Review undertaken in respect of a death experienced by a child known to the child protection system:

May 2014

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 Chief Executive Officer of the Child & Family Agency and from there to the National Review Panel. The CEO 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.

HIQA conditionally agreed to this method of classifying cases for a trial period pending the review of the guidance.

4. Child Death.

This review concerns the serious illness and subsequent death of a young child here called John who had a disability and was diagnosed with a serious illness. In this case, the child's family withheld consent for continuation of the treatment recommended by his hospital consultant, opting instead for alternative and complementary medicine. John died in hospital from his illness and no inquest was held.

5. Level and Process of Review.

This was conducted primarily as a desktop review and was carried out by Jean Forbes, panel member and Dr. Helen Buckley, Chair of the NRP. The methodology used was an examination of the written files which were submitted by the social work department (SWD). Consultations were held with two staff members from the Children's Hospital in order to clarify some matters.

6. Terms of Reference.

- To examine the quality of and timeliness of service provided to John and his parents by the HSE SWD and other HSE funded services.
- To examine the level of compliance with procedures, protocols and standards of good practice.
- To provide an objective report to the Child & Family Agency.

7. Details of the Child and his Family.

This case concerned a young child who lived with his siblings and both of his parents. This family had never been involved with social work services until there was a difference of opinion between them

and the hospital regarding the most appropriate treatment for their young child who had a very serious illness.

8. List of services involved with John and his Family.

A) A liaison nurse from a voluntary agency who was in on-going contact with the family.

B) A chiropractor who had been treating John.

C) A home tutor who went to the family home once a fortnight.

D) A consultant in a separate children's hospital who had reviewed the child's disability annually.

E) The family's general practitioner.

F) The hospital in which John's illness was being treated.

G) A legal team for the parents

H) A legal team representing the hospital

I) A legal team representing the HSE.

J) Two separate medical consultants in two separate jurisdictions outside Ireland

K) A practitioner of alternative and complementary medicine who was treating John

L) The hospital medical social work department

M) The HSE SWD

9. Background.

This case involved a young child with a disability, here known as John, who was diagnosed with a serious and potentially terminal illness. His parents agreed to the treatment recommended by the medical consultant in the children's hospital during the acute phase of John's illness but refused consent for the remainder of the treatment programme because they felt it was too difficult for John to endure. Their refusal was regarded by the medical consultant to be endangering the child's prospects of long term survival, in accordance with best practice protocol generally accepted in the developed world.

John's parents believed in alternative and complementary medicine and were convinced that John was better served by this treatment which was more easily tolerated by him, particularly as he had a disability. There was evidence to show that children with this disability are more sensitive to particular treatments and tolerate them less well than other children. The parents also questioned

the diagnosis of John's disease. At the time of referral to HSE Child and Family Services John's condition was relatively stable. The commencement of his recommended treatment had been delayed by five months at the time of referral.

10. Brief summary of John's needs.

There was a fundamental disagreement about John's needs throughout the time the case was open to the HSE SWD. The medical team from the hospital where John was attending, together with the HSE Children and Family Services believed that John needed the conventional standard treatment which was recommended for his illness. His parents disagreed; they believed that the earlier course of conventional treatment had been harmful and put his life at risk. They refused consent for the conventional treatment, and felt his needs would be better served by alternative and complementary medicine.

11. Chronology of contact between John and his family and the HSE Child and Family Services.

When John was almost four years old, a referral was sent to the HSE SWD by the social worker on the medical team in the hospital. The referral outlined the concern of the team that treatment which was considered necessary for John had been refused by his parents some five months earlier. The referral reported that when John was diagnosed with his illness, treatment had been commenced. On the basis of results from tests taken during the initial phase the consultant recommended increasing the intensity of his treatment. This would have involved more hospital visits and more uncomfortable side effects for John. His parents felt this would be too difficult for him to endure and opted to keep him on the less intensive programme.

However, after the initial phase of treatment had been completed, John's parents withdrew consent for any continuation of the treatment programme into the next phase and commenced him on a programme of alternative and complementary medicine under the advice of alternative medicine practitioners. They reported that he was doing quite well with this programme. Over the next few months, John's consultant and the medical social worker attached to his team met regularly with John's parents and tried to convince them of the importance of resuming his treatment. In the meantime, the consultant referred the matter to the hospital ethics committee for direction. The hospital's legal team became involved and offered third party intervention but this was rejected by John's parents. An application to the High Court to dispense with parental consent to treatment was being considered by the legal team and the medical team was keen for this to take place as soon as possible. There were no child protection concerns, and the application would have been for the sole purpose of getting John the life saving medical treatment that he required. However, the legal team ultimately decided that as John was not an in-patient but was living in the community, the case should be handled with by community services and it was subsequently referred to the local HSE Social Work Department (SWD). At this point, John's recommencement of his treatment was five months overdue.

The day after receiving the referral from the hospital, the HSE social work team leader (SWTL) faxed a request to the consultant in charge of the case requesting a medical report outlining his concerns. A record of all meetings and communications with the family in the hospital was sent to the SWD. These had included a meeting with a professor (who was not involved in John's treatment) specialising in the type of illness being experienced by John. The treating consultant also provided a report, which stated his view that without the recommended treatment, John's chances of survival would be reduced by 50%. He also gave his view that a relapse would require him to have more intensive treatment later and would lessen his chances of survival. He added that the hospital had offered a third party review which had been declined by John's parents. The consultant also made the point that discussions with John's parents had been amicable and he understood that the father's views were as strongly held as his own.

The HSE SWD commenced an initial assessment immediately and the HSE legal team became involved. The social work team leader (SWTL) and social worker met John's parents four days after the referral was received by the SWD. The record of this meeting notes that John's parents impressed as committed and as prioritising their child's best interests. They disputed the conventional medical protocol for treatment of John's illness, particularly as it applies to children with John's particular disability. They reiterated their view that the conventional treatment had very adverse side effects which they believed had not been taken sufficiently seriously and they provided details of the alternative therapy they had arranged for him. They expressed their view that the medical profession had little regard for alternative and complementary medicine. They also commented that if John had a relapse, they would then consider further conventional treatment.

As part of the assessment, the SWTL contacted all the services and individuals who were involved in supporting the family in relation to John's disability as well as his illness. No concerns about the family's care for John were expressed, and a very positive picture emerged which portrayed a high level of commitment on the part of the parents to the wellbeing of their children. It was noted that the family had used alternative and complementary medicine since John's birth, but had agreed to conventional treatment for John when his illness had been diagnosed. They saw that it was very harsh for John and this had caused great distress for them. This had led them to seek what they believed was a better way for him. Although the treating consultant was agreeable to John receiving alternative therapy alongside conventional treatment, his parents were not open to giving consent for this as they felt that the two treatments would be incompatible.

The social work team leader spoke to the alternative and complementary medicine practitioner who was treating John. He explained that alternative and complementary medicine looked at why the body produced illness rather than treating the actual illness. He believed that John's father was very well read on the subject and stated that he, the practitioner was very pleased with John's progress.

The social work team leader concluded that the parents were not refusing treatment for their child but had chosen a different type of treatment. The SWD did not consider it

appropriate to remove John from his family's care. The issue of the rights of parents to choose the treatment for their child was given careful consideration in light of the facts put before them. An independent medical review, including an opinion as to the likely consequences of the further delay, was immediately sought. A suitable consultant in a children's hospital in another jurisdiction was identified and agreed to review the case. Two days later information was sent to the independent consultant from both the hospital and the family. All this occurred within two weeks of the referral having been received by the SWD.

It was clear from the social work record that the broader child welfare perspective was considered. It was noted that all the professionals involved considered that John's parents had the child's best interests in mind. It was agreed that the impact of the diagnosis and treatment of John's illness had been traumatic for the family and had led them to seek what they thought to be a better way of managing it.

The report from the independent medical consultant was received seven weeks after the initial referral, although the contents had been conveyed verbally nine days earlier. The independent consultant offered the view that the original diagnosis and treatment plan had been correct and should be continued. He acknowledged the family's concern for the increased sensitivity of children with John's disability to the treatment. However, he was satisfied that the prescribed treatment programme, which had been tailored for a child with John's sensitivities, was the best way forward.

In response to the independent medical review, the child care manager wrote to all the professionals involved, including the lawyers, to the effect that John's parents would be advised about the independent consultant's opinion and asked to give consent for resumption of the already prescribed conventional treatment. The child care manager outlined that should they disagree, the HSE should put the matter before the High Court, requesting that the parents' consent to treatment should be set aside, and seeking an order to allow the HSE to ensure that John resumed the recommended treatment.

Two days later the SWTL and social worker met with John's parents as planned. John's parents maintained their position at that meeting. Further, John's father still queried whether the original diagnosis had been correct. He reiterated that John was currently doing well, and could have any test that would be required to prove this. He repeated his belief that the medical profession held a fixed view, and pointed out that the independent medical consultant had previously written a paper arguing that a significant number of children with the same illness as John were being over treated.

The HSE (i.e. the professionals, senior managers and legal team involved in the case) concluded that in the light of the two medical opinions, it was in John's best interests to undergo the recommended conventional treatment. Subsequently, the SWTL arranged to meet John's parents to inform them of their decision to go ahead with High Court proceedings. It was noted that the SWTL was anxious to preserve a good relationship with the family.

The case was heard in the High Court very soon afterwards. A small number of adjournments were granted to John's parents to allow them to seek further medical opinion. The HSE had reluctantly consented to these in an effort to try and reach agreement without a court order. The further medical opinion was provided three weeks later, and affirmed the prior view of both John's consultant and the independent consultant. Following this the parties conducted discussions through their legal representatives and it was agreed that the treatment would recommence in three days, a medical appointment was arranged and the court case was adjourned. However, the family failed to keep the appointment and it transpired shortly afterwards that John had been taken out of the country by one of his parents with the full consent of the other. The remaining parent described this decision as extremely stressful and sad for their family and stated in an affidavit that as parents, they had felt pressured by the hospital, the HSE and the court to recommence the treatment. They had felt overwhelmed and were unable to go through with it. The remaining parent declined to meet with the SWTL.

The SWTL noted his concerns for the child on file and highlighted questions that he considered needed further investigation. John's name was listed on the Child Protection Notification System. A referral was made by the SWTL to the Gardaí on the basis that the issue of noncompliance with medical treatment represented neglect and was a relevant matter to pursue. A response from the Garda legal section stated that the referral was not in fact a matter for the Gardaí to pursue given that there was no evidence of child abduction or immigration issues involved.

The High Court was made aware that John had been removed from the jurisdiction. However, the Judge declined to make an order in the circumstances, in case it would deter the parent from returning with John and reuniting the family; the Judge believed it was not in the remaining parent's best interests to be separated from John or for John to be in a foreign country. The Judge acknowledged that both the HSE and the hospital had done all they could to secure the child's best interests.

Following the decision of the High Court Judge, the child care manager contacted senior management in Children and Family Services disagreeing with the judgement and expressing his view that the HSE should take the case to the Supreme Court to vindicate John's right to treatment. He believed that the implications of the judgement contravened John's right to life under the UN Convention on the Rights of the Child. However, it was ultimately decided that the options available to the Court might not be workable in the circumstances as it was unlikely that the parents would comply and the execution of orders would be complicated by the fact that John was living in another jurisdiction.

On the basis of the above the HSE decided not to apply for any order but to complete a detailed affidavit for the court. This affidavit was to outline the situation prevailing at the time and their dissatisfaction with the way they were being hampered in the discharge of their duties.

Arrangements were made for the child protection authorities in the country where John now resided to contact him and his parent. However, within a few days, John's parents' legal

representative conveyed the information that John had suffered a relapse. His consultant in Ireland was concerned about the consequences for John if a treatment programme was not started immediately, and he offered, via the legal teams, to provide information to the medical team treating him in the country where he resided. The offer was not taken up.

The social work file records a call made by the social work team leader to the parent who was still residing in this country, to sympathise with both parents on the news of John's relapse and offer any support that the family needed at that time including assistance with travel or any other issues that might be proving difficult. The social worker noted that that the family were still unlikely to allow John to undertake further treatment as they considered it to be too harsh.

The file notes that the HSE had decided at that stage not to initiate an application for compulsory enforcement of medical treatment or for any other order of that type because of the shortness of time and the grave circumstances that then existed for John. It further notes that the HSE recognised that it had a duty to try to be effective in the discharge of its functions and it did not intend to initiate a legal step that would not bring about a positive welfare benefit for this child.

John's parent brought him back to Ireland and he died some time later in a children's hospital. The coroner was informed of the circumstances of his death but no inquest was held.

12. Analysis of involvement of HSE Children and Family Services with this Case.

12.1 Initial response of HSE to this case.

Once the HSE SWD received the referral about John, an immediate response was made. The social work team leader (SWTL) was thorough in gathering information from all the relevant services. He met with the family in a few days and initial legal advice was sought and obtained within eight days.

12.2 Assessment.

The assessment was challenging for the SWD as it involved a disagreement about medical facts and opinions. This was outside the competence of the SWD to evaluate, and required consultation with medical experts. Given the complex legal situation, it also involved consultation with senior management in HSE Children and Family Services. In addition, the SWTL contacted all the services and individuals who had worked with this child and his family and gathered sufficient information to allow a conclusion that John's parents were diligent and caring, and that there were no concerns about his wellbeing other than the matter of their refusal of conventional medical treatment.

The assessment was thorough and reflected the acknowledgment of the social worker and others who were involved, that the period of initial treatment that John had undergone had been very traumatic for his parents, who felt it was endangering his life and believed that the medical team was underestimating his ability to cope with this treatment. It noted their determination not to put him through anymore of this treatment despite assurances from all who were consulted that the next phase of treatment would be less harsh.

12.3 Compliance with regulations.

The HSE SWD operated under the Children First guidance. There was no precedent for a case of this nature. It was clear that the staff involved did everything they could to bring about a different outcome for John and his family.

12.4 Quality of practice.

12.4.1 Interaction with the Child and Family.

The records indicate the interaction with the family by the SWD was mostly with John's father who seemed to be the spokesperson for the couple. There were, however, references to John's mother's refusal of conventional treatment and the notes record that she had been present on at least two occasions. The record indicates that efforts were made by John's parents and by all those who came into contact with them to maintain workable relationships. Mention was made of 'cordial',' amicable' meetings and of 'preserving the good relations which had been built up'. There was a respect for their differing point of view and 'their strongly held beliefs' by both the SWTL and the treating consultant. The HSE agreed, albeit reluctantly, to the adjournment in the High Court to enable the family to get another opinion from another jurisdiction after the second opinion had been reported, out of deference to the family.

12.4.2 Child and family focus.

It was not considered necessary or appropriate to meet John directly due to his young age. It was notable from the records that the SWD perceived a conflict between John's rights and those of his parents, and this appeared to be a strong motivating factor in their approach to the case. In a context where a number of interests were represented in the proceedings, the file reflects that John's welfare was given paramountcy. Difficult decisions were made, and agreements reached in order to preserve John's emotional wellbeing. As outlined previously, strenuous efforts were made to build and maintain an open and amicable relationship with his parents. It was notable that the SWTL contacted John's parent in Ireland to convey sympathy and offer support.

12.4.3 Quality of recording.

The notes in the file were mostly typed and were clear and comprehensive. Unusually in this file there are many legal letters, reports and affidavits as well as medical letters and reports. There was much evidence of the SWD key-working the case, communicating within the HSE as well as with solicitors, barristers and consultants in an efficient way. All the events are well documented.

12.5 Management.

12.5.1 Allocation.

The case was allocated immediately upon receipt of the referral and was held through the nine months until John's sad death by the SWTL leader with the support of the principal social worker, the child care manager and the national office. There was a sense of cohesion within the HSE team who were trying to achieve an outcome which they believed to be in John's best interests.

12.5.2 Inter-agency meetings or conferences.

There were a number of meetings, many of which involved the legal team acting for the HSE and different levels of senior HSE management as well as hospital staff.

12.5.3 Supervision.

The records contain notes of group supervision involving several team leaders and the principal social worker. John's case was discussed and noted at each supervision session. There was also evidence of other informal communication within the HSE. Frontline staff appeared to be well supported by senior management in the HSE as well as local line management.

12.5.4 Inter-agency collaboration.

The record indicates an excellent level of inter-agency communication between the hospital and the SWD and other HSE staff.

13. Conclusions.

The review team acknowledges the grief and stress experienced by John's parents and family, and extends sincere sympathy to them. We also acknowledge the high level of emotion that must have been experienced by all parties involved in this case.

The review has found that the SWD acted promptly in response to the referral of this case. The SWD and the child care manager in particular demonstrated a strong commitment to John's rights under the UNCRC and made every effort to secure the best outcome for him. At no time did they or any other person involved, take any action that may have undermined John's welfare. In the opinion of the review team, neither the HSE nor the hospital staff could have done anything more to prolong John's life.

The review has also found that despite the very difficult circumstances and the gulf that existed between the wishes of John's parents and the opinion of the HSE and hospital professionals, the parties involved worked at all times to secure the cooperation of John's parents and managed to develop and maintain a respectful working relationship. This is commendable, particularly given the very legalistic turn taken in the case.

14. Key Learning Points.

- This case concerns a complex issue that is likely to recur from time to time and raises a number of issues about children's rights and child protection. Considerable efforts were made by those involved to uphold John's rights whilst showing respect for his parents' care and positive intentions for him. The latter is evidenced by the compromises that were offered in order to assist his parents to understand his condition and get further expert medical opinion prior to making an application to the High Court to dispense with their consent. The apparent lack of clarity in respect of whose responsibility it was to take legal action, together with the number of compromises reached with the child's parents caused a delay of several months. This highlights the need to reflect on the circumstances of this case and anticipate a strategy for dealing with similar cases in the future.

- In this case there was evidence of excellent communication between various levels of the HSE. It is likely that this provided support to the staff and it provides an example of good practice.

15. Recommendations.

- The Child and Family Agency should clarify with partner agencies and services the strategy to be adopted when parents refuse medical treatment for their child and clearly outline where responsibility for immediate action lies.

- While it is not in the remit of this panel to make recommendations about the regulation of non Child & Family Agency staff, we suggest that the Child & Family Agency highlight with the appropriate authorities the necessity to regulate practitioners of alternate and complementary medicine who may be involved in the treatment of children's illnesses.

- The review team believes that an inquest in this case would have been a useful exercise particularly in light of its view that while the circumstances of the death of John could be

considered unusual it is the opinion of the review team that similar facts will certainly be presented in the future.

- The review team is legally advised that Section 24 of the Coroner's Act 1962 permits the Attorney General to direct an inquest to be held where she *'…has reason to believe that a person has died in circumstances which in (her) opinion make the holding of an inquest advisable'.* The review team is of the strong belief that the Office of the Attorney General should be made aware of the circumstances presented in this case and of the fact that no inquest has been held and of the view of the review team in this regard, by way of request for a direction pursuant to Section 24 of the Act of 1962 to compel the holding of an inquest.

- It may also be considered appropriate for correspondence to be entered into with the coroner who took the decision not to hold an inquest so as to gain an understanding of why that decision was taken.

Dr. Helen Buckley

Chair, National Review Panel

13th May 2014