with those organisations providing care. Also, the precariousness of funding for the non-profit sector was a source of anxiety for many, as it was felt this impacted heavily on the ability to feel assured services would continue to be provided into the future.

One participant noted that, upon ratifying the CRPD, the State took on an obligation to ensure equal treatment for people with disabilities and this form of outsourced care provision may constitute a breach of that obligation.

**Continuity of Care**

There is a significant problem with lack of continuity of care within treatment services for psychosocial disabilities. Participants of MHR's CRPD consultations attending psychiatric care, reported seeing a different clinician from one appointment to the next. This causes a range of problems, including,

1. Inability to form a therapeutic relationship and foster trust.
2. Re-traumatisation caused by the person having to re-tell their story.
3. Lack of relapse prevention services in the public system.
4. Fragmented information and outcomes.
5. Each episode is dealt with in isolation rather than in an integrated way.
6. Lack of patient focus.

This feedback echoes the findings of Mental Health Reform's *My Voice Matters (2019)* study;[25] a national consultation with people using mental health services in Ireland and their families, friends, and carers. This was the first large-scale (n=1,118), national survey in recent years to provide in depth and up-to date feedback on the direct experiences of people who access community and inpatient mental health services.[26] According to this study, experiences of mental health service users were, at best mixed, with significant efforts noted as being needed to achieve a modern, recovery-orientated, and human rights focused mental health service. Findings included:

1. 19.5% of respondents reported that they did not feel like they were treated with dignity and respect by Community Mental Health Services

[25]Mental Health Reform, (2019). *My Voice Matters* https://www.mentalhealthreform.ie/my-voice-matters/
[26] Ibid.

2. 46% of participants were most dissatisfied with the therapeutic supports when in inpatient mental health services.
3. 1 in 6 reported having had a change of psychiatrist 'more than four times' in the last two years.
4. Of the participants who reported having gone to an Emergency Department to seek support for their mental health difficulty, 49.3% did not feel they got the support they needed**.**
5. 60.3% of participants reported a high focus on medication as part of their treatment and care.
6. 66.2% of respondents reported they did not have a written recovery / care plan developed with their mental health team.
7. Of those who complained, 52.1% reported that 'nothing had been done' about their complaint.
8. 49.0% reported high levels of satisfaction with the mental health care received from a GP.

**Geographic Barriers and Inequities**

Participants in MHR's CRPD consultations reported being negatively impacted by the location of specialist services, citing inaccessibility caused by a concentration of services in Dublin. This poses a range of barriers to access including,

1. Practical logistical barriers, such as transportation.
2. Financial barriers, particularly for those on fixed incomes.
3. Anxiety caused by having to move outward from familiar surroundings.

Geographic variations in availability and access to mental health care and resources also impact on people's daily lives, their mental health status, and outcomes. Historically the approach to budget allocation in the Irish public health service has not been based on the level and prevalence of local need, but instead on local budgetary allocation. This has resulted in severe inequities of access and outcomes – the so-called "postcode lottery" – resulting purely from budget allocation and not on evidenced need.

The ESRI report from July 2019[27] shows clear inequalities in supply of all health and social care services, particularly in the wider Dublin region and eastern seaboard area. That report argues that population health care need must dictate resource planning and allocation, otherwise inequalities in health status and outcomes will persist.

The new HSE Regional Integrated Care Areas, announced in July 2019, will play a significant role in facilitating the planning for and delivery of integrated care across acute and community settings in six regions. Despite Covid-19 demands, this development must be supported to improve service user referral, progression, and experience of mental health services throughout their healthcare journey.

[27]Smith, S., Walsh, B., Wren M A., Barron, S., Morgenroth, E., Eighan, J., and Lyon, S. (2019). *Geographic Profile of Healthcare Needs and Non-Acute Healthcare Supply in Ireland.* Dublin. ESRI. Available at: https://doi.org/10.26504/rs90 [Accessed 10th February 2020]. Data on ten public health services were studied, using 2014 data: GPs, Community Nurses, Public Occupational Therapists, Speech & Language Therapists, Podiatrists, Counsellors & Psychologists, Social Workers, Public Home Care Hours and both and private physiotherapists and nursing home beds.

**Technical and Logistical Barriers**
MHR CRPD consultation participants also cited logistical and technical barriers as a key cause for concern in their ability to access appropriate healthcare services. This included,

1. Deaf people being required to request and self-advocate for the provision of Irish Sign Language interpretation services in service delivery settings. Participants falling into this category noted specific examples of having such requests dismissed as unnecessary with the suggestion that written notes could be used instead. This was felt to be particularly discriminatory.
2. Lack of access to technical equipment and services, particularly during the Covid19 pandemic, including,
    a. Not having phone credit for telephone and internet meetings, and
    b. Not having the technology to engage in remote ways of accessing services.
3. Financial barriers exist in terms of paying for transport, subsistence, and other such outlays when appointments are taking place far outside the person's local community.

**MHR Recommendations**
Sections 215, 262 – 266, and 329 – 339

*1.* Although AHD are discussed in section 215 of the State's Draft Report, it does not highlight the differential treatment of people living with psychosocial disabilities with respect to AHD. This must be addressed and parity of esteem given to people living with psychosocial disabilities in having their AHD recognised, as is the case with AHD relating to physical health. The recognition of such directives should also apply to people who are involuntarily detained under the *Mental Health Acts 2001 – 2018.*

2. While Irish Sign Language (ISL) is recognised as a language in Irish law and the right to ISL interpretation exists, anecdotal evidence suggests that accessing such services is not always possible for those experiencing psychosocial disabilities. It should be noted that Mental Health Service for the Deaf Community have only recently re-established, and are not fully operational and unable to meet the significant needs. Sections 262 – 266 of the State's Draft Report should reflect that progression towards a universally accessible system of ISL interpretation,, has not yet been achieved despite significant progress in recent years.

3. While sections 329 – 330 focus on improving outcomes, the significant health inequalities resulting from inequitable access to health and social care services (due to the oversubscribed, underfunded services, lack of investment and long waiting lists in the public health system) are not acknowledged in the State's Draft Report. Some reference to this ongoing situation must be made to ensure the State acknowledges and commits to improving the current issues faced by many in accessing healthcare at the point of need. This could be done*, inter alia*, by reference to the De Buitléir Report,[28] which sets out an explicit road map to remove

[28] De Butleir et al (2019) *Report of the Independent Review Group established to examine private activity in public hospitals*. Dublin. Department of Health

private health care from publicly funded hospitals as it is central to the effective delivery of the Sláintecare reforms.

4. Lack of reference in the State's Draft Report to *Reducing Harm Supporting Recovery 2017 – 2025* the national drug and alcohol strategy is concerning, as is the lack of any mention of recovery in the document. Given the acknowledged need for Ireland to move to a recovery oriented model of mental health service delivery, it is important that this aspect of care and treatment is acknowledged and provided for.

5. Trauma oriented service provision and cultural competency guidelines must be adopted across State services. This will ensure equal access and non-discrimination practice becomes embedded within the architecture of the State's healthcare services.

## Freedom from Torture or Cruel, Inhuman or Degrading Treatment or Punishment

*Article 15*

Sections 186 and 187 of the State Report concern the Criminal Justice (*United Nations Convention against Torture*) Act 2000. Section 187 notes the visit in October 2019 to Irish prisons by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment. It is concerning that the State's Report does not refer to the issues raised in that report. The report documents poor conditions and inadequate treatment of prisoners experiencing acute mental health difficulties in the high support units in Cloverhill, Cork and Mountjoy, where it found resources were insufficient.[29]
Prison settings are inappropriate for prisoners experiencing significant psychosocial disabilities.[30] It is concerning that sufficient capacity does not exist within the prisons and mental health services systems, to accommodate all prisoners in need of specialist mental health care and treatment at the point of need. This has reached such a point of crisis that prison staff and members of an Gardaí Síochána have displayed significant concern for the welfare of prisoners, who are denied access to specialist mental health care and treatment. [31] This is wholly unacceptable.

In 2019, the average waiting time for admission to the Central Mental Hospital was 120.86 days, with the range between seven and 504 days. Every month in the period 2019 to 2020 there was between 20 to 32 prisoners on a waiting list for the Central Mental Hospital.[32] Due to insufficient capacity, such people are forced to remain within the general prison setting. Both the poor ratio of psychologists to prisoners (which remains problematic and not at the recommended rate of 1:150 [33]) and the long waiting times experienced by prisoners waiting for interventions from the psychology services, are of concern.[34]

It is of paramount importance that a range of talking therapies are developed and made available across the prison system. While there is limited data and research available in this area, it is reasonable to ascertain that the need for mental health services and supports across prisons in Ireland may increase due to the COVID-19 pandemic. Considering the crisis, people in prison have experienced many challenges. These challenges include extended lengths of time for individuals on remand due to suspension or delays with court sittings, suspension of prison visits and lack of human contact, and reduced access to occupational, recreational and even mental health supports.

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[29] https://rm.coe.int/0900001680a078cf
[30] https://www.iprt.ie/iprt-in-the-news/unacceptable-conditions-for-mentally-ill-prisoners/; https://www.irishtimes.com/news/ireland/irish-news/prison-is-wholly-inappropriate-for-mentally-ill-people-say-chaplains-1.3956552; https://www.irishtimes.com/news/health/mentally-ill-prisoners-waiting-up-two-years-for-central-mental-hospital-transfer-1.4011612?mode=sample&auth-failed=1&pw-origin=https%3A%2F%2Fwww.irishtimes.com%2Fnews%2Fhealth%2Fmentally-ill-prisoners-waiting-up-two-years-for-central-mental-hospital-transfer-1.4011612
[31] https://www.irishtimes.com/news/crime-and-law/garda%C3%AD-in-three-hour-standoff-with-staff-at-gates-of-central-mental-hospital-1.4517141?mode=sample&auth-failed=1&pw-origin=https%3A%2F%2Fwww.irishtimes.com%2Fnews%2Fcrime-and-law%2Fgarda%25C3%25AD-in-three-hour-standoff-with-staff-at-gates-of-central-mental-hospital-1.4517141
[32] Irish Penal Reform Trust, (2020). *Progress in the Penal System: Assessing progress during a pandemic*, https://www.iprt.ie/site/assets/files/6845/progress_in_the_penal_system_2020.pdf.
[33] 313 Porporino, F. (2015), *"New Connections" Embedding Psychology Services and Practice in the Irish Prison Service*, p. 25, http://www.irishprisons.ie/wp-content/uploads/documents_pdf/porporino_report.pdf.
[34] https://pips.iprt.ie/site/assets/files/Progress-in-the-Penal-System-2019.pdf

The lack of psychological and other talking therapy supports manifests in over-reliance on medication to treat mental health difficulties among the prisoner population to date. In the latest reports of the European Committee for the Prevention of Torture and Degrading Treatment (CPT), serious concerns were highlighted over the prescription of medication in Irish prisons and the lack of adequate supervision or follow-up assessments. The CPT found that there was an over-reliance on pharmacological treatment and an underdevelopment of non-pharmacological interventions. The CPT highlighted that, contrary to WHO standards, prisoners who had self-harmed or attempted suicide were not considered to require psychiatric assessment, and were rarely provided with any psychological support.

Poor capacity is not the only issue affecting mental health treatment provision in Irish prisons. Poor collaboration and siloed working practices between the Department of Justice and HSE Community Mental Health Teams, also impact negatively on prisoners. This is particularly apparent on discharge when their referral pathway to community mental health services is inadequate, and care falls between the cracks of poor protocols and follow up.

**MHR Recommendations**
*Sections 179 – 185*

1. Community-based mental health services should be resourced to prevent individuals coming into contact with the criminal justice system wherever possible.

2. Resource deficiencies in the care and treatment of prisoners living with psychosocial disabilities must be addressed in the State's Report.

## Government Supports
*Article 4*

### Financial Supports
As outlined the section on Work and Employment within this submission, Mental Health Reform continues to highlight the fundamental need for a flexible benefits system. This will facilitate opportunities for people living with psychosocial disabilities, to enter and re-enter the work force when they need and wish to without fear of losing income support.

Mental health difficulties can be episodic in nature and it can take years before some people settle into managing their condition and maintaining stability. Anxiety is itself a significant psychosocial disabilities, and can exacerbate underlying mental health vulnerabilities. The threat of losing access to State-based income and service supports can cause anxiety and deter people living with psychosocial disabilities from seeking work.

In the Department of Social Protection's review of Disability Allowance, fear of losing social welfare benefits and fear of losing the medical card were most highly reported as barriers to achieving individual employment goals. The recent *Make Work Pay for People with Disabilities Report (2017),*[35] documents that the potential loss of the Medical Card is the single most important disincentive to taking up employment. This Report further identifies that Ireland (along with the US) appears to be unusual amongst OECD countries, in that people must forfeit entitlements to free medical care upon taking up work, which occurs at relatively low levels of income. The OECD's 2010 Report entitled *Sickness, Disability and Work: Breaking the Barriers* [36] argues that health and other entitlements related to a person's disability should not be affected by benefit or labour market status.

This feedback was echoed in the contributions of MHR CRPD Consultation participants, who highlighted that one size does not fit all when it comes to financial supports for people living with psychosocial disabilities. Means test thresholds were seen as blunt instruments, with those above them often eliminated entirely from social protection, university fees grants, medical cards, and other such supports. This was felt to result in poverty traps that make it difficult, if not impossible, for many to move into part-time or full-time employment or education -despite having a clear and demonstrable wish to do so.

The documentary and evidentiary requirements of applications for disability related financial supports were also felt to be highly demanding. The process of applying for welfare and benefits was therefore felt to lack trauma orientation or cultural sensitivities, Application often presents significant barriers to those experiencing literacy difficulties, those for whom English is their second language, and those living with psychosocial disabilities, which make personal administration and organisation challenging.

Importantly, *Sharing the Vision*, Ireland's new national mental health policy, recommends that

[35] https://www.gov.ie/en/publication/0fb542-make-work-pay-report/
[36] https://www.oecd.org/publications/sickness-disability-and-work-breaking-the-barriers-9789264088856-en.htm

> in line with the strategic priorities of the Comprehensive Employment Strategy for People with Disabilities, the way people come on/off income supports should be streamlined to maximise entry or re-entry to the workforce with confidence and security. This should happen without threat of loss of benefit and with immediate restoration of benefits where they have an episodic condition or must leave a job because of their mental health difficulty.[37]

The current Partial Capacity Benefit scheme in Ireland often discourages people living with psychosocial disabilities from taking up work. This is because they must undergo a review of work capacity that can result in removal of their existing disability benefit and secondary benefits (including their medical card), in full or in part. Mental Health Reform considers that the risk of losing benefits to take up employment should be removed for people living with psychosocial disabilities to support their recovery. This is in line with principles of existing mental health policy and encourages participation in the labour market.

**MHR Recommendation**
Sections 138 and 38

1. Section 138 of the State's Draft Report sets out the income support measures introduced by government to counteract the income related effects of the Covid19 pandemic. While the upper limit of the Pandemic Unemployment Payment is set out as €350 per week, no reference is made in this section or in any other, to the challenges faced by those who rely on payments such as Disability Allowance and Partial Capacity Benefit, which are paid at significantly lower rates than this. The levels at which these payments are made do not provide for anything but basic survival, and in some cases not even that. These rates do not reflect the obligation of the State to ensure all people living with disabilities can live with dignity. MHR recommends that this aspect of income provision for people living with disabilities be reflected in the State's final report.

2. Section 38 of the State's Draft Report lists rights to various supports such as social welfare and medical cards as part of the right to equality before the law. However, the risk of losing benefits (incl. secondary benefits) should be removed for people undergoing assessment for Partial Capacity Benefit (PCB), for the purposes of increasing the numbers of people with psychosocial disabilities availing of PCB and ultimately engaging in employment. This may include legislating for a change to the Social Welfare Act, 2017 to remove any risk of loss of benefits for people seeking transition from Invalidity Pension (IP) or Illness Benefit (IB) to Partial Capacity Benefit.

3. The Department of Employment Affairs and Social Protection should also promote public awareness that individuals will not be at risk of losing existing benefits should they undergo assessment of PCB.

[37] *Sharing the Vision*, (2020). (pp. 69, recommendation 73)

## Statistics and data collection

*Article 31*

MHR sees the inadequate, and at times absence, of data and its management and analysis as a business-critical weakness across Government Departments. In relation to mental health this data is patchy and at times absent totally. This has a negative effect on the ability to engage in accurate and real time service planning to meet population health needs.

### MHR Recommendations

*Sections 437 - 450*

1. While a range of data collection sources and initiatives are set out between sections 437 and 450 of the State's Draft Report, there is an overall lack of reliable, complete, and standardized data to monitor mental health services and delivery. A mental health monitoring index, or dashboard, containing all mental health related actions and measures in Government policies and strategies should be developed. This monitoring index should have indicators that measure progress, in real time, across the various departments and specify the accountable unit/department for each. The maintenance of this index should be the remit of an independent research institute or body.

2. This mental health-monitoring index should link outcomes to expenditure thereby greatly improving effectiveness and transparency.

3. Mental health service users' journeys through the mental health services, between community and acute settings, should be tracked in a uniform way in each Community Healthcare Organisation. This would enable comparative data analysis and allow providers to track service users' outcomes against expenditure. Tracking in this way will support transparent and effective use of resources and achieve better service user outcomes.

## Conclusion

The progress made in relation to policy development and some changes to legislation does suggest positive commitment on the part of Government in upholding and vindicating the rights of persons with disabilities. However, the fact that the reality of service users' experiences varies from the progress made at the strategic level, must be reflected in the State's Initial Report on the CRPD.

This incongruence is broad ranging and includes indicators such as,

1. Lack of financial commitment to effective mental health service delivery as indicated by stretched resources, long waiting lists, geographically concentrated service delivery among others.

2. Delays in bringing about human rights compliant law reform, specifically the 10-year process that is still underway to review Ireland's Mental Health Act, 2001, failure to commence key legislation (in whole or in part) such as the Assisted Decision-Making Act 2015 and the Mental Health (Amendment) Act, 2018.

3. Failure to plan for and deliver healthcare services in line with population-level need.

4. Lack of capacity to provide appropriate treatment and care to people within the prison system who are living with psychosocial disabilities, and failure to gather and use uniform, accessible and reliable data on healthcare needs and uses.

5. Continued use of benefits and supports qualifications matrices that disincentiveise labour market and educational access for many living with disabilities who cannot afford to relinquish key supports such as medical cards or income support.

Including authentic feedback on the challenges faced by the State in bringing about tangible, ground-level change to vindicate the rights of people living with disabilities would be a very positive step on the part of the State. It would help to ensure that the existing barriers to the vindication of rights under the CRPD are identified, acknowledged, and owned by the State, so that a roadmap for future progression of the State's obligations under the CRPD can be set out. To do otherwise is to deny the lived experience of thousands of Irish citizens and residents and the difficulties that they experience in their daily lives.

Mental Health Reform

Promoting Improved Mental Health Services


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