PAVEE POINT
TRAVELLER AND ROMA CENTRE

Submission to the Special Joint Committee on key issues affecting the Traveller Community: Health

October 2019

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 majority 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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Key Recommendations

1. Publish and implement the National Traveller Health Action Plan as a matter of urgency, including the establishment of an institutional mechanism with the HSE and Department of Health to drive its' delivery and implementation. The Plan must be inclusive of clear targets, indicators, outcomes, timeframes and budget lines.
2. Sláintecare recommends access to universal GP care within 5 years. We recommend that Travellers be prioritized and fast-tracked in this process. We further recommend that with immediate effect all Travellers employed in Primary Health Care Projects are entitled to a medical card (similar to Disability/Community Service Programme/CE). This is circa 300 medical cards.
3. The Traveller specific health infrastructure, including Traveller Health Units and Traveller Primary Health Care Projects, should be protected and receive increased resources for their expansion and development in line with the National Traveller and Roma Inclusion Strategy (Action 76). It is important that health reforms do not undermine the work and progress of the THUs given their institutional knowledge and their impact on the ground.
4. Ensure that a clear budget is allocated and protected to address Traveller health inequalities at national level.
5. Ensure that Traveller health inequalities are mainstreamed within the Department of Health and across HSE and into existing and forthcoming policy that impacts on Traveller health.
6. Implementation and rollout of ethnic equality monitoring, including a standardised ethnic identifier across all health administrative systems to monitor access, participation and outcomes of Travellers, and to inform the development of evidenced-based policies and services.

Introduction

Pavee Point Traveller and Roma Centre ('Pavee Point) welcomes the opportunity to make this submission and commend the Committee in giving visibility to the key issues affecting Travellers. The work of Pavee Point in addressing health inequalities has significantly influenced government policy on health towards Travellers since the early 1990s, resulting in the Traveller health structures which have been developed at national, regional and local levels in Ireland. It has also resulted in an evidence based approach to policy making and service provision. Central to our analysis is the Right to Health as a human right; Traveller participation and the use of the Primary Health Care (PHC) model. Our work also involves the use of a mainstreaming approach as well as developing targeted measures as a mechanism to increase Traveller access to mainstream services. This includes ensuring Travellers are mainstreamed in a range of broader health policies[1]. While we acknowledge the support and goodwill of some individuals in the Department of Health and in the HSE level. We cannot rely on individual goodwill alone and believe that a structure mechanism between the two is fundamental in prioritising and driving Traveller policy forward.

This submission sets out the current challenges to addressing Traveller health inequalities and provides clear and strategic recommendations to address these challenges.

National Traveller Health Action Plan

Research unveils stark inequalities for Travellers in relation to access, participation and outcomes in health. The *All Ireland Traveller Health Study* (AITHS) revealed the following results for Travellers in comparison to the general population:

- 134 excess Traveller deaths per year
- Traveller mortality is 3.5 times higher
- Life expectancy for Travellers is on average 13 years less; 15.1 years less for Traveller men and 11.5 years less for Traveller women
- Infant mortality rate is almost 3.7 times higher
- Suicide rate among Traveller men is 6.6 times higher and accounts for over 1 in 10 of Traveller deaths[2]

The AITHS acknowledge the broader structural inequalities and failure to address the social determinants of health[3] in underpinning Traveller health inequalities. This is clearly evidenced in Census 2016, with only 3 per cent of Travellers reaching 65 years; 63 per cent of Travellers are under 25 years;[4] only 13 per cent of Travellers complete secondary education;[5] and less than 1 per cent of Travellers go on to third level education. Furthermore, Traveller overcrowding is 7 times the national rate; 80.2 per cent of Travellers are unemployed in comparison to an overall national figure of 7 per cent; and according to the Department of Housing, 15% of all Travellers are homeless,[6] this is equivalent to 709,632 people in the general population.

The AITHS also found that at all ages and for all causes of death, Travellers experience a higher mortality than the general population, concluding:

> The problem is endemic and complex and will not be solved in the short term without considering the wider contextual issues. The fact that an identifiable disadvantaged group in our society is living with the mortality experience of previous generations 50-70 years ago cannot be ignored. The fact that the gap between Traveller

[1] This includes the National Health Strategy, the National Strategy for Women and Girls, the Women's Health Strategy, the Primary Care Strategy and the Intercultural Health Strategy

[2] Department of Health (2010) *Our Geels All Ireland Traveller Health Study*. These findings have been fully supported by more recent research by the Economic and Social Research Institute, Dorothy Watson, Oona Kenny and Frances McGinnity, *A Social Portrait of Travellers in Ireland*.

[3] This includes poor accommodation conditions, poverty, illiteracy and discrimination. For more information see: World Health Organisation (2007) *A Conceptual Framework for Action on the Social Determinants of Health.* Commission on Social Determinants of Health

[4] Compared with 35 per cent of the general population

[5] Compared with 92 per cent of the general population

[6] The Department of Housing, Planning and Local Government's Annual Count reflects that 15% of Travellers are need in accommodation; with 1,115 Traveller families are 'sharing' accommodation. This number has been rapidly increasing each year, with the most recent count indicating an almost 30% increase of Travellers sharing accommodation since 2014. Sharing is in effect being homeless and it meets the criteria for homelessness as defined by the European descriptive typology (ETHOS) which is also used by the Central Statistics Office, as people living in insecure accommodation.

> mortality and that in the general population has widened in the past 20 years shows that comprehensive approaches to address this situation are required and are indeed vital. [AITHS, 2010:13]

2020 will mark ten years since the publication of the AITHS, with Traveller health inequalities remaining stagnant, and in some instances, due to improvements in the national population, Traveller health disparities have widened. Travellers are effectively dying of the same causes as the general population (cancer, CVD and respiratory issues), however, in far greater numbers. This is comparable to the experiences of other indigenous and minority ethnic groups internationally and is indicative of institutional racism. Various UN treaty-monitoring bodies, European institutions and national equality and human rights bodies have called on the State to address Traveller health inequalities, however, their calls have largely been met with inaction.

In 2018, Pavee Point welcomed the development of detailed action Traveller Health Action Plan (NTHAP), as per Action 73 of NTRIS.[7] We supported the comprehensive regional consultation process took place in with participation of Travellers, Traveller organisations, statutory and voluntary agencies. As reflected in the HSE Summary of Regional Consultations document[8], a clear mandate was identified by all stakeholders, that was:

1. The establishment of an institutional mechanism to work in partnership with the Department of Health, HSE and Traveller organisations to drive implementation and delivery of the NTHAP;
2. There is a named individual with exclusive responsibility for Traveller health within Department of Health and within HSE to prioritise Traveller health needs and ensure Traveller health is mainstreamed within all divisions and policies of the Department of Health; within work of CHOs/regional health areas and Chief Officers and supporting the work of the Planning Advisory Body for Traveller Health (PATH).
3. Development of a SMART[9] NTHAP, underpinned by community development, inclusive of timelines, ring-fenced resources and a strong monitoring and evaluation framework

We, alongside other Traveller organisations and key stakeholders were completely underwhelmed by the draft Plan which was circulated by the HSE National Social Inclusion Office in March 2019 as it completely ignored these recommendations. In the absence of dedicated resources and an institutional mechanism to drive implementation, performance indicators and/or verification measures, we believe that the plan is effectively doomed from the outset. This was observed in 2019 by the Council Of Europe Advisory Committee for the Protection of National Minorities which urged Ireland to:

> Implement health measures listed in the National Traveller and Roma Inclusion Strategy without delay, including the adoption of a detailed action plan, as referred to under Action 73, with clear targets, indicators, timeframes and resources. The measures taken should be monitored, in close cooperation with the representatives of the Irish Travellers, to ensure that they address their respective objectives.

While we acknowledge the HSE's commitment to revise the Plan, there is a need to ensure that the revised Plan includes the establishment of a new institutional mechanism under the aegis of the Department of Health and Health Service Executive (HSE) to drive the implementation of the Plan. This is pertinent given that the principal statutory structure to develop and drive measures to improve Traveller health outcomes (the Traveller Health Advisory Committee) has been dormant since 2012. This renewed institutional mechanism must also have political accountability. The Plan must be inclusive of clear targets, indicators, outcomes, timeframes and budget lines.

Lack of prioritisation of Traveller Health Inequalities in the Department of Health

We believe that the Department of Health have absolved themselves of any responsibility for Traveller health inequalities as evidenced in the draft National Traveller Health Action Plan and we remain concerned that Traveller health has become a political football that is not prioritised and that by simply applying a mainstreaming/ 'one cap fits all approach' this will somehow address the glaring health inequalities experience by the Traveller community. This is clearly reflected in the Department's development of an 'inclusion health

[7] The Health Service Executive will develop and implement a detailed action plan, based on the findings of the All Ireland Traveller Health Study, to continue to address the specific health needs of Travellers, using a social determinants approach.
[8] https://www.paveepoint.ie/hse-report-on-consultations-for-national-traveller-health-action-plan/
[9] SMART is an acronym that stands for Specific, Measurable, Achievable, Realistic and Timely.

strategy'[10] without the participation and/or consultation with Traveller organisations, this, despite reports of the inclusion of Travellers and Roma in such strategy. We also do not believe that the principle of proportionate universalism is understood and/or not being applied to our knowledge and as the European Commission has stated in their assessment of Ireland in 2016, a mainstreaming approach alone is not adequate enough to address health inequalities, and rather, targeted measures must also be adopted:

> A mainstreamed approach is sufficient when outcomes are identical for all components of the target groups; when evidence shows a clear gap between the situation of Roma and Travellers versus the rest of society (e.g. regarding their health and housing situation), policies should be adjusted and specific measures should also be developed.

Further, despite support by Minister for Health, Simon Harris T.D. that the statutory structure tasked with developing Traveller health policy, the Traveller Health Advisory Committee (THAC) would be re-established, this has been ignored by Departmental officials. Pavee Point and other Traveller organisations are ready, willing and able to work with the Department to drive this forward.

Fair Current Terms and Conditions for Traveller Workers

There have been a range of very positive initiatives in relation to Traveller health, specifically the emergence a strong Traveller health infrastructure with the establishment of Traveller Health Units and the Primary Health Care for Travellers Projects. Primary Health Care has been demonstrated to be an effective approach in bridging the gap between a community experiencing high health inequalities and a health service unable to reach and engage that community effectively in health service provision. This approach has also been proven internationally as an effective method of engaging and including minority ethnic groups in health service provision.

Primary Health Care for Travellers Projects have had a significant impact on Traveller health, for example there has been a 35% reduction in Traveller women's mortality since 1987. This improvement is very slightly larger than the 33% reduction seen in the general female population, though of Traveller female mortality remains much higher than in the general population. It also further demonstrated in relation to raising vaccination levels and improving screening for cancer and helping to ensure that the gap in health inequalities faced by women and men has not widened further than they could have in the period of austerity 2008-2016.

There have also been positive improvements in some aspects of infant and maternal care to which Traveller Health Units and Primary Healthcare projects have contributed. For example, there has been a dramatic reduction in the number of Traveller families with 10 children and more over the Census period 2011 -2016. This reduction will contribute to better maternal well-being and is likely a combination of factors such as better health awareness and access to contraception through targeted primary care initiatives as well as general trends in Irish society. This is further evidenced in Traveller women's uptake in maternity and other services with 98% of Traveller women utilising maternity services and 25% of Traveller women had breast screening for cancer, compared with 13% of women in the general population and 23% of Traveller women had a cervical smear test compared with 12% of women in the general population[11]. Therefore it is important that health reforms, including those planned at regional level, do not undermine the work and progress of the THUs given their institutional knowledge and their impact on the ground.

It is important to recognise that Traveller CHWs come from the Traveller community and that they and their families experience similar levels of health inequalities to the overall Traveller community. Traveller CHWs are on the minimum wage and are providing a culturally appropriate and culturally competent service to a community that is difficult for the health service to reach, and are increasing the appropriate use of health services by Travellers. Therefore, it is important that CHWs are valued and recognised for their ability to undertake this role effectively. There is a clear rationale to provide CHWs with a derogation from engagement in activation programmes (as they are already activated) and also to support them with a range of supports – _medical card, rent allowance, maternity leave etc. as recognition for the work they are doing.

[10] https://www.oireachtas.ie/en/debates/question/2019-02-26/415/
[11] Department of Health (2010) *All Ireland Traveller Health Study: Summary of Findings*. Dublin: Stationery Office.

SláinteCare recommends access to universal GP care within 5 years. While we recommend that all Travellers are prioritized and fast-tracked in this process given the level of health inequalities, we recommend that with immediate effect all Travellers employed in Primary Health Care Projects, similar to those with disabilities are facilitated to retain their medical card. This is circa 300 Traveller Health Workers who are working part time and are on the minimum wage. The positive implications from such an initiative cannot be over-stated. It would be a huge confidence building measure to the Traveller community and would also ensure that the resources that Traveller organisations, and the funding the state, have invested in Traveller PHC workers over many years would not be lost and they could continue to undertake the essential public health initiatives that are so well regarded within the community and by a range of public service providers.

National investment and ring-fenced budget needed to address Traveller health inequalities

There has been a disproportionate disinvestment in Traveller health which has pre-dated austerity. This was identified in 2009 to the Joint Committee on Health and Children[12] in which we highlighted to the Committee that in 2007, €1 million was allocated for Traveller health developments, of which €100,000 was allocated towards the all-Ireland Traveller health study and the remainder was put towards balancing the HSE budget. Similarly, in 2008 a further €1 million was allocated to Traveller health developments and the HSE introduced a stipulation that one could only spend in 2008 what was spent in 2007. Therefore, once again €900,000 of the Traveller health budget went to balancing the HSE budget. Out of a potential €2 million for Traveller health development funding, given Traveller health status, given the all-Ireland study and given the significant needs, €1.8 million was used to balance the HSE books. This is unacceptable, and in our view immoral, given the health status of the Traveller community.

We believe this reflects a lack of prioritisation of Traveller health and a disregard for Traveller health inequalities. While we acknowledge once off funding from the HSE in terms of the Dormant Accounts Fund 2017-2019 (Action Plan Mental Health Initiative for Travellers) and the appointment of 9 HSE Mental Health Service Coordinators (8 of which are in post) for Travellers, Traveller health has not receive any new development funding from the Department of Health since 2008. This, despite efforts to secure resources through the estimates process and Traveller health inequalities widening.

Ethnic Equality Monitoring

Statutory bodies and policymakers, including those in health, have increasingly supported the need for reliable and ethnic data to inform efficient, well-targeted, and well-implemented policies to combat discrimination and advance social inclusion.

The Department of Health and the HSE requires disaggregated data as part of strategic population health planning, as we are currently operating within a vacuum, lacking accurate and reliable information to develop and plan cost-effective and evidence-based policies. Put simply, unless policymakers have information on the extent and causes of inequalities they will not be able to develop effective interventions and policies and to monitor progress. Information on ethnicity is necessary to develop knowledge on discrimination, establish objectives, monitor progress towards equality, evaluate the effectiveness of policy initiatives and develop targeted funding for innovative initiatives that deliver better outcomes to minority ethnic groups. Further, ethnically disaggregated data is critical to informing policy decisions and promoting equality of access, participation and outcomes in the areas of health, education, accommodation and employment. The collection and monitoring of ethnic data can be used to eliminate forms of discrimination in addition to justifying positive and affirmative action to ensure that the specific needs of minority ethnic groups are met.

Ethnic equality monitoring is government policy, however, it has not been prioritised and/or systematically rolled out across all routine administrative systems. As a consequence, where ethnic data collection exists it is not used constructively, primarily resulting in very poor statistical information. Further, ethnic identification has been ascribed to minority groups including Travellers rather than the application of a universal question on ethnicity

[12] https://www.oireachtas.ie/en/debates/debate/joint_committee_on_health_and_children/2009-03-10/3/

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 and data protection principles. Various national and international institutions have observed Ireland's data deficit and have urged the State to develop a standardised approach to data collection in accordance with relevant human rights standards.[13]

Ethnic equality monitoring and the roll out of an ethnic identifier across all health and social care administrative systems, is required to monitor access, participation and outcomes for Travellers (and other minority ethnic groups). This will provide an evidence base to inform Traveller health policy, service utilisation and provision and the tackling of Traveller health inequalities. It will also contribute to a more effective and efficient health service. It will also ensure that public health bodies comply with the statutory requirements under Section 42 of the Irish Human Rights and Equality Act 2014 which mandates all public bodies to take proactive steps to assess equality and eliminate discrimination.[14]

Conclusion

Travellers and Traveller organisations continue to mobilise, innovate and make positive contributions to close health inequality gaps. Pavee Point continues to work in partnership with a range of health service providers when the opportunities arise, and this positive role has been widely recognised and influenced other non-Traveller health advocates. There is significant progress in the acknowledgement of Traveller health inequalities in Ireland and in the understanding of how to address these issues at a conceptual level. However, we still have a long and winding road before the challenges highlighted.

[13] See e.g. UNCEDAW, 2017; UNCRC, 2016; UNCESCR, 2015; HRC, 2014; FCNM, 2019; ECRI, 2019; ECRI, *Second Report on Ireland*, CRI (2002) 3, 23 April 2002.

[14] *Irish Human Rights and Equality Commission Act 2014*, Section 42. Available at: http://www.irishstatutebook.ie/eli/2014/act/25/section/42/enacted/en/html.