Painéal Náisiúnta Athbhreithnithe
NATIONAL REVIEW PANEL

Review of the death of a child known to Tusla child protection and welfare services

Fiona

Executive Summary

March 2019

Introduction and background

This report concerns a nine year old child, here called Fiona, who died in hospital from a long term serious illness. She and her family had received services from Tusla over a two year period, having been referred by the medical social work service in the hospital. The reason for referral was that Fiona's medical team were concerned about her parents' apparent non-compliance with her treatment programme which was due to last for a further two years.

When a Tusla social worker visited Fiona's parents, they reported that they found it difficult and distressing to give her medication because of its side effects and because of her own resistance to taking it, and also because the process of administering it was complicated. They worried that the treatment was harming her. The duty social worker carried out an initial assessment. She found that in all other respects Fiona's parents were providing their children with care and stability, and advised them of the importance of administering the correct dosage. She also gave them information about peer support programmes. They undertook to give Fiona her medication and the case was closed.

A further referral was made eight months later by the hospital, reporting that Fiona's blood tests indicated that she was not getting her full dosage of medication. A social worker followed this up and talked at length with Fiona's parents about the devastating impact that her illness had on the whole family and the difficulties they were experiencing in giving her the prescribed medication. She spoke to them about the potential grave consequences of not complying with the medical regime. The social worker's assessment concluded that the parents were in need of emotional support and encouragement, and a family support referral was made. There was a delay of several months before a family support worker was appointed because of a lack of resources. The social worker kept in touch with them by telephone during this time and they continued to receive support from the hospital. Once in place the family support worker visited the family regularly, and carried out parenting work with them, helped them to develop routines and boundaries with the children and deal with the stress that they were experiencing. In the interim, Fiona was admitted to hospital for a long period of supervised treatment, and her mother spent a lot of time with her there. The family support worker stayed involved with Fiona's sibling who had been upset by his mother's absence and advised his father how to help him. Sadly, Fiona did not respond to her treatment and passed away nine months later.

Findings

The review found that the responses made by the social work department to referrals about Fiona were timely and appropriate. It has noted that a further assessment was recommended following the second referral and was not carried out because of staff shortages. It has also found that the referral to family support services had positive results, and the input of the family support worker was regular, consistent and well evidenced in the case records. Practice in the case was child and family centred. The review found, however, that opportunities for multi-agency meetings were missed. Such meetings would have facilitated a more comprehensive exchange of information.

Conclusions

Fiona died from natural causes after she failed to respond to a prolonged and supervised treatment programme in hospital. The NRP extends its sincere sympathy to her family on their very sad loss. Given the difficulty experienced by her parents in adhering to the demanding medical regime prescribed for her, the hospital ultimately took appropriate action by keeping her, with her parents' agreement, in a specialised child friendly unit within the hospital in order to ensure that she was able to take advantage of the treatment options available to her.

- The social work department responded in a timely way to referrals and conveyed the seriousness of a child protection report to the family in an effort to persuade them to comply with the treatment regime. They also identified and responded to the family's need for emotional and practical support.

- The family support service worked consistently and regularly, particularly with the youngest child, over a number of months and provided good evidence of the work undertaken.

- The review has identified some deficits which would not have affected the outcome of Fiona's illness but were not in keeping with good practice standards. These include communication gaps between the parties involved and the lack of any interagency or interdisciplinary meetings to discuss the serious concerns that were identified and to plan a coordinated response.

Key Learning Points

Interagency working

Given that noncompliance on the part of caregivers administering medication in such cases could result in grave consequences, an interagency meeting could add considerable value to any strategy to protect the child. An interagency forum may have helped Fiona's parents to establish a consistent pattern of administration. In addition, their participation in it may have helped them to perceive her treatment regime as therapeutic rather than something they were enforcing against her will.

As the involvement of the SWD was predicated by Fiona's medical condition, closer liaison between the SWD and other services than is evident in the records, might have been beneficial to the overall management of the case. In particular, a multi professional approach to Fiona's parents may have had a stronger impact than the sole intervention of a social worker.

Holistic approach

Where one child in a family is the focus of concern, it is not unusual for other children to get somewhat lost within this context. In this case, the family support worker paid particular attention to the needs of Fiona's sibling in that regard, and helped his father to support him despite his own stress. For further reference, the Children's Hospital of Philadelphia offer guidance[1] on how to support siblings of a hospitalised child, pointing out that they may commonly experience confusion, guilt, fear of getting sick themselves, anger and jealousy. It notes that siblings may express their feelings through various means such as acting out, clinging or regression. The guidance suggests that siblings would benefit from age appropriate, accurate information about the needs of their brother or sister or at times, simply someone to listen to their frustrations about the situation and acknowledge and allow them to express anger or other strong feelings. It offers advice on helping siblings to interact with the sick child and find creative ways of preserving their relationship and encourage their involvement by letting them choose toys and books for their brother or sister and help them to communicate their needs to hospital staff.

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[1] https://www.chop.edu/health-resources/support-siblings-hospitalized-child