Painéal Náisiúnta Athbhreithnithe
NATIONAL REVIEW PANEL

# Review undertaken in respect of a death of a baby who had contact with

**Tusla and the HSE**

**Kim**

**Executive Summary**

**September 2019**

## 1. Introduction and background.

This review concerns a baby, here called Kim, who died from SIDS when she was ten months old. Her death was notified to the National Review Panel because she and her family had been known to the HSE and Tusla social work services.

Kim's parents were members of the travelling community, and during her lifetime Kim lived in three different administrative areas, Areas A, B and C. She had been born three months prematurely and as a result she was medically vulnerable and needed specialist care to assist her to reach her developmental milestones. She remained in hospital for three months. Kim's mother, here called Kate, had an intellectual disability and had been educated in a special school. She had an intermittent relationship with Kim's father, here called Joe. Both parents received support from their extended families. They also received services from a community organisation for members of the travelling community.

Kim was born in Area B. As there were concerns about both parents' ability to provide adequate care for Kate, it was agreed by the services that she would be mainly cared for by extended family. She was transferred from the maternity hospital in Area B to a hospital in Area C, nearer her grandmother's home. She was discharged at three months old with Kate to her maternal grandmother's home in Area C. Soon afterwards, the family moved to Area A. After a few weeks, Kate moved back to Area B to be with Joe and they lived with his mother. Kim became ill there, and was admitted to hospital. She was five months old at this point. Concerns remained about both her parents' capacity to meet her needs. Her diet needed special attention and she was to be assessed by the Early Intervention Team. When making plans for her discharge, it was considered that her paternal grandmother's accommodation was unsuitable for a baby so she was ultimately transferred to a hospital in Area A and then discharged to the primary care of Kate's mother in Area A following a multidisciplinary meeting. Joe and Kate were reported to have ended their relationship at this point and he was not involved in her day to day care. Kim was then six months old.

A social worker was allocated to the family and they were also linked with a voluntary agency which was assisting them in efforts to get adequate accommodation as their current living arrangement was temporary. A public health nurse for traveller health was also involved. Kim was considered to be well cared for and was developing well, but over the next few weeks the family had to leave their accommodation and had to return to a cramped campervan. All the services involved advocated for suitable housing for the family; the housing department informed the SWD that the family had been

previously housed on a number of occasions and had left their accommodation. Kim continued to do well, and although some medical appointments were missed, others were kept and she had the necessary vaccinations. The hospital consultant considered her to be making excellent progress. The SWD organised a family support plan review where it was concluded that Kim continued to do well, the main problem being experienced by the family was their poor and unsuitable accommodation.

Sadly, Kim passed away at ten months old from Sudden Infant Death Syndrome (SIDS).

## 2. Review Findings

The SWD responded to referrals about Kim and her family promptly, and a number of meetings took place to make arrangements for her safe discharge and ensure that services were in place. An assessment had been carried out in a timely manner but lacked certain detail about Kate's family's ability to be Kim's primary carer. Following Kim's illness, concerns about her parents' capacity to meet her particular needs were clearly identified and appropriate plans were put in place. Transfers between the different SWDs were handled well and it is evident that there was management oversight. A number of multidisciplinary meetings were held to facilitate exchange of information. Given that different hospitals in different areas were involved in Kim's care, communication between in-patient and community health services was challenging. While the same social worker was consistently involved, her face to face contact with the family was minimal. However, other services were actively involved.

## 3. Conclusions

The review team notes the loss that has been experienced by Kim's family and the professionals who worked with the family and extends sympathy to them. The following conclusions were reached.

- Kim sadly died from SIDS.
- There was evidence of early identification and assessment of the challenges faced by her mother in caring for Kim in both the maternity and children's hospitals in Area B given her intellectual disability. Subsequently, Area A responded to referrals and carried out an initial assessment promptly. However, the assessment lacked certain detail about Kate's mother's ability to be Kim's primary carer given her other care duties.
- There was a strong focus on Kim's needs by professionals and agencies. Most of the professionals involved did their best to maintain a positive relationship with the family and

to support them in meeting Kim's needs. In addition, many professionals consistently advocated on the family's behalf to the housing department in an attempt to secure appropriate housing but unfortunately without success

- There was evidence of very good inter-professional and inter-agency communication and co-operation for much of the time. The family led a transient lifestyle which resulted in Kim being referred to four different hospitals in Areas A, B, C which led to some communication issues between services. In this instance, the communication issues had no adverse consequences.
- Whilst there was regular contact between the family and many professionals, face to face contact between SWD A and the family was confined to one home visit and one family support review meeting once Kim was discharged from the local hospital. It is noted, however, that other services were in regular contact.

## 4. Key Learning Points

This report has attempted to reflect on the challenges faced by Kim and her family and the staff who worked with them. The review team consider that there are areas where lessons can be learnt:

- The Child Protection and Welfare Practice Handbook (HSE, 2011) highlights that many parents with learning difficulties are likely to need additional support from their families and relevant services in order to care for their children adequately. This is even more critical when their children are vulnerable or have special needs. Therefore, it is important that a thorough assessment is carried out.
- Travellers are among the most disadvantaged and marginalised people in Ireland and like other such groups suffered disproportionately from the effects of the financial crisis in recent years (Department of Justice and Equality, 2017)[1]. Whilst good-quality, affordable, safe accommodation is considered crucial to wellbeing, accommodation has long been an issue for travellers. While research has shown that most travellers lived in houses, about 12 per cent of Travellers were still living in a caravan or other temporary structure in 2011. Travellers were also more likely to live in crowded accommodation and to lack adequate

[1] Department of Justice and Equality (2017) *National Traveller and Roma Inclusion Strategy 2017 – 2021.* https://www.paveepoint.ie/wp-content/uploads/2015/04/National-Traveller-and-Roma-Inclusion-Strategy-2017-2021.pdf

central heating and sanitary facilities[2]. It has been argued that the current housing crisis has led to more overcrowding for Travellers[3].

- The health inequalities that lead to poor health status amongst Travellers are highlighted in the All Ireland Traveller Health Study (2010)[4]. Overall, Traveller mortality is 3.5 times higher than for non-Travellers. Infant mortality is generally considered to be a good gauge of a population's level of health and development. Infant mortality is 3.6 times higher among Travellers than among the general population. Travellers have a 14.1% infant mortality rate, compared to that of the settled population at 3.9%[5].
- There is vast international literature on well-recognised barriers to service provision for minority groups according to the All Ireland Traveller Health Study (2010)[6]. Such barriers are multifaceted and include factors such as discrimination, literacy, language, and education. They may also include mobility/transience of populations and distance from care. As nomadism remains part of the lifestyle of some Travellers, this may present challenges in travellers accessing specialist services and ensuring good quality and timely communication between services providers.
- There should be a clear plan about the frequency of contact by the social worker with the child and her family. Undertaking regular home visits allows social workers to see a child in their own environment. An assessment of a family's living conditions (including safety factors) is important given that it may affect family functioning and well-being. The Tusla Handbook on Child Protection and Welfare (2011) contains some useful guidance on carrying out home visits.

**Dr Helen Buckley**

**Chair, National Review Panel**

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[2] Watson, D., Kenny, O. and McGinnity, F. (2017) *A Social Portrait of Travellers in Ireland* RESEARCH SERIES NUMBER 56 January 2017 Available to download from www.esri.ie © The Economic and Social Research Institute.

[3] https://www.paveepoint.ie/wp-content/uploads/2013/10/Travelling-with-Austerity_Pavee-Point-2013.pdf

[4] The All Ireland Traveller Health Study (2010) https://www.ucd.ie/t4cms/AITHS_SUMMARY.pdf

[5] Department of Justice and Equality (2017) *National Traveller and Roma Inclusion Strategy 2017 – 2021.* https://www.paveepoint.ie/wp-content/uploads/2015/04/National-Traveller-and-Roma-Inclusion-Strategy-2017-2021.pdf

[6] The All Ireland Traveller Health Study (2010) https://www.ucd.ie/t4cms/AITHS_SUMMARY.pdf