

## Social Deprivation among Children with Inherited Metabolic Disorders

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### Abstract

#### *Aim*

There are strong associations between socio-economic status and health outcomes. Marginalised communities such as Irish Travellers and Roma have poorer health outcomes, due in part to socio-economic status. Some marginalised communities also have a higher incidence of recessively inherited disorders, including inherited metabolic disorders (IMDs). We sought to examine the socio-economic status of inpatients attending the Irish paediatric metabolic service, as well as the proportional representation of children from Traveller and Roma communities.

#### *Methods*

We collected demographic data for all patients with IMDs admitted to a paediatric metabolic ward in one tertiary centre over a three year period (January 2021-December 2023, n=256). Social deprivation was assessed using the Pobal HP Deprivation Index 2022.

#### *Results*

55 (21.5%) metabolic patients lived in deprived areas, including 22 (8.6%) patients who lived in very or extremely deprived areas, compared to 3.8% of the total population of Ireland (n=195, 374). 32 (12.5%) were from the Irish Traveller Community, who make up less than 1% of the Irish population.

#### *Discussion*

The proportion of paediatric metabolic patients living in very or extremely deprived areas was more than twice that of the general population. Children from Traveller and Roma communities were represented in high proportions, with higher rates of deprivation found

among Traveller children. An inclusion health approach would help ensure better health and wellbeing outcomes for these children and their families.

## Introduction

There are known associations between socio-economic status and health outcomes<sup>1</sup>, with socio-economic deprivation being associated with a broad range of poor health outcomes and diseases<sup>2</sup>. A recent Irish report has found that people living in disadvantaged areas are four and a half times more likely to report not having good health, compared to those living in the most affluent areas<sup>3</sup>. Children are particularly vulnerable to the adverse health effects of socio-economic deprivation<sup>4,5</sup>. Paediatricians are becoming increasingly aware of the need to consider the social determinants of health, defined by the World Health Organisation as *“the conditions in which people are born, grow, live, work and age”*, that their patients encounter<sup>5,6</sup>.

In Ireland, certain ethnic minorities are known to be at increased risk of socio-economic deprivation, specifically members of the Irish Traveller and Roma communities, with the two communities having been described as “among the most disadvantaged and marginalised people in Ireland”. The Irish Traveller community are an indigenous, traditionally nomadic group, who have a distinct value system, language, customs and tradition<sup>7</sup>. In the face of persistent discrimination and social exclusion, Irish travellers were recognized as an ethnic minority in Ireland and the European Union in 2017. According to the 2022 Census there are 32 949 Travellers currently living in Ireland<sup>8</sup>. Despite sharing common ancestry with the settled Irish population, Travellers have a long history of social deprivation and discrimination<sup>9</sup>. Mortality rates within the community are considerably higher than those of the general population. Infant mortality is 3.6 times higher among Travellers than the general population, and average life expectancy is 15 years lower among Traveller males than the corresponding national average, and 11 years lower among Traveller females<sup>10</sup>. Discrimination, poor living conditions, low levels of educational attainment and high levels of unemployment are among the underlying causes linked to these health inequalities<sup>11</sup>. As recently as 2021, there were 3000 Travellers living without ready access to toilets, electricity or running water<sup>12</sup>. The Traveller community also has an increased incidence of a broad range of autosomal recessive genetic diseases<sup>13</sup>, including higher rates of inherited metabolic disorders, influenced by the community’s traditional practises in relation to consanguineous marriage.

The Roma, while a distinct ethnic group to the Irish Travellers, face similar challenges in relation to social deprivation, increased mortality rates and increased rates of certain genetic diseases<sup>14</sup>. The group originated in Northwest India but have lived for centuries in Europe and are now the largest ethnic minority group in Europe<sup>15</sup>. The term encompasses numerous

subgroups with various differences in tradition and language. Compared to Travellers, they represent a smaller and less researched group in Ireland, with the Irish Census first recording the Roma as a distinct ethnic group only in 2022 <sup>16</sup>, with a population of 16 059, 26.3% of whom are children under 14 years of age <sup>8</sup>. Data regarding Roma morbidity and mortality in Ireland is limited, but a range of European studies suggest that most Roma populations suffer more ill-health compared to non-Roma, with higher mortality rates, including infant mortality <sup>17</sup>. Difficulty accessing healthcare services is a frequent issue, with many Roma unable to access primary care or medical cards due to difficulty proving habitual residency <sup>18</sup>. Access to maternity services is also poor, with many Roma women receiving no antenatal care; for a quarter of women surveyed in one study, their first healthcare intervention in pregnancy was at delivery <sup>18</sup>.

The National Centre for Inherited Metabolic Disorders (NCIMD) is the Irish tertiary referral centre for children with inherited metabolic disorders (IMDs). It has a dedicated inpatient department where the majority of metabolic patient admissions occur. It has been noted by staff that there appears to be high rates of social deprivation among patients and families attending the department, as well as a high proportion of patients from both Irish Traveller and Roma communities, however this has not previously been formally studied. A recent German study has found that many parents of children with IMDs report both a psychosocial and a financial burden as a result of their child's diagnosis <sup>19</sup>. This study examines social deprivation among inpatients under the care of the Irish paediatric metabolic service, as well as the proportional representation of children presenting from the Irish Traveller and Roma communities as ethnic minorities known to experience social deprivation and exclusion in Ireland.

## Methods

Demographic data, including data regarding ethnicity and socio-economic deprivation, was collected from a cohort of metabolic patients who were admitted to the metabolic ward at Children's Health Ireland (CHI) over a three-year period, from 1<sup>st</sup> January 2021 to 31<sup>st</sup> December 2023 inclusive. All patients with an IMD who were admitted to the designated metabolic ward during this period were included. Patients of other specialities who were admitted to the metabolic ward were not included and metabolic patients admitted to other areas of the hospital were not included. Socio-economic deprivation was assessed using the Pobal HP Deprivation Index 2022 <sup>20</sup>. This index uses information from the 2022 National Census, grouped under three domains: demographic vitality, social class composition, and labour market situation, with data points making up those domains including age dependency, population change, level of educational attainment, unemployment rates, occupational status, number of persons per room, and lone parenthood. This model aims to measure the

lived experience of disadvantage beyond income poverty. The index then provides a deprivation/affluence score for each Small Area in Ireland, a Small Area being a geographic unit of approximately 100 households. The index assigned each Small Area a score of between 1 (very affluent) and 7 (extremely disadvantaged). Individual patient rates of hospital admission during the three year period were collected, and compared to deprivation index and ethnicity. Comparative data for ethnicity was obtained from the most recent Irish national population census<sup>8</sup>. Statistical analysis was carried out using IBM SPSS Statistics for Windows, version 30.0.0. All data was anonymised and the research was conducted according to the ethical principles of the Declaration of Helsinki.

## Results

256 patients with IMDs were admitted to the metabolic ward at CHI during the study period. Metabolic patients admitted to other wards across CHI were not captured. Reasons for admission ranged from elective admissions for multidisciplinary team input, parental education or elective treatments or procedures, to unwell patients admitted in metabolic crisis. 55 (21.5%) patients were found to live in deprived areas (areas with a deprivation index of 5-7), including 22 (8.6%) patients who live in very or extremely deprived areas (areas with a deprivation index of 6-7), compared to 3.8% of the total population of Ireland (n=195,374)[6]. 32 patients (12.5%) were members of the Irish Traveller community, who make up less than 1% of the Irish population [5]. Three patients (1.2%) were from the Roma community, who make up 0.3% of the population. 13 of the 22 patients (59%) living in very or extremely deprived areas were members of the Traveller community. The mean deprivation index was 3.72 (SD 1.16). The mean deprivation index among the Traveller cohort was 5 (SD 1.22), and among the Roma group it was 2.67 (SD 1.15), with the mean deprivation index for the entire group 3.72 (SD 1.16) (*see Table 1*).

There were 557 admissions of metabolic patients to the metabolic ward during the study period, involving 256 patients. 156 admissions (28%) were of patients from the Traveller community. 82 admissions (14.7%) were of patients from very or extremely deprived areas. The mean number of admissions per patient was 2.18 (SD 3.146), with a mean of 3.83 (SD 6.7) among very disadvantaged patients and 3.5 (SD 4.36) among the extremely disadvantaged group (*see Table 2*). Among the Traveller cohort, the mean number of admissions per patient was 4.84 (SD 5.826), and among the Roma cohort it was 1 (SD 0.0)(*see Table 3*).

| Member of Irish Traveller Community |                        |     |                |
|-------------------------------------|------------------------|-----|----------------|
|                                     | Mean Deprivation Index | N   | Std. Deviation |
| no                                  | 3.54                   | 224 | 1.04           |
| yes                                 | 5.00                   | 32  | 1.22           |
| Total                               | 3.72                   | 256 | 1.16           |

  

| Member of Roma community |                        |     |                |
|--------------------------|------------------------|-----|----------------|
|                          | Mean Deprivation Index | N   | Std. Deviation |
| no                       | 3.73                   | 253 | 1.16           |
| yes                      | 2.67                   | 3   | 1.15           |
| Total                    | 3.72                   | 256 | 1.16           |

Table 1: Deprivation index by ethnicity

| Deprivation Index | Mean Number of Hospital Admissions | N   | Std. Deviation |
|-------------------|------------------------------------|-----|----------------|
| 1                 | 1.00                               | 2   | .00            |
| 2                 | 1.53                               | 30  | 1.22           |
| 3                 | 1.74                               | 87  | 1.92           |
| 4                 | 2.28                               | 82  | 3.31           |
| 5                 | 2.67                               | 33  | 3.36           |
| 6                 | 3.83                               | 18  | 6.70           |
| 7                 | 3.50                               | 4   | 4.36           |
| Total             | 2.18                               | 256 | 3.15           |

Table 2: Hospital admissions by deprivation index

| Member of Irish Traveller Community | Mean Number of Admissions | N   | Std. Deviation |
|-------------------------------------|---------------------------|-----|----------------|
| no                                  | 1.79                      | 224 | 2.33           |
| yes                                 | 4.84                      | 32  | 5.83           |
| Total                               | 2.18                      | 256 | 3.15           |

| Member of Roma Community | Mean Number of Admissions | N   | Std. Deviation |
|--------------------------|---------------------------|-----|----------------|
| no                       | 2.19                      | 253 | 3.16           |
| yes                      | 1.00                      | 3   | .00            |
| Total                    | 2.18                      | 256 | 3.15           |

*Table 3: Hospital admissions by ethnicity*

## Discussion

This study found far higher rates of socio-economic deprivation among our patient cohort compared to the general population, according to the Pobal index. The proportion of children living in very or extremely deprived areas was over twice that of the general population <sup>21</sup>. Children from the Traveller and Roma communities were both represented in higher proportions compared to their proportion of the general population, particularly Travellers, who were represented at 12 times the expected proportion in our cohort, at least partly reflecting their higher incidence of IMDs. There were higher rates of hospital admission among patients from deprived areas, as has been seen in other adult studies <sup>22</sup>. Hospital admission is known to be a stressor for families, and particularly families of lower socioeconomic status, with families experiencing stress due to logistical and transport issues, financial burden and emotional distress <sup>23</sup>. Our centre is a national tertiary referral centre with patients attending the department from all over Ireland, some travelling considerable distances to do so, and enduring financial and logistical burdens and family separation as a result. There were higher rates of both deprivation and hospital admission among the Traveller cohort. Traveller children made up nearly a third of admissions, an extremely large proportion, even given their over-representation in the patient cohort. Due to the small number of Roma children (three) admitted during the study period, conclusions cannot be made about this group.

There are a number of limitations to our study. The Pobal Index is Ireland's primary social gradient tool, and is similar to other small-area deprivation measures that have been used in many other countries. Like all deprivation measures, it is an estimate of deprivation and not a perfect tool. As the index categorises small areas together, extreme deprivation within an individual household e.g. due to overcrowding may not be captured. It is also possible that some patients may have been living in temporary accommodation, and as such their given address may not have accurately reflected the degree of deprivation they were experiencing. Given that this was a study of inpatients, it is possible that the study was affected by sampling bias, as it has been found that there is an association between residential area deprivation and hospital admission <sup>24</sup>, and indeed our study found higher individual rates of admission among patients from very and extremely deprived areas. Another limitation is that this was a single-centre study involving patients admitted to one specialist ward in a tertiary centre, and did not include patients with IMDs who were managed closer to home in local paediatric units. As such, it may not be possible to draw accurate national conclusions from this study, though the patients included in the study were a geographically diverse cohort, with children from all 26 Irish counties represented. It is very possible that deprived children were also overrepresented in those children who were managed closer to home, in recognition that the burden of transferring a child to a tertiary centre for management is highest on deprived families who may lack the requisite social and financial support structures. A final limitation is that it was not possible based on the available data to give the rates of emergency versus elective admissions among the cohort, which may have been useful.

Despite the known limiting factors, this study has shown high rates of social deprivation amongst paediatric metabolic inpatients in Ireland. These high rates of deprivation should inform service resourcing to support these children through an inclusion health approach. Inclusion health, as a concept, aims to develop care pathways that are patient-centred, focused on overcoming visible and invisible obstacles to engagement with healthcare services, for people with poor health due to poverty, marginalisation, and multimorbidity <sup>25</sup>. Health care equality and access is important to stress for these patients as due to their marginalisation, they are underrepresented in patients advocacy groups.

The metabolic service at CHI has many initiatives in place to try to support vulnerable families, including a dedicated social work team, in-person interpreters, and pictorial dietetic guides to aid families with poor literacy in following an individualised diet. There are strong links between the hospital allied healthcare professional teams and local services, providing support and education to community multidisciplinary teams and schools to support families in optimising patients' wellbeing and quality of life. Outreach metabolic clinics have been established to remove the burden of travel for some families, and there is metabolic nursing and medical advice available to patients and local centres at all times including out-of-hours,

to support both care at home and acute admissions in children's local units, with the aim of avoiding unnecessary admissions to the tertiary centre for patients for whom this would be a burden. Further integration of children's services in line with Sláintecare and national reorganisation of health services should also benefit these children and families. Managing these patients with an inclusion health approach and together with the provision of the necessary resources and initiatives such as those above will prove indispensable in ensuring that paediatric metabolic patients are supported to receive the highest standard of care, to improve clinical outcomes, and to enable them to enjoy their childhood in the best possible health.

**Declarations of Conflicts of Interest:**

None declared.

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