



**PAVEE POINT**  
TRAVELLER AND ROMA CENTRE

## **Submission on The Future Direction of Children's Nursing in Ireland October 2020**

### **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 welcomes the opportunity to make a submission on ‘The Future Direction of Children’s Nursing in Ireland’ and urge the Department of Health and HSE to ensure that Travellers and Roma are included in any children’s nursing health initiatives, policies, programmes or services being developed in partnership with the Traveller health infrastructure, including Traveller Health Units and local Traveller organisations/Primary Healthcare for Traveller Projects (PHCTPs).

As minority ethnic groups, Travellers and Roma are among the most marginalised and excluded individuals and groups in Ireland. They experience stark health inequalities, poor accommodation conditions, poverty, low educational attainment and literacy levels, high levels of unemployment and intersectional forms of discrimination and racism.

We recognise the immense pressure COVID-19 has put on all aspects of our health care system, including on medical professionals. At the same time, we are concerned that during the pandemic many Traveller and Roma children did not have access to vital paediatric and/or nursing health services. This, along with the move to telehealth/remote working, has potentially further marginalised Travellers and Roma from the health system and exacerbated health inequalities.

This submission sets out some of the key issues and challenges experienced by Traveller and Roma children in Ireland, and provides strategic recommendations to address these challenges. Two overarching recommendations, from which the others included in this submission flow from, are:

- **Immediate publication of the long-awaited National Traveller Health Action Plan**, and associated Community Healthcare Organisation implementation plans, which must address the health needs of Traveller and Roma children, including their access to children’s nurses and outcomes from these services.
- **Implementation of *Sláintecare*** with priority to progressing work on ethnic data, Traveller and Roma representation and participation in community health networks, and ensuring positive action measures and outcomes from the Early Years Intervention Programme including the National Healthy Childhood and Nurture Infant Health and Wellbeing Programme.

Some key facts and figures about Travellers and Roma in Ireland can be found in the Appendix.

## Pavee Point recommendations

### 1a. What will children and their families need from children’s nurses in the next 5-10 years in relation to hospital care?

#### Implementation and rollout of an ethnic identifier

Since 1993, Pavee Point has advocated for the collection, analysis and use of disaggregated data on the basis of ethnicity, inclusive of Travellers and Roma, in line with data protection laws and within a human rights framework. This work has directly resulted in the introduction of a question on ethnicity in the national census as well as being used in a number of official routine datasets including those in health.<sup>1</sup> It has been successfully piloted in Temple Street Children’s Hospital, the Rotunda Maternity Hospital and Tallaght Hospital. However, there remains a significant gap in

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<sup>1</sup> See: Pavee Point Traveller and Roma Centre. (2016). *Policy and Practice in Ethnic Data Collection and Monitoring*, [online]. Available at: [https://www.paveepoint.ie/wp-content/uploads/2016/04/Counting-Us-In-A4\\_WEB.pdf](https://www.paveepoint.ie/wp-content/uploads/2016/04/Counting-Us-In-A4_WEB.pdf) [Accessed 2 Sept. 2020]; Fay, R. and Kavanagh, L. (2019). “If We Are Not Counted, We Do Not Count: A Bottom-up Approach to Ethnic Equality Monitoring in Ireland,” in Cortés Gómez, I. and End, M., (eds) *Dimensions of Antigypsyism in Europe*. Brussels: ENAR, 231-246.

relation to children's health in Ireland in the absence of an ethnic identifier across all routine administrative systems.

Access to ethnic data within health services would assist in tracking admission rates and monitoring disease patterns, respiratory conditions, childhood cancers, and others, among different groups relative to the general population. Having such data would assist with planning and evaluation of hospital services, highlight gaps, increase effectiveness, quality and efficiency of services and inform preventive programmes.

#### **Recommendation**

- Implement and rollout ethnic equality monitoring, including an ethnic identifier (in line with human rights standards) across all routine pediatric datasets.

#### **Hospitals must become culturally safe spaces**

Hospitals are often the sites of our most stressful times in life, and navigating them can be overwhelming. The experience can be even more daunting if English is not your first language. When giving the results of tests or the prognosis of a disease is being explained, nurses must be mindful of the low literacy and education levels in both Traveller and Roma parents. A nurse could ask if there is a specific person in the family or someone they would trust from outside the family to be at the meeting with the doctors. This could be someone from a PHCTP or local Traveller or Roma organisation.

If the prognosis is very poor and death of a child may be imminent the staff need to engage with the Chaplain, or contact the Parish of the Travelling People, to ensure someone is available to the family. They also need to be aware of cultural practises around death and dying, including being prepared for a large number of visitors. As this is a very traumatic time for all parents it is important to the community to be supportive and visit. This should be facilitated where possible.

Culturally safe care recognises that structural discrimination is embedded in many policies and services. It is not enough for individual children's nurses to practice cultural safety if the policies, structures and institutions they work within are culturally unsafe.<sup>2</sup> Hospitals across Ireland must embrace the challenge of learning how to become culturally safe and commit to adapting their practices as required.

#### **Recommendations**

- Implement Action 86 of the National Traveller and Roma Inclusion Strategy (NTRIS): *The Health Service Executive will work towards ensuring access to interpreters for Roma in GP consultations and across health services as appropriate.*
- Mandatory anti-racism and discrimination training (initial training and Continuous Professional Development) for all children's nurses working in hospitals (please see below).
- Implementation of statutory public sector duty (Section 42 Irish Human Rights and Equality Commission Act) which promotes equality, combats discrimination and protects human rights.
- Include Traveller and Roma-specific health promotion posters, imagery and artwork in all hospitals, including the new children's hospital, to create a welcoming and inclusive environment.
- Put in place appropriate communication and support mechanisms when providing information on diagnosis, prognosis and treatment.

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<sup>2</sup> Brascoupé, S. and Waters, C.. (2009). Cultural Safety: Exploring the Applicability of the Concept of Cultural Safety to Aboriginal Health and Community Wellness. *Journal of Aboriginal Health*, 5, 6-41.

- Ensure culturally safe practises to support Traveller and Roma families during death and dying.
- Development and use of a culturally appropriate bereavement support program.

### Transition to new children's hospital

As work continues on the new national children's hospital, it is vital that the Traveller and Roma communities are meaningfully consulted on it, so that they feel part of the project and, when it opens, comfortable within it.

#### Recommendations

- Engagement of Roma and Travellers in youth and patient advisory forums used by the hospitals, for consultation on new initiatives.
- Traveller and Roma proofing new hospital developments and initiatives.

## 1b. & 1c. What will children and their families need from children's nurses in the next 5-10 years in relation to care in the home and care in the community?

### Improved communication

In relation to care in the home, there needs to be improved communication with the parents and family of the Traveller and Roma child at discharge, so they clearly understand what condition/disease their child has and that they know the correct treatment, diet or medication they have to provide at home. The *AITHS* noted that functional literacy is less than 50% among Traveller adults, so there can't be an assumption they can follow written advice and instructions.

The hospital also needs to ensure they have a clear understanding of the living situation of the family so they don't have unreal expectations (e.g. of daily baths or physio walks with crutches if they live in a trailer on an unserviced site with no paths, water or electricity). This could be an appropriate time to link with the local PHCTP, to follow up and visit to see how the family is coping.

#### Recommendations

- Ensure diagnosis, treatment and medications are clearly understood by the parents on the child's discharge.
- Liaise with the social worker, Public Health Nurse and local Traveller/Roma support groups as appropriate to understand the context and supports required for families on discharge from hospital.

### Ensure a smooth transition from paediatric care to adult care

Travellers experience a disproportionate amount of chronic health conditions which often require Traveller children to be hospitalised. There can often be a hiatus in the transition from children's services to adult services, resulting in regression in conditions. A planned transition needs to take place.

#### Recommendation

- Planned transition from paediatric services to adult services with the appointment of dedicated Traveller children's liaison nurses to coordinate these transitions.

## 2. What supports need to be in place to ensure children's nurses can meet these needs?

### Implement compulsory anti-racism training for children's nurses

The *AITHS* found that Travellers had low levels of trust in healthcare professionals and concerns about the quality of care they received when they engaged with services. Compulsory anti-racism training modules in undergraduate and post-graduate curricula for all health professionals as set out in Action 80 of the NTRIS is needed. The training should be provided by Traveller and Roma organisations. Similar in-service training should also be available for children's nurses who are at different stages of their career.

**Recommendation**

- The Department of Health, the HSE, and Nursing Departments within the Universities should work with Traveller and Roma organisations to ensure a compulsory pre and in-service training module for all nursing staff is developed and delivered, including sessions on the social determinants of Traveller and Roma health, the what, why and how of cultural safety, the importance of data collection, and how to recognise and challenge racism and promote trust and dignity within their practise.

**3. Any other ideas/comments?**

**Support Travellers and Roma to become children's nurses**

Action 80 of NTRIS commits the Department of Health and other relevant departments to collaborate with educational institutions and programmes, including the Schools of Nursing and Midwifery, to develop initiatives that promote access by Travellers to education and accreditation programmes that enhance their ability to compete on an equitable basis for mainstream health posts. Targeted measures are needed to support both Travellers and Roma to become nurses and to attain employment with health services. Traveller and Roma children's nurses would be able to, among other things, help bridge the existing cultural divide that can cause anxiety among Travellers and Roma while engaging with the health care system.

**Recommendation**

- Special measures to be introduced in Higher Education institutions to support Traveller and Roma access to training and qualifications as children's nurses.

## Appendix: Traveller and Roma Health Inequalities at a Glance

### Traveller Health Inequalities at a Glance<sup>3</sup>

Irish Travellers are an indigenous minority ethnic group in Ireland. There are a little over 36,000 Travellers in Ireland, representing less than 1% of the Irish population. In 2016, 39.7% of the Irish Traveller population was under 15 years of age, compared to 21.4% of the general population.<sup>4</sup>

- Infant mortality rate for Travellers is 3.7 times the national rate (14.1 per 1,000 live births compared to 3.9 per 1,000 live births) and 2.8 times the EU average
- Neonatal mortality rate for Travellers is almost 2 times the EU average
- Post-neonatal mortality rate for Travellers is 4.5 times the EU average
- Life expectancy at birth for male Travellers is 15.1 years less than males in the general population, and 11.5 years less for female Travellers than females in the general population
- Traveller children have higher reported prevalence of hearing, eyesight and speech problems
- Traveller overcrowding is 7 times the national rate. Approximately 1,700 Travellers live on the roadside without basic facilities<sup>5</sup> and 15% of all Travellers are homeless
- Overall Traveller suicide rate is 6 times higher than the general population
- 40% of Travellers experience discrimination in accessing health services
- Over 40% concerned they were not always treated with respect and dignity
- 53% worried about 'experiencing unfair treatment' in the health services
- Over 50% of Travellers had concerns about the quality of care they received when they engaged with health services

### Roma Health Inequalities at a Glance<sup>6</sup>

An estimated 5,000 Roma live in Ireland, many of whom are second and third generation in the country. State policy (Habitual Residence Condition) leaves many Roma outside the social protection system and, thus, vulnerable to poverty and social exclusion.

- 24% of women do not access health services while pregnant
- Over 1 in 3 (38.9%) Roma do not have a GP
- Nearly 1 in 2 (49.2%) households with children were not successful in their application for social protection payments, which means they were not receiving the child benefit
- Half of Roma do not have a medical card
- 24% of Roma live in households of 8 or more people
- 1 in 4 (25%) children go to school hungry
- 57.5% report not having enough money for school books and uniforms
- 93.3% felt discriminated against in getting accommodation and 84.3% in getting social welfare
- The vast majority (61%) of Roma in Ireland speak Romani, followed by Romanian at 14.3%, Czech at 10.4%, English at 9.7% and Slovakian at 4.5%

<sup>3</sup> Unless otherwise indicated, all data is from: *Our Geels All Ireland Traveller Health Study*. (2010). Dublin: University College Dublin and Department of Health and Children.

<sup>4</sup> Central Statistics Office, (2017). *Census 2016 Profile 8 - Irish Travellers, Ethnicity and Religion*. [online] Available at: <https://www.cso.ie/en/csolatestnews/presspages/2017/census2016profile8-irishtravellersethnicityandreligion/> [Accessed 29 Sept. 2020].

<sup>5</sup> Department of Housing, Planning and Local Government. (2017). *Total Number of Traveller Families in all Categories of Accommodation*. Dublin: Stationery Office.

<sup>6</sup> All data from: Pavee Point Traveller and Roma Centre & Department of Justice and Equality. (2018). *Roma in Ireland – A National Needs Assessment*.