

National Review Panel

**Overview of five internal reviews and one case summary in respect
of children known to the child protection services whose deaths
were from natural causes**

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1. Introduction

Under guidance issued by the Department of Children and Youth Affairs, the National Review Panel has the discretion to decide not to conduct a review where a child or young person has died from natural causes and there are no other indicators of concern. A number of cases have been notified where the deaths of the children concerned were from natural causes and were predictable. It was decided that the NRP did not need to replicate the internal reviews which were carried out in five of these cases. This report presents an overview of the main issues arising in the internal reviews and in one case summary. The case that was summarised rather than reviewed had very little social work contact because the family were known for a very short period prior to the baby's birth and the baby remained in hospital for the five and a half months of his life.

2. The children

Five of the children who died had been born with complex congenital diseases and were not expected to live to adulthood. The sixth child suffered from cancer and died a few months after her diagnosis when she was twelve years old. Three of the children had been received into State care before they died; two because of child protection concerns and the third because her parents were unable to cope with the high level of need that her condition presented. Court orders had been granted in respect of one of the children and the other two were in care with the voluntary agreement of their parents. As might be expected in cases where children had complex health needs, their care arrangements were often shared with medical services. One child never left hospital care and died at five and a half months old. Another child lived in foster care and had frequent respite in specialist residential services for children with complex health needs. She died at four years old. Another child lived in foster care until she was seven and then went to a specialist residential unit where she died at thirteen years.

Three out of the six children were never in care; two of them lived with their families until they died, including the child with terminal cancer, and one stayed in hospital for medical reasons. They were five and a half months, two and a half years and twelve years old respectively.

The family problems that precipitated the placement in care of two of the children included domestic violence, neglect, homelessness and parental alcohol abuse. In three cases, the families had been known to HSE social work services either prior to the birth of the children who

later died or, in one case, prior to the diagnosis of the terminal illness of the child who later died. As five of the six children had high medical needs all their lives, they received services from a wide range of hospital, primary care, disability and social work services.

The case summary raised no issues of concern, and the case, which had been classified as 'welfare' had been known to the SWD for a very short period. The five internal reports raised a number of matters and while the number was small, the frequency with which some issues arose indicates that they may be common to situations where families are vulnerable and children have very complex health needs. These are addressed below.

3. Issues arising in the five internal reviews

3.1 The children who were in State care

3.1.1. Challenges in finding placements to meet the children's very complex needs

Not surprisingly, the internal reviews demonstrated a considerable amount of difficulty in finding suitable foster placements for very sick children. In one case, a young child was cared for by a former care assistant that came forward requesting to foster her. This followed a two year search for foster carers and one unsuccessful trial placement for the child concerned. In another case a short term foster carer opted to change her status to long term so that she could continue caring for the child in her short term care. In one other case, foster carers were found easily. It was not always possible to maintain the child in a foster placement once their medical and care needs became very acute; one child eventually needed to be moved into specialist medical residential care. It was notable that in two cases, members of the child's birth family expressed a preference for residential care because it would have made visiting easier for them. However, in each case the SWDs believed that the child's interests would be best met in a family setting and so prioritised their welfare in making placement decisions.

3.1.2 Provision of respite

Respite care was necessary where the children were in foster care. One child had frequent stays in a specialist unit before she ultimately went to live there. Two foster placements had backup foster carers to provide respite; one of them also had backup from domiciliary carers from time to time. Two of the families received respite that was financed by the Jack and Jill Foundation. It was noted that one of the respite carers was not approved as a foster carer but as the child was in voluntary care and his parents agreed to the arrangement, a decision was made that her best

interests would be served by the provision of this respite arrangement. This flexibility appears to have worked well in the child's interests.

3.1.3 Access

In all three cases where the children were in care, access was facilitated by the SWDs involved. This proved challenging at times and it is evident that a small number of parents needed active encouragement to visit their children as time went on. The records indicate that social workers did their best to keep birth parents as involved as possible. The internal review in one case noted a lack of information about why the child had no contact with her half sibling. As in all foster care situations, access became complicated when parents were separated and in one case, where domestic violence had been an issue it was necessary to monitor it carefully.

3.1.4. Consents

The issue of consent arose in two of the cases. In one, the mother (the child's main guardian) was difficult to contact. As the child was in voluntary care, this created difficulties in respect of numerous important medical matters. Ultimately she was warned that the HSE would have to take legal action if she did not make herself available to give consent and she became more cooperative. The other instance where this arose was in respect of resuscitation and withdrawal of treatment. In one case, the child was in voluntary care and the SWD had to approach the parents every year to ask them if they wanted to retain the child's 'do not resuscitate' status.

3.1.5 Medical equipment and additional payments

In three cases, delays in obtaining medical equipment caused difficulties. In one, there were delays receiving a medical card, clothing grants and other equipment. In another case where a very ill child was with a foster carer, it was noted that funding and commissioning were managed by different departments with a mix of budget holders which made the process of getting the necessary items very cumbersome. In a different case, respite foster carers were not approved for oxygen equipment and it was necessary for the SWD to negotiate a loan of an oxygen tank from a residential unit. In a further case, foster carers had been promised additional payments to compensate for extra work but the promise was later withdrawn.

3.1.6. Compliance with Child in Care regulations

Two children were left without allocated social workers for periods of time, the longest being six months. Otherwise there was good compliance with regulations in all the cases, and Child in Care reviews were held regularly as required alongside numerous other multi-disciplinary

meetings and conferences. It was noted in two cases that the care plans were rarely changed significantly though it was acknowledged that the children's plans and lives generally were determined by a number of health related decisions and events. In two cases, 'end of life' plans were agreed with parents by the SWD.

3.1 Issues that affected children both at home and in care

3.2.1. Relationships between the SWDs and families

Hostility, particularly at the early stages of contact, may often be anticipated in child protection work with families. The additional stress and anxiety experienced by families when a child is terminally ill puts further pressure on relationships and there was evidence in some of these cases that families projected their anger at both health and social services. There is evidence that in all cases, particularly when the children were in alternative care, SWDs tried to ensure that the families were kept informed of all developments in relation to their children. In one case where a child was living at home, cultural and language differences created barriers at the outset but this appears to have gradually improved with both the use of interpreters and the development of trust between the SWD and the family. In another case the SWD negotiated payment for the funeral as the parents could not afford it.

3.2.2 Quality of social work support offered

In both cases where children died while still living with their families, there had been concerns about neglect, including medical neglect (hygiene, compliance with treatment programme). In each case there is evidence that the SWD conducted assessments and evaluated improvements to maintain acceptable levels of care.

3.2.3. Direct contact with children

Working or communicating directly with the children was complicated by communication difficulties in some situations but there is evidence in most cases that the social workers knew the children, had observed them and had asked other professionals for their observations about them so that they were able to make judgements about their needs and about their relationships. There is evidence where appropriate that social workers advocated on behalf of the children.

3.2.4. Communication between agencies

Although interagency and interdisciplinary tensions are common to child protection work, there appears to have been generally good collaboration between all the disciplines involved in these cases. There were large numbers of professionals from different organisations involved in offering services to the children and families and there is no evidence of any breaches of communication or lapses in cooperation. All appeared to be very focused on the welfare of the children concerned.

4. Conclusion

This report is not a review; it is an overview of internal reviews carried out by managers in the different areas. Notwithstanding the limitations caused by this, this overview has found no evidence to suggest that any action or inaction on the part of the services contributed to the deaths of the six children all of which were, sadly, predicted at the time of involvement. It appears from the evidence presented in the internal reviews that a good standard of support was offered to the children by different services and where the SWDs were required to be active in care planning and/ or responding to concerns, they accomplished their tasks to a good standard.

5. Key Learning

5.1 There were good examples in the internal reviews of support being provided to parents and siblings following the death of a child in their family. Where a SWD has been working with a family during a child's illness, the natural next step should be to provide or arrange bereavement support and counselling. This should be adopted as a routine practice.

5.2 It was evident from this overview that getting consent for various matters can become complicated in situations where parents were avoidant or hard to reach. The learning point here is that the matter of consents for very ill children who are received into State care should be addressed at an early stage to pre-empt any avoidable delays in matters affecting either their treatment or their welfare. If difficulties are anticipated, legal advice should be sought at an early stage.

6. Recommendations

The recommendations below reflect the comments and suggestions made by the Child and Family Agency managers who conducted the internal reviews;

1. A national database should be established listing approved foster carers who are trained and sufficiently skilled to care for very ill children with complex needs. There should be a clear policy with regard to additional payments and provision of equipment.
2. The issue raised in this overview about delays in the provision and delivery of equipment may be further complicated since the child protection and welfare services separated from the HSE. It is recommended that a joint managerial strategy be established so that case managers and budget holders can collaborate and avoid obstacles to making a speedy response when required.

Professor Helen Buckley

Chairperson, National Review Panel