

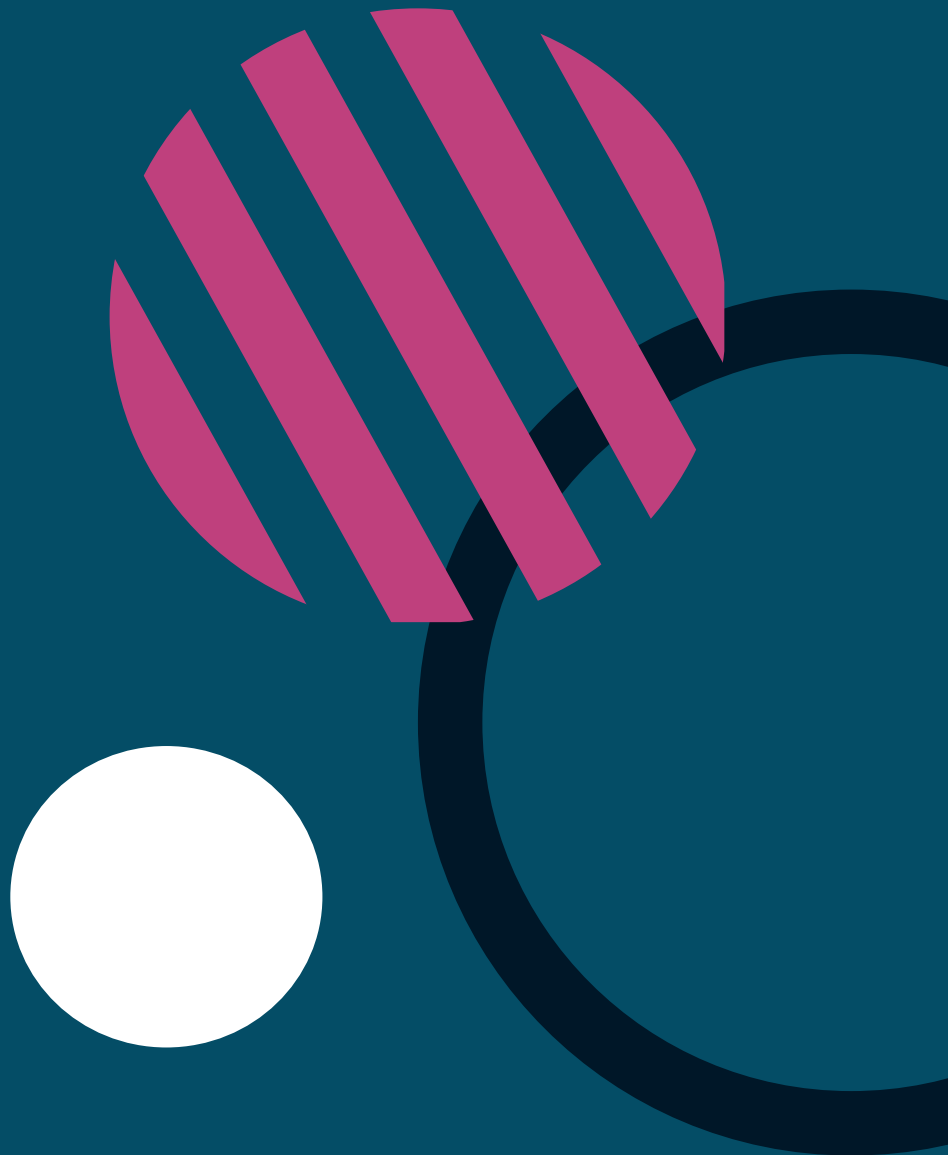


ombudsman
do leanaí
for children

Child Death Review

The Case for a National Statutory Review
Mechanism for the Deaths of Children in Ireland

April 2025



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Abbreviations

2002 Act	Ombudsman for Children Act 2002 (as amended)
CAMHS	Child and Adolescent Mental Health Services
CDOP	Child Death Overview Panel
CHI	Children’s Health Ireland
Committee	United Nations Committee on the Rights of the Child
CSO	Central Statistics Office
DCYA	Department of Children and Youth Affairs
DCEDIY	Department of Children, Equality, Disability, Integration and Youth
DPC	Data Protection Commission
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
ENOC	European Network of Ombudspersons for Children
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IMF	HSE Incident Management Framework 2020
IMP	Tusla Incident Management Policy 2022
NCMD	National Child Mortality Database
NICCY	Northern Ireland Commissioner for Children and Young People
NIMS	National Incident Management System
NRP	National Review Panel
NOCA	National Office of Clinical Audit
NPMA	National Paediatric Mortality Audit
NPMR	National Pediatric Mortality Register
OCO	Ombudsman for Children’s Office
SAO	Senior Accountable Officer
SBNI	Safeguarding Board of Northern Ireland
SIDS	Sudden Infant Death Syndrome
SIMT	Serious Incident Management Team
Tusla	Tusla, the Child and Family Agency
UNCRC	United Nations Convention on the Rights of the Child

Dedication

While we have only included the experiences of six families, this report is dedicated to all the families in Ireland who have experienced difficulties trying to get answers after their children died.

We know that many families are often left in a state of uncertainty, carrying their grief for years and burdened by the knowledge that other tragic deaths may have been prevented if the services could only learn from their experience.

We sincerely hope that the Irish Government and services implement these recommendations in memory of these children.

Section 1: Introduction

1.1 About the Ombudsman for Children's Office

The Ombudsman for Children's Office (OCO) is an independent statutory body established in 2004 under the [Ombudsman for Children Act 2002](#) (2002 Act). The Ombudsman for Children reports directly to the Oireachtas in relation to the exercise of the OCO's statutory functions. Under the 2002 Act, as amended, the Ombudsman for Children's Office has two core statutory functions:

- to promote the rights and welfare of children up to the age of 18 years; and
- to investigate complaints made by or on behalf of a child concerning the administrative actions of public bodies, which have had, or may have had, an adverse effect on the child.

1.2 Rationale for this report

At present there is no definitive figure on the number of children in Ireland who die of unnatural causes each year, and much of the data that is available is dependent on the parents or family of the young person proactively engaging and making the data available.

The National Office of Clinical Audit (NOCA) indicates that 1,490 children and young people aged 18 and younger died between 2019 and 2023.¹ There is no central register for the collection of comprehensive data on children's deaths that could assist in the identification of targeted interventions to prevent further deaths of children.

Since the OCO commenced its work in 2004, we have received numerous complaints about children who have died of unnatural causes and in concerning circumstances. We understand that not all deaths are preventable and there can be tragic outcomes despite timely and considered interventions. However, some deaths are preventable, and we were deeply concerned that, due to the lack of robust review mechanisms, there are missed opportunities to assess policy and practice in protecting children. Some of these children have died by suicide, homicides, drug overdoses, in accidents or suddenly from other unexpected causes.

These include children who had been in the care of the State or who the State had engaged with through one or more agencies. Some of these children were known to State agencies and yet, in too many cases, we do not know how or why they died. Children have also died in contexts not involving public services but in which a duty of care was owed to the child and answers should be provided to their families.

Through the OCO's work to promote the rights and welfare of children, we have also become concerned by the response of State agencies to families of children who die by filicide or familicide. These children may not have been known to State agencies, but their parents were. It is of concern to the OCO that State agencies do not have a review process in place to learn lessons from these cases and to provide families with answers.

¹ National Office of Clinical Audit (2025), *National Paediatric Mortality Register Annual Report 2025: Data from 1 January 2019 to 31 December 2023*, p. 51.

In 2007, the OCO recommended that a mechanism to systematically review child deaths in Ireland be established. To actively progress same, the OCO held a high-level seminar in 2008 to facilitate a discussion among key stakeholders about the possible development of a review mechanism here in Ireland. Subsequently, in 2009 the OCO published an options paper that brought together the key issues identified from those discussions.²

Since then, several mechanisms have been established to conduct reviews of child deaths and serious incidents for children known to our health and social services. Despite these developments the OCO continues to receive complaints from the families of children who have died in unexpected circumstances.

These bereaved families have outlined to us the difficulties and challenges they have faced, and continue to face, in trying to get information and answers about the circumstances of their children's deaths. The recurring themes we hear are that the review mechanisms are ad-hoc, have no legislative or statutory basis and have no compellability or enforcement powers. Families have also told us that there are no consistent timelines for reviews which can further compound their grief, as they may be waiting years for answers. For many families, they simply want lessons to be learned from the tragic death of their child to prevent other families experiencing their pain and uncertainty. However, through our work we also found that there is not even an agreed mechanism to share learnings derived from the various reviews which could help to prevent further deaths.

In line with the State's obligations under the UN Convention on the Rights of the Child (UNCRC), the Irish Government has a duty to respect, protect and fulfil children's right to life, survival, and development. The OCO is of the view that a child death review mechanism is a key part of fulfilling this right, to ensure that deaths of children are examined with a view to identifying lessons to inform preventive strategies. Considering the OCO's statutory function under section 7 of the 2002 Act, to promote the rights and welfare of children, we have produced this report to:

- Highlight the challenges families experience in getting answers from public bodies about the circumstances and context of their children's deaths.
- Show the gaps in legislation, policy and procedures that present obstacles for public bodies when reviewing deaths of children.
- Outline the State's children's rights obligation, as contained in International and European standards, to review the deaths of children.
- Show how Government Departments and public bodies can learn from cases where children have died to inform preventive strategies and save lives.
- Make recommendations on how the issues identified can be addressed.

2 Ombudsman for Children's Office (2009), *Child Death Review Options Paper*.

1.3 Methodology

This report's methodology has two components: a desk-based review of relevant materials and engagement with relevant Government Departments and public bodies. The desk-based review and analysis of documentation for this report included:

- Relevant national legislation and policy.
- Relevant examples from other jurisdictions, including information on child death review mechanisms received from other [European Network of Ombudsperson's for Children \(ENOC\)](#) member states.
- Relevant national and international children's rights standards and guidance.
- Research on child death reviews in Ireland and in other jurisdictions.

Engagement with key stakeholders was conducted to gather information and to understand the perspectives of the different organisations on the limited services that do exist and to explore their views on the need for a national child death review mechanism. The OCO has also met with the Safeguarding Board of Northern Ireland (SBNI) and Northern Ireland Commissioner for Children and Young People (NICCY) to consider practices and developments in that jurisdiction. In this regard the OCO has engaged directly with the:

- Dublin District Coroner's Court
- Department of Children, Equality, Disability, Integration and Youth (DCEDIY)
- Department of Education
- Department of Health
- Department of Justice
- Department of Social Protection
- Health Information and Quality Authority (HIQA)
- Health Service Executive (HSE)
- National Office of Clinical Audit (NOCA)
- National Review Panel (NRP)
- The Child and Family Agency (Tusla)
- Data Protection Commission (DPC)

Importantly, this report has also relied on, and benefited from the families whose children have died and who shared those experiences with the OCO. We are deeply grateful to these families for sharing the stories of their experiences.

Section 2: What happens when a child dies of unnatural causes in Ireland?

2.1 History and background in Ireland

As referenced above at Section 1.2, in April 2007 the OCO contacted the then Minister for Health and Children to recommend that consideration be given to the establishment of a mechanism to systematically review child deaths in Ireland. Following same, the OCO held its high-level seminar in April 2008 to facilitate a discussion among key stakeholders about the possible development of a review mechanism in this State. This led to the publication of an options paper in 2009 that brought together the key issues identified from those discussions.³

The NRP was established in August 2010 as part of the Implementation Plan associated with the Report of the Commission to Inquire into Child Abuse (Ryan Report) to review deaths and serious incidents of children in care.⁴ The NRP is commissioned⁵ by Tusla, and its purpose is to conduct reviews of child deaths and serious incidents for children in care or known to child protection and welfare services. However, it was not established on a statutory basis and, as such, has no powers to compel public bodies to engage with its reviews or to ensure that its recommendations are acted upon.

In 2010, the HSE established the Independent Child Death Review Group to review case files from the HSE and information from coroners' offices relating to the deaths of 196 children in care, aftercare or known to child protection services between 2000 and 2010.⁶ Based on this review, as well as an examination of best practices in child death reviews in other jurisdictions, the report recommended that a Child Death Review Unit be established in Ireland to investigate every death of a child in care, in aftercare, and known to Tusla. It proposed that the unit must be established on a statutory basis, be answerable only to the Oireachtas, be given appropriate powers to compel the production of information and be required to publish the reports on its investigations. It also proposed that the unit should be independent of the HSE who held the statutory responsibility for child protection and welfare services at that time. It recommended that the unit be established within the then Department of Children and suggested that other models were also possible, such as incorporation within the OCO or as function to be discharged by coroners, with the appropriate legislative framework and resources. It also recommended that the mechanism should maintain a register of child deaths to ensure reliable complete data.

A Child Death Review Unit was not established as it was considered that strengthening the NRP and conducting reviews in accordance with HIQA agreed guidance was the most appropriate structure for future reviews.⁷

³ Ibid.

⁴ Houses of the Oireachtas, Dáil Éireann Debate, *Departmental Reports* [16935/15], 29 April 2015.

⁵ Tusla has informed the OCO that it has never undertaken a commission of the NRP and could more accurately be described as administering the funding.

⁶ G. Shannon and N. Gibbons (2012), *Report of the Independent Child Death Review Group*.

⁷ Houses of the Oireachtas, Dáil Éireann Debate, *Departmental Reports* [16935/15], 29 April 2015.

In 2016, HIQA was tasked with reviewing the work of the NRP against published national guidance⁸ and a final report was submitted to the then Department of Children and Youth Affairs (DCYA) and Tusla in January 2017.⁹ Though the report has still not been published, key points made in the report were set out by the then Minister in response to parliamentary questions.

The report found “a number of issues with the NRP in relation to governance matters, with the concerns raised largely relating to matters outside of the control of the NRP and arising from the ad-hoc nature of the Panel’s establishment in 2010.”¹⁰ Among the other issues highlighted include a perception that the NRP was not fully independent; difficulties in accessing files and interviewing personnel for review purposes; as well as governance and structural issues.¹¹ Having considered the options to address the issues identified by HIQA, the Government approved the then Minister for Children and Youth Affairs’ recommendation that the NRP be established as an independent statutory body in November 2018.¹² In February 2019, the Minister for Children and Youth Affairs stated that it was intended that the NRP would have the power to seek cooperation from relevant parties to facilitate access to pertinent files and personnel across relevant agencies.¹³ The Minister noted that DCYA officials had begun the preliminary work to draft the necessary legislation but no timeline was provided for this.

In 2021, the DCEDIY published new guidance on the operation of the NRP,¹⁴ which is intended to serve as interim guidance that will be reviewed immediately and amended as appropriate following a decision by the DCEDIY regarding the operating model of the NRP. The NRP’s annual report in 2023 continues to note that the NRP’s governance, independence and inter-agency cooperation remains an outstanding issue that requires urgent action from the DCEDIY.¹⁵

In November 2023, the DCEDIY informed the OCO that it “is cognisant of the fact that there has been a considerable passage of time since the Government decision of 2018 in respect of the NRP being placed on a statutory footing. In the intervening period there have been several potentially relevant developments, not least the commencement of GDPR. Considering such developments, the Department is actively reviewing the options available, in relation to the most effective model for the NRP function going forward.”¹⁶

8 HIQA (2017), *Annual Report 2016*, p. 2 and p. 31.

9 Ibid.

10 Ibid.

11 Ibid.

12 Dáil Éireann Debates, *Child Abuse Reports* [8748/19 and 8749/19], 20 February 2019; National Review Panel (2019), *Annual Report 2018*, p. 3.

13 Dáil Éireann Debates, *Child Abuse Reports* [8748/19 and 8749/19], 20 February 2019.

14 DCEDIY (2021), *Interim Guidance for Tusla on the Operation of the National Review Panel*.

15 National Review Panel (2024), *Annual Report 2023*, p. 13.

16 Information provided to the OCO by the DCEDIY in November 2023.

2.2 Current child death review mechanisms in Ireland

Coroner Service

The Coroners Service is a network of Coroners located throughout Ireland.¹⁷ Coroners have a duty under the *Coroners Act 1962* as amended to conduct an inquest into a death of a person in their local area and they are of the opinion that the death was unnatural. If the cause of death is unknown or unnatural the Coroner will direct a Post Mortem and will then decide if an Inquest is necessary. Inquests are mandatory in certain circumstances such as when a person dies while imprisoned or in the care or custody of the State and in all cases where the cause of death is unnatural. The purpose of the Inquest is to establish the identity of the person who died, how where and when the death occurred and the circumstances in which the death occurred. The Coroner is not allowed to consider civil or criminal liability, it is the role of the Coroner to determine whether the law requires an Inquest to be conducted.

Coroners sometimes have difficulties in identifying with Tusla and the HSE what information those agencies may have in relation to a child's death and subsequently accessing materials to assist their role. Coroners may make recommendations at an Inquest designed to prevent future similar deaths but the Coroner has no powers to ensure such recommendations are followed.

A review of the Coroners system in 2000 identified the need for major reform of the system.¹⁸ The Irish Council of Civil Liberties have also identified the need for reform to bring the Coroners systems in line with Ireland's human rights obligations relating to the investigation of deaths.¹⁹ Though the 1962 Act has been amended the structure remains largely unchanged since 1962.²⁰ The Department of Justice launched a public consultation on the reform of the Coroners system in October 2023²¹ and the Programme for Government 2025 commits to enact Legislation to establish a modern fit for purpose Coronial system.²²

HSE Incident Management Framework 2020

The HSE Incident Management Framework 2020 (IMF)²³ covers all publicly funded health and social care services in Ireland and its objective is to provide clarity in relation to the roles and responsibilities of staff at all organisational levels and provide learning to improve the quality of services. A Senior Accountable Officer in the region or area where an incident occurs has responsibility for ensuring that an appropriate review takes place in a timely manner. The IMF requires services to manage incidents in a manner which is consistent with the elements and processes outlined in it.

17 Gov.ie, *Coroner Service*.

18 Department of Justice, Equality and Law Reform (2000), *Review of the Coroner Service*.

19 Irish Council for Civil Liberties (2021), *Death Investigation, Coroners' Inquests and the Rights of the Bereaved*.

20 Department of Justice (2023), *Public Consultation on the Reform of the Coroner Service*, p. 4.

21 Ibid.

22 Government of Ireland (2025), *Programme for Government 2025: Securing Ireland's Future*, p. 120.

23 HSE (2020), *Incident Management Framework*.

Acute paediatrics is mainly provided in paediatric departments in general hospitals with inpatient and outpatient care. There are 13 local hospitals and 3 Regional Hospitals outside of Dublin and in Dublin there is 1 hospital – CHI currently delivering secondary and tertiary care in 4 locations (Crumlin, Temple Street, Tallaght and Connolly).

We are advised by the HSE that when a child dies in hospital, specifically in one of the four Children’s Health Ireland (CHI) hospitals, the death is notified to the Significant Incident Review Group where a decision will be made to commission a review or not. If a review is commissioned by the Chief Executive Officer of CHI, it would be conducted in line with the IMF and follow the IMF Comprehensive Review process.

In interview, the HSE did share concerns that the guidance provided by the IMF is not specific in the circumstances of the complexity surrounding child deaths. It was also acknowledged that key performance indicators are not always appropriate, and that there is no agreed methodology for applying the framework and no national joined-up approach to learning on conclusion of such reviews. It was also noted that, when the IMF is invoked, staff, usually at consultant level, must be taken away from their primary duties to conduct reviews which further adds to delays.

HSE National Independent Review Panel (NIRP)

The National Independent Review Panel (NIRP) was set up in 2017 and became operational in 2018. Its purpose is to enable the HSE to undertake reviews when things go seriously wrong for adult or child service users within the HSE community health and social care sector or within HSE funded services. We are advised that the aim of the NIRP review process is to promote learning from cases where there have been serious concerns about the safety and wellbeing of children or adults.

The NIRP reports focus on the identification of changes that could be made relating to how services are commissioned. Those reports suggest what enablers, in terms of changes in legislation and policies, are required and how management systems can be improved to ensure appropriate oversight and accountability arrangements are in place throughout community health and social care services. The NIRP have, at the time of writing this report, completed seven major reviews into serious reportable events where there has been a Serious Incidence Management Team (SIMT) established and an independent review recommended.

A report on the future role and functionality of the NIRP was commissioned by the CEO of the HSE and completed in July 2024. The report was not published but we understand that it made a series of recommendations about its future iteration.

National Review Panel (NRP)

The NRP, established in 2010, was part of the implementation plan associated with the Report of the Commission to Inquire into Child Abuse (2009) commonly referred to as The Ryan Report. The implementation plan had stated that a system needed to be put in place to investigate serious incidents, including deaths of children in care, in order to establish the facts, to learn lessons for the care system and make services safer in future, and to reassure the public.²⁴ On foot of the implementation plan, HIQA published guidance

²⁴ Department of Health and Children (2009), *Report of the Commission to Inquire into Child Abuse, 2009: Implementation Plan*, pp. 36-37.

for the HSE in 2010 on the review of serious incidents including deaths of children in care. This required the HSE to establish a panel of professionals to review cases under specified criteria.²⁵ Revised guidance for the NRP was produced by DCYA in 2013.²⁶

In this context, the NRP is commissioned²⁷ by Tusla for the purpose of investigating serious incidents including the deaths of children in care or known to child protection services. However, governance of the NRP lies with the DCEDIY, as Tusla is mindful of protecting the independence of the NRP. The objective of the NRP is to promote learning and best practice from its review of cases, with the aim of minimising the possibility of similar deaths and/or serious incidents to children and young people using their services. The NRP is independent in the performance of its functions, making findings of fact and producing reports that are objective and independent of Tusla. We are aware that there are currently significant challenges between the DCEDIY, Tusla and the NRP as to the governance and functioning of the NRP.

The interviewees advise that lack of a statutory basis for the NRP does raise challenges regarding the basis for requests for information to inform child death reviews. This is impacting the completeness and timeliness of those processes. In this context it was noted that the HSE's response to the NRP's request for information as part of their reviews is that they should seek the information under Freedom of Information legislation.

While the NRP does engage directly with families the issue of dissemination of NRP reports to families was raised and it was explained that decisions made in respect of same by Tusla are made on a case-by-case basis and very much informed by the details of the case, family views and the information generated during the review. This, it was agreed, results in difficulties responding to parents in the absence of guidance, or pinning down of any process for sharing the report with families, thus some reports are never published.

Tusla Incident Management Policy 2022 (IMP)

The IMP provides for a rapid review process to be carried out internally in the circumstances of serious incidents and/or child deaths. The notification of such a death is inputted on the National Incident Management System (NIMS) and, in keeping with the DCEDIY Interim Guidance for Tusla on the Operation of the National Review Panel,²⁸ the NRP is notified within 3 days. A redacted version of this report is sent to HIQA.

We are informed that the purpose of reviewing an incident under the IMP is to identify learnings which in turn can prevent recurrences of similar incidents in the future.

²⁵ National Review Panel (2011), *Annual Report 2010*, p. 3.

²⁶ Ibid.

²⁷ Tusla informed the OCO that it has never undertaken a commission of the NRP and could more accurately be described as administering the funding

²⁸ DCEDIY (2021), *Interim Guidance for Tusla on the Operation of the National Review Panel*.

Health Information Quality Authority (HIQA)

The 2021 interim guidance for the NRP published by the DCEDIY clearly states that HIQA has no remit to conduct reviews of deaths of children.²⁹ In September 2024, the Minister for Health commenced the *Patient Safety (Notifiable Incidents and Open Disclosure) Act 2023*, which requires health service providers to notify serious patient safety incidents, including unintended or unanticipated deaths, to HIQA or the Mental Health Commission depending on the nature of the incident. Representatives from HIQA noted in interview that this requirement enables it to obtain and use information about incidents for the purposes of improving patient safety.³⁰

Once it receives a notification of a death, the HIQA representatives advise that their agency will review it from a regulatory risk perspective to inform a response. This may involve seeking further information or assurance from health service providers, using the information to inform an inspection, or to inform other appropriate bodies or agencies, where HIQA determines it necessary to do so for the purpose of patient safety.³¹

Gaps in review mechanisms in schools

However, while the above sets out what happens in health and social care settings, there are no robust statutory review mechanisms to review the tragic deaths of children outside of these settings. For example, there is no review mechanism in schools for when a child tragically dies and parents are seeking answers from the school. This is especially relevant for children who may take their own lives due to bullying they experienced. Parents are directed towards the complaints process in the school which are completely inappropriate and indeed may be perceived as an inhumane response for dealing with such requests from grieving parents. It is simply unacceptable that there is no such review mechanism that can seek relevant information from schools. We have raised this issue with the Department of Education and urged them to put in place a mechanism to help school communities review and learn from such tragic deaths and provide much needed answers to bereaved families.

29 Ibid.

30 HIQA (2024), *Guidance for health services providers on notifying HIQA of notifiable incidents under the Patient Safety Act*, p. 4.

31 Ibid., p. 13.

Section 3: Experiences of families

3.1 Jake's story (his real name as requested by his parents)

When Jake was 12 years old, he was diagnosed with Asperger's Syndrome, and was, from time to time, seeing a psychologist at the Child and Adolescent Mental Health Services (CAMHS). Jake's parents told us that overall he was a happy child.

However, Jake began to get anxious about upcoming state exams and his school recommended he see a counsellor, leading his parents to seek help from CAMHS. The psychologist at CAMHS referred Jake to a consultant psychiatrist. At his first appointment on the 31st January 2013, the psychiatrist prescribed a selective serotonin reuptake inhibitor (SSRI) anti-depressant.

Tragically, just over seven weeks later, on 20th March 2013, when he was 14 years of age, Jake was found by his parents in his bedroom with a self-inflicted gun wound. He passed away later in hospital, leaving his grieving family with many questions about how this could have happened.

Experiences of seeking answers from the HSE

Jake's parents spent the next 10 years after his death looking for answers.

They wanted to understand why he was immediately prescribed an anti-depressant on his first visit when they believed he was suffering from anxiety. They wanted to know why there was no patient leaflet information provided with the medication from the pharmacist as they had subsequently discovered that the patient information leaflet advises that with this medication, there is an increased risk of side-effects including suicidal thoughts. They wanted to understand why they were not provided with information about off label medicine use, or about an informed consent procedure.

In this regard they contacted the CAMHS team, they wrote to senior managers in the HSE, lodging a formal complaint through the HSE's complaint handling mechanism "Your Service, Your Say". All to no avail up until 2022 when the HSE finally agreed to carry out a review. However, they were told that this would be limited to a 'lookback review', as a full review was not possible due to the passage of time since his death.

Jake's parents were assured that the lookback review would be completed within 90 days. When that commitment was not kept and, after several months unsuccessfully pursuing the matter with the HSE, Jake's parents complained to the OCO.

We found that there had been poor communication with Jake's family as to the scope of the review, its ongoing status, and what would be shared with them at its conclusion. During our initial enquiries, Jake's parents were subsequently provided with the review report, almost 10 years after Jake's death and 18 months beyond the promised 90-day deadline.

* Pseudonym used to protect their identity.

Jake's parents told us that the content of the review report caused further distress to them. They were upset at what they believed was inaccurate information about how actively suicidal Jake had been and they were frustrated that the consultant responsible for Jake's care had not been involved in the review. There was also no reference to the medications given to Jake, the process in relation to same, nor the lack of written informed consent.

To this day, they remain without the answers they need. His mother told us how they suddenly found themselves fighting a system that should have been helping them to try to join the dots and put in place supports immediately for all involved.

She told us that no parent should have to fight for years and or to hire a solicitor to try get answers. She commented that mistakes can never be learnt from until they are acknowledged, and she believes that families are prevented from grieving whilst having to fight for answers. She tells us that State bodies need to be open and transparent and recognise any shortcomings when dealing with the death of a child.

3.2 Tori*

Tori suffered with scoliosis and severe epilepsy, and this impacted all aspects of her life, at home, at school, and with her peers. She had been on the waiting list for spinal fusion surgery in CHI for several years but experienced multiple delays and remained on the waiting list. Eventually, in 2021, her parents were told by CHI that Tori was too high risk for spinal fusion surgery and efforts to manage her pain was the only intervention that was available to her. Tori tragically died the following year aged 9 years of age.

Her devastated parents had serious questions as to whether delays in accessing consultations with her medical team over the years and extensive waitlists for spinal fusion surgery contributed to her death.

Experiences of seeking answers from the HSE

Tori's parents have been in contact with the Patient Advocacy service at CHI looking to access information about her care over the years. With only limited information being provided, Tori's parents sought to make a complaint to "Your Service, Your Say", the HSE's complaint handling mechanism.

Their daughter died over two years ago but they are still without answers and no review has been conducted, nor a response provided to their complaint.

Tori's parents want a review of her care pathway through CHI. They want to be part of that review, consulted throughout, and they want that review to meaningfully contribute to the care of other children in similar circumstances, in terms of what was done well and what was not done well.

* Pseudonym used to protect their identity.

3.3 Paul*

In March 2023, the OCO received a complaint on behalf of a child named Paul who had died by suicide in 2021, aged 16 years. Paul and his siblings had been in the care of Tusla since 2006 and the children were placed in temporary foster homes between 2006 and 2009. In 2009, Paul was placed in a long-term foster placement where he remained for the next seven years. In 2021, Paul was moved to a residential unit approximately 200 miles from both his foster family and his biological family. Paul's mother informed us that he did not want this move and, shortly after being moved, Paul died by suicide in the residential unit.

Experiences of seeking answers from from Tusla and the NRP

As Paul was in state care at the time of his death, his case was reviewed internally by Tusla and referred to the NRP. Paul's mother is anxiously awaiting the outcome of the NRP review and, in the circumstances of the delay in the review, the complaint was made to our Office. Following our enquiries with the NRP, some clarity was provided in relation to the status of the review, in that we were assured it is near conclusion.

However, at the time of writing this report, the NRP review has not concluded, nearly four years after Paul's death. We are also advised by Tusla that, when the NRP issue them with a copy of the final report, decisions can only be made at that time as to how the information within it will be shared with Paul's mother.

Paul's mother wants the report concluded soon and she wants a copy of it to be provided to her at that time. She wants an explanation as to why the review has taken so long and, importantly, she also wants answers to the questions she raised at the time of Paul's death. Paul's mother has also said that she wants consideration to be given to support for herself and Paul's siblings in the circumstances of what the review might conclude.

3.4 Aoife (her real name as requested by her family)

Aoife was 14 years old when she tragically died in 2015 following a drowning incident at Hook Head, Co. Wexford, whilst on a residential trip with a youth service during Storm Desmond. In 2018, our Office received a complaint from Aoife's mother as no one would answer her questions about what had happened on the day her daughter died. Aoife's mother learned that there was no mechanism she could access and that's why she brought Aoife's case to our attention.

Experiences of seeking answers from the youth service

Aoife's mother told us that she received limited communication from the youth service following Aoife's death and no acknowledgement or apology. Understandably, she was angry that the service declined to provide a report of the incident to the Coroner's Court, and no oversight body was able to hold the service to account, despite it receiving significant state funding.

* Pseudonym used to protect their identity.

Since the time of her death, Aoife's family have continued to seek justice and it took Aoife's mother taking a civil case in 2017 and numerous delays by the organisation before they finally admitted liability, eight years after Aoife's death.

Again, via the legal route in 2025, Aoife's family received a copy of the report commissioned by the organisation in 2020, as well as an offer to meet to apologise for the tragic loss of Aoife. Aoife's family remain unhappy with the report.

Having read the report, Aoife's family remain concerned about this issue as, in their opinion, the organisation does not appear accountable or to have identified any specific learning. Additionally, they are deeply concerned that there was no consultation with the family regarding the report and alleged inaccuracies therein.

Our Office was unable to investigate this complaint under the Ombudsman for Children Act 2002, as amended, as the youth service is not within our remit. Surprisingly, we found that no other organisation has the power to investigate such a serious incident. This highlights a serious deficit in the oversight of such organisations. Thus, the only option open in the tragic circumstances of this case was the civil courts, but that is not an option for everyone, due to the high financial costs. Aoife's mother also feels it is important to highlight that navigating the legal process as a grieving parent is gruelling and she found the system to be cold and callous throughout.

Aoife's mother still has unanswered questions about what occurred on the day of her daughter's death, and she remains clear that she had not given permission for Aoife to attend the venue where the incident occurred. Aoife's mother remains deeply concerned that she had entrusted her daughter into the care of the organisation, and she feels that that trust was breached.

She believes there needs to be a mechanism, that is clear and accessible, for parents and families to be supported through the tragedy of losing a child and one that can address the hard questions that inevitably arise in that context, to learn how future tragedies can be avoided.

Aoife's mother would like organisations that receive state funding to be accountable and to have robust policies, procedures, and oversight in place to protect and safeguard children in their care.

3.5 Bobby*

Bobby was a 15-year-old teenager who died by suicide in 2021. Bobby had been known to the HSE's Child and Adolescent Mental Health Services (CAMHS) and to Tusla's Child Protection and Welfare Services for several years. During this time, Bobby had repeated incidents of self-harming as their mental health deteriorated.

Bobby's parents struggled to try and get much needed mental health supports. After one incident of self-harm, out of desperation, Bobby's parents made the difficult decision to refuse to take them home from the local hospital emergency department until CAMHS and Tusla provided an appropriate service. In this regard, Bobby's parents were concerned that there was no structured, coordinated care plan in place, with services operating in isolation rather than in collaboration. The struggle and distress they had as a family in accessing necessary supports compounded their grief when Bobby subsequently died.

Experiences of seeking answers from the Tusla and the HSE

Bobby's father made a complaint to the OCO in 2024 as the family had been frustrated in getting information and answers from Tusla and the HSE about the circumstances of Bobby's death.

Bobby's father told us that Tusla conducted an internal rapid review of Bobby's case, which he was advised he could not access but which formed part of a referral to the NRP. The NRP did conduct a review, which did involve the family and they produced a report two years later. However, Bobby's parents were only allowed read the NRP report in the presence of Tusla staff and they were not given a copy to keep to read. When we contacted Tusla, we were advised that decisions are made on a case-by-case basis as to what information is shared with families following a NRP review. They could not confirm if Bobby's parents would ever receive a copy of the report and advised that no decision had been made in relation to its possible publication.

Bobby's father advised us that, despite numerous requests, no contact had been forthcoming from the HSE between 2021 and 2024 regarding any review they had conducted into Bobby's death. When we contacted the HSE, we were informed that the CAMHS team responsible for Bobby's care had conducted an internal review under their Incident Management Framework. However, Bobby's parents were not party to this review and were subsequently advised that they would not be provided with feedback on this review, or a copy of it. In these circumstances Bobby's parents had to seek a copy of the CAMHS review through a Freedom of Information request.

Bobby's father has told us that he does not have confidence that services will learn from Bobby's experience, and this may be a missed opportunity to prevent other deaths in the future.

3.6 Baby James*

We received a complaint in May 2023 about a baby boy, James, who had died in September 2022. James was born alongside his twin in June 2022. He was born with Down Syndrome and a heart defect (this had been diagnosed antenatally at 20 weeks), but otherwise was a healthy little boy. Unfortunately, in the days following his birth, his health declined, and he was transferred to a hospital. James subsequently died whilst receiving medical care on the Paediatric ICU ward three months later.

Experiences of seeking answers from the HSE

The family have several concerns regarding the care that James received whilst in the regional and national hospital. They are concerned regarding the transfer and communication of medical diagnosis and treatment between hospitals and how this may have impacted the care James received when he entered the cardiac specialist ward. This has meant that they have queried James's cause of death and therefore remain without a death certificate for him. They have brought their concerns to the coroner but have been unsuccessful in finding a resolution to their concerns. The family have also raised issues regarding the services and care provided to them whilst James was unwell, in preparing them for his death and the social work, bereavement and practical support provided following his death.

They have made several complaints, which have largely been dealt with via the Quality Patient Safety route and National Incident Management Framework (IMF). Through this process, they have attended a variety of meetings with a range of medical professionals who provided care to James between both hospitals. However, this process has been unable to answer the questions that James's mother has around the circumstances that led to his death.

James's family believe that an independent mechanism such as the one proposed would have been beneficial to her and her family following James's death. James's mother further believes that the hospital should provide improved and robust social work services to families, both in preparing families for and following the death of a child. In particular, she has highlighted the lack of appropriate, practical guidance on the steps a parent must take following a child's death. These include practical supports and longer-term signposting to relevant and appropriate services.

Section 4: Children's rights standards and international practices

4.1 Children's rights standards

UN Convention on the Rights of the Child

By ratifying the United Nations Convention on the Rights of the Child (UNCRC) in 1992, Ireland is obliged under international law to respect, protect and fulfil the rights of all children living in Ireland. These rights include the four general principles, which are integral to the realisation of all children's rights under the UNCRC:

- Article 2 provides that all children must be able to enjoy their rights without discrimination of any kind, irrespective of their circumstances or those of their parents/guardians.
- Article 3 requires children's best interests be treated as a primary consideration in all actions concerning them.
- Article 6 recognises children's right to life, survival, and development. In this regard, States are expected to interpret 'development' as a holistic concept encompassing all aspects of children's development and are obliged to provide optimal conditions for childhood.³²
- Article 12 provides for children's right to express their views freely in all matters affecting them and for due weight to be given to children's views, in accordance with their age and maturity.

Of relevance to the absence of a national child death review mechanism in Ireland is Article 6, which requires countries that have ratified the UNCRC (States Parties) to recognise the inherent right to life of every child and ensure to the maximum extent possible the survival and development of the child. The UNICEF handbook on implementing children's rights discusses child death reviews in the context of children's right to life, survival and development under Article 6 of the UNCRC.³³ It states that establishing an obligation and a procedure in legislation for investigating all child deaths reduces the possibility that real causes could be covered up. It notes that where States have set up systematic procedures for investigating all child deaths, many more deaths have been revealed in which some form of violence or neglect is implicated. It notes that adequate investigation informs preventive strategies.

The Committee regards recording information on child deaths as an important facet of a State's obligations under Article 6 of the UNCRC. In its guidelines for States Parties on the form and content of periodic reports that outline how States Parties are implementing the UNCRC, the UN Committee on the Rights of the Child (the Committee) states that information should be provided on the measures taken by States Parties to register

³² UN Committee on the Rights of the Child (2003), *General Comment No.5: General measures of implementation of the Convention on the Rights of the Child*, CRC/CGC/2003/5, p. 4.

³³ UNICEF (2007), *Implementation Handbook for the Convention on the Rights of the Child*, pp. 92-93.

children's deaths.³⁴ It also states that States Parties should provide data, disaggregated by age or age group, sex, location (rural or urban area), minority or indigenous group, ethnicity, religion, disability or any other category considered appropriate, on the deaths of children under 18 years of age:

- a) As a result of extrajudicial, summary, or arbitrary executions.
- b) As a result of capital punishment.
- c) Due to illnesses, including HIV/AIDS, malaria, tuberculosis, polio, hepatitis, and acute respiratory infections.
- d) As a result of traffic or other accidents.
- e) As the result of crime and other forms of violence.
- f) Due to suicide.³⁵

In its list of questions in 2020 ahead of its review of Ireland's children's rights record, the Committee asked the Irish State to provide information in its periodic report on child deaths caused by child abuse and neglect, suicide and accidents, including road accidents and drownings.³⁶ The State did not respond to this question in its periodic report to the Committee in 2022.³⁷

While not specific to child deaths, the Committee has also identified national accountability mechanisms as key for implementing the child's right to health under Article 24 of the UNCRC.³⁸ National accountability mechanism should monitor, review and act on their findings. In this regard:

- o Monitoring includes providing data on the health status of children and reviewing the quality of children's health services.
- o Reviewing includes analysing the data and consulting with children, families, other caregivers, and civil society to determine whether improvements have been made and whether Governments and other actors have fulfilled their commitments.
- o Acting means using evidence emerging from these processes to repeat and expand what is working and to remedy and reform what is not.

In its review of States Parties' implementation of the UNCRC, the Committee has urged certain States to establish statutory child death reviews. The Committee recommended in 2023 that both Finland and Sweden establish inter-agency child death review teams

34 UN Committee on the Rights of the Child (2015), *Treaty-specific guidelines regarding the form and content of periodic reports to be submitted by States parties under article 44, paragraph 1 (b), of the Convention on the Rights of the Child*, CRC/C/58/Rev.3, para. 26(b).

35 Ibid., paras. 1–2 and para. 6.

36 UN Committee on the Rights of the Child (2020), *List of issues prior to submission of the combined fifth and sixth reports of Ireland*, CRC/C/IRL/QPR/5-6, para. 36.

37 Government of Ireland (2022), *Combined fifth and sixth periodic reports submitted by Ireland under article 44 of the Convention, due in 2021*, CRC/C/IRL/5-6.

38 Committee on the Rights of the Child (2013) *General comment No. 15 on the right of the child to the enjoyment of the highest attainable standard of health (art. 24)*, CRC/C/GC/15, para. 118.

with the aim of strengthening preventive measures.³⁹ It similarly recommended that Japan introduce automatic, independent and public reviews of unexpected death or serious injury involving children.⁴⁰ It also recommended that Estonia establish the root causes of child mortality resulting from accidents and injuries and strengthen preventive measures.⁴¹ The Committee has consistently urged the UK to implement robust child death review mechanisms. Since 2002, the Committee has expressed concern over the lack of adequate follow-up on child deaths and recommended statutory child death inquiries in the UK.⁴² While it welcomed the introduction of such reviews in England and Wales, the Committee remains concerned about the absence of these mechanisms in other parts of the UK, particularly for children in custody, care and mental health institutions. In recent years, the Committee has repeatedly called for automatic, independent and public reviews of unexpected deaths or serious injuries involving children in all territories of the UK.⁴³

The United Nations Rules for the Protection of Juveniles Deprived of their Liberty emphasises the importance of an independent inquiry into the cause of death of any child in detention.⁴⁴ Rule 57 states that upon a juvenile's death, their nearest relative has the right to inspect the death certificate, view the body, and determine the method of disposal. An independent inquiry into the cause of death must be conducted and the report should be accessible to the nearest relative. This inquiry is also required if a juvenile dies within six months of release and there is reason to believe the death is related to their detention.

European Convention on Human Rights

The European Convention on Human Rights (ECHR), as discussed in our 2009 [options paper](#), is relevant to the lack of a national child death review mechanism in Ireland. Article 2 of the ECHR states that everyone's right to life shall be protected by law. Section 3 of the [European Convention on Human Rights Act 2003](#) requires all State organs to act in a way that is compatible with the State's obligations under the ECHR. The European Court of Human Rights (ECtHR) jurisprudence on the right to life under Article 2 of the ECHR, particularly the procedural duty to investigate certain deaths, is therefore highly relevant.

39 UN Committee on the Rights of the Child (2023), *Concluding observations on the combined fifth and sixth periodic reports of Finland*, CRC/C/FIN/CO/5-6, para. 15; UN Committee on the Rights of the Child (2023), *Concluding observations on the combined sixth and seventh periodic reports of Sweden*, CRC/C/SWE/CO/6-7, para. 19.

40 UN Committee on the Rights of the Child (2019), *Concluding observations on the combined fourth and fifth periodic reports of Japan*, CRC/C/JPN/CO/4-5, para. 20(c).

41 UN Committee on the Rights of the Child (2024), *Concluding observations on the combined fifth to seventh periodic reports of Estonia*, CRC/C/EST/CO/5-7, para. 19.

42 UN Committee on the Rights of the Child (2002), *Concluding observations: United Kingdom of Great Britain and Northern Ireland*, CRC/C/15/Add.188, para. 41.

43 UN Committee on the Rights of the Child (2008), *Concluding observations: United Kingdom of Great Britain and Northern Ireland*, CRC/C/GBR/CO/4, paras. 28-29; UN Committee on the Rights of the Child (2015), *Concluding observations on the fifth periodic report of the United Kingdom of Great Britain and Northern Ireland*, CRC/C/GBR/CO/5, paras. 28-29; UN Committee on the Rights of the Child (2023), *Concluding observations on the combined sixth and seventh periodic reports of the United Kingdom of Great Britain and Northern Ireland*, CRC/C/GBR/CO/6-7, para. 22.

44 OHCHR (1990), *United Nations Rules for the Protection of Juveniles Deprived of their Liberty*.

Two key aspects of the ECtHR's Article 2 jurisprudence are pertinent to child death review:

- the positive obligation on the State to take preventive measures to safeguard the right to life; and
- the procedural obligation to investigate deaths where the State's ECHR responsibilities might be engaged.

The ECtHR has held that Article 2 not only imposes an obligation to refrain from the intentional and unlawful taking of life but also imposes a positive obligation on States to take appropriate preventive measures to safeguard the lives of those within its jurisdiction. In *Osman v UK*, the ECtHR has held that, for a State to be found in violation of its positive obligations in this regard, the authorities must have known or ought to have known of a real and immediate risk and failed to take reasonable measures to mitigate it.⁴⁵

The ECtHR has also determined that Article 2 of the ECHR, in conjunction with the State's duty under Article 1 to secure to everyone within its jurisdiction the rights and freedoms defined in the ECHR, implies an obligation to conduct effective, official investigations when an individual's right to life has been violated. In *Edwards v. UK*, the ECtHR emphasised that investigations are required not only for deaths directly caused by State agents but also for those resulting from the State's failure to fulfil its duties.⁴⁶

While the ECtHR has not specified the exact form such investigations should take, it has outlined essential principles: investigations must be State-initiated, independent, adequate and capable of determining responsibility,⁴⁷ prompt, sufficiently transparent for accountability purposes, and inclusive of next-of-kin to safeguard their legitimate interests.⁴⁸

Even in cases of deaths where the State's direct or indirect responsibilities under Article 2 are not engaged, systemic problems may have contributed to those deaths. While a full Article 2 investigation might not be necessary in those circumstances, the principle of learning from such deaths to prevent future ones remains valid. To align with the spirit of the ECHR, we should consider moving beyond the minimum ECHR requirements and adopting a preventive approach to child death review.

Implementing a child rights-based approach

To guide States with implementing their obligations to children under the UNCRC, the Committee has identified several broad measures that States need to pursue to implement children's rights in practice. Outlined in the Committee's **General Comment Number 5**,⁴⁹ these general measures include:

45 *Osman v UK* (1998), 29 E.H.R.R. 245, [116].

46 *Edwards v UK* (2002), 35 E.H.R.R. 19.

47 The ECtHR recognises this as an obligation of means rather than result; a criminal trial or other investigative mechanisms may fulfil this obligation in different contexts.

48 *Edwards v UK* (2002), 35 E.H.R.R. 19, [69–73]. See further: Council of Europe (2024), **Guide on Article 2 of the European Convention on Human Rights: Right to life**.

49 UN Committee on the Rights of the Child (2003), **General Comment No. 5 General measures of implementation of the Convention on the Rights of the Child (arts. 4, 42 and 44)**, CRC/GC/2003/5, para. 6.

- **Legislation** – Working to incorporate the UNCRC into domestic law and reviewing existing national legislation to ensure it complies with the UNCRC.
- **Redress** – Putting in place effective, child-friendly procedures for children to pursue remedies for breaches of their rights.
- **Strategy** - Developing and implementing a comprehensive national strategy or plan of action for children that is rooted in and builds on the UNCRC.
- **Coordination** - Putting in place mechanisms to support coordinated action to implement children’s rights among Government Departments and State agencies, between central and other levels of government, and between Government and civil society.
- **Monitoring and assessment** – Monitoring, including independent monitoring, of progress to implement children’s rights, as well as assessing the potential impact and evaluating the actual impact of measures on children and their rights.
- **Data** - Establishing effective and comprehensive systems to collect, disaggregate and analyse data on children.
- **Resources** – Ensuring that public budgets contribute to the realisation of children’s rights in a structured and systematic way, allocating sufficient resources (including financial resources) to implement these rights, and monitoring and evaluating the adequacy of allocations made.
- **Awareness raising and training** – Implementing measures to raise awareness of children’s rights and the UNCRC, including among children, and to provide training on children’s rights to all those involved in implementing the UNCRC (e.g. government officials, parliamentarians, and members of the judiciary) and all those working with and for children.

In developing a child death review mechanism in Ireland to secure children’s right to life, taking a child rights-based approach will be important.

4.2 What happens in countries that do have a child death review mechanism?

Child death review mechanisms across various jurisdictions provide valuable examples of comprehensive, independent processes designed to improve child safety and reduce preventable deaths. The options paper published by the OCO in 2009 examined mechanisms in other countries to inform how Ireland could learn from existing practices in the establishment of its own child death review mechanism.⁵⁰ For the purpose of this report, the OCO surveyed members of European Network of Ombudspersons for Children (ENOC) and conducted a desk-based literature review on mechanisms in Europe and other jurisdictions, to build on the information gathered in the options paper. Of the 44 ENOC members, 12 responded to the OCO’s survey and only 3 (England, Wales and Norway) reported that there is a child death review mechanism in place in their

⁵⁰ OCO (2009), *Child Death Review Options Paper*.

jurisdiction.⁵¹ Among the ENOC members that reported no mechanism in their countries, the Children's and Youth Rights Department at the Office of the Chancellor of Justice in Estonia noted that the Estonian Social Insurance Board, which has statutory oversight powers in relation to child protection and social services, is developing a mechanism to examine deaths of children in specific circumstances. The Ombudsman for Children in Finland highlighted that an investigation into the death of a child in 2013 concluded that Finland should establish a child death review mechanism to learn from child deaths.

We have selected a few examples in this report based on our desk-based research and the response of ENOC members. Though the mechanisms examined as part of this report vary in their form, independence, scope, and methods, many encompass all child deaths up to the age of 18, allowing a broad overview of risk factors and trends, and have their basis in legislation, which offers several advantages. Research on child death review mechanisms in different jurisdictions note that child death review mechanisms are effective when grounded in a statutory framework that:

- o ensures that all aspects of the review processes are standardised.
- o gives mechanisms the power to compel the provision of the information that they need to conduct reviews and eliminates the difficulties that mechanisms face in obtaining information held by various bodies; and
- o enables such mechanisms to follow up on recommendations arising from their reviews.⁵²

Similarly, research notes that the narrow focus of certain mechanisms on deaths in certain contexts, such as deaths of children that were known to child protection authorities, can hinder their preventive potential. It notes, for example, how many mechanisms in the US, which were initially focussed on reviewing the deaths of children who had been victims of abuse and neglect, gradually expanded to cover deaths of all children following calls by stakeholders for an expansion in remit.⁵³

By learning from other countries, Ireland can implement an effective system with a broad remit, ensuring that all child deaths are thoroughly examined to prevent future deaths.

51 The ENOC members that responded to the OCO's survey were the Basque Country, England, Estonia, Finland, Georgia, Kosovo, Latvia, Luxembourg, Montenegro, Northern Ireland, Norway and Wales.

52 J. Fraser, P. Sidebotham, J. Frederick, T. Covington, E. A. Mitchell (2014), *Learning from child death review in the USA, England, Australia, and New Zealand*, *Lancet*, Col. 394, pp. 894-902; S. Vincent (2014), *Child Death Review Processes: A Six-Country Comparison*, *Child Abuse Review*, Vol. 23, pp. 116-129.

53 S. Vincent (2014), *Child Death Review Processes: A Six-Country Comparison*, *Child Abuse Review*, Vol. 23, pp. 116-129.

United Kingdom

In the United Kingdom, child death review mechanisms are in place in England, Wales, and Scotland, though Northern Ireland remains without a fully functioning system.

England

Since 2008, local authorities and Integrated Care Boards in England have been required to implement child death review processes. A total of 58 Child Death Overview Panels (CDOPs) across England are responsible for reviewing the deaths of all children up to the age of 18, in accordance with the [Children Act 2004](#). This process ensures independent, multi-agency oversight aimed at understanding the reasons behind child fatalities and implementing interventions to protect other children and minimise the risk of future deaths. The Department for Health and Social Care has responsibility for policy and guidance on CDOPs. Child Death Review Statutory and Operational Guidance, published in 2018, sets out statutory requirements that must be followed and key features of a good child death review process.⁵⁴ The CDOPs are also covered by statutory guidance on multi-agency working.⁵⁵

A separate process is also in place in England to review the deaths of, and serious incidents involving, children who are in care or where abuse or neglect is known or suspected. These events must be reported by local authorities to the [Child Safeguarding Practice Review Panel](#), an independent public body that is provided with administrative support by the Department of Education.

In 2019, the National Child Mortality Database (NCMD) was established to collect standardised data from CDOPs on all children who die between birth and their 18th birthday. CDOPs are legally obligated to gather this data and submit it to the NCMD. They must collect information from all agencies that interacted with the child, both during their life and after their death, including health and social care services, law enforcement, and educational institutions.⁵⁶ Additionally, CDOPs play a role in supporting the families of children who have died.

It is the view of the OCO that the child death review process in England serves as a strong example of best practice, as the CDOP is based in primary legislation, has the power to gather information from bodies that have information on the child, covers the deaths of all children up to the age of 18, provides support to families of children who have died, and data on child deaths is gathered in a national database.

Wales

Wales has been conducting a National Child Death Review Programme since 2012. This programme involves the collaborative effort of multiple agencies, guided by a strategic steering group that fosters stakeholder engagement and on which the Children's Commissioner for Wales sits.⁵⁷ The programme is operated by Public Health Wales and covers the deaths of all children up to 18 years old. In certain cases, deaths of young

54 *HM Government (2018), Child Death Review Statutory and Operational Guidance (England).*

55 Department of Education, *Statutory guidance: Working together to safeguard children.*

56 National Child Mortality Database (2022), *Child Death Review Data: Year ending 31 March 2022*, p. 3.

57 Public Health Wales, *Child Death Review Programme.*

people aged 18-25 may be included for specific thematic reviews. Rather than focusing on individual cases, the programme delves into broader themes to identify factors that could be modified to prevent future deaths. While the programme has no statutory basis, it has been recommended that it be made statutory, like in England, to ensure comprehensive information can be obtained to maintain oversight of all deaths of children in Wales.

Scotland

Following the establishment of a child death review working group and pilot model in 2014,⁵⁸ Scotland's system for reviewing child deaths was formalised in 2021 with the creation of the National Hub for Reviewing and Learning from the Deaths of Children and Young People.⁵⁹ This mechanism adopts a multidisciplinary approach and is responsible for ensuring that all deaths of children under the age of 18, as well as care leavers up to the age of 26, are subject to rigorous review. The hub builds upon pre-existing review processes, which include a statutorily mandated local authority review of deaths of children in care,⁶⁰ and focuses on improving the quality and consistency of reviews, with a view to channelling insights into actionable changes to reduce preventable deaths. The hub also aims to improve the experiences of, and engagement with, families in the review process, including through provision of information to families on the review process and available supports. Ongoing efforts to update statutory requirements are being made to ensure full, effective multi-agency collaboration and to develop guidance to streamline the review process.⁶¹

Northern Ireland

Northern Ireland currently has a local review process carried out by the SBNI in cases where a child dies or is seriously injured due to abuse or neglect. However, despite the provisions of the [Safeguarding Board \(Northern Ireland\) Act 2011](#), which places a duty on the SBNI to establish an independent child death overview panel, these provisions have never been commenced and a comprehensive child death review system has yet to be fully implemented. While the groundwork exists, progress has been slow. An independent review of the SBNI in 2016 noted broad support in Northern Ireland for the commencement of the child death review function.⁶² However, it recommended a phased approach, with themed reviews initially, followed by progression to individual reviews once the system is working effectively. A 2018 inquiry recommended the introduction of a Child Death Overview Panel in Northern Ireland.⁶³ This recommendation was strongly supported by NICCY, who has repeatedly expressed frustration over the lack of

58 Scottish Government (2014), [Child Death Review Report: Scottish Government Child Death Review Working Group](#).

59 Healthcare Improvement Scotland, [Healthcare Improvement Scotland](#).

60 Scottish Government (2010), [Guidance on Looked After Children \(Scotland\) Regulations 2009 and the Adoption and Children \(Scotland\) Act 2007](#).

61 National Hub for Reviewing and Learning from the Deaths of Children and Young People (2023), [Overview Report: Year 1 \(Implementation year\)](#); Health Improvement Scotland (2024), [National Hub for Reviewing and Learning from the Deaths of Children and Young People – Data Overview Report: March 2024](#).

62 A. Jay and K. Somers (2016), [A Review of the Safeguarding Board for Northern Ireland \(SBNI\)](#).

63 The Inquiry into Hyponatraemia-related Deaths (2018), [The Inquiry into Hyponatraemia-related Deaths Report](#), p. 95.

meaningful progress.⁶⁴ A report published by NICCY in 2022 sets out a new framework for the independent review of child deaths, with proposals for amendments to legislation to provide for a child death overview process. Despite the legislative framework, the statutory duty to review all child deaths—introduced in 2011—remains unfulfilled.⁶⁵

Australia

In Australia, child death review mechanisms are organised at the state level. New South Wales and Western Australia provide notable examples of statutory bodies responsible for reviewing child deaths. In New South Wales, the Child Death Review Team, established in 1996, reviews all child deaths and maintains a statutory register.⁶⁶ The team's focus is on identifying trends and modifiable factors in child fatalities, with statutory powers enabling the collection of relevant information. Similarly, in Western Australia, the Ombudsman – whose remit includes child welfare – has statutory responsibility for reviewing 'investigable child deaths' under the [Parliamentary Commissioner Act 1971](#). An advisory panel supports the Ombudsman, ensuring that lessons are learned from each review and shared across relevant sectors to improve child safety.

New Zealand

New Zealand has conducted child death reviews since 2002 under the oversight of the Child and Youth Mortality Review Committee. This system covers the deaths of children from 28 days old to 24 years of age. A key strength of the New Zealand model is its secure national Mortality Review Database, which compiles data from across the country to identify trends and inform policy decisions. With statutory support from the [Pae Ora \(Healthy Futures\) Act 2022](#), the committee is empowered to compel information, ensuring that reviews are comprehensive and that preventive measures are implemented effectively. Together with Australian child death review teams, New Zealand is a member of the Australian and New Zealand Child Death Review and Prevention Group, which was established in 2005 to develop nationally and internationally comparable child death statistics to better understand and prevent child deaths. The UN Committee on the Rights of the Child has recommended that Australia continue to support the work of this Group.⁶⁷

64 NICCY, [Preventing child deaths: why Northern Ireland must do more](#), 16 December 2019; NICCY (2022), [Statement on Children's Rights in Northern Ireland 3: Main Report](#); Northern Ireland Commissioner for Children and Young People, Children and Young People's Commissioner Scotland and Children's Commissioner for Wales (2022), [Report of the Children's Commissioners of Northern Ireland, Scotland and Wales to the United Nations Committee on the Rights of the Child](#), p. 20.

65 NICCY (2019), [Preventing child deaths: why Northern Ireland must do more](#).

66 The Child Death Review Team is established under the [Community Services \(Complaints, Reviews and Monitoring\) Act 1993](#).

67 UN Committee on the Rights of the Child (2019), [Concluding observations on the combined fifth and sixth periodic reports of Australia](#), CRC/C/AUS/CO/5-6, para. 21.

Norway

Norway introduced a voluntary death scene investigation model in 2010 for sudden, unexpected deaths of children under 4 years of age without criminal suspicion.⁶⁸ The purpose of this model is to help clarify how a child died and to obtain information that can help prevent similar cases. While voluntary, it is guided by established guidelines and complements mandatory police investigations under the 2011 Criminal Procedure Act. This initiative, coordinated by Oslo University Hospital and funded by the Norwegian Parliament, is part of broader child protection efforts. Parents receive detailed information about the investigation process, including being given the option to consent. Research has recommended that the death scene investigations process should be made mandatory.⁶⁹

The experiences of other jurisdictions demonstrate the critical importance of establishing a statutory, comprehensive child death review system in Ireland. By learning from systems in countries like England and New Zealand, where reviews are broad in scope and supported by statutory powers, Ireland can ensure that all child deaths are examined for preventable factors.

68 Oslo University Hospital, *Investigating unexpected deaths of small children*.

69 L. Bøylestad, A. Stray-Pedersen, A. Vege, S. Osberg and T. Rognum (2020), “*Death-scene investigations contribute to legal protection in unexpected child deaths in Norway*”, *Acta Paediatrica*, Vol. 109 No. 12, pp. 2627-2635.

Section 5: Current issues and challenges

The information gathered from research conducted and meetings we had with Government Departments and public bodies show that the different approaches and mechanisms for reviewing children's deaths that do currently exist in Ireland incorporate different stakeholders and methodologies. These play different roles in identifying issues, patterns, gaps in services and potential areas for improvement. Challenges for the effective operation of these child death reviews were also identified.

5.1 Involvement of families, provision of information and lack of supports

The Independent Child Death Review Group noted in its report in 2012 that the involvement of family members in the death review process is vital, with most families eager to contribute.⁷⁰ The OCO's options paper in 2009 had recommended that, when developing a child death review mechanism in Ireland, consideration should be given to the principles underpinning the involvement of family members in the process of reviews, with due regard to the need to deal very sensitively with those who are grieving the loss of a child.⁷¹

This is particularly important in contexts where the purpose for which reviews are being conducted and the expectations of the families are not the same. This can pose challenges for the family involved who are seeking answers as to what happened to their child.

Our research and experience dealing with complaints from families identified challenges with the way in which information is provided to families as part of the child death review process, the type of information provided, as well as how family members are involved in the process itself. There is a lack of clarity for families about the purpose for which reviews are being conducted and what they can expect in terms of the outcome of these reviews.

The level of involvement of families in the different processes varies, as does the information that is provided to families during and after the completion of the review processes. There are often delays in the processes, and even expected delays, such as wait times for the commencement of an inquest, are not outlined to the families involved.

The families that have complained to the OCO also told us about how difficult it was getting practical support from the various services that they were engaged with in the immediate aftermath of their child passing away. While many staff members were kind and empathic, it was a struggle to get answers about what happened to their child and, especially important, whether it could have been prevented. Some families told us that they had to engage a solicitor, which required a significant financial burden but still may not get them answers. They told us how they felt they had to fight a system that should have been helping them. They felt it would be very beneficial to have a specific person from the service to help and signpost them to services they might need, such as bereavement services for their other children, as well as for themselves.

70 G. Shannon and N. Gibbons (2012), *Report of the Independent Child Death Review Group*, p. 387.

71 OCO (2009), *Child Death Review Options Paper*, p. 13.

We also noted an absence of support for the siblings of children who have died. Some processes appoint a family liaison worker to support the family involved, while others don't.

The second pillar of *A Study on Familicide and Domestic and Family Violence Death Reviews* commissioned by the Minister for Justice looked at the provision of supports to families who are victims of familicide. This report has identified the need for the provision of various family supports, both in the immediate aftermath of a death and in the longer term when dealing with the mechanisms in place to investigate these deaths.⁷² Suggested supports were wide ranging and included financial supports for funerals, mental health supports for family members and child-specific supports for children impacted by a death.

The example of the child death review mechanism in England, which has a role in supporting families of children who have died, is a good example of how a mechanism can provide information and support to families as part of the review process.

5.2 No standardised methodology

We note that there is no standard approach in undertaking child death review practices. Existing review processes vary according to where the service is located and whether the review is completed internally or by an external review body. There are differences in:

- the focus of review
- the methodology
- the timelines for completion of the review
- the involvement of the family in the review
- the support to the family during the view
- whether the findings of the review are published and/or provided to the family of the child involved
- what happens with the findings and recommendations that come from the review.

5.3 Review system inadequate to prevent further child deaths

Findings from death review mechanisms can help provide answers for the families of children who have died in unexpected circumstances. They also create an opportunity for public bodies, professionals, and Government Departments to learn from what happened and to put measures in place to reduce the possibility of similar incidents occurring in the future. Reviews can also help identify new trends so that supports can be put in place to address or prevent the recurrence of these trends.

⁷² Department of Justice (2023), *A Study on Familicide and Domestic and Family Violence Death Reviews*, pp 82 - 187.

In 2019, the Minister for Justice commissioned independent research, *A Study on Familicide and Domestic and Family Violence Death Reviews*, which was published in May 2023.⁷³ One of the two pillars of the study focuses on international best practice in the conduct of domestic homicide reviews. When outlining the purpose of the different death review mechanisms reviewed, it stated that “*broadly speaking, they share the objective of learning from the circumstances of domestic and/or family deaths to identify how the domestic and family violence system can change for the ultimate purpose of preventing such deaths in the future.*”⁷⁴

However, it is unclear as to whether the learnings from the existing review mechanisms are put to such use in a systematic way. The impact of the learnings that can come from review mechanisms are also reduced where there are significant delays in completing these reviews or by limited publication or circulation.

5.4 Lack of statutory underpinning for reviews

The lack of a statutory basis for reviews in Ireland brings challenges, including regarding the independence of the mechanism, accountability, and the lack of a legal basis to ensure that relevant bodies cooperate and provide the necessary information to inform child death reviews. The Independent Child Death Review Group had already identified in its report in 2012 that a lack of inter-agency information sharing is one of the great obstacles to successful death review structures.⁷⁵ It noted that providing statutorily enshrined powers to a child death review mechanism to compel information from whom it is required is the only manner in which to guarantee the provision of necessary information.⁷⁶ In a report commissioned by the OCO in 2007, Kilkelly recommended that a child death review body be established as an independent statutory body with full powers to investigate how a child died, who is responsible, and make binding recommendations to prevent such tragedies reoccurring.⁷⁷

The lack of a legal authority to compel cooperation from services and the provision of records held by services was cited as early as the first year of the NRP’s operations.⁷⁸ The NRP noted in its 2011 annual report that invitations for interviews were refused by some services and that the authority upon which the NRP requested participation or access to records had been queried.⁷⁹ The NRP noted that this hindered the NRP’s ability to properly investigate a case and that this was a matter of considerable concern. HIQA’s review of the NRP in 2016 also identified accessing files for review purposes among the issues faced by the NRP in carrying out reviews.⁸⁰ The NRP has raised the issue of access to records again in its reports from 2019 onwards, citing challenges in the ability of the NRP to access records and to secure participation from services that are neither managed nor funded by Tusla, with the NRP noting that GDPR is cited by these services

73 Department of Justice (2023), *A Study on Familicide and Domestic and Family Violence Death Reviews*.
74 Ibid., p. 227.

75 G. Shannon and N. Gibbons (2012), *Report of the Independent Child Death Review Group*, p. 386-387.

76 Ibid.

77 Kilkelly (2007), *Barriers to the Realisation of Children’s Rights in Ireland*, pp. 109-110.

78 National Review Panel (2012), *Annual Report 2011*, p. 9.

79 Ibid.

80 Houses of the Oireachtas, Dáil Éireann Debate, *Child Abuse Reports* [8748-8750/19], 20 February 2019.

as a barrier to providing information.⁸¹ The NRP has stated that these issues will only be fully resolved when the NRP is established as a statutory body.⁸²

The OCO recognises the NRP has undertaken 124 reviews since 2010 and has made significant positive contributions to the child protection and welfare system since its establishment, however, the lack of a clear governance structure also means there are no mechanisms in place to address operational issues within the NRP, such as resourcing and reporting on key performance indicators. Tusla's responsibility to engage with the NRP is also blurred, with no agreed timelines for the provision of information, no agreement about who will be able to access the report nor any process for reporting on the impact of recommendations.

A Study on Familicide and Domestic and Family Violence Death Reviews recognises that a legislative mandate is crucial for review teams to have an impact.⁸³ It outlines how legislation may specify the purpose and structure of reviews, key stakeholders who should be involved, provisions for information sharing, confidentiality and how review teams may be protected from liability.⁸⁴ This study makes express reference to the issues faced by the NRP in seeking information and has stressed the importance of a review team having a legislative basis to gather the information necessary to complete reviews.⁸⁵ This study recommends that the proposed review mechanism should be empowered to seek and receive information from any person or entity that may have relevant information.⁸⁶ As regards the location of death review mechanisms, this report stated that *"it is key that they are independent, have authority and are adequately resourced."*⁸⁷

5.5 Data gaps

The collection of sufficient and reliable data on children, disaggregated to enable identification of discrimination and/or disparities in the realisation of rights, has been identified by the UN Committee as an essential measure for implementing children's rights.⁸⁸

As the OCO noted in its options paper in 2009, the nature of data that can be obtained by a child death review mechanism is heavily dependent on the structures and protocols already in place for recording and sharing information on child deaths.⁸⁹ The OCO recommended at that time that existing sources of information on child deaths should be evaluated to determine their accessibility and whether gaps need to be addressed.

81 National Review Panel (2020), *Annual Report 2019*, p. 5; National Review Panel (2021), *Annual Report 2020*, p. 6; National Review Panel (2022), *Annual Report 2021*, p. 18; National Review Panel (2024), *Annual Report 2023*, p. 13.

82 National Review Panel (2020), *Annual Report 2019*, p. 5.

83 Department of Justice (2023), *A Study on Familicide and Domestic and Family Violence Death Reviews*, p. 230.

84 Ibid., p. 231.

85 Ibid., p. 262.

86 Ibid., p. 264.

87 Ibid., p. 241.

88 UN Committee on the Rights of the Child (2003), *General Comment No. 5 General measures of implementation of the Convention on the Rights of the Child (arts. 4, 42 and 44)* CRC/GC/2003/5, paras. 48-50.

89 Ombudsman for Children's Office (2009), *Child Death Review Options Paper*, p. 14.

The current situation is as follows:

- The **Civil Registration Act 2004** requires all deaths in Ireland to be registered within 3 months of the date of the death, but the Department of Social Protection say that this legal requirement is met in four out of five cases.⁹⁰ The family of the person who dies is required to register the death by completing a death notification form provided by a medical practitioner. This form is submitted to the Civil Registration Service, which issues a death certificate. Certain deaths must be referred to the coroner. Where the coroner is notified, this will result in a delay in registering the death, although the coroner may provide an interim death certificate. Where the coroner directs that an inquest or post-mortem examination be carried out, the coroner will determine the cause of death and send the civil registration service a coroner's certificate to register the death.
- The **Civil Registration (Electronic Registration) Act 2024** states that all deaths will be electronically notified by medical officials to the General Register Office within 5 working days. However, this Act has not yet been fully commenced. From the interviews conducted for this report, we understand that the HSE are currently developing an IT programme to allow the registration process to happen, but this may take up to a year to advance.
- The National Paediatric Mortality Register (NPMR) compiles and analyses data relating to child deaths in Ireland.⁹¹ The aim of the NPMR is to provide a national database of all deaths of children and young people in Ireland, generating data to provide an evidence base with the aim of driving improvements in the quality of care and services for children in Ireland and ultimately reducing the number of unnecessary deaths. The NPMR evolved as an extension of the work of the National Sudden Infant Death Syndrome (SIDS) Register. Based in CHI from 1992, the SIDS Register collected data on all sudden unexpected deaths in infants aged under 2 years and conducted a population-based case control study of risk factors for SIDS in the Irish paediatric population. Subsequently, the SIDS Register's remit and data collection system was extended to include all paediatric deaths regardless of cause and age and renamed as the NPMR in 2010, with the primary objective of addressing preventable deaths in all age groups.⁹² In 2020, the NPMR was transferred from CHI to NOCA.⁹³

90 General Register Office (2021), *Consultation on the revision of the method by which deaths are notified and registered in Ireland*, p. 1.

91 National Office of Clinical Audit (2023), *National Paediatric Mortality Register 2023: A review of mortality in children and young people in Ireland*, p. 70.

92 National Paediatric Mortality Register (2015), *Statistical Report 2015*; National Office of Clinical Audit (2023) *National Paediatric Mortality Register 2023: A review of mortality in children and young people in Ireland*.

93 National Office of Clinical Audit (2023), *National Paediatric Mortality Register 2023: A review of mortality in children and young people in Ireland*, p. 25.

The Central Statistics Office (CSO) gathers and reports annual data on deaths occurring in Ireland disaggregated by age.⁹⁴

Deaths of children under 18 years of age (2007 - 2022)⁹⁵			
2007	453	2015	369
2008	504	2016	359
2009	436	2017	329
2010	436	2018	313
2011	409	2019	327
2012	416	2020	311
2013	402	2021	309
2014	396	2022	313

The CSO also reports data on deaths disaggregated by the place of occurrence and cause of death.⁹⁶ Of the deaths of children in 2022, the CSO reports the place of occurrence as follows:

Place of death of children under 18 years of age (2022)⁹⁷	
General and Orthopaedic Hospitals	82
Private Hospitals	2
Maternity Hospitals	82
Paediatric Hospitals	81
Domiciliary	56
Elsewhere	7
Hospices	3
Total	313

94 Central Statistics Office, [VSA111 - Revised Deaths Occurring](#).

95 Ibid. (data retrieved 22 January 2025). This data contains late-registered deaths and is revised over time to include any further late-registered deaths the CSO receives.

96 Ibid.

97 Data provided by the CSO to the OCO on 7 February 2025.

Of the deaths of children in 2022, the CSO reports the cause of death as follows:

Cause of death of children under 18 years of age (2022)⁹⁸	
Infectious and parasitic diseases	8
Neoplasms	35
Diseases of the blood and blood forming organs and certain disorders involving the immune mechanism	1
Endocrine, nutritional and metabolic diseases	6
Mental and behavioural disorders	1
Diseases of the nervous system	17
Diseases of the circulatory system	11
Diseases of the respiratory system	10
Diseases of the digestive system	1
Diseases of musculoskeletal system and connective tissue	1
Certain conditions originating in the perinatal period	85
Congenital malformations, deformations and chromosomal abnormalities	79
Symptoms, signs and abnormal clinical and laboratory findings not elsewhere classified	22
Codes for special purpose	1
External causes of injury and poisoning	35
Total	313

⁹⁸ Data provided by the CSO to the OCO on 7 February 2025. Further information on the cause of death categories is available here: WHO, [International Statistical Classification of Diseases and Related Health Problems 10th Revision](#).

Using data obtained from the CSO, the State of the Nation’s Children report published by the DCEDIY presented data on the cause of death of children in 2022 disaggregated by age group under 18.⁹⁹

Deaths of children by cause of death and age group (2022)¹⁰⁰						
Age	< 1	1–4	5–9	10–14	15–17	Total
Malignant neoplasms	1	2	11	11	9	34
Certain conditions in the perinatal period	84	0	0	0	1	85
Congenital malformations	69	5	1	2	2	79
Sudden infant death syndrome	16	0	0	0	0	16
External causes of injury and poisoning	0	8	4	10	13	35
Other causes of death	18	17	6	12	11	64
Total	188	32	22	35	36	313

99 DCEDIY (2024), *State of the Nation’s Children, Part 1 Sociodemographics*, p.10.

100 Ibid.

NOCA provides further information on trends over time in the deaths of children under 18 years of age in its reports on the NPMR. NOCA indicates that 1,490 children and young people aged 18 and younger died between 2019 and 2023, which was broken down as follows:¹⁰¹

Deaths of children by cause of death, sex, age group and place of death (2019-2023)					
Age	<1 year	1-4 years	5-9 years	10-14 years	15-18 years
Total Deaths	898 (60.3%)	115 (7.7%)	101 (6.8%)	131 (8.79%)	245 (16.4%)
Boys	53.2%	55.7%	62.4%	62.6%	67.8%
Girls	46.8%	44.3%	37.6%	37.4%	32.2%
Place of Death	92.5% in-hospital	63.2% in-hospital			37.4% in-hospital
	6.1% at home	30.8% at home			45.5% at home
	0.7% scene of injury/other	2.6% at scene of injury			9.8% at scene of injury
	0.8% at hospice	2.3% at hospice			2.5% at hospice
		<0.5% other			4.9% other

Data is also available for the deaths reviewed by the NRP, with 29 deaths of children and young people in care, aftercare or known to Tusla notified in 2023 – an increase of 6 compared to 2022.¹⁰² Of these, 18 died of natural causes, including sudden infant death syndrome, 4 died by suicide and 5 in accidents. 2 were categorised as unknown, as the coroner or post-mortem had not reached a conclusion for cause of death.¹⁰³

Research conducted by NOCA has highlighted that there is no centralised database for timely reporting and analysis of data on child deaths and there is no existing dataset that provides the complete and accurate national data that would be required to conduct

101 National Office of Clinical Audit (2025), [National Paediatric Mortality Register Annual Report 2025: Data from 1 January 2019 to 31 December 2023](#), pp. 40-41, 51-52; National Office of Clinical Audit (2025), [National Paediatric Mortality Register Annual Report 2025: Data from 1 January 2019 to 31 December 2023 - Appendices](#), pp. 7-9. NOCA notes that this data is subject to change following revision, as the data is based on year of registration and may differ from final figures for each year in which the deaths actually occurred.

102 National Review Panel, [Annual Report 2023](#), p. 5.

103 Ibid.

an informed national audit of the deaths of children and young people in Ireland.¹⁰⁴ This research has also found that data reported to the CSO, which gathers data on death certification, lacks the detail to thoroughly describe the main causes of child deaths and factors that contribute to these deaths.¹⁰⁵ NOCA also notes that data is subject to inaccuracies relating to the categorisation of some deaths.¹⁰⁶ The lack of disaggregated data has also been identified as an issue in investigating mortality rates in subgroups of the population, for example the Traveller and Roma communities, in which higher mortality rates and suicide rates have been identified.¹⁰⁷

Delays in registering child deaths creates further issues in collecting complete data. It is currently a legal requirement to register deaths within 3 months of the death,¹⁰⁸ unless an inquest is being conducted.¹⁰⁹ NOCA notes that delays in the registration of deaths mean that data on deaths in any given year are not available until several years following a death.¹¹⁰ Although not yet commenced, the Civil Registration (Electronic Registration) Act 2024 provides that all deaths will be electronically notified by the relevant medical officials to the General Register Office within 5 working days from the date of death¹¹¹ and next-of-kin will be notified of their duty to register the death within 28 days, either in-person or through electronic means.¹¹² While the Department of Social Protection has stated that this will help ensure accurate and timely gathering of death information,¹¹³ it is unclear as to whether the information recorded will be sufficient to provide the complete and accurate data required to conduct an informed national audit of the deaths of children and young people in Ireland.

A Study on Familicide and Domestic and Family Violence Death Reviews notes the importance of data and has recommended that a national database should be established to report on domestic and family violence deaths, as well as domestic abuse and violence.¹¹⁴ It recommends that the review body should work with the CSO and others to develop a minimum dataset for national reporting on domestic and family violence deaths and that this data should be used to routinely report on domestic and family violence deaths in Ireland.

NOCA have outlined that lack of data or incomplete data, results in an inadequate understanding of why children die in Ireland. Standardised data triangulated from multiple sources in a timely fashion is required at the national level to identify issues and trends in child mortality and assist in the development of intervention policies. For example, NOCA

104 National Office of Clinical Audit (2023) *National Paediatric Mortality Register 2023: A review of mortality in children and young people in Ireland*, p. 12 and 46.

105 Ibid., p. 16 and p. 23.

106 Ibid., p. 23.

107 Government of Ireland (2024), *Statistical Spotlight No.13, Child and Youth Mortality in Ireland*, p. 10.

108 Department of Social Protection (2023), *Register a death in Ireland*.

109 Department of Justice (2021), *Register a death with the Coroner*.

110 National Office of Clinical Audit (2023), *National Paediatric Mortality Register 2023: A review of mortality in children and young people in Ireland*, p. 23.

111 Section 14 of the *Civil Registration (Electronic Registration) Act 2024*.

112 Section 11 of the *Civil Registration (Electronic Registration) Act 2024*.

113 Department of Social Protection, *Legislation to reform Ireland's Civil Registration System enacted*, 19 July 2024.

114 Department of Justice (2023), *A Study on Familicide and Domestic and Family Violence Death Reviews*, p. 79.

emphasised the need for more detailed classification data on children that die in road traffic accidents, which accounted for 26.5% of trauma-related deaths of children aged 1 to 14 and 13% in children aged 15-18 between 2019 and 2023.¹¹⁵ This information could inform public safety awareness campaigns leading to behaviour change and less preventable deaths.¹¹⁶

5.6 Lack of inter-agency cooperation

The cases that have come to the attention of the OCO highlight the lack of inter-agency cooperation in the review of child deaths among the different agencies and professionals involved, including in:

- relation to the sharing of relevant information and data;
- identifying who holds relevant information;
- establishing a shared understanding of obligations when engaging with review processes; and
- making decisions that are centred on the children who have died and their families.

These issues highlight the challenges faced by review mechanisms operating in the absence of a statutory underpinning. They also highlight the need to secure full and open participation from different agencies and professionals involved in cases that are subject to review, including those in both the public and private sector.

The importance of strong inter-agency cooperation and coordination has been identified as a necessity for the effective operation of death reviews.¹¹⁷ However, it is also recognised that there may be constraints on public information sharing if criminal proceedings are outstanding, as it may not be possible to provide information to a review mechanism until legal proceedings are completed.¹¹⁸

115 National Office of Clinical Audit (2025), *National Paediatric Mortality Register Annual Report 2025: Data from 1 January 2019 to 31 December 2023*, p. 66 and 68.

116 Ibid., p. 14 and p. 109.

117 Department of Justice (2023), *A Study on Familicide and Domestic and Family Violence Death Reviews*.

118 Ibid., p. 237.

Section 6: Conclusions and recommendations

In line with the State's obligations under the UNCRC, the Irish Government has a duty to respect, protect and fulfil children's right to life, survival and development. A child death review mechanism is a key part of fulfilling this right by ensuring that deaths of children are reviewed with a view to informing preventive strategies. Several children's rights and welfare organisations, experts and healthcare professionals have consistently recommended the introduction of an independent, statutory child death review mechanism in Ireland over the last 20 years.

It is unacceptable that there is no clear pathway for parents to seek answers when their child dies unexpectedly. This includes pathways for parents of children with life limiting conditions who die unexpectedly; the deaths of these children should be treated the same as any other unexpected death, to determine cause of death and any contributory factors.

The current systems need significant reform.

This report sets out a series of recommendations that call on the State to introduce a statutory mechanism to review the deaths of children in Ireland and that will inform the State's work to achieve this, building on recommendations previously made in this regard by the OCO and other organisations.

6.1 Recommendations

Planning for the future

1. A statutory review mechanism for child deaths should be set up in Ireland

We welcome the commitment in the Programme for Government 2025 to establish a statutory national child death review mechanism.¹¹⁹ We urge that this is progressed without delay and that a lead Department be assigned to deliver it. This lead Department should report on progress into the Cabinet Committee on Children, Disability and Education who is overseeing the Programme for Government commitments relating to children. This should be informed by the views of families that have experienced such reviews under the current system.

Consideration should be given to whether this statutory review mechanism should be established within an existing body or as a separate entity. Most importantly, it should complement and not duplicate, other review mechanisms. It should have the dual purpose of reviewing individual cases which can bring to light systemic problems that place children at risk and from which lessons can be learned, as well as gathering data relating to the total number of child deaths; identifying the leading causes of preventable deaths; and the groups of children and young people most affected.

¹¹⁹ Government of Ireland (2025), *Programme for Government 2025: Securing Ireland's Future*, p. 65.

2. A road map to set up a review mechanism

The allocated lead Department should set up a cross departmental working group without delay to progress the introduction of the child death review mechanism. This working group should include, at a minimum, the DCEDIY, the Departments of Health, Justice, Social Protection and Education, as well as existing child death review mechanisms referenced in this report. Of note is the work currently underway by the Department of Justice in implementing the recommendations of A Study on Familicide and Domestic and Family Violence Death Reviews, which may provide useful insights. This should be informed by the views of families that have experienced such reviews.

6.2 Immediate actions pending set up of a national review mechanism

3. Guidance on best practice in undertaking child death reviews

A key priority of this interdepartmental working group should be the immediate development of interim national guidance on best practice in conducting child death reviews. This should be informed by the views of families that have experienced such reviews and specifically include provision to conduct joint agency reviews. It should be applicable to all agencies in receipt of government funding.

This interim guidance should be subsequently placed on a statutory footing in the future as part of the new statutory child death review mechanism.

4. Support for families

Services must actively engage with and provide a liaison person for the families of children who have died unexpectedly and facilitate them to access any support they may need. They should also:

- Provide practical support and information on next steps when their child dies.
- Offer financial support for funeral arrangements if required.
- Arrange bereavement support for parents and surviving siblings.
- Provide information for families outlining how the current review processes work, what information they can expect to receive at the end of the process, what their engagement in the process will look like, and how long the process should take.

5. DCEDIY and the National Review Panel

The NRP was never established on a statutory basis and this fundamental flaw has greatly impacted its ability to undertake its work effectively with limitations in accessing information, engaging with other agencies and fundamental governance. It can no longer continue in its current form. The DCEDIY must immediately engage with the Ombudsman for Children's Office to find a resolution pending the establishment of the new statutory child death review mechanism.

6. Look Back: Status of current reviews of children known to Tusla, services who have died unexpectedly

- Tusla must take steps to be assured that all current and pending child deaths have been reviewed in accordance with their policies and notified to the NRP. Reports from the NRP should be shared with families and every effort must be made to remove barriers preventing same.
- They should also develop a framework to support the implementation of key and relevant recommendations arising from previous National Review Panel reports, that may help prevent further deaths.

7. Looking forward: Addressing current shortcomings known to Tusla

Tusla should take the following steps:

- Develop a framework to support the implementation of recommendations in reducing deaths.
- Ensure that findings and recommendations from NRP Reports are shared with families and address any barriers to same.
- Strengthen existing inter-agency relationships, especially between HSE and Tusla, so that joint reviews can occur when a child dies and is known to both agencies. It is important that there is a structure in place to share learning with other agencies from reviews that may prevent further deaths.
- The Quality and Regulation Directorate should ensure the NRP receives all necessary reports and documents within specific timelines to help inform their decision making and progress their reports, and update policies to reflect same.

8. Look back: Status of current reviews of children in HSE services who died unexpectedly

- The HSE must take steps to be assured that all current active and pending child death reviews in their services and funded services are completed in accordance with their policies, and all outcomes shared with families.
- The HSE should take steps to be assured that any recommendations arising from such reviews have been implemented and learning disseminated across relevant services.

9. Looking forward: Address current shortcomings in undertaking reviews within the HSE

- The HSE should immediately address the current shortcomings in how they review unexpected deaths of children known to their services due to the lack of a consistent approach across services.
- Pending the development of the national guidance, the HSE should review its current incident management policy alongside the findings from the commissioned review into the National Independent Review Panel. The outcome of this process should ensure child death reviews are completed in a consistent and timely manner and that findings and recommendations are shared with families.

10. New review process for schools

Similar to the procedures the Department has issued to schools on child protection and bullying, the Department of Education should issue procedures for schools to follow upon the death of a child in circumstances where there may be learning for the school. These procedures should be informed by experiences of families.

11. Inform government policy developments

All child death review reports should be submitted to the relevant Government Department, and they should also share these reports with other Departments if a recommendation is more relevant to their remit. A joint working group should be established to analyse these reports, in order to identify areas for improvement in Government policy.

12. Information sharing

Relevant Government Departments and public bodies should engage with the Data Protection Commission to ensure that all necessary information that can be shared is shared for these reviews and agree a mechanism to address any barriers.

13. Data gathering

The Departments of Social Protection and Health should establish a national child death register. This register would collect mandatory data on all child deaths, to inform the review of child deaths, from which comprehensive, disaggregated data on child deaths can be published. This data must be standardised and triangulated from multiple sources in a timely fashion at the national level, to enable the identification of issues and trends in child mortality and assist in the development of intervention policies.

Without delay, the relevant sections of the Civil Registration (Electronic Registration) Act 2024 should be commenced to ensure that all deaths of children and young people are notified to the new central national database. The HSE should ensure that the implementation of the proposed changes to the death notification process is aligned with the NPMR.

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