Painéal Náisiúnta Athbhreithnithe
NATIONAL REVIEW PANEL

Overview of four local reviews in respect of children/young people known to the child protection services whose deaths were from natural causes

April 2016

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 local reviews and summaries which were completed in four of these cases. This report presents an overview of the main issues arising in the local reports.

2. Terms of Reference

- To examine the quality of service provided to the children and families during the period prior to the deaths of the children and the young person
- To examine the level of coordination between the health and child protection services
- To identify any issues particular to cases where children who are terminally ill or have a short life expectancy and are involved with child protection and welfare services

3. Level of review and methodology used

This was a desktop review. The methodology used for the composite report was a review of two local summaries and two local reviews, as well as a more extensive systems review conducted on one of the cases. One of the local reviews and the systems review involved interviews with members of the relevant SWDs and the remainder of the reports had been based on records only.

4. The children and the young person

Two of the children that died were born with congenital diseases and were not expected to survive beyond a few months. Both infants lived mainly with their mothers. In one case the infant had older siblings and in the other case, mother and baby spent time living with extended family. They were supported by palliative care services provided by outreach nursing staff and a children's charity as well as primary care services. Both infants died in their family homes at four months old.

The third child was seven years old and had a number of physical disabilities which had left her with extreme and complex needs. She lived with her mother and had no extended family in Ireland. There were no concerns about her mother's care of her and she was admitted into care on two separate occasions for very brief periods only because her mother was in hospital and no alternative carers were available. The first admission was made on an emergency basis for few days, the second one was anticipated, and although it was intended to last a month, it was terminated after ten days because it had involved three changes of foster carer, none of whom had the capacity to meet the child's many needs. Inevitably, the little girl found the experience to be very distressing. A home care package was put in place between the placements and subsequent to the second placement. The child died in hospital four months later from complications related to her disabilities.

The fourth case involved a young person with a terminal illness that he developed in his teens. He had spent a period in care when he was thirteen years old, followed by three years living with one of his parents during which time he was under a supervision order for two years. He had a close relationship with a family who were providing foster care to some of his siblings and shortly after he was diagnosed with a terminal illness, he opted to live with them. His mother signed a voluntary care agreement. When he turned 18, he was provided with an aftercare service. He remained living with his foster family and died in their care a few months after his 18th birthday. He had undergone treatment for his illness but opted to cease medical intervention and had palliative care during his final months.

5. Background and reason for contact with the child protection service in each case

The two infants were born to mothers who had had contact with the child protection services over a number of years. In the first case, there was a history of substance abuse and child neglect by both parents, who later separated. The older siblings spent periods in care and had been returned to their mother a few months before the baby's birth. No subsequent child protection concerns were reported either prior to or after the birth of the baby.

In the second case, the baby was the only child of a young mother who had recently been in care and was in receipt of an aftercare service. Over a period of four weeks, a number of referrals to the duty child protection were made by family members as well as professionals (who were reiterating the family's concerns) when the baby was between two and three months old. It was reported that the baby's father was a heroin addict who was known to be violent at times and that the mother's care of her baby was wanting in certain respects, mainly to do with hygiene. The infant's special needs meant that her care placed extra pressure on her mother, and numerous supports were provided. A decision was made for allocation to a social worker. After two weeks on a waiting list a social worker was allocated and the baby died six weeks later.

In the third case, there were no actual child protection concerns and the Tusla SWD was involved only to provide a respite foster care service. In the fourth case, the young person had come to the attention of child protection services in his teens because of neglect of himself and his siblings. He spent one year in care and two years on a supervision order with one of his parents. The supervision order had been discharged about a year when he became very ill and ultimately opted to live with his siblings' foster carers with his mother's agreement.

6. Services involved with the children

As would be expected where children and young people are experiencing chronic illness and disability, multiple services were involved in each case, carrying out frequent visits to the family homes. The services were provided by a combination of statutory and voluntary organisations including a charity. They included medical, nursing, (both hospital and community based), outreach, respite, palliative care and disability services. Drug treatment services and family support services were involved with the mother of one of the infants. In the fourth case, three private foster care providers were involved and a private agency provided a home care support package.

7. Needs of the children and families concerned

The infants and young child were cared for by their mothers, all of whom required support to deal with the practical needs of their children and the psychological burden of knowing that they were terminally ill. The two infants had the normal needs of small babies and in addition, they required special feeding and hygiene regimes due to their medical conditions. The mother of one of the infants had experienced substance misuse in the past. The mother of the other infant was a young adult who had spent a recent period in care. The seven year old child had numerous needs related to her multiple disabilities including feeding, mobility, personal care and communication and required respite foster care while her mother was in hospital. She and her mother had experienced deep trauma in an earlier phase of their lives in another jurisdiction. The young person was seriously and terminally ill and required palliative care as well as the support of his family and professionals.

8. Issues arising in the delivery of services in the four cases

8.1 Response of HSE/Tusla services to reported child protection concerns

In the case of one of the infants, the family had previously received what appeared to be robust responses from the relevant SWDs when child protection concerns had originally been reported. Siblings of the infant had been in care.

In the case of the second infant, several referrals about the safety and welfare were made a number of times over a short period, mainly instigated by family members and also passed on by professionals. A duty social worker met with the mother and was satisfied with her care of her baby. Checks with professionals involved in her health and palliative care revealed no immediate child protection concerns. However, due to the nature of the reports and the baby's health needs, the case was wait-listed for allocation, albeit for a brief period. The fact that it was allocated only a short time before her death and just prior to a holiday period meant that there was no time for a strategy meeting and little opportunity for intervention.

There were no child protection concerns in the case of the seven year old child, whose main need was for short term foster care while her mother got medical attention.

There were no specific child protection concerns in the case of the young person at the time that he was diagnosed with a terminal illness. He chose to re-enter the care system at this time, and his decision was supported by the HSE and his mother. The main focus was on the provision of palliative interventions.

8.2 Child and family focus

Two of the children were infants, so the main focus of attention was on their parents' capacity to care for them. In three of the four cases, it is notable that the easing of pressure and listening to the concerns of the children and families involved was an important objective. In the case of the first infant, where multiple child welfare and health services were involved, it was decided to reduce the number of providers to the minimum required, in order to avoid overlap and concentrate on interventions to help the parent and family cope with a child that had not long to live.

In the case of the second infant, it is noted that despite the expected short life of the infant, there was a delay of two weeks prior to allocation and the fact that it was a holiday period meant that the allocated worker did not get to meet the mother for a further two weeks and then had only one face to face contact with the family with the remainder taking place by phone. It is noted that she was resistant to social work and complained that she was overwhelmed with services and there was insufficient time to build up a relationship so it is difficult to see how the mother could have found her contact with the SWD to be helpful.

The seven year old child suffered a lot of distress because of the number of changes brought about by lack of suitable placements and the amount of travel and disruption involved in moving her. However, it is noted that efforts were made to try and keep the inevitable level of trauma as low as possible.

The young person who developed a terminal illness in his teens expressed his views about where he wanted to reside as well as the management of his treatment, and these were fully respected, thus allowing him dignity and control over his situation.

8.3 Inter-agency coordination

This is not the first review of cases concerning ill or disabled children in the child protection system, and the requirement for improved coordination of services has been highlighted in a previous composite report by the NRP in 2015. In the cases reviewed here, there are examples of both good and weak coordination. It is to be anticipated that cases where children are very sick or disabled will involve multiple health, social care and respite services. Where it worked well in the cases reviewed here, the coordination of services was planned so that the family's welfare and capacity to deal with their responsibilities did not become overwhelmed with the number of different providers coming into the family home. Where it was judged to be weak, the opposite had occurred, resulting in one case with a young carer feeling that she could never leave the home becuse of the numbers of professionals calling on a daily basis. Communication was also a key factor where strategic service delivery was concerned; in one case weak or absent communication has been noted in relation to discharge from a maternity service of a very vulnerable infant whose care was going to be complex and demanding.

In the case of the young child with serious disabilities, no child protection concerns were ever suspected or identified. Difficulty in finding a suitable short term respite arrangement resulted in three changes of placement in ten days and additional distress for the child. A local review queried whether responsibility for sourcing a placement lay with Tusla or with the HSE Disability Services. This is a pertinent matter which needs to be addressed and agreed between services in order to avoid delays in placement when similar cases recur.

When other home based services were sought in the same case, the eligibility criteria applied by the HSE (i.e. a requirement for an assessment of needs) resulted in delay to agreement of a support package and the necessity to escalate the case to senior management in Tusla and the HSE. Confusion was also noted about which service held budgetary responsibility. Both of these factors have become more significant now that health and social care are provided by separate organisations. The need for coordinated planning particularly where children are on medication regimes and require special equipment was also highlighted. The co-existence of disability and child protection concerns is not rare and a recurrence of these difficulties is predictable unless measures are taken to address them.

8.4 Availability of suitable placements

In the case of the seven year old child, an urgent request for a placement was received by the SWD from the hospital that was being attended by her mother. There were no child protection concerns, and the fact that she had such a high degree of dependency becuse of her disabilities meant that it was difficult to get foster carers with the capacity to meet her needs. It was queried at the time whether the responsibility for placement should have been with disability services and there continued to be challenges related to supports for the various placements that she had. In the absence of any alternative, her first emergency placement was with the Crisis Intervention Service and even though her second admission to care was anticipated, it consisted of one night in an Emergency Department and three other separate placements over a ten day period, two of which were provided by a private service provider. Although it had been intended to provide a month of foster care (to give her mother time to recover from a difficult pregnancy and childbirth) she returned home more quickly than planned due to the inability of the services to provide care for her. Overall, these were very upsetting experiences for a child whose quality of life was already extremely compromised and for a parent who was going through a very stressful period.

9. Conclusions

- The conclusions of this composite review mirror the findings from a previous composite review published in 2015. An overview of statistical data from the time the NRP was established (published in the 2015 Annual Report) shows that around one third of deaths of children known to child protection services are from natural causes, and a substantial number of these were from terminal or congenital chronic illness and disabilities. Some of these children and young people have been in the care system. Overall, the reviews of cases where children and young people died of predictable causes have demonstrated a good standard of intervention. However, they have also demonstrated that unnecessary hardship has been experienced by families due to lack of coordination and of suitably skilled foster carers and these matters have recurred in relation to some of the cases in this composite review.

- Challenges in coordination are inevitable where a child is receiving multiple services from health and social services. This composite review has highlighted the importance of timely exchange of information, agreement on discharge dates and plans, synchronization of service provision and a shared understanding of budgetary and administrative responsibility for special arrangements between health and child welfare and protection services.
- The review has also highlighted the potential for families to feel overwhelmed by services and has demonstrated the importance of coordinating visits and interventions, and anticipating how children and families will experience pressures. This was achieved better in some cases than in others.

10. Key Learning

It is inevitable that where child protection and health concerns co-exist, and particularly where children are terminally ill, the family will be in receipt of numerous services. In these circumstances pressure and distress experienced by families could be reduced if one discipline or team took the lead in coordinating services to reduce pressure on the family and avoid overwhelming them. This task could be assumed by any of the services involved and would best be agreed at interagency strategy meetings.

11. Recommendations

11.1 Placements

The challenge of finding suitable placements for children who are very sick or have disabilities has arisen in previous reviews done by the NRP and remains to be addressed. In a composite report from 2015, a recommendation was made for the establishment of a national database listing approved foster carers who are trained and sufficiently skilled to care for very ill children with complex needs, along with a clear policy with regard to additional payments and provision of equipment. This composite review endorses the previous recommendation. The challenges involved in identifying suitable families who are available at the time they may be required are not underestimated. However, this is clearly a matter of some importance which, as some of the local reviews point out, has become less straightforward as the health and child welfare and protection services have separated.

11.2 Joint strategy

The previous composite report also recommended a joint managerial strategy for collaboration between case managers and budget holders in order to expedite responses to cases of ill or disabled children in receipt of child protection and welfare services. This report endorses that recommendation.

Professor Helen Buckley

Chair, National Review Panel