PAVEE POINT
TRAVELLER AND ROMA CENTRE

Submission on 'Review of the Mental Health Act 2001'
March 2021

Pavee Point Traveller and Roma Centre

Pavee Point Traveller and Roma Centre ('Pavee Point') have been working to challenge racism and promote Traveller and Roma inclusion in Ireland since 1985. The organisation works from a community development perspective and promotes the realisation of human rights and equality for Travellers and Roma in Ireland. The organisation is comprised of Travellers, Roma and members of the general population, who work together in partnership to address the needs of Travellers and Roma as minority ethnic groups experiencing exclusion, marginalisation and racism. Working for social justice, solidarity and human rights, the central aim of Pavee Point is to contribute to improvement in the quality of life and living circumstances of Irish Travellers and Roma.

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Introduction

Pavee Point Traveller and Roma Centre welcomes the opportunity to make a submission on the 'Review of the Mental Health Act 2001' and through our recommendations advocate for culturally safe mental health service provision for Travellers and Roma in Ireland. New legislation incorporated within the Mental Health Act 2001 setting out how service users should be treated, and what the responsibilities of mental health teams are must take into consideration the diversity of service users. This requires that culturally safe responses are developed for engaging with the Traveller and Roma Community in partnership with Traveller and Roma organisations and Traveller Primary Health Care Projects.

Travellers are an Irish minority ethnic group whose ethnicity was formally acknowledged by the Irish State in March of 2017. According to the national census (CSO, 2016) there are a little over 30,000 Irish Travellers in Ireland, representing less than 1% of the nation's population. Figures according to the All Ireland Traveller Health Study (AITHS, 2010)[1] however put this estimate at closer to 36,000. An estimated 5,000[2] Roma live in Ireland, many of whom live in poverty due to lack of access to work and restrictive social welfare measures. As minority ethnic groups, Travellers and Roma experience persistent racism and discrimination on the basis of ethnicity, gender and other grounds. As a result, Travellers and Roma are among the most marginalised and excluded individuals and groups in Ireland.

Pavee Point works at national, regional and local level. At national level we resource and coordinate national networks including the National Traveller Health Network and at regional level we coordinate the Traveller Health Unit Mental Health Sub Group (THU MHSG) in the Eastern Region. The key objective of the Eastern Region THU Mental Health Sub Group is to:

1. improve Travellers' access to and uptake of mainstream mental health services;
2. improve the delivery of mental health services to Travellers;
3. identify and explore barriers to mental health services.

The Eastern Region THU MHSG covers CHOs 6, 7 and 9 (Wicklow, Kildare & Dublin). The work takes both a mainstreaming and targeting approach and the work plan is implemented through regional THU initiatives; 9 local Primary Health Care for Travellers Projects (PHCPs)[3] and a specialist health initiative. The 9 PHCPs employ Traveller Community Health Care Workers on a part-time basis and they undertake health advocacy in a range of health arenas including mental health.

Travellers and Roma remain largely invisible in mental health legislation, policies and strategies, despite the disproportionate levels of poor mental health experienced by them,

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[1] [1] All Ireland Traveller Health Study (AITHS) Team (2010) All Ireland Traveller Health Study, Our Geels.

[2] Pavee Point Traveller and Roma Centre & Department of Justice and Equality (2018) Roma in Ireland – A National Needs Assessment.

[3] Pavee Point Traveller and Roma Centre; St Margarets PHC; TravAct, Southside Travellers Action Group; Balbriggan Travellers Project; Tallaght Travellers; Clondalkin Travellers Development Group; Kildare Traveller Action Group; Wicklow Travellers Group and Blanchardstown Traveller Development Group.

including the highest rate of suicide in the country. The acute and chronic mental health needs of Travellers and Roma are not appropriately addressed by service providers due to lack of specific guidance and actions. Targeted measures are urgently required to respond to this reality.

Findings from the *All Ireland Traveller Health Study (AITHS)*2 are well-established both nationally and internationally as they quantify the extent of the Traveller mental health crisis, identifying Travellers as a 'high-risk' group in relation to suicide and poor mental health (including frequent mental distress). The Roma in Ireland; A National Needs Assessment[4] also identifies poor mental health amongst the Roma Community in Ireland, experiencing a higher burden of poor mental health and suicide, when compared to the general population:

Mental Health and Suicide – Traveller and Roma Community

- 62.7% of Traveller women and 59.4% of Traveller men reported their mental health was not good for one or more days in the last 30 days, compared to 19.9% of the non-Travellers[5]
- 56% of Travellers said that poor physical and mental health restricted their normal daily activities, compared to 24% of the non-Travellers
- 51.3% of Roma respondents reported their mental health was not good for more than 14 days of the previous month[6]
- 34% of Roma respondents said they did not experience one day in the previous month when their mental health was not poor
- 33.3% of Roma respondents said their daily activities were interrupted by mental health difficulties in all of the preceding 30 days.
- Overall Traveller rate suicide is 6 times higher than general population
- Suicide is 7 times higher for Traveller men and most common in young Traveller men aged 15-25
- Suicide accounts for approx. 11% of all Traveller deaths
- Suicide is 5 times higher for Traveller women

Notwithstanding a small number of agencies and services[7], mental health services lack comprehensive data on Traveller and Roma service users, as most service providers have not implemented ethnic equality monitoring, despite this being national policy. Generally, where ethnic data collection exists it is not used consistently or constructively, primarily resulting in very poor statistical information. In addition to the lack of systematic and consistent data, ethnic identification has been ascribed to minority ethnic groups including Travellers and Roma, rather than the application of a universal question on ethnicity through voluntary self-identification. Information is not disaggregated, analysed or provided to relevant stakeholders within an appropriate timeframe. Such practices reflect a significant breach and disregard for human rights standards[8] data protection principles. In addition, mental health services need to engage in ethnic data collection as part of their

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[4] Pavee Point Traveller and Roma Centre & Department of Justice and Equality (2018) Roma in Ireland – A National Needs Assessment.

[5] All Ireland Traveller Health Study (AITHS) Team (2010) All Ireland Traveller Health Study, Our Geels.

[6] Pavee Point Traveller and Roma Centre & Department of Justice and Equality (2018) Roma in Ireland – A National Needs Assessment.

[7] For example, CAMHS and the National Psychiatric Inpatient Reporting System (NPIRS).

[8] As per the United Nations, Human Rights Approach to Data, the key human rights principles which are underpin data collection include; (1) Voluntary self- identification; (2) transparency-A universal question; everyone is asked the question, not just minority ethnic groups; (3) data are only used for the purpose for which it is collected; (4) data disaggregation and collection by population group; (5) data are available to stakeholders in a timely manner; and (6) participation- active community participation and consultation with key stakeholder groups throughout the process.

statutory obligation to do so in line with Section 42 of the Irish Human Rights and Equality Commission Act (2014).

This results in significant gaps in knowledge on the access, participation and outcomes to mental health and suicide prevention services for Travellers. Key data on Travellers and mental health is derived primarily from the AITHS. While the AITHS confirmed that mental health services were available to Travellers, services were perceived as inadequate and substandard, resulting in Travellers' low engagement. Findings from AITHS indicate various institutional, cultural, social and structural barriers that restrict Travellers from accessing and engaging with mental health services. These include:

a) Discrimination and racism (both at individual and institutional levels)
b) Lack of trust with healthcare providers and inappropriate service provision
c) Lack of culturally appropriate mental health materials and service signposting
d) Lack of engagement from service providers with Travellers and Traveller organisations

Similar barriers to accessing services are identified within the Roma Needs Assessment along with gaps and knowledge and information about services. For example, it was reported that there was a lack of access to community-based services such as Child and Adolescent Mental Health Services (CAHMS) and counselling because of language barriers.

There is a strong recognition that Irish mental health services are not equitable and/or operating in a culturally safe manner, thus making it more difficult for Travellers and Roma to access the services they require. Racism and discrimination underpins Travellers' and Roma community members lack of engagement, trust and access to mainstream mental health services and supports.

In the National Roma Needs Assessment[9]:

- 70.5% of respondents felt discriminated against in health services

This was also clearly highlighted in the AITHS[10], which reported that:

- 64.4% of Travellers experienced discrimination in accessing health services
- 53% of Travellers "worried about experiencing unfair treatment" from health providers
- 43% of Travellers did not have complete trust in health service providers
- 12% of Travellers felt they received worse treatment than others from the mental health services
- Over 40% of Travellers had a concern that they were not always treated with respect and dignity
- Over 50% of Travellers had concerns of the quality of care they received when they engaged with services

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[9] Pavee Point Traveller and Roma Centre & Department of Justice and Equality (2018) Roma in Ireland – A National Needs Assessment.

[10] [10] All Ireland Traveller Health Study (AITHS) Team (2010) All Ireland Traveller Health Study, Our Geels.

- This was confirmed by 66.7% of service providers who agreed that discrimination against Travellers occurs sometimes in their use of health services.

Health service providers also admitted that anti-Traveller discrimination and racism were evident within the services, resulting in substandard treatment of Traveller service users.

"It does exist [...] there is that sentiment that Travellers are less deserving hence give them substandard services." Health Service Provider, AITHS

"Racism is one of the factors but won't be said officially as they (institution) will be in trouble." Health Service Provider, AITHS

This submission outlines key gaps in the current Act under headings provided by the Department of Health and responds to recommendations set out in the Report of the Expert Group on the Review of the Mental Health Act 2001, to provide key recommendations to improve the provision of mental health services for Travellers and Roma in Ireland.

1. Inspection, regulation and registration of mental health services

Pavee Point agrees with the changes suggested by the Expert Group Report in relation to inspection and regulation of mental health services. We add the need for ethnic equality monitoring, and the roll out of a standardised ethnic identifier (aligned with the national census) across all routine data administrative systems, to monitor access, participation and outcomes for Travellers, Roma and other minority ethnic groups.

The UK NHS 2020 Mental Health Act Statistics, Annual Figures[11] finds that black people are 4 times more likely to be detained under the Mental Health Act and people from Asian and minority ethnic communities are also disproportionately subject to detention. Findings of these systemic inequities have sparked major reforms[12] of the Mental Health Act in the UK which aim to also address racial disparities in mental health services.

Involuntary admissions to Irish mental health services require ethnic data and strong attention to the human rights aspects of admissions as in the UK. In the absence of an ethnic identifier or ethnic equality monitoring we do not have data on how many Travellers, Roma or indeed members of other minority ethnic groups, are admitted involuntarily into Irish mental health services each year. We are aware through anecdotal evidence that there is an over-representation of Travellers within the forensic mental health services.

Data informs good governance and equality of outcomes. Ethnicity and gender disaggregated data is critical as part of the process of "identifying potential issues before they become problems" and focusing on the principles as suggested in the report of:

- improvement and specifically to generate data and intelligence that enable Inspectors more quickly to calibrate the progress of reform in their sectors and make appropriate adjustments

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[11] https://files.digital.nhs.uk/DB/3F97BA/ment-heal-act-stat-eng-2019-20-back-data-qual-rep.pdf

[12] https://www.gov.uk/government/news/landmark-reform-of-mental-health-laws

- mental health outcomes
- the service user perspective

The collection and use of ethnic data (ethnic equality monitoring) within a human rights framework is necessary to combat racism, eliminate discrimination, promote equality of opportunity and protect human rights. Ethnic equality monitoring is government policy and a number of public bodies routinely collect and use ethnic data to inform policy and practice. It is also recommended within our national policy framework for mental health services, *Sharing the Vision (2020 – 2030).* Failure to collect such data potentially puts more lives at risk for Travellers and other minority ethnic groups which already have higher mortality and morbidity rates, particularly as it relates to mental health. Ireland needs to have this data for reporting under to the EU National Traveller and Roma Inclusion Strategy and potentially other UN monitoring bodies.

"There is a need to prioritise the implementation of recommendations and actions that will directly impact on the lives of people with mental health difficulties as soon as possible"[13].

Further, Section 42 of the Irish Human Rights and Equality Commission Act (2014), mandates all public bodies to have regard for the need to eliminate discrimination, promote equality and ensure human rights are respected. Without reliable information on ethnicity it is not possible for public bodies to demonstrate that they have met statutory obligations. Access to disaggregated data on the situation of service users is essential to implementing this positive duty requirement and demonstrating that the general duties to eliminate discrimination and the promotion of equality and opportunity are being met.

2. Inclusion of guiding principles

Travellers are one of the most marginalised communities in Ireland and experience severe mental health inequalities with suicide rates 6 times higher than that of the general population. Findings from the All Ireland Traveller Health Study (2010) show that while mainstream mental services are available to Travellers; racism and discrimination from mental health service providers prevent Travellers from engaging with such vital services[14]. As noted, similar findings emerged from the Roma Needs Assessment. The International Convention on the Elimination of All Forms of Racial Discrimination (CERD) also sets out that all human beings are entitled to equal protection of the law against any discrimination and against any incitement to discrimination. Compliance through reform of the Mental Health Act 2001 is required as part of Ireland's obligation to meet the stipulations of CERD.

As previously noted Section 42 of the Irish Human Rights and Equality Commission Act 2014 sets out the statutory obligation of public bodies to take steps to prevent discrimination and promote human rights and protect equality of opportunity to those to whom they provide services. Travellers and Roma, along with other minority ethnic groups in Ireland, must have access to mental health services that are free of discrimination and that proactively strive to be anti-racist, inclusive and culturally appropriate in their service provision. Public sector duty legislation is applicable to all public bodies in Ireland which includes the HSE and means such bodies must put policies and practices in place in relation to human rights and

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[13] (Department of Health (2020) Sharing the Vision; 73)

equality issues within their workplace. Public bodies must incorporate this obligation as part of their overall strategic planning cycle and provide evidence of their actions in line with this.

In respect of these obligations we suggest two additional guiding principles should be included within the guiding principles of the Mental Health Act. These are (1) person centred; (2) and anti-racist culturally competent care. We believe embedding these two principles into practices and services are important in working towards closing the mental health gap experienced by the Traveller Community and members of other minority ethnic groups.

3. Mental health tribunals

As noted under section one, ethnically disaggregated data must be collected in order to identify systemic or indirect gaps within services in relation to minority ethnic groups. Mental health tribunals are important independent instruments of justice that must ensure parity across all equality dimensions and to do so must have access to data and information based on ethnicity to identify and to rectify any such systemic gaps.

In addition, experiences of the mental health tribunals can vary. Members of the Traveller and Roma Community frequently have inequitable experiences in relation to practices around informed consent due to inaccessible language, understanding processes and steps in their mental health care. It is important that tribunal panel members receive mandatory anti-racism and discrimination training provided by Pavee Point and ensure that Travellers, Roma and members of other minority ethnic groups are adequately prepared for and supported through the tribunal process.

The Expert Group on the Review of the Mental Health Act 2001 notes aspects of tribunal operations which require improvement – we agree with all points, particularly the need to rename to Mental Health Review Boards. We also suggest that when reviewing individual care plans the tribunal panel members take care to establish that a culturally appropriate approach that takes account of the service users wishes is being implemented and supported across by members of multi-disciplinary team. The process must take into account specific cultural needs of relevance to marginalised and minority ethnic groups, such as Travellers and Roma. We strongly recommend that mandatory equality impact assessment and equality proofing take place. This would establish the potential impact (positive and negative) of the process of tribunals on Travellers and Roma with regard to achieving equality of outcome.

4. Information and individual care/recovery planning

The AITHS (2010) and Roma Needs Assessment (2018) findings show low engagement rates by Travellers and Roma with mental health services and high rates of mental health inequalities. A holistic approach that is grounded in a human rights approach is a key step towards addressing this and ensuring equality of access, participation and outcomes for Travellers, Roma and other minority ethnic groups in Ireland. *Sharing the Vision* emphasises a partnership approach to care and ensuring that service users and their families are central to, and co-produce, their individualised recovery care plan. Development of individualised care plans are also important to ensure continuity and integration of care between primary care and mental health specialists as part of the approach embedded within Community Health Networks – also recommended in *Sharing the Vision*.

Safeguarding the legal right to an individual care plan is paramount, not just as part of addressing actions set out in Sharing the Vision, but also as part of ensuring Traveller and Roma human rights to care and treatment that is appropriate, non-discriminatory, effective and seamless between specialist and community services is protected.

5. Children

As the Expert Group acknowledges, children of any age can be impacted by mental illness or mental health difficulties. Mental health difficulties are a serious concern within the Traveller Community - suicide is 7 times higher for Traveller men than the general population and most common in young Traveller men aged 15-25. It is likely there will be a number of young Travellers engaging with mental health services. The Traveller Community is a young population - 63% of Travellers are under the age of 25 according to the national census (CSO, 2016).

We again stress the need for the collection, analysis and use of disaggregated data on the basis of ethnicity and gender, inclusive of Travellers and Roma, in line with data protection laws and within a human rights framework. Having such data in mental health services would assist with planning and evaluation of mental health services for young Travellers, highlight gaps, increase effectiveness, quality and efficiency of services and inform preventive programmes.

Under recommendations to: change the definition of a child under the Mental Health Act 2001 to that of the Children Act 2001 which defines a child as ‘a person under the age of 18 years’ and allowing children aged 16 to 17 to refuse or consent to admission and treatment it is important to take a culturally sensitive approach to such recommendations. There must be recognition of the reality that some Travellers may be married by age 18 and therefore applying that framework may not be appropriate. Adult services may be a more suitable service than child and adolescent services for some young Travellers who view themselves as contributing financially to the family or are parents themselves. We recommend a culturally safe approach is taken to this definition and this should be included within the guiding principles in the children’s part of the Act.

6. Provision of information on Admission to Approved Centres and Complaints Mechanisms

In relation to both voluntary and involuntary patients Pavee Point agrees that the definition of a voluntary patient must be brought in line with international human rights standards and obligations – and that informed consent must be sought on an ongoing basis. However we add that the AITHS noted that functional literacy is less than 50% among Traveller adults, which has implications for understanding written advice and instructions. Involuntary detention is a difficult experience for many and if supports are not provided that emphasise the service users right to culturally appropriate information, care and dignity and meaningful involvement where possible in their care the experience has the potential to be extremely traumatic.

Culturally appropriate support must be given for Traveller service users who are voluntary or involuntary patients to understand all decisions being made in relation to their care in order to ensure that informed consent is fully given and given on an ongoing basis. It is important that mental health services work in partnership with Traveller organisations and Traveller Primary Health Care Projects in relation to the provision of accessible and culturally appropriate materials as part of this process.