Review undertaken in respect of the death of a young person known to the child protection system

October 2011

Executive Summary

Introduction

This review was concerned with a young person who died three months before his 18th birthday of complications associated with Diabetes Type 1. The young person, here known as C, had been known to the child protection services during the six months prior to his death. The terms of reference were:

- To review the service provided to C by the HSE Children and Family Services and ascertain whether action or inaction on the part of the HSE was a contributory factor in C's death
- To determine whether compliance with relevant procedures, standards and regulations was satisfactory
- To examine inter-agency and inter-professional relationships
- To provide an objective report to the HSE including an executive summary, conclusions and recommendations.

Methods

The methods employed were reading of the case records and interviews with key persons involved with the case. The records in this case consisted of a single file containing case notes, correspondence and referral forms. Personal interviews were conducted with the following HSE staff: two social workers, two principal social workers (PSWS) and a social work team leader. An interview was also conducted with C's mother. Telephone interviews were held with the Youthreach manager, the GP and the hospital consultant. A letter was sent to the Juvenile Liaison Officer inviting them to participate in an interview but received no response. The two PSWs, the team leader, one of the social workers and the Youthreach manager also made written submissions to the review team. The timeline of the review is from November 2009 to April 2010. The review was chaired by Helen Buckley, Chair of the National Review Panel with the assistance of Bill Lockhart, Deputy Chair of the National Review Panel.

Background

C had been referred to the HSE Children and Family Services because he planned to live independently and was still under eighteen years of age. This arrangement was by mutual agreement between himself and his main carer, his mother, who was moving to another part of the country to take up employment. C had particular illness-related needs, and it was considered by himself and his mother that these would best be met if he remained in the town where he had an established relationship with health services and was attending a Youthreach project that had benefited him considerably. He was adamant that he did not want to leave the area, and had also stated his intention to leave home once he reached 18, which would have been six months hence. The referral to the HSE Social Work Department (SWD) was made by the Youthreach manager, who had concerns about C's ability to live alone. Contact was made with the family by two separate social workers following two separate referrals and C was interviewed. C and his mother at one point requested a foster care or supported lodgings placement from the HSE to meet his accommodation needs. This request was considered by the SWD but turned down on the basis that it would not be in the best interests of a seventeen and a half year old young person to enter the care system. It was considered that at the time of referral, C was not at risk as he was still in the care of, and the responsibility of, his mother. Ultimately, C's mother assured the SWD that when she moved, she would put sufficient supports in place to ensure that C would be able to manage independently and that she would be in constant contact with him. The case was subsequently closed.

C lived alone in an apartment for approximately four months, with a lot of support from Youthreach staff. During this time he got into some trouble with the Gardai over alleged anti-social behaviour. The gardai made a referral to the HSE when they discovered C was living alone. He was subsequently cautioned by the JLO in the presence of his mother. The SWD only became aware at this point that his mother had moved out of the area, and following this referral a decision was made to carry out an initial assessment of C's situation. The assessment was wait-listed for two months due to pressure and high caseloads in the SWD and tragically, before it could be conducted, C was found dead in his apartment. A post mortem report determined that his death was due to complications related to his Diabetes.

C's medical practitioners, i.e. his GP and Hospital Consultant, were interviewed for the purposes of the review. Both commented that his attendance at clinics had been poor, and his GP acknowledged that the fact the C was attending both services meant that he may have assumed that C was attending the diabetic clinic, while the clinic may have assumed he was attending his GP and that with such an overlap, 'people can fall between the cracks'. The GP acknowledged the need for greater vigilance in respect of young people suffering from chronic illnesses that can change quickly. The social workers and social work managers who were interviewed acknowledged that they had been unaware of either the serious implications of Diabetes 1 or the fact that C's attendance at his clinics was erratic.

There was some evidence of communication gaps in this case, and some instances in which information which was alleged to have been passed was not received. It was also apparent that medical information and a report from CAMHS which were in the possession of some practitioners was not known to the Social Work Department and may have expedited the initial assessment had it been known. However, it is not at all certain that this would have prevented the outcome.

Findings

The review team noted the deep regret about C's death expressed by every one of the personnel who participated in the review and acknowledges the impact that this tragic event has had on his family and friends.

- The review concludes that action or inaction by the HSE Children and Family Services was not a contributory factor to C's very sad death. The outcome of an initial assessment, had it been conducted at the time it was planned, may have been the provision of a service or better coordination of existing services. However it is not at all certain that this would have prevented C's death. Nonetheless, the fact that initial assessments can be delayed for a two month period is a cause for concern. The social work managers have pointed out that recent additional posts have relieved pressure and that assessments are now conducted more quickly.

- C was a young person with a complicated personal history who had achieved a great deal but still had needs and would have benefited from assistance in achieving a safe level of independence. His particular needs fell below the threshold for intervention by Children and Family Services and he was receiving exceptional support from Youthreach but there was nevertheless a gap that may have been filled by the provision of, for example a mentoring or youth advocacy service. The lack of such services in the area where he lived is noted.

- The review did not find any lack of compliance with procedures, but found communication gaps which had implications for C's physical wellbeing and would have similar implications for other vulnerable young people living in the community with chronic health conditions.

- It is not within the remit of this review to evaluate the practices of hospital services or general medical practitioners, but the lack of coordination of services for young people with diabetes was an obvious matter for concern and the lacuna between information held by medical services and its availability to Children and Family Services prior to their embarking on an initial assessment was demonstrated in this case.

Key Learning Points

This review has highlighted a number of opportunities for learning for all professions working with children.

- Firstly, it cannot be assumed that if a vulnerable young person is involved with a number of services that he or she is actively engaging with them. The review has shown the importance of knowledge about the risks associated with chronic illnesses in young people, particularly adolescent males. The GP identified diabetes, epilepsy and asthma as three illnesses that can change quickly and he stressed the fact that teenagers are less compliant than adults with the necessary treatment regimes. While responsibility for medical treatment, including

follow up of missed appointments, remains with medical practitioners, this information needs to be known and utilised by all professionals.

- The review has also indicated that children or young people who are not at obvious high risk can still require and benefit from other services in the community.
- Finally, although this review has not found any evidence of inter-agency tensions between the services involved with C, communication problems between them meant that information that could have significantly changed decisions about service provision was not shared or picked up.

Recommendations

- The HSE Children and Family Services should adopt a screening tool which would highlight particular issues, such as chronic illness in a child or young person or previous contact with CAMHS which may inform and expedite the process of initial assessment
- The HSE Children and Family Services should draw the attention of the relevant medical authorities to the issues that have arisen in this review in respect of coordination of diabetic services for young people and strategies for the follow up of missed appointments by high risk groups.
- When developing or commissioning services within a local health area, the HSE should endeavour to identify and fill gaps that may exist between community based services and the HSE Children and Family Services so that children and young people who have needs that do not meet the threshold for child protection will receive an early intervention service through either formal or informal channels.
- The local area needs to improve their strategies for the exchange and recording of information between areas where it concerns children or young people who are vulnerable or at risk.
- The HSE Children and Family Services should introduce mechanisms for the sharing of information between services within the limitations imposed by data protection legislation.

Signed: Helen Buckley

Helen Buckley, Chair, National Review Panel

Date: 5 - 10 - 11

Review undertaken in respect of the death of a young person known to the child protection system

October 2011

1. Introduction

This review has been carried out in accordance with the HIQA 'Guidance for the Health Service Executive for the Review of Serious Incidents including Deaths of Children in Care' issued in 2010. Under this guidance, the following deaths and serious incidents must be reviewed by the National Review Panel:

- Deaths of children in care including deaths by natural causes
- Deaths of children known to the child protection system
- Deaths of young adults (up to 21 years) who were in the care of the HSE in the period immediately prior to their 18th birthday or were in receipt of aftercare services under section 45 of the Child Care Act 1991
- Where a case of suspected or confirmed abuse involves the death of, or a serious incident to, a child known to the HSE or a HSE funded service
- Serious incidents involving a child in care or known to the child protection service

2. National Review Panel

A national review panel was established by the HSE and began its work in August 2010. The panel consists of an independent Chairperson, a deputy Chair, and approximately 20 independent persons who have relevant expertise and experience in the areas of child protection social work and management, psychology, social care, law, psychiatry and public policy. The panel has functional independence and is administered by the HSE. When a death or serious incident fitting the criteria above occurs, it is notified through the HSE to the National Director's Office and from there to the National Review Panel. The National Director and the Chairperson of the NRP together decide on the eligibility of the case for review, and the level of review to take place.

3. Levels of Review

Under the HIQA guidance, reviews should be conducted by individual teams of between two and four members including the chair. The process to be followed consists of a review of all documentation and data that is relevant to the case, interviews with parents or carers, families and children, and site visits. A report will be produced which contained a detailed chronology of contact by services with the child and family, an analysis thereof, and conclusions, recommendations and an action plan. When the HIQA guidance was developed, it was envisaged that the National Review Panel (NRP) may need to review up to two deaths per annum and three to five serious incidents. However, during the first six months of the operation of the NRP, the numbers of notifications considerably exceeded expectations. As a consequence, and in an effort to deal with the demand for reviews, the NRP proposed that reviews should be differentiated into different levels, as follows:

Major review to be held where contact with the HSE services prior to the incident has been long in duration (five years and longer) and intense in nature, where the case has been complex, for example includes multiple placements, and where the level of public concern about the case is high. The review team should consist of at least three panel members including the chair. The methodology should include a review of records and interviews with staff and family members. The output should be a comprehensive report with conclusions and recommendations.

Comprehensive review: to be held where involvement of HSE services has been over a medium to long period of time (up to five years) and/or where involvement of services has been reasonably intense over a shorter period. The review team should consist of at least two members with oversight by the chair. The methodology should include a review of records and interviews with staff and family members. The output should be a report with conclusions and recommendations

Concise review: to be held where the involvement of HSE services is either of a short duration or of low intensity over a longer period. The review team should consist of at least two members including the chair. The methodology should include a review of records, and interviews with a small number of staff and family members. The output should be a report with conclusions and recommendations

Desktop review to be held where involvement of HSE services has been brief or the facts of the case including the circumstances leading up to the death or serious incident are clearly recorded, and there is no immediate evidence that the outcome was affected by the availability or quality of a service. This would include cases of death by natural causes where no suspicions of child abuse are apparent. The review should be conducted by the chair or deputy chair of the NRP. The methodology should include a review of records with the option of consultations with staff and family members for clarification. The output should be a summary report with conclusions and recommendations. If issues arising from the review of records or consultations point to the need for a fuller exploration of the facts, the review will be escalated to the next level.

Recommendation for internal local review to be made where the notification refers to a serious incident that has more local than national implications, e.g. where a child has been abused in a

particular care setting, where a child is regularly absconding from a placement, or where a specific local service outside Child and Family Social Services is implicated.

4. Death of young person here referred to as C

C was three months short of his 18th birthday when he died in the spring of 2010 of complications related to Diabetes Type 1. The case was notified to the National Review Panel because he had been known to the HSE Children and Family Services during the period prior to his death.

5. Level and Process of Review

This was conducted as a concise review. The methods employed were reading of the case records and interviews with key persons involved with the case. The records in this case consisted of a single file containing case notes, correspondence and referral forms. Personal interviews were conducted with the following HSE staff: two social workers, two principal social workers (PSWS) and a social work team leader. An interview was also conducted with C's mother. Telephone interviews were held with the Youthreach manager, the GP and the hospital consultant. A letter was sent to the Juvenile Liaison Officer inviting them to participate in an interview but received no response. The two PSWs, the team leader, one of the social workers and the Youthreach manager also made written submissions to the review team. The timeline of the review is from November 2009 to April 2010. The review was chaired by Helen Buckley, Chair of the National Review Panel with the assistance of Bill Lockhart, Deputy Chair of the National Review Panel.

6. Terms of Reference

i. To review the service provided to C by the HSE Children and Family Services and ascertain whether action or inaction on the part of the HSE was a contributory factor in C's death

ii. To determine whether compliance with relevant procedures, standards and regulations was satisfactory

iii. To examine inter-agency and inter-professional relationships

iv. To provide an objective report to the HSE including an executive summary, conclusions and recommendations.

7. C

C was the second child in his family, and was living in an apartment on his own at the time of his death three months short of his 18th birthday. Prior to 2010, he had lived with his mother and younger siblings. He had never been in care, and had been known to the HSE Children and Family Services only from late 2009. C had suffered from Diabetes Type 1 since he was two years of age. He had been attending Youthreach for the previous two years. C was described by his mother as 'difficult to live with' in his early teens, but his behaviour had reportedly improved over recent years, following his attendance at an Anger Management course and his attendance at Youthreach. His

mother described him as having matured a lot in recent times. A social worker who met him described him as 'warm, easy to speak to', 'insightful' and more able than most other young people of his age. C enjoyed Youthreach and had a number of friends in the area. He was keen to gain independence and had signalled his intention to move out of home when he was 18.

8. Services involved with C and his family

During the period under review, the following services had been involved with C and his family

- HSE Children and Family Services for three brief periods starting in late 2009
- Youthreach, for the previous two years
- The family GP, for the previous four years
- A clinic at the hospital in the town where he lived, for the previous year.
- The Gardai had been involved with C two months before his death over an incident of anti social behaviour and he had received a caution from the JLO.

9. Background to recent service provision and reason why C was referred to child protection services

C had been referred to the HSE Children and Family Services in late 2009 by the manager of Youthreach. The event that precipitated the referral was the decision made by C's mother to move to another area to take up employment, and C's own decision, agreed by his mother, to remain in his home town. The referral had been made because the Youthreach manager was concerned about C's ability to live independently. Two later referrals were made because of related concerns. The case was ultimately taken up by the social work team leader for initial assessment but this had not been conducted by the time that C died in the spring of 2010.

10. Brief summary of C's needs

10.1 Medical needs

C suffered from Diabetes Type 1 for most of his life and needed ongoing medical surveillance of his treatment regime. He administered his own injections and looked after his other requirements such as blood checks and diet. His mother told the review that he was generally good at managing his diabetes, but occasionally had episodes where he got weak or passed out. She spoke very positively about the service that had been provided by his GP and hospital consultant

C's GP described him as a 'brittle' diabetic, which, as he explained, meant that 'his control wasn't great'. The GP informed the review that C's attendance at medical appointments at his surgery and at the hospital based diabetic clinic was poor and that they did not see him very often. C was able to order and collect his prescriptions at the GP clinic without necessarily seeing a doctor.

10.2 Educational Needs

C also had educational needs, and was attending a local Youthreach project which he greatly enjoyed and which had enabled him to make considerable progress over recent years. C's mother told the review that he had been disadvantaged by his illness as a younger child, and had been quite isolated by the fact that other families were nervous about inviting him to their homes. During his early adolescence, C had exhibited challenging and quite aggressive behaviour which his mother associated with his frustration about the impact of his illness. She described him as having been quite difficult to live with, and said that she had found it extremely difficult to get professional help for him. Eventually, C had attended an anger management course provided by CAMHS prior to attending Youthreach and both had benefitted him considerably, particularly the latter.

10.3 Accommodation and Support Needs

At the time of the referral, it was considered by the Youthreach manager that C was doing really well, but was vulnerable and needed support with accommodation and supervision in the event of his mother moving elsewhere. The HSE social workers who met him also considered that he would benefit from support if he was to live independently. However, it was the view of social work management that it was not the responsibility of the HSE to provide a service to C in the circumstances, and that responsibility for his welfare and safety belonged to his mother. C's mother considered that C was by now capable of managing his diabetes and living away from his family. She believed that his attendance at Youthreach and the very good medical attention he was receiving in the area were essential to maintain, and that on balance, his need to remain in the area superseded his need to live with his family. She also felt that he would benefit from any supports that could be provided by the HSE and elsewhere.

11. Chronology of contact by HSE Children and Family Services with C and his family

Late 2009

First referral: The first referral to the HSE Children and Family Services in respect of C was made by the manager of Youthreach in late 2009. He was concerned about C's ability to live independently in the event of his mother's move to another county. The referral was made on the Standard Reporting Form and sent to the duty system following an informal conversation between the Youthreach manager and the social worker for the area in which the project was situated. Unfortunately, the Standard Reporting Form had been mislaid and was not available to the review. The Youthreach manager told the review that he had clearly stated his concern about C's ability to manage his illness on this form. The note in the social work file indicates that the Youthreach manager was concerned about C's living arrangements, but does not specify C's diabetes as an issue.

The referral was processed by the duty team, and a telephone conversation took place between the duty social worker (Social Worker A) and C's mother, during which the latter explained that she had a particularly attractive opportunity to move herself and her younger children to another county and that C did not want to move with her but was happy for her to go without him. She further explained that C had a history of challenging behaviour associated with the fact that he had suffered all his life with Type 1 Diabetes. She pointed out that he had been doing particularly well at Youthreach over

the previous couple of years and both she and he were reluctant to disrupt his current arrangements. She further explained that he was due to turn 18 in a few months' time and had strongly expressed the view that as he intended to leave home at that point, it made more sense to leave him in the situation in which he was making good progress. C's mother told the social worker that to force C to come with her would put him at risk of absconding, which could endanger his health as it would disrupt his treatment routine. She was basing this possibility on a previous episode where he had been found unconscious, having run away from home. She told the social worker that she planned to put supports in place to ensure his safety and wellbeing. Another sibling of C's also wanted to remain in the area and C's mother was arranging for her to stay with friends from Monday to Friday. Following this conversation, it was decided at the intake team meeting to take no further action on the referral. This information was conveyed to the Youthreach manager and he was invited to convey any further concerns he might have to the Social Work Department.

Second referral: A further referral was made a few weeks later when the Youthreach manager raised concerns about the arrangements that C's mother had put in place for his younger sibling. A home visit was conducted by the then duty social worker here called Social Worker B. She met with C and his mother. By this time, C's mother had decided to bring the younger sibling with her and she had wondered if C might be placed in foster care by the HSE so that he would not be on his own. Social Worker B talked to C on his own; she found him to be very mature for his age, and very determined to remain in his home town. He told her that his preference would be to live with a family because he was inclined to spend too much time on his own and become isolated. Fostering and supported lodgings were discussed but no undertakings made by Social Worker B. When Social Worker B brought the matter up at the Child Protection Intake Meeting the following day, a long discussion followed and a decision was ultimately made not to provide an alternative care service. A letter to that effect was sent to C's mother.

It emerged from interviews held by the review team with HSE staff that there were differing views on this decision; Social Worker B would have preferred to offer a placement to C because she considered the request for fostering or supported lodgings to be well founded, and that C had the ability and motivation to use it well. Social Worker A was of the view that it would have been helpful to provide the service. However, It was the view of social work management that to take a young person of seventeen and a half years of age into the care of the state and move him into a new parenting environment while his mother was capable of caring for him would not be in the interests of C or his family and could be difficult for him. PSW 2 informed the review team that other frontline staff, apart from Social Workers A and B, agreed with this view. It was considered at that point that C was not a child in need or at risk because his main carer was still looking after him. PSW1 told the review panel that the decision was not made on the basis of resources; this view was later reiterated by PSW2.

Early 2010

Third referral: A further referral was made by the Gardai to the Social Work Department in early 2010. On the report form, the box entitled 'neglect' was ticked as the reason for referral. It transpired that C had got into an altercation in the company of some other young people and the Gardai had been called. The referring garda was concerned on hearing that C was living independently. It was only at this point that the Social Work Department became aware that C's

mother had actually moved out of the area. Over the next two weeks Social Worker A contacted C's mother, who had herself been in touch with the Gardai about the altercation. C's mother was of the view that C's behaviour was illness related because he could act erratically when he was starting to become hypoglycaemic. She said she had been initially annoyed at the way the Gardai had targeted C, but had accompanied him to be cautioned by the Juvenile Liaison Officer and was satisfied that the matter was, at that stage, resolved and that the Gardai were being helpful. She reassured the social worker that she had addressed the problem of C spending time with certain other young people and that there were extra supports in place. She said that he was currently managing well.

Following her conversation with C's mother, Social Worker A contacted the Youthreach manager who told her that C was doing extremely well and appeared very relaxed and happy. Youthreach staff were providing him with food in the evenings as well as during the day and were keeping a careful eye on him. It was decided nonetheless that an initial assessment should be conducted, and the social work team leader undertook to complete this task. She made an attempted home visit in February 2010 but found nobody at home. She told the review team that she had twenty assessments to conduct, and had prioritised this one as the least urgent. For his reason, she was not able to conduct the assessment on C before he died. There was no other contact by HSE Children and Family Services with C.

There is some conflicting information about a telephone call made in respect of C during February 2010 by the Youthreach manager. In mid-February, about two weeks after the aforementioned telephone conversation between Social Worker A and C's mother, C had suffered a hypoglycaemic episode; he was on work experience and out of his normal routine. He became unconscious and was brought to the local hospital, where he was treated. The Youthreach manager told the review panel that he had contacted the HSE Social Work Department with this information. When this was put to the social work team leader, she told us that the Social Work Department had not received that information. She also said it was very unlikely that a message of that nature would not be passed on to her.

12: Analysis of the involvement of HSE Children and Family Services

12.1 Initial response and assessment

As outlined above, there is some dispute as to whether the initial referral specifically mentioned C's diabetes as an issue of concern and as the Standard Reporting Form was missing; it was not possible to verify that it was mentioned. In fact, the social workers told the review that at no time was C's ability to manage his illness on a day to day basis brought up as a risk factor to them. The risk to his health was framed, in their unanimous view, in terms of how it might be affected if his mother insisted on moving him away and he subsequently absconded. The initial referral was addressed by Social Worker A by speaking to C's mother on the telephone. She was satisfied that C's mother had made arrangements for C and subsequently closed the case after writing to the Youthreach manager inviting him to contact the social work department if he had further concerns. On the basis of the knowledge they claimed to have had about C, this seems a reasonable response. It is not possible to say with hindsight what their reaction would have been if they had understood the depth of the

concern held by the Youthreach manager about C's ability to manage his diabetes, but it may have been different.

As outlined in the previous section, the two social workers had a different view to their managers when the question of providing foster care arose. The social workers were inclined towards providing a service but the managers felt it would be an inappropriate response to make to a seventeen and a half year old whose parent was capable of looking after him adequately. They believed that if C's mother decided to move, as she planned, that she had a responsibility to set arrangements in place to meet his needs. As outlined above, the issue of C's compliance with his medication or of his illness presenting a life threatening or child protection risk was not considered by them.

The differing perspectives of the social workers extend to the rationale for the decision against providing a service. The social workers told the review that the refusal was a consequence of scarce resources, in the sense that to provide a service to C would be to deprive another child who may be in greater need. However, the social work managers claimed that the decision was based, not on the availability of resources, but on principles of best practice. It must be also borne in mind that both C and his mother were confident, and expressed this confidence at the time, that C's diabetes would not present an obstacle to his living independently; their concerns were more that he may become isolated and lonely. The social work managers offered the view that concerns of this nature do not meet the threshold for services.

When the Social Work Department received the third referral, Social Worker A contacted the Gardai, C's mother and the Youthreach manager. They ascertained from the Gardai that C was falling into undesirable company and formed the view that, as PSW1 expressed it 'he wasn't doing well', was on the 'neglect' spectrum and required assessment. The social work file shows that both C's mother and the Youthreach manager reassured the duty social worker that C was managing well at that time. He was being provided with meals and food to bring home each day, and a family friend was calling regularly to him. PSW1 told the review panel that there did not appear to be an 'immediate concern' on the basis of these reassurances, and this dissipated any urgency to prioritise this assessment over others. This response seems reasonable to the review team.

The review team was told that during the time span under review, it was not possible to complete an assessment within the timeframe that they considered optimal. However, it was made clear that if the team leader had been carrying a smaller caseload, the initial assessment would have been conducted in a more timely fashion. It was also pointed out that the appointment of additional social work staff in the meantime had alleviated the pressure experienced during the previous year.

12.2 Knowledge about C's diabetes and its impact on his wellbeing

The social workers and social worker managers told the review that they were not only unaware at the time of the risks posed to C by his illness, but were also unfamiliar with the implications of diabetes. They emphasised that the only illness related risk expressed to them had been the possibility that C would have absconded if forced to move with his mother and that his medication regime would be disrupted as a consequence.

C's medical practitioners both told the review panel that there are particular risks associated with adolescent diabetes, particularly with young males, because of a tendency on their part to 'deny' the illness and not to comply with the required treatment regime. They both concurred that C fitted this stereotype, commenting that his attendance at medical appointments was erratic. Both cited examples of where he had either missed appointments or failed to make appointments when asked to do so. The consultant had written to the GP in October 2009, six months before C died reporting that he had missed his last three two-monthly appointments at the diabetic clinic, between April and September. The GP acknowledged that the fact the C was attending both services meant that he may have assumed that C was attending the diabetic clinic, while the clinic may have assumed he was attending his GP and that with such an overlap, 'people can fall between the cracks'. He commented that sometimes letters from the diabetic clinic can take a number of months to reach GPs. When asked if he would normally contact a parent if a young person was missing appointments, the GP responded that it was difficult because doctor/patient confidentiality would not really permit it, and that it was difficult in this case because of C's wish to be independent.

The GP was aware that C was living on his own, but said it didn't ring alarm bells for him at the time as he had assumed that arrangements were in place for him. The hospital consultant told the review that he was not personally that aware C was living alone, but that his registrar had recorded the fact in his notes.

The GP told the review that his surgery was now paying more attention to missed appointments by young people with medical conditions that can change quickly such as diabetes, asthma and epilepsy, and would no longer make assumptions that that they were being treated in another service.

The Youthreach manager told the review that, from the time of the first referral onwards, he had consistently expressed his concern to the Social Work Department about C's ability to manage his diabetes. He said that he had, on several occasions, voiced concerns about C when he was talking to one or other of the social workers about different young people with whom his service was involved. He also said that he made a phone call to the social work department in February 2010 when C had to be brought to hospital following an acute hypoglycaemia. Neither that telephone call, nor the other concerns expressed by him about C's illness were recorded anywhere in the social work files, nor does the Youthreach manager have any record that he voiced them, so it is difficult to make a judgement on this information. While the Youthreach manager is emphatic that he made the telephone call about C's hospitalisation, the team leader is equally emphatic that the department did not receive the message, and that it would be highly unlikely that a message of that nature would go unrecorded or fail to be passed on. She also told the review that such information would have immediately prompted her to expedite her assessment.

Had the relevant social workers and their managers been more versed about the risks associated with 'brittle' adolescent diabetes in males, and the fact that C's attendance at appointments was erratic, their decisions would have been informed by medical evidence and may have been different. The problem at this point was not so much the way in which judgements were made as the fact that they were made in the absence of certain information. Paradoxically, these factors would have been highlighted in an assessment, but the fact that they were at that stage unknown meant that the need for an assessment did not appear to be compelling. The social workers told the review that

they consistently used a standard assessment framework that would have captured information on complex health needs. Conducting an assessment would have required the worker to contact medical personnel and they would presumably then have been informed of the risks associated with adolescent diabetes and also of C's erratic attendance at his medical appointments. They would also have been more keenly aware of the Youthreach manager's view. The social workers and their managers told the review panel that their response in the future to reports about children or young people suffering from diabetes would be quite different.

On the other hand, C's mother told the review that she was well aware of the issues involved in C's diabetes and was confident that they did not present an obstacle to his living alone. She was of the view that people with illnesses should not be denied independent living. C had himself declared his intention to leave home at 18 and was confident of managing his diabetes. It cannot therefore be claimed with certainty that had the initial assessment been completed in time that the outcome would have been different.

12.3 Compliance with regulations

In general, there was no evidence of non-compliance with regulations in this case. However, as later sections will show, there were problems of communication between the Youthreach service and the social work department which give rise to concern.

12.4 Quality of practice

12.4.1 Interaction with the young person and his family.

On the occasion where Social Worker B met with C and his mother, she appears to have engaged well with them, to the point where she was keen to advocate for a service on their behalf. She made a point of speaking individually to C and listening to his perspective on his mother's proposed move and the likely outcome for himself. Both she and Social Worker A expressed the view that a situation like this, where a family was making a difficult decision that appeared to be ultimately in all their interests, should ideally be supported. However, they acceded that this was not the type of service normally provided by HSE Children and Family Services.

The later contact between the team leader and C's mother was, from both their accounts, quite acrimonious and sadly, because of the delay in carrying out the assessment, there was no opportunity for a resolution to occur. C's mother told the review that she was not surprised that the HSE would not provide supports to C when she was planning to move, as her previous experience of the HSE and of Social Services in the UK, was that as long as she demonstrated ability to cope, she got no help. She expressed the view that C had always had special needs that had adversely affected his life and that while she did not believe that inaction by Children and Family Services was responsible for his death, his last few months might have been more pleasant and comfortable if services had been available to him.

12.4.2 Quality of recording

The records in this case are contemporaneous, clearly written and signed. They provide a clear picture of C and his mother. The record is limited because contact between C, his mother and the HSE services was very brief. The fact that the first Standard Reporting Form sent by the Youthreach

manager went missing indicates a shortfall in the storage of information in the Social Work Department.

12.5 Management

Interviews with staff conveyed the impression of a well managed, but pressurised department that was struggling to cope with a high referral rate. In order to avoid a waiting list, efforts were made to allocate all cases reaching the threshold for services, and this included the allocation of a number of cases to team leaders as frontline social workers were carrying unacceptably high caseloads. There appeared to be good management oversight of the work being undertaken at the frontline.

12.5.2 Inter-agency meetings or conferences

There were no inter-agency or multi-disciplinary meetings held to discuss C's situation. It seems reasonable to assume that if an initial assessment had been conducted, the need for multi-disciplinary discussion would have become apparent and opportunities would have been available for the sharing of medical knowledge, information about C's management of his illness, and concerns held by Youthreach staff.

12.5.3 Supervision

It was apparent from the interviews with staff that a lot of support was provided to workers by their immediate line managers, and that an atmosphere existed whereby concerns and views about cases could be aired and debated at regular and frequent team meetings. The physical proximity of the staff members promoted this type of communication. As this case was not allocated for long term work, the issue of supervision is not relevant, but it is evident from the records and interviews that management had oversight of the nature and volume of workers' caseloads, and also of the stresses to which they were subject. The review team were given to understand that formal supervision takes place every three or four weeks between team leaders and frontline social workers, and that peer supervision without managers takes place monthly.

12.5.4 Inter-agency and inter-professional collaboration

As this report has already demonstrated, there were communication gaps in this case. For example, the Youthreach worker told the review that he had informed the HSE of his concerns over C's management of his illness, at the time of initial referral and on other occasions later on. Yet this information does not seem to have been picked up by the Social Work Department. Information conveyed in later telephone call made by the Youthreach manager when C was brought to hospital after falling unconscious was not received by the relevant staff member.

In addition, there was a considerable amount of information in the possession of different health services, some of which are within the HSE. A comprehensive report from CAMHS in 2007 had been provided to Youthreach, but was not in his Children and Family Services social work file. This report gave the results of an assessment conducted on C which indicated that he had some short term memory deficits, and it also gave a history of his behavioural difficulties. As would be expected with a young person who suffered from a chronic illness, C was known to his GP and hospital consultant.

Notes in each setting recorded a high level of non attendance by C at his medical appointments. As outlined in the previous section, coordination of C's treatment between the GP and the hospital was not smooth. His hospital consultant was unaware that C had been living independently from December 2010 onwards. C's last contact with the clinic took place two months before he died, when he was admitted to hospital after a hypoglycaemic episode. On that date, the consultant told him to return in six weeks for review, which would have been on a date approximately two weeks before he died. The norm would be for the patient to make their own appointment with the receptionist on exiting the consultant's room. The hospital has no record that C made an appointment and no further record of his attendance at the clinic. In fact, the hospital consultant was unaware that C had died until he was contacted by the National Review Panel nearly a year later.

Had the medical information been readily accessible to the Social Work Department, it may have expedited the initial assessment.

13. Conclusions

The review team noted the deep regret about C's death expressed by every one of the personnel who participated in the review and acknowledges the impact that this tragic event has had on his family and friends.

- The review concludes that action or inaction by the HSE Children and Family Services was not a contributory factor to C's very sad death. The outcome of an initial assessment, had it been conducted at the time it was planned, may have been the provision of a service or better coordination of existing services. However it is not at all certain that this would have prevented C's death. Nonetheless, the fact that initial assessments can be delayed for a two month period is a cause for concern. The social work managers have pointed out that recent additional posts have relieved pressure and that assessments are now conducted more quickly.

- C was a young person with a complicated personal history who had achieved a great deal but still had needs and would have benefited from assistance in achieving a safe level of independence. His particular needs fell below the threshold for intervention by Children and Family Services and he was receiving exceptional support from Youthreach but there was nevertheless a gap that may have been filled by the provision of, for example a mentoring or youth advocacy service. The lack of such services in the area where he lived is noted.

- The review did not find any lack of compliance with procedures, but found it unacceptable that the initial Standard Reporting Form went missing. There were also communication gaps which had implications for C's physical wellbeing and would have similar implications for other vulnerable young people living in the community with chronic health conditions. For example, the fact that the views of the Youthreach manager about C's medical needs were not picked up by the social work department is a matter for concern. The review was not able to ascertain precisely why this occurred.

- It is not within the remit of this review to evaluate the practices of hospital services or general medical practitioners, but the lack of coordination of services for young people with diabetes was an obvious matter for concern and the lacuna between information held by medical services and its availability to Children and Family Services prior to their embarking on an initial assessment was demonstrated in this case.

14. Key Learning Points

This review has highlighted a number of opportunities for learning for all professions working with children.

- Firstly, it cannot be assumed that if a vulnerable young person is involved with a number of services that he or she is actively engaging with them. The review has shown the importance of knowledge about the risks associated with chronic illnesses in young people, particularly adolescent males. The GP identified diabetes, epilepsy and asthma as three illnesses that can change quickly and he stressed the fact that teenagers are less compliant than adults with the necessary treatment regimes. While responsibility for medical treatment, including follow up of missed appointments, remains with medical practitioners, this information needs to be known and utilised by all professionals.

- The review has also indicated that children or young people who are not at obvious high risk can still require and benefit from other services in the community.

- Finally, although this review has not found any evidence of inter-agency difficulties between the services involved with C, communication problems between them meant that information that could have significantly changed decisions about service provision was not shared or picked up. In addition, a Standard Reporting Form went missing. A key learning point is the importance of careful receipt and storage of information.

16. Recommendations

- The HSE Children and Family Services should adopt a screening tool which would highlight particular issues, such as chronic illness in a child or young person or previous contact with CAMHS which may inform and expedite the process of initial assessment

- The HSE Children and Family Services should draw the attention of the relevant medical authorities to the issues that have arisen in this review in respect of coordination of diabetic services for young people and strategies for the follow up of missed appointments by high risk groups.

- When developing or commissioning services within a local health area, the HSE should endeavour to identify and fill gaps that may exist between community based services and the HSE Children and Family Services so that children and young people who have needs

that do not meet the threshold for child protection will receive an early intervention service through either formal or informal channels.

- The local area needs to improve their strategies for the exchange and recording of information between areas where it concerns children or young people who are vulnerable or at risk.
- The HSE Children and Family Services should introduce mechanisms for the sharing of information between services within the limitations imposed by data protection legislation.

Signed:

Helen Buckley, Chair, National Review Panel

Date: 5-10-11