Coimisiún Meabhair-Shláinte | Mental Health Commission

Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Health Information
and Standards

# Evidence review to inform the development of Overarching National Standards for the Care and Support of Children Using Health and Social Care Services

January 2021

Safer Better Care

## About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent statutory authority established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public.

HIQA's mandate to date extends across a wide range of public, private and voluntary sector services. Reporting to the Minister for Health and engaging with the Minister for Children, Equality, Disability, Integration and Youth, HIQA has responsibility for the following:

- **Setting standards for health and social care services** — Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.

- **Regulating social care services** — The Chief Inspector within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.

- **Regulating health services —** Regulating medical exposure to ionising radiation.

- **Monitoring services** — Monitoring the safety and quality of health services and children's social services, and investigating as necessary serious concerns about the health and welfare of people who use these services.

- **Health technology assessment** — Evaluating the clinical and cost-effectiveness of health programmes, policies, medicines, medical equipment, diagnostic and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.

- **Health information** — Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information on the delivery and performance of Ireland's health and social care services.

- **National Care Experience Programme** — Carrying out national service-user experience surveys across a range of health services, in conjunction with the Department of Health and the Health Service Executive (HSE).

## About the Mental Health Commission

The Mental Health Commission (MHC) was established under the Mental Health Act, 2001 to promote, encourage and foster the establishment and maintenance of high standards and good practices in the delivery of mental health services in Ireland.

The MHC's remit includes the broad spectrum of mental health services including general adult mental health services, as well as mental health services for children and adolescents, older people, people with intellectual disabilities, and forensic mental health services.

The MHC's role is to regulate and inspect mental health services, support continuous quality improvement, and to protect the interests of those who are involuntarily admitted and detained under the 2001 Act. Legislation focuses the MHC's core activities into regulation and independent reviews.

In addition, under the provisions of the Assisted Decision-Making (Capacity) Act 2015, the MHC's remit has been extended to include the establishment of the Decision Support Service (DSS). The DSS will support decision-making by and for adults with capacity difficulties and will regulate individuals who are providing those supports. The main functions of the MHC are:

**Regulation:**

- Registration and enforcement: registering approved centres and enforcing associated statutory powers, such as attaching registration conditions.
- Inspection: inspecting approved centres and community mental health services and reporting on regulatory compliance and the quality of care.
- Quality improvement: developing and reviewing rules under the 2001 Act. Developing standards, codes of practice and good practice guidelines. Monitoring the quality of service provision in approved centres and community services through inspection and reporting.

**Independent reviews:**

- Mental Health Tribunal Reviews: administering the independent review system of involuntary admissions. Safeguarding the rights of those detained under the 2001 Act.
- Legal Aid Scheme: administering the mental health legal aid scheme.

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## Executive Summary

All children have a right to health and social care services that are focused on their needs, and to care and support that is delivered in a consistent and coordinated way by the range of services they engage with. To do this, children's needs must be assessed by these services, and the care and support they receive must be well planned, integrated, and responsive to their individual needs and circumstances. The Health Information and Quality Authority (HIQA) and the Mental Health Commission (MHC) recognise the importance of increasing the quality and safety of care and support for all children when they are using health and social care provided by statutory agencies, as well as by voluntary and private service providers. These services include general practitioners (GPs), primary care services, hospitals, child protection and welfare services, children's residential centres, services for children with disabilities, and mental health services. The development of these overarching national standards represents an opportunity to support improvements in the quality, consistency and continuity of all health and social care services involved in the care and support of children.

HIQA is the statutory body established under the Health Act 2007 to drive high-quality and safe care in health and social care services. HIQA supports improvement through the development of person-centred standards and the regulation and monitoring of health and social care services. The MHC has a statutory mandate under the Mental Health Act 2001 to 'promote, encourage and foster the establishment and maintenance of high standards and good practices in the delivery of mental health services'. The MHC's remit includes mental health services for children and adolescents. The MHC recognises the importance of ensuring that children accessing mental health supports receive the highest quality care, and that overarching national standards will provide a framework to facilitate improvements across the range of children's services.

HIQA and the MHC are developing Overarching National Standards for the Care and Support of Children using Health and Social Care Services. These standards will drive improvement and promote best practice in order to improve the experience of all children using health and social care services, by promoting clarity, consistency and continuity within and between services, and to focus services on the needs of the child first. These standards, based on evidence and stakeholder input, will help health and social care services to plan for and deliver high-quality child-centred care and support. In developing these standards, HIQA and the MHC are taking a broad focus by actively engaging with stakeholders from health and social care services with a wide range of experience at all stages of the standards development process. While not all of these services come within HIQA and the MHC's regulatory and or monitoring functions, the expectation is that all services will work to achieve compliance with a set of national standards that will provide a framework for best practice in providing integrated and child-centred care and support, with a clear focus on better outcomes for children, regardless of the child's point of contact with the services.

This document provides an overview of the evidence gathered to date to inform the development of Overarching National Standards for the Care and Support of Children using Health and Social Care Services. This evidence is drawn from: a review of health and social care services working with children in Ireland, an international review of health and social care services working with children in seven jurisdictions*, and an evidence synthesis of national and international literature, which sought to identify characteristics of effective child-centred practices for children engaged in health and social care services.

## Overview of findings

The model of service for health and social care services for children in Ireland is unique when compared to international jurisdictions. In Ireland, there are two main bodies involved in the organisation and delivery of health and social care services that work with children and their families: these are the Health Services Executive (HSE) and the Child and Family Agency (Tusla). Internationally, the service delivery systems that are in place to meet the needs of children and their families are more complex than Ireland. However, the review demonstrates that despite differences in how services are structured, there are important lessons that Ireland can learn from these jurisdictions in terms of the extensive legislation and wide range of guidance, policies and strategies that are in place to promote the overall health and wellbeing of children and their families. Across all of the jurisdictions reviewed, there is a government-wide commitment to promoting equality and reducing health inequalities for children and their families. This is evident in the strong legislative frameworks that underpin policies designed to safeguard children and promote their overall health and wellbeing in a number of jurisdictions. Across a number of jurisdictions, including England, Scotland and Northern Ireland, there has been a move towards a strong focus on integrated working to meet the health and social care needs of children. It is evident from the review that the introduction of legislative frameworks that place a responsibility on public bodies to work together is helping to embed a culture of integrated working. For example, in Scotland, the Public Bodies (Joint Working) Act 2014 outlines the framework for integrating health and social care in Scotland into one single integrated system. This legislation

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* These jurisdictions are Scotland, England, Northern Ireland, Australia, Sweden, America, and New Zealand.

underpins the policy '*Getting It Right for Every Child*' which is Scotland's national approach to improving children's lives through early intervention and is focused on the importance of interagency working.

## *Ireland*

Ireland has a wide range of legislation, guidance, policies, standards and services that seek to promote the health and wellbeing of children and their families, and to protect children who are at risk of harm. A number of Government departments are responsible for the development of policy for children and overseeing the delivery of services. The primary responsibilities lie with the Department of Health (DOH) who oversee the delivery of a range of health and social care services by the HSE, and the Department of Children, Equality, Disability, Integration and Youth who oversee the delivery of child protection and welfare services by Tusla. Additionally, the Department of Education holds responsibility for primary, secondary and third level education and the Department of Justice, Equality and Law Reform holds responsibility for juvenile justice. There is a Government-wide commitment to improving outcomes for all children, as set out in *'Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014-2020'* and *'First Five: A Whole-of-Government Strategy for Babies, Young Children and their Families 2019-2028'*, as well as in strategies that relate to children with additional needs, such as the *'National Disability Inclusion Strategy'* and *'Sharing the Vision: A Mental Health Policy for Everyone'*.

However, it is evident from a number of overview reports of services provided to children, particularly to children with additional needs, that delivering consistent integrated care and support continues to be a challenge.(1,2) In comparison to a number of other jurisdictions, Ireland does not have legislation which supports integrated working between public bodies, and a number of reports have called on the Government to take action to address gaps in the provision and coordination of the appropriate range of services through legislation, regulation and policy to address this.(3,4,5) Furthermore, these reports highlight that there is a wide variation in resources, processes and practices in different sectors and geographical areas in Ireland that is leading to delays in the allocation of services and poor coordination of care and support. While there are a number of regulatory bodies in place in Ireland to monitor health and social care services, the systems in place to monitor compliance with these standards, and the regulations underpinning them, are complex and fragmented. Additionally, many of the standards, are service-specific, and do not follow a child's pathway of care and support through the range of services they use. All of this impacts on children's immediate and long-term health and wellbeing.

## *International jurisdictions*

The international review set out in this document provides an overview of how Scotland, England, Northern Ireland, Australia, Sweden, America, and New Zealand deliver health and social care services to children in their jurisdictions. These seven jurisdictions were chosen following findings from both the evidence synthesis and input from key stakeholders. The review involved engaging with international subject matter experts to understand how health and social care services work with children in practice in these jurisdictions. The evidence shows that each jurisdiction has extensive legislation, regulation, strategy, policy, and service delivery systems in place to meet the needs of children. Each jurisdiction demonstrated progression towards enhancing child health and wellbeing, and set out how the improvement of child wellbeing would be achieved in national strategies. The main findings from the international jurisdictions are:

### Legislation and policy for integrated working

The evidence shows that there is a strong focus in all of the jurisdictions on promoting equality and reducing health inequalities for children. One example of this is in Sweden, where a commission for equitable health to assess the health disparities between socio-economic groups has been established to drive change in this area in the next decade. At a legislative and policy level there are examples in a number of jurisdictions of a move towards integrated working, with a focus on early intervention, to meet the health and social care needs of children. A number of jurisdictions, including England, Scotland and Northern Ireland, have put the responsibility of all services to work together to meet children's health and social care needs, and to promote their wellbeing on a statutory footing. This has resulted in a shift towards more formal collaboration between NHS organisations and local authorities to deliver integrated care and support to children.

The evidence also shows that despite national commitments to improve the health and wellbeing of children, and the extensive programmes to realise such commitments, there are challenges to the delivery of consistent and integrated health and social care services to children with additional needs across the jurisdictions. Reports from Scotland, England and Northern Ireland show that although there are government-wide commitments to improve the coordination of health and wellbeing of children in many jurisdictions, practice on the ground remains inconsistent. These reports highlight that children with complex needs, and children who are more vulnerable due to their lower socio-economic status and living conditions fare worst when health and social care services are uncoordinated and inconsistent.

## Standards for children and young people

In most jurisdictions reviewed there has been a focus on developing standards for services provided to children and young people with additional needs to ensure they receive a safe and high-quality service. These standards are an attempt to provide a common language and framework for supporting children. An example of this can be seen in Scotland, where the government commitment to children's health and wellbeing is echoed through the 2018 '*Health and Social Care Standards: My Life, My Support*'.(6) Other examples of this can be seen in New Zealand where general and targeted standards have been developed to improve the experience of children with additional needs. Examples of these standards are the '*Health and Disability Services Standards*' (HDSS) 2008, which are mandatory for a wide range of health and disability service providers who provide services to children, and the 2019 '*National Care Standards*' which sets out the standard of care that every child in the care of the State needs in order to do and be well.(7,8)

## Regulation and monitoring

The review found that while all jurisdictions reviewed have a process for assessing the safety and quality of services provided to children, this can vary quite significantly depending on the jurisdiction and the nature of the service being provided. For example, in Sweden the governmental agency with responsibility for inspecting care assesses how well services collaborate, as well as assessing the overall rationale for decisions around the provision of care and support, rather than assessing the performance of individual health and social care services. Another example of differences in the regulation and monitoring processes can be seen in England and Scotland, where there are a number of agencies involved in assessing the safety and quality of health and social care services provided to children. In recent years, these agencies have worked together to undertake joint inspections in strategic areas, such as the delivery of integrated care and support.

## Service delivery

In a number of jurisdictions, reports showed that there were long waiting lists for services and a lack of services for children with additional needs. The review identified that this was particularly acute in children's social services and mental health services in America, England and Northern Ireland, where staff shortages and poor retention rates of experienced staff compounded the waiting times for children. Due to this, such services were often reactive and crisis-driven, rather than proactively meeting children's needs.

While there has been a focus on supporting children to transition between and out of health and social care services, timely and coordinated planning, the availability of appropriate follow-on care, and effective resource allocation, continues to be problematic across all jurisdictions. For example, the review identified that Australia did not have a systematic approach to supporting children who had been in care to transition into adulthood, and the findings for England highlight that for children with complex needs there is often a lack of suitable follow-on support when they reach adulthood.

### Health inequalities

The review also found that in a number of jurisdictions there are disparities among the health and wellbeing of indigenous and non-indigenous children. In New Zealand and Australia, the review found that indigenous children report significantly poorer outcomes across all health and wellbeing outcomes, are more likely to be living in poverty, and are more likely than their non-indigenous peers to be taken into care.

### Data collection

All jurisdictions reviewed gather data in relation to health and social care services provided to children, however, the focus of this data varies between jurisdictions. A number of jurisdictions, including Northern Ireland and New Zealand, have developed outcome-based frameworks to provide measurable indicators for child health and wellbeing. These frameworks seek to assess the impact that services are having on child health and wellbeing, and also the impact that policies and programmes have on the lives of children more generally. In contrast, the data gathered in America in relation to these services is mainly quantitative, and is used to inform the funding allocation to services. This focus makes it difficult to assess the impact of health and social care interventions and to identify whether services are achieving positive long-term outcomes for children.

The findings from the international review are consistent with the key findings from the evidence synthesis of national and international literature. The findings from the evidence synthesis are documented under the four interlinked principles that will underpin all National Standards developed by HIQA.[†] These are:

- a human rights-based approach
- safety and wellbeing
- accountability

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[†] In May 2020, HIQA commenced a project to identify a set of principles that could be used consistently across all national standards developed by HIQA, irrespective of the setting or service type. This move reflects developments internationally, as evidenced by the Scottish Health and Social Care Standards, and the inclusion of guiding principles in legislation and associated codes of practice in a number of jurisdictions.

- responsiveness.

## A human rights-based approach

In supporting a human rights-based approach, the evidence emphasises the importance of services and staff creating a culture of dignity and respect. Central to this culture are staff who take the time to develop a relationship with the child and their family, through listening to the child and their families and treating them in a non-discriminatory manner. A human rights-based approach ensures that children and their family can participate in decisions about their care and support, and that their views are acted upon. To do this, services must put structures and systems in place to support meaningful participation. The evidence emphasises the importance of respect, fairness and of valuing children as individuals in this process, as well as taking into account the strengths of families. It also highlights the importance of giving children power to influence the decisions that are made about their care and support, and to include families as partners in this process.

## Safety and wellbeing

In protecting and promoting a child's safety and wellbeing, the evidence highlights the importance of examining the child's health and wellbeing holistically, rather than simply responding to the presenting need. The evidence recognises that some children may be more vulnerable to poorer health and wellbeing outcomes for a range of reasons, including the complexity of their needs, their family and living circumstances. Additionally, when children are transitioning in and out of services, they are at increased risk of less focused and coordinated care. As such, the evidence highlights the importance of children receiving tailored care and support that mitigates these potential negative impacts on their health and wellbeing.

## Accountability

The evidence shows that in order for a service to be accountable to children and other stakeholders, it needs strong leadership and governance. Leaders and managers must work to strengthen and encourage their service's quality and culture, and to ensure that resources are deployed effectively to achieve high-quality and consistent services. The evidence highlighted that an accountable service works collaboratively with a wide range of professionals, organisations and services to ensure that children's needs are met effectively. Accountable services identify short, medium and long-term outcomes and measure the achievement of these outcomes using a range of agreed indicators.

## Responsiveness

The evidence sets out that a responsive service ensures that children are cared for and supported by staff who are skilled, trained and experienced. These staff communicate openly and honestly with colleagues in and outside of their service, and with children, their families and advocates. The evidence shows that responsive staff use their professional judgement to ensure that children receive the care and support that is right for them and support families to act as advocates to ensure their needs are met. Staff regularly reflect on their practice to ensure it is meeting the diverse needs of children.

# 1. Introduction

## 1.1. Overview

All children have a right to health and social care services that are focused on their needs and that work to meet these needs in a consistent and coordinated way. To do this, children's needs must be assessed properly by these services, and the care and support they receive must be well planned, integrated, and tailored to their individual needs and circumstances. The Health Information and Quality Authority (HIQA) and the Mental Health Commission (MHC) recognise the importance of increasing the quality and safety of care and support for all children when they are using health and social care provided by statutory agencies, as well as by voluntary and private service providers. These services include general practitioners (GPs), primary care services, hospitals, child protection and welfare services, children's residential centres, services for children with disabilities, and mental health services. The development of these overarching national standards represents an opportunity to support improvements in the quality, consistency and continuity of all health and social care services involved in the care and support of children.

HIQA is the statutory body established under the Health Act 2007 to drive high-quality and safe care in health and social care services. HIQA supports improvement through the development of person-centred standards and the regulation and monitoring of health and social care services. The MHC has a statutory mandate under the Mental Health Act 2001 to 'promote, encourage and foster the establishment and maintenance of high standards and good practices in the delivery of mental health services'. The MHC's remit includes mental health services for children and adolescents. The MHC recognises the importance of ensuring that children accessing mental health supports receive the highest quality care, and that overarching national standards will provide a framework to facilitate improvements across the spectrum of children's services.

HIQA and the MHC are developing Overarching National Standards for the Care and Support of Children using Health and Social Care Services to drive improvement and promote best practice to improve the experience of all children using health and social care services, by promoting clarity, consistency and continuity within and between services, and to focus services on the needs of the child first. These standards, based on evidence and stakeholder input, will help health and social care services to plan for and deliver high-quality child-centred care and support. In developing these standards, HIQA and the MHC are taking a broad focus by actively engaging with stakeholders from health and social care services with a wide range of experience at all stages of the standards development process. While not all of these services come within HIQA and the MHC's regulatory and or monitoring functions, the expectation is that all services will work to achieve compliance with a set of national standards that will provide a framework for best practice in providing integrated and child-centred care and support, with a clear focus on better outcomes for children, regardless of the child's point of contact with the services.

The Overarching National Standards for the Care and Support of Children using Health and Social Care Services are high level and it is anticipated that supporting material in the form of standards, guidance and support tools will be required to ensure the consistent implementation of these standards across all health and social care services working with children. One example will be the National Standards for Children's Social Services.[‡]

Once approved by the Minister for Health, in consultation with the Minister for Children and Youth Affairs; the Overarching National Standards for the Care and Support of Children using Health and Social Care Services will be used to support and guide improvement in the wide range of health, mental health and social care services that children interact with. These standards will ensure that the interests of the child are put first, and will promote a consistent, child-centred approach to service delivery.

## 1.2. Standards development framework

The Overarching National Standards for the Care and Support of Children using Health and Social Care Services will be set out under a number of principles. A number of themes emerged from the evidence review and extensive stakeholder engagement to inform the development of the Overarching National Standards for the Care and Support of Children using Health and Social Care Services. These themes are in line with the principles being developed by HIQA to support all national standards for health and social care services.

These are:

- a human rights-based approach
- safety and wellbeing
- accountability

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[‡] The National Standards for Children's Social Services arose from HIQA's 2018 report on the investigation into the management of allegations of child sexual abuse against adults of concern by Tusla. In this report it was recommended that HIQA develop National Standards for Children's Social Services. These standards includes all children's social services, from the point of their referral to a service until they transfer to another service or are discharged. These standards are in development by HIQA and it is anticipated that they will be submitted to the Minister for Health, in consultation with the Minister for Children, Equality, Disability, Integration and Youth, for approval in 2021.

- responsiveness.

The Overarching National Standards for the Care and Support of Children using Health and Social Care Services will consist of three sections:

- **Principles**
  Following each principle, there will be an explanatory section setting out how a service works in line with that principle.
- **Standard statements**
  These standard statements are a set of high-level outcomes that describe how services can achieve safe, quality, child-centred care and support for children accessing children's social services. The standard statements are written from the perspective of the child and include what a service must do to meet this standard.
- **Features of a service likely to be meeting the standard**
  These features, taken together, demonstrate how a child should experience a service that is meeting the standards. The features provided under each standard statement is not exhaustive and the service may meet the requirements of the standards in other ways.

The four principles and the standard statements and features that support them, are intended to work together. Collectively they describe how children's health and social care services provide safe, consistent and high-quality care, that is tailored to meet the needs of any child receiving care and support from these services.

## 1.3. How the overarching national standards will be developed

The overarching national standards will be informed by the evidence review presented in this document and by the evidence review to inform the development of the Draft National Standards for Children's Social Services published by HIQA in 2020.(9) All documents and publications identified were reviewed and assessed for inclusion in the evidence-base to inform the development of the overarching national standards.

This document provides the results of an extensive programme of research conducted to underpin the standards which consists of:

- **A review of children's health and social care in Ireland** — this includes a description of the current model and arrangements for children's health and social care, an overview of legislation, strategy, policy and standards in place, and a review of outcomes. This review was informed by academic papers, authoritative national websites, annual reports and statistical reports from key organisations, alongside collaboration with experts in this area. This review describes the context in which the Overarching National Standards for the Care and Support of Children using Health and Social Care Services are being developed.

- **An international review of children's health and social care** — this includes Scotland, England, Northern Ireland, Australia, Sweden, America, and New Zealand. These seven jurisdictions were chosen following feedback from the scoping consultation, findings from the evidence synthesis and input from key stakeholders. A further desktop review, involving web-based searches of relevant literature and websites, identified a number of key organisations and experts to contact and engage with. The international review includes a review of information from authoritative international websites, national reviews, annual reports and statistical reports from key organisations, academic papers and teleconferences with international experts in this area.[§]
- **A literature review** — of relevant academic material relating to good practice in the development and delivery of children's health and social care drawn from search databases.

The Overarching National Standards for the Care and Support of Children using Health and Social Care Services will also be informed by extensive stakeholder engagement. An Advisory Group has been convened comprised of a diverse range of interested and informed parties. HIQA and the MHC have also convened a Children's Reference Group comprised of young people and families with experience of health and social care services to inform the development of the standards.

A public scoping consultation was held which involved consulting with people who have experience of children's health and social care services. The consultation gave people an opportunity to identify the key areas that the standards should address and to provide examples of good practice.

Consultations will be undertaken with children, young people and families who have experience of children's health and social care services and with staff working in these services, to discuss their experiences and obtain their opinions, as to what Overarching National Standards for the Care and Support of Children using Health and Social Care Services should address. In addition a public consultation process

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[§] See Appendix 1 for the names and affiliations of the experts with whom HIQA engaged.

will be undertaken for members of the public and all interested parties to submit their views on the draft standards.

Following approval by the respective Boards of HIQA and the MHC, the standards will be submitted to the Minister for Health, in consultation with the Minister for Children, Equality, Disability, Integration and Youth, for approval. The approved standards will be made publicly available on the HIQA and the MHC websites.

### 1.4. Structure of this report

This document sets out the findings of the review undertaken to inform the development of the Overarching National Standards for the Care and Support of Children using Health and Social Care Services as follows:

Section 2: Overview of health and social care services working with children in Ireland
Section 3: International Review
Section 4: Evidence Synthesis Methodology
Section 5: Evidence Synthesis Findings
Section 6: Summary, Conclusion and Next Steps.

# 2. Overview of health and social care services working with children in Ireland

This section describes the organisation and delivery of health and social care services for children in Ireland and also the impact that these services are having on health and wellbeing outcomes for children. This section is set out under the following headings:

- Overview of health and social care services working with children
- Model of service
- Legislation
- Strategies, policies and standards
- Findings from reviews
- Summary.

## 2.1. Overview of health and social care services for children in Ireland

According to the 2016 census, children under the age of 18 make up almost one quarter of the population in Ireland, with 1.25 million children aged 0-18.(10) Of that, the 2016 census indicates that over 16,000 children have a physical, sensory or intellectual disability.(11) In 2018 almost 11,000 children required mental health support from the Child and Adolescent Mental Health Services (CAMHS)(12) and in 2019 almost 65,000 children received care and support from the Child and Family Agency (Tusla) through their child protection and welfare services, alternative care, aftercare, education and community services.(13)

Ireland has ratified both the UN Convention on the Rights of the Child (the UNCRC)(14) and the UN Convention on the Rights of People with Disabilities (UNCRPD)(15), Article 7 of which explicitly focuses on the rights of children with disabilities. Both of these conventions apply established human rights principles drawn from the UN Declaration on Human Rights and set benchmarks for signatories in the achievement of these rights. Rights include, but are not limited to:

- the right to non-discriminatory treatment, that is that all children have the same right to develop their potential in all situations and at all times.
- protection from abuse and neglect
- that the views of children are considered in decisions that affect them
- and that the best interests of the child are paramount.

Ireland has committed itself to upholding the rights of all children and to the advancement of these rights through changes to legislation, and service provision.

In Ireland, two government departments hold responsibility for children's health and wellbeing. They are the Department of Health (DOH) and the Department of Children, Equality, Disability, Integration and Youth. Additionally, the Department of Education holds responsibility for primary, secondary and third level education and the Department of Justice, Equality and Law Reform holds responsibility for juvenile justice, including oversight of Ireland's only juvenile detention centre, Oberstown. At a Government-level there is a drive to ensure consultation between all departments when developing policies that affect children's lives.(16)

The DOH holds primary responsibility for developing health legislation and policy frameworks, and for funding and overseeing the delivery of a wide range of health, mental health and disability services for adults and children through the Health Service Executive (HSE).[**] The DOH's 2017 '*Sláintecare'* report(17) sets out a long-term vision for health and social care reform. Among the commitments set out in the report are the resourcing and development of a universal child health and wellbeing service to address health inequalities, an increased focus on primary care and home care, and a strong commitment to the improvement of mental health services for children and adolescents. This report, and other strategies and policies in this area, will be discussed in more detail in Section 2.4.

Established as a separate department with a full ministry in 2012 to improve the coordination of policy-making for children between relevant Departments,(18) the Department of Children, Equality, Disability, Integration and Youth (formerly the Department of Children and Youth Affairs) holds responsibility for child wellbeing, including the protection and welfare of children at risk or in the care of the State, and funds delivery of services in these areas through Tusla. In 2014, the Department set out its vision for children and young people in Ireland in its strategy '*Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014-2020.*'(16) This framework, and other strategies and policies in this area, will be discussed in more detail in Section 2.4.

There are a range of statutory organisations and bodies who work to ensure that the safety and quality of health, including mental health, personal social services, and educational services to children is of a high standard, and that both service providers and the State are held accountable for this. These bodies include the Health Information and Quality Authority (HIQA), the Mental Health Commission (MHC), the National Disability Authority (NDA), and the Office of Children's

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[**] Currently the DOH holds responsibility for a wide range of services for children, however at the time of this review, responsibility for these services is under review by the Department of Health and the Department of Children, Equality, Disability, Integration and Youth.

Ombudsman (OCO) which will be discussed in Section 2.4. Findings from reports on children's services by these bodies will be discussed in Section 2.5.

## 2.2. Model of service

In Ireland, there are two main organisations involved in organising health and social care services that work with children; these are the HSE and Tusla. These services are delivered through a wide range of statutory, voluntary and private service providers.(19) This section sets out the organisation and delivery of the following service for children and young people:

- General healthcare services for children and young people
- Children's social services
- Disability services for children and young people
- Mental health services for children and young people.

### Organisation and delivery of general healthcare services for children

The HSE is the national provider of all of Ireland's public health services in hospitals and communities across the country. The HSE was established in 2005 under the Health Act 2004(20) as the single body with statutory responsibility for the management and delivery of health and personal social services to the population of Ireland. The HSE, in consultation with a wide range of stakeholders, has developed a National Health Charter for Children(21) that describes the key principles that inform high-quality healthcare for children and their families. These principles focus on ensuring:

- Access
- Dignity and respect
- Safe, appropriate and effective care
- Communication and information
- Play, education and recreation
- Privacy
- Promoting health and wellbeing
- Giving feedback
- Protection of children.

As set out in the Charter, these principles are based on the HSE's National Healthcare Charter, as well the United Nations Convention on the Rights of the Child and is informed by the Charter of the European Association for Children in Hospital.(21)

Healthcare services are delivered mainly by the HSE, with public acute hospitals, mental health services, and most community services funded directly by the HSE.

The HSE also has contracts with a large number of private and voluntary providers, including general practitioners (GPs), community pharmacies, providers of community and residential care services for adults and children with physical, sensory, or intellectual disabilities.

Health and social care services for children, as well as for adults, are delivered at primary, secondary and tertiary level. Children up to the age of six are entitled to free GP care. GP care is the first contact for most children when engaging with healthcare and many conditions are managed entirely by the GP. However, if the child has a chronic or acute need that cannot be managed by them, the GP can then refer the child to primary care services, to paediatric or to specialty services.

Primary care in the community is provided through a mix of national public health services and privately contracted GP services. Public health nurses visit newborn infants and their parents post-birth in their home and for a short period after this, and continue to engage, if required. Public health doctors and allied health professionals provide services in the local community. Children receive health checks in specific areas throughout their school years, however, if a child needs further assessment for a specific condition or in relation to a disability they are referred to the appropriate services. While therapy services are provided through allied health professionals in primary care services, children with more complex needs are seen by specialised early intervention teams.

Children up to the age of 16 receive outpatient care in paediatric centres in specialist, regional, and general hospitals, while children’s inpatient care is provided in children’s wards in general and regional hospitals. Children are referred to these services through their GP, allied health professionals and also through emergency departments. Currently there are three specialist children’s hospitals, all based in Dublin. These hospitals provide care and support to children with serious and life-limiting conditions. A new national paediatric hospital to unify the work of all of these services is currently under construction.(18)

When a child has a long-term healthcare need it is generally their parents and or families who provide this care. A referral for support from homecare and respite services, where required, is made by community or acute services and may be provided by HSE, private or voluntary organisations.

### Organisation and delivery of children’s social services

Until the establishment of Tusla in 2014, the HSE held statutory responsibility for child protection. Under the Child and Family Agency Act 2013,(22) the role of Tusla is to support and promote the development, welfare and protection of children and the effective functioning of families. Tusla is now responsible for a range of universal and targeted services, which include early childhood care and education, community-based early intervention services, education support services, domestic, sexual and gender-based violence services, child protection and welfare services, alternative care (including foster care and residential care) and aftercare, to support young people with a history of care. Tusla seeks to place children with complex needs within Ireland. However, in some limited circumstances children may have to travel overseas if services to meet their specific needs are not available in Ireland.

Under the Child Care Act 1991 social workers, employed by Tusla, have a statutory obligation to identify children who are not receiving adequate care and protection and investigate allegations of abuse, including suspected abuse within families, suspected extra-familial abuse, suspected retrospective abuse and retrospective disclosures by adults. When Tusla is responding to concerns, it must take into account:

- that the welfare of the child is paramount
- the wishes of the child having regard to their age and understanding
- the rights and duties of parents
- the principle that it is generally best for the child to be brought up in their own family
- that consultation and engagement with children and families is essential in achieving positive outcomes.

Tusla and An Garda Síochána have separate but complementary roles in the care and protection of children. Tusla formally notify An Garda Síochána if there is a concern that a child is being abused, as set out in the *'Joint Working Protocol for An Garda Síochána/Tusla – Child and Family Agency Liaison'*. As part of their legal obligations, where An Garda Síochána suspects that a child is being abused, either wilfully or unintentionally, they formally notify Tusla.

A detailed overview of the work and impact of Tusla can be found in HIQA's 2020 publication *'Evidence review to inform the development of National Standards for Children's Social Services'.*(9)

## Organisation and delivery of disability services for children

Children with a disability are entitled to an assessment of health and educational needs under the Disability Act 2005(23) in the form of a service's statement, however, this statement does not confer an entitlement to actually receive these services. Services to meet children's needs are met in a variety of ways, through services provided by voluntary services, private providers or HSE delivered services, or often a mix of these three. To address the fragmentation and duplication of services, the HSE established the Progressing Disability Services for Children and Young People

Programme in 2010. The aims of the programme are to provide services for children with disabilities, physical, sensory and intellectual, as close to their home and school as possible and to coordinate the care and support provided to them by the range of services that they need.(24) As set out in the HSE programme, the intention is to combine the HSE's Disability Teams, as well as other voluntary services, to create new Children's Disability Network Teams, so that children will have easy and equal access to supports regardless of where they live or the nature of their disability. The intention is that these teams will work with children and their families to identify their goals and agree how the team will meet these objectives. These services are based on 12 principles, agreed in consultation with families using the services and include the principles of inclusion, accessibility, accountability, a focus on the whole child and family, integration, and an outcomes focus. A review of one community health area showed that the service had made significant positive progress since its establishment in setting up an integrated team from across multiple statutory and voluntary organisations and establishing a family-centred service model. However, the review highlights that the service had difficulty providing a continuity of service to families because of high levels of staff turnover and an inability to fill vacancies quickly. Other issues that were identified included primary care services being withdrawn when a child was referred to the Disability Network Teams, and even when a child was accepted by the Disability Network Teams, long waiting periods before there was active service engagement with the family.(25)

There are a number of protocols in place to support the achievement of these principles and the programme aims of coordinated, integrated and local support for children with disabilities. These include the *'Primary Care, Disability, Child and Adolescent Health Joint Working Protocol'*(26), which aims to ensure that HSE Community Services and voluntary organisations that work together to support children with a disability and their families to access the range of services required in a timely manner; the *'Joint Protocol for Interagency Collaboration between the HSE and Tusla*(27) which sets out the responsibilities of both organisations in working together to support children with a disability and or mental health condition who is also in the care of the State, as well as the responsibilities of these services to plan for these children's care and support once they reach adulthood.

It must be noted that these are voluntary protocols and there have been issues with the consistent implementation of these. This is outlined in more detail in Section 2.5.1. in the report by the OCO on interagency cooperation in relation to children with a disability who are also in the care of the State.(3)

### Organisation and delivery of mental health services for children

Services for children up to the age of 18 with mental health needs are provided by the HSE through CAMHS, and are guided by the national policy, '*Vision for Change*' developed in 2006(28), and updated in 2020(29). Practical guidance on good practice in caring for and treating children and adults is set out in the HSE's 'B*est Practice Guidance for Mental Health Services*', which explains the legal and regulatory responsibilities of child and adult services, as well as outlining best practice guidance, checklists and a self-assessment framework, this is intended to support quality improvement within mental health services.(30)

Mental health services for children and adolescents are delivered by CAMHS, through multidisciplinary teams comprised of consultant psychiatrists, doctors in training, clinical psychologists, CAMHS nurses, social workers, speech and language therapists and occupational therapists. Referrals to the service come through GPs, social work and psychology. The community CAMHS teams provide outpatient services that include assessments of emergencies, as well as urgent and routine referrals from primary care. CAMHS teams also evaluate the need for a referral to specialist inpatient or day patient services and engage with children and families in the community. Community and residential treatment services are provided to children presenting with moderate to severe mental health needs, and where a child is assessed by CAMHS as having a milder mental health need they are referred back to community-based services. CAMHS engage in interagency meetings and provide written reports to the education, social care, and legal systems relating to the mental health needs of young people. The '*Joint Protocol for Interagency Collaboration between the HSE and Tusla'* also applies to children with mental health needs who are in the care of the State, placing an onus on CAMHS and Tusla to work together to provide coordinated care and support.

## 2.3. Legislation

There is a wide range of legislation framing the health and wellbeing of children in Ireland. This legislation sets out:

- when a child should receive a relevant health or social care service due to their health needs or a need for protection from harm
- how they should receive it – setting out the responsibilities of the statutory or voluntary body provided by the health or social care service.

This section will look at the following acts related to children's health and wellbeing, their safety and welfare, their disability needs and their mental health. The acts looked at in this section are:

- Health Act 1970-2007
- Equal Status Act 2000-2018
- Child Care Act 1991
- Children Act 2001
- Education Provision for Special Educational Needs Act 2004
- Disability Act 2005
- Mental Health Act 2001.

A high level summary of legislation for children at risk or in the care of the State is provided in this section. For a more detailed review of the legislation in this area please refer to HIQA's 2020 publication '*Evidence review to inform the development of National Standards for Children's Social Services'*.(9)

### 2.3.1. The Health Act (1970-2007)

Since 1947, the Health Act has been continually reviewed and updated to provide a legislative framework for safer, better care for all those using health and social care services. The act provides for the establishment of statutory bodies to deliver health and social care services, the setting of regulations to enforce the delivery of the act, and the establishment of a system of external oversight and monitoring of health and social care services.

The Health Act 2004 established the HSE as the single body with statutory responsibility for the management and delivery of health and social services in Ireland, taking over the running of the 11 health boards that had previously administered health services.(20) The act sets out that the HSE 'is to use the resources available to it in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public.'(31) The overall aim of this centralised administration is to promote consistency, reduce costs and increase efficiency.

The Health Act 2007 makes a provision for the reform of the regulation of health and social care services in Ireland, providing for the establishment of HIQA. It also established a registration and inspection system for a number of residential services for children, including children in need of care and protection, as provided by special care units and children with a disability receiving care and support in residential centres. Under this act, regulations to underpin this system are set out in the *Health (Care and Welfare of Children in Special Care Units) Regulations 2017* (32) and in the *Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities*.(33) In addition to this, the Health Act 2007 also sets out HIQA's role in setting standards in relation to services provided by the HSE and Tusla.

### 2.3.2. Equal Status Act 2000-2018

Since 2000, the Equal Status Act 2000-2018(34) has been continually amended and updated to prohibit discrimination in the provision of goods and services, accommodation and education. The acts cover nine grounds of gender, marital status, family status, age disability, sexual orientation, race, religion, and membership of the Traveller community. The act also prohibits discrimination in the provision of accommodation services against people who receive statutory payments in respect of rent, housing assistance, or social welfare payments. In relation to children, the acts place a duty on educational establishments and public services to accommodate children with a disability and to take positive action to promote equality.

### 2.3.3. The Child Care Act 1991

The Child Care Act 1991 is the fundamental piece of legislation which sets out the responsibilities of statutory bodies, that is Tusla and An Garda Síochána, to promote the welfare of children who may not be receiving adequate care and protection and to protect them from harm through a range of measures, including the provision of alternative care.(35)

The act covers the following main areas:

- promotion of the welfare of children
- the functions of what is now Tusla
- protection of children in emergencies, which includes the powers of An Garda Síochána to take a child to safety
- care proceedings, including the different types of care orders which can be made by a court
- a legal framework for responding to children in need of special care or protection due to the risk posed by their own behaviour or specific circumstances
- the provision of private foster care
- the appointment of a Guardian ad Litem to represent a child’s views[††]
- children in the care of Tusla
- supervision of pre-school services
- the governance of children’s residential centres.

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[††] The Guardian ad Litem are independent persons appointed by the Court for the duration of Court proceedings relating to a child. The Guardian ad Litem gives the child a voice in the proceedings and advises the court in respect of the child’s best interests by acting as an advocate for the child.

Arising from this act, and subsequent amendments to the act, are a number of childcare regulations. These are formulated by the Department of Children, Equality, Disability, Integration and Youth and compliance with these regulations is monitored by the HIQA. There are a number of regulations relevant to children in care as set out in Table 1 on page 34 of this document.

These regulations set out what Tusla is required to do when they place a child in alternative care. Tusla must consider if the placement is suited to the child's needs and whether the location of the placement will allow access to family and community. Tusla must develop a care plan that sets out the support to be provided to the child and where relevant, the foster parents and review this regularly to ensure it continues to meet the child's needs.

At the time of writing, the Child Care Act 1991 is under review by the Department of Children, Equality, Disability, Integration and Youth.

### 2.3.4. The Children Act 2001

The Children Act 2001 introduced significant new sections to the Child Care Act 1991 with its focus on preventing criminal behaviour, diversion from the criminal justice system. The act also introduced principles of restorative justice through family welfare conferences and diversion projects.(35)

Under the act, the use of detention for a child is to be a last resort and requires that statutory services consider all other options before it is used. The main principles of the Children's Act are:

- any child who accepts responsibility for his or her offending behaviour should be diverted from criminal proceedings, where appropriate
- children have rights and freedoms before the law equal to those enjoyed by adults and a right to be heard and to participate in any proceedings affecting them
- it is desirable to allow the education of children to proceed without interruption
- it is desirable to preserve and strengthen the relationship between children and their parents and or family members
- it is desirable to foster the ability of families to develop their own means of dealing with offending by their children
- it is desirable to allow children to reside in their own homes
- any penalty imposed on a child should cause as little interference as possible with the child's legitimate activities, should promote the development of the child and should take the least restrictive form, as appropriate

- due regard to the interests of the victim; a child's age and level of maturity may be taken into consideration as mitigating factors in determining a penalty
- a child's privacy should be protected in any proceedings against them.

Under this act, regulations set out what a service must achieve in order to be in compliance with the legislation. These are the minimum standards that a regulator will assess a service against. These service specific regulations are set out in Table 1 on page 34 of this document.

### 2.3.5. Education for Persons with Special Educational Needs (EPSEN) Act 2004

The EPSEN Act 2004(36) sets out to promote inclusive education for children with special educational needs (SEN). The act established a statutory framework for the assessment of special educational needs and the development of individual education plans for children with such needs. The act outlines the responsibilities of schools in this regard and provided for the establishment of the National Council for Special Education (NCSE).

However, only certain sections of the act have been implemented. These are the sections that led to the establishment of the NCSE and these have been used to promote an inclusive approach to the education of children with SEN within the mainstream school system. Crucially, the parts of the act that have not yet been implemented are those that relate to a child's right to assessment and their education plans. A 2020 report by the OCO highlighted that in the absence of a procedure under the EPSEN Act, students who require an assessment of their special educational needs are applying for an AON under the 2005 Act and that this places further pressure on the 2005 Act mechanism.(37)

### 2.3.6. Disability Act 2005

The Disability Act 2005(23) was developed to promote the participation of people with disabilities in society through the provision of disability specific services and by improving access to mainstream public services.(38) The act places obligations on statutory services. These obligations include undertaking an assessment of need for children and adults with a disability, on public bodies to make buildings and services accessible to people with disabilities, and sets out the requirement for sectoral plans in key service areas.

According to the act, the definition of a person with a disability entitled to disability specific services are those with a 'substantial restriction' which is permanent or likely to be permanent, and necessitates ongoing care and support. If the person is a child, the act indicates the need for services to be provided early in life to lessen the effects of the disability.(38)

The act establishes the process for the assessment of need of a person with a disability, and sets out that the result of this assessment is an assessment report. This report indicates: whether a person has a disability and its nature and extent; the health and education needs arising from the disability; the services considered appropriate to meet those needs; the timescale ideally required for their delivery; and when a review of the assessment should be undertaken. Where a person is found to have a need for disability-related services a service statement is prepared. The statement sets out the health and education services that can be provided to the person in line with their assessed needs. However, there are limits to the provision of these services as they are dependent on the person's eligibility criteria for services, the practicability of providing the service and the financial resources available. The act also provides for a complaint system where an individual believes that there has been a failure to provide these entitlements.

### 2.3.7. Mental Health Act 2001

The Mental Health Acts 2001-2018 (the 2001 Act) provides for the establishment of the independent statutory body, the Mental Health Commission (MHC). The MHC is responsible for protecting the interests of any person admitted involuntarily into an approved mental health service and also to promote, encourage and foster the establishment and maintenance of high standards and good practices in the delivery of mental health services. The MHC do this through the development of standards and good practice guidance, as well as through annual inspections of all approved centres.(39)

The 2001 Act sets out in what circumstances a person can be admitted involuntarily to an approved centre, for example to a hospital, how a person should be treated when they are admitted and what the person's rights are under the 2001 Act.

The 2001 Act provides for the involuntary admission of a child or an adult who requires inpatient treatment in an approved centres for a mental disorder.(40) Section 25 of the 2001 Act provides for the involuntary admission of children, setting out that the HSE may make an application to the District Court for an order authorising the detention of a child suffering from a "mental disorder" in an approved centre.(39)

The 2001 Act identifies key rights that all mental health services must work to uphold:

- That the best interests of the person should be considered before any decision about their care and support is made.

- That the person is included in discussions and decisions about their health and care
- That there is a review by an independent body of every order involuntarily admitting or detaining a person
- That the approved centre operates to a high standard of care and support, as set by the regulator, the Mental Health Commission.

A series of recommendations to amend the provisions relating to the voluntary admission and involuntary detention of children have been provided for inclusion in a Heads of Bill being developed by the Department of Health.(12) The MHC was asked and made a Submission to the Department of Health in May 2020 in relation to these revised provisions. The Heads of Bill from the Department include but are not limited to - having a completely separate Part of the 2001 Act dedicated to children; that a person who is 16 or 17 years of age is presumed to have capacity to consent to and refuse mental health care and treatment taking the age, maturity and level of understanding of the child into account ; for children under 16 consent shall be obtained from the parents or guardians but that the views of the child shall be taken into consideration with regard to their diagnosis, admission and treatment and these views should be given due weight, in accordance with their age; the service type and location should be suitable for their age and in close distance to their family.

In addition, the following two Acts are of relevance:

- The Criminal Justice (Withholding of Information on Offences against Children and Vulnerable Adults) Act 2012.(41) Under this Act, it is a criminal offence to withhold information from An Garda Síochána in relation to serious, specified offences committed against a child or vulnerable adult.

- The Children First Act 2015 which was commenced on 11 December 2017.(42) This is relevant is relation to the reporting of child protection and welfare concerns.

## 2.4. Strategy, policy and national standards

Ireland has a significant number of national strategies, policies and standards that set out specific commitments to protecting and ensuring the health and wellbeing of children and young people. This section describes key strategies, policies and standards that have been developed to promote positive outcome for children. This section also describes how compliance with the standards is assessed in Ireland.

The key legislation, and the regulations and national standards[‡‡] that support its implementation, are set out in Table 1 below. While there are a number of regulatory bodies in place to monitor health and social care services, the systems in place in Ireland to monitor compliance with the standards, and the regulations underpinning them, are complex and fragmented. Further details the standards and the systems to monitor compliance with them are set on in Section 2.4.8. Additionally, many of the standards, and the regulations underpinning these standards, are service-specific, as illustrated in Table 1, below, and do not follow a child's pathway of care and support through the range of services they use.

Supporting legislation, regulations and national standards are a series of strategies that apply across a range of health and social care services provided to children. These include *'Healthy Ireland', 'Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People, 2014-2020', 'Sláintecare', 'Sharing the Vision: A Mental Health Policy for Everyone'* and the *'National Disability Inclusion Strategy'.* Taken together these strategies, policies, regulations, and standards evidence a commitment to safe, high-quality services for children.

## Table 1. Legislation, regulations and standards for children's services

| Service Type | Legislation | Regulations | National Standards |
|---|---|---|---|
| Child Protection and Welfare Services | Health Act 2007 (as amended) | None | National Standards for the Protection and Welfare of Children (HIQA, 2012) |
| Foster Care Services | Child Care Act, 1991, as amended | Child Care (Placement of Children in Foster Care) Regulations, 1995<br>Child Care (Placement of Children with Relatives) Regulations, 1995 | National Standards for Foster Care (Department of Health and Children, 2003) |

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[‡‡] Regulations give force to a specific requirement set out in law. In the context of this document regulations can be understood as as governmental orders having the force of law and are used by the relevant regulator to register (as appropriate), monitor and inspect health, mental health and social care services. National Standards can be understood as high-level outcomes that describe how services can achieve safe, quality, person-centred care and support. They are evidence-based and informed by engaging with those who use and provide health, mental health and social care services.

| **Service Type** | **Legislation** | **Regulations** | **National Standards** |
|---|---|---|---|
| Special Care Units | Health Act, 2007 (as amended) | Health Act 2007 (Registration of Designated Centres) (Special Care Units) Regulations 2017<br>Health Act 2007 (Care and Welfare of Children in Special Care Units) Regulations 2017<br>Health Act 2007 (Care and Welfare of Children in Special Care Units) Regulations 2018 | National Standards for Special Care Units (HIQA, 2014) |
| Children Detention Units | Children Act, 2001 as amended by Criminal Justice Act, 2006 | None | Standards and Criteria for Children Detention Schools (Department of Justice, Equality and Law Reform, 2008) |
| Children's Residential Centres | Child Care Act, 1991 (as amended) | Child Care (Placement of Children in Residential Care) Regulations, 1995 | National Standards for Children's Residential Centres (HIQA, 2018) |
| Residential Centres for Children with a Disability | Health Act, 2007 (as amended) | Health Act (Registration of Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013<br>Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013 | National Standards for Residential Centres for Children and Adults with Disabilities (HIQA, 2013) |
| Healthcare settings for children | Health Act, 2007 (as amended) | None | National Standards for Safer Better Healthcare (HIQA, 2012)<br>National Standards for Safer Better Maternity Services (HIQA, 2016) |
| Mental healthcare settings for children | Mental Health Act 2001 | Mental Health Act 2001 (Approved Centres) Regulations 2006 | Quality Framework for Mental Health Services in Ireland (MHC, 2007) |

| **Service Type** | **Legislation** | **Regulations** | **National Standards** |
|---|---|---|---|
| Health and personal social services | Disability Act 2005 | None | None |

At a high level, the Healthy Ireland framework developed in 2015 by the Government expresses four goals for improved health and wellbeing for the whole population.(43) These goals are:

- increase the proportion of people who are healthy at all stages of life
- reduce health inequalities
- protect the public from threats to health and wellbeing
- create an environment where every individual and sector of society can play their part in achieving a healthy Ireland.

The framework highlights the importance of investment in early intervention initiatives aimed at children and families in terms of child development, educational disadvantage and parenting. Research cited in the framework finds that the most effective time to intervene to reduce inequalities and improve health and wellbeing outcomes is before birth and in early childhood. This finding is reiterated in many of the strategies, policies and standards discussed in this section.

This section will look at the following strategies, policies and standards related to children's health and wellbeing, their safety and welfare, their disability needs and their mental health:

- Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014-2020
- National Strategy on Children and Young People's Participation in Decision-Making 2015-2020
- First Five: A Whole of Government Strategy for Babies, Young Children and their Families 2019-2028
- Sláintecare
- HSE Model of Care for Paediatric Healthcare
- National Disability Strategies
- National Standards for health services, children's social services, disability services and mental health services.

### 2.4.1. Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014-2020

*'Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014-2020'*(16) is a Government-wide national policy framework for children and young people aged 0-24 years. Its purpose is to coordinate policy and action across Government Departments, as well as services provided by statutory bodies, such as Tusla and the HSE, and private and voluntary providers who are working with children and young people to achieve better outcomes for all children. The framework is supported by a number of high-level policies and strategies setting out how the it will be supported at Government level and implemented in practice.(45)

The framework recognises that some children and families may be more at risk than others due a range of factors including socio-economic issues, family difficulties and enduring health conditions. The framework highlights the importance of early identification and intervention through universal systems open to all, such as early years services, primary healthcare services and schools, and additional targeted interventions by state services; including child protection and welfare, youth justice and adolescent mental health. It sets out five national outcomes that the Government is looking to achieve for children and young people. The framework identifies a number of areas that need to be stronger in order to achieve these outcomes. These 'transformational goals' are considered essential in ensuring that policies and services are made more effective in achieving better outcomes. These outcomes and transformational goals are shown in Figure 1, below:

## Figure 1. Better Outcomes, Bright Futures Outcomes and Goals

Our vision is for ***Ireland to be one of the best small countries in the world in which to grow up and raise a family,*** *and where the rights of all children and young people are respected, protected and fulfilled; where their voices are heard and where they are supported to realise their maximum potential now and in the future.*

**Source:** DCYA. (2014). *Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014-2020.*(16)

To achieve both the outcomes and the transformational goals, '*Better Outcomes, Brighter Futures'* recognises the need for services to work in partnership with children, families and the community and to build on their strengths. The strategy highlights the importance of strategic leaders who build a culture of collaboration and communication within their organisation and with communities, and for these leaders to support their staff and volunteers in order to achieve the outcomes of the national strategy. *'Better Outcomes, Brighter Futures'* was reviewed in 2018 and key messages arising from this indicated that while the implementation structures, such as the Children and Young People's Services Committees (CYPSCs), have worked well,[§§] the overall framework is complicated, with a huge range of commitments contained within it. The report recommends the need to focus on particular priorities, such as child poverty and child homelessness.(46) While intended to establish a government alignment of policy and activity, this has been problematic, with a policy and strategy mismatch at times between Departments. Further to this, the review found that there was a low level of awareness at community and individual level with regards to the purpose and strategic objectives of the framework.

### 2.4.2. National Strategy on Children and Young People's Participation in Decision-Making 2015-2020

Developed in 2015 by the then Department of Children and Youth Affairs to support the implementation of *'Better Outcomes, Brighter Futures'*, this strategy focuses on how children and young people can influence decisions that affect their day-to-day lives.(47) The stated objectives of the strategy are that children and young people will have a voice in decisions made in relation to their:

- local communities
- early education, schools and the wider formal and non-formal education systems
- health and wellbeing, including the health and social services delivered to them
- interaction with the Courts and legal system.

Using the Lundy Model[***], seen in Figure 2 below, to visualise participation, the strategy also identified structures to ensure that participation was made real in day-to-day practice. A Participation Team within DCYA was established to build, develop and sustain structures and processes for children and young people, with a particular focus on ensuring that the voices of seldom heard young people were included. Structures such as Comhairle na nÓg, Dáil na nÓg and the EU Structured Dialogue were established so that children's voices were heard at a national and international level. DCYA also established Hub na nÓg to support Government Departments, statutory bodies and non-government organisations to give children and young

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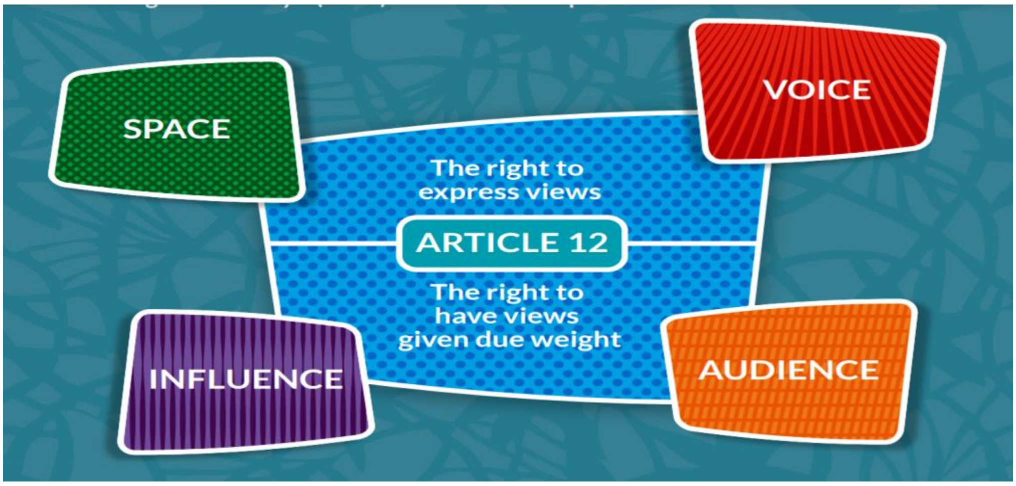
[§§] CYPSCs plan and coordinate services for children and young people in Ireland. The age remit spans all children and young people from 0 to 24 years. The purpose of the CYPSC is to ensure effective interagency coordination and collaboration to achieve the best outcomes for all children and young people in their area.

[***] Developed in 2007, the Lundy model of participation was designed to aid practitioners to meaningfully and effectively implement a child's right to participate by focusing attention on the distinct but interrelated elements of Article 12 of the UNCRC which gives children the right to have their views given due weight in all matters affecting them.

people a voice on decisions that affect their lives, with a focus on rarely heard children and young people. Children and young people have had opportunities to input into new policies and strategies, such as adoption proceedings, a change process and the new Youth Justice Strategy, as well as the reform of fundamental legislation such as the Child Care Act 1991.

**Figure 2. Lundy's Model of Participation**



**Source:** DCYA. (2015). *National Strategy on Children and Young People's Participation in Decision-Making 2015-2020.*(47)

The strategy was reviewed in 2019, and the findings show improvement across Government Departments in consulting with children and young people at policy and strategy level(48). However, the review notes that this is not always replicated in health and social care services that work with children, or if it is, it is not recorded and shared more widely. The review sets out a new action plan to achieve the objectives of the strategy and allocates responsibility to named bodies, including the Government Departments, local authorities, Tusla, HSE, HIQA, and the Mental Health Commission.

### 2.4.3. First Five: A Whole of Government Strategy for Babies, Young Children and their Families 2019-2028

This is the first national strategy for early childhood, and sets out a whole of Government approach to ensuring that babies and young children have a strong and equal start.(49) The strategy starts with a vision that illustrates how each part of the child's life will be supported to ensure that they have the best possible outcomes.

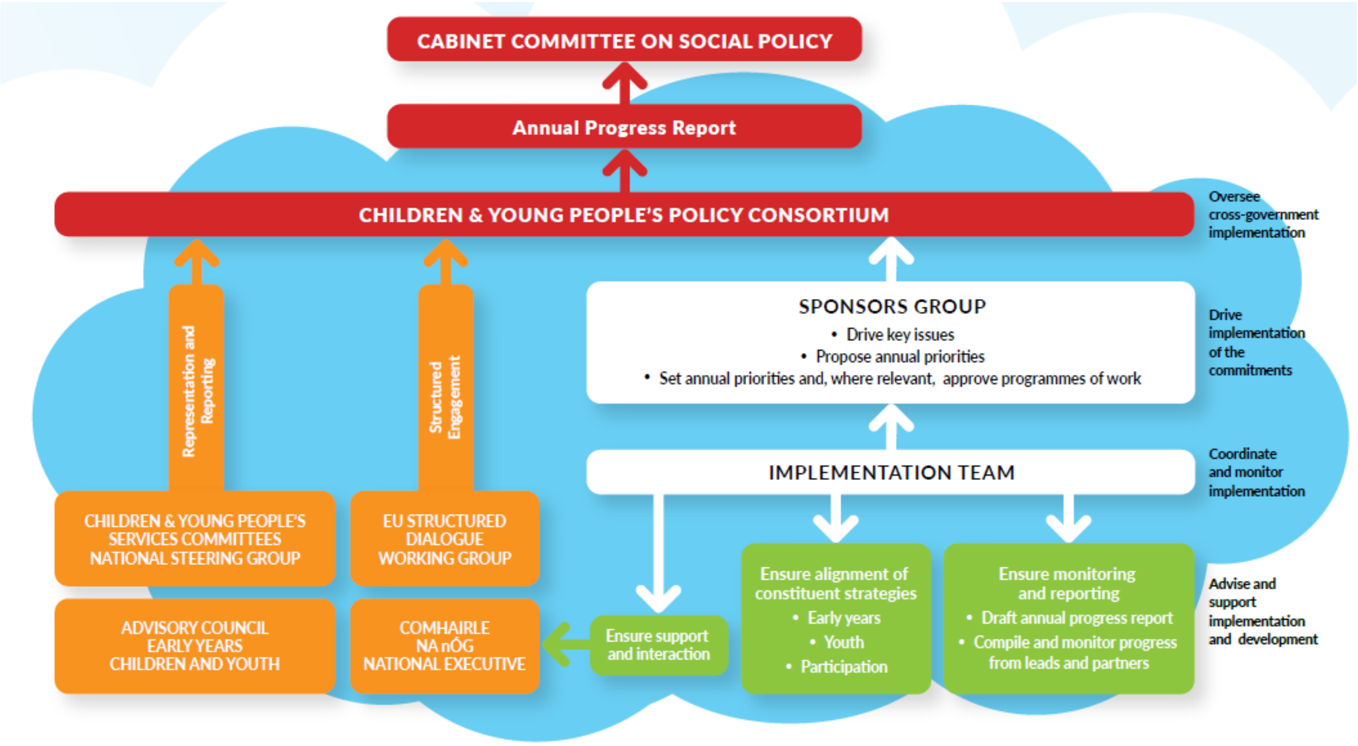
The strategy has four goals, underpinned by a series of objectives and indicators. These goals are aligned to '*Better Outcomes, Brighter Futures*' and are:

- strong and supportive families and communities

- optimum physical and mental health
- positive play-based early learning
- an effective early childhood system of services and supports.

According to the new strategy, the oversight of implementation of the goals and objectives set out in '*First Five*', is within the existing implementation framework for '*Better Outcomes, Brighter Futures*' to enable a consistent and coordinated approach to services and supports. This framework is illustrated in Figure 3 below.

**Figure 3. Implementation framework for the 'First Five' strategy**



**Source:** Government of Ireland. (2019). *First Five: A Whole-of-Government Strategy for Babies, Young Children and their Families 2019-2028.*(49)

### 2.4.4. Sláintecare

*'Sláintecare'* is the cross-party health report that sets out a vision for the reform of healthcare in Ireland.(17) The development of the *'Sláintecare'* report in 2017 was undertaken by a cross-party committee who worked in a collaborative way. This approach aimed to remove party politics from the policy-making process, while still ensuring that health policy was in the political domain. In 2015, research found that '*the Irish health system was at a critical juncture, where it could maintain the status quo or embark on a journey of delivering universal healthcare'*. In the development

and implementation of *'Sláintecare'* there has been a drive to embark on this journey of universal healthcare and undertake a programme of reform.

The *'Sláintecare'* report highlighted that up until the consolidation of services through the HSE in 2005, that health and social care services were delivered through health boards; voluntary, public and private hospitals; and a range of charitable and other organisations resulting in what the authors termed '*fragmented and unsatisfactory care*'. However, despite the consolidation of services, the report also found that the HSE itself has been in a continuous state of re-organisation and restructuring with *'little apparent benefit to users of services and persistent disruption for staff.'* The report noted that in recent years to address this fragmentation and disruption, the HSE has been developing five integrated care programmes in the areas of chronic disease, older people, children, maternity, and patient flow. The integrated care programme for children is guided by the *National Model of Care for Paediatric Healthcare Services in Ireland*.(50)

Unlike previous high-level health strategies, the *'Sláintecare' report* makes specific recommendations regarding the reform of children's services, including resourcing and developing a universal child health and wellbeing service, highlighting the impact that social determinants of health have on longer-term health and wellbeing outcomes for children. The report also sets out recommendations to improve access to psychology services at primary care level and a significant expansion of CAMHS.

Of significance within the report are issues raised in relation to integrated service delivery between State agencies. Advocacy bodies highlighted the lack of cohesion between mental health agencies and other services such as maternity services, addiction services and child protection services.

The Sláintecare Programme Implementation Office, situated within the Department of Health, was set up to establish and monitor the actions taken to realise the vision of *'Sláintecare'*. In 2020, the Office published the '*Sláintecare Action Plan Year-End Report for 2019*'.(51) The report sets out that substantial progress has been made in relation to a number of commitments made in the 2019 Action Plan. Of particular note for children are actions taken in relation to GP care and disability services. The yearend report notes that investment in GP services over the next four years will ensure that chronic conditions can be managed by GPs, reducing the need for hospital care, resulting in an expected benefit to more than 400,000 patients. Furthermore, the report notes that in 2019 progress was made on the implementation of children's services under Progressing Disability Services policy on disability services, which included the recruitment of skilled staff to support the assessment of need process.

### 2.4.5. Model of Care for Paediatric Healthcare

Developed by the HSE in 2016, the '*Model of Care for Paediatric Healthcare'* sets out how healthcare services should support children throughout their journey of using healthcare services, from their first point of contact to discharge or transfer to another service. The model highlights the importance of this model being live and taking into consideration how speciality policies and programmes affect the achievement of the integrated model.(52)

The model demonstrates how care can be provided as close to home as possible, by strengthening both primary and community care for children. It focuses on the need to build strong support for GPs to manage childhood illness and keep children at home, finding that 'rates of hospitalisation vary across the country and are too high in many places.'(52) Recognising that children may need specialist care, the model emphasises the need for each speciality to work together in a coordinated and consistent way to provide integrated care that meets the child's needs, including when the child is at risk.

The vision set out in this model, illustrated in Figure 4 below, is that all children should be able to access safe, high-quality services in the right place and at the right time, regardless of where they live or what their social background is.

**Figure 4. Vision for High Quality Children's Services**

**Source:** HSE. (2016). *Model of Care for Paediatric Healthcare.*(52)

### 2.4.6. National Disability Strategies

Developed by the National Disability Authority (NDA) in 2004, the *'National Disability Strategy'* aimed to support equal participation of people with disabilities in society.(53) The strategy built on existing policy and legislation, and intended to provide a whole of government approach to promoting equality and inclusion. The strategy focused on activating and progressing three key areas:

- Legislation, including the Disability Act 2005 and the Education for Person's with Special Educational Needs Act 2004
- Statutory Sectoral Plans for Government Departments, covering employment, environment and housing, health and disability services, social welfare, transport and communications
- A multi-annual investment programme into disability services.

A 2013 report reflecting on the strategy, while accepting that the government of the time was committed to the strategy in principle, found that there was little coherent action to address the reality that austerity was having on people with intellectual disabilities and their families.(54) The report sets out that cuts to respite services; non-replacement of front-line staff; a shortage of services to children with disability; and the sharp reduction in community-based supports undermined the strategy.

The '*National Disability Strategy'* was replaced in 2017 by the '*National Disability Inclusion Strategy*' (NDIS).(55) Similar to the 2004 strategy, the 2017 strategy takes a whole of Government approach to improving the lives of people with disabilities and sets out specific actions and timescales for delivery under the themes set out below. These are:

- equality and choice
- joined up policies and public services
- education
- employment
- health and wellbeing
- person-centred disability services
- living in the community
- transport and access to places.

Implementation of the NDIS is overseen by the National Disability Inclusion Strategy Steering Committee (NDISSG). A mid-term review of the strategy was undertaken by the Department of Justice and Equality in 2020 to assess progress and set out plans to further support the implementation strategy.(56) The report sets out a number of achievements under the strategy including: the ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018; the implementation of the

Access and Inclusion Model[†††] supports for children accessing early childhood education services; and the reduction in the number of people with disabilities living in congregated settings. The report notes that with the ratification of the UNCRPD, Ireland now has obligations to ensure that the Convention is implemented in practice for children and adults in all aspects of their lives. The Department consulted with a wide range of stakeholders to inform the review, and feedback indicated the need for sectoral plans to underpin actions in the NDIS, and for adequate resources to underpin the implementation of actions. Stakeholders also stated that actions in the strategy should be made more 'concrete' and that there should be clear targets as indicators of success, noting that the achievement of these targets through monitoring will assist in tracking any real progress.

### 2.4.7. Sharing the Vision: A Mental Health Policy for Everyone

The 2006 '*Vision for Change*'(28) policy set out a vision for holistic and responsive mental health services in Ireland, with the stated aim that '*Each citizen should have access to local, specialised and comprehensive mental health service provision that is of the highest standard.*' The policy recommended that, using a person-centred treatment approach, there should be a multidisciplinary approach to addressing the range of factors that contribute to mental health problems. The report placed a strong focus on involving people who are using services in their care and support. In relation to children, the report set out that services needed to recognise the importance of having a range of services available to children that recognised their unique needs and strengths. The policy highlighted the need for early intervention and health promotion programmes, primary and community care services, right up to the need for specialist mental health services when dealing with more complex mental health needs.

In 2020, a 'refreshed' national mental health policy was launched. *'Sharing the Vision: A Mental Health Policy for Everyone'*(29) sets out both what has been achieved in mental health services since 2006 and the ambition for mental health services for the coming years. This policy is based on stakeholder engagement and evidence. The policy focuses very strongly on developing a 'whole system' mental health policy for all of the population. The policy maps the future for mental health services with a strong focus on supporting children in a more tailored and integrated way, closer to their home and community with an emphasis on recovery and building resilience.

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[†††] The Access and Inclusion Model is a model of supports designed to ensure that children with disabilities can access the Early Childhood Care and Education (ECCE) Programme. Its goal is to empower pre-school providers to deliver an inclusive pre-school experience, ensuring that every eligible child can meaningfully participate in the ECCE Programme and reap the benefits of quality early years care and education.

The policy states that it is closely aligned with the main provisions of *'Sláintecare'* as it sets out that mental health supports should be tailored to meet the needs of each individual case in the most appropriate setting. The policy is guided by four core values, which are set out in Figure 5.

**Figure 5. Core Values of 'Sharing the Vision: A Mental Health Policy for Everyone'**

| CORE VALUES | |
|---|---|
| Respect | Respecting each person as an individual and treating everybody with dignity at every level of service provision |
| Compassion | Treating everybody in a friendly, generous and considerate manner and developing a rapport with each person – demonstrating understanding and sensitivity |
| Equity | Access to services characterised by inclusiveness, fairness and non-discrimination |
| Hope | Interactions during the course of service delivery full of positivity, and empowerment, with a strengths-based focus |

**Source:** Mental Health Commission. (2020). *Sharing the Vision: A Mental Health Policy for Everyone.*(29)

### 2.4.8. National standards for health and social care services working with children

As set out on Table 1 on page 34 of this document, a wide range of standards have been developed to drive improvement and assess the quality of care provided to children by statutory, private and voluntary services in individual care settings. Taken together, these standards aim to promote practice that is up to date, evidence-based, effective and consistent. However, as noted in the introduction to this overall section, many of the standards, and the regulations underpinning them, are service-specific and do not follow a child's pathway of care and support through the range of services they use. Further, the systems to monitor the compliance of health and social care services with the standards are complex and fragmented with HIQA having a monitoring role in healthcare (hospital) services, child protection and welfare services, foster care services, children's residential centres and children's detention centres, and having a regulatory role in registering and monitoring residential services for children with disabilities and children's special care units. The MHC regulate approved mental health centres for children and adolescents with mental health needs.

This section will broadly cover standards that apply to health services, disability services and mental health services. A high level of summary of standards for children at risk or in the care of the State is provided in this section. For a more detailed review of standards in this area please refer to the 2020 publication '*Evidence review to inform the development of National Standards for Children's Social Services'.*

This section will look at the following standards related to children's health and wellbeing, their safety and welfare, their disability needs and their mental health:

- National Standards for Safer Better Healthcare
- National Standards for children at risk or in the care of the State
- National Standards for Residential Services for Children and Adults with Disabilities
- Quality Framework for Mental Health Services in Ireland.

## National Standards for Safer Better Healthcare

The '*National Standards for Safer Better Healthcare'* were developed by HIQA in 2012 to drive improvements in healthcare in order to provide high-quality, reliable and safe care.(57) These standards are designed to support all healthcare services provided or funded by the HSE to improve the quality and safety of services. The standards set out a number of 'quality dimensions' which are:

- person-centred care and support
- effective care and support
- safe care and support
- better health and wellbeing.

The standards identify that a culture of quality and safety is essential to ensuring that these dimensions are lived out in practice in healthcare services, highlighting the importance of strong, accountable and supportive leadership and governance in achieving this culture. HIQA uses specific themes to inspect and monitor hospitals, including children's hospitals, using the standards to assess compliance with the theme.

Following a number of investigations[‡‡‡] into concerns raised in relation to the care and treatment of women in maternity hospitals, HIQA developed a set of standards for maternity services, *'National Standards for Safer Better Maternity Services'.* The National Standards support the implementation of the '*National Maternity Strategy*'(58) and sit within the overarching framework of the '*National Standards for Safer Better Healthcare*'. Importantly for child health and wellbeing, these standards set out that good maternal health, that is supported by safe, high-quality maternity care throughout pregnancy and after birth, can have a significant impact on the health and wellbeing of newborn babies, and on children's healthy development and their resilience to problems encountered later in life.

## National Standards for children at risk or in the care of the State

A number of standards have been developed to drive improvement and assess the quality of care provided to children at risk or in the care of the State by statutory services in individual care settings. These are:

- National Standards for Foster Care (Department of Health and Children, 2003)(59)
- Standards and Criteria for Children Detention Schools (Department of Justice, Equality and Law Reform, 2008)(60)
- National Standards for the Protection and Welfare of Children (HIQA, 2012)(61)
- National Standards for Special Care Units (HIQA, 2014)(62)
- National Standards for Children's Residential Centres (HIQA, 2018)(63).

HIQA monitors how Tusla fulfils its obligations against the standards by meeting with social workers and social care workers responsible for the care and support of children, as well as with children, families and foster carers, where appropriate. Inspectors will judge the level of a service's compliance with the standards and provide the service with a report of findings and identify scope for improvement, if necessary. HIQA publishes a report assessing compliance with the standards and highlights areas for improvement based on an assessment of evidence provided,

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[‡‡‡] These are the investigations into the safety, quality and standards of service provided by the HSE to patients in the Midland Regional Hospital, Portlaoise, and the investigation into the safety, quality and standards of service provided by the HSE to patients, including pregnant women, at risk of clinical deterioration, including those provided in University Hospital Galway, and as reflected in the care and treatment of Savita Halappanavar.

interviews with staff, children, parents and foster carers, and observations of practice.

HIQA is in the process of developing Draft National Standards for Children's Social Services that will replace these service-specific standards, (with the exception of the *'Standards and Criteria for Children Detention Schools'*, developed by the Department of Justice, Equality and Law Reform). The scope of the draft national standards includes all children's social services, including aftercare services, provided to young people with care experience, from the point of their referral to a service until they transfer to another service or are discharged. These standards will be aligned to the Overarching National Standards for the Care and Support of Children using Health and Social Care Services.

### National Standards for Residential Services for Children and Adults with Disabilities

The '*National Standards for Residential Services for Children and Adults with Disabilities'*(64) were developed by HIQA in 2013. The standards were developed to assess the performance of statutory, private and voluntary providers of residential services and to identify areas for quality improvement. The standards set out that both adults and children have the right to be safe, to receive person-centred, high-quality services and supports and to have access to the services they need in order to maximise their independence and choice and enable them to lead a fulfilling life.

The standards highlight the importance of providing care and support through well led, consistent services that:

- are in the best interests of the child
- are tailored to the child's developmental and psychological needs
- balance safety with independence and autonomy
- uphold the child's rights
- promote participation and inclusion.

HIQA is legally responsible for the monitoring, inspection, and registration of all residential services for adults and children with a disability. A report on the first five years of inspection and registration of these services in Ireland was published by HIQA in 2019 and will be discussed in further detail in Section 2.5.3.

### Quality Framework for Mental Health Services in Ireland

The '*Quality Framework for Mental Health Services'*(65) was published by the Mental Health Commission in 2007 and applies to all mental health services, including services for children and adolescents. The '*Mental Health Act 2001 (Approved*

*Centres) Regulations 2006'*(66) are incorporated into the quality framework. The framework sets out themes, standards and criteria that aim to provide clear guidance for people using mental health services, their families and or advocates, service providers and the public as to what to expect from a mental health service.

The framework is comprised of eight themes. Six of these themes focus on ensuring that the experience of both the person using the service and their family and or advocate is positive and recovery oriented. The final two themes set out the 'enablers' to achieving these outcomes.

Similar to National Standards developed by HIQA, the framework sets out that children and adults using mental health services should, in the first instance, have an individual care and treatment plan that is tailored to their needs, and in a safe environment that protects their dignity and privacy. The framework strongly focuses on a preventative and early intervention approach, highlighting that care and treatment should be provided in the community, insofar as possible. Transitions between community and hospital services should be planned, with a strong focus on supporting people to settle back into their community. The framework recognises the importance of respectful relationships between those using the service, their families, as appropriate, and staff. It sets out that the care and support received should take into account their specific values, beliefs and experiences. The active participation of children and adults who are using the service in planning their care and support is central to the framework, and services are required to have participation mechanisms that support them to exercise choice in this. Enablers to the achievement of this care and support are staff with appropriate skills and training who deliver outcome and recovery-focused care and treatment, alongside a strong management team who ensure there is good governance within the service.(65)

## 2.5. Findings from reviews

According to UNICEF's 2020 annual report card, Ireland ranks 12th among 38 OECD and or EU countries for child wellbeing and higher again in a separate league table of conditions for child wellbeing. However, UNICEF Ireland notes that Ireland ranks in 26th place in terms of mental wellbeing and also scored lower in terms of physical health, ranked in 17th place overall.(67) In association with these rankings are findings from the Growing Up in Ireland survey, a longitudinal Government-funded study of children in Ireland.(68) In 2020, GUI published the report *'The Lives of 17/18 Year Olds'* looking at the first cohort of children who began their participation in study in 1998.(69) At a very high level, the report showed that children in this group expressed positivity about their lives, with the group expressing a high level of satisfaction with their lives and generally showing positive levels of emotional wellbeing. However, the report also showed that there had been an increase in the experience of depression since the previous survey of the group, with one quarter of girls in the survey, and one in six boys, experiencing some form of depression. The report also sets out that exercise amongst this group  was well below the WHO recommended levels, with higher levels of overweight and obesity, and risk-taking with alcohol.

Nationally, health and wellbeing outcomes for children using health and social care services in Ireland are typically measured by reports from statutory bodies such as HIQA, the Mental Health Commission, and the Office of the Children's Ombudsman, as well as from advocacy organisations, such as the Children's Rights Alliance. Although each of these reviews has a different focus, they all work to include the perspectives of children and young people on their experience of the services they receive. A number of these reports will be discussed in this section.

Overall, the reports and reviews discussed in this section show that there is a strong commitment to improving child health and wellbeing at a strategic level. This is evidenced in the number and range of services and programmes to support this aim.(70) However, there continues to be issues at a service delivery level with reports identifying common themes, such as a shortage of services leading to extensive waiting lists, poor interagency working, service criteria that excludes children with specific or complex needs, and inconsistent family support services.(1,2,3,4,5,50,71)

This section sets out findings from key reports that provide an overview of health and wellbeing outcomes for children and young people in general and also children and young people with additional needs.

### 2.5.1. Overview of findings from the Office of the Children Ombudsman on health and social care services working with children

This section sets out findings from reports by the OCO on health and social care services working with children.

#### Report to the UN Committee on the Rights of the Child on the examination of Ireland's consolidated Third and Fourth Report to the Committee

In 2015, the OCO published an independent report to the UN Committee on the Rights of the Child on the experiences to date since Ireland ratified the UNCRC in 1992.(4) This report was primarily informed by the statutory investigations undertaken by the OCO. Among the issues raised in the report were issues around education, children's participation and children's rights to be heard in relevant legislation, homelessness among children, child protection, disability services for children, mental health services for children, and direct provision for children seeking asylum.

The report made a series of recommendations which include an obligation for public bodies to strictly apply the best interest principle and to ensure that children's views are appropriately considered in the context of decision-making, noting that staff need to be aware of the impact of not including children in decision-making, and how quickly harm can be done to children.

The report also identified geographical disparities and the fragmentation of services as being a challenge facing children with disabilities in Ireland. While recognising the work being done by the HSE to address these issues by developing the Progressing Disability Services for Children and Young People Programme, the report noted that there was still inconsistency in the development and delivery of this programme.

The report recommended that the State must ensure that child and adolescent mental health services are significantly improved to meet the needs of young people, urging the resourcing of multidisciplinary community teams, inpatient services and out-of-hours facilities.

### Molly's* case: How Tusla and the HSE provided and coordinated supports for a child with a disability in the care of the State

In 2018, the OCO published a report relating to a complaint made in respect of a young person, known as Molly in the report, with a learning disability living with her foster family.(3) Molly required a high level of physical care from her foster parents, as well as a wide range of therapies and supports to ensure that her health and developmental needs were met. The complaint, made by Molly's foster parents, indicated that Molly was not receiving the level of support that she needed from Tusla and the HSE to ensure that these needs were met in a timely and proportionate way. The OCO undertook an investigation into this complaint and found that there was a lack of coordination between the two agencies with each organisation only focusing on the area that they had responsibility for, rather than taking Molly's whole needs into account and acting in her best interests. The OCO concluded that this approach meant Molly was not being given the opportunity to reach her full potential, noting that based on the complaints that the office had received, and feedback from across the sector, that this was a common issue for children with disabilities in care.

The OCO made a number of recommendations to Tusla and the HSE, including taking action to address gaps in the provision and coordination of the appropriate range of services through legislative, regulatory, policy and or budgetary means. Tusla and the HSE accepted these findings and committed to actions to address the issues raised. The OCO published a follow-up report(72) in 2020 to assess progress on the recommendations. Despite some progress in the implementation of the *'Joint Protocol for Interagency Collaboration between the Health Service Executive And Tusla'*(73), which was intended to promote the best interests of children and families, the OCO found that coordination between Tusla and the HSE is still an issue. The report concludes that this is having a profound effect on the lives of children with a disability and the committed foster parents who look after them. The OCO sets out that the Government has an important role to play ensuring that the joint protocol is used effectively and ensuring that there is a system, alongside adequate resourcing, for assessing the needs of these children as soon as they come to the attention of services.

A further report by the OCO in 2020 on the assessment of need (AoN) highlights the challenges faced by children with a disability in Ireland who require an assessment of their needs.(37) The report outlines that the number of complaints received by the OCO between 2017 and 2019 rose to 95, up from 34 between 2013 and 2016, with a number of parents highlighting that delay in obtaining an AoN meant that their children had 'aged out' of early intervention services, resulting in potential delays to their development. The report sets out a number of factors that are impacting on timely assessments. These include the use of the AoN process to assess children's educational needs, as the relevant sections of the EPSEN Act have not been enacted; the sharp increase in the applications for AoNs which, due to the lack of resources within the HSE, has led to a backlog; and inconsistency in the number of applications processed, assessments undertaken, and Service Statements finalised across the HSE's Community Healthcare Organisations. The report made a number of recommendations to address these issues in order to ensure that children's needs are assessed in a timely and consistent way. These include the allocation of additional resources to address waiting lists and amendments to the Disability Act so that when an assessment is being undertaken it looks at the child's whole needs, and not just their disability.

### Office of the Children's Ombudsman 'Joining the Dots' report

In 2018, the OCO, in partnership with Children's Health Ireland, produced a report, *'Joining the Dots'*(5) which, using a child rights framework, brought together the views of children, young people, parents and or guardians, staff and management, in the three children's hospitals on how these services were being delivered. The report looked at seven different areas and, using a child-friendly questionnaire with 24 questions tailored to each area, asked participants to rate the quality of each of these areas, and to provide qualitative feedback on the reasons for their ratings. These areas were:

- getting good quality care
- being treated equally and fairly
- rest, play and learning
- getting information and being listened to
- cleanliness and food
- being safe
- getting help with pain.

The report found that children, parents and carers believe that there is a good quality of care overall in the hospitals, that they are respected by staff, and that they are protected from harm while in hospital. However, the report also found areas for improvement, such as supporting children and parents and carers to ask questions about their treatment, tailoring the service to the meet the age and developmental needs of the child, allowing parents and carers to stay with the child overnight, and more privacy for children, a finding echoed in the National Inpatient Experience Survey.(74)

### 2.5.2. Children's Rights Alliance Annual Report Card 2020

The Children's Rights Alliance is an umbrella organisation that brings together the views of a wide range of organisations working with children. The Alliance produces an annual 'Report Card' setting out how the Government has performed in relation to children's rights issues which is used by the Alliance and its members to advocate for policy and service improvement in areas of concern. The 2020 Report Card(71) awards the Government an overall 'C+' grade for its performance on children's rights issues. The report notes some positive changes for children in the previous year, such as the extension of free GP care to under 6s, and planned budget expenditure to address child poverty. However, the report points to the continuing inequalities faced by children seeking asylum and living in direct provision services. The report also highlights a sharp increase in the number of children experiencing family homelessness, discrimination experienced by Traveller and Roma children in regards to their right to public services, and continued concerns about access to mental health treatment with inadequate availability of age-appropriate mental health units, long waiting lists to access mental health supports and the lack of out-of-hours services.

### 2.5.3. Overview of findings from HIQA on health and social care services working with children

The 2019 overview of five years of regulation of residential services for adults and children with disabilities by HIQA showed a marked improvement in the services people receive, with a gradual improvement year-on-year.(75) Feedback from people using these services show that these improvements have had a positive impact on their lives. The report notes, however, that there have been continued levels of non-compliance in relation to governance and management, with governance having a direct impact on the care and support of people using the service.

While the report does not explicitly focus on the experiences of children living in or using these services for respite, it does note that residents that they spoke to, which include children, felt that HIQA inspections had increased staff awareness of the rights of people using these services, and that they felt that the staff had put in place systems to support them to exercise their rights. However, the report also notes that safeguarding issues continue to be an issue , finding that in 2018, almost one in three centres failed to ensure that residents of these services were adequately safeguarded in line with the regulations.

HIQA monitors and inspects a wide range of children's social services against regulations and standards. The '*Annual overview report on the inspection and regulation of children's services – 2019'*(2), noted that there have been improvements in the broad range of services regulated and monitored by HIQA, and that there is evidence of the ongoing commitment of staff in these services to provide safe and effective care. The report noted that Tusla is implementing a specific approach, Signs of Safety[§§§] to support a consistent experience for all children and families who their services work with. The report also notes the extensive work that has been undertaken to embed an Electronic National Child Care Information System (NCCIS), to improve the reliability of information on which to report on, monitor and guide service provision on a local, regional and national basis.

However, the report notes that risks in some children's services remain and that there are challenges in relation to the pace of implementing a workforce strategy that attracts more social workers into the service and retains current social work staff. The report recognises that there was a variance across regions, with a number of areas struggling to meet the demand for care and support, as well as managing existing children's cases on waiting lists.

In 2020 HIQA published an '*Overview report of five years of HIQA monitoring in Irish public acute hospitals against national standards: 2015–2019'*(1), which looks at how acute hospitals, who provide adult and paediatric services and maternity hospitals, have been working to meet selected national standards. While the report does not focus specifically on the experiences of children using these services it

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[§§§] SoS is a strengths-based approach to child protection casework that was developed in Western Australia in the 1990s.

provides an overview of areas of improvement, as well as issues, in these services that affect all patients. The report finds that there have been sustainable improvements in governance structures at hospital level leading to a more integrated approach at local, regional and national healthcare levels. HIQA has undertaken two specific monitoring programmes; in the area of infection prevention and control, as well as medication safety.

The report found that there have been improvements in the area of infection prevention and control, and medication safety that includes strengthened governance and leadership structures at hospital and national level, an increase in the number of specialised staff and improved screening processes, and improved knowledge sharing across the sector. However, the report also finds that the level of compliance with national standards across public acute hospitals varied greatly, leading to inconsistencies in the quality of care provided across public acute hospitals. The report also highlights that there are insufficient resources, poor infrastructure and challenges with the physical environment in meeting the standards.

### 2.5.4. National Patient Experience Survey 2019

In 2019, HIQA, in partnership with the HSE and the Department of Health, undertook the third National Inpatient Experience Survey(74), which sought the views of people who had been inpatients in acute hospitals in the month of May 2019. The survey asks a series of questions on each stage of a person's care, focusing on admission, time on the ward and discharge or transfer to another service. Included for the first time in this target group were young people aged 16-18 who were inpatients in adult wards during this time. 158 young people aged 16-18 responded to the survey, compared with 12,185 people older than this. Those aged 16-18 gave lower ratings for each stage of care, with the exception of discharge or transfer, and for overall experience. For overall experience, 48% of 16-18 year olds said they had a 'very good' overall experience, compared with 56% of older respondents. The factor that had the biggest impact on whether young people had a positive experience of hospital was whether they had someone to talk to about their experience. This was different to older respondents where the most important factor in their overall experience was whether they felt they were treated with respect and dignity. Of interest is the lower levels of satisfaction for young people around two issues. Fifty-seven percent of young people felt that that they had enough privacy while being examined or treated in the Emergency Department compared with 69% of older respondents. Also, 16-18 year olds rated hospital food much lower than people older than that with 21% rating the hospital food as 'very good', compared with 37% of older respondents. More positively, 72% of 16-18 year olds said they were 'completely' told how they could expect to feel after an operation or procedure, compared with 65% of older respondents.

### 2.5.5. Reviews of mental health services

In 2017 the Inspector of Mental Health Services compiled a report into CAMHS which was published as part of the MHC's 2017 Annual Report.(76) The report examines CAMHS inpatient units as well as community CAMHS. The report found that community CAMHS teams were inadequately staffed, with staffing at only 60% of that recommended by *'A Vision for Change'*. The report highlighted the absence of adequate services for children and young people with an intellectual disability or Autistic Spectrum Disorder (ASD) which meant that children with these difficulties were referred to CAMHS. In respect of inpatient CAMHS units, the Inspector noted that young people often had to be admitted to CAMHS units at considerable distance from their homes and families. Three of the five CAMHS approved centres used seclusion. It was noted that it was often difficult for referral agencies to source a bed in CAMHS units even when beds were empty. The process of sourcing a bed was frustrating, time-consuming and often resulted in a young person being admitted to an adult mental health unit.

Research presented in the 2017 *'National Model of Care for Paediatric Services'*(50) outlined that there are ongoing gaps in the primary care provision of psychology, educational psychology, and early and school age intervention teams. Increased referrals to CAMHS has impacted on the capacity of CAMHS to respond in a timely fashion to those with moderate-to-severe mental health problems. Furthermore, the document outlines that CAMHS teams remain underresourced, with only 50% of the staffing recommended. While the report noted that there has been an increase in funding to support these services, many of the outpatient and inpatient services are still underdeveloped, and on-call services severely restricted. Additionally, CAMHS services for children with higher levels of intellectual disability are scarce and where the services are in place they generally do not have the full complement of professional disciplines recommended.

A 2020 study looking at the levels of burnout experienced by consultants in CAMHS in Ireland showed a very high level of work related and personal burnout with participants in the study citing a lack of confidence in the government commitment to investment in the services and perceived ineffective management.(77) Participants stated that factors that contributed to these high levels of burnout in recent years were the massive increase in referrals to their services, which they already stated were fragmented and poorly resourced. The study showed that participants felt there was a sense of a lack of support from both HSE management, who they saw as coming up with 'quick fix' solutions to systemic problems, and from government, coupled with unrealistic public expectations of CAMHS, all of which contributed to their high levels of self-reported burnout.

## 2.6. Summary

The findings from the review of health and social care services working with children shows that there is a wide range of legislation, strategies, policies, standards, programmes and services to promote the health and wellbeing of children and their families.

There have been high-level commitments in Ireland to drive consistency and integration of the wide range of health and social care services that children engage with over their childhood to achieve the best outcomes for them. In some instances these commitments have been underpinned by strategies, policies and services to support their implementation, such as the introduction of free GP care for children under six, an increase in the number of primary care services, and the introduction of Children and Young People Services Committees (CYPSCs) across the country to coordinate care and support to children with complex needs. However, it is clear from years of reports and reviews by oversight and advocacy bodies that the provision of health and social care services remains inconsistent and that geographical disparities in the provision of services impact most negatively on children who are already vulnerable due to their living circumstances. There are very real challenges for children with mental, intellectual and physical care needs, as well as for children who are at risk in the community, in accessing services that meet these needs in a timely and proportionate manner.(2,3,4) While there is evidence of good practice and positive outcomes for children using health and social care services, often these relate to children with a specific need that can be addressed by one service alone. A number of reports highlight that for children with complex care and support needs, service provision can be fragmented and inconsistent and, at worst, absent at a time when care and support is critical to ensuring positive longer-term outcomes.

# 3. International review of health and social care services working with children

Internationally, the service delivery systems that are in place to meet the needs of children are complex, whereas in Ireland there are two main bodies involved in the organisation and delivery of health and social care services for children. While Ireland is also unique in terms of the legislation, policies and strategies that are in place to promote the health and wellbeing of children, there are important lessons to be learned for Ireland from approaches taken in other countries, particularly regarding legislative frameworks for integrated working and policies to safeguard and promote the health and wellbeing of children and their families.

The international review set out in this document provides an overview of how seven jurisdictions deliver health and social care services to children. The jurisdictions included in the review are:

- Scotland
- England
- Northern Ireland
- Australia
- Sweden
- America
- New Zealand.

These seven jurisdictions were chosen following findings from an initial scoping review, the evidence synthesis and input from key stakeholders. The review also involved engaging with international subject matter experts to understand how health and social care services supporting children work in practice in these jurisdictions. A further desktop review of these seven jurisdictions involving web-based searches of relevant literature and websites identified a number of key organisations and experts to contact and engage with.

As part of the international review, teleconference calls were held with experts in Scotland, England, Northern Ireland, and Australia between September and October 2020. See Appendix 1 for the list of contacts in these jurisdictions. Attempts were made to contact experts in Sweden, America and New Zealand, however, at the time of writing, it had not proven possible to secure contact. The experts were primarily leaders in regulatory organisations, policy bodies, academic institutions and advocacy bodies. They provided key information on the current developments in health and social care services working with children within their jurisdictions and they assisted with providing relevant reference material and supporting documents relevant to the topic. Lessons from developing, supporting and sustaining consistent good practice in children's social services from their respective jurisdictions were discussed.

For each of the international jurisdictions, the review looks at five key areas:

1. Overview of health and social care services working with children
2. Model of service delivery
3. Legislation
4. Strategies, policies and standards
5. Findings from reviews
6. Lessons for Ireland.

Population-level statistics are provided for children within each jurisdiction. However, at the time of writing, it was not possible to obtain comparative statistics across all jurisdictions as some jurisdictions do not have systems in place to measure such statistics. As such, we have presented the population of children in Scotland, England, Sweden and New Zealand as a percentage of the overall population and we have provided whole figures for different age groups in Northern Ireland, Australia and America.

## 3.1. Scotland

This section describes the organisation and delivery of health and social care services for children in Scotland and also the impact that these services are having on health and wellbeing outcomes for children. This section is set out under the following headings:

- overview of health and social care services working with children
- model of service
- legislation
- strategies, policies and standards
- findings from reviews
- lessons for Ireland.

### 3.1.1. Overview of health and social care services working with children

In 2018, the number of people under the age of 18 in Scotland was estimated at just under 1 million, which represented 17% of the total population.(78) There is a government-wide commitment to upholding the health and wellbeing of children, underpinned by the principles of dignity and respect, compassion, inclusion, responsive care and support and wellbeing.(79)

At a national level, the Children and Families Directorate works across a number of government bodies to support improved outcomes for children and young people.

This directorate also leads on the development of legislation, statutory guidance and policy on how the child welfare and protection system should work. Separately, the Health and Social Care Directorate provides leadership for the delivery of the health services, public health and social care. The Cabinet Secretary for Health and Sport in Scotland is responsible for the integration of health and social care services. The primary responsibility for children's social services and child protection in Scotland is with local authorities, although the police also have a role in the latter.

Section 3.1.2. describes how health and social care services are delivered to children in Scotland through the National Health Service and local authorities, and the joint responsibilities of these bodies to meet the needs of children in their area. Section 3.1.3. sets out, at a high level, the key pieces of legislation in place in Scotland to support children's health and wellbeing, their safety and welfare, their disability needs and their mental health. Section 3.1.4 looks at the different strategies, policies and standards that are focused on improving outcomes for all children, such as the national policy *'Getting It Right For Every Child'* (GIRFEC) and the recent '*Health and Social Care Standards: My support, my life*' which sets out how children and adults should experience the health and social care services they use.(6,80) This section also provides a high-level view of the inspectorates that monitor the implementation of the standards in practice. Section 3.1.5 sets out the findings from reviews of health and social care services undertaken by regulators, advocacy bodies and independent primary bodies involved in the monitoring and regulation of health and social care services for children and young people.

### 3.1.2. Model of service

There are a number of governmental bodies involved in organising the health and social care services which work with children. In line with a government-wide commitment to children and young people, the Children and Families Directorate, local authorities and the HIS provide services to support the health and wellbeing of children and young people. This section sets out the organisation and delivery of the following services for children and young people:

- general healthcare services for children and young people
- children's social services
- disability services for children and young people
- mental health services for children and young people.

As mandated for in the Public Bodies (Joint Working) (Scotland) Act 2014, Integration Joint Boards (IJBs) have been established to implement the delivery of improved outcomes for all children using health and social care services, as well as services to children who are at risk. Each IJB has a strategic leadership responsibility for a select number of children's services, with the exact services covered varying from area to area. A number of IJBs assume responsibility for the majority of child health and social work services, such as Highland, the City of Edinburgh Council and East Ayrshire. In these cases, the IJB typically holds responsibility for coordinating a multi-agency response to child protection issues, as well as other issues. Community Planning Partnerships are another way that public bodies in Scotland work with each other, and with their local communities, to develop and deliver effective services. In total there are 32 Community Planning Partnerships (CPPs) in Scotland, located in each council area. CPPs focus the collective efforts and resources of partners in order to add value to local communities and to help tackle inequality.

### Organisation and delivery of general healthcare services for children

The Cabinet Secretary for Health and Sport is responsible for overseeing health and social care services for adults and children. Health services in Scotland are almost entirely free and delivered through the NHS Scotland, while a small contingent of the sector includes private and non-profit organisations. The Cabinet Secretary is advised by the Health and Social Care directorates where to allocate funding for health and social care. These directorates are responsible for health and social care policy, management of NHS Scotland and oversee social care provided by local authorities, private and non-profit organisations. Figure 6 below shows the organisational flow of the health and social care system in Scotland.

Funding for the health care system in Scotland is mostly directed through 14 geographical areas, based on NHS Boards, who are responsible for the planning and delivery of services which meet the needs of the local area. Recent years have seen growing focus on the role of NHS Boards, and their partner organisations, in driving health improvements among Scotland's child and adult populations. The Scottish government and NHS Boards provide assistance to NHS Scotland on a number of issues, one being the improvement of referral waiting times to the Child and Adolescent Mental Health Services (CAMHS) which work with children and young people with mental health and other needs. NHS Boards are divided into 31 Health and Social Care Partnerships (HSCPs), which are run jointly by the local authority and the NHS. Each HSCP has a responsibility for adult social care and primary health, unscheduled hospital care, and children's services.

Primary care in Scotland is delivered by a wide range of professionals who are typically seen as 'gatekeepers' for patients looking to access secondary or tertiary services. Primary care entails a number of health care professionals working together to deliver care and support to their local populations. Increasingly GPs are seen as part of a multidisciplinary team to improve child health, along with midwives, nurses, health visitors and other allied health care professionals.

Secondary and tertiary care is mostly provided to children in hospital settings and in Scotland this care is primarily provided by NHS Scotland and a small number of private organisations.

NHS Scotland provides a universal health promotion programme to all children and their families called the Child Health Programme. The aim of this programme is to provide children with a high standards of healthcare through screening, immunisations, health promotion, and the provision of a structured assessment of need, parental supports. These free services are provided to children by health visitors, school nurses and other healthcare professionals.

### Figure 6. Health and Social Care Systems in Scotland

**Source:** Steel, D. (2012). *United Kingdom (Scotland): Health system review.*(81)

## Organisation and delivery of children's social services

Together Police Scotland, NHS Boards and local authorities are the key agencies that have individual and collective responsibilities for child protection. Main responsibility falls on local authorities who are responsible for promoting, supporting and protecting children in their area. The Children (Scotland) Act 1995 sets out that the duty to safeguard and promote the welfare of children in need falls upon the local authority as a whole and includes social work services, health, education, housing and any other relevant services required to safeguard and promote the welfare of such children.(82) While there is a strong emphasis on the involvement of children and families in decision-making, reports indicate that the complexity of the system and differing approached taken by local systems does not lend itself to consistent involvement.(83,84)

Each local authority has a Child Protection Committee (CPC), who is responsible within the local authority for the multiagency child protection policy, procedure, guidance and practice. CPCs work with local agencies, such as children's social work, health services and the police, to protect children. In each local authority, child protection services are overseen by a Chief Social Work Officer (CSWO). The CSWO is accountable for decisions made within the authority in relation to child protection and welfare.

A detailed account of the model of service for children's social services in Scotland is provided in the 2020 publication '*Evidence review to inform the development of the Draft National Standards for Children's Social Services*'.(9)

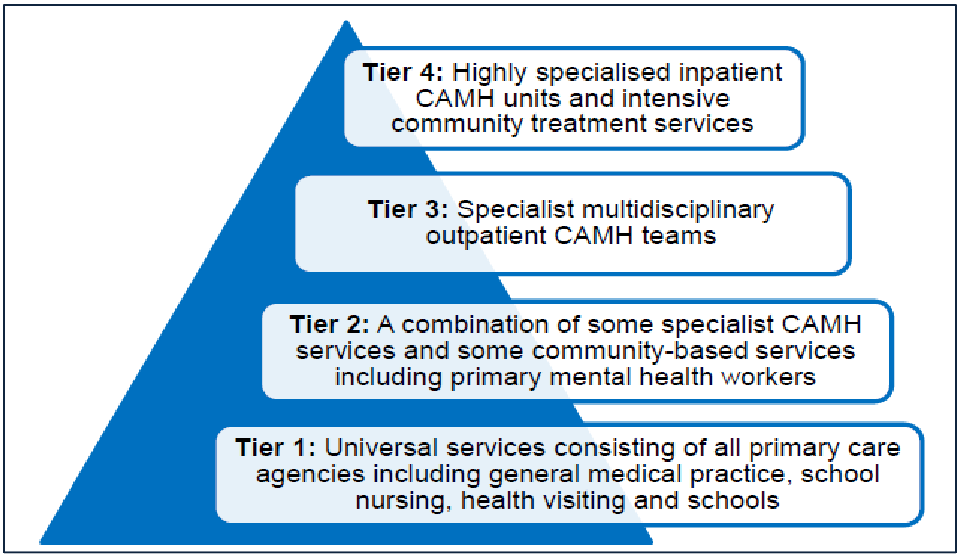
## Organisation and delivery of disability services for children

The Children and Families Directorate are responsible for the delivery of services to children with a disability. Children with a disability in Scotland have access to the same standardised support and entitlements that apply to all families, including additional supports where needed. Under the Children (Scotland) Act 1995, local authorities have a general duty to safeguard children and to promote their needs and best interests.(82,85) As such, local authorities are responsible, under Section 23 of the Act, for carrying out assessments of children with disabilities.(85) This assessment informs what services are deemed necessary for the child, and carers can also be assessed to determine what supports they require to ensure the best outcomes for the child.

## Organisation and delivery of mental health services for children

NHS Scotland provide mental health services to children through CAMHS. Multidisciplinary teams undertake assessments and provide treatment for emotional, developmental, environmental and social factors for children and young people who are experiencing mental health issues. CAMHS Scotland supports both universal and additional services for children and young people. Children, young people and their families are able to access support which focuses on emotional distress through Community Mental Health and Wellbeing Supports. Community supports work closely with CAMHS, health and social care services, education and children's services to ensure that there is a clear pathway for children and young people to access supports appropriately delivered by these services. Scotland's '*Mental Health Strategy'* stresses the importance of early intervention in child mental health and efforts have been directed to support children and young people in educational settings, as well as in traditional responsive services.(86) CAMHS are planned for and provided in a four-tier model, starting with universal services and moving through more highly specialised inpatient services see Figure 7.

### Figure 7. CAMHS Tiered Diagram



**Source:** The Scottish Government. (2017). *Scottish Government Mental Health Strategy* 2017-2027.(86)

An independent joint task force commissioned in 2018 by the Convention of Scottish Local Authorities and the Scottish Government have released recommendations which acknowledge the importance of focusing on preventative measures when supporting the mental health and wellbeing of children and young people.(87) Additionally, the Taskforce released recommendations calling for a top-down approach from leadership within the Scottish government and local authorities to prioritise child and adolescent mental health. The recommendations endorsed the whole system approach proposed in '*Getting It Right For Every Child',* which will be discussed in more detail in Section 3.1.4.1., and the promotion of preventative action to reduce need, alongside proportionate and timely responses which improve the outcomes for children who require support.(87)

### 3.1.3. Legislation

Scotland has a wide range of legislation and regulation in place which contributes to the safeguarding of children and promotes their overall health and wellbeing. There are a number of pieces of legislation which seek to protect and promote the rights of children in Scotland. There has been a strong move in Scotland towards more integrated health and social care services and underpinning legislation in the form of the Public Bodies (Joint Working) (Scotland) Act 2014 which seeks to bring health and social care into one single integrated system. This has resulted in the introduction of Integration Authorities and Integration Joint Boards which have worked to provide joined-up services for children and adults, with a focus on early intervention and prevention.

The Children and Young People's Commissioner in Scotland is responsible for the promotion and safeguarding of children and young people's rights. The Commissioner achieves this by reviewing law, policy and practice which relates to the rights of children. Additionally, the Commissioner has the power to investigate and make recommendations to Parliament on the basis of their investigations. This section sets out legislation which applies to all children in Scotland, specific legislation which applies to children at risk and also legislation that applies to children with disabilities and children with mental health issues.

### The Public Bodies (Joint Working) (Scotland) Act 2014

The Public Bodies (Joint Working) (Scotland) Act 2014 outlines the framework for integrating health and social care in Scotland to ensure the provision of quality and sustainable care services for those with complex, multiple or long-term conditions.(88) The act mandates for the integration of governance, resourcing and planning for children's health and social care services. The act requires that local authorities and NHS Boards work together to prepare a joint Integration Scheme, which sets out how health and social care integration should be planned, delivered and monitored within each local area. The act also sets out national outcomes which apply across health and social care, focused on health and wellbeing. The NHS Boards and local authorities are held jointly accountable for the achievement of these outcomes.(88)

### Children and Young People (Scotland) Act 2014

The Children and Young People (Scotland) Act 2014 placed the guiding principles of the UNCRC into Scottish legislation.(89) The act places an obligation on government and public bodies to take children's rights into consideration in all aspects of their work, and to report on how they are working to progress children rights. Additionally, the act places extra powers on the Children and Young People's Commissioner in Scotland.(89) The powers of the Commissioner were strengthened to include their ability to investigate matters relating to children and young people. The act places key elements of GIRFEC, the national approach to improving the wellbeing of children, into law. The eight GIRFEC indicators of wellbeing, which are discussed in more detail in Section 3.1.4.1., have been included in the act and place a responsibility on all children's services to refer to these when assessing children's needs and planning and delivering services to meet these needs.(90)

## The Children (Scotland) Act 1995

The Children (Scotland) Act 1995 is a central piece of legislation in the care of children and sets out the responsibilities of parents and the rights of children in Scotland.(82) The act outlines the duties of local authorities in supporting children and families, and intervening where a child's welfare and or safety is at risk. The act seeks to incorporate the three key principles of the UNCRC, that is non-discrimination (Articles 2); a child's welfare as primary consideration (Article 3); and listening to children's views (Articles 12) – into Scottish legislation and practice.(82) The key principles behind the act and which underpin current regulations are:

- each child has a right to be treated as an individual
- each child who can form a view on matters affecting them has the right to express those views if they so wish
- parents should normally be responsible for the upbringing of their children and should share that responsibility
- each child has the right to protection from all forms of abuse, neglect or exploitation
- so far as is consistent with safeguarding and promoting the child's welfare, the public authority should promote the upbringing of child's welfare by their families
- any intervention by a public authority in the life of a child must be properly justified and should be supported by services from all relevant agencies working in collaboration.

## Social Care (Self-directed support) (Scotland) Act 2013

The Social Care (Self-directed Support) (Scotland) Act 2013 creates the legislative framework so that individuals who are eligible for social care support have greater choice over the services they receive.(91) The act mandates that local authorities meet the needs of children and young people with disabilities, those who are adversely affected by the disability of another family member and those whose health or development is impaired. Self-directed support describes how adults, children and young people with a disability are given choice over how their support is provided and who provides it, by giving them control over their 'Personal Budget'. Personal Budgets are paid to an individual or a third party by local councils to fund any social care services with the main focus being that the child or young person's views are central to the assessment, planning and decision-making. While a young person over the age of 16 has a right to make decisions on the support they receive, unless there are questions as to their capacity to do so, children under 16 have to rely on their carer to include them in the decisions made regarding their care and support.

### Mental Health (Care and treatment) (Scotland) Act 2003

The Mental Health (care and treatment) (Scotland) Act 2003 sets out how and when people with a mental disorder will be treated, and when people can be sectioned against their will. It also outlines their individual rights in such a situation, and defines the safeguards which protect these rights.(92) The act places a responsibility on the local governments[****] to provide care and support to those with mental health issues. The act introduced changes to how community-based mental health services are provided, and how service users and unpaid carers are involved in decisions regarding treatment. Additionally, the act sets out the rights of carers in addressing their own individual needs and the rights they have in their role as a carer.

The act sets out a number of underlying principles which are to be considered by any person using the provisions of the act, including the principle that the welfare of children with mental health disorders is paramount. The act highlights that it is particularly important to take into account the views and wishes of children and their carers, the needs and circumstance of carers at the time of a child’s discharge, and places a responsibility on services to ensure that the information provided to carers is useful to them when they are caring for their child. Additionally, the act stresses the importance of ensuring that if a child or young person has been sectioned, that appropriate services are allocated to them, and that where a child or young person is receiving care for a mental health disorder that there are minimum restrictions to their freedom.

### 3.1.4. Strategies, policies and standards

Scotland has diverse strategies, policies and standards in place to support the health and wellbeing of children. The Scottish Government supports the principles and the model of working outlined in GIRFEC and it is embedded into all Government policies which support children and their families.(90) Overarching standards for all health and social care are provided in ‘*Health and Social Care Standards: My Support, My Life*’. These standards set out what it is that children and adults can expect when they are using health, social care or social work services.(6) They also provide a guideline for how services and organisation can achieve high-quality care. This section describes

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[****] In Scotland local government is organised into 32 local authorities, which provide public services, including, social care, libraries, planning, education and waste management.

key strategies, policies and standards and also describes a number of inspectorates that assess compliance with standards.

#### 3.1.4.1. Strategies and policies

The strategies and policies included in this section set out a vision for child health and wellbeing in Scotland. This section sets out strategies and policies that apply to all children and young people and also ones that apply specifically to children and young people at risk.

#### Getting it right for every child (GIRFEC)

The Scottish Government has made an overarching commitment to improving the lives of all people living in Scotland as set out in the '*National Performance Framework and National Outcomes*'. As outlined in a number of sections, GIRFEC is the national approach supporting action to improve the wellbeing of children at all stages of childhood. This approach recognises that some children and their families may need more support at difficult times, or may need ongoing support to deal with complex issues. The aim of GIRFEC is to support children as they grow up to make them feel loved, safe and respected so that each child realises their full potential.(90)

It aims to promote a shared language, approach and accountability that builds solutions with and for children and their families to improve their life chances. Importantly, GIRFEC is about improving the lives of all children through early intervention and targeted supports. The importance of understanding the wellbeing of a child in their current situation, considering the wider influences which exist in a child's life and their developmental needs, in order to be able to offer the right support at the right time, is key to the implementation of GIRFEC. GIRFEC also focuses on how single agency, multiagency and interagency work is informed by the approach. The core components of the approach are presented in Table 2.

**Table 2. Ten core components of the GIRFEC approach**

| | |
|---|---|
| 1. | Improving outcomes for children based on a shared understanding of wellbeing. |
| 2. | A common approach to gaining consent. |
| 3. | Involvement of children and families in assessment, planning and intervention. |
| 4. | Coordinated approach to identifying concerns, assessing needs and taking action. |
| 5. | Ensuring that systems are in place to deliver the right help at the right time |
| 6. | High standards of cooperation, joint working and communication at an interagency level, when required |
| 7. | A named person or lead professional for each child. |

| | |
|---|---|
| 8. | Building the skills of the wider workforce to address children's needs. |
| 9. | Ensuring that the workforce is competent and confident. |
| 10. | Capacity to share relevant information within and across agencies. |

### A Fairer Healthier Scotland: A strategic framework for action 2017-2022

*'A Fairer Healthier Scotland: A strategic framework for action 2017-2022'* outlines the strategic priorities which aim to improve the physical health of Scotland's population.(93) First published by NHS Scotland in 2012, and updated in 2017, '*A Fairer Healthier Scotland'* emphasises the need to address social determinants of health and reduce health inequalities among the population.(93) This strategy outlines the need for collaborative work between local authorities, NHS Boards, the government, Community Planning Partnerships and Integrated Joint Boards in order to deliver practical solutions. The framework is based on five strategic priorities of which children, young people and families are one. The framework pledges to improve children's services, overall mental wellbeing, reduce children's deprivation and improve levels of educational attainment. Each of the five priorities focuses on the social determinants of health and highlight the value of preventing adverse childhood experiences for long-term health and wellbeing.(93)

### Mental Health Strategy 2017-2021

The Scottish Government's *'Mental Health Strategy 2017-2021'* acknowledges that mental illness can affect a person at any stage of their life and sets out that, in the majority of cases, mental health issues are preventable and treatable.(86) Under this strategy, the Department of Health have committed to the provision of supports and services in an effective and timely manner, while allowing service users to maintain their rights, free of discrimination and stigma. The strategy sits under the wider framework '*Fairer Scotland Action Plan'*[††††] and emphasises the importance of an integrated system of care through focusing on prevention and early intervention, enabling access to services and ensuring quality of service experience. Additionally the strategy aims to meet the physical needs of those with mental health problems, uphold the rights of service users and use data to progress actions in the strategy.(86)

A number of the actions outlined in the strategy set out specific expectations for children and young people. The strategy emphasises the need to focus on the early development of children by educating health visitors, midwives and school nurses in

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[††††] 'Fairer Scotland Action Plan' is a Scottish Government initiative setting out 50 actions which aim to tackle poverty, reduce inequalities and to build a fairer and more inclusive society in Scotland.

the early identification of risk factors and initiators of mental health issues. Additionally, the strategy highlights the need to focus on the mental health needs of children with disabilities or long-term conditions as they are often at greater risk of experiencing mental health issues.

#### 3.1.4.2. Standards for health and social care services working with children

A number of standards and regulations have been developed to drive improvement and assess the quality of care provided to people living in Scotland. This section sets out the standards that are specific to the health and wellbeing of children and young people and will also detail standards that relate to the population as a whole. This section also describes how compliance with the standards is assessed in Scotland.

##### Health and Social Care Standards: My Support, My Life

The Scottish Government published health and social care standards in 2017 and, following extensive stakeholder engagement, the standards came into effect in 2018. These standards apply to the NHS, in addition to health and social care services registered with the Care Inspectorate and Healthcare Improvement Scotland (HIS). These standards reflect changes in national and local policies, developments in inspection and improvement systems, and focus on better outcomes for people using services. While they do not remove the need to comply with legislation or replace previous healthcare standards and outcomes, they do replace the 23 sets of national care standards which were used previously by registered health and social care providers.(6)

The standards seek to provide better outcomes for everyone; to ensure that individuals are treated with respect and dignity, and that the basic human rights that everyone is entitled to are upheld. The health and social care standards are underpinned by five principles of dignity and respect; compassion; inclusion; responsive care; and support and wellbeing. These principles inform the five outcomes that people using health and social care services should experience:

1. I experience high-quality care and support that is right for me.
2. I am fully involved in all decisions about my care and support.
3. I have confidence in the people who support and care for me.
4. I have confidence in the organisation providing my care and support.
5. I experience a high-quality environment if the organisation provides the premises.

These standards sit above GIRFEC, and at a very high level, inform the work of services to children. The impact of these standards is being monitored nationally and reported on through www.newstandards.scot. The Care Inspectorate have begun to phase in the implementation of the new standards, beginning with residential centres of older persons and are developing an inspection framework for children's services. At the centre of this new approach is a quality framework which sets out key elements that support services to self-evaluate their work in line with the standards and aid them in preparing for the inspection process.(94)

## Inspectorates

The Public Services Reform (Scotland) Act 2010 created two regulatory bodies, the Care Inspectorate as the national regulator of care and Healthcare Improvement Scotland (HIS) who supports the government's healthcare priorities. In 2017, Healthcare Improvement Scotland (HIS) and the Care Inspectorate began undertaking joint inspections of CPPs to assess their effectiveness in commissioning and planning care in an integrated way. These inspections also focus on how well the leadership in the health and social care partnerships are using information to support and inform their planning and commissioning of services.

### The Care Inspectorate

The Care Inspectorate undertakes inspections of social care and social work services provided by local authorities, as well as day care and support services. Their role is to give assurance and provide protection for people who use services, their families and carers and the wider public, and to drive improvement in the sector.

Since 2012, the Care Inspectorate, together with HIS, and other relevant inspectorates, have undertaken joint inspections of the effectiveness of the delivery of services by Community Planning Partnerships (CPPs) in Scotland to meet the needs of children and young people. During that time they have led a series of 32 joint inspections of services for children and young people in each of Scotland's local authority areas.

In 2017, to support the integration of health and social planning in local authority CPPs, the Care Inspectorate began working closely with HIS to carry out joint inspections of services for children and young people in need of care and protection, as well as services for older people. This has worked to reduce the duplication of inspections and lessens the impact on services in preparing for inspections and showing evidence to inspectors.

In 2018, following the introduction of the *'Health and Social Care Standards: My Support, My Life'*, the Care Inspectorate published the self-assessment framework *'A*

*Quality Framework for children and young people in need of care and protection'* to support the implementation of the new standards by Community Planning Partnerships (CPPs) responsible for developing Children's Services Plans.(6,95) This framework mirrors the joint inspection framework which poses a central question to CPPs, which is: 'How well do we plan and commission services to achieve better outcomes for people?'(95)

To date, the Care Inspectorate have published updated quality frameworks for care homes for children and young people, school care accommodation, support services, and mainstream boarding schools and school hostels. The quality framework draws on the health and social care standards to reflect the change of focus and aims to assist services to carry out self-evaluations. The frameworks use quality indicators which cover a range of areas, depending on the topic. Each indicator has illustrations which work to describe what good and poor practice looks like and can be used by services to understand where their performance falls.

### Healthcare Improvement Scotland (HIS)

HIS regulates and inspects healthcare providers in Scotland, and works with them to improve the quality of services. It is also responsible for informing the public about healthcare quality. As part of NHS Scotland, HIS works to support the healthcare policies of the Scottish Government. HIS is also currently focusing on the promotion of person-centred care and greater input from patients and communities.

HIS aims to drive improvements in quality by:

- supporting and empowering people
- undertaking inspections
- providing quality improvement support
- providing clinical standards, guidelines and advice.

In 2017, the Scottish Government's Child Protection Improvement Programme outlined its goals for the child protection system in Scotland, one which puts children's wellbeing in the centre of all of its actions. Healthcare Improvement Scotland work in collaboration with the Care Inspectorate, Education Scotland and Her Majesty's Inspectorate of Constabulary in Scotland to revise the inspection model, which looks at the children and young people who are in the need of care and support.(96)

### 3.1.5. Findings from reviews

In recent years the Scottish government has committed to improving outcomes for children, to ensure that they are given the best start in life and supported to fully reach their potential. The Scottish government has, through GIRFEC, detailed their aspirations to reduce health inequalities and improve outcomes for children in the state. Under GIRFEC, the role of a 'Named Person' was intended to be the clear point of contact for a child or young person to help them to get support they need when it is needed. However, opposition to Named Persons has been the cause of a judicial review of the Children and Young People (Scotland) Act 2014.(80) While unsuccessful in its campaign, the opposition to Named Persons have argued that this is an intrusion in the private life of a family and perceived the action as a net-widening of surveillance powers by the state. Criticism of GIRFEC also notes that while placing the child and its family at its centre, GIRFEC does little to challenge the power relations between families and professionals.(80)

Joint inspections of CPPs have noted overall a greater commitment to integrated working on behalf of health, social work, education and housing. While reports like the 'State of Child Health 2020: Scotland' and the Children and Young People's Taskforce respectively, have stressed the importance of early intervention and access to services for children and young people with mental health difficulties.(97)

This section sets out findings from key reports that provide an overview of health and wellbeing outcomes for children and young people in general and also children and young people who are at risk.

### State of Child Health 2020: Scotland

The Royal College of Paediatrics and Child Health published their '*State of Child Health 2020: Scotland'* report which provides a valuable overview of child health in the state.(97) Using mortality as an important marker for overall health, infant mortality had decreased in recent years to become the lowest in the UK at 3.2 per 1,000 per live births. However, the report calls for a renewed allocation of resources and investment into the Child Health Programme to align the policy with the most up-to-date evidence. While Scotland has achieved the immunisation target for the 5-in-1 vaccine, as set out by WHO, which affords children protection, the report expresses dissatisfaction in the rate of the MMR vaccination. Additionally, overall negative health behaviours like smoking, drinking and the consumption of drugs have been decreasing in Scotland since 2018.(87,97) Findings from the State of Child Health 2020: Scotland has highlighted the need for renewed interest and investment in the Child Health Programme as it requires realignment with an up-to-date evidence-base.(97)

The report stresses the importance of early intervention in mental health problems as being the cornerstone to reducing long-term damage to children(97). Scotland has the highest rate of CAMHS admission in the UK at 61 children or young people per 100,000 and the rate of suicide, along with the England, Wales and Northern Ireland, is on the rise. The report calls for universal community-based therapies for children, young people and families which address a number of mental health needs. Furthermore, the report highlights the need for local authorities to provide local pathways, which would improve mental health services, supports and resources.(97)

## Joint inspections of Community Planning Partnerships 2012-2017

In 2018, the Care Inspectorate published the overall findings from its '*Joint strategic inspection of services for children and young people from 2012-2017'*.(96) Three main indicators were considered in this report. These were:

- improvements in outcomes for children and young people, primarily improvements in their wellbeing
- the impact of services on children and young people
- the impact of services on families.

The report notes that, generally, there has been an improvement in outcomes for children, and a greater commitment to integrated working between social work, health, education and housing.(96) This improvement was most evident where there was strong leadership from Chief Officers, a culture of collaborative working, learning and development, and one where evidence-based performance management was in place.

However, despite these improved outcomes for children and young people, the joint inspections found that the overall medium and long-term wellbeing outcomes for looked after children, particularly children with experience of residential care, were lower than those for other children. Another key finding noted the delay experienced by some children and young people in accessing the right healthcare at the right time, which included issues with access to mental health services.(96)

While the scope of the inspection did not include disability, it did meet children and young people with disabilities and noted that they experienced particular challenges in ensuring positive outcomes. It was noted that families were concerned over restricted access to services, after a young person ages out of education or during school holidays. Families highlighted the isolation experienced when these restrictions were enforced. Additionally self-directed support was not found to be developed enough to ensure personalised and effective support to families. A good practice identified by the inspections were the personalised family support programmes, which were programmes tailored to the individualised needs of families who were experiencing difficulties managing their child's complex needs.

## Children and Young People's Mental Health Taskforce

The Children and Young People's Mental Health Taskforce is a joint venture commissioned by both the Scottish Government and Convention of Scottish Local

Authority (COSLA)[‡‡‡‡] in June 2018.(87) The primary purpose of the Taskforce was to support children, young people, families and carers in receiving good mental health services and access to these services in a way that is local, responsive, and delivered by people with the right skills.

The Taskforce made a number of recommendations to the Scottish Government and COSLA in 2019, and these recommendations are intended to act as a blueprint for how services should support children and young people's mental health.(87) The Taskforce delivered a clear message, that children and young people must experience a 'single door' approach when seeking help and support for their mental health. This approach requires that professionals across agencies work together to create a single system where they are collaborating to meeting children's needs where they are at. The Taskforce highlighted the need for co-designed solutions with children and young people and stated that services would not be fit for purpose until children and young people are actively engaged in their creation.(87) A Delivery Group, comprised of senior leaders from the NHS, CAMHS, and partner agencies, are in the process of planning for the implementation of these recommendations.

## Integrated Children's Services in Scotland: Practice and Leadership

In 2019, HIS, the Care Inspectorate and Social Work Scotland (SWS) commissioned the independent organisation, Children in Scotland, to conduct a review of integrated children's services in Scotland and to highlight the central pieces needed in order to support children.(98) The review looked at indicators of progress, as well as challenges involved in the integration of these services across Scotland. The review also looked at stakeholder engagement between government officials, senior members of staff within health and social care, and local leaders working with IJBs, finding that practitioners viewed GIRFEC as a unifying framework between these stakeholders. Stakeholders felt that GIRFEC provided a common language and approach to work in a way that managed risk, and helped to address prevention and early intervention across a number of organisations(98) Practitioners felt that they could overcome organisational barriers with the help of joint principles and professional practice.

The review found examples of collaborations between health professionals and social workers through co-location and joint management. Instances of mixed professional teams were seen to improve efforts towards early intervention and child protection. The review noted that shared budgets between health and social work were received

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[‡‡‡‡] COSLA are the Scottish national association for Scottish councils and acts as an employers' association for its 32 local authorities. The Children and Young People Team in COSLA lead on education and children's services.

positively, and highlighted that, in order for joint arrangements to work, there needs to be confidence in governance arrangements.(98) A review of the literature highlights that when restructuring, good governance structures have the power to unite organisations, however, it also has to power to hinder improvement.(99) In situations where an established line of accountability and responsibility becomes marginalised, many leaders with strategic and operational responsibility become overstretched. In the context of continued change, public service reform itself becomes a barrier to success.(99)

### 3.1.6. Lessons for Ireland

Lessons for Ireland includes the development of significant pieces of legislation and structures to support integrated working. The Children and Young People (Scotland) Act 2014 and the Public Bodies (Joint Working) (Scotland) Act 2014 sets out a legislative framework to improve outcomes for children and young people in need of health and social care services. The establishment of Integration Joint Boards (IJBs) and Health and Social Care Partnerships have worked to see that these pieces of legislation are enacted across Scotland.

GIRFEC is a landmark children's policy which works to improve the wellbeing of children through early intervention, a universal provision of services and a multiagency approach to care. It provides a common language and a unifying approach to assessing and responding to child health and wellbeing. However, criticism of the policy has highlighted the scope for interpretation in the legislation governing the policy and the tensions around data gathering.(80) While interagency collaboration in the area of child health is generally perceived to be important by users of a service and the professionals operating the service, there are a number of significant barriers in achieving this collaboration. These barriers include a lack of resourcing, inadequate interagency communication, problems with data sharing and poor understanding across the professions.(99)

The Scottish Government's commitment to participation of children and families in decision-making is not always supported within the complex child protection system, as the complexity does not tend to lend itself to involvement. Additionally, while the legislative system in Scotland sets out a framework where integrated services are supported, of note for Ireland are the challenges found in the reviews of integrated working in Scotland. These reviews identified issues in the delivery of consistent and preventative services which produce positive outcomes for children and young people in care.

In Scotland, there is a clear understanding that early health and mental health interventions, as well as universal access to care and support, is the best route to ensuring positive long-term health and wellbeing outcomes.(97) Children, young people and their families can access support, provided by NHS Scotland, which focuses on emotional distress through Community Mental Health and Wellbeing Supports. However, the '*State of Child Health Report 2020: Scotland*' highlights that the responsibility of early identification and intervention in child and adolescent mental health should fall to professionals who engage with children regularly, rather than relying solely on mental health services. This is an important lesson for Ireland, as children have a greater chance of succeeding when a range of professional groups work together to safeguard children. The review of Scotland shows that it is important for professionals to be educated in order to identify concerns, and to signpost children and their families to resources and accessible services before a concern reaches crisis point.(97)

## 3.2. England

This section describes the organisation and delivery of health and social care services for children in England and also the impact that these services are having on health and wellbeing outcomes for children. This section is set out under the following headings:

- overview of health and social care services working with children
- model of service
- legislation
- strategies, policies and standards
- findings from reviews
- lessons for Ireland.

### 3.2.1. Overview of health and social care services for children in England

In 2019, the number of children under the age of 18 in England is estimated at over 12 million, of a total population of over 56 million. The main government department with responsibility for the health and wellbeing of children is the Department of Health and Social Care. The key priorities set out by the department which guide its work plan are: keeping people safe; maintaining health and independence in communities; supporting the NHS to deliver quality services; supporting research and innovation; ensuring accountability; and improving health and social care services provided to people.(100) The main department with responsibility for the delivery of children's social services at a local level is the Department of Education. The department sets out that it is committed to helping disadvantaged children and young people to achieve their potential, and making sure that local services support and protect children.(101)

As set out in Section 3.2.2, local authorities are responsible for the delivery of services at a local level. Separately the Department of Health and Social Care funds the delivery of healthcare and channels the majority of its funding into the National Health Service (NHS) England. The NHS in turn allocates funding to Clinical Commissioning Groups (CCGs), the amount of which is determined by the population and the level of deprivation in each area. CCGs assess the health needs of the local population and purchase services based on these needs.

There is a wide range of legislation developed to improve the health and wellbeing of children in England. Sections 3.2.3. and 3.2.4. outline key pieces of legislation and different strategies and policies that are focused on improving outcomes for children. A number of government initiatives focus on the overall wellbeing of children, for example, the Child Healthy Programme provides universal preventative services, screening programmes, immunisations, and health advice. In addition, National Institute for Health and Care Excellence (NICE) clinical guidelines and quality standards provide guidance for practitioners and quality standards for those commissioning and providing health and social care services. These standards are monitored against and Section 3.2.4.2. sets out the primary bodies involved in the monitoring and regulation of health and social care services for children and young people.

### 3.2.2. Model of service

In England, the Department for Education is responsible for child protection at a national level, while the Ministry for Housing, Communities, and Local Government provides the funding to local authorities who are mandated to provide child protection and welfare services at a local level. The Department of Health and Social Care holds responsibility for healthcare in England, with the NHS running day-to-day operations and commissioning services based on local health needs. This section sets out the organisation and delivery of the following services for children and young people:

- general healthcare services for children and young people
- children's social services
- disability services for children and young people
- mental health services for children and young people.

#### Organisation and delivery of general healthcare services for children

The Department of Health and Social Care provides stewardship for the health system in England. However, the day-to-day running of the NHS lies with NHS England as a separate public body. NHS England was created in 2013 after the Health and Social Care Act 2012 brought in substantial changes to the way healthcare is delivered, such as the introduction of Clinical Commissioning Groups (CCGs)[§§§§] and the abolishment of strategic health authorities.(102) NHS England manages budgets, oversees over 200 local CCGs across England in their delivery of health services, and sets out the NHS strategy. The primary role of local CCGs is to commission NHS services, both acute and community services. CCGs buy a suite of health services from providers ranging from NHS Trusts who run community services and hospitals, to GP practices, to non-governmental organisations (NGOs). CCG's commission services such as, rehabilitative care, most community services, mental health and learning disability services, most planned hospital care and urgent and emergency care including out-of hours-care.(103)

As of 2014, changes to the way in which healthcare organisations and services work together were ushered in when NHS England published the '*NHS Five Year Forward View*'.(104) This view, or strategy, aims to deliver preventative healthcare, provide patients with more control over their own care and promotes new models of integrated care which work towards providing a cohesive experience for patients between services. Fifty local areas, termed 'vanguard sites', across England have been trialing this new model of delivering integrated care. To support this collaboration the NHS has created Sustainability and Transformation Partnerships (STPs) who work to deliver the objectives set out in the *'NHS Five Year Forward View'*.(104) Importantly, this strategy called for more preventative practice to be introduced to public health, however, to date there has been little action in this regard.(104)

In England children's services in local authorities specialise in developing, commissioning and leading the delivery of children's services, including health, education, social care, and youth and early years. Public health budgets are the responsibility of local authorities, who are also required to establish Health and Wellbeing Boards in each area. These boards aim to reduce health disparities, and together with the CCGs, produce a health and wellbeing strategy for the local population. Additionally, Health and Wellbeing Boards work towards improving coordination of local services, such as disability services. Health and Wellbeing Boards provide integrated care through producing joint strategic needs assessments (JSNAs) and joint health and wellbeing strategies.

As part of the Healthy Child Programme (HCP) in place across all local authorities, each family with a newborn baby is assigned a health visitor and a midwife who

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[§§§§] Clinical Commissioning Groups, established under the Health and Social Care Act in 2012, are groups of GPs who work together to commission services for their local area, for example, mental health services, urgent and emergency care, community care and elective hospital care.

monitor the health of the child. The programme provides universal preventative services to all children up to the age of five. These include child health promotion programmes, health screening, immunisations, child health surveillance, and individual child development reviews in order to improve outcomes for children. The HCP ensures that children are offered five annual health reviews by health visitors, which provides invaluable insight into the needs of children, their families and environments. The aim of the programme is that health visitors provide families with sufficient levels of support to meet their needs and work in partnership with a range of services to provide a robust programme of support. Later in life the child's GP acts as their gatekeeper to further specialist services. While a child is in education, school nurses are available to provide support and information to children with long-term conditions. For older children, local authorities provide sexual health services for teenagers in their community.

## Organisation and delivery of children's social services

While the Department for Education bears final responsibility for children's social services, local authorities are responsible for the delivery of services at a local level. Each individual local authority has a statutory obligation to ensure children and young people are looked after. The local authorities, along with the police, also have primary responsibility for responding to child protection concerns. Within the 152 local authorities in operation across England, the Children's Services departments within local authorities are responsible for investigating and responding to child protection and welfare concerns. Each local authority's remit is in improving the wellbeing of children in the areas of:

- physical and mental health and emotional wellbeing
- protection from harm and neglect
- education, training and recreation
- the contribution made by them to society
- social and economic wellbeing.(9)

Under the Children Act 2004, local authorities are required to set up local Safeguarding Children's Boards (SCBs) who are charged with overseeing the delivery of social services related to the care and provision of services for children. SCBs are comprised of members of the local authority, the police and the NHS clinical commissioning group where each partner bears equal and joint responsibility for local child safeguarding arrangements.(9)

## Organisation and delivery of disability services for children

Children and young people up to the age of 18 in England make up one fifth of the population. The NHS holds responsibility for meeting the medical and healthcare needs of all children, including children with disabilities and children with mental health needs, through their local NHS health services. For all non-medical care of children with disabilities, such as homecare and respite care, the responsibility falls to local authorities. Local authorities also work to ensure there are safeguards in place to protect each local population from health risks, which includes preventative measures, such as immunisation and health screening.

### Organisation and delivery of mental health services for children

To support children and young people with mental health needs Child and Adolescent Mental Health Services are provided through the NHS. Specialised community Child and Adolescent Mental Health services (CAMHS) typically adopt a multidisciplinary approach and provide assessment, advice and treatment for children and young people with complex-to-severe mental health needs. CCGs have partnered with local organisations which include housing, education, the voluntary sector and local authorities, to implement steps in the '*Mental Health Implementation Plan*'.(105) Together this range of bodies aims to provide 24/7 crisis services to all children and young people who require it, by the end of 2024. In late 2019, NHS England announced plans to set up a new taskforce to tackle an over-reliance on inpatient care for children and young people's mental health, disability and autism services. The taskforce aims to improve specialist mental health services, as well as learning disability and autism services, for children and young people.

## 3.2.3. Legislation

England has a wide range of legislation and regulation in place which supports the health and wellbeing of children who use health and social care services generally. However, unlike Ireland, there is no specific legislation regarding the care and support of adults and children with disabilities. Instead, the Equality Act 2010 is the primary piece of legislation which sets out the rights of people with a disability and the expectations on public services to uphold these rights.

### The Children Act 1989 and 2004

The Children Act 2004 supplements the 1989 legislation which provides the framework for the care and protection of children in England up to the age of 18.(106) This act defines the roles and responsibilities of parents, guardians and local authorities when responding to child welfare and child protection concerns. The act outlines the responsibility of the local authority, NHS services and NHS trusts, the police, probation services and young offender's institutions to cooperate together to safeguard and promote the welfare of children. Staff in these services may be subject to disciplinary hearings should they fail to report suspected cases of child abuse. These services and organisations are obliged to follow guidance set out in

'*Working Together to Safeguard Children'*.(107) This 2018 statutory guidance stresses that everyone who comes into contact with a child and their family has a role in ensuring they are safeguarded and that their welfare is promoted. The act sets out that local authorities are required to create a Local Safeguarding Children Board (LSCB), whose functions include undertaking reviews in cases where abuse, neglect or the death of a child has occurred.(106)

## The Children and Families Act 2014

The Children and Families Act 2014 was designed to reform services for children in need by providing them with greater protection and helping parents and families. The act brought in a number of reforms and new duties for local authorities in relation to how supports and services are delivered to children and young people with special educational needs. Local authorities are required to involve children and their families in decisions relating to their care and education, while also providing advice and support to children and families. The act sought to bring together education, social care services and healthcare services to provide clear and effective services to children and young people. Additionally the act brought about changes to the role of the Children's Commissioner, which was broadened from a representative role to include the promotion and protection of children and young people.

## The Health and Social Care Act 2012

The Health and Social Care Act 2012 is one of the primary pieces of legislation relating to health and social care in England.(102) It was introduced in an effort to modernise the NHS, while simultaneously reducing health inequalities across England. The act outlines specific requirements for health bodies such as the Department of Health and Social Care, Clinical Commissioning Groups (CCGs), Public Health England, and NHS England. The act brought in changes for local authorities on public health functions. Under the act it is the role of local health authorities to address the health, safety and wellbeing of their population, to establish thorough plans to protect the local population, address health inequalities and to provide assistance for CCGs. The act also introduced Health and Wellbeing Boards, whose statutory position was to bring together the NHS, social care and public health leaders within each local council with the purpose of coordinating the commissioning of their services.

## The Mental Health Act 1983 and 2007

The Mental Health Act 2007 supplements the 1983 legislation which provides healthcare professionals with powers, in some circumstances, to detain, assess and treat adults and children with mental disorders in the interests of their own or the public's safety.(108) The act also outlines safeguards which work to ensure that patients are not treated inappropriately under the provisions of the act.

Many provisions of the act came into effect in 2008, with the most notable being the extension of involuntary treatment applied to patients in the community, also known as Supervised Community Treatment (SCT).(108) Under an SCT many patients who had previously been compulsorily detained in hospital will, on discharge from hospital, be subject to a community treatment order which requires them to comply with a number of conditions, such as taking medication. Other changes included the widening of professional groups that can now apply to hold roles which exercise powers under the act, such as a responsible clinician (RC) and an approved mental health professional (AMHP).

The act sets out that that children and young people being treated in mental health settings must be treated in suitable and 'age appropriate' settings. The act also requires that 'appropriate national authorities', such as Social Services in local authorities, make advocacy services available to patients subject to SCT, most detained patients, and those in guardianship arrangements.(108)

### Carers and Disabled Children Act 2000

Under the Carers and Disabled Children Act 2000, local authorities are able to offer financial support to those providing care and support to a child with a disability. The act allows local authorities to pay individuals for services that address their own needs, meaning that 16 and 17 year olds with a disability can gain payment directly for the services they need. The act gives power to local authorities to provide certain services to carers of children with a disability following their assessment of need.(109) Furthermore, the act allows local authorities to carry out assessments in cases where an individual was previously refused an assessment for community services.(109) The act also allows those who assume parental responsibility for a child with a disability to access services they deem acceptable for their child's needs, as opposed to relying on services provided by their local authority. Lastly, the act provides local authorities with the power to charge carers for any services they receive.

Ultimately the aim of the government in introducing this act was to provide supports to carers in order to protect their own health and wellbeing so that they could provide ongoing care and support to a child with a disability.(109)

### The Equality Act 2010

The Equality Act 2010 is the central piece of legislation which governs the rights of adults and children with disabilities in the UK.(110) The act states the nine protected characteristics, of which disability is one, on the basis of which discrimination is unlawful. The Equality and Human Rights Commission is the regulatory body whose role is to enforce the act. Prior to this act the Disability Discrimination Act 1995 provided legislation to prevent discrimination against persons with a disability. In 2016, the House of Lords *Select Committee on the Equality Act 2010 and Disability* carried out an investigation on the effect of the Equality Act 2010 on people with disabilities.(111) The investigation found that including disability amongst the nine protected characteristics did not benefit people with disabilities and that people with disabilities were better protected under previous legislation.(110) A number of recommendations were made by the Committee, specifically relating to children with disabilities and special educational needs, with the Committee calling for schools to make facilities more encouraging and supportive in order to address educational inequalities for children with disabilities.

### 3.2.4. Strategies, policies and standards

The standards, guidance and policies which govern child health and social care services in England focus on integrated working across services, applying evidence-based practice to daily working and protecting the health and wellbeing of all children. This section also looks at the inspectorates who assess compliance with standards.

#### 3.2.4.1. Strategies and policies

The strategies and policies included in this section set out a vision for child health and wellbeing in England. This section sets out strategies and policies that apply to all children and young people and also ones that apply specifically to children and young people at risk.

#### NHS Long Term Plan

In its 2019 *'NHS Long Term Plan'*, NHS England set out goals aimed at providing children with a strong start in life.(112) This includes the creation of a Children and Young People's Transformation Programme which will run in conjunction to the Maternity Transformation Programmes. NHS England have committed to providing mental health services in an age-appropriate setting for those aged 0-25 years. The plan sets out goals to improve mental and physical health services for children and young people. These are:

- bring services closer to patients, by providing pre-hospital care, learning disability, and disability services in the community, and by managing emergency department admissions in primary care or community services where possible
- tackle waiting times

- deliver services which are based on the needs of children and young people.

### The Healthy Child Programme

The Healthy Child Programme (HCP), introduced in 2009, is an early intervention and preventative public health programme delivered by health visitors in schools and in the community. The programme provides children and families with the opportunity to have their needs identified early and allows for supports to be provided, where necessary. The 2011 publication *'The Health Visitor Implementation Plan 2011-2015'* committed to increasing the health visiting workforce and improving the quality of health visiting for children and their families.(113) This plan states that the delivery of the HCP would be led, on a local level, by health visitors, who in turn would work in coordination with GPs, midwives and nurses to meet the needs of their local population.

An evaluation on the effectiveness of the HCP in 2018 by the Early Intervention Foundation, noted that the HCP is a good delivery mechanism for early interventions for children and families in their early years.(114) The HCP ensures that each child from birth to the age of five is offered five mandated health reviews carried out by the health visiting services. These reviews provide an opportunity to identify what supports are needed by a child or their family, in order to ensure the child gets the best start to their life. The '4-5-6 model' provides health visitors and school nurses with an evidence-based framework, as leaders of the HCP, to identify what supports are needed by a child or their family, and what impact they can have on the health and wellbeing of a child and their family.

## 3.2.4.2. Standards for health and social care services working with children

A number of standards and regulations have been developed to drive improvement and assess the quality of care provided to people living in England. This section sets out the standards that are specific to the health and wellbeing of children and young people and will also detail standards that relate to the population as a whole. This section also describes how compliance with these standards is assessed in England.

### Working Together to Safeguard Children

Nationally, key guidance for child protection and for all organisations and professionals who work with children in England is *'Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children',* published in 2006 by the Department of Education.(9) This guides those working with or coming into contact with children in a wide range of settings. Similar to 'Children First: The National Guidance for the Protection and Welfare of Children' in Ireland, this document sets out how professionals such as teachers, social workers, and the police should be vigilant for signs of child abuse and neglect, and how these professionals should communicate effectively to safeguard children.(9)

## NICE clinical guidelines and quality standards

The primary function of the National Institute for Health and Social Care Excellence (NICE) is to improve outcomes for those using the NHS and other health and social care services. This is achieved by developing evidence-based guidance for practitioners and quality standards for those commissioning and providing health and social care services. NICE standards for the transition from children's to adults services details how a child's move to adult services is managed during the period before, during and after.(115) They have also developed a range of tools and resources which are intended to support services applying guidance and standards into practice.

### Quality standards for early years: promoting health and wellbeing in under 5s

NICE has developed these quality standards to assist services in promoting and supporting the health, social and emotional wellbeing of children under the age of five.(116) While these quality standards apply to home visiting by healthcare providers, early intervention services provided by social services, and early education, they do not apply to clinical treatment or child protection services.

These quality standards call for a coordinated response from services when promoting the health and wellbeing of children under five, and require that staff are sufficiently trained and supported to develop the competencies needed in order to deliver the actions required. The standards acknowledge the importance and role of families and carers in the care and support of children under five, encouraging health, public health and social care practitioners to be inclusive of family members and other carers involved in a child's life.(116)

### Transition from children's to adult services for young people using health or social care services

NICE has also developed quality standards for the period of time before, during and after the transfer of young people from children's services to adult services.(117) This includes young people up to the age of 25 who are using child health and social care services and are expected to transition to adult services. These quality standards encompass young people who have a disability or require long-term care, those with mental health needs, life-limiting needs and also young people who are under the care of local authorities.

These quality standards include five quality statements which cover the following areas:

- early planning and preparation for the transition to adult services is to begin by the age of 13 or 14
- annual planning meetings to review the upcoming transition between services
- appointment of a named staff member to ensure continuity of care, before and during transitions
- early engagement with new service providers
- flexibility and contingency planning to support the young person in their transition.(117)

## NICE clinical guidelines and quality standards for identifying, diagnosis and treatment of children and young people with mental health conditions

NICE has developed clinical guidance and quality standards which help services identify needs, diagnose and treat children and young people with mental health conditions. Of importance are:

- NICE: psychosis and schizophrenia in children and young people: recognition and management (guidance)(118)
- NICE: depression in children and young people(119)
- NICE: eating disorders(120)
- NICE: self-harms (quality standard)(121)

Quality standards developed by NICE aid services in identifying areas where improvements can be made in delivering supports to children and young people. For example, NICE quality standards on eating disorders sets improved coordination of care across a number of services as a priority and requires that a risk assessment be carried out when a child is moving between services.(115)

## Inspectorates

There are a number of bodies involved in the inspection and regulation of children’s health and social care services, and at times these services work together to deliver joint inspection programmes. The Care Quality Commission (CQC) monitor, inspect and regulate hospitals, care homes, GPs, services provided in the home, dentists, clinics, community services and mental health services, to ensure they meet the CQC’s fundamental standards of quality and safety. Ofsted are the Office for Standards in Education, Children’s Services and Skills and they inspect services providing education and skills, as well as care services for children and young people.

Since 2016, Ofsted and CQC have carried out a number of joint inspections on how local areas fulfil their duty to children and young people, up to the age of 25, who have special educational needs or disabilities (SENDs). Inspections are carried out in education, health and social care services, early year's settings and specialist services. These inspections are carried out under the Children Act 2004 to ensure that local areas are meeting their requirements under the Equality Act 2010. The joint inspections use the inspection framework *'The framework for the inspection of local areas' effectiveness in identifying and meeting the needs of children and young people who have special educational needs and/or disabilities'*.(122)

## The Care Quality Commission (CQC)

The CQC is an independent body who works towards ensuring that health and social care services are delivered safely, effectively and with a high degree of quality of care. They do this through registering care providers who meet the required regulations and by monitoring these services through inspections. The CQC inspects care services most of which are services provided by NHS Trusts. NHS services for children that CQC inspects include:

- inpatient and outpatient wards
- palliative care
- paediatric surgery
- paediatric intensive care units
- arrangements for the transfer to adult services.

Where health and social care services specialise in the treatment of young people with life-long or complex needs who are moving from children's services to adult services, the CQC inspects the handling of this transition against NICE guidelines, as set out in Section 3.2.4.2 of this review.

The CQC also inspects services in the community, including community clinics, school nursing, health visiting, as well as community paediatric services and therapy services. These services provide care and treatment for children with disabilities, complex needs, and long-term conditions. Additionally, the CQC inspects child and adolescent mental health wards and specialist community mental health services for children and young people. The CQC inspects universal and specialised services for children against their '*Inspection framework: Community health services*'.(123)

The Care Quality Commission inspect using a key line of inquiry, which includes five questions that are asked of all care services. These are:

- Are they safe?
- Are they effective?

- Are they caring?
- Are they responsive to people's needs?
- Are they well led?

### Office for Standards in Education, Children's Services and Skills (Ofsted)

Ofsted is a non-ministerial department which both inspects and regulates local authorities providing care for children and services that provide education, social care and skills for young people. Ofsted reports directly to Parliament and is independent and impartial. Ofsted primarily use the '*Social Care Common Inspection Framework*' to inspect social care services and for local authorities it uses the '*Inspection of Local Authority Children's Services*'.(9) They also have more specific regulation for other organisations like child minding services and further education and skills providers.

Both the '*Social Care Common Inspection Framework*' and '*Inspection of Local Authority Children's Services*' have respectively adopted three principles. These principles are: the effectiveness of senior leaders and managers; the impact these staff have on the lives of children and young people; and the quality of their professional practice. Explanations are provided as to how each principle works in practice to inform inspections.

### 3.2.5. Findings from reviews

Overall, reports such as the '*State of the Nation 2019: Children and Young People's Wellbeing*' have found that children and young people in England are happy in their lives, however, they note that there is a proportion of this group that are not as content.(124) A number of reports have covered the state of child health in England over the past decade. The primary aim of most recent report, the '*State of Child Health 2020*', is the bring together a number of measures such as measles, infant mortality and childhood obesity.(125) Reports published by the CQC and the Children's Commissioner all aim to highlight any health inequalities experienced by children and young people.(125,126)

The CQC has published reports on CAMHS, finding that poor collaboration between services resulted in fragmented care and created an ineffective system which impacts on the delivery of effective, high-quality care for children and young people using these services.(127)

The role of the Children's Commissioner is to advocate for children and young people to policymakers so they are represented when decisions are being made about them. The Commissioner gathers evidence on issues which affect children's lives and also provides advice on issues which affect children and young people. The Commissioner releases annual reports which outline the key issues faced by children.

The 2019 report published by the Department of Education *'State of the Nation 2019: Children and Young People's Wellbeing'* has reported that, overall, children and young people in England are happy in their lives. However, the report highlights that there are a proportion that are not, stating that the wellbeing of children decreases as they age and that females are more likely to experience anxiety over compared to their male counterparts.

### State of Child Health 2020 – England

The *'State of Child Health'* (SOCH) report was published by the Royal College of Paediatrics and Child Health (RCPCH) initially in 2017, and since then there have been a number of developments in the sector that warranted an updated publication.(125) In the most recent version, the RCPCH outlines the priorities for government, which are to reduce inequalities in child health, prioritise public health, and increase the focus on prevention and early intervention. The 2020 SOCH recommends that child health systems, including local authorities, are given additional funding in order to address health inequalities after an extended period of austerity, and that they focus on prevention and early intervention, as well as building interagency working on a local level.(125)

A high-level examination of this report shows that a number of indicators for child health and wellbeing in England had come to a standstill or, in some cases, had gone into reverse. Infant mortality has remained relatively unchanged since 2017, there has been an increase in the number of children aged five to 15 reporting a mental health disorder, and there has also been a sharp increase in suicide rates amongst those aged 15-24 since 2017.(125) Across most of the measures, it was found that children from less advantaged socio-economic areas had poorer outcomes compared to their peers. These results show increasing inequalities in outcomes since the RCPCH originally published this report in 2017. The report attributes many of these inequalities to budget cuts to local authorities.(125) The RCPCH called for sufficient resources to be allocated to ensure that all children from birth to the age of two have access to universal preventative services.

### Care Quality Commission reports

The CQC has published two reports examining the state of child and adolescent mental health services in England. The initial report in 2017 *'Review of children and young people's mental health services: Phase one report'* found that the overall system is 'complex and fragmented'.(127) The CQC highlight that poor communication and collaboration between services resulted in fragmented care and created an ineffective system which impacts on the delivery of effective, high-quality care for children and young people using these services. The report stressed that where good care was identified there was often strong interagency collaboration involved. Additionally, the report found that in many cases the professionals who work with children and young people are not always equipped with the skills to help them to identify mental health concerns amongst children and young people.

Published in 2019, phase two of the report entitled *'Are we listening? A review of children and young people's mental health services'* found, similar to the previous report, that the systems which tend to the mental health needs of children and young people are complicated and do not always work in favour of those using the service.(126) The report highlights the important contribution of the staff who provide attentive care and support to children and young people, but finds that these staff are extremely overworked and are provided with limited resources, concluding that this is as an unsustainable way of working.

## The Children's Commissioner

In 2017, the Children's Commissioner reported on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD). In their submission, the Commissioner called for increased monitoring and information into violence perpetrated against children with disabilities.(128) The report notes the need to amplify the voice of children with disabilities, particularly in decisions that affect their lives. The report highlighted the barriers that children with disabilities experience when physically accessing services, such as space to manoeuvre in schools and classrooms or when accessing public transport. Additionally, the Commissioner noted concerns over the extent to which CAMHS services are made accessible to children and young people with disabilities.

The Commissioner published their third annual report on *'The state of children's mental health services'* in March 2020.(129) While the report highlights the improvements made by the NHS, it warns that services are not adequately equipped to meet the needs of the nearly 13% of children in England who require attention for mental health problems. Although the report showed that the average waiting time for children to enter treatment was now under eight weeks, down 53 days since 2019, it highlighted that children experience a huge variance in the quality of treatment across the country.

## UN Committee on the Right of People with Disabilities

The UK ratified the UN Convention on the Rights of People with Disabilities in 2009 and since 2016, the UN Committee on the Rights of People with Disabilities has published two reports.(130) The Committee expressed, in both reports, concern over the level of protection and the supports provided for people with disabilities. The report made 11 recommendations which include calling on the government to conduct an impact study on spending cuts to people with disabilities. Additionally, the report recommends that the government work to ensure the human rights of people with disabilities are upheld.(130) The UN Committee noted the severe impact austerity measures had for children with disabilities and their families. Concern was expressed over a lack of governmental action in addressing poverty experienced by children with disabilities and their families. The Committee recommended that childcare is universal for children with disabilities and stressed the importance of setting up an independent monitoring process to review the school experience of children with disabilities.

#### Council for Disabled Children

Published in 2017 and commissioned by the Department of Health and Social Care, *'These are our children'* is a review carried out by the Director of the Council for Disabled Children (CDC).(131) The report called for immediate national action to prevent the institutionalisation of children from a young age which at a macro level comes at a cost to the population, and at an individual level prevents the child from reaching their full potential. The report notes that although children with disabilities as a group are not ignored by the government, there are failures occurring in the systems of care. The report calls for an immediate shift in how children with disabilities are viewed in their community, stating they should not be viewed as 'special cases', but, as members of their community who have inherent rights to the same access to health and education, as well as to a family and community life on a par with their peers.

### 3.2.6. Lessons for Ireland

England's Healthy Child Programme (HCP) is universal and ensures that children from birth to five years old are entitled to five mandated health visiting reviews. A key lesson for Ireland can be seen in the reach of the programme and how, through the leadership of the health visitor, a number of services are led in a coordinated effort to improve outcomes for children. The HCP reviews provide children and their families with access to the supports required to provide children with the best possible start in life.

An important lesson for Ireland is the focus across England's health and social care system on improving interagency cooperation in order to provide effective delivery of care and support to children. This move towards greater integration is seen in the Health and Wellbeing Boards whose purpose is to bring together leaders in the NHS, social care and public health in each local council, in order to provide coordinated services to children and young people. It is important to note that despite these structures, reviews have identified fragmentation in service delivery, especially in child and adolescent mental health services, with negative effects on children and young people.

An additional lesson for Ireland are the joint inspections undertaken by different regulators which provide a holistic view of the work of children's social services and how services are performing. These inspections allow insight into the journey of individual children as they access different services, and the inspections work to highlight any inconsistencies or gaps that can result in child protection and welfare issues not being fully addressed. They also allow for joint responses by relevant agencies and facilitate a strategic approach to problem solving.

## 3.3. Northern Ireland

This section describes the organisation and delivery of health and social care services for children in Northern Ireland and also the impact that these services are having on health and wellbeing outcomes for children. This section is set out under the following headings:

- overview of health and social care services working with children
- model of service
- legislation
- strategies, policies and standards
- findings from reviews
- lessons for Ireland.

### 3.3.1. Overview of health and social care services working with children

The number of children under the age of 18 in Northern Ireland was estimated at under 431,000 at the last census in 2011.(132) The Department of Health, previously the Department of Health, Social Services and Public Safety, is responsible for the management and administration of health and social care matters for children and adults in Northern Ireland. As set out in Section 3.3.2, children's health and social care services are delivered by Health and Social Care (HSC) Trusts who provide, manage and administer integrated health and social care services. Health and social care services are publicly financed and mostly free at the point of use.

Northern Ireland has a number of pieces of legislation which govern the delivery of health and social care services, for example, the Health and Social Care Reform Act 2009, sets out the statutory footing for the establishment of a number of key organisations in the sector.(133) Section 3.3.3. sets out this legislation at a high level. There are a number of strategies, policies and guidelines which govern the area of child health and wellbeing. '*The Children and Young People Strategy*' aims to provide a unified framework from which organisations work to provide children and young people with the best start to life.(134) Additionally, the policy '*Co-operating to Safeguard Children and Young People in Northern Ireland*' details how health and social care services should work in unison to safeguard children.(135) Section 3.3.4 outlines the strategies, policies and standards that are focused on improving health and wellbeing outcomes for children. One example of this is the '*Quality Standards for Health and Social Care*', developed by the Department of Health, intended to increase the quality of health and social care services provided through primary care, community care and hospitals to the population in Northern Ireland.(136) The implementation of these standards is monitored by the Regulation and Quality Improvement Authority (RQIA) and Section 3.3.4.2. also sets out the role of RQIA in involved in the monitoring and regulation of health and social care services for children and young people.

### 3.3.2. Model of service

The legislative framework for children's services is set out in The Children (Northern Ireland) Order 1995.(137) The Department of Health delivers health and social care services in Northern Ireland and Health and Social Care (HSC) Boards are charged with the commissioning of children's services. In turn, the HSC Boards commission six Health and Social Care (HSCs) Trusts to deliver children's services to the local population. The section sets out the organisation and delivery of the following services for children and young people:

- general healthcare services for children and young people
- children's social services
- disability services for children and young people
- mental health services for children and young people.

#### Organisation and delivery of general healthcare services for children

The Department of Health is responsible for the delivery of an integrated health and social care system in Northern Ireland. This integrated system of care involves a number of organisations, such as HSC Trusts, HSC Boards and the Public Health Agency (PHA), working together to plan for and monitor the delivery of health and social care in Northern Ireland. The HSC Board sits in between the Department of Health and the HSC Trusts. The HSC Board is responsible for the management of family health services provided by community pharmacists, general practitioners, dentists and opticians, as these services are not provided directly by HSC Trusts. Sitting on the HSC Board are local commissioning groups whose primary focus is on the planning and resourcing of services. These commissioning groups operate inside the same geographical area as the HSC Trusts.

In total there are six HSC Trusts, five of which provide integrated health and social care services at a local level. The Northern Ireland Ambulance Services is the sixth trust and operates as one single state-wide service. The role of the five local HSC Trusts is to manage and administer facilities where a range of health and social care services are provided to communities. These facilities include hospitals, residential homes, health centres and day centres. As set out in the Health and Personal Social Services (Northern Ireland) Order 1994, the HSC Trusts have a statutory obligation to improve the health and wellbeing of its local population, to provide health and social care services and to work towards reducing health inequalities at a local level.

The Public Health Agency (PHA) is a statutory body who work in an advisory capacity and whose primary function includes health protection, improving health and wellbeing, providing public health support to the commissioning of services and policy development, as well as research and development in health and social care. Under the Health and Social Care (Reform) Act (NI) 2009 the PHA and HSC Trusts have a responsibility to work together to improve health and wellbeing of the population in Northern Ireland.(133) The PHA works with local government to ensure that these key functions are fulfilled and to ensure that health inequalities are reduced.

Health and social care services are, for the most part, publicly funded and nearly entirely free, for both children and adults, from point of entry. Northern Ireland's integrated delivery of services differs from other jurisdictions in the UK in that local authorities in Northern Ireland are not responsible for the provision of health and social care services. Care and support is divided into nine programmes of care, into which finance and resources are allocated, so as to provide a management framework. Child health is a programme in and of itself. Programmes of care are integrated, however, variations exist and children's social services suffer from poor interdisciplinary practice.

HSC Trusts manage and administer health centres, hospitals, day centres, residential homes and other health and social care services in the community. In Northern Ireland, when a child requires hospitalisation they may need to access services in other parts of the United Kingdom, as Northern Ireland does not offer a full range of paediatric specialists, mostly due to the population size. Community health services for children are delivered by HSC Trusts and include social paediatric services for children with behavioural issues, cognitive or physical disabilities.

In 2010, the Department of Health, published the '*Healthy Child, Healthy Future'* detailing the framework under which the universal Child Health Programme is delivered in Northern Ireland.(138) This framework sets out a number of goals, which include providing care that keeps a child safe and happy, early identification of needs, promoting healthy eating amongst children and families, and the prevention of diseases. There is a strong focus in the framework on the importance of early intervention and prevention and the framework sets out a timeline for child health reviews, starting within the first 10 days of life continuing up to two years old.(138) Health and development reviews occur through primary school where targeted reviews for long-term conditions are applied and children are risk-assessed for TB. During post-primary age children and young people again receive targeted reviews for long-term conditions, while also receiving HPV and 'school leaver' immunisation.(138)

## Organisation and delivery of children's social services

Children's social services in Northern Ireland include children who are cared for by the state, services provided to young care leavers, early intervention programmes and adoption services. HSC Trusts hold ultimate responsibility for the provision of children's social services, in that services are either provided through the HSC Trusts or through a commissioned service. The individual HSC Trusts work collaboratively with local police to investigate child protection concerns. The local child protection planning for services is carried out by Safeguarding Panels. Safeguarding Panels support the Safeguarding Board Northern Ireland (SBNI)[*****] work and are responsible for facilitating safeguarding and child protection practice at a local level. These panels are primarily made up of representatives from the SBNI, among other local services. Safeguarding Panels are made up of: an independent chair, representatives from the HSC Trusts, representatives from the police and justice services, medical representatives, and representatives from charities, and youth and community services.

## Organisation and delivery of disability services for children

Each HSC Trust holds responsibility for the delivery of community disability services. The HSC Trusts work with respective education authorities and social services to identify the needs of children with disabilities and to provide the necessary supports. HSC Trusts, education authorities and social services work together to create support networks for children with disabilities consisting of doctors, health visitors, educators, social workers and specialists, such as physiotherapists and speech therapists. Family Fund NI is a United Kingdom charity, largely funded by the

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[*****] The SBNI coordinates and ensures the effectiveness of work to protect and promote the welfare of children and includes representatives from groups concerned with child protection and welfare. Five Safeguarding Panels support the SBNI's work at a regional level by allocating resources and efforts in a region. Safeguarding Panels are responsible for facilitating safeguarding and child protection practices at a local level.

Department of Health in Northern Ireland, whose primary role is providing grants for families who are caring for children with a disability or a serious illness. Family Fund help families of children with disabilities to gain access to grants in order to purchase essential items like computers, kitchen appliances and family holidays. The government has also developed the Sure Start initiative which supports children in disadvantaged areas. The initiative, through the Sure State Local Programme, also supports children under four years of age, by bringing together early educations, health care, childcare and family support services. The initiative helps to provide services to families with children who have a disability or special needs.

In Northern Ireland, a large proportion of children with disabilities live at home and are supported to stay with their parents, families or carers, while a small number live in residential settings.(139) Services for children with disabilities focus on prevention, early intervention and specialist support from within the community. As such the Children and Young People Strategic Partnership (CYPSP) was set up to ensure that the needs of children and young people are reflected in the planning, commissioning and provision of services, and that the partnership has a specific focus on children with disabilities. CYPSP is a strategic partnership consisting of senior leaders in statutory agencies, community and voluntary sectors.(140)

### Organisation and delivery of mental health services for children

Child and Adolescent Mental Health Services (CAMHS) work with HSC Trusts to provide care to children and young people with mental health needs. As a result of the Regulation Quality Improvement Authority's (RQIA) 2011 '*Independent Review of Child and Adolescent Mental Health Services (CAMHS) in Northern Ireland*', the HSC Board have developed a model of service, the stepped care module, and HSC Trusts have begun to align their services with the model of care.(141,142) This aim of this model is to enable children and young people to fulfil their potential by combating the impact of mental health issues through coordinated care across social care, child health and CAMHS services. The stepped model of care also places an onus on HSC Boards and Trusts to work with community and voluntary sectors to avail of local knowledge and to appoint key contacts during early intervention stages. The five steps in this model entail a targeted effort towards: prevention; early intervention; specialised intervention services; integrated crisis intervention and child and family services; and inpatient and regional specialist services.

### 3.3.3. Legislation

Northern Ireland has a somewhat dissimilar legislative framework in comparison to the rest of the UK. One example of note is the Equality Act 2010, which was enacted in the rest of the UK and mandates for the protection of people with disabilities, but was not extended to Northern Ireland.(110) There is no one single piece of legislation dedicated to children's social services in Northern Ireland. The Children (Northern Ireland) Order 1995 consolidated relevant child protection legislation, with the Safeguarding Board Act (Northern Ireland) 2011, creating a single body charged with the primary responsibility for safeguarding the children and young people of Northern Ireland.(137) The Children's Services Co-operation Act (Northern Ireland) 2015 was enacted with the primary focus of drawing together organisations and prioritising the safety and wellbeing of children and young people.(143) There are two separate pieces of legislation that apply to mental health services for children and adolescents in Northern Ireland, these are the Mental Health Order 1986 and the Mental Capacity Act 2016.

### The Children (Northern Ireland) Order 1995

The Children Order enacted in 1995, is a central statute which dictates the responsibility the public has over the upbringing, care and safeguarding of children in Northern Ireland.(137) The order imposes a general duty on HSC Trusts to provide a range of services for children in need of additional supports, within their area and provides a definition for a child in need. These duties include those related to the provision of care and accommodation for children in the care of the State.

### Health and Social Care Reform Act (Northern Ireland) 2009

The Health and Social Care Reform Act 2009 established the current legislative structure which delivers health and social care in Northern Ireland, and also sets out the role of the minister in this regard.(133) The act also provides the statutory footing for the establishment of a number of bodies, which include HSC Boards. The role of the HSC Boards is to manage the commissioning of services, in partnership with the Public Health Authorities, on the basis of the identified needs of the local population. Furthermore, the act consolidated the previous 19 HSC Trusts into six trusts, including one dedicated ambulance trust.(133)

### Children's Services Co-operation Act (Northern Ireland) 2015

The Children's Services Co-operation Act (Northern Ireland) 2015, was enacted to enhance cooperation across department and agencies in order to improve the wellbeing of children and young people.(143) The act sets a requirement of the Northern Ireland Executive (the Executive), to develop and implement a strategic direction, with the ultimate aim being the improvement of child wellbeing in the state. The act sets out an obligation for the Executive to adopt this strategy which would work towards improving the wellbeing of children.(9) More detail on the strategy can be found in Section 3.3.4.1.

This act places a statutory obligation on numerous organisations to cooperate and work together in achieving the targets set out in the Children and Young People Strategy. The act applies to the following agencies which are defined as children's authorities under the act:

- Northern Ireland Government Departments
- District Councils
- HSC Trusts
- Regional HSC Boards
- Regional Agency for Public Health and Social Wellbeing
- Education Authority
- Northern Ireland Housing Executive
- Police Service for Northern Ireland
- Probation Board for Northern Ireland.

## Mental Capacity Act (Northern Ireland) 2016

Following recommendations from the Bamford Review[†††††] in 2002, the Mental Capacity Act (Northern Ireland) was enacted in 2016, replacing the Mental Health (Northern Ireland) Order 1986.(144) The act was the first piece of legislation in Northern Ireland to define mental capacity, as well as providing definitions for key terms such as 'lacking capacity' and 'best interest decision-making'. The act creates provisions for Independent Mental Capacity Advocates whose support is essential when making best interest decisions. Additionally, the act allows for the protection, treatment and care for those who lack capacity. The act defines the role of the High Court in making decisions on behalf of a person, which includes their role in appointing deputies who act on behalf of an individual.(144)

While the Mental Capacity Act covers young people over the age of 16, the Mental Health (Northern Ireland) Order 1986 has been retained to cover children and young people under the age of 16 who are deemed to lack capacity to make informed decisions about their care and treatment.(145) The Bamford Review recommended the reform of the 1986 order as it considered it inappropriate for children and young people, with the review recommending additional safeguards for children.(146) The government in Northern Ireland have indicated their intention to bring forward a new legislative framework for children who are under 16 years of age, however, at the time of writing there is no agreed timeline for this.

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[†††††] Published in 2002 by the Department of Health *the 'Bamford Review of Mental Health and Learning Disability'* was an independent and major review of law, policy and provisions affecting people with learning disabilities and mental health needs in Northern Ireland.

### 3.3.4. Strategies, policies and standards

There are a range of standards, policies and guidelines which detail the care and support to be provided to children. This section describes key strategies, policies and standards that have been developed in Northern Ireland. This section also describes a number of inspectorates that assess compliance with standards.

#### 3.3.4.1. Strategies and policies

The strategies and policies included in this section set out a vision for child health and wellbeing in Northern Ireland. This section sets out strategies and policies that apply to all children and young people and also ones that apply specifically to children and young people at risk.

#### The Children and Young People Strategy

The '*Children and Young People's Strategy*', published in 2019, details a strategic framework to improve the overall wellbeing of children and young people in Northern Ireland and to provide them with the best possible start in life.(134) This strategy is strengthened by a legislative duty, set out in the Children's Services Co-operation Act 2015, where key organisations are compelled to work in cooperation to achieve the strategies desired outcomes.(143) The strategy outlines eight outcomes to be achieved for all children and young people and highlights the key areas of improvement and the pathways to fulfilling these outcomes. These outcomes encompass most aspects of a child's life, for example, their physical and mental health, learning and succeeding, pastimes and leisure, safety and stability, contribution to society, rights, equality, and economic and environmental wellbeing. The opinions of children and young people were gathered and they identified issues that were of importance to them such as, access to early intervention, mental health and emotional wellbeing, the inclusion of people with disabilities in services, reducing inequalities between the rural and urban divide, race, discrimination, religious beliefs and sexual orientation.(134) While the strategy has been delayed due to a suspension of the assembly in Northern Ireland, there are plans to finalise the framework at the end of 2020.

#### Cooperating to Safeguard Children and Young People in Northern Ireland Policy

Published initially by the Department of Health in 2003, and updated in 2017, this document sets out a policy framework for the safeguarding of children and young people in private, statutory, independent, community, and voluntary sectors.(147) The policy provides guidance for organisations and individuals who work with children in a range of settings from health and social care services provided by HSC Trusts, the justice system, education, housing, ambulance and fire and rescue services, as well as voluntary, charitable, faith and community-based organisations.

The guiding principles of this policy are:

- the child or young person's welfare is paramount
- the voice of the child or young person should be heard
- parents are supported to service parental responsibility and families helped to stay together
- partnership
- prevention
- responses should be proportionate to the circumstances
- protection
- evidence-based and informed decision-making.

#### 3.3.4.2. Standards for health and social care services working with children

A number of standards and regulations have been developed to drive improvement and assess the quality of care provided to people living in Northern Ireland. This section sets out the standards that are specific to the health and wellbeing of children and young people and will also detail standards that relate to the population as a whole. This section also describes how compliance with the standards is assessed in Northern Ireland.

##### Quality Standards for Health and Social Care

The '*Quality Standards for Health and Social Care*', developed by the Department of Health, are intended to increase the quality of health and social care services provided through primary care, community care and hospitals to the population in Northern Ireland.(136) Launched in 2006, these standards set a benchmark which the RQIA measure against. The standards work to promote the implementation of a human rights-based approach to service delivery, provide a formal assessment framework for health and social care services, and help users of health and social care to understand what to expect when they use a service.

The five quality themes which underpin these standards are:

- corporate leadership and accountability of organisations
- safe and effective care
- accessible, flexible and responsive services
- promoting, protecting and improving health and social wellbeing
- effective communication and information.

The RQIA adopted these quality standards to assess the quality of care provided by the HSC Boards and the RQIA report their findings to both the Department and the public. The RQIA use the quality standards to inform their review programmes. During the planning for these review and during the reporting of the findings, RQIA focus on three questions: Is care safe? Is care effective? Is care compassionate? These focused questions help to build on work carried out during previous reviews. Children's Services that the RQIA include mental health and learning disability hospitals, domiciliary care agencies, independent hospitals and day care centres.

## Domiciliary Care Agencies - Minimum Standards

Developed in 2011 by the by the Department of Health the '*Domiciliary Care Agencies – Minimum Standards'* details the requirements for providers when offering services for adults and children in their own home, similar to homecare in Ireland.(148) The principles underlining these standards are:

- dignity and respect
- independence
- rights, equality and diversity
- choice
- consent
- confidentiality
- safety.

These standards aim to promote a multiagency response when providing care and support in a person-centred manner. The '*Domiciliary Care Standards'* promote the empowerment of persons using services and encourages their participation in decisions that affect their lives. These standards set out a requirement for services to protect and safeguard children, to ensure that children are protected from abuse, complaints are dealt with effectively and taken seriously and that services provide safe and healthy working practices.(148)

## Inspectorates

RQIA, established in 2005 under the Health Personal Social Services Order 2003, are an independent health and social care regulator in Northern Ireland. RRQIA has responsibility for monitoring and inspecting the 'availability and quality' of health and social care services. A wide range of health and social care services are obliged to register with RQIA, for example, domiciliary care, residential centres and independent hospitals and inspections of services. These inspections are based on care standards and are carried out on nursing homes, residential centres, children's homes, day care agencies, nursing agencies, as well as a number of independent healthcare services. Additionally RQIA holds a role in quality assurance of services provided by HSC Board, HSC Trusts and agencies in attempts to ensure that standards laid out by the Department of Health are met. As set out by the Health and Social Care Reform Act 2009, RQIA also hold a number of responsibilities towards those with a mental illness or a learning disability, which includes the prevention of ill treatment; 'remedying any deficiency in care or treatment; terminating improper detention in a hospital or guardianship; and preventing or redressing loss or damage to a patient's property.'(149)

### 3.3.5. Findings from reviews

Reviews of child and adolescent mental health services and disability services show a dedicated workforce who are in some cases struggling against a lack of funding and training or the general complexity of care systems in Northern Ireland.(141,146) The 2002 *'Bamford Review of Mental Health and Learning Disability'*, initiated over a decade of reviews of CAMHS and disability services in Northern Ireland, from organisations like RQIA and the Children's Commissioner. The findings from the Bamford Review stressed the importance of interagency collaboration and addressing the individual needs of children. Reviews of CAMHS from the RQIA and NICCY, while complementary of the work from professionals in the area, have highlighted inconsistencies in service provision across the HSC Trusts, long waiting times and a fragmented system of care.(141,150)

#### Bamford Review of Mental Health and Learning Disability

In 2002, the Department of Health initiated an independent review, the *'Bamford Review of Mental Health and Learning Disability'*, the aim of which was to review the law, policy and service provision of those with learning disabilities and mental health needs in Northern Ireland. The review's steering committee published 11 phased evidence-based reports between 2005 and 2007. '*A Vision of a Comprehensive Child and Adolescent Mental Health Service'* was published in 2006 which set out the strategic direction to be adopted by children's mental health services.(151) The review stressed the importance of interagency collaboration when delivering child mental health services in a holistic manner. A key recommendation from the review proposed that all aspects of child health and social care services be brought under one management system, which would in turn work in partnership with other agencies, for example, youth justice, education, community and voluntary sectors. The review highlighted the importance of the education sector promoting good mental health in the classification and early identification of issues amongst children and young people.

With regard to children and young people with learning disabilities, the steering committee published a report in 2005, '*Equal Lives: Review of Policy and Services For People with a Learning Disability in Northern Ireland'*.(152) This review recommended that children are supported to grow in an environment which recognises their differences and supports their involvement in their community. The review stressed the importance of supporting children and young people to get the best start in life possible and experience equal access to services compared to their peers.

### Independent Review of Child and Adolescent Mental Health Services (CAMHS) in Northern Ireland

An '*Independent Review of Child and Adolescent Mental Health Services (CAMHS) in Northern Ireland*', published in 2011 by RQIA, sought to examine the quality and availability of services and professional groups in the delivery of specialist mental healthcare in community settings for children and young people.(141) Although this review excluded any non-specialist services, for example school nurses or health visitors, RQIA recognises their importance in early identification of mental health issues amongst children and young people. The five HSC Trusts and Boards were reviewed, partially against the recommendations which resulted from the Bamford Review, as discussed in the next section.(141)

The review team found that improvements had been made since the 2002 Bamford Review. These included the instalment of a purpose-built inpatient service which has increased capacity to treat young people requiring hospitalisation. Additionally, a service targeted at treating eating disorders and crisis intervention have all contributed to improving the range and availability of CAMHS in Northern Ireland.(141) The review concluded that the workforce operating within CAMHS were committed to the care and support of children and young people, a sentiment that was reinforced by statements from children and young people.

However, the review highlighted gaps in addressing the needs of children and young people with mental health issues in an appropriate timeframe and by suitable staff. When looking across the five trusts, the lack of an overall strategy for CAMHS was evident as each trust was developing services independently of one another. Inconsistencies across the trusts included the availability of specialised and targeted services and access to community and early interventions services for children and young people in need of mental health supports.

### Northern Ireland Commissioner for Children and Young People – 'Still Waiting' A Rights Based Review of Mental Health Services and Support for Children and Young People in Northern Ireland

The Northern Ireland Commissioner for Children and Young People (NICCY) published the report '*Still Waiting*' in 2018, which assessed the adequacy of the mental health services and supports provided to children and young people in

Northern Ireland.(150) The review gathered the views and experiences of children and young people when engaging with mental health services, asking them about the barriers and facilitators they experienced when accessing services. The review also asked children and young people to identify areas of good practice and to make recommendations for quality improvement.

Over the course of the review, NICCY found a system under considerable pressure, struggling to keep abreast of the demand and the complexity of mental health issues children and young people were presenting with. The review also noted poor investment in CAMHS, issues with funding allocation, and inconsistent service provision, as reflected in the experiences of children and young people. Additionally, the review noted a lack of awareness of the Stepped Care Model for CAMHS among non-mental healthcare professionals. General practitioners highlighted the need for training in child and adolescent mental health, resources to access self-help supports for children and young people, improved communication and links between CAMHS and primary care, as well as clarity around the threshold for referral to CAMHS.

### RQIA – A Baseline Assessment and Review of Community Services for Children with a Disability

In 2013, RQIA published *'A Baseline Assessment and Review of Community Services for Children with a Disability'* as part of its three-year-review programme.(139) The review focused on children with a physical and sensory disability and found that there was a considerable level of variation between the range and quality of services provided to children with disabilities across the jurisdictions and identified a shortage of suitable community supports for children with learning disabilities. Additionally the review, in noting the variation between the range and skill of staff, recommended that services be assessed to ensure they are meeting the individual needs of children.

The review found improvements in the quality of communications between educations, health and social care. However, the review also noted that each trust relied on an informal information sharing network as opposed to clearly defined clinical pathways and that sharing of innovative practices between trusts was almost non-existent. RQIA called on HSC Trusts to review duplication of effort by community disability teams.

As part of this review the views of young people with disabilities were obtained, and it was highlighted that young people with learning disabilities found the transition from child to adult education to be fraught with challenges. These challenges stemmed from complex systems governing transitions between services.

### 3.3.6. Lessons for Ireland

A key lesson from Northern Ireland is the commitment at a legislative level through the Children's Services Co-operation Act, and at a structural level through the HSC Trusts, to integrate working across health and social care to meet the needs of children and adults in Northern Ireland. The introduction of additional structures in regards to child protection and welfare include the Safeguarding Board of Northern Ireland and local Safeguarding Panels, which create a structure for all services involved in child protection and welfare to jointly tackle issues and pursue goals and strategies, without treating local areas as entirely uniform in their needs and means.(9)

Although there is a clear commitment to upholding the rights of children in Northern Ireland, as evidenced in the '*Children and Young People's Strategy*'(134), gaps remain in this respect in relation to services for children with a disability. Reports highlight that there are gaps in legislation which mandate for equality in Northern Ireland and which protect children and adults with a disability.(146) While a Single Equality Bill was considered in in Northern Ireland as long ago as 2004, it has not been progressed. As a result of this disparity, people with disabilities, and their carers, experience less protection than those in the Republic of Ireland or the remainder of the UK.(153)

Another lesson for Ireland are the efforts at an interdepartmental level to address continued issues experienced by children seeking support from mental health services. As recommended in the 2018 '*Still Waiting*' review of CAMHS in Northern Ireland, an interdepartmental group has been set up, and for the first time voluntary services have been brought into such a government group.(150) Representatives from the departments of education, communities, justice, the HSC Boards, Educational Authorities, RQIA and voluntary and community sector bodies are now all working together to progress a timeframed action plan.

## 3.4. Australia

This section describes the organisation and delivery of health and social care services for children in Australia and also the impact that these services are having on health and wellbeing outcomes for children. This section is set out under the following headings:

- overview of health and social care services working with children
- model of service
- legislation
- strategies, policies and standards
- findings from reviews

- lessons for Ireland.

### 3.4.1. Overview of health and social care services for children in Australia

The number of children living in Australia has increased in recent decades and the most recent figures from 2018 estimated that 4.7 million children aged 0-14 years lived in Australia.(154) The key federal level organisation responsible for the health of children in Australia is the Department of Health, which has a vision of better health and wellbeing for all Australians, now and for future generations.(155) With regards to child wellbeing, at a federal level, the Department of Social Services (DSS) holds responsibility for developing national policies and programmes for children and families. The mission of the DSS is to improve the wellbeing of individual and families in Australian communities and ensure that the values of impartiality, accountability, respect and an ethical approach guide the way in which the Department works.(156)

Children's health services are delivered through Primary Health Networks (PHNs), which the Department of Health are responsible for overseeing. State and territory governments hold responsibility for child protection with individual departments responsible for the coordination and delivery of child protection and welfare services. Section 3.6.2. describes how health and social care services are delivered in Australia.

In Australia, a wide range of legislation, strategies and policies are in place which echo governmental commitment to improving the lives of children and young people. While each state and territory government is governed by independent acts, a number of key pieces of federal level legislation provide guidance for child protection and welfare services at all levels of government. Section 3.6.3. provides an overview of this legislation. A number of the national frameworks and strategies, such as the *'National Framework for Protecting Australia's Children 2009-2020'*(157) signify a move towards an integrated way of working across health and social care services in order to achieve positive outcomes for children and young people. Section 3.6.4. describes a number of these key strategies and provides an overview of standards that are specific to the health and wellbeing of children and young people.

### 3.4.2. Model of service

In Australia, governmental responsibility for the organisation and delivery of health and social care services for children is shared across federal, state and local governments. This section sets out the organisation and delivery of the following service for children and young people:

- general healthcare services for children and young people
- children's social services
- disability services for children and young people
- mental health services for children and young people.

## Organisation and delivery of healthcare services for children

Responsibility for running Australia's health system is allocated between federal, state, territory and local governments. At a federal level, the Australian Government is primarily responsible for leading the development of national health policy, funding and providing oversight of PHNs, administration of Medicare, regulation of private health insurance and funding of community-controlled indigenous primary healthcare.(158) PHNs are independent organisations funded by the Australian government that coordinate health services in local areas across Australia and were established by the Australian government to improve the effectiveness and efficiency of patient care in Australia. PHNs are advised by local doctors, health workers and patients in the community. There are currently 31 PHNs in Australia and their functions are to:

- support community health centres, hospitals, general practitioners (GPs), nurses, specialists and other health professionals to improve patient care
- improve coordination between different parts of the health system, for example, communication between a hospital and GP upon the discharge of a patient
- assess the health needs of their local area to tailor health services to meet the needs of the community
- provide extra services that are needed, such as, after-hours services, mental health services and health promotion programmes.

PHNs work closely with Local Health Networks (LHNs) which were established by state governments to devolve operational management for public hospitals and accountability for local service delivery, to a local level.(159) LHNs directly manage single or small groups of public hospital services and are responsible for the provision of public hospital services in defined geographical areas.

A key responsibility of the Australian government is the administration of Medicare, Australia's federally-funded, universal healthcare scheme, which is in place since 1984.(158) Medicare guarantees all Australians access to a wide range of health and hospital services at low or no cost. These services include primary healthcare services, medical services by doctors, specialists and other allied health professionals, treatment in public hospitals and prescription medicines.(160) Children can be enrolled in Medicare as soon as they are born and are eligible to get their own Medicare card when they reach 15 years of age. Children have a right to access all services covered by Medicare, including primary healthcare services and hospital care in public hospitals. Children and young people receive inpatient and outpatient care in paediatric wards in Australian public hospitals. Access to this care is through referral by a GP, an allied health professional or through an emergency department. Australia also has a number of specialist children's hospitals which provide a range of inpatient and outpatient services for children and young people. Access to specialist treatment for children is through referral from a GP or through a specialist or consultant physician.(161)

## Organisation and delivery of children's social services

Governmental responsibility for children's social services in Australia is allocated between federal and state and territory governments. At federal level, the Department of Social Services (DSS) is a department of the Australian government that aims to improve the wellbeing of individuals and families in Australian communities. The DSS is responsible for supporting families and children through funding and the delivery of structured, community-based prevention and early intervention parenting programmes. The DSS also provides financial support to families through a number of national benefits and payments and offers support to young people who are leaving formal care.(162)

Australia has shifted focus from a statutory child protection system to one that is focused on prevention and early intervention approaches. This shift in focus has led to the adoption of a public health model of child protection, as can be seen in the '*National Framework for Protecting Australian's Children 2009 -2020'*.(157) In this model of child protection, primary services are focused on promoting the welfare of all children and families before problems occur, secondary services, or early intervention services, are targeted at vulnerable children and families, and tertiary services provide targeted services to children and families who are identified as being potentially at risk. The concept underpinning this model is that investment in primary prevention programmes will have the greatest likelihood of preventing progression along the care continuum, reducing the burden on child protection services and delivering better outcomes for children(163)

In Australia, there are a number of key pieces of federal level legislation that establish guiding principles for child protection and welfare services at a national level (these acts are set out in Section 3.4.3. of this review). However, statutory child protection is the responsibility of state and territory governments. Each jurisdiction is governed by its own independent child protection legislation and is guided by its own policies and practices. Jurisdictions also have individual departments that coordinate child protection and welfare services. Each department is responsible for assisting vulnerable children, within their jurisdiction, who have been, or are at risk of being, abused, neglected or otherwise harmed, or whose parents are unable to provide adequate care and protection. Although, each jurisdiction is subject to its own child protection legislation, policies and practices, the main child protection processes used across Australia are broadly similar. An illustrative example of how child protection services in Western Australia are accessed and delivered can be found in the recently published '*Evidence Review to inform the development of National Standards for Children's Social Services'*.(9)

## Organisation and delivery of disability services for children

The National Disability Insurance Agency (NDIA) is the independent federal government agency responsible for administering the National Disability Insurance Scheme (NDIS). The NDIS aims to support a better life for Australians with a significant and permanent disability and the lives of their families and carers. The nationally-funded scheme is designed to provide access to lifelong support for people living with a disability. The scheme also provides support for children up to the age of 18 who are living with a disability. Eligibility to the scheme is based on age, residency status, the nature of an impairment or condition, and the impact it has on a person's daily functions. The NDIS has a national approach to early childhood intervention that aims to provide children up to six years of age with timely access to support that is tailored to their needs. This support may be in the form of information, emotional support, referral to other services such as community health services and early intervention supports (for example, a speech pathologist or occupational therapist), playgroups or peer support groups. If parents have a concern regarding their child's development or if their child has been diagnosed with a disability, they can contact the NDIA directly to request access to an NDIS early childhood partner. This partner helps parents find supports and services within their community and also helps parents request access to the NDIS if their child needs long-term early intervention supports. Access is also provided through referral by a GP, child and family health nurse, paediatrician or childcare educator. NDIS provides early intervention for children over the age of seven only if they have a permanent and significant disability. Access for this age group is generally through a GP or paediatrician.(164)

## Organisation and delivery of mental health services for children

Services for children and young people with mental health needs are funded and delivered by individual state and territory governments. One illustrative example of how mental health services for children and young people are delivered in Australia is in the services provided by the government of Western Australia.(165) The Child and Adolescent Mental Health Services (CAMHS) in Western Australia offers support, advice and treatment to children and adolescents, and their families, who are experiencing mental health issues. Referral to CAMHS is through GPs, schools, community organisations, specialists and therapists. CAMHS provides recovery-focused programmes and services for children from birth up to 18 years old. In contrast to Ireland where CAMHS services for children with higher levels of intellectual disability are scarce and often without the full complement of disciplines recommended, CAMHS teams in Western Australia provide community mental health clinics that offer assessment, case coordination and multidisciplinary treatment services for children and adolescents with severe, complex and persistent emotional, psychological, behavioural, intellectual, social and or mental health problems. CAMHS teams also provide access to hospital-based mental health services, including eating disorders services, gender diversity services and a paediatric consultation liaison programme. CAMHS teams in Western Australia can refer children and adolescents to the Mental Health Inpatient Unit in Perth's Children's Hospital which is the state-wide assessment and treatment facility for children up to 16 years old with complex and acute mental health issues. The unit offers short-term assessment, intervention and therapeutic group programmes, depending on the needs of the patient.(165)

### 3.4.3. Legislation

In Australia, child protection and welfare services are governed individually by each jurisdiction. However, there are key pieces of federal legislation that provide collective guidance that is applicable to child protection and welfare services at a federal level. A number of these acts (the Family Law Act 1975 and the Australian Human Rights Commission Act 1986) have established guiding principles for child protection and welfare services. These principles are; best interest of the child, early intervention and participation of children and young people in decision-making. This section sets out the legislation that applies to all children in Australia at a federal level and also human rights legislation which provide disability and mental health rights for children.

#### The Family Law Act 1975

The Family Law Act 1975 is administered by the Australian Parliament.(166) It provides the Family Court of Australia and the Federal Magistrates Court of Australia the governance to make decisions about children, which are usually part of family law proceedings. These proceedings include decisions regarding divorce, parenting arrangements between separated parents (irrespective of marital status), property separation, and financial maintenance involving children or divorced or separated parents. With respect to child wellbeing, the act aims to ensure that children receive adequate and proper parenting to help them achieve their full potential, and to ensure that parents fulfil their duties, and meet their responsibilities concerning the care, welfare and development of their children.(167) The act focuses on the rights of children and the responsibilities that each parent has towards their children, rather than on parental rights. It aims to ensure that children can enjoy meaningful relationships with each of their parents and are, at all times, protected from harm. The act is guided by the principle of 'the best interests of the child' and sets out that in all Family Court proceedings, the best interests of the child should be a primary consideration of the court. Under the act, the court must also consider how the views of a child are expressed. When determining the best interests of a child, the act sets out that the court must consider the benefit to the child of having a meaningful relationship with both parents, and also the need to protect the child from physical or psychological harm or from being subjected or exposed to abuse, neglect or family violence.(167)

### The Disability Discrimination Act 1992

The Disability Discrimination Act (DDA) 1992 is administered by the Australian Human Rights Commission.(168) The DDA provides protection against discrimination based on disability and makes it unlawful to discriminate against people, including children, with disabilities. The DDA aims to give effect to Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and to improve the lives of people and children with disabilities in Australia. The definition of disability under the act refers to people (including children) who may have physical, intellectual, psychiatric, sensory, and neurological or learning disabilities. It also includes physical disfigurement and conditions, such as epilepsy and diabetes. The DAA sets out disability discrimination as being either direct or indirect.[‡‡‡‡‡]

Under the DAA, disability discrimination extends to circumstances where a person or a child may have a current or past disability, may develop a disability in the future or is believed by others to have a disability. The DAA requires governments, businesses and community organisations to enable people with disabilities to participate in their services in the same way as other members of the community. Under the DAA, education and community services are obliged to support children with a disability to fully access and participate in their programmes. This may require services to make

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[‡‡‡‡‡] Direct disability discrimination occurs when people with a disability are treated less favourably than people without a disability. Indirect disability discrimination occurs when people are treated less fairly because they are relatives, friends, carers, co-workers or associates of a person or a child with a disability.

adjustments, or provide additional support, in their programmes or environments to enable children with disabilities to participate fully in meaningful ways.

### Australian Human Rights Commission Act 1986

The Australian Human Rights Commission Act 1986 is administered by the Australian government.(169) The act was enacted in 1986 following Australia becoming a signatory to a number of United Nations conventions including:

- United Nations International Covenant on Civil and Political Rights(170)
- United Nations Convention on the Rights of the Child(14)
- United Nations Declaration on the Rights of Disabled Persons.(171)

Under the act, the Australian Human Rights Commission was established in 1986, and is the statutory body responsible for investigating alleged infringements of Australia's anti-discrimination legislation in relation to federal agencies. The Commission can investigate matters of discrimination on the grounds of age, medical record, criminal history, disability, martial or relationship status, nationality, sexual orientation or trade union activity.

The rights of children with mental illnesses are not specifically set out in federal legislation. Rather, mental health rights are provided for through human rights legislation. As Australia is a signatory of the United Nations Convention on the Rights of the Child (UNCRC), the Australian government has a duty to ensure that all children in Australia enjoy the rights set out in the UNCRC. In addition, amendments to the act were made in 2012 which established the position of the National Children's Commissioner within the Australian Human Rights Commission. The purpose of the Children's Commissioner is to help promote the rights, wellbeing and development of children and young people in Australia, and ensure their voices, including those of the most vulnerable, are heard at a national level. The Commissioner has responsibilities for promoting public discussion and awareness of issues affecting children, conducting research programmes and consulting directly with children and representative organisations. While the Commissioner does not have a monitoring function with regard to children's health and social care services, they are responsible for examining relevant existing and proposed federal legislation to determine if it adequately recognises and protects children's rights in Australia.(172)

### 3.4.4. Strategies, policies and standards

Australia has a number of national strategies, policies and standards that set out specific commitments to protecting and ensuring the health and wellbeing of children and young people. This section describes key strategies, policies and standards that have been developed to promote positive outcome for children. This section also describes how compliance with the standards is assessed in Australia.

#### 3.4.4.1. Strategies and policies

The strategies and policies included in this section set out a vision for child health and wellbeing in Australia. This section sets out strategies and policies that apply to all children and young people, children and young people with disabilities and mental illnesses, and also ones that apply specifically to children and young people at risk.

#### The National Action Plan for the Health of Children and Young People: 2020-2030

Developed by the federal government and led by the Department of Health, the *'National Action Plan for the Health of Children and Young People 2020-2030'* outlines Australia's national approach to improving health outcomes for all children and young people, particularly those at the greatest risk of poor health.(173) Launched in May 2019, the action plan aims to drive improvement in the health of all children and young people in Australia across the life course, noting challenges of disparity and inequity in health outcomes between individuals, geographical areas and different sections of the population. The action plan recognises that there are a range of health needs, risks and influences experienced by children and young people at different stages of their life, and focuses on the importance of specific investments to maximise physical, mental and social health at every age. In order to improve outcomes and ensure the health of Australian children and young people, the Action Plan sets out five priority areas:

- improve health equity across populations
- empower parents and caregivers to maximise healthy development
- tackle mental health and risky behaviours
- address chronic conditions and preventive health
- strengthen the workforce.

The five priority areas are interrelated and are considered to be of equal importance. For each of these five priority areas, a series of key actions are set out to drive efforts, along with a number of approaches and activities that can be implemented to support each action. The priority areas, actions and activities set out in the action Plan have all been guided by key principles; prevention and early intervention; strengths-based approaches, environmental influences, health equity and proportionate universalism. At the time of writing, no progress update on the action plan was available.

## National Framework for Protecting Australia's Children 2009-2020

*'The National Framework for Protecting Australia's Children 2009-2020'* was Australia's first ever national policy roadmap aimed at achieving a substantial and sustained reduction in child abuse and neglect in Australia.(157) The framework commits federal, state and territory governments and an extensive national coalition of community sector organisations to an ambitious national approach of improving outcomes for children and young people across Australia. Under the framework, child protection is everyone's business and the overarching focus of the framework is on the need for federal, state and territory governments, non-government organisations and service providers to work together to ensure the safety and wellbeing of Australia's children. The aim of the framework is to drive improvements across all child protection systems and all jurisdictions and highlights that national leadership will help to deliver consistency and integration in child protection responses on a national level. The framework consists of one high-level outcome, supporting outcomes, strategies and actions to be delivered through a series of three-year action plans and indicators of change that can be used to monitor progress. The high-level outcome of the framework is that Australia's children and young people are safe and well. Key achievements of the action plans to date include the establishment of Australia's first National Children's Commissioner, the development of national standards for out-of-home care, the development of national principles for child safe organisations, and the development of the Child Protection National Minimum Dataset (CPNMDS).

An evaluation of progress under the National Framework was conducted in 2015 and it was highlighted that establishing attribution for change and improvement remains a key challenge for measuring the success of the framework.(174) The framework aspires to make child safety and wellbeing 'everyone's responsibility' and change the way governments, NGOs and the broader community, act to protect children. However, assessing how successful it has been in informing or driving this change remains difficult to determine. Contributing to this difficulty is the fact that a large proportion of the framework's indicators of change with regard to child wellbeing are not easily measurable and are therefore unreportable. Although the development of the CPNMDS provides for a nationally consistent administrative dataset detailing child protection activity across jurisdictions, data on child wellbeing indicators are not being measured. The evaluation report expressed concern that a true measure of the prevalence of child abuse and neglect in the community was absent. This absence was considered very limiting for advancing and embedding the public health model of child protection.

## National Principles for Child Safe Organisations

The Royal Commission into Institutional Responses to Child Sexual Abuse was established by the Australian government in 2013 to inquire into and report upon responses by institutions to instances and allegations of child sexual abuse in Australia. Over the course of the five-year inquiry, the Commission identified what makes institutions safe for children and young people and made recommendations on how to create cultures and practices that protect children.(175) One of the key national priorities recommended by the Commission was the establishment of the National Office for Child Safety. The office was responsible for the development of National Principles for Child Safe Organisations which aim to provide a consistent approach to creating organisational cultures that foster child safety and wellbeing.(176) The office also has a role in the development and implementation of the *'National Framework for Protecting Australia's Children 2009—2020'*.

The development of The National Principles for Child Safe Organisations represents a key achievement of the *'National Framework for Protecting Australia's Children 2009-2020'*.*(176)* The National Children's Commissioner, through the Australian Human Rights Commission, was also involved in the development of the principles. Endorsed by all federal, state and territory governments, the development of the principles also gives effect to a key national reform in response to recommendations made by the Royal Commission into Institutional Responses to Child Sexual Abuse.(177) The principles aim to provide a nationally consistent approach to creating organisational cultures that foster child safety and wellbeing and to support the next stage of development of the *'National Framework for Protecting Australia's Children 2009-2020'*. The principles have a broader scope that goes beyond child sexual abuse to cover other forms of potential harm to children and young people. While the national principles are not mandatory, they are aligned with existing child safety approaches at the state and territory level and some government agencies are making them part of the criteria to receive funding. The national principles are listed on Table 3.(177):

### Table 3. National Principles for Child Safe Organisations

| | |
|---|---|
| 1. | Child safety and wellbeing is embedded in organisational leadership, governance and culture. |
| 2. | Children and young people are informed about their rights, participate in decisions affecting them and are taken seriously. |
| 3. | Families and communities are informed and involved in promoting child safety and wellbeing. |
| 4. | Equity is upheld and diverse needs respected in policy and practice. |
| 5. | People working with children and young people are suitable and supported to reflect child safety and wellbeing values in practice. |
| 6. | Processes to respond to complaints and concerns are child-focused. |

| | |
|---|---|
| 7. | Staff and volunteers are equipped with the knowledge, skills and awareness to keep children and young people safe through ongoing education and training. |
| 8. | Physical and online environments promote safety and wellbeing while minimising the opportunity for children and young people to be harmed. |
| 9. | Implementation of the national child safe principles is regularly reviewed and improved. |
| 10. | Policies and procedures document how the organisation is safe for children and young people. |

## The National Disability Strategy

The '*National Disability Strategy'* (NDS) is a ten-year national plan (2010-2020) for improving the life experiences of Australians with disabilities, their families and carers.(178) This strategy applies to all Australians, including children and young people. It seeks to foster an inclusive society that enables people with disabilities to fulfil their potential as equal citizens. The DSS, in partnership with federal and state governments, is responsible for the implementation of the NDS which represents the overarching policy framework for all Australian disability policy. This is the first time in Australia's history that all governments have committed to a unified, national approach to improving the lives of people with a disability, their families and carers, and to providing leadership for a community-wide shift in attitudes. The strategy sets out six policy areas as shown on Figure 8 below.

### Figure 8. National Disability Strategy Policy Areas

1 **Inclusive and accessible communities**—the physical environment including public transport; parks, buildings and housing; digital information and communications technologies; civic life including social, sporting, recreational and cultural life.

2 **Rights protection, justice and legislation**—statutory protections such as anti-discrimination measures, complaints mechanisms, advocacy, the electoral and justice systems.

3 **Economic security**—jobs, business opportunities, financial independence, adequate income support for those not able to work, and housing.

4 **Personal and community support**—inclusion and participation in the community, person-centred care and support provided by specialist disability services and mainstream services; informal care and support.

5 **Learning and skills**—early childhood education and care, schools, further education, vocational education; transitions from education to employment; life-long learning.

6 **Health and wellbeing**—health services, health promotion and the interaction between health and disability systems; wellbeing and enjoyment of life.

**Source**: Commonwealth of Australia. 2011. *National Disability Strategy*.(178)

Since its implementation in 2011, significant achievements have been made across each of the policy areas. Progress reports have highlighted positive actions by each level of government and the community towards the creation of a more accessible and inclusive environment. However, insights from people with disabilities indicated that a number of areas required renewed focus and more action was required to create a more inclusive response to disability across governments, business and the community.(179) As the NDS will finish at the end of 2020, the Australian government is currently leading the development of a new national disability strategy to replace the current NDS. Federal, state, territory and local governments across Australia are working together in consultation with people with disabilities to develop the new strategy which is due to take effect from the start of 2021. The development of the new strategy is being informed by recent inquiries and through insights from people with disability, their families, carers, advocates, and service providers. At the time of writing, the development of the new strategy was in the consultation phase where members of the public are invited to share their feedback on the key features that governments are proposing to include in the strategy.(180)

#### The National Children's Mental Health and Wellbeing Strategy

In August 2019, as part of the Australian government's Long-Term National Health Plan, the Minister for Health announced the development of a '*National Children's Mental Health and Wellbeing Strategy'*. The purpose of the strategy is to guide and inform the government's investment and commitment to the health and wellbeing of Australian children and will provide a framework for preventing mental illness and reducing its impact on children, families and the wider community. At the time of this review, the strategy had not been published, with a draft strategy due to be delivered to the Australian government in late 2020.(181)

### 3.4.4.2. Standards for health and social care services working with children

A number of standards have been developed to drive improvement and assess the quality of care provided to people living in Australia. This section sets out the standards that are specific to the health and wellbeing of children and young people and also describes how compliance with the standards is assessed in Australia.

#### National Standards for Out-of-Home Care

The National Standards for Out-of-Home Care are a further development arising from the *'National Framework for Protecting Australia's Children 2009-2020'*. The standards have been designed to drive improvements and deliver consistency in the quality of care so that children and young people in out-of-home care have the same opportunities as their peers to reach their potential in life.(182) The standards focus on the key areas that directly influence better outcomes for those living in out-of-home care settings. The areas identified were: health; education; care planning;

connection to family; culture and community; transition from care; training and support for carers; belonging and identity and safety, stability and security. Each standard has indicators as a means by which progress against the standards can be monitored over time. Monitoring progress against the national standards is conducted by data collection through the CPNMDS, however, the standards are not inspected against.(183)

## The National Standards for Disability Services

In 2013, the National Standards for Disability Services were endorsed by the Standing Council on Disability Reform, and aim to promote and drive a nationally consistent approach to improving the quality of disability services.(184) These standards are set out in legislation under the Disability Services Act 2014 and are considered critical under the NDIS.(185) The DSS has responsibility for managing and monitoring these standards. The standards focus on rights and outcomes for people with a disability, including children who are living with a disability. The standards take a person-centred approach, whereby people with a disability are supported to take control of their own lives and are at the centre of planning and delivery of services. These approaches are implemented with the support of families, friends, carers and advocates. The six standards that apply to disability service providers are; rights; participation and inclusion; individual outcomes; feedback and complaints; service access; and service management. The standards are considered a critical aspect of good service delivery under the NDIS and the Australian government adopted the standards for its employment and advocacy services for people with a disability in 2014. Each standard is made up of the following elements; rights for people, outcomes for people, standards for service and indicators of practice. The indicators of practice provide guidance on what services need to do in order to meet each standard and also set out when individuals, families and carers can expect from each standard.

## Inspectorates

The National Standards for Out-of-Home Care are monitored at a federal level through the CP NMDS and the National Survey of Children and Young People. Similarly the National Standards for Disability Services are managed and monitored at a federal level by the DSS. At a state and territory level, each jurisdiction has a number of strategies, policies and standards that aim to protect and ensure the health and wellbeing of children and young people in their jurisdiction. Many jurisdictions therefore have their own inspectorate and monitoring bodies that have legislative roles in safeguarding and promoting the wellbeing of children within their jurisdiction. An illustrative example of how health and social care standards for children and young people are monitored in Western Australia can be found in the recently published '*Evidence Review to inform the development of National Standards for Children's Social Services'*.(9)

### 3.4.5. Findings from reviews

Australia is currently ranked 32 out of 41 OECD countries in terms of child wellbeing outcomes.(186) The UNICEF report highlighted the poor outcomes for Australian children in terms of mental wellbeing, physical health and academic and social skills.(186) Furthermore, the Australian Council of Social Service (ACOSS) estimates that over 17% of all children in Australia are living in poverty, with rates of poverty notably higher among children living in one-parent families. In addition, the 2018 '*Children's Report'* released by the Australian Child Rights Taskforce highlighted that the Australian government has made insufficient progress in policies and programmes to support children and young people, particularly children who are considered to be the most vulnerable and disadvantaged.(187) Specifically, the report indicated that Aboriginal and Torres Strait Islander children, children with a disability, LGBTI+ children, asylum seeker and refugee children, children living in regional and remote areas and children in out-of-home care are experiencing poorer outcomes than their counterparts. The report indicates that among children in Australia, one in five is starting school developmentally vulnerable, one in seven has experienced a mental disorder, and youth suicide is the leading and increasing cause of death among children and young people today. The academic performance of Australian children has also experienced a consistent downward trend across all school sectors since 2000. According to a 2018 UNICEF report, Australia ranks in the bottom third of all OECD countries in terms of educational equality across early, primary and secondary education.(188) This section sets out findings from reports that provide an overview of health and wellbeing outcomes for children and young people at risk and also findings of a survey which assessed the mental health of children in Australia.

#### National Framework for Protecting Australia's Children 2009-2020: Annual Report 2018

The 2018 annual report of the '*National Framework for Protecting Australia's Children 2009-2020'* reported a year-on-year increase in the number of children and young people using child protection services from 2014 to 2016.(189) The report highlighted disparities between Indigenous and non-Indigenous children, with Aboriginal and Torres Strait Islander children seven times more likely to be the subject of child protection substantiations when compared to their non-Indigenous counterparts. Furthermore, recent statistics from the Australian Institute of Health and Wellbeing (AIHW) indicate that that there has been a marked increase in the number of Australian children living in out-of-home care, with the number of children entering and remaining in out-of-home care having increased by 18% from 2013 to

2017.(190) Factors contributing to this increase have been identified as a growing population, an increase in domestic violence and increasingly complex issues developing in children's lives.

## Views of Children and Young People in Out of Home Care

A recent national survey, *'Views of Children and Young People in Out of Home Care',* provided an overview of results from a 2018 national data collection on the views of children and young people in out-of-home care.(191) The report indicated that the vast majority (92%) of children in out-of-home care feel safe and secure in their placement. Two-thirds of young people aged 15 to 17 years also reported that they were receiving sufficient support to make decisions about their future when they will transition out of care. However, as acknowledged in the report, survey results must be interpreted cautiously, as they are based on small sample sizes and may not be representative of the wider population. Despite the high numbers of children living in out-of-home care in Australia, the survey also emphasised the lack of research into long-term outcomes of children living in out-of-home care. At the time of this review two longitudinal studies were underway: '*Beyond 18*' in Victoria, and '*Pathways of Care*' in New South Wales. A recent report from *'Beyond 18'* indicated that a significant proportion of care leavers were experiencing poor outcomes with a high prevalence of mental health issues and psychological distress and higher reported rates of self-harm and suicidality when compared to young people who had not lived in out-of-home care.(192) Further findings from these longitudinal studies will provide valuable information about the life course development of children and young people who have spent time in out-of-home care facilities and will also provide evidence to inform policy and practice to improve outcomes for children and young people in out-of-home care.

## Young Minds Matter Survey

The *'Young Minds Matter Survey'* (Mental Health of Children and Adolescents Survey), is the largest national survey examining the mental health and wellbeing of Australian children and adolescents. Funded by the Australian government, the most recent survey was conducted between 2013 and 2014, the survey involved interviews with more than 6,000 Australian families to examine the emotional and behavioural development of children and young people aged between four and 17 years.(193) The survey reported worrying mental health trends among children and young people, with one in seven children surveyed identified as having a mental health disorder. While the prevalence of mental health disorders among children has remained relatively stable since 1998, when the first national survey was conducted, there has been an increase in the prevalence of major depressive disorders among children and young people. The survey also reported on increasing rates of self-harm and suicidal behaviour among children and young people, with the highest prevalence of both reported among teenage girls. Rates of suicidal behaviours were markedly higher in young people with major depressive disorders, with prevalence rates again highest in young females.

### 3.4.6. Lessons for Ireland

There is a wide range of strategies, policies, frameworks and standards in place in Australia to promote the health and wellbeing of children and their families. Child protection in Australia has adopted the approach that everyone has a responsibility for protecting and providing support to children. With this collaborative approach, parents, communities, and both statutory and non-statutory organisations all have a role to play in reducing the risk of child abuse and neglect. Establishing strong partnerships between statutory and non-statutory organisations could help facilitate interagency collaboration in Ireland. An integrated approach to child protection across all organisations could help alleviate the sense of fragmentation and inconsistency that has been reported in Irish care and support services, with shared responsibility and use of resources reducing the burden on all services. In addition, ensuring integrated approaches are focused on prevention and early intervention strategies can ultimately lead to positive outcomes for children and young people and their families.

As evidenced in this review, there is a need to develop a national outcomes-based framework to accurately track outcomes across all child wellbeing domains. A number of child wellbeing indicators in the *'National Framework for Protecting Australia's Children 2009-2020'* are not measurable and are therefore not reportable. There is very little comprehensive and cohesive reporting on child wellbeing in Australia, with the focus mostly on inputs and outputs such as the number of child protection reports generated or the number of children discharged from care. The absence of reliable national surveillance data on children's wellbeing means that trends in outcomes for children are not comparable over time. Development of national data systems will help to improve effective resource allocation and allow services to be targeted towards populations in need and improve outcomes for children and young people.

## 3.5. Sweden

This section describes the organisation and delivery of health and social care services for children in Sweden and also the impact that these services are having on health and wellbeing outcomes for children. This section is set out under the following headings:

- overview of health and social care services working with children

- model of service
- legislation
- strategies, policies and standards
- findings from reviews
- lessons for Ireland.

### 3.5.1. Overview of health and social care services working with children

There are just over two million children in Sweden, representing about one-fifth of the total population.(194) In Sweden, political power is decentralised and the responsibility for health and social care is devolved to a municipal level. The Swedish government have developed a health care system with the aim of being a socially conscious and responsible system. The Ministry of Health and Social Affairs is in charge of policy related to social welfare, social services medical and health care, health promotion, and the rights of children and people with disabilities. The Ministry discharges its responsibilities to develop standards and regulation for health and social care through the 'Socialstyrelsen' which is the National Board of Health and Welfare. The Health and Social Care Inspectorate (IVO) inspects social services and health provided by individual municipalities, including each municipality's compliance in executing decisions around care and support.

A wide range of legislation, strategies and policies are in place which frame governmental commitment to the health and wellbeing of children in Sweden. One example of this is that Sweden have put the UNCRC on a statutory footing which passed into law in 2020.(195) Another example is the '*National Public Health Policy'* which sets out to foster social conditions which ensure good health and wellbeing for the whole population, and to establish ways to improve health outcomes for the most vulnerable in society.(196) Sections 3.5.3. and 3.5.4. outline key pieces of legislation and different strategies and policies that are focused on improving outcomes for children. In Sweden, standards and guidance for healthcare are developed by the National Board for Health and Welfare (Socialstyrelsen) which also compiles statistics related to social care and protection.(197) The main piece of guidance in relation to children's social services is the '*Children's Needs in Focus'* (Barns Behov i Centrum BBIC) which provides guidance on how children's social services should treat children and young people.(197) Section 3.5.4. also sets out the primary bodies involved in the monitoring and regulation of health and social care services for children and young people.

### 3.5.2. Model of service

The Swedish health care system is built to be a socially conscious and responsible system, with three administrative levels: national, regional (consisting of 21 county councils) and local (which contains 290 municipalities).(198) While counties and municipalities vary in size, there is no hierarchical relationship between them and each have their own self-governing local authorities. Public health works across the three levels of government and operates both within and outside of the health system. The section sets out the organisation and delivery of the following services for children and young people:

- general healthcare services for children and young people
- children's social services
- disability services for children and young people
- mental health services for children and young people.

## Organisation and delivery of general healthcare services for children

At a national level, the Ministry of Health and Social Affairs is responsible for overall health and health care policy, working in conjunction with 15 government agencies directly involved in the areas of health, health care, and public health.[§§§§§] Funding and the provision of services largely lies with the county councils. These councils are responsible for hospital care and general practice, and the municipalities provide care through smaller services like clinics, homecare services and nursing homes.(198) As county councils and municipalities are self-governing with their own local authorities who hold responsibility over different services, they have considerable freedom when planning for the delivery of care and which explains the level of variation in regions. The Public Health Agency of Sweden, which sits under the Ministry of Health and Social Affairs, is a key player in the area of national public health. The agency's primary focus is on the development and support of health promotion, preventing illness and the improvement of preparedness for health threats. Most of the agency's work operates outside of the health sector and generally concerns itself with environmental health and takes responsibility for the environment and public health reports at the Socialstyrelsen, the National Board of Health and Welfare. These national public health reports are submitted by the Socialstyrelsen to the Swedish government which describes the population health, habits and morality.

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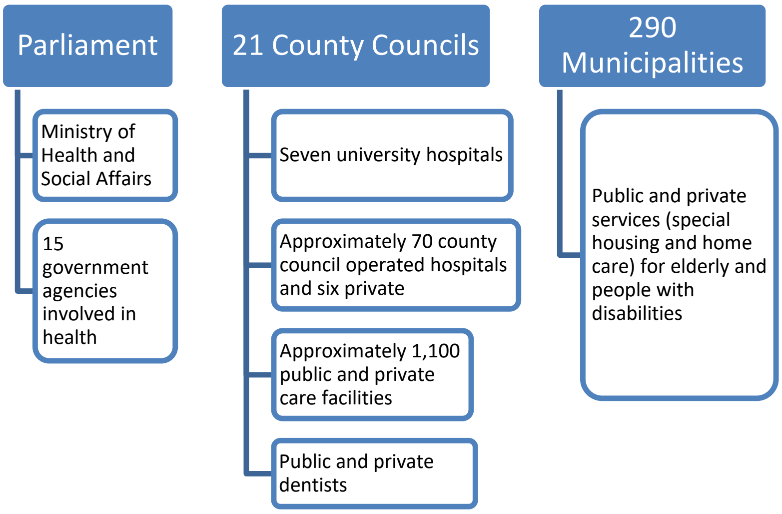
[§§§§§] There are 15 government agencies involved in the area of health, medical care, and public health: the Dental and Pharmaceutical Benefits Agency, the Health and Social Care Inspectorate, the Medical Product Agency, the Medical Responsibility Board, the National Board of Health and Welfare, the National Food Agency, the Public Health Authority, the Swedish Agency for Health and Care Services Analysis, the Swedish Agency for Participation, the Swedish Council on Technology Assessment in Health Care, the Swedish eHealth agency, the Swedish National Board of Institutional Care, the Swedish Research Council for Health, Working, Life and Welfare, the Swedish Social Insurance Agency, and the Swedish Social Insurance Inspectorate.

The Socialstyrelsen collect, compile and analyse information related to social and health services, which is made available to policymakers and the public. They develop standards based on legislation and information collected, and maintain health data registers and official statistics.(197) When developing guidance, the Socialstyrelsen uses six interlinking principles to underpin what good health and social care should look like for a child or adult accessing the system, as set out here:

- knowledge-based
- safe
- patient and user-orientated
- efficient
- equal
- accessible.(197)

In Sweden, there are three government administrative levels: the national governments (Riksdag); the 21 county councils (Landsting); and the 290 municipalities (Kommuner). Figure 9 below illustrates how each of these systems operate at a high level in regards to healthcare.(199) While the overall responsibility for healthcare lies with the national government, the system is decentralised and at each level is informed by three fundamental principles: equal access; care which is based on need; and cost effectiveness. The Swedish healthcare system is publicly financed, and health services for children and young people are free up until the age of 19. Family physicians are a provided by both private and public services, and healthcare professionals must undertake a mandatory three-month training programme on paediatrics in order to qualify.

## Figure 9. Organisational Chart of the Swedish Healthcare System



**Source:** Adapted from Wettergren, B, et al *Child Health Systems in Sweden* (2016).(199)

Healthcare provision in Sweden is divided into seven parts. These are:

- primary care
- emergency services
- hospitalisation
- outpatient care
- elective care
- specialist treatments
- and dental care.

Under the Health and Medical Services Act 1982, each county council is required to plan for the development of healthcare based on its population needs.(200) While the county councils make fundamental decisions around the allocation of resources within individual regions, there has been a history of collaboration between the regions when allocating resources for highly specialised health services and investments in technology. The Socialstyrelsen, along with other agencies, gather information on current and projected demands in each region.

In Sweden, the CHS (Child Health Service) is a service offered free of charge to all children aged birth to five years old, and the participation rate is estimated to be almost 100%. The CHS aims to contribute to children's physical, psychological, and social health by promoting health and development, preventing illness, detecting emerging problems early, and intervening when needed to optimise development. Antenatal and maternity health care is generally provided by midwives at maternity care centres, where special attention is paid to the identification of women who may be more vulnerable and developing interventions to support them.

Primary care is a major aspect of the healthcare system, and in comparison to other jurisdictions a GP does not need to act as a gatekeeper and refer patients to specialist services. Over 370 primary care centres provide healthcare for children, providing regular check-ups, vaccinations, and support to pre-school children. Nurse-led services operate within school settings, and physicians and paediatricians also consult in these services. Parents are strongly encouraged to opt-in to general immunisation programmes carried out by child healthcare centres.(199)

All children in Sweden receive emergency hospital care regardless of socio-economic status and citizenship. Specialised inpatient care for children is concentrated in six public teaching hospitals in the major cities in Sweden. Most hospitals which deliver paediatric care provide access to hospital-based teachers for children to facilitate their education, as well as play therapists who work to engage children and maintain their spirits. In paediatric wards for older children, it is often expected that parents will remain with the child and take up an active role in their child's medical care. This involvement entails medicine administration, nutritional intake, the measurement of blood glucose and recording their child's temperature.(199)

## Organisation and delivery of children's social services

There are 90 municipalities in Sweden, each with its own social services department which is charged with delivering social services and is managed by a local Social Welfare Board (SWB). The SWB is comprised of politically appointed laypersons who are mandated by the Social Services Act 2001 to ensure that children at risk of harm are given protection and support.(201)

Municipalities are responsible for providing all social services to their areas in Sweden, including responsibility in the case of child protection concerns.(202) The child welfare system in Sweden puts an emphasis on providing universal services and interventions for families to strengthen them and build their capacity to provide nurturing care to their children. Families can apply for support themselves or it may be given as a result of a report being submitted to the local social authorities, which is more common.(203)

Similar to Ireland, the role of the Ombudsman (Barnombudsmannen) in Sweden is to represent children regarding their rights under the UNCRC.(204) The Ombudsman is organised under the Ministry of Health and Social Affairs and is tasked with the responsibility of advocating for children and monitoring how the UNCRC is implemented by county councils, municipalities and other government agencies. The Ombudsman may publish reports based on interviews carried out with children or young people, or information it requests from agencies, which is one of the statutory powers of the office.

Further detail on the model of care for children at risk is outlined in the 2020 publication *'Evidence review to support the development of Draft National Standards for Children's Social Services'*.(9)

## Organisation and delivery of disability services for children

Services for children with disabilities who require health and social or educational are provided by community services, Child and Adolescent Habilitation. Here, children are supported by teams consisting of specialists in neurology, physiotherapists, habilitation trained nurses, psychologist, speech therapists and social workers. These teams support the participation of children and families in their communities and in their daily lives, while supporting parents who are caring for children with disabilities. The teams work with primary care health centres, schools, child welfare centres and caregivers, as well as social work teams, adolescent psychiatry teams and local government to support the child's whole health and wellbeing. While children with additional needs are educated in mainstream settings with the provision of extra supports, there are specific schools for children with hearing impairments and students with complex needs.

### Organisation and delivery of mental health services for children

Child psychiatry departments in Sweden are run by the county councils. In recent years there has been a reduction in the number of children in inpatient care, in favour of providing treatment to children through outpatient care and support. While children with moderate-to-severe psychiatric symptoms are treated in specific units, children with moderate symptoms are generally treated in their local primary care centres.

## 3.5.3. Legislation

In 2020, Sweden put the UNCRC on a statutory footing and states that local authorities are obliged to use the UNCRC as a set of guiding principles when making decisions regarding children.(195) While Sweden does not have any specific legislation related to child welfare, or child health and wellbeing, instead these areas are integrated into key pieces of legislation, such as the Social Services Act 2001 and the Health and Medical Services Act 1982.(200,205) The former act sets out the role of the Health Care Inspectorate (IVO) and is supplemented by the Care of Young Persons Act 1990, an act regulating compulsory care.(205) The Health and Medical Services Act 1982 sets out to create equal access to health based on need, and states that county councils and municipalities hold responsibility for ensuring that it's population have access to good healthcare.(200) As an integrated part of the healthcare system, mental health services are subject to the same legislation as other health services, with the addition of two separate laws to cover the sectioning of people: the Compulsory Psychiatric Care Act 1991 and the Forensic Mental Care Act 1988.(199,206,207)

### Health and Medical Services Act 1982

The Health and Medical Services Act 1982 is a primary piece of legislation in Swedish healthcare, and provides the foundation for the provision of good and equitable healthcare based on individual need for all in Sweden.(200) The act places responsibility for the delivery of good and equitable healthcare with county councils and municipalities who, under this act, have substantial freedom to organise and deliver health services in their area. The act also clearly defines the financial and planning responsibilities that county councils have in relation to healthcare services.

In 2010, an amendment was made to the act which allowed citizens in Sweden to choose their primary healthcare provider and allowed for the creation of private primary health care practices, once in line with defined criteria. The stated objective of this amendment was to increase patient choice, expand the private sector and to boost innovation and competition among providers.(208)

### The Patient Act 2015

The Patient Act 2015 brought in measures to strengthen the rights of patients, and supports their involvement and decision-making in the care they receive.(209) The act works to clarify and broaden the responsibility of healthcare providers to present information to patients, to provide patients with information on treatment methods and any risk of complications. Furthermore, the act ensures that patients have a choice over their outpatient specialised care and also provides the right to a second opinion. The act additionally works to reduce the waiting times for patients by allowing them the right to seek alternative treatment in regions outside of their own. If a patient choses to receive care outside of their home region, the state are obliged to pay for the patients care, travel and accommodation.(209)

### Social Services Act 2001

The Social Services Act 2001 is the primary legislation in relation to children in Sweden.(201). The act took Sweden's social services in a new direction, becoming more goal-oriented and focused on prevention and early intervention through voluntary and supportive measures. It is amended regularly to incorporate the rights of children and to reflect best international practice at the time.(210) Important updates to the act include the increased supervision of social services by the Health and Social Care Inspectorate (IVO), the right of people to appeal decisions made about assistance made by social services, and the obligation of social services to create a care plan for children who are transferring to alternative care.

In relation to child protection, the act primarily focuses on how all families should be supported by social services and how decisions related to families should be made.(201) The act sets out that all decisions made regarding a child be made with their best interests as the central focus.(201) The act also allows for individual social workers to exercise discretion in their decision-making and avoids outlining actions that must be taken in certain circumstances.

## 3.5.4. Strategies, policies and standards

This section describes key strategies and policies that have been developed in Sweden to promote and protect child health and wellbeing. Unlike other jurisdictions which have a range of national standards to guide the quality of services, the system in Sweden places the responsibility on each municipality to ensure quality services are provided and assesses this through inspections of the service delivery chain, as will be described in this section.

## National Public Health Policy

In 2003, under the Public Health Objectives Bill 2003, the Swedish government released their comprehensive '*National Public Health Policy'* which was renewed again in 2008 and provides 11 general objectives for public health.(196) The aim of the policy is to foster social conditions which ensure good health and wellbeing for the whole population, and to establish ways to improve health outcomes for the most vulnerable in society. The policy closely links public health to social determinants of health and wellbeing. As such, the policy focuses on creating the societal conditions which are conducive to good health amongst the Swedish population.(211)

The policy focuses particularly on children, young people, and older people in Sweden and sets out a requirement for local governments to fulfil certain criteria and are guided by the policies 11 objectives.(196) These objectives include strengthening and supporting parents, the promotion of healthy eating and physical activity, a focus on suicide prevention, and reducing the use of tobacco.

Sweden's public health policy is underpinned by the principle of equality and the policy aims to reach a wide range of people in society through different levels of government administrations and bodies. The national policy sets out that services should work to empower patients so that they can actively participate in decisions being made around their treatment. Additionally, the policy aims to improve disease prevention, health promotion and the working environments of healthcare staff. (211)

## Child Health Service's National Programme

Based on guidance published by the Socialstyrelsen, the Child Health Services (CHS) developed a national programme, agreed by each region in Sweden.(212) This national programme operates a three-tier system. The CHS provides these services at centres during home visits, vaccinations and during parental support services. The first tier includes interventions that are applicable to all children and is intended to promote health and development, and prevent injuries, diseases, as well as psychological, physical and social problems. At this tier, the programme outlines interventions which include engaging with both the child and their parents in a way that is responsive to their needs. The second tier consists of interventions provided to children on a needs-led basis with the intention of preventing the negative development of children's physical, social, and psychological health. Interventions at this tier may include parental support, home visits, health guidance and follow-up care and support. The third tier includes additional needs-based interventions, provided by healthcare professionals and social services, in collaboration with other necessary professional resources.(212)

### Children's Needs in Focus (Brand Behov I Centrum BBIC)

BBIC is a tool that aims to place children at the centre of the social support system.(213) According to a study of seven municipalities, there are mixed views on the efficacy of BBIC, with social workers reporting that while BBIC has led to better assessments it has also increased paperwork and administration.(214) The study showed that BBIC assessments were considered to provide a holistic understanding of children's needs and that the assessment process was more inclusive of children by actively engaging them in the process and ensuring their views were included in the decision-making process. The study showed that the introduction of BBIC assessments led to improved outcomes for children, as social workers and parents were better able to clearly understand and meet their needs.(214)The final, 2006 report on the trialling project of BBIC was largely positive in that it provided a more consistent and thorough assessment than was previously available. It has subsequently been rolled out across municipalities on the condition that it is open to change and development so that is continues to suit the needs of children and families.(197,215)

### Inspectorates

County councils and municipalities conduct and apply public health efforts, taken from the 11 health objectives set out in the national public health policy. In most of the county councils, and in over half of the municipalities, specific indicators are applied to measure achievements in attaining these public health measures. There are other indicators used to measure the outcomes of public health work, for example, 'Open comparisons' gathers information from municipalities on quality, results and costs in a number of county councils and municipalities who are responsible for the health and social care, public health and education.(216) Published by the Public Health Agency of Sweden the 'Open Comparisons Public Health (OCPH) 2019' is an indicator-based study which reported on the public health comparisons among the regions and municipalities. The primary aim of the study was to probe policymakers, politicians, public health experts, and leaders in the community to exchange ideas and to encourage strategic work in the area.(217) At a high level the study found that while levels of health have improved in some areas, health disparities remained according to sex, age, educational level and neighbourhood.

### The Health and Social Care Inspectorate (IVO)

The IVO is the governmental agency with responsibility for inspecting care from the point of admission to transfer from or between services, and also inspecting how services collaborate with one another. Additionally, the IVO can advise restriction on licences to healthcare professionals who they have concerns about. However, the IVO does not have this power in relation to social workers, as social work is not legally protected in Sweden.(218,219) The IVO inspects social services and health provided by individual municipalities, including each municipality's compliance in executing decisions. The IVO carries out 'supervision' of social services, healthcare, and services for people with disabilities. Supervision is an independent examination of services to ensure that they are following the relevant laws and regulations.

The IVO responds to complaints about social services and carries out inspections routinely in response to these, although it is not obliged to investigate all complaints. The IVO's annual reports primarily focus on what is not working in the health and social care system. Recent findings mirror similar findings in reports on social services internationally, pointing to a shortage of staff and poor staff competence, which exposes children and adults using health and social care services to serious risk.(220)

### 3.5.5. Findings from reviews

The Innocenti Report Card (UNICEF) was published in 2020 and is designed to compare performances across child mental wellbeing, their physical health and skills, which, taken together, provides an indicator of child wellbeing across European countries.(67) Sweden sits in the top five ranking countries in relation to child wellbeing and has the second lowest child deprivation rates in Europe, however, they fall slightly in the rankings in 22nd position for mental health wellbeing. On balance Sweden's overall ranking for child health and wellbeing sits in ninth place, internationally.

Overall, there is a rising inequality between families in Sweden, large cities are now experiencing increasing unemployment rates and the life expectancy rates in these areas have reduced by between five and nine years.(199) The mental health of children and adolescents is decreasing and is not seen to improve at the same rate as physical health, and suicide rates in the country among adolescents have not improved in recent years.(199) As noted in the 2017 review of mental health services in Sweden, professionals in educational settings prove to be ideally situated to identify early signs of mental health issues among adolescents.(221) However, to utilise this it is important that staff are sufficiently trained and supported.

In 2019, the Swedish government commissioned an investigation '*Consistent good and close care for children and young people'*, into the conditions in healthcare services for children and young people. While recommendations and findings from the investigation have yet to be published, evaluations considered by the investigative team have shown there to be fragmentation in children and young people's access to care, especially for those with mental health issues who, the report finds, are at risk of incoherent care.(222) The investigative team have also identified the need to focus on how primary care services address the needs of children and families in crisis. Reports on the investigations findings are expected to be finalised in 2021.

In 2015, the Swedish government appointed a special commission, the Commission for Equality in Health, who is tasked with submitting reports to help reduce health inequalities in society. The Commission published three reports between 2016 and 2017, where it highlighted the need for a broad approach, spanning a number of sectors, in order to close the health inequality gaps.(223) The Commission's reports recommended that children be provided with the basic requirements, such as basic healthcare and equality in access of quality pre-school, in order to develop their abilities based on their individual conditions. The reports stress that to achieve this, adequate maternal and child healthcare are required for all in Sweden, as well as equal access to pre-school education. The reports also noted that, in order reduce health inequalities, it would be necessary to effectively coordinate a number of policy areas such as childcare policies, labour policies, social protection policies and educational policies.

### A Child Health Index for Sweden's 290 Municipalities: A System of Indicators and Indices for Monitoring Children's Health on the Local Level (2018)

A survey based on data gathered by municipalities of children's health and wellbeing in Sweden's municipalities looks at a set of 13 high-quality indicators.(224) The indicators were structured into four domains:

- demographic and socio-economic
- health and wellbeing status
- risk and protective factors
- service, support and health policy.

Overall, this survey indicates that children's health is generally good, showing a mean Child Health Index of 88 out of 100 which ranges from 81 to 93. However, the survey showed that many children in economically disadvantaged areas are more likely to experience health problems. Risk indicators, for example low birth weight and abortions amongst teens, also showed higher variations among municipalities.(224) Health and wellbeing indicators vary across municipalities and mental health problems were reported less in smaller municipalities and also amongst children with immigrant backgrounds. These indicators provide information when considering the strengths and weaknesses of individual municipalities which in turn helps to inform policy.

### Mental health among youth in Sweden: Who is responsible? What is being done?

In 2017, the Nordic Centre for Welfare and Social Issues published their report '*Mental Health Among Youth in Sweden: Who is responsible? What is being done?*' (221) This report highlights the increasing number of mental health issues being reported among children and adolescents, noting an overall deterioration in the mental health in this group. A consequence of poor mental health can be seen in education, where there are higher numbers of young people with mental health issues who are not completing their education. One of the key issues identified in the report is the role of school nurses in identifying mental health concerns.(221) As it stands, school nurses allocate 20 minutes per student to discuss their health. This time is used to cover a number of aspects of health and wellbeing. The report considered that this time was too short to detect whether or not a student has mental health problems. The report called for additional resources to be allocated to schools so that they could employ school psychologists to meet the needs of students in order to keep them in education.(221)

### 3.5.6. Lessons for Ireland

The ultimate aim of public health policy in Sweden is the creation and provision of good and equitable health for all to reduce health inequalities. However, recent years have seen an increase in social disparities in health regardless of the general strengthen of public health in the country.(225) Sweden's healthcare system focuses on family services and provides ongoing care to children up to the age of 19. However, an important note for Ireland is Sweden's approach that child health and wellbeing is everyone's responsibility. For example, the 2017 review of CAMHS services noted the ideal position of educators in identifying concerns of child and adolescent mental health. It is important to note that in order for professionals to take on this role they require supports and resources.

The appointment of Sweden's Commission for Equality in Health is a novel move and works to further emphasise the governments focus on reducing the health inequalities of its population. The Commission's reports promote the provision of good healthcare to children in order to support positive outcomes for them.

An important lesson to be drawn from Sweden is the data available for policy makers to make informed decisions around child health. A survey of child health in Sweden's 290 municipalities provides data not readily available in other countries and provides local governments an opportunity to monitor the health and wellbeing of children in their area.(224)

## 3.6. America

This section describes the organisation and delivery of health and social care services for children in America and also the impact that these services are having on health and wellbeing outcomes for children. This section is set out under the following headings:

- overview of health and social care services working with children
- model of service
- legislation
- strategies, policies and standards
- findings from reviews
- lessons for Ireland.

### 3.6.1. Overview of health and social care services working with children in America

The US Census Bureau has estimated that in 2018, there were over 35.8 million children aged eight years and under and approximately 37.6 million children between the ages of nine and 17 years living in America.(226) Medicaid, is a federal and state programme that provides health coverage for eligible low-income children and families. The Children's Bureau within the Department of Health and Human Services is the national agency that holds responsibility for child wellbeing. The vision of the Children's Bureau is to establish children, youth, families, individuals and communities who are resilient, safe, healthy and economically secure. The values of the Bureau include:(227)

- dedication to promoting hope and opportunity
- excellence in performance, exemplified by innovations and solutions that are anchored in available evidence
- professionalism in the manner in which services are provided
- integrity as an organisation
- stewardship of data and accountability for and transparency in our actions
- respect for those we serve, with whom we work and partner.

The central piece of federal legislation which includes provisions for healthcare for children and young people is the Affordable Care Act 2010, which aims to improve the availability of affordable health insurance and provide extended dependent coverage for young people.(228) Section 3.6.3. outlines the key pieces of legislation that are focused on improving outcomes for children, including those that are at risk and those that have disabilities or mental health illnesses. There are a number of federal initiatives which set a vision for child health and wellbeing, however, these initiatives are often administered and reported on at a state level. Individual states are responsible for developing health and social care standards and for monitoring against standards to assess the quality of care provided to children and young people within each jurisdiction. Section 3.6.4. provides an overview of the standards that are specific to the area of child welfare.

The United Nations Convention on the Rights of the Child (UNCRC) is a human rights treaty which sets out the civil, political, economic, social, health and cultural rights of children.(14) The UNCRC came into force in 1990 and to date, it has been ratified by all member states of the United Nations, except for America. It has been suggested that opposition to ratifying the Convention in America is due to concerns regarding the potential limitation of American sovereignty, the potential for government interference in family life and the differences between the Convention and American law and practice in relation to the child and youth justice system.(229) The UNCRC prohibits the use of the death penalty for offences committed before the age of 18 years, whereas some states in America allow executions of juvenile offenders. Despite opposition, there have been calls that ratification of the Convention would have a positive impact on children's rights and the establishment of mechanisms to protect children's rights in America.(229)

### 3.6.2. Model of service

In America, Medicaid is responsible for organising and delivering healthcare services to eligible low-income children, adults and older people. The Children's Bureau holds responsibility for the funding of children's social services which are administered by local governments at a state level. This section sets out the organisation and delivery of the following services for children and young people:

- general healthcare services and disability services for children and young people
- children's social services
- mental health services for children and young people.

#### Organisation and delivery of general healthcare services and disability services for children

In America, healthcare is a complex mix of private and public funding. The vast majority of American citizens who have private health coverage have an employer-sponsored healthcare plan. For those without private health insurance, the American government provides two federal programmes, Medicare and Medicaid. Medicare is the federal health insurance programme that primarily provides health insurance for

Americans aged 65 years and older, but also provides cover for people aged under 65 years who have disabilities or have end-stage renal disease. Medicaid is a federal and state programme that provides health coverage to eligible low-income adults, children, pregnant women, elderly adults and people with disabilities.(230) The programme is jointly funded by state and federal government and currently provides support to over 68 million Americans.

Medicaid is administered by state governments, and each state determines how Medicaid is implemented in that jurisdiction. Federal law requires all states to provide certain mandatory benefits including, inpatient and outpatient hospital services, Early and Periodic Screening, Diagnostic and Treatment Services (EPSDT), care provided in community health centres and rural health clinics, paediatric and nurse practitioner services and transportation to medical care. Medicaid also covers many optional services and states have flexibility to decide what optional services they provide. Optional services may be provided on a co-payment basis. Examples of optional services include, prescription drugs, occupational therapy, speech and language services, dental coverage and hospice care.(231) Disability services for children and adults are also administered at a state level through Medicaid and can include free or low-cost supports for children and adults with disabilities.

Medicaid also provides a specific benefit for children and young people, which is known as the EPSDT benefit. The EPSDT benefit provides comprehensive and preventive healthcare services for children under the age of 21 years who are enrolled in Medicaid.(232) EPSDT consists of regular screening services for infants, children and young people. The screenings are designed to identify health and developmental issues as early as possible and includes comprehensive health and developmental checks, physical exams, immunisations, laboratory tests and health education. EPSDT also provides for vision, dental and hearing services and diagnostic services, whereby necessary healthcare services must be made available for the treatment of all physical and mental illnesses or conditions discovered by any screening and diagnostic procedures.

## Organisation and delivery of children's social services

The Children's Bureau (CB) is a federal agency which operates under the Department of Health and Human Service's Administration for Children and Families. The CB partners with federal, state, tribal and local agencies to improve the overall health and wellbeing of children and families living in America.(233) The work of the CB is focused on the following key areas:

- Safety – preventing and responding to maltreatment of children
- Permanency – stablilising children's living situations and preserving family relationships and connections

- Wellbeing – enhancing families' capacity to meet their children's physical, mental health and educational needs

The CB provides states and tribes with funding to support programmes, research and monitoring systems that strengthen families and prevent child abuse and neglect, while ensuring that children who are victims receive treatment and care. While the overarching responsibility for children's social services lies with the CB, each individual state has its own legal and administrative structures and programmes in place that address the needs of children and families. However, in order to be eligible for federal funding, state-level child welfare services must comply with federal requirements and guidelines.(234) An illustrative example of how child welfare and protection services are provided at a state-level in Vermont, is provided in the '*Evidence Review to inform the development of National Standards for Children's Social Services'*.(9)

The CB and state governments monitor state child welfare services through a number of different reporting systems. Examples of these reporting systems include the Adoption and Foster Care Analysis and Reporting System which collects case-level information from state agencies on all children in foster care and the National Youth in Transition Database which is a federal reporting system designed to collect information on young people transitioning out of foster care.(235) While these systems provide reliable statistics on the number of children in care, due to their quantitative focus, they provide little information on whether services are achieving positive outcomes for children.

Established in 1985, the National Children's Advocacy Centre (NCAC), models, promotes and delivers excellence in child abuse responses and prevention through service, education and leadership. The NCAC established a multidisciplinary team approach to respond to child sexual abuse which included representatives from law enforcement, child protective services, mental health, medical health and victim advocacy, working together to assure the protection of children.(236) Prior to the establishment of the NCAC, there was a lack of cohesion between child protection services and the criminal justice services which often created a fragmented and repetitious experience for children. The multidisciplinary approach has been widely adopted as best practice in responding to child sexual abuse in America and there are now more than 1,000 Children Advocacy Centres (CACs), using this approach across America. When investigating child abuse cases, CACs provide specialised forensic interviews, medical evaluations and victim support and advocacy to children and their families.

The National Adolescent and Young Adult Health Information Centre (NAHIC), supported by the Maternal and Child Health Bureau was established in 2014 to help states improve the quality of preventive services among adolescents and young adults. The centre aims to promote adolescent and young adult health by strengthening the abilities of State Programmes, as well as public health and clinical health professionals, to better serve children and young people between the ages of 10 to 25 years. The focus of the NAHIC is on the intersection of public health, systems of care and clinical practice. The NAHIC provides support to research projects, which aim to increase the delivery of and quality of preventative services among adolescents and young people with a special focus on mental and behavioural health screening.(237)

### Organisation and delivery of mental health services for children

EPSDT also provides cover for mental health services for children and young people. Under EPSDT, treatment for mental health and substance use issues is available under a number of Medicaid services categories, including hospital and clinic services, physician services and services provide by a licensed professional such as a psychologist. More specifically, many states provide inpatient psychiatric services for individuals under 21 years of age, through psychiatric residential treatment facilities. These facilities provide comprehensive mental health treatment to children and young people who, due to mental illness, substance abuse, or severe emotional disturbance, need treatment that can most effectively be provided in a residential treatment facility.(238) To qualify for this support, all other care resources available in the community must have been determined to not meet the immediate treatment needs of the child or young person. Specific outcomes of the mental health services include the child or young person returning to their family or to another less restrictive community living situation as soon as clinically possible. Residential treatment facilities aim to work closely with families, other agencies, and the community to offer strengths-based, culturally competent, medically appropriate treatment designed to meet the individual needs of the child or young person.

## 3.6.3. Legislation

In America, legislation governing children’s health and social services is set out between federal law, which applies to every state, and individual state laws. In terms of disability and mental health, federal level legislation such as the Mental Health Parity and Addiction Equity Act 2008 and the Americans with Disabilities Act 1990, do not include provisions for children and young people with mental health illness or disability. In contrast, federal level legislation such as the Affordable Care Act 2010 and the Individuals with Disabilities Education Act 1975, include a number of provisions for the health of children. These also include provisions for children with disabilities and mental health illnesses. Federal level legislation provides state child protection and welfare agencies with guidance and structure for the development of their policies and practices. While these federal level pieces of legislation provide oversight across states regarding mental health, states have the power to make decisions about their mental health systems and implement state legislation and regulations.(239) Therefore, mental health services can vary considerably across states. This section describes key federal level legislation which sets out how children's health and wellbeing systems are governed at a national level. Specific legislation which applies to children at risk and also disability and mental health legislation that apply to children and young people are also set out in this section.

## Affordable Care Act 2010

The Affordable Care Act (ACA), formally known as the Patient Protection and Affordable Care Act, and most commonly known as Obamacare, is an American federal statute enacted in 2010.(228) ACA has three primary goals; improve availability of affordable health insurance; expand the Medicaid programme to cover all low-income adults; and support innovative medical care delivery methods designed to lower the costs of healthcare generally. For children and young people, a key provision of the ACA is the extension of dependent coverage, allowing children to remain on their parent's insurance up to the age of 26 years. The ACA also prevents health insurance plans from denying coverage for children with pre-existing medical conditions. Another key provision of the ACA is that it includes coverage without co-payments for preventative health services for children, for example, screening for hearing and vision, developmental checks and immunisation.(240) The ACA also aims to improve access to mental healthcare by offering people with mental illness the opportunity to have affordable health insurance. The act requires all health insurance plans to include mental healthcare as an essential health benefit. Similarly, under the act, health plans must include mental health preventative services for children at no additional cost, such as behavioural assessments.

## The Child Abuse Prevention and Treatment Act 1988

The Child Abuse Prevention and Treatment Act (CAPTA) is the key overarching federal legislation that addresses child abuse and neglect in America. CAPTA provides federal funding and guidance to states in support of activities that are focused on prevention, assessment, investigation, prosecution and treatment of child abuse.(241) States are required to comply with CAPTA in order to receive federal level funding for intervention and protection programmes. CAPTA also sets out the federal legal definitions of child abuse, which state-level intervention and protection programmes are required to incorporate in their legal terms.

### Family First Prevention Services Act 2018

The Family First Prevention Services Act 2018 aims to shift the focus of children's social services from intervention to prevention as the act sets out that children have the best results when they are supported to stay with their families, in a safe and stable environment that supports children's long-term wellbeing. The act provides funding to support prevention and community-based early intervention services, to improve the quality and oversight of services and to improve services for older children as they transition out of care.(242)

### Individuals with Disabilities Education Act 1975

The Individuals with Disabilities Education Act (IDEA) is a piece of federal legislation that ensures students with a disability are provided with free appropriate public education to meet their unique needs and prepare them for further education, employment and independent living. IDEA was previously known as the Education for All Handicapped Children Act (EHA) from 1975 to 1990. IDEA governs how states and public agencies provide early intervention, special education, and related services to children and youth with disabilities. IDEA provides support to children with disabilities from birth through to high school graduation or age 21, whichever comes first. The act provides for the establishment of early intervention services to children up to three years of age and special education for older children. In order to qualify for support under IDEA, a child must be diagnosed with a disability under one of the following categories; autism, deaf-blindness, deafness, blindness, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopaedic impairment, other health impairment, specific learning disability, speech or language impairment or traumatic brain injury. In order to be eligible for support under IDEA, children must, as a result of their disability, need special education to make progress at school.(243)

### Mental Health Services for Students Act 2020

The Mental Health Services for Students Act was enacted by the American Senate in September 2020.(244) It is a competitive grant programme established to fund partnerships between county behavioural health departments and local education entities for the purpose of increasing mental health services, including screening, treatment and outreach programmes in schools. Funding for these programmes will be distributed by the Substance Abuse and Mental Health Services Administration, which will also be responsible for setting guidelines and measuring the outcomes of the funded programmes. As this act was only enacted in September 2020 there is no current information available its progress.

### 3.6.4. Strategies, policies and standards

In America, there are a limited number of national strategies and initiatives that set out a vision for child health and wellbeing. Each individual American state has a number of strategies, policies and standards in place that set out specific commitments to protecting and ensuring the health and wellbeing of children and young people within that jurisdiction. Similarly, individual states are also responsible for developing and monitoring against standards to assess the quality of care provided to children and young people within each jurisdiction. This section describes one of the few national child health and wellbeing initiatives that is in place in America. This section also describes the Standards of Excellence for Child Welfare Services which are considered to be the foundation for child welfare practice in America.

#### Bright Futures

Bright Futures is a national health promotion and prevention initiative led by the American Academy of Pediatrics, and supported, in part, by the US Department of Health and Human Services, the Health Resources and Services Administration (HRSA), and the Maternal and Child Health Bureau (MCHB). The HRSA launched the Bright Futures programme in 1990 in order to provide unified guidance in relation to paediatric health check-ups. Bright Futures addresses children's health needs in the context of family and community, and provides a range of theory-based and evidence-driven guidance for all preventive care screenings and child developmental checks.(245) The programme aims to improve health outcomes for children and young people by increasing the quality of primary and preventive care through maintenance and dissemination of age-specific, evidence driven clinical guidelines.(246) The primary goal of Bright Futures is to support primary care practices in providing developmental checks for children and providing adolescent care in targeted settings including private practices, hospital-based or affiliated clinics, school-based health centres, public health clinics, community health centres and other primary care facilities.

#### Standards of Excellence for Child Welfare Services

The Child Welfare League of America (CWLA) is a coalition of private and public agencies that works to advance policies, best practices and collaborative strategies that will result in better outcomes for children, young people and families that are vulnerable. The CWLA developed the Standards of Excellence for Child Welfare Services which provides goals for the continuing improvement of services for children and families. The CWLA standards are widely accepted as the foundation for child welfare practice across America and are considered useful in planning, organising and administering services at both federal and state levels.(247) The standards promote nationwide consistency and standardisation of child welfare practices and serve as a resource for people in other fields who are concerned with the care and protection of children, such as judges, educators, health and mental health professionals and law enforcement personnel.(248) There are 13 volumes of the CWLA standards which include:

- standards for adoption and foster services
- child care and education services
- out-of-home care services
- residential group care services
- services to strength and preserve families with children and
- transition, independent living and aftercare services.

The CWLA develops new standards and regularly revises existing standards through a robust and rigorous process that includes discussion with child welfare agency representatives and a range of national experts to address persistent and emerging issues, and to develop a shared vision for child welfare. There is currently no information available as to whether or how these standards are monitored.

### 3.6.5. Findings from reviews

America is currently ranked 36 out of 41 OECD countries in terms of overall child and wellbeing outcomes, with UNICEF reporting poor trends in mental wellbeing, physical health and developmental skills among American children.(186) This poor ranking is attributed to a number of factors including the high cost of childcare in America, a lack of early childhood investments, and rising numbers of uninsured children.(249) In addition, America is experiencing an increasing number of children engaging with child welfare and protection services and coming into statutory care.(242) This section sets out findings from key reports that provide an overview of health and wellbeing outcomes for children and young people in general and also children and young people who are at risk.

#### The State of America's Children 2020

The Children's Defense Fund's report, '*The State of America's Children 2020*', provides a comprehensive insight into the status of America's children across the areas of childhood poverty, income and wealth inequality, housing and homelessness, child hunger, child health, early childhood, education, child welfare, juvenile justice and gun violence.(249) The report found that child poverty in America remains an issue with one in six American children living in poverty. The report highlighted that after years of progress in terms of children's health coverage, 2017 and 2018 marked the first increases in the number of uninsured children in America in over a decade. These rising rates of uninsured children may indicate that a growing number of children have no access to healthcare. Reports suggest that the curtailment of enrollment assistance for Medicaid and changes in immigration laws where it is more difficult for immigrants who rely on assistance such as Medicaid, to obtain legal status may be contributing to the rising number of uninsured children.(249) The report also emphasises that the lack of national investment in early childhood has resulted in many children not having access to quality care during critical years of brain development. The growing numbers of children and young people entering statutory care were noted in the report, with young children aged under seven years being disproportionately affected. As evidenced in the report, significant inequalities exist between health and wellbeing outcomes for white children when compared to outcomes for Black or Hispanic children. Black or Hispanic children were found to be more likely to be living in poverty when compared to white children, and reported poorer outcomes across all indicators captured in the report.

### Report from the CWLA

The majority of reports into child welfare and protection are prepared at a state level. Each year, the CWLA publishes a report *'Children at a Glance'* for the child population from each federal state, this covers information such as a child poverty rates, numbers of abuse cases, the total number of children in care, and the child welfare workforce in the relevant area. While these reports focus on data specific to each state, recent CWLA reports have identified nationwide staff shortages and high levels of staff turnover in the children's social services sector across all states. The report finds that high turnover rates can have negative outcomes for children, including placement disruptions and increased time in out-of-home care.(250)

### Child and Family Service Reviews

The CB conducts Child and Family Service Reviews (CFSRs), which are periodic reviews of state child welfare systems. The purpose of these CFSRs is to ensure conformity with federal child welfare requirements. CFSRs are also intended to help the CB to determine what happens to children and families when they engage with child welfare services within a particular state and to assist states in helping children and families achieve positive outcomes in terms of safety, permanency and wellbeing. Following completion of a CFSR, states develop a Programme Improvement Plan to address areas in their child welfare services that need improvement.(251)

Published in 2020, the *'Child and Family Services Review Aggregate Report'* presents key findings from the analysis of state performance data for states reviewed in 2015 and 2016. In total, 24 states were reviewed during this timeframe. The report describes results of a preliminary examination of the strengths and areas needing improvement identified across those states, finding that of the states reviewed, very few met the performance standards established by the CB for outcomes. This included poor conformity to two outcomes:

- children are first and foremost protected from abuse and neglect
- children receive appropriate services to meet their education needs.

The review found inefficiencies across states regarding the timeliness of initiating investigations of reports of child maltreatment. Issues with permanency and stability of foster care placements were also widespread across states, with a lack of agency responsiveness in addressing concerns reported. One strength highlighted in the report was that substantial conformity existed across states with regards to operating a statewide information system that can readily identify the status, demographic characteristics, and location and placement goals for every child that has been in the care of the state.

### 3.6.6. Lessons for Ireland

Following the introduction of the ACA in 2010 progress was made in terms of children's health coverage. However, recent reports from the Children's Defense Fund indicate a widespread decline in child enrollment in Medicaid in 2017 and 2018. Factors contributing to this decline include reduced funding for outreach assistance, the effect of proposed immigration policies, and stricter and more frequent reviews of eligibility. A decline in child enrollment can have negative consequences for children and their families, including less access to primary and preventive care, increased medical debts and potentially longer term educational and economic impacts. There have been calls for the Federal Government to take action to prevent a further decline by reinvesting in outreach assistance and asking states to collect more specific data on disenrollment cases.(252) Issues regarding children's access to health and social care services are also pertinent within an Irish context. As evidenced in this review, the provision of health and social care services is inconsistent in Ireland as children with complex mental, intellectual and physical care needs experience difficulties in accessing services that meet these needs.

Similar to other jurisdictions in this review, wide health disparities exist between ethnic groups, with Black or Hispanic children reporting higher rates of poverty and poorer outcomes across all health and wellbeing indicators when compared to white children. In recent years, there has been an increasing number of children from different ethnic backgrounds living in Ireland, including Traveller and Roma children, children in families who ae seeking asylum, and children in families seeking to regularise their immigration status. Owing to this increase, the need to consider potential issues that can lead to inequalities in child health and wellbeing outcomes among ethnic minority groups is something that should be considered within an Irish context.

The introduction of the Family First Prevention Services Act in 2018 places a statutory obligation on state governments to invest in early intervention services in order to reduce the numbers of children entering into state care. It will be interesting to see if this will have an impact at both an individual state level and also at a national level in terms of reducing numbers of children in care and improving their outcomes and also in terms of easing the burden on child protection systems.

Federal agencies and State Governments in America operate a number of different reporting systems which provide reliable statistics on the number of children in care. While this is useful to inform decisions regarding funding and policies, they provide little insight into whether social services are achieving positive outcomes for children. While it is logical that governments collect data on children that are within the care of the state, data on wider health and wellbeing outcomes, including physical and mental health, are lacking in America both at state and federal level.

## 3.7. New Zealand

This section describes the organisation and delivery of health and social care services for children in New Zealand and also the impact that these services are having on health and wellbeing outcomes for children. This section is set out under the following headings:

- overview of health and social care services working with children
- model of service
- legislation
- strategies, policies and standards
- findings from reviews
- lessons for Ireland.

### 3.7.1. Overview of health and social care services working with children

In 2018, it was estimated that there were over 1.2 million children under the age of 18 years living in New Zealand, which represented almost a quarter of New Zealand's entire population.(253) The key organisation responsible for the health of these children is the Ministry of Health. The values which guide how the Ministry of Health works and interacts with people who use the health and disability system include: results driven, informed decisions, diversity, active collaboration, trust and confidence, innovation, client-focused and responsiveness to Māori.(254) While these values are not described as principles, as seen in other jurisdictions, the terms principles and values are often used interchangeably. The Ministry for Children

(Oranga Tamariki) is the key organisation that holds responsibility for child wellbeing, specifically children at risk of harm and children in the care of the state. The vision of Oranga Tamariki is that New Zealand values the wellbeing of children above all else. The work of Oranga Tamariki is guided by the principles of putting children first and challenging things when they are not right for children, working together in love to create solutions with others, working with families and communities, respecting people's own inherent rights, following through on actions, and recognising the impact of interventions on children and families.(255)

While health and disability services are delivered through a network of different governmental and non-governmental bodies and organisations, child protection services are delivered through Oranga Tamariki. Section 3.7.1. describes how health and social care services are delivered in New Zealand.

A wide range of legislation, strategies and policies are in place which frame governmental commitment to the health and wellbeing of children in New Zealand. For example, the '*Child and Youth Wellbeing Strategy 2019*' provides an overarching unifying framework that aims to drive and align policy to support collective action to improve child and youth wellbeing.(256) Sections 3.7.3. and 3.7.4. outline key pieces of legislation and different strategies and policies that are focused on improving outcomes for children. In addition, New Zealand has in place national standards for children and young people. The National Care Standards set out the standard of care that every child and young person in the care of Oranga Tamariki needs in order to do well.(257) Section 3.7.4.2. provides an overview of standards that are specific to the health and wellbeing of children and young people in New Zealand. These standards are monitored against and Section 3.7.4.2. also sets out the primary bodies involved in the monitoring and regulation of health and social care services for children and young people.

### 3.7.2. Model of service

There are two main organisations involved in organising health and social care services that work with children, these are the Ministry of Health and the Ministry for Children (Oranga Tamariki). These services are delivered through a range of statutory and voluntary service providers. The section sets out the organisation and delivery of the following services for children and young people:

- general healthcare services for children and young people
- children's social services
- disability services for children and young people
- mental health services for children and young people.

## Organisation and delivery of general healthcare services for children

The Ministry of Health is responsible for healthcare in New Zealand and works across the health sector to deliver better health outcomes for all. New Zealand's health and disability system is delivered through a complex network of organisations including District Health Boards (DHBs), crown entities and agencies, the Mental Health Review Tribunal, the National Ambulance Sector Office (NASO), public health units, primary health organisations, health alliances, professional and regulatory bodies, and non-governmental organisations.

Most of the day-to-day business of the health sector, and approximately three quarters of New Zealand's healthcare funding, is administered by New Zealand's 20 DHBs. DHBs are responsible for planning, managing, providing and purchasing health services for the population of their district to ensure services are arranged effectively and efficiently for all of New Zealand.(258) This includes funding for primary care, hospital services, public health services, aged services and services provided by other non-governmental health providers including Māori and Pacific providers. Allocation of funding is dependent on the total number, age, socio-economic status and ethnic mix of the population within each DHB. The remaining public funding provided to the Ministry of Health is used to fund national services such as disability support services, public health services, specific screening programmes, mental health services, and Well Child services.

In New Zealand, healthcare services for children, as well as for adults, are delivered at primary, secondary and tertiary level. Primary care is provided and delivered by Primary Health Organisations (PHOs) which are funded by individual DHBs. PHOs ensure the provision of essential primary healthcare services, mostly through general practices, to people who are enrolled with the PHO. PHOs provide primary health services either directly or through their contracted providers. If necessary, children can be referred to targeted services, including specialist services, following assessment and referral from a primary healthcare provider.(259)

Hospital care in New Zealand is part of the activity of individual DHBs. Public hospitals are run, owned and funded by individual DHBs. Public hospitals provide publicly-funded services such as medical, surgical, maternity, diagnostic and emergency services. The range of services provided by each hospital is determined by both the size of the local population and the services offered by other hospitals in the region.(260) Children and young people receive outpatient care in paediatric centres in regional public hospitals. Access to this care is through referral by a general practitioner, an allied health professional or through an emergency department. Currently there are two specialist children's hospitals in New Zealand, Starship Children's Health which is based in Auckland City and Kidz First Children's

Hospital which is based in South Auckland. These provide a range of inpatient, outpatient, day-stay and community-based services for children and young people.

The Ministry of Health provides a number of free healthcare initiatives specifically for children, which are all delivered through individual DHBs. The National Immunisation Schedule includes a series of vaccines that are offered free-of-charge to all babies and children from birth up to 12 years of age. The Well Child Tamariki Ora programme is a service that includes a series of health visits and supports that are free to all families for children from six weeks of age up to five years of age.(261) The service involves a number of home visits conducted by midwives and the visits cover:

- child growth and development
- family health and wellbeing
- immunisation information
- oral health checks
- early childhood education
- vision and hearing checks
- health and development checks for school.

All children are offered the 'B4 School Check' when they reach 4 years of age. This is a nationwide programme which aims to identify and address any health, behavioural, social or developmental issues that may be present before they enter into the school system.(262) DHBs also deliver a number of health promotion initiatives that are also targeted at children, including Health Promoting Schools (HPS) and Fruit in Schools. HPS is a school community-led development approach to health promotion, where schools include health and wellbeing in their planning and review processes, teaching strategies, curriculum and assessment activities.(263)

## Organisation and delivery of children's social services

In April 2015, an Expert Advisory Panel was established by the Minister for Social Development to review New Zealand's care and protection system. This review was in response to findings of racism and inequity within the care and protection system.(264) The review provided children and young people with an opportunity to share their experiences of social services and their outcomes. The review recommended that an urgent transformation of the care and protection and youth justice system was required to give vulnerable children and young people the protection and life opportunities they deserve. The review outlined the need to develop a child-centred care and protection system that prioritises the earliest opportunity for a stable and loving family, and enables all children to feel a sense of identity, belonging and connection.(264)

Prior to the review, the Child, Youth and Family (CYF) was the government agency responsible for protecting children and young people at risk of abuse or neglect and at risk of offending. Following review recommendations, the CYF was replaced by the Ministry for Children (Oranga Tamariki) in 2017. Oranga Tamariki holds responsibility for ensuring children and young people are safe and nurtured in their families and communities. The stated aim of Oranga Tamariki is to support any child in New Zealand whose wellbeing is at risk of harm now or in the future. Oranga Tamariki also works with children and young people who may have offended or are likely to offend and are at risk of entering the Youth Justice system.(265) Oranga Tamariki works in partnership with Māori organisations, community groups and other non-government organisations to deliver care and protection services. Oranga Tamariki also provides extended support to young people up to 25 years as they leave state care or the youth justice system and transition to adulthood.(266)

The Oranga Tamariki Outcomes Framework reflects the emerging operating model of Oranga Tamariki and sets out the main services it provides.(267) The framework is intended to ensure that the policies, practices, and services of the Oranga Tamariki have regard for the specific needs, identity and culture of children and young people and the responsibilities of their families or carers. The framework also sets out how Oranga Tamariki intends to deliver services to children and young people in a way that is different to the past. The framework is closely aligned to the '*Child and Youth Wellbeing Strategy 2019*',(268) which sets out a shared understanding of what is important for child and youth wellbeing, and what the government and other organisations can do to help. The framework is underpinned by the government's vision to make New Zealand the best place in the world for children and young people. The framework translates what these goals mean for children and young people when they are engaging in care and protection services and sets out that Oranga Tamariki will:

- ensure early participation of children and young people in decisions affecting them
- work with children and young people to prevent entry into state care
- place children and young people with their siblings and members of their families
- support children and young people to establish, maintain or strengthen cultural identify and connections
- support, strengthen and assist children and young people and their families to prepare for return home or transition into the community.

The stated objective of Oranga Tamariki is to provide early support for families and opportunities for families to care safely for their children. However, in instances where a social worker has identified that a child may be at risk of harm and is in need of care or protection, the first step is to hold a Family Group Conference (FGC) where social workers share their concerns with a child's family and agree how the concerns can be addressed. In cases where it is not possible to identify a way of keeping a child safe, social workers may apply to the Family Court for a non-custodial order or a custodial agreement or order. The stated aim of Oranga Tamariki is to work towards a permanency goal to ensure that children in the care of the state have a safe and stable home. This decision is made with others involved in the life of the child including family members or a wider network of friends and social workers. While the preference is for the care of the child to include their parents wherever it is safe and possible, the decision has to be agreed by the Family Court.

### Organisation and delivery of disability services for children

Children with a disability or a serious condition can be referred by their GP, midwife or nurse to the Needs Assessment and Service Coordination (NASC) service. NASCs are organisations that are contracted by the Ministry of Health to work with children and adults with disabilities and their families to identify appropriate supports.(269) NASCs may refer children to the Child Development Service, which is a non-medical, multidisciplinary allied health and community-based service.(270) This service provides specialist assessments for children and works with other agencies to ensure children receive integrated support. The service is focused on early intervention to achieve the best results for children. Services are usually provided in the children's home but can also be delivered in other community-based settings. In disability services, a person is considered to be a child if they are aged under 15 years and are considered a young person if aged 15 to 24 years.

### Organisation and delivery of mental health services for children

Services for children with mental health needs are provided by the Ministry of Health and are delivered through and funded by individual DHBs. All DHBs fund primary mental health services for young people aged 12 to 19 years old, irrespective of whether they are enrolled with a GP. Across all DHBs, mental health services for children are delivered through outpatient services and acute inpatient services. One illustrative example of how mental health services are delivered in New Zealand is in the Capital and Coast DHB. The Capital and Coast DHB is based in Wellington and covers a population of over 300,000 people. Within this DHB, the Mental Health, Addictions and Intellectual Disability Service (MHAIDS) provides services for children with mental health needs. One such service run by MHAIDS is the Child and Adolescent Mental Health Services (CAMHS), which provides children up to the age of 18 years with specialised input from mental health professionals.(271) A referral to CAMHS can be made by a child or a young person, their parents or caregivers, a GP, or the child's or young person's school. CAMHS teams assess, treat and provide ongoing evaluation of children, young people and their families. The teams consist of family therapists, occupational therapists, psychiatrists, psychologies, mental health nurses, social workers and psychotherapists. MHADIS also provides the Regional Rangatahi Adolescent Inpatient Service (RRAIS), which is an acute adolescent inpatient unit. The RRAIS service is for young people aged 12 to 17 years who are experiencing acute mental health problems. Referrals are made through CAMHS or a child and adolescent psychiatrist.(272)

### 3.7.3. Legislation

There is a wide range of legislation in place which frames the health and wellbeing of children in New Zealand. The legislation sets out when and how a child or young person should receive a relevant health or social care service, which is determined by their health needs or need for care and protection from harm. However, the rights of people with disabilities are not specifically set out in legislation in New Zealand. Rather, disability rights are provided for through human rights legislation (Human Rights Act 1993) and through the United Nationals Convention on the Rights of Persons with Disabilities (UNCRPD). While there is no specific piece of legislation that sets out the rights for children and young people with mental health illnesses, the Mental Health Compulsory Assessment and Treatment Act 1992 sets out a number of special provisions relating to children and young people under the age of 17 years.(273) These include provisions for consent, assessment and membership of review tribunals. This section sets out legislation which applies to all children in New Zealand, specific legislation which applies to children at risk and also legislation that applies to children with disabilities.

#### The Child Poverty Reduction Act 2018

The purpose of the Child Poverty Reduction Act 2018 is to help achieve a significant and sustained reduction in child poverty in New Zealand which will improve child wellbeing.(274) The objective of the act is to encourage a focus on child poverty reduction, facilitate political accountability against published targets, ensure transparent reporting on child poverty levels and create a greater commitment by Government to address child wellbeing. Under the act, Government is required to set long-term (ten year) and intermediate (three year) targets for a defined set of child poverty measures, against which they must report annually. In an effort to enhance political accountability and achieve targets set out, the New Zealand Government has implemented a number of policies to reduce child poverty. The initiatives are designed to directly help children living in poverty by increasing income support to vulnerable families and most recently, introducing a number of initiatives to ease financial pressures associated with COVID-19, including mortgage and rent freezes and protection from evictions.

## Oranga Tamariki Act 1989

The Oranga Tamariki Act 1989, also known as the Children's and Young People's Wellbeing Act, is administered by Oranga Tamariki (Ministry for Children). The act is one of the primary pieces of legislation relating to the wellbeing of children in New Zealand and provides for the care and protection of children and youth justice.(275) The act sets out how the state can intervene to protect children at risk from abuse and harm, and it also determines how the state can prevent and address child and youth offending. Under this act the Family Group Conference was introduced as a method for including families throughout the decision-making process regarding the care and protection of young people. At the time, this method was considered radical. Under the act, the Office of the Children's Commissioner has a statutory responsibility to monitor and assess the policies and practices of Oranga Tamariki and other organisations contracted by Oranga Tamariki to provide care services for children, young people and their families or caregivers.(257) A number of significant amendments to the act came into force in July 2019 and included changes to allow young people to remain or return to living with a caregiver until the age of 21, with transition support and advice services available up to the age of 25. The amendments also included an extension of the youth justice system to include 17 year olds.

## Care of Children Act 2004

The Care of Children Act 2004 is administered by the Ministry of Justice and replaces the Guardianship Act 1968. The purpose of the act is to promote children's welfare and best interests, and facilitate their development, by helping to ensure that appropriate arrangements are in place when the courts are determining their guardianship and care.(276) The act is underpinned by the following principles relating to a child's welfare and best interests:

- a child's safety must be protected and a child must be protected from all forms of violence
- a child's care, development, and upbringing should be primarily the responsibility of his or her parents and guardians
- a child's care, development, and upbringing should be facilitated by ongoing consultation and cooperation between his or her parents, guardians, and any other person having a role in his or her care under a parenting or guardianship order
- a child should have continuity in his or her care, development and upbringing

- a child should continue to have a relationship with both of his or her parents and a child's relationship with his or her family should be preserved and strengthened
- a child's identity should be preserved and strengthened.

## The Children's Act 2014

The Children's Act 2014 (previously named the Vulnerable Children Act 2014) is administered by the Oranga Tamariki (Ministry for Children) and the Ministry of Education. It represents significant measures to protect and improve the wellbeing of vulnerable children and to strengthen New Zealand's child protection system. The act prohibits people with specific serious convictions, such as child abuse, sexual offending or violence-related convictions from being employed as a child or young person's care worker. The act seeks to protect young people at risk of child abuse by bringing a child-centred approach to policies and processes for government agencies working with children. Furthermore, the act seeks to safeguard children and young people by ensuring that there is a safe and competent workforce that can recognise and act on behalf of a child who may be vulnerable to abuse. Under this act, employers can be charged with an offence if they breach the workforce restrictions.(277)

## The New Zealand Public Health and Disability Act 2000

The New Zealand Public Health and Disability (NZPHD) Act 2000 is administered by the Ministry of Health.(278) The NZPHD establishes the structure, underlying public sector funding and the organisation of health and disability services. DHBs were established under the act, which also set out the duties and roles of the Minister of Health, Ministerial committees, and health sector provider organisations. Under the NZPHD Act, the Minster for Health is responsible for:

- determining health and disability strategies
- determining strategies for standards and quality assurance programmes
- negotiating and monitoring Crown funding agreements
- establishing ministerial committees including health and disability advisory committees and public health advisory committees.

Ministerial committees provide the Minister with independent expert advice and offer a forum of representatives of the sector to have a role in decision-making. The NZPHD aims to reduce health disparities in New Zealand by improving the health of Māori and other population groups. A further objective of the NZPHD Act is to facilitate access to, and the dissemination of information for the delivery of appropriate, effective and timely disability services in New Zealand.

### Health and Disability Services (Safety) Act 2001

The Health and Disability Services (Safety) Act 2001 is administered by the Ministry of Health(279), and is the core piece of legislation that underpins the certification of healthcare services for adults and children and young people. The purpose of the act is to:

- promote the safe provision of health and disability services to the public
- enable the establishment of consistent and reasonable standards for providing health and disability services to the public safely
- encourage providers of health and disability services to take responsibility for providing those services to the public safely
- encourage providers of health and disability services to continuously improve the quality of those services.

Service providers seeking certification under the act are required to meet the Health and Disability Services Standards 2008.(280) It is mandatory for hospitals, rest homes, and some providers of residential disability care needs to meet these standards. These standards are discussed in more detail in section 3.7.4.2.

## 3.7.4. Strategies, policies and standards

New Zealand has a number of strategies, policies and standards that set out specific commitments to protecting and ensuring the health and wellbeing of children and young people. This section describes key strategies, policies and standards that have been developed in New Zealand. This section also describes a number of inspectorates that assess compliance with standards.

### 3.7.4.1. Strategies and policies

The strategies and policies included in this section set out a vision for child health and wellbeing in New Zealand. This section sets out strategies and policies that apply to all children and young people and also ones that apply specifically to children and young people at risk.

### Child and Youth Wellbeing Strategy 2019

The '*Child and Youth Wellbeing Strategy'* was launched in August 2019 and sets out a shared understanding of what is important for children and youth wellbeing in New Zealand.(256) The strategy provides an overarching unifying framework that aims to drive and align policy, both inside and outside of government to support collective action to improve child and youth wellbeing. The Department of the Prime Minister and Cabinet led the development of the strategy, in collaboration with other agencies, and it was further informed by extensive engagement with children and young people. The strategy consists of a vision statement for child and youth health and wellbeing, a set of guiding principles and six wellbeing outcomes. The vision for the strategy is that New Zealand is the best place in the world for children and young people. A set of nine principles, which promote wellbeing and equity for all children and young people, have been developed to guide the development and implementation of the strategy. The guiding principles outline the importance of working together for real impact, of developing strong relationships with children and young people and seeing their whole needs, of respecting children's rights, the importance of supporting and working with families, and focusing on outcomes from the beginning. The strategy also sets out six high level and interconnected wellbeing outcomes that signpost the social, economic and environmental factors needed for child and youth wellbeing.(281) The outcomes are that children and young people:

- are loved, safe and nurtured
- have what they need, including income, resources and other important aspects of material wellbeing such as food and housing
- are happy and healthy, including physical and mental health
- are learning and developing
- are accepted, respected and connected, this includes living free from racism and discrimination
- are involved and empowered, this includes support to make positive choices and develop autonomy.

For each of the above outcomes, there is an accompanying set of indicators to measure progress of the outcome. The first annual report on progress against the outcomes of the strategy is due to be published in early 2021. The report will include analysis of data for each of the specified outcomes and an analysis of the disparity of outcomes by ethnicity.

### A Better Start: Future Strategy 2019 – 2024

In 2014, the Ministry of Business, Innovation and Employment established The National Science Challenges, which aims to tackle the biggest science-based issues and opportunities facing New Zealand. The Challenges are cross-disciplinary, mission-led programmes that bring together New Zealand's top scientists to work collaboratively to achieve their objectives. One of the challenges is '*A Better Start*', which aims to improve the potential for young people in New Zealand to have healthy and successful lives.(282)

Launched in 2016, *'A Better Start'* aims to:

- research improved methods and tools to predict, prevent and intervene so children have a healthy weight

- identify and address learning and mental health problems so children and young people are resilient, successful learners and are emotionally and socially well adjusted.

These aims are leveraged to support the economic, environmental, cultural and social benefits for New Zealand. The research strategy adopted by *'A Better Start'* aims to target at risk children at an early stage, engage their communities, draw together different disciplines and take a holistic approach to issues such as obesity, learning, and mental health difficulties. This research strategy is considered novel for New Zealand as these are areas of health and wellbeing which are often studied in isolation. Big data, as captured by a range of government agencies is being used to inform progress in each of these areas.(283) The research strategy sets out three priority areas; equity of outcomes, delivering impact, and strengthening research themes through integration. It is envisaged that these priority areas will deliver excellent quality research and will also facilitate research outcomes to support positive change. *'A Better Start'* also has a focus on research reviews and on stakeholder and policy engagement in order to map out methods for effective impact measurement.(283) It is anticipated that this focus will enable researchers to propose holistic solutions that are both practical and evidence-based to make a measureable difference in the health and wellbeing of children and young people.

*'A Better Start'* sets out a number of key measurable targets that are to be achieved by June 2024:

- At least a 15% reduction in prevalence of overweight and obesity in children aged four to five-years of age.
- At least a 15% increase in attainment of age-expected early literacy achievement in children aged five to six years of age.
- Improvement in the mental health and social functioning of vulnerable adolescents as measured through secondary school function (improved school retention, reduced school absences), a reduction in Emergency Department presentations with self-harm and a reduction in depression, anxiety and substance abuse within communities.

## The Children's Action Plan 2012

The '*Children's Action Plan'* (CAP) is a cross-agency programme established to protect vulnerable children by aiming to proactively reducing child abuse and neglect. CAP sets out key actions required to ensure better results for vulnerable children.(284) Following the release of CAP in October 2012, the New Zealand Government announced a set of actions to fundamentally change and improve the way vulnerable children and young people are identified, supported and protected. These actions included:

- a range of legislative changes to better protect and respond to vulnerable children
- the establishment of cross-sector children's teams across New Zealand to identify and address unmet needs of children at risk
- support for information sharing, recording and reporting
- workforce capability development.

Legislative changes consisted of the introduction of the Vulnerable Children's Act 2014 (now known as the Children's Act) which restricts people, in the home and at work, who pose an undue risk to the safety of children from living or associating with children.(277) Another important change to the care and protection system was the implementation of the recommendations of the Expert Advisory Panel, as set out in Section 3.7.2. of this review, convened to review the care and protection system. Implementation of these recommendations resulted in fundamental changes to the operating module of the CYF, and eventually to the formation of Oranga Tamariki in 2017.

Following the publication of CAP, Children's Teams were also introduced by Oranga Tamariki to the care and protection system in New Zealand. Children's Teams represent a new interagency way of working so that children at risk are identified by child protection and welfare services, and that their families or caregivers receive the services and supports they need to care for children.(285) Children's Teams form part of Oranga Tamariki's early intervention system and bring together practitioners and professionals from health, justice, education and social services to create a single child-centred plan to help and support children up to the age of 18 who are at risk of abuse and neglect. Children's Teams focus on agencies working together and sharing information to reduce duplication and improve outcomes for children who are at risk. Furthermore, Children's Teams continually try to build workforce capability to identify child abuse and to identify ways of developing and implementing safe and effective child protection policy. At the time of writing, evidence on the impact Children's Teams are having on at risk children is not available. A review of the early intervention system would provide an opportunity to learn what impact the interagency approach is having on outcomes for children.

#### 3.7.4.2. Standards for health and social care services working with children

A number of standards and regulations have been developed to drive improvement and assess the quality of care provided to people living in New Zealand. This section sets out the standards that are specific to the health and wellbeing of children and young people and will also detail standards that relate to the population as a whole.

This section also describes how compliance with standards is assessed in New Zealand.

## The National Care Standards

In 2019, Oranga Tamariki published the National Care Standards which set out the standard of care that every child in the care of Oranga Tamariki needs in order to do and be well.(8) The Standards also set out the support all caregivers can expect to receive when they are caring for children. These standards are set out in regulations and are based on good social work practice and on what children and young people in care have said is most important to them, as gathered through extensive consultation with children, young people with experience of care, caregivers, care providers and social workers.(257) The standards focus on supporting children and young people to express their views, keeping them connected to their families and communities, giving them opportunities to participate in their culture and ensuring their education, health and recreation needs are met.

There are six parts to the standards as set out below:

1. Assessments, plan and visits: Every child in care should receive a holistic needs assessment that reflects their views, wishes, aspirations and strengths.
2. Support to meet needs of children in care: Every child in care should receive support that addresses their identified need and assist them to access other support they may need.
3. Assessments, plans and support for caregivers: Caregivers need access to information about children in their care that will help them understand their needs and contribute towards meeting those needs.
4. Voice of the child: Every child in care needs a way to capture the important things that happen in their life. They should be supported to express their views and contribute to their care experience.
5. Supporting children during care transitions: Children in care need to be well supported when they leave care and transition into adulthood.
6. Monitoring and reporting on compliance with the Care Standards: The Office of the Children’s Commissioner serves as an independent monitor for compliance with the Care Standards and reports to the Minister for Children regarding compliance with the Care Standards. Oranga Tamariki and organisations that have legal custody of children to self-monitor and report on compliance with the regulations.

The standards include a child-friendly Statement of Rights to ensure that every child in care understands what they are entitled to and knows how to speak up and make a complaint. The child-friendly statement translates what the standards mean for children when they are in care and explains the process of what happens when they come into care. This includes details on what information is shared with other people, what happens if the child is transitioning from care and information on who can provide the child with support.(286)

## Health and Disability Services Standards

Health and Disability Services Standards (HDSS) 2008 are mandatory for those health and disability service providers that are subject to the Health and Disability Services Act 2001.(279) Under the 2001 act, hospitals, rest homes and providers of residential disability care must undergo certification audits against the HDSS. HealthCERT is responsible for monitoring the HDSS standards through these certification audits. The HDSS are also mandatory for all relevant service-based contracts that receive health funding. Primary healthcare services, including those provided by general practitioners or a primary healthcare organisation, are not included under requirements of the 2001 Act. The HDSS came into effect in June 2009, replacing the previous 2001 version.(7) They aim to promote good and safe practice by providers and apply to health and disability services across New Zealand. The HDSS are made up of four sets of standards as follows:

- Health and disability services (General) Standards.(287)
- Health and disability services (Core) Standards.(288)
- Health and disability services (Restraint minimisation and safe practice) Standards.(289)
- Health and disability services (Infection prevention and control) Standards.(290)

## Inspectorates

This section sets out the primary bodies involved in the monitoring and regulation of health and social care services in New Zealand. The Office of the Children's Commissioner (OCC) is the key independent and external monitor of Oranga Tamariki. The Office of the Ombudsman is responsible for oversight and investigations of complaints about Oranga Tamariki and its approved providers, and other government agencies who interact with children in care. HealthCERT, part of the Ministry of Health, has a central role in the regulation of health and disability services in New Zealand. Mental Health District inspectors are appointed by the Minister of Health to protect the rights of people, including children and young people who are receiving compulsory mental healthcare.

## The Office of the Children's Commissioner

The OCC holds an advocacy role for the interests and wellbeing of children and young people and also acts as the independent and external monitor of Oranga

Tamariki. Under the Oranga Tamariki Act 1989, the OCC has a statutory responsibility to monitor and assess the policies and practices of Oranga Tamariki and other organisations contracted by Oranga Tamariki to provide care services for children, young people and their families or caregivers.(275) This statutory responsibility gives the Commissioner for Children the mandate to monitor all care and protection and youth justice services across New Zealand. The OCC monitors a range of residences across New Zealand including, youth justice residences, care and protection residences, special purpose residences, and mother and baby units.

The OCC also has a role in overseeing the complaints process for young people in residences. If a young person feels they have been treated unfairly, unreasonably or illegally while living in a residence, they have the right to make a complaint. Each quarter, the OCC receives detailed reports of every complaint made by a young person in a residence and investigates to ensure the right processes were adhered to.(291)

### Office of the Ombudsman

The primary role of the Ombudsman is to investigate complaints against government agencies. Similar to the OCC, the Ombudsman also plays a specific role in supporting children in the care of Oranga Tamariki and is responsible for investigating the practice of Oranga Tamariki when it removes newborn babies from their parents or other caregivers. In August 2019, it was announced that the Chief Ombudsman was to be given a strengthened role in resolving and investigating complaints relating to children in care. Under this expanded the role, the Chief Ombudsman is responsible for oversight and investigations of complaints about Oranga Tamariki and its approved providers, and other government agencies who interact with children in care. Under this expanded role, the Chief Ombudsman will:

- be notified by Oranga Tamariki of any serious or significant incidents relating to children or young people in care
- have additional powers to obtain information and work with other oversight bodies
- have explicit duties requiring engagement with and a focus on improved outcomes for Māori children.

### HealthCERT

HealthCERT, which is part of the Ministry of Health, has a key role in administering, implementing and enforcing legislation and regulations. HealthCERT is responsible for ensuring hospitals, rest homes, residential disability care facilities and fertility providers provide safe and reasonable levels of service for people who use services, as required under the Health and Disability Service Act 2001.(279) As part of their regulatory role, HealthCERT works to administer and enforce the legislation, issue certificates, review audit reports and manage legal issues. The legislation underpins the certification of healthcare services, promotes the safe provision of health and disability services to the public and enables standards to be established for this purpose. In addition to this regulatory role, HealthCERT holds a subsection on the Ministry's website called YourHealth. This catalogue of certified health providers enables the public, residents and their families to search for various services across New Zealand including rest homes, hospitals and fertility clinics. This database also provides summaries of rest home audits reports, allowing residents and their families to view important information, if they are planning to move to a rest home or are currently living in one. Through this system, they can check that the service provides the best quality care possible. There is also information provided on how to make a complaint about certified providers of healthcare services.

#### Mental health district inspectors

Mental health district inspectors provide an important safeguard for people, including children and young people under the age of 17 years, who have concerns about compulsory care or treatment.(292) District inspectors are lawyers who are appointed by the Minster of Health to protect the rights of people receiving treatment under the Mental Health (Compulsory Assessment and Treatment) Act 1992(293) and the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003(294). Both of these acts include provisions for children who are under the age of 17 years. The main responsibilities of district inspectors is to ensure that the provisions of these acts are upheld, monitor quality and safety of mental health services providing treatment to people who are subject to these acts and investigating complaints and conducting inquires. A district inspector must meet with the patient or care recipient early in the compulsory assessment process to advise them of their situation and their right to a review in the District Court. District inspectors can also facilitate legal representation for such a review.

### 3.7.5. Findings from reviews

New Zealand is currently ranked 35th out of 41 OECD countries in terms of overall child wellbeing outcomes. UNICEF New Zealand identified poor trends in childhood obesity, youth suicide and a declining proficiency in reading and math as contributing factors to the poor OCED ranking.(186) UNICEF has called for significant investment and policy reform in an attempt to improve child wellbeing outcomes. Furthermore, despite extensive transformation of New Zealand's care and protection system in recent years, widespread criticism of the actions of Oranga Tamariki with regards to early intervention prevails.(295) While the introduction of children's teams represents a move towards working in an integrated way to meet the needs of children and young people, data on how these teams are performing is not yet available following their implementation in 2017.

Although the New Zealand government is committed to improving outcomes for all children and young people, including vulnerable and children at risk and young people, findings from reviews indicate that children and young people are still experiencing poor outcomes. A proportion of these poor outcomes can be attributed to the relatively high levels of children living in poverty in New Zealand. Living in poverty can constrain and undermine the potential impact that good health and care support systems can have on the lives of young people by preventing them from achieving their full potential. This section sets out findings from key reports that provide an overview of health and wellbeing outcomes for children and young people in general and also children and young people who are at risk.

### The United Nations Committee on the Rights of the Child: Fifth Periodic Report 2015

In its Fifth Periodic Report, the United Nations Committee on the Rights of the Child (UNCROC) made a number of recommendations for the New Zealand Government in order to improve child wellbeing outcomes. The report highlighted the need to adopt urgent measures across a number of areas, including violence, abuse and neglect, children deprived of a family environment, standard of living, children belonging to minority or indigenous groups, child labour and juvenile justice.(296) The report recommended the need to develop a comprehensive strategy to combat abuse and neglect encompassing all children in all settings, with particular attention given to Māori children and children with disabilities. It was also recommended that education programmes to prevent and combat child abuse, would be strengthened by involving children, including those with disabilities and those from indigenous communities, in the development and implementation of such programmes.

While the report welcomed the transformation of New Zealand's care and protection system and the establishment of Oranga Tamariki, recommendations for improving services were made. In terms of family environments, the report recommended that the efforts to provide appropriate assistance to parents and legal guardians are intensified. The report highlighted the importance of care and protection services providing a timely response, with particular reference to the provision of culturally appropriate services to Māori and Pasifika populations. The report also called for improvements to be made in terms of how data on child wellbeing outcomes are collected in order to facilitate evidence-based approaches being implemented in the care and protection system.

### Child Poverty Monitor: Technical (National Report) 2019

The Child Poverty Monitor is a partnership between the OCC, the JR McKenzie Trust (a philanthropic family trust) and the New Zealand Child and Youth Epidemiology Service at the University of Otago. Development of the partnership stems from a 2012 OCC report on child poverty that identified the need to measure and report on child poverty rates annually in an attempt to identify ways to reduce rates of child poverty.(297) The 2019 Technical Report reported that an estimated quarter of a million children (23% of all children) in New Zealand were living in poverty. In addition, an estimated 13% of children did not have access to essential items required for them to achieve and maintain a decent standard of living to allow them to survive, develop and thrive.(298)

The report found that children living in the most disadvantaged communities in New Zealand are twice as likely to be hospitalised when compared to those living in advantaged communities. The report also indicated that food security remains a significant issue for children and young people in New Zealand, particularly low-income households, with one in five children living in a household without access to nutritionally adequate foods. The report emphasises that a significant acceleration in child poverty reduction is necessary for the Government to achieve child poverty reduction targets as set out in the Child Poverty Reduction Act.(274,298) In order to achieve these child poverty reduction targets, all children and young people in New Zealand need to be able to access essential resources to thrive, which include an adequate income, access to essentials to maintain a decent standard of living, promotion of wellbeing and opportunity through good health, and safe living environments.

### Hawke's Bay Practice Review into the Hastings Case 2019

In May 2019, Oranga Tamariki sought and was granted a 'without notice' custody order for a newborn baby who had been born to a young Māori couple. The couple were known to Oranga Tamariki as they had previously had a child removed from their care. Following the custody order, numerous attempts were made by Oranga Tamariki to remove the baby from the parents care. However, following resistance from the parents, Oranga Tamariki withdrew their removal attempts and an agreement was reached on a plan for the mother and baby. The attempt made by Oranga Tamariki to bring the baby into care attracted significant media and public scrutiny. As a result, Oranga Tamariki commissioned a Professional Practice Group to conduct a Practice Review to examine the actions of Oranga Tamariki.(299) The review concluded that while there were legitimate concerns for the safety of the baby that warranted Oranga Tamariki involvement, there was an overreliance on historical information and poor attempts made at understanding the parents current circumstances. The review made a number of system-wide recommendations in order to promote safe statutory practice and to ensure a culture of accountability, reflection, challenge and transparency are operating as intended.

In response to the 2019 Hastings Case, the Chief Ombudsman published an Investigation Report in August 2020 which examined the systems and practices of Oranga Tamariki to identify if there were systemic issues within the policies, practices and procedures for the removal of newborn Māori babies from their parents or caregivers.(295) The investigation focused on a two-year period (2017 to 2019) and included 74 cases where Māori babies aged up to 30 days old were removed from the care of their parents, without prior notice. The report highlighted the cultural incompetency of staff, coupled with high caseloads resulted in Oranga Tamariki not following processes in a timely way. The report further noted that often parents did not receive the assistance of advocacy services that they required. Recommendations made by the report include improvements to Oranga Tamariki's guidance and practice, the use of tools in a timely manner, using effective reporting frameworks and quality assurance, prioritising engagement with parents and enhancing the cultural competency of staff.

### 3.7.6. Lessons for Ireland

Despite government-wide commitments to improve the health and wellbeing of all children in New Zealand, children and young people are scoring among the lowest of all OCED countries in terms of overall health and wellbeing outcomes. As evidenced in reports conducted by the Child Poverty Monitor and the UNCROC, the outcomes for children and young people in New Zealand are particularly poor with regard to overweight and obesity levels, standard of living, and youth suicide rates. Significant disparities between indigenous and non-indigenous children also continue to be present in New Zealand. Indigenous children have reported poorer outcomes across all areas of health and wellbeing and higher rates of child poverty when compared to their non-indigenous counterparts. While poverty remains a major issue in New Zealand, the government has committed to achieving a significant and sustained reduction in child poverty through the introduction of the Child Poverty Reduction Act in 2018. One of the objectives of the act is to facilitate political accountability against published targets for reducing child poverty. While, no hard data is currently available on the impact of the act, it will be interesting to observe whether this legislation will improve child poverty in New Zealand.

Similar to Ireland, issues regarding high caseloads and low staffing levels were identified as contributing factors to inefficiencies in child protection processes. Specifically, the *'Hawke's Bay Practice Review'* identified the limited number of Māori specialist staff as a significant issue contributing to the high numbers of Māori babies being removed from the care of their parents. Given that there are growing numbers of children from different ethnic groups living in Ireland, ensuring the cultural competency of staff in the Irish child protection system is an important factor to consider.

The introduction of Children's Teams to Oranga Tamariki's early intervention system also represents an interagency approach to the child protection system in New Zealand. While it is too early to draw conclusions on the impact of the Children's Teams on outcomes for children, this collaborative way of working can facilitate information sharing across agencies and bodies which can help improve outcomes for at risk children. Similarly the introduction of the Oranga Tamariki Outcomes Framework will provide measurable and reportable indicators for child wellbeing outcomes, which assess the impact services are having on the wellbeing of children.

## 3.8. Summary of findings from the international review

The international review set out in this document provides an overview of how Scotland, England, Northern Ireland, Australia, Sweden, America, and New Zealand deliver health and social care services to children in their jurisdictions. The evidence shows that each jurisdiction has extensive legislation, regulation, strategy, policy, and service delivery systems in place to meet the needs of children. Each jurisdiction demonstrated progression towards enhancing child health and wellbeing, and set out how the improvement of child wellbeing would be achieved in national strategies. The main findings from the international jurisdictions are:

### Legislation and policy for integrated working

The evidence shows that there is a strong focus in all of the jurisdictions on promoting equality and reducing health inequalities for children. One example of this is in Sweden, where a commission for equitable health to assess the health disparities between socio-economic groups has been established to drive change in this area in the next decade. At a legislative and policy level there are examples in a number of jurisdictions of a move towards integrated working, with a focus on early intervention, to meet the health and social care needs of children. A number of jurisdictions, including England, Scotland and Northern Ireland, have put the responsibility of all services to work together to meet children's health and social care needs, and to promote their wellbeing on a statutory footing. This has resulted in a shift towards more formal collaboration between NHS organisations and local authorities to deliver integrated care and support to children.

The evidence also shows that despite national commitments to improve the health and wellbeing of children, and the extensive programmes to realise such commitments, there are challenges to the delivery of consistent and integrated health and social care services to children with additional needs across the jurisdictions. Reports from Scotland, England and Northern Ireland show that although there are government-wide commitments to improve the coordination of health and wellbeing of children in many jurisdictions, practice on the ground remains inconsistent. These reports highlight that children with complex needs, and children who are more vulnerable due to their lower socio-economic status and living conditions fare worst when health and social care services are uncoordinated and inconsistent.

## Standards for children and young people

In most jurisdictions reviewed there has been a focus on developing standards for services provided to children and young people with additional needs to ensure they receive a safe and high-quality service. These standards are an attempt to provide a common language and framework for supporting children. An example of this can be seen in Scotland, where the government commitment to children's health and wellbeing is echoed through the 2018 '*Health and Social Care Standards: My Life, My Support*'.(6) Other examples of this can be seen in New Zealand where general and targeted standards have been developed to improve the experience of children with additional needs. Examples of these standards are the *'Health and Disability Services Standards'* (HDSS) 2008, which are mandatory for a wide range of health and disability service providers who provide services to children, and the 2019 *''National Care Standards'* which sets out the standard of care that every child in the care of the State needs in order to do and be well.(7,8)

## Regulation and monitoring

The review found that while all jurisdictions reviewed have a process for assessing the safety and quality of services provided to children, this can vary quite significantly depending on the jurisdiction and the nature of the service being provided. For example, in Sweden the governmental agency with responsibility for inspecting care assesses how well services collaborate, as well as assessing the overall rationale for decisions around the provision of care and support, rather than assessing the performance of individual health and social care services. Another example of differences in the regulation and monitoring processes can be seen in England and Scotland, where there are a number of agencies involved in assessing the safety and quality of health and social care services provided to children. In recent years, these agencies have worked together to undertake joint inspections in strategic areas, such as the delivery of integrated care and support.

## Service delivery

In a number of jurisdictions, reports showed that there were long waiting lists for services and a lack of services for children with additional needs. The review identified that this was particularly acute in children's social services and mental health services in America, England and Northern Ireland, where staff shortages and poor retention rates of experienced staff compounded the waiting times for children. Due to this, such services were often reactive and crisis-driven, rather than proactively meeting children's needs.

While there has been a focus on supporting children to transition between and out of health and social care services, timely and coordinated planning, the availability of appropriate follow-on care, and effective resource allocation, continues to be problematic across all jurisdictions. For example, the review identified that Australia did not have a systematic approach to supporting children who had been in care to transition into adulthood, and the findings for England highlight that for children with complex needs there is often a lack of suitable follow-on support when they reach adulthood.

### Health inequalities

The review also found that in a number of jurisdictions there are disparities among the health and wellbeing of indigenous and non-indigenous children. In New Zealand and Australia, the review found that indigenous children report significantly poorer outcomes across all health and wellbeing outcomes, are more likely to be living in poverty, and are more likely than their non-indigenous peers to be taken into care.

### Data collection

All jurisdictions reviewed gather data in relation to health and social care services provided to children, however, the focus of this data varies between jurisdictions. A number of jurisdictions, including Northern Ireland and New Zealand, have developed outcome-based frameworks to provide measurable indicators for child health and wellbeing. These frameworks seek to assess the impact that services are having on child health and wellbeing, and also the impact that policies and programmes have on the lives of children more generally. In contrast, the data gathered in America in relation to these services is mainly quantitative, and is used to inform the funding allocation to services. This focus makes it difficult to assess the impact of health and social care interventions and to identify whether services are achieving positive long-term outcomes for children.

# 4. Evidence Synthesis Methodology

## 4.1. Overview of the evidence synthesis process

A detailed synthesis and review of existing literature and evidence is undertaken to inform the development of national standards and guidance. These reviews describe the Irish and international context in which the work is being conducted and ensure that the work is informed by quality evidence and reflects international best practice. This is detailed in '*HIQA's Evidence Synthesis Process: Methods in the development of National Standards, Guidance and Recommendations for the Irish health and social care sector*.(301) The evidence synthesis process has two phases: Phase 1 involves a scoping review and Phase 2 consists of a systematic search and literature review.

## 4.2. Scoping review

The scoping review was a time-limited review and was a preliminary assessment of the potential size and scope of the existing literature and how long it would take to review relevant literature. Through the scoping review, relevant databases and websites were identified. Three grey literature[******] repositories were identified: Lenus, Open Grey and HEN. The academic databases identified were: Embase, PsycInfo, CINAHL, and Social Sciences. The scoping review also informed the development of a tailored research question, search terms and search limiters. The returns were catalogued according to the type of article and the source of the article. The findings from the scoping review were integrated and used to inform Phase 2 of the evidence synthesis.

## 4.3. Objectives

The aim of the evidence synthesis was to assess and appraise available evidence to identify characteristics of good child-centred practice in children's health and social care services.

Phase 2 of the evidence synthesis included the following objectives:

- To conduct a formal systematic search of the following literature sources, as identified in Phase 1:
  - grey literature repositories
  - academic databases
- To screen all articles for inclusion in the evidence synthesis.

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[******] Grey literature refers to information and research that is not commercially published. Some examples of grey literature include, newsletters, government reports and policy statements.

- To conduct a quality appraisal of all included articles in the evidence synthesis.
- To describe and critically evaluate the articles and to identify emerging themes.

- To formally consult with stakeholders and subject matter experts through a scoping consultation to generate additional suggestions of evidence for inclusion in the evidence synthesis.

## 4.4. Search strategy methodology

### 4.4.1. Conducting a formal systematic search

Search terms identified in Phase 1 of the evidence synthesis were used to identify, retrieve and evaluate literature from academic databases and grey literature repositories from between 2012 and 2020[††††††]. Four electronic academic databases were searched between May and June 2020: Embase, PsycInfo, CINAHL, and Social Sciences. A combination of search terms was used; these related to the population (for example 'child', 'young person' and 'adolescent'), type of service (for example 'development', 'mental health', 'physical health', and 'wellbeing'), setting (for example, 'community care', 'residential care', 'detention' and 'primary care'). Terms such as 'practice', 'standard', 'guidance', 'guideline' and 'recommendation' were included to classify the ways of providing a service to children.

Three grey literature repositories were searched: Lenus, Open Grey and HEN. The search terms used for the academic databases were also applied to the grey literature.

### 4.4.2. Screening articles for inclusion

Evidence was deemed to be eligible for inclusion in the evidence synthesis if it described elements of children's health and social care services. Quantitative, qualitative, mixed methodologies, reviews and opinion pieces were considered in the evidence synthesis. The following exclusion criteria were applied at three stages of study selection (screening by title, screening by title and abstract and during the assessment of the full text):

- documents focusing on services for education, housing or other services for children who do not need child health and social care services

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[††††††] The *National Standards for Safer Better Healthcare*, aimed at protecting patients and improving services, were produced by HIQA in 2012 following a comprehensive review of international evidence. It was agreed that we should build on HIQA's existing research and knowledge. As such a decision to put a date limiter of 2012 was agreed.

- documents focusing on developing countries
- books, book reviews, editorials and letters.

## 4.5. Scoping consultation and suggested resources

A scoping consultation was completed to inform the development of Overarching National Standards for Children's Health and Social Care Services. The scoping took place in September 2020 and ran for a two-week period. The purpose was to consult with people delivering and using services at the initial stages of the standards development process. The consultation asked what areas the standards should address and respondents were asked to provide examples of good practice. Respondents were also asked to provide key sources of evidence that would inform the development of the standards. In total, 71 responses were received from organisations and individuals. Following the removal of duplicate suggestions, 152 sources of evidence were suggested. These suggestions included legislation, books and journal articles, and information on websites. All suggested sources of evidence were screened and reviewed for relevance.

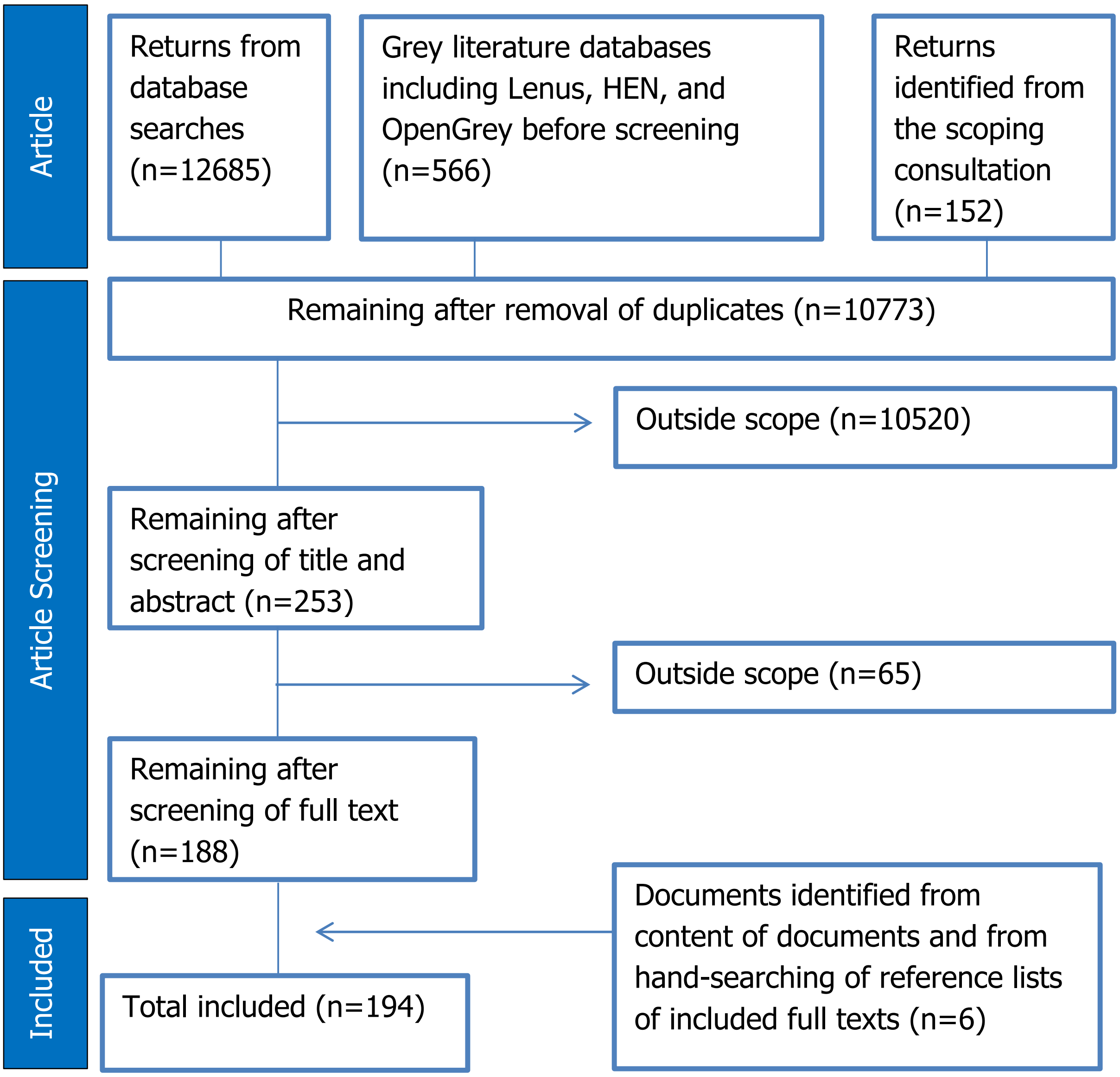
## 4.6. Summary of search results

Figure 10 depicts a flow chart of the selection process for relevant articles based on the combined evidence. Following the removal of duplicates, 10,774 potential documents were identified for inclusion. Two reviewers independently screened titles and abstracts and or executive summaries for potential relevancy. The remaining documents were read by one reviewer to determine eligibility for inclusion. Discrepancies about whether a paper or document met the inclusion criteria were discussed with a third reviewer and a final decision was made based on consensus. Additional documents were identified from the content of documents and from hand-searching of reference lists of included full texts. One hundred and ninety four documents were identified for inclusion in the evidence synthesis following a review of full texts.

### 4.6.1. Quality appraisal

The AACODS checklists were used to appraise the quality of the grey literature and assessed the literature using the following criteria: Authority, Accuracy, Coverage, Objectivity, Date and Significance.(302) Grey literature articles assessed through this process made a significant contribution to the evidence synthesis. The articles came from reputable and credible authors or organisations and the findings were presented in a balanced and objective manner. The Mixed Methods Appraisal Tool (MMAT) was used to assess the quality of empirical studies.(303) The Critical Appraisal Skills Programme (CASP) was used to evaluate systematic reviews.(304) Peer-reviewed academic articles were also assessed using the AACODS checklist, as they did not have a methodology consistent with a particular MMAT or CASP checklist.

**Figure 10. Prisma Flow-chart of Evidence Synthesis**



# 5. Evidence Synthesis Findings

## 5.1. Structure of the literature review

During the evidence synthesis a number of themes emerged from the literature in relation to how health and social care services support child health and wellbeing. These are in line with the principles being developed by HIQA to underpin all national standards for health and social care services. These principles have been used to structure this section and are:

- a human rights-based approach
- safety and wellbeing
- accountability
- responsiveness.

Although these principles can be seen as distinct, in reality single issues can relate to several principles, for example, when deciding on what intervention is appropriate for a child[‡‡‡‡‡‡], children's health and social care services must consider the child's safety and wellbeing, but also the right of the child to participate in their care and support. In the literature review, topics that relate to more than one principle are discussed in the context of each relevant principle.

## 5.2. Principle 1: A human rights-based approach

### 5.2.1. Introduction

Children have the right to be treated with dignity and respect, and to be recognised as individuals who are able to participate in and exercise a level of control over the lives, and their health and wellbeing.(305,306,307) The rights of children are clearly stated and protected under current legislation in Ireland and human rights treaties which Ireland has agreed to uphold.(35,305) The UNCRC outlines rights which are specific to children and the obligation of the Irish State to aid in the care and protection of the children's survival, developments, protection and participation rights.(305)

In 2020, HIQA published an evidence review to inform the development of National Standards for Children's Social Services. This review highlighted that all children's needs are different, and taking a personal approach builds on what a child knows about their rights and ensures that children's voices are heard and elevated.(9) This

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[‡‡‡‡‡‡] The UNCRC defines the child as a person under 18 years of age. In this review, the term 'child' is used to refer to children and adolescents under 18 years of age. Where a study, or a point being made, directly refers to adolescents or young people, the term 'adolescent' is used in this review.

section sets out how children's health and social care service providers can ensure that they are protecting a child's right to dignity and respect, and to participate in their care and support. The findings from the evidence reviewed are set out under these headings:

- Dignity and respect: Children should be treated in a non-discriminatory manner and staff caring for and supporting the child should develop a relationship with the child and show them respect.(9,305)
- Fairness: Fairness means ensuring that when a decision is made with a person using a service about their care and support, that the person is at the centre of the decision-making process.(308) Children's health and social care service providers should encourage fairness in all aspects of the decision-making process through supporting the child's participation.

### 5.2.2. Dignity and respect

Dignity and respect are central to providing child-centred care and support. Children who use health and social care services must be listened to, and what is important to them must be viewed as important to the service.(9,305,306,307,309) The evidence highlights that to achieve this, children should not be discriminated against. A strong relationship between the child and their health or social care provider is important, and the child should be shown respect. This section is presented under the following headings:

- non-discriminatory practice
- relationships
- respect.

### Non-discriminatory practice

Children should be treated in a non-discriminatory manner and it should be acknowledged that every child's needs are different. The rights set out by the UNCRC apply to every child regardless of race, colour, gender, language, religion, ethnicity, disability or any other status.(305) This section sets out the evidence on how services can develop non-discriminatory practices.

Research shows that lesbian, gay, bisexual, transgender and intersex (LGBTI+) youth are vulnerable to discrimination from health and social care service providers.(309) In a 2017 American study looking at whether primary health care services are perceived as adequately addressing the needs of LGBTI+ children, the authors found that most children attending LGBTI+ focused community-based services did not feel that their healthcare needs were well met. Many felt they experienced poor communication with the healthcare provider, and that they were treated in a judgmental, disrespectful manner.(309) The majority of participants had the following negative attitudes in regard to the issue of special clinics for LGBTI+: the risk of isolation from other children, concerns about being 'labelled' by going to such a clinic, and a belief that all health and social care professionals should be prepared to care for all children.(309) An alternative approach to the delivery of these services, proposed in a 2019 American study, was to have special volunteers in general clinics.(310) This study looked at parent[§§§§§§] experience with volunteers in a difference of sex development (DSD) clinic. The results highlighted how volunteers who have a DSD or are a parent of a child with a DSD act as a bridge that connects the child, parents, and the healthcare professionals.(310)

Decisions in children's health and social care can be influenced by the cultural and religious diversity of the professional, the child, and the child's family. Research undertaken in America in 2016 looked at the risk associated with religious-based decisions, such as the refusal of blood transfusions as a life-saving therapy by patients who practice the Jehovah's Witnesses faith, and the refusal to seek medical care when medically necessary, by patients who are Christian Scientists.(311) The authors concluded that children, regardless of their parent's religious beliefs, deserve effective medical treatment.(311) Research undertaken in Canada in 2015 has found that many social care staff working with children lack knowledge of a child's religion and spirituality, resulting in reluctance by these staff to bring these practices into the child's day-to-day routine, regardless of their wishes.(9) Health and social care professionals have to balance their own beliefs with the need to respect the parent's and child's religious beliefs, and the need to protect the child.(9,311,312)

Difficulties can also arise when families and professionals do not share a common language, and one study highlighted the importance of using interpreters to enhance communication.(311) This topic is discussed in further detail in Section 5.3.4. Although addressing language barriers is important, language represents only one component of delivering culturally sensitive care. The research shows that that families of various minority racial or ethnic groups experience reduced engagement from professionals in relationship building, information exchange, and decision making.(312) Integrating culturally sensitive care in health and social care settings is an important way to address care disparities between children.(313,314) Evidence from across health and social care services show that it is important for service providers to practice self-reflection, self-knowledge, and self-critique to ensure the care they provide is culturally sensitive, and unbiased.(9,314)

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[§§§§§§] In this review, the term 'parent' is used to refer to parents and caregivers for children.

## Building relationships

The evidence shows that it is important not to underestimate the need for children to feel loved and to be nurtured by those providing care and support.(9) A strong relationship between the child and staff contributes to the child feeling loved and secure in their environment. Research in the area of children's social services highlights that providing a nurturing environment for children in their home, and in the wider community, requires integrated support from the wide range of health and social care professionals who engage with children in these settings.(9)

The research highlights the importance of the keyworker relationship******* for children navigating health and social care systems.(9,315) This relationship is particularly important when children are transitioning out of the system, for example, as a child moves out of residential care and into post-care independence, or from child to adult-based care.(9) A 2015 study undertaken in America looked at lessons learned in building a hospital-wide transition programme that could help a child to transition from paediatric to adult-based care regardless of their condition or if the child had a disability. The authors found that key to the success of the programme was identifying one staff member on both the paediatric and the adult service teams who was assigned the role of planning for the transition of care.(315) Research highlights that the keyworker is a valuable advocate, as well as a source of security for the child. The relationship between a child and the keyworker in a residential care setting can be influenced by a number of factors, such as the amount of time allocated to building relationships, the level of choice a child has over their keyworker, and the environment within which the child is cared for.(9)

A stable and continuous relationship between parent and child is important for the child when they engage in health and social care services, in particular child welfare or child protection services.(9,315) These parental relationships, when nurturing and beneficial to the child, should be encouraged and supported by children's health and social care services.(9) Section 5.2.3. details how family-centred care can improve outcomes for children and their family, improve their experience, increase their satisfaction, build on their strengths, and improve adherence to a proposed care or treatment plans. Within child welfare and protection systems, interventions carried out by professionals are intended to build on the existing strengths within the family and in most instances, the reunification of children with their parents is a common goal.(9) The evidence shows that family support programmes and post-reunification

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******* A keyworker carries particular responsibility for the child, liaises directly with them, coordinates health and social services, and acts as a resource person.(28)

follow-up services improve outcomes for children and help to reduce the rate of a child's re-entry into the care system.(9)

### Respect

Respect in children's health and social care services encompasses a number of factors, including respect for children's personal information.

Good information governance is essential in ensuring that important and sensitive information is only shared with relevant staff providing care and support to a child.(9) Research shows that staff need education and guidance to clearly understand what information should be documented and shared and what to treat as private information which is to be kept confidential.(9) One illustrative Irish study undertaken in 2016, found that a common practice among healthcare professionals has included the sharing of sensitive sexual health information of young people in state care. The study highlighted that the resulting mistrust and fear of breaches in confidentiality may lead to a young person not choosing to access health services in the future.(9) A 2019 study, undertaken in America, aimed to improve the rate of adolescents completing their own patient-generated health data on pre-visit screening questionnaires. Confidentiality is paramount to adolescent healthcare, yet this study found that it was the adolescents caregivers who were completing pre-visit questionnaires in more than half of the encounters. Simply asking adolescents to complete the form themselves was associated with a significant increase in the rate of self-reporting among younger adolescents. The study highlighted the need for adolescent-friendly questionnaires and a focus on supporting adolescents to self-report in order to get a fuller and more nuanced understanding of their needs.(316)

## 5.2.3. Fairness

Children have a right to fair treatment when decisions are being made about their lives and they are entitled to participate in these decisions.(306,307,316,317,318,319) This section sets out how children's health and social care service providers should encourage fairness in the decision-making process by supporting active participation at all stages of the process.

Children are capable of providing unique perspectives on their own health and wellbeing, and on the services they engage with.(306,307) There are key elements of active participation embedded in Article 13 of the UNCRC.(305) These elements are that the child receives relevant information, they are given an opportunity to freely express their own views, and their opinions are considered in the decision-making process.(305) The research shows that the participation of children in decisions surrounding their health and wellbeing should always be sought, and their involvement should be informed by both their abilities and circumstances.(306,316,317,318,319)

Children should be provided with developmentally appropriate information and options, so that they know what to expect, what is expected of them and can participate in a developmentally appropriate way.(311,317,320) A 2017 study undertaken in Australia explored children's experiences of growing up with a long-term condition, such as hemophilia or Crohn's disease.(321) The children interviewed demonstrated different levels of understanding of their condition. Some of this was attributable to their age, but also their level of experience of living with the condition. The study showed that the children had gained information mostly from their parents, while others had found information from books and online.(321) A similar study undertaken in 2013 in America explored the satisfaction of parents and children using hospital-based psychiatric services. Both parents and children in this study highlighted that their satisfaction with the service was closely linked to how effectively the psychiatrist communicated their clinical impressions and recommendations to the family.(322) The results from both of these studies show the need for staff working with children to engage them in conversations in order to explain information to them in an age-appropriate and descriptive manner so that it makes sense in their day-to-day lives.(321,322)

Decision-making capacity denotes a person's ability to make choices. The presence of decision-making capacity is determined if an individual can do the following:

- communicate a decision
- understand relevant information
- appreciate the situation and likely consequences
- reason about treatment options.(317,323)

Studies show that children's health and social care services could improve the health and wellbeing of children by supporting and empowering them to exercise their right to participate in decisions surrounding their health and wellbeing.(311,318,319,324) In order to acknowledge them as partners in their care and support, the questions of 'if' and 'when' children can contribute needs to be overcome in favour of the question 'how' they can contribute.(319) It is the responsibility of caregivers and healthcare professionals to create an environment that allows children to exercise their capacity and learn to make decisions.(323)

The literature shows that legislation across the world acknowledges that the capacity to make decisions does not suddenly appear when a person reaches the age of majority and grants decision-making rights to those children who demonstrate sufficient capacity.(311,323,325) The research points to the fact that developmental changes which occur during adolescence can lead to increased decision-making capacity, but also increased risk-taking behaviour. This can lead to seemingly poor choices.(311) Meanwhile, some children with cognitive impairments and special needs may never develop the capacity to allow meaningful participation in decision-making.(311) A 2019 study undertaken in Canada recommended that children whose capacity to consent is of concern should be no less entitled to some confidentiality consideration and should be granted privacy to whatever extent possible.(325) The evidence shows that it is important that children's health and social care service providers take a nuanced approach to assessing capacity for decision-making, and recognise that decision-making capacity may fluctuate over time and should be continuously reassessed.(311,316,319)

In the vast majority of situations children live and thrive within a family system. Family-centred care is based on the understanding that the family is the child's primary source of strength and support. A family-centred, shared decision-making model best respects and supports the emerging capacity of the child.(311,317,322,324,326,327,328,329,330)

An American study undertaken in 2017, shows that the parent is often the only participant playing a consistent role across a child's care, for example, they might be involved in organising and following up on all appointments.(331) Family-centred care is grounded in collaboration among children, families, and care professionals in the planning, delivery, and evaluation of the care and support that a child receives when they are using health and social care services. These collaborative relationships are guided by the following principles:(327,332,333,334,335,336,337,338,339,340,341)

- Listening to and respecting each child and their family: Honouring racial, ethnic, cultural and socio-economic background and lived experiences and incorporating them in accordance with family preference into the planning and delivery of care.
- Ensuring flexibility in organisational policies, procedures, and practices so services can be tailored to the unique needs of the child.
- Sharing information with children and families on an ongoing basis and in ways they find useful, so that they may effectively participate in care and decision-making to the level they choose.
- Providing formal and informal support for the child and family during each phase of the child's life: The individual needs of the parent and child are varied and can change across different developmental age spans, treatment regimes, prognoses, and settings.
- Recognising and building on the strengths of individual children and families and empowering them to discover their own strengths, build confidence, and

participation in making choices and decisions about their care.(327,332,333,334,335,336,337,338,339,340,341)

The evidence shows that family-centred care can improve outcomes for children and their family, improve their experience, increase their satisfaction, build on their strengths, and improve adherence to the proposed treatment plan. For providers, family-centred care can increase professional satisfaction, and lead to more effective use of healthcare resources.(327,332,335,336,342,343,344) This approach to care recognises that children and their families are integral members of the care team and so they should have the opportunity to participate in the development of goal-directed care programmes and have ownership of it.(332,345,346) One example of using a family-centred approach can be found in a 2019 study undertaken in America that examined the development of a homecare education intervention for children with a congenital health disease.(347) Using a collaborative approach, the care professionals worked with parents to co-create an intervention that could be delivered through web-based technology. The input of parents into the process meant that the intervention was usable and relevant to the target population.(347)

This finding is further supported by a 2019 study undertaken in Iceland. This study examined the drivers of satisfaction among families of children with cancer, kidney, liver and gastrointestinal diseases in a hospital setting.(348) The onset of severe physical illnesses such as these, and the subsequent periods of hospitalisation, are recognised as stressful life events for families and children. The results suggest that families need to be supported by care professionals while their child is in hospital. The findings showed that parents reported feeling more satisfied with the quality of care when they felt supported and involved in their child's care.(348)

Goal setting with children and families requires flexible processes that will accommodate changing family and child roles over time.(349) The evidence shows that goal setting is also relevant to parents of children with life-limiting or life-threatening conditions as they approach end of life. A 2014 study undertaken in England explored this issue.(349) The results of this study highlight the importance of involving the family is discussions about the child's care. Through this families could identify realistic goals and make choices about end-of-life care that helped them to feel prepared, and improved satisfaction with care.(349) A separate study undertaken in England in 2014, explored the changes that occurred to the parent-care professional relationship when parents realised their child was dying.(335) The concept of parents and staff working on the same team occurred when a collaborative, respectful relationship was forged. Parents described feeling included in the care team, noting that "we all worked together for the common cause which was my son". Parents were encouraged to participate, to the extent they felt able, with care professionals.(335)

The evidence also supports family-centred interventions for children with emotional and behavioural health concerns. Generally these interventions take an approach that focuses on enhancing children's ability to manage their emotions and behaviours through specialised parenting tools and approaches. Because the parent-child relationship is a central force in the early emotional and behavioural wellbeing of children, interventions focus on enhancing that relationship to promote child wellbeing. Each intervention focused on enhancing parents ability to identify and respond to the child's emotional needs.(350,351)

A 2013 Canadian study examined factors that are most important in determining parent perceptions of family-centred care.(352) A cross-sectional survey was completed by parents, service providers, and CEOs, from organisations delivering children's rehabilitation services for children with disabilities including cerebral palsy, spina bifida, and developmental delay. The findings from this study indicated that parent satisfaction with services was strongly influenced by the perception that services are more family-centred.(352) The authors suggest that organisations can employ out the following family-centred behaviours:

- formally adopting a family-centred approach
- having a specific person or team lead the development of family-centred care
- providing information about family centred care to families
- training staff in family centred care delivery
- changing procedures to be more family centred, for example involving parents in goal setting.

The topic of how children's health and social care services can encourage children and families to participate in decisions surrounding the child's health and wellbeing is discussed in Section 5.5.4.

## 5.3. Principle 2: Safety and wellbeing

### 5.3.1. Introduction

All children's needs are different and each child requires an approach tailored to their individual strengths and needs.(9,353,354,355) It is important that health and social care services address the whole needs of the child, not just the needs the child presents with. Services providers should take into consideration the impact of social and environmental factors, as well as the developmental stage of the child on the child's overall health and wellbeing.(353,356,357,358,359,360,361) In doing so, services can ensure the best outcomes for children and support them to fulfil their potential.

The findings from the evidence reviewed are set out under the following subheadings:

- The child's whole needs: When deciding on what intervention is appropriate for a child, health and social care service providers must consider the child's wider environment and their evolving developmental abilities.(356,357,358,359,360,361,362,363)
- Access to care: The evidence also identified groups who may encounter difficulties in accessing health and social care services such as: children with complex needs, children with mental health issues, and children living in isolated locations.(338,364,365,366)
- The child's best interests are paramount: The holistic assessments of the child's whole needs is vital to support better outcomes for children. This section focuses on children who may be more vulnerable to poorer health and wellbeing outcomes, tailored interventions for children, and the transition out of care, or from child to adult care services.(314,367,368,369)

### 5.3.2. The child's whole needs

It is important that health and social care services address the whole needs of the child, not just the needs the child is presenting with. A child's health and wellbeing is influenced by a wide range of societal and environmental factors which include access to housing, food, education, transportation, and community-based supports.(356,357,358,359,360,361,362,363)

Childhood is a crucial period for the development of physical and mental wellbeing.(370,371) There is a substantial body of knowledge regarding the impact societal and environmental factors have on a child's health and wellbeing outcomes, as well as their health and wellbeing outcomes in adult life.(356,357,362,372,373,374,375,376) For example, social disadvantage in pregnancy is associated with high risk of preterm birth which has been shown to affect adolescent and adult health.(356) The evidence shows that exposure to childhood adversity[†††††††], and low socio-economic status are also key predictors of mental illness.(376,377,378,379,380,381,382) Despite this understanding regarding the impact of social factors on health outcomes, the social context, and its impact on child health and wellbeing, has tended to be overshadowed by the dominance of the 'medical model' of care which falls short of addressing the underlying factors influencing health.(356,357,372,375,383,384) A functional or medical perspective may focus on the presenting problem and suggest a goal oriented, relatively static solution.(374) In contrast, the social model of care describes the importance of environmental influences on children's health and wellbeing. The

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[†††††††] Childhood adversity most commonly includes abuse at the hands of a caregiver, parent substance use problems, family psychiatric problem, parent separation or divorce, witnessing domestic violence, and family member incarceration.(372)

emphasis is on encouraging children to pursue goals, and to actively participate within their environment. In doing so they can influence the social structures of their environment.(374)

Children's health and social care services can build strength and capacity in children, their families and their communities.(9) The goals of this work include prevention and early identification. This issue is also explored in the context of the child and family in Section 5.2.3. The evidence highlights that community-based prevention and early intervention strategies can 'interrupt the cycle of disadvantage and inequality passed through generations'.(9) The research shows that early recognition and a focus on mental health wellbeing can support better outcomes for children.(379,385) A 2018 study undertaken in Ireland suggests that by the age of 13 years, one in three children in Ireland are likely to have experienced some type of mental disorder and by the age of 24 years, that rate will have increased to over one in two.(379) A further study undertaken in 2019 in Canada reported that approximately half of all lifetime cases of mental illness emerge before the age of 12.(370) Preventive interventions have demonstrated powerful, lasting effects on mental health, relationships, physical health, education and social wellbeing into adulthood.(379,385)

Childhood is a time when patterns of lifestyle behaviours are established.(370,380,386) A number of studies point to the fact that the leading causes of morbidity and mortality in adulthood have direct underpinnings in modifiable behaviours in childhood, such as obesity, substance use, and physical inactivity.(387,388,389,390,391,392,393,394) When deciding on what intervention is appropriate for a child, health and social care service providers must consider the child's evolving developmental abilities. Adolescence in particular is a key time for health promotion efforts that will influence overall health in adulthood.(378,388,390,395,396) The evidence shows that recognising and targeting lifestyle behaviours at this developmental stage can improve prevention outcomes for physical and mental illness.(370,380,388,391)

### 5.3.3. Access to care

Access to care is defined as the opportunity to reach and obtain appropriate care and support services in situations of perceived need.(367) Services providers should take into consideration the impact of social and environmental factors on a child's ability to access services when deciding on what intervention is appropriate for a child.(356,357,358,359,360,361,362,363) The implications of the socio-economic position that the child lives in is looked at in Section 5.3.4. The evidence also highlights certain groups of children who may encounter difficulties in accessing health and social care services and are at risk of adverse outcomes. This includes, children with complex care needs, children with mental health issues, and children living in isolated locations.(338,364,365,397,398)

Children's complex care needs are individual and are affected by family, the environment, health and social care structures. The nature of complex care needs means that children living with such needs pose challenges for integrated health and social care delivery for many reasons, including:

- they require dynamic and responsive health and social care over a long period
- they require service delivery coordination functions
- the clinical presentation can be rare and therefore challenge care management.(338)

A 2018 study examined approaches to care management of children living with complex care needs[‡‡‡‡‡‡‡] in 30 European countries, and the implications for service delivery. The analysis showed that less than half of the countries surveyed had policies and procedures in place to support care coordination for children living with complex care needs.(338) The authors noted that there are generally few opportunities for children and their families to express any concerns, often because the considerable time required by parents to care for their children does not leave them with time to pursue this issue with services. This issue carries a risk of heightened health inequality where parents are not able to advocate strongly for their children's needs. The issues of geographical isolation and of geographical equity of access to care were also identified as key barriers to care coordination.(338)

Children with mental health concerns require access to specialised services.(399) However, the evidence shows that most specialised services cannot be accessed directly and referral routes can be hard to navigate.(399) A 2017 UK study found that a lack of knowledge about available services, and limited understanding of how to access appropriate care are among the key barriers to accessing mental health services encountered by children and parents.(364) In 2017, a study undertaken in America identified that for many children and families in crisis, emergency departments were often the first point of contact with the mental health care system, because they are always accessible and do not require and appointment or referral.(365) Findings from these studies show that providing step-by-step guidelines and explaining in a user-friendly age-appropriate manner how to access mental health care and support, may facilitate access to mental health care.(364)

Long waiting times and the limited availability of specialist services add another barrier to access.(397,398) One possible solution, identified in the literature, is to shift the focus from one in which individual specialists provide direct services to children,

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[‡‡‡‡‡‡‡] This study looked at the complex care needs of children living with traumatic brain injury, long-term ventilation, and intractable epilepsy.

to one in which specialists are engaged in consultative and collaborative care activities with primary care providers.(397,398,400,401,402,403,404) The research indicates that children and parents are more willing to access a collaborative model of care.(347,398,400,405,406) One Australian study undertaken in 2019, found that the majority of parents prefer to receive information and support from their primary care provider. Parents valued the specialist knowledge of their primary care provider and the fact that the service was free and or convenient to attend.(405)

A 2012 study undertaken in America examined if a collaborative care model was associated with improved access to child psychiatry services. In this programme, primary care providers had access to phone consultations with psychiatry specialists. The specialists conducted an evaluation over the phone and developed a treatment plan in collaboration with the primary care provider.(400) A collaborative care model could allow mental health specialists to influence the treatment of a larger number of children, and a large proportion of children would stay with their primary care provider for ongoing treatment.(400)

Limited availability and the distant geographical location of specialist services were identified as barriers for access to timely care and support, and this is especially prominent in isolated areas.(364) The lack of health and social care facilities and the difficulty in accessing specialised health care for isolated communities puts children within these communities at risk of poor health and wellbeing outcomes.(401,407) Understanding the barriers these communities face can provide important information to overcome some of the obstacles to accessing appropriate care.(407) For example, a 2013 study on outpatient non-attendance in England found that those not attending their appointments are more likely to travel by means other than car, and have longer journey times.(408) The authors examined the views of clinical, and managerial healthcare staff regarding the management of non-attendance. The results show that responsibilities regarding missed appointments are not clear across healthcare sectors, but GPs are uniquely placed to address non-attendance issues by addressing any potential reasons for non-attendance with parents prior to making a referral.

The findings from the evidence show that technology can be used in all areas of health and social care. The research shows that children prefer tailored, technology-based, interactive programmes versus more traditional paper diary programmes for targeting lifestyle behaviours. Therefore, interventions using these methods may be a more favourable addition to clinical care compared to traditional methods.(409) Mobile health has the potential to enhance access to care for children in isolated locations.(409,410,411) A 2019 study undertaken in America examined how a mobile-health tool could assist children and parents in making important decisions as to where and when to seek care. The study found that most participants would use a mobile health application to assist in screening their needs and they would avoid an emergency hospital visit if the mobile health tool suggested that their needs were low risk.(410) the literature indicated (or similar wording) that providing mobile-health options to children in isolated locations can help them to reach and obtain appropriate care and support services.

The evidence also suggests that using technology to deliver mental health services can be an effective way of increasing access for users.(364) In a UK based survey undertaken in 2020, young people highlighted the importance of online and digital tools to facilitate ongoing support where face-to-face support was not available.(412) However, some respondents highlighted technological challenges as well as personal preferences and effectiveness. Most respondents felt that support by phone or online would be ineffective or less effective than face-to-face support, because of a lack of privacy at home or a fear of their family overhearing the session. In some cases, family relationships are at the centre of young people's therapy, and so it would be difficult to discuss concerns while at home.(412)

### 5.3.4. Childs best interests are paramount

#### Vulnerable children

The evidence highlights that some groups of children may be more vulnerable to poorer health and wellbeing outcomes. These groups include children and parents who speak limited English, or have low health literacy[§§§§§§], migrant children, and children who are experiencing homelessness.(367,368,413)

Language barriers between children and health and social care providers have been shown to reduce the quality of care and increase the risk of adverse events for children both in hospitals and primary care settings.(367,368,371,414,415) Research shows that the number of people who have a primary language other than English has been steadily increasing for decades.(368) The impacts of this are perceived strongly in the health and social care setting. The evidence shows that there are five specific impacts on children and parents who speak limited English:

1. Decreased access to care: children are less likely to have a regular source of care and have greater problems accessing specialised care.
2. Decreased quality of care: children have poorer management of medical conditions than their English speaking peers. Additionally they are more likely to utilise acute or emergency care services over primary care services.

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[§§§§§§] The ability to read information and instructions, as well as to understand the health system, is defined as a person's health literacy.(362)

3. Decreased patient-provider bond: language barriers make it more difficult to establish and maintain a patient-provider relationship.
4. Patient dissatisfaction: parents of children with providers who do not use or understand the same language report worse interpersonal care.
5. Provider dissatisfaction: providers report being frustrated when they feel that important information is not being communicated.(368)

One of the most important methods to bridge a language gap was found to be through interpreter services. The research shows that children who receive interpreter services get more recommended preventative services, make more visits to their primary care provider, and have more prescriptions written and filled.(368) It is also important to consider that children are often used as ad-hoc interpreters in the children's health services. Children, particularly young children, often lack the maturity and knowledge to interpret in a medical setting and this can result in the miscommunication of important information. For example, the evidence shows that children who were asked to interpret their own medical information to their parents were embarrassed by, and tended to ignore, questions about menstruation, bowel movements, and other bodily functions.(368)

Research shows that language appropriate written materials and visual aids can supplement verbal communication and provide a visual tool for sharing information.(314,368,369,415,416) Health literacy has been shown to predict health behaviours and outcomes.(417) Parents are often the main gatekeepers and advocates for their children. Their health literacy may be critical to the child's compliance with recommended health promotion, disease prevention, and disease management plans for the child.(418) An American study undertaken in 2012 assessed the accuracy of parent understanding of children's prescribed medications. Twenty eight percent of the sample had low-health literacy and the results show that while parents might think they understand what the doctor has told them about medications and administration, the information is not typically communicated effectively from the doctor to the parent.(369) Knowledge of parental capacity to understand and carry out tasks is necessary to ensure that parents can work collaboratively with staff in promoting the health and wellbeing of their children.(314,418)

All countries in the EU have signed the UNCRC which states that migrant children, regardless of their legal status, have the right to health and social care of the same standards as non-migrant children.(305) Research highlights that migrant children are a particularly vulnerable group and have increased health risks.(314,367) Unaccompanied migrant children are at higher risk for mental health problems, which is associated with the stress of separation from parents, traumatic events including the risk of sexual and gender-based violence, and the lack of social support.(414,416,419)

Research undertaken in the Netherlands in 2016 shows that paediatricians experience several barriers that impact on the accessibility and quality to healthcare for migrant children. The main barriers reported were:

- Frequent relocations: the impact of the disruption in the continuity of care ranged from failing to attend a follow-up appointment, to missing a planned and sometimes life-saving treatment.
- Unknown medical history: refugee children usually enter the country without any medical record from their country of origin. The health screening performed in the Netherlands relies solely on oral information provided by children and parents. This is especially a problem with unaccompanied children who often do not know their medical history.
- Poor handovers of medical records: complications arose due to the lack of a central medical record form in the Netherlands. This lead to impaired communication between services.
- Poor health literacy: errors with medication were reported. Prescriptions were not understood and allergies were not communicated, resulting in medication errors leading to severe allergic reactions.
- Cultural differences: cultural background can define the presenting symptoms and the presenting need. For example, in one report a psychotic child was admitted to a paediatric ward where the child's family gathered exorcists to expel the bad spirits. The paediatrician contacted a transcultural psychiatrist to offer treatment to the child in collaboration with the family.(367)

To overcome these barriers and improve health and wellbeing outcomes for migrant children, strategies that acknowledge the unique needs of the child must be implemented at all levels of the healthcare system.(9,366,416) Widespread lack of guidelines and specific provider training should be addressed. In doing so, health and social care providers will be better able to provide linguistically, and culturally appropriate care to migrant children.(366,416) Research undertaken in Ireland in 2018 found that statutory services working with unaccompanied minors have a level of discretion in their work that allows them to safeguard the child's best interests.[********](9) In this study, staff carried out a multidisciplinary risk and needs

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[********] This Tusla group of social workers engage with children who are seeking asylum, under 18, outside of their country of origin, who have applied for asylum and who are separated from the parent or legal career.

assessment, to inform the child's asylum process and to ensure appropriate wrap-around services were provided to support them.(9)

In order to address child health and wellbeing concerns, health and social care professionals need to understand how poverty affects the wellbeing and functioning of children and their families.(9) The evidence suggest there are four elements to developing staff practice so that they can work effectively with children and families experiencing poverty. These are:

- recognising individual differences in the experiences of poverty
- understanding the links between poverty, family functioning and individual behaviour
- developing the capacity to talk about poverty issues with families
- developing the anti-poverty potential of health and social care services as agents of change.(9)

Homelessness among families remains a persistent social and public health challenge.(353,354,413) The literature documents a range of challenges associated with homelessness in childhood, distinct from that of low-income children more broadly. Children experiencing homelessness are at greater risk for health concerns including under-nutrition, chronic illness, behaviour problems, and dental decay.(413) In addition, children who are experiencing homelessness perform worse academically and often struggle with social functioning, compared with their peers who are living in secure housing.(413)

There is an increased awareness of the role that children's health and social care providers can play in providing comprehensive, longitudinal, collaborative care for children experiencing homelessness. However, research undertaken in 2017 in America has shown that accessing this care can be difficult for families who are experiencing homelessness with higher outpatient and emergency care use observed for these families, compared with their housed peers.(413) This study found that primary care providers should assist and support children who are experiencing homelessness to access health care services by promoting appropriate services.(413) Determining how interventions can be tailored to the varying logistical, emotional and financial needs of families, is vital.(353,354)

### Tailored interventions for children

Adopting a child-centred approach to practice means focusing on the individual needs of the child and offering tailored support to children. This includes children with disabilities, and children at risk of child welfare and protection issues.

Children with a physical disability often come across restrictions in their everyday lives.(355) The research shows that parents have knowledge and experience on how to shape the child's environment to support engagement in preferred and desired activities.(355) A 2017 study undertaken in the Netherlands aimed to gain insight into what parents actually do every day to enhance their child's participation at home, at school, and in the community. Parents completed a diary over a seven-day period. All participants had a child with a physical disability that was neurological and non-progressive in nature, such as cerebral palsy or spina bifida, and who was living at home.(355) In one week, on every single day, all participating parents described several efforts to enhance the participation of their children with a physical disability by using, enabling, or changing the social and physical environment, or by supporting their child to perform or engage in meaningful activities. These actions were primarily a result of challenges caused by restrictions in social and physical environments. Parents expressed a need for 'accessible products and environments' like playgrounds, and showed their own initiatives to change the physical environment into a more suitable one to support their child's participation.(355) The results of this study show that in order to effectively support parents while enabling the participation of their children in daily life, tailored approaches are needed. These approaches may also contribute to stress reduction and better health and wellbeing of parents.(355)

The evidence also addresses the issue of professional discretion afforded to social workers working with children where there are child welfare or protection concerns. Recognition and analysis of the following factors contributes to the type, timing and duration of interventions considered for use in child welfare and protection:

- gender
- age
- developmental stage
- family make up
- ethnicity
- parental circumstances
- the nature of the abuse
- the child's pathway through the child welfare and protection system.(9)

Supporting the importance of professional discretion, the research highlights that, in current practice, social workers will often follow procedures set out by their organisations, at times using these in place of professional judgement.(9) This can lead to practitioners 'doing things right, not doing the right thing'. This study calls for an approach that recognises that social workers must tailor their response to the individual child, their circumstances and best interests.(9)

## Transitions of care

Effective transition from children's services to adult services, or out-of-care services, is intended to ensure continuity of developmental and age appropriate care for all children.(420) The evidence suggests that well planned, structured transitional care can prevent deterioration in children's health and wellbeing and improve the young adult's self-management skills and satisfaction.(315,421,422,423,424,425) Adolescents are recognised as a vulnerable group in terms of high rates of behavioural health risks and susceptibility to worsening chronic health conditions.(426,427,428,429,430) The transition from child to adult care is known to be a period of risk for poor health outcomes.(420,423) Therefore, the transfer of adolescents from child to adult services is a crucial time in the health of young people who may potentially fall into a poorly managed 'care gap'.(429)

The evidence reviewed highlights childhood cancer as a disease which has seen survival rates increase over the past several decades, resulting in an increasing population of long-term survivors.(431,432,433) These improvements have resulted in increased numbers of survivors transitioning from cancer care to care for complex needs associated with their recovery.(431,432) One 2017 study undertaken in Australia found that children engaged in follow-up care had better health and educational outcomes.(432) Another study undertaken in 2018 in America found that children benefitted from being empowered by health care professionals to become knowledgeable about their medical history and to become effective self-advocates of their care in the future.(431)

Discharge from hospital to home is one of the most common transitions in children's health care. Although returning home after hospitalisation often signifies a positive event for children and their families, the child's safety is at risk if the discharge process does not adequately coordinate future care.(434) Inadequate discharge communication and planning has been shown to contribute to hospital readmissions.(434) The evidence also shows that transition is experienced differently for those of varying socio-economic statuses. Financial stressors, barriers to accessing follow-up care and limited health literacy can complicate recovery from acute illness.(353) Developing and implementing an effective discharge plan and coordinating future care is paramount to improving outcomes for children.(418,434) A 2016 study undertaken by the American Academy of Pediatrics found the following principles reflect effective transition of care from hospital to homecare:

- assigned accountability for tasks and outcomes
- clear and direct communication of treatment plans and follow-up expectations
- involvement of the child and family members.(435)

For young people with experience of residential or foster care, their transition from children's social services into independent living can be challenging and disruptive and they require ongoing support to navigate this change.(9) Research conducted in Australia in 2014 shows that the transition from care to independent living is an unsettled time for children and one study questioned how developmentally ready the young person is, having just turned 18, to face the challenges that await them in adulthood and in a newly self-sufficient life. The research shows that, in this transition the importance of early planning, coordinated care and support, the provision of secure housing, financial support, and community resources can help to reduce the vulnerability of young people leaving care during their transition into adulthood.(9)

There is substantial evidence of children from child care to adult care for children with chronic conditions.[††††††††] Advances in medicine have increased the likelihood that children with chronic conditions will transition to adulthood, and so to adult services.(315,420,421,423,427,436,437,438) Transition in the context of adolescents is described as 'a purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents as they grow up learning to live with their lifelong health condition.'(421) This description highlights that the transition from paediatric to adult care occurs at a time when young people face numerous life changes including education, employment, relationships and living arrangements.(421,428,439)

A 2014 study undertaken in America identified transition programmes that exist for children with special healthcare needs, such as diabetes, organ transplant, sickle-cell disease.(420) Generally, studies defined successful transition as attendance in adult care or continued medication adherence.(420) Common components of care included educational materials, a special clinic for children in transition, and the use of a transition coordinator.(420)

The research indicated that intellectual disability can be associated with some chronic diseases that affect children transitioning to adult care. The severity of disability influences the degree with which a young adult can manage his or her own care.(420) Physical and developmental delays or impairment can affect the ability of individuals to navigate the medical system independently. Transition needs to include allowances for cognitive ability and developmental delay for the subjects, if variability exists.(420)

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[††††††††] Chronic conditions discussed in the evidence reviewed include cystic fibrosis, sickle cell disease, congenital health disease, diabetes, asthma, obesity, and neuromuscular disorders.

The evidence highlights key barriers to effective transition from paediatric to adult care. These include:

- the relationship with the paediatric care provider
- the impact of increased responsibility on the child as they transition into adulthood
- the changing role of parents as their child grows.

From the evidence reviewed, the most prominent barrier mentioned by children with chronic conditions and parents is difficulty in leaving their paediatric care providers with whom they have had a long-standing relationship.(421,426,427,436) Children and parents report that the approach to care in the paediatric setting feels personalised and welcoming, and they have concerns about moving away from that.(428,429) A 2019 study from Ireland found that some adolescents felt rejected by the paediatric services.(421) Another study undertaken in America in 2019 reported that young adults had difficulties engaging with adult-oriented providers. They feel they must advocate more strongly for themselves with adult providers than paediatric ones.(428)

Services providing care and support to children are often more apt to interact with parents 'on behalf of' children, whereas the adult care system is more likely to hold the young adult person responsible for self-management.(438,439,440) The evidence indicates that some adolescents were concerned about enhanced responsibility as they lacked confidence in their self-management capabilities and communicating with professionals. However, the majority welcomed the move to adult services as they looked forward to being treated as an adult. Positive perspectives on actual or anticipated transfer included a growing sense of responsibility and access to age-appropriate communication.(421) The evidence shows that adolescents require support and education to develop self-management and self-advocacy skills for lifelong condition management.(421,429,439,441)

In parallel with their adolescent child, parents were required to go through their own process of transition. Parents are required to adjust their caregiving role, gradually relinquishing control of their child's long-term care and supporting their child's growing independence.(436) The research shows that parents generally view their child's progression towards self-care as a positive and incremental process which they seek to facilitate through supporting their child's development of self-management skills.(421,436) However, parents often find transition difficult due to this changing role, anxiety regarding their child's health, wellbeing and developmental trajectory, and lack of information and preparation.(421,436)

A 2013 study undertaken in the Netherlands examined parents experiences with the transfer from children's to adult care services for children with profound intellectual and multiple disabilities.(437) Parents valued the care provided by the children's services and wished to see it continued.(437) They were critical about how they had been prepared for transfer to adult care. Parents provided suggestions to improve transitional care, such as early start, information provision, and a joint consultation between child and adult care.(437)

The evidence highlights that parents can be key facilitators of their child's transition, supporting and encouraging them to gradually assume responsibility.(421,428,442) Staff need to work in partnership with parents, in order to help them to facilitate their child's transition, and to maintain their own wellbeing.(436,439) The research shows that adult providers should listen to the parents as the expert caregivers of their grown child, and support them as they adjust their role to that of 'partner'; sharing management with their child in a state of interdependence, as a bridge to full independence.(436,437,441) Parents need clarification on their role, specific guidance, and support from service providers so that they can support their child in the transition process.(421,436,437)

## 5.4. Principle 3: Accountability

### 5.4.1. Introduction

The evidence shows that accountable children's health and social care services are services that have a clear vision for their work, support their staff to deliver on this vision, work well with other relevant services, and that regularly assess the impact of their work on those that they are caring for and supporting.(9,363,443,444,445,446) This principle is divided into the following subheadings:

- leadership
- interagency collaboration
- measuring impact.

Leadership plays a key role in terms of service or organisation's accountability. Leadership is needed at every level of a service, and specifically at local level to ensure care is coordinated effectively across children's health and social care services, and to improve outcomes for children.(443,444)

Accountable children's health and social care services should work together to ensure the best outcomes for children. Services should be open to developing structures and systems that improve interagency collaboration, and they should have clear lines of accountability when working together to care for and support children. This encourages effective and sustainable cooperation, both within and between children's health and social care services.(9)

The evidence shows that children's health and social care services should focus not just on the delivery of their service, but also on the impact this service is having on children and their families. They should develop suitable outcomes and indicators for their work and monitor against there to continuously improve services, and outcomes for children.(9,447)

### 5.4.2. Leadership

The research highlights strong leadership as one of the factors most important to achieving good practice and ensuring strong collaboration to achieve the best outcomes for children.(443,444) The research shows that managers should receive training and coaching to improve leadership skills.(444) In addition, leadership training should include an emphasis on creating a supportive culture of listening and communicating with staff and those using the service, as well as training and development for staff. Strong leadership impacts on the values, and motivation of individual staff. This in turn shapes how these staff provide care and support to achieve the best outcomes for children.(9,443,444) How this impacts on care service delivery and quality is looked at in detail in Section 5.5.

The research specifically highlights that strong and skilled leadership is required at a local level to sustain reform.(356,362,375,378,379,380,448,449,450,451,452,453,454,455) Section 5.3.2. looks at how a child's health and wellbeing is influenced by a wide range of social and environmental factors. While reducing the adverse effects of these factors on children requires leadership at the national political level, the evidence suggests that there are other opportunities for local leadership to improve health and wellbeing outcomes for children. Based on their gatekeeper role to a wide range of health and social care services, their approachability and their continuous care relationship with families, GPs are in a unique position to identify children at risk of adverse effects, and to lead and coordinate care and support for them.(356,362,375,378,379,380,448,449,450,451,452,453,454,455,456)

A study conducted in England in 2015 explored GPs perspectives about their role in the care of children with long-term conditions, such as cystic fibrosis, epilepsy, and type 1 diabetes. The study revealed that GPs believe that they are the coordinators of care, but are often unsure of their roles and responsibilities in supporting children.(457,458) Participants in the study highlighted the importance of knowing their own limits and having an awareness of where to seek advice and support that would assist them in specialist areas. The authors suggest that improving communication between health and social care services would clarify roles and help improve the confidence of GPs.(457)

GPs also play an important role in meeting mental health needs of children. Children attend their GP regularly and, as they can often present with several coexisting risk behaviours or psychosocial problems, GPs are ideally placed to recognise symptoms of mental illness, holistically address those issues, and refer the child to a specialist if required.(456,459,460,461,462,463,464,465) A 2012 study undertaken in the UK looking at child mental health in primary care highlighted the need for a good system of communication between primary and secondary healthcare services.(460) Such improvements in communication would ensure that GPs have accurate information to share with parents about both the procedures involved with a referral and the length of time it might take before interventions can commence.(460)

A 2020 study undertaken in the Netherlands investigated GPs sensitivity towards anxiety disorders using pictures describing the mixture of problems that might be disclosed during consultations.(456) Before being presented with the vignettes, the majority of participants reported that they would refer a child to specialised services when they suspect anxiety disorders. However, when presented with vignettes that were constructed to mimic how children would present with symptoms of anxiety disorders, the majority of GPs did not notice the depicted symptoms as anxiety disorder, and only 12% of the GPs who recognised anxiety in the vignettes actually selected the referral option. The authors conclude that improving GPs familiarity with initial symptom presentation has the potential to improve timely recognition and referral.(456) These findings are supported by a study undertaken in Ireland conducted in 2012. The authors of this study suggest that training could influence the quality of consultations with children in primary care and improve GPs knowledge, skills and self-perceived competence.(459)

A 2013 study undertaken in England explored the issue of missed appointments in primary care clinics. The authors note that non-attendance is particularly concerning for children as they do not themselves choose to miss appointments, rather they are not brought to these appointments by parents.(408) The results from this analysis show that non-attendance was related to parent’s perceptions, for example, when they disagreed with the need for the appointment, or they believed the cost of attending the appointment outweighed the benefits. In some instances, missed appointments indicated family vulnerability and potential threats to children’s welfare.(408) The authors recommend that GPs are uniquely situated to address parent’s concerns and prevent missed appointments.

### 5.4.3. Interagency collaboration

Research highlights that accountable children’s health and social care services should understand the benefits of interagency collaboration, such as better use of their shared resources, minimising duplication, and learning from each other to ensure that children and families get the best outcomes possible.(345,398,445,446,466,467) Health and social care services should be open to developing structures and systems that improve interagency collaboration.

The evidence shows that no single discipline or service can address the whole needs of the child.(445) An integrated and collaborative care model is defined in the literature as a team-based approach that endorses the partnership of children and families working together with a multidisciplinary team from varied disciplines and services. Their aim is to provide care tailored to the unique and changing needs of the child, and to improve the child's experience.(345,398,445,446,466,467)

The evidence highlights that vulnerable groups of children with complex needs may need care and support from more than one discipline or service type.(468) The international evidence points to youth in the juvenile justice system as a vulnerable population with complex needs.(446,469) Children involved in the juvenile justice system often have high rates of mental health difficulties and related behaviour problems. These children require a multidisciplinary effort from agencies including justice, mental health, education, and child welfare.(446,469)

One American study undertaken in 2019 interviewed representatives of youth probation, mental health, education, and health services who participated in multi-agency reforms.(446) The interviews showed that most participants felt they were engaged in a collaborative effort – joined together to achieve a common goal to foster better outcomes for young people in detention.(446) Another 2019 study undertaken in America also looked at the feasibility of implementing an evidence-based intervention in a juvenile justice setting.(469) The intervention integrated the perspectives and expertise of psychologists, judges, detention staff, and probation officers. The judges, detention staff, and probation officers had valuable information about the high number of adolescents in detention and had identified a need to reduce the number of children entering the system on charges of family violence. The psychologists held expertise in evidence-based practices for addressing adolescent's aggression, problematic family dynamics, and related mental health problems. Together they committed to addressing this problem by pooling their diverse areas of expertise. They adopted a collaborative, values-driven, and committed approach.(469) The authors found that the behavioural skills they taught to participants such as conflict resolution and active listening, were integral to the success of the intervention.(469)

Section 5.3.2. looks at the topic of prevention in more detail. The research shows that prevention of major threats to children's health and wellbeing, such as behavioural issues, access to care, and the control and management of chronic diseases requires integrated approaches across a range of services.(345,398,406,445,466,470,471)

Behavioural health is related to issues such as substance use or eating disorders. The evidence shows that for children, care to address these issues requires integrated care coordination from a diverse team of providers who work alongside the family to address complex needs and circumstances.(362,373,374,376,377,450) One example that a child, family and a support team might address is the impact that the child's exposure to adverse childhood experiences has had on them, and the effect of this on their long-term wellbeing.(471) Integrated care coordination programmes can involve families, physicians, nurses, social workers, and community partners, for example schools.(362) The evidence shows that when team-based, integrated care coordination programmes are adopted, service provision for children and families shifts from reactive and episodic to proactive and comprehensive.(362,373,374,376,377,450) A 2016 study undertaken in America examined the scope of integrated behavioural health services in children's primary care. The authors found that integrated behavioural health professionals working in these settings provided a variety of services to children and families ranging from prevention and health promotion activities to screening and identification processes to more traditional intervention around mental health issues.(471) The study found that these services have the potential to prevent, identify and treat various mental health and environmental concerns early in a child's life and preventing problems from escalating.

The evidence demonstrates the importance of taking a joined-up view of children, families, and communities. A systematic review undertaken in 2016, found that staff in children's social services often addressed child welfare and protection concerns, without taking into account the wider issues that families were dealing with and that could be contributing to these concerns, such as addiction or poverty. The authors suggest that this lack of joined-up thinking leads to poorer outcomes for children. To address this, the authors recommended that relevant services work together to develop an appropriate suite of interventions for these family-related factors, as well as developing interventions to address the child's presenting need.(472)

This is supported by findings from a 2015 European study that interviewed subject matter experts working in child welfare systems, had several recommendations relevant to integrated work.(473) The experts stressed that children should be thought of within their family, their school and their community and that organisations working with them in each of these contexts needed to work together to achieve the best outcomes for children. The study highlights the importance of strong governance structures to ensure that interagency protocols are embedded into day-to-day practice, highlighting the need for relationship building between disciplines, as well as training that cuts across 'traditional disciplinary boundaries'.(473)

The research also highlights the importance of interagency collaboration for children with additional needs, for example visual impairments. Visual impairment impacts on all aspects of a child's life, with far reaching consequences for development, social adjustment, emotional wellbeing and education. A 2015 study conducted in the UK reported on the experiences of visually impaired children aged 10-15 years about growing up with impaired sight.(474) The data showed that, in addition to the many functional limitations, restrictions and lack of independence that these children experience, their visual disability contributed to social exclusion, stigma and isolation, which sometimes resulted in feelings of frustration and vulnerability in terms of their privacy and self-esteem.(474) The findings offer insights into the complex realities of living with visual impairment. They can also serve to help improve the understanding of health professionals working with visually impaired children, enabling them to better support them. A 2003 study conducted in Northern Ireland suggests that children diagnosed with a visual impairment are often not known to the wide range of services who could support them. The authors of this study highlighted the importance of bringing together a developmental team to supplement medical services including social services and educational support built around the child and family.(475)

The evidence reviewed shows that importance of increasing the quality of care for children who are living away from their families in the care of the state. The research shows that children with intellectual disabilities are more likely than non-disabled children to live away from their families.(476) A 2012 study used national data on over 700 children from Ireland to monitor their living arrangements over a ten year period.(476) Proportionately more children with intellectual disability of all ages moved away from their families over the ten year period, and only small proportions of children returned to their families or moved from residential to foster care. The findings highlight the need for cross-sector working between mainstream child and family services with specialist and residential disability services to ensure that the care and support that a child with a disability is right for them.(476)

Section 5.3.4. looks at the importance of child and adult services working together to meet the needs of children transitioning into adult care and support services. The research also highlights the role of interagency collaboration in meeting these needs. With the knowledge that nearly 60% of Indiana's children with special healthcare needs ages 12-17 had unmet transition needs, the authors of a 2014 study undertaken in America developed a state-wide transition support programme to support children with special healthcare needs in the transition between child and adult health care settings.(438) The development team included government agencies, family and community organisations and multidisciplinary health care providers. The model included an initial consultation with the child and subsequent care coordination. It was agreed that a 'whole-life' rather than a purely medical approach to services was needed. In one year the programme dealt with 139 consultations for children with an intellectual disability and or physical disability. Services included care coordination of complex health and community service needs, alongside support for families. The evolving interagency team adapted their methods to collaborate with children, family and care providers.(438)

The research shows that a key feature of good interagency collaboration is effective communication.(477) A 2015 American study sought to understand what parents preferences were on sharing information between their children's primary care and mental health providers. Parents consistently described communication among their children's primary care and mental health providers as important, yet frequently reported that such communication was not currently taking place between services. As a result of this parents reported that they were often called upon to act as 'communication bridges' between professionals caring for their children. These results suggest that health and mental health providers need to be particularly vigilant about communication if they are seeking to provide truly collaborative care.(477)

The evidence reviewed highlights the benefits of interagency work for health and social care services. If interagency work is thoughtfully implemented and fully supported, each team member's contribution to the overall wellbeing of the child is valued. When staff feel their contributions matter, they have a relationship with the child and family, and they have the ability to focus on what they do best, this forms the basis for personal satisfaction.(445,446) As such, health and social care services should be open to developing structures and systems that improve interagency collaboration.

The research highlights the following care commitments as the foundation for an integrated model of care and support for children:

- being child-centred and family engaged
- respecting and partnering with children and families
- pursuing care that is high-quality, readily accessible, and equitable
- providing care across the age spectrum and life span, integrated into the continuum of care
- ensuring that all service providers can provide basic care and consult specialists in a timely manner
- improving care through research and quality improvement efforts.(478)

Health and social care services should foster an environment that builds on the five key elements of a high-functioning team: shared goals, clear roles, mutual trust, effective communication, and measurable processes and outcomes.

The research provides evidence on how an integrated collaborative care team should ideally function. They should:

- partner with children and families to identify and address their needs
- align goals so that all team members are working to the same outcome
- recognise that primary care practitioners are uniquely qualified to address multifaceted issues in the community setting, and lead interagency collaborative work.
- the teams composition and leadership will change as the needs of the child and family change
- work to address gaps in the system that may limit optimal care of the child and family. This includes establishing professional partnerships, community linkages, and collaborations to address the requirements of children and families with complex medical, developmental, mental health, and socio-economic challenges
- communicate in an effective and timely fashion among all members of the team, remembering that the child and family are at the centre of all interactions
- incorporate the five key elements of a high-functioning team
- conduct ongoing evaluation to ensure care plans continue to be appropriate and effective.(345,445,468,479,480)

One study undertaken in America in 2019 interviewed representatives of youth probation, mental health, education, and health services who participated in multiagency reform in a juvenile facility.(446) The interviews showed that most participants felt they were engaged in a collaborative effort – joined together to achieve a common goal to foster better outcomes for young people in detention.(446) Recommendations for effective interagency collaboration from this study included strong leadership across agencies, ongoing training and coaching for stakeholders, and feedback on collaborative efforts.(446) These topics are discussed in further detail in Section 5.5.

The evidence also highlights the challenges to interagency work for health and social care services. Services who work with the same children and families do not necessarily work well together. Services can be reluctant to share resources and there can be delays and a lack of continuity, with children ending up on multiple waiting lists.(9) The research suggests that in order to address these barriers to interagency work, health and social care services should develop a set of agreed interagency protocols, undertake staff training on interagency working, and set out a vision for how they can support a continuum of care to improve outcomes for children.(9)

### 5.4.4. Measuring impact

Children's health and social care services should focus not just on the delivery of their service, but also on the impact this service is having on children and their families. The evidence shows that services often do not set out what long-term outcomes are important for children and their families as they move between and out of health and social care services, instead focusing on addressing the child's presenting need.(9) It emerged that if services are to set outcomes for children based on data, this data should be appropriate, reliable, and gathered over time. Once suitable outcomes are determined, indicators must be developed and monitored to determine the service's performance against these outcomes.(9)

Two studies looking at integrated care pathways (ICPs) that use a measurement-based care framework (MBC) found that these processes can offer a solution to the problem of the evidence-practice gap.(445,447) ICPs can help to coordinate medical and social approaches to care and clarify the roles of multidisciplinary team members to optimise outcomes for children. The MBC seeks to improve outcomes through a feedback system whereby the treatment plan is changed if the current treatment not be working. The resulting ICP with an MBC framework provides a tool to facilitate bridging the gap between evidence and clinical practice.(445) The authors of a 2020 American study reported on the development an ICP with an MBC framework for the treatment of adolescent depression in outpatient settings. The purpose of the ICP was to support staff to comply with recommendations, and ultimately improve outcomes for adolescents with depressive disorders.(447) As part of the ICP all adolescents are offered a multi-family psychoeducation session, a 16-session Group Cognitive Behaviour Therapy and team reviews every four weeks that included measurement-based care. This project is currently being implemented and represents a novel approach towards improving outcomes of adolescents in a systematic and standardised way.(447)

A 2012 study undertaken in the UK interviewed parents to develop a set of quality standards for child mental health in primary care. The agreed 10 quality standards reflected healthcare domains involving access, confidentiality for young people, practitioner knowledge, communication, continuity of care, and referral to other services.(460) The quality standards highlight areas that should be prioritised for quality improvement programmes and service delivery that aims to improve outcomes for children. Quality standards, such as these ones, are useful markers to assess quality of care.

## 5.5. Principle 4: Responsiveness

### 5.5.1. Introduction

Responsive children's health and social care services respond to the needs of the children and families they work with. The findings from the evidence reviewed to support this principle are set out under the following subheadings:

- effective listening and communicating
- flexible approach to meeting the needs of children
- encouraging active participation
- reflective practice
- training and development.

Responsive services take the child's and the families voices into account in the provision and planning of their services.(9) As well as listening, responsive services ensure that they are also communicating appropriately with children and their families.(421) Staff are trained in how to effectively listen and communicate with children and families.(481)

Services that are responsive understand that all children and families are unique and they address the whole needs of the child, not just the needs the child presents with.(362) They recognise that within this work there is scope for professional discretion and flexibility. Staff engage with children and families and encourage active participation in their care and support.(9)

The evidence shows that responsive services reflect on their work so that they can be proactive in addressing the needs of children and families rather than reacting to their most urgent need. Reflection is a valuable tool for staff and services. It helps staff understand how they have treated children and families and facilitates assessment of whether they have achieved their individual and organisational goals.(9,482,483) Services understand that both formal and informal training and development is required for all staff on an ongoing basis.(484,485,486)

### 5.5.2. Effective listening and communicating

Section 5.2.2. outlines the importance of listening to children who use health and social care services, and communicating in a way that meets their needs. Research shows that services that do not take the child's voice into account in the planning of their care are not only failing to uphold a child's right to be heard and to participate in their care planning, they are also missing opportunities for service improvement.(9) Paediatric services, communication about a child's diagnosis, prognosis and treatment can be complex, uncertain and emotionally charged. There is a need for sensitivity to each individual family's situation and needs.(317,405,487,488,489,490) Sections

5.3.4 and 5.4.3. outline the importance of services and departments working together to meet the whole needs of the child. The research shows that effective communication is one of the key elements required for successful collaborative care and support.(421,422,427,438)

Children and parents value being listened to, and this encourages the establishment of good therapeutic relationships.(306,321,322,377,421) A 2015 study conducted in Ireland found that the lack of communication between healthcare professionals and children was a major barrier to identification of mental health problems. Healthcare professionals identified several factors as possible reasons for communication issues, for example, concealing substance use, fear of violent family members, choosing to talk to peers instead of parents or healthcare workers, lack of maturity, low self-esteem, and most notably the child feeling uncomfortable disclosing problems in the presence of parents.(377) A systematic review conducted in 2016 showed that establishing rapport and trust between a primary care provider and the child or family may lead to reporting of the actual reason for the visit, increased child and family satisfaction, and improved adherence to treatment recommendations.(481) The results of this study suggest that healthcare professionals require training in effective listening and communicating. The authors highlight online courses as an efficient option for training of a diverse group of health and social care professionals from a wide range of geographical locations.(481)

Effective communication is also one of the key elements required for successful transition from children's services to adult services. The most common obstacles reported by both child and adult services are the lack of communication and coordination, and the different practice styles between different professionals.(422,427) These obstacles can create negative consequences including a lack of engagement from the child and family, as well as poor adherence to the care and support plan. Many adult services report discomfort when treating young adults, finding adolescents challenging, as the staff are often unfamiliar with their specific history and are unaware of their developmental and psychosocial needs.(421,439,491) To address these issues, the research finds that teamwork is key to improving coordination and communication during this transition process.(422,428) Routinely identifying, engaging, and communicating with the care teams who will be working with the young person in advance of – and during – care transfers will increase the likelihood that adult care teams have the information and guidance needed to safely care for these children throughout the high-risk time of transition.(427,439,440)

A 2017 study undertaken in Australia explored the issues encountered by social workers in their everyday practice communicating with families and other professionals in a paediatric hospital setting. Participants identified five main communication challenges. They are:

1. Holding troublesome knowledge: participants described being concerned about what information to share with other team members and what to keep private. For example, one participant described how they obtained information about a family's circumstances. Some of this information was relevant to pass on to the medical team, however, some of the information provided background context which was sensitive and if disclosed without the family's consent might be considered a breach of their privacy.
2. The need for diplomacy: the diplomacy challenge concerned how best to communicate information within the health team so as to respect different professional knowledge, whilst also advocating on behalf of the child. A challenge central to this was the hierarchical nature of hospital work.
3. Conciliation: conciliation refers to situations where participants described needing to address a misalignment in expectations or understanding between the health professionals and their family.
4. 'Every man and his dog in family meetings': this concerns the problematic nature of team care when there are a large number of people involved in giving information. Having too many people or constantly changing team members was described as potentially overwhelming families and diminished their capacity to understand key information.
5. Systems and processes presenting a brick wall: this challenge referred to the system of procedures and aspects of hospital bureaucracy acting as a potential barrier for parents, which in turn meant social workers taking on the role of explaining and interpreting the system for the family.(487)

The five challenges highlight how communication can be improved to ensure it works to benefit the health and wellbeing of the child. For example, the 'everyman and his dog' challenge highlights a need to agree the goals of a family meeting in advance so that decisions can be made as to who should be present from the care team, and considerations can be given about how the family is likely to respond to the information.(487) The results from this study highlight that, in order to improve outcomes for children and families, there is a need to develop communication processes based on the needs of the child and family, rather than relying on established lines of authority within teams.

Developmental and behavioural issues can complicate management of acute healthcare needs. Children with autism spectrum disorders are a vulnerable, often poorly understood group, who may experience periodic and chronic health challenges, in addition to their primary developmental social and communication problems. A 2015 Canadian study sought to understand the experiences of children with autism spectrum disorders, their families, and their healthcare providers in order to inform hospital-based care.(492) The problems identified in the results included communication and sensory challenges, and the degree of flexibility of healthcare providers. Supportive healthcare providers were those who acknowledged parents as experts, inquired about the requirements of a child with autism spectrum disorder, and implemented strategies that accommodated the unique clinical presentation of the individual child.(492)

Similar problems were identified in a 2013 study undertaken in America. This study explored the attitudes, experiences, and implementation of family-centred care within a children's critical care setting.(327) This review highlighted that the way information is received or delivered by care providers, parents, and children is influenced by many factors. Honesty, respect, time, and relationships were expressed as key factors that facilitated positive communication experiences during critical illness. Parents conveyed that information needed to be clear, consistent and in many cases, repeated.(327) The authors conclude by recommending that ongoing education, workshops, and clinical follow-up for care providers would enhance communication skills with trainee care professionals.(327)

### 5.5.3. Flexible approach to meeting the needs of children

As discussed in Section 5.3.4. adopting a child-centred approach to practice means focusing on the individual needs of the child and offering tailored support to meet these needs.(9,353,354,355) Responsive staff address the whole needs of the child, not just the needs the child presents with. They achieve this by taking into consideration the impact of social and environmental factors, as well as the developmental stage of the child on the child's overall health and wellbeing.(353,356,357,358,359,360,361)

Section 5.3.4. also addressed the need for professional discretion in assessment and generating solutions. The research suggests that having this discretion can result in staff being better able to listen and respond to the individual needs of the child. To do this, staff should have a wide range of activities and tools to engage children but should be prepared to move on from them if they are not suited to meeting the needs of the child.(9)

The research also highlights the importance of taking a flexible approach to meeting the needs of children who have additional requirements, for example children with physical disabilities. Many children with physical disabilities need additional support to participate in daily life.(318) Finding ways to consult with children with a disability and to inform them of decision being made regarding their care provides these children with the opportunity to express their views and concerns.(9) The evidence on child protection and welfare amongst children with disabilities shows that there are higher instances of abuse in this group in comparison to their peers without disabilities. Children with disabilities face challenges to report this abuse, including communication difficulties, perceived threat and the fear of not being believed.(9) Training staff on how to uphold the rights of children with disabilities is essential when maintaining best practice and ensuring that the rights of children with a disability are recognised and upheld in staff day-to-day practices. The evidence shows that adopting a child-centred approach can be seen by staff to be a challenge when engaging with a child with disabilities, as staff tend to sympathise with the stress and coping needs of the parents, rather than seeing them as the potential cause of any additional difficulties the child is having.(9)

### 5.5.4. Encouraging active participation

As discussed in Section 5.2.3., children's health and social care service providers should encourage fairness in all aspects of the decision-making process through supporting the child's participation. The research shows that the participation of children, young people and families in the provision of their services can increase children's confidence and enhance engagement in planning.(9) A child's age should have little bearing on their ability to have a 'voice'. Beyond speech and language, the concept of voice includes non-verbal and emotional expressions used to communicate feelings, perspectives, and decisions.(307,318,493,494)

The importance of incorporating the voice of the child and their family in decisions is increasingly being recognised among policy makers as promoting best outcomes for children's health and wellbeing.(324,495) However, health and social care professionals may still be uncertain as to how to engage children and families to actively participate in decisions concerning their care.(493)

Staff need to take time getting to know the child as an individual and work with their parents to involve them in their care and support. This is particularly important in situations where children may be exposed to increased risk in the care setting. Children with an intellectual disability are one such population, with evidence indicating that these children are particularly susceptible to what should be avoidable harm in hospital care.(496) A 2019 study undertaken in Australia highlighted that hospital staff rely on the presence of parents to attend to the needs of children with an intellectual disability.(496) The results show the importance of role negotiation between parents and staff and the importance of building trusting relationships.(496)

Many children with physical disabilities need additional support to participate in daily life.(318) A 2017 study undertaken in Austria interviewed children with disabilities, their parents and teachers to explore the issue of collaborative goal setting.(497) The study shows that children and parents are important sources for therapeutic goal setting. The authors encourage a child-centred approach in working with children with disabilities, and taking time to explore the motivations of children and parents when collaboratively setting goals.(497)

A 2018 study undertaken in America developed a list of criteria healthcare professionals could adhere to when involving children and their families in a developmentally appropriate way:

- healthcare professionals should be informed about, and act in accordance with, laws and regulations governing consent to treatment within their jurisdiction
- healthcare professionals must provide children and their parents with all the information they need to participate effectively in the decision-making process
- agreement or disagreement should both be respected whenever possible
- healthcare professionals, children and families should work together to reach medical decisions based on the child's best interests or outcomes
- in cases of serious disagreement or competing interests, the healthcare professionals primary responsibility is to the child
- in complex social situations, a collaborative process should be agreed upon to clearly identify the substitute decision-maker in a timely fashion
- healthcare professionals should be aware of the conflict resolution process in place in their practice environment
- in situations of conflict, healthcare professionals have an obligation to seek and access resources to help resolve that conflict and to facilitate child and family access to such assistance.(317)

### 5.5.5. Reflective practice

The evidence shows that when team-based, integrated care coordination programmes are adopted, service provision for children and families shifts from reactive and episodic to proactive and comprehensive.(362,373,374,376,377,450) Although it can be a challenge to find the time, staff can benefit from reflecting on their work so that they can be proactive in addressing the needs of children and families rather than reacting to their most urgent need. By relying on one another and collaborating, care teams can reflect on their strengths and work to improve their weaknesses.(482)

Reflective practice is valuable for staff in understanding how they have treated children and families and assessing whether their work has achieved better outcomes for children, and is aligned to organisational goals.(9) For example, the research highlights that staff working in children's social services should regularly reflect on their practice so that they understand how the system is treating children and families, in order to avoid dehumanising families and becoming authoritarian.(9)

A study undertaken in England reported on the implementation of a reflective practice project undertaken by social work professionals in Brighton.(483) The majority of respondents reported that reflection had a positive impact on their professional identity, capacity to manage work related emotions, and capacity to reflect on the complexity of their work. The authors comment that while people might not be willing, or able, to reflect on their practice, a reflective space can be designed to maximise the possibility for reflection.(483)

The research shows that it is helpful for staff to share experiences (good and bad) to assist in providing opportunities for improvement in organisations.(484) A 2017 study undertaken in Northern Ireland explored the experiences of 15 care team staff who provide end-of-life care within a children's hospice. The results presented in this study show that the organisation supported staff to address the challenges attached to their roles by offering peer support and providing regular training in key aspects of care.(498) The participants in this study saw more experienced colleagues as invaluable for easing anxieties in relation to communicating with families about end-of-life care issues. However, there was also consensus that advanced communication skills training should be available to all staff, not just more senior staff. The authors suggest that harnessing the expertise of more experienced staff could be a beneficial and cost-effective way for organisations to deliver this kind of training.(498)

### 5.5.6. Training and development

Staff working in children's health and social care services deal with a range of issues that affect children and families, and these issues are often complex and challenging. As such, training for staff should appropriately reflect this complexity. The research shows that both formal and informal training and development is required for all staff on an ongoing basis.(484,485,486)

The research shows that while the parent is arguably the best advocate for a child, they may not always be effective in ensuring the best outcome for their children.(486) Sometimes advocacy must extend beyond what the parent might consider as their remit, for example, tackling systems and issues within society; instead health and social care professionals may be better placed to do this. One study shows that advocacy is an important skill for paediatricians and that training can help them to understand the need for advocacy, and ways to improve implementation.(486) The authors highlight that in order to improve implementation staff should move from having knowledge to thinking more laterally, engaging more deeply with children's issues, developing advocacy skills, and integrating them into everyday practice.(486)

The evidence shows that social care staff need ongoing support from within their organisation to build their capacity and skills to work with parents who are displaying hostile or intimidating behaviour.(9) When there is a lack of proactive supports, the strain felt by social workers can result in burnout and lead to high levels of staff turnover. As a consequence of this turnover, there is an increased number of inexperienced staff who have less peer guidance from experienced staff to support their development, leading in turn to burnout in these newer staff.(9)

As discussed in Section 5.3.4. integrating culturally sensitive care in health and social care settings is an important way to address care disparities between children.(313,314) Service providers should practice self-reflection, self-knowledge, and self-critique to ensure the care they provide is culturally sensitive, and unbiased.(314) It is important that staff are culturally competent and they acknowledge cultural norms and differences, without compromising the wellbeing of children. The evidence shows that staff who develop cultural competency have a genuine understanding of families and children and move past stereotypes.(9)

The importance of effective communication skills was discussed in Section 5.5.2. A 2014 study focused on a clinic in America that implemented a physician training and practice improvement project, focused on physician communication behaviours that impacted the management of obesity in children. During sessions, physicians learned about motivational interviewing techniques, and tools to enable providers to determine the child’s motivation and capacity for health behaviour change. They also learned specific counselling language to help them to communicate information to parents. The results of the training showed an increased physician knowledge of communication principles, improvements in weight management counselling rates, and opportunities for children and families to actively engage in their treatment.(485)

## 5.6. Summary of evidence synthesis

The project team carried out an evidence synthesis to retrieve and document evidence (from both grey and black literature) in relation to children’s health and social care services. The results were documented according to four principles and subsequently by subheadings, as outlined in previous sections. These principles are:

- a human rights-based approach
- safety and wellbeing
- accountability
- responsiveness.

The evidence reviewed shows that children have the right to be treated with dignity and respect, and to be recognised as individuals who are able to participate in and exercise a level of control over their lives, and their health and wellbeing. All children’s needs are different and each child requires an approach tailored to their individual strengths and needs. In order to meet a child’s need for both safety and wellbeing, it is important that the whole needs of the child are addressed, not just the needs the child presents with. Children's health and social care services should take into consideration the impact of social and environmental factors, as well as the developmental stage of the child on the child's overall health and wellbeing. In doing so, services can support children to reach their full potential.

The evidence indicates that accountable children's health and social care services have a clear vision for their work, and strong leadership at an organisational and local level to ensure that plans are carried out effectively. Based on their gatekeeper role to a wide range of health and social care services, the evidence highlights the unique position of GPs to identify children at risk of adverse effects, and to lead and coordinate care and support for them. Accountable services support their staff to deliver on their vision, and understand the importance of interagency working. The evidence shows that when team-based, integrated care coordination programmes are adopted, service provision for children and families shifts from reactive and episodic to proactive and comprehensive.

Well led and managed services also regularly assess the impact of their work on the children and families that they are caring for and supporting. The evidence reviewed shows that as well as listening, responsive services ensure that they are also communicating with children and their family. Responsive services understand that the family is the child's primary source of strength and support. They take a family-centred approach and encourage children and their family to participate in making choices and decisions about their care. The research shows that responsive services focus on the individual needs of the child. They take a flexible approach and offer tailored support to each child and family to meet these needs and support positive outcomes for children in the short and long-term. Responsive services reflect on their work and receive training and development so that they are proactive in addressing the evolving needs of children and families.

## 6. Summary, conclusion and next steps

This document sets out the evidence that was reviewed by the project team to inform the development of Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services.

This included:

- an overview of relevant approaches to delivering children's health and social care in Ireland
- an overview of the model of services, legislation, strategies, policies and standards for delivering children's health and social care in Scotland, England. Northern Ireland, Australia, Sweden, America, and New Zealand
- an evidence synthesis of academic and grey literature relating to children's health and social care described under the principles of a human rights-based approach, safety and wellbeing, accountability, and responsiveness.

### Summary of findings from Ireland

Ireland has a wide range of legislation, guidance, policies, standards and services that seek to promote the health and wellbeing of children and their families, and to protect children who are at risk of harm. A number of Government departments are responsible for the development of policy for children and overseeing the delivery of services. The primary responsibilities lie with the DOH who oversee the delivery of a range of health and social care services by the HSE, and the Department of Children, Equality, Disability, Integration and Youth who oversee the delivery of child protection and welfare services by Tusla. Additionally, the Department of Education holds responsibility for primary, secondary and third level education and the Department of Justice, Equality and Law Reform holds responsibility for juvenile justice. There is a Government-wide commitment to improving outcomes for all children, as set out in *'Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014-2020'* and *'First Five: A Whole-of-Government Strategy for Babies, Young Children and their Families 2019-2028'*, as well as in strategies that relate to children with additional needs, such as the *'National Disability Inclusion Strategy'* and *'Sharing the Vision: A Mental Health Policy for Everyone'*.

However, it is evident from a number of overview reports of services provided to children, particularly to children with additional needs, that delivering consistent integrated care and support continues to be a challenge.(1,2) In comparison to a number of other jurisdictions, Ireland does not have legislation which supports integrated working between public bodies, and a number of reports have called on the Government to take action to address gaps in the provision and coordination of the appropriate range of services through legislation, regulation and policy to address this.(3,4,5) Furthermore, these reports highlight that there is wide variation in resources, processes and practices in different sectors and geographical areas in Ireland that is leading to delays in the allocation of services and poor coordination of care and support. While there are a number of regulatory bodies in place in Ireland to monitor health and social care services, the systems in place to monitor compliance with these standards, and the regulations underpinning them, are complex and fragmented. Additionally, many of the standards, are service-specific, and do not follow a child's pathway of care and support through the range of services they use. All of this impacts on children's immediate and long-term health and wellbeing.

## Summary of findings from international jurisdictions

The evidence from the international review shows that each jurisdiction has extensive legislation, regulation, strategy, policy and delivery systems in place to meet the health and social care needs of children. Each jurisdiction demonstrated progression towards enhancing child health and wellbeing, and set out how the improvement of child wellbeing would be achieved in national strategies. The evidence also shows that there is a strong focus in all of the jurisdictions on promoting equality and reducing health inequalities for children and adults.

### Legislation and policy for integrated working

The evidence shows that there is a strong focus in all of the jurisdictions on promoting equality and reducing health inequalities for children. One example of this is in Sweden, where a commission for equitable health to assess the health disparities between socio-economic groups has been established to drive change in this area in the next decade. At a legislative and policy level there are examples in a number of jurisdictions of a move towards integrated working, with a focus on early intervention, to meet the health and social care needs of children. A number of jurisdictions, including England, Scotland and Northern Ireland, have put the responsibility of all services to work together to meet children's health and social care needs, and to promote their wellbeing on a statutory footing. This has resulted in a shift towards more formal collaboration between NHS organisations and local authorities to deliver integrated care and support to children.

The evidence also shows that despite national commitments to improve the health and wellbeing of children, and the extensive programmes to realise such commitments, there are challenges to the delivery of consistent and integrated health and social care services to children with additional needs across the jurisdictions. Reports from Scotland, England and Northern Ireland show that although there are government-wide commitments to improve the coordination of health and wellbeing of children in many jurisdictions, practice on the ground remains inconsistent. These reports highlight that children with complex needs, and children who are more vulnerable due to their lower socio-economic status and living conditions fare worst when health and social care services are uncoordinated and inconsistent.

### Standards for children and young people

In most jurisdictions reviewed there has been a focus on developing standards for services provided to children and young people with additional needs to ensure they receive a safe and high-quality service. These standards are an attempt to provide a common language and framework for supporting children. An example of this can be seen in Scotland, where the government commitment to children's health and wellbeing is echoed through the 2018 '*Health and Social Care Standards: My Life, My Support'*.(6) Other examples of this can be seen in New Zealand where general and targeted standards have been developed to improve the experience of children with additional needs. Examples of these standards are the *'Health and Disability Services Standards'* (HDSS) 2008, which are mandatory for a wide range of health and disability service providers who provide services to children, and the 2019 *''National Care Standards'* which sets out the standard of care that every child in the care of the State needs in order to do and be well.(7,8)

### Regulation and monitoring

The review found that while all jurisdictions reviewed have a process for assessing the safety and quality of services provided to children, this can vary quite significantly depending on the jurisdiction and the nature of the service being provided. For example, in Sweden the governmental agency with responsibility for inspecting care assesses how well services collaborate, as well as assessing the overall rationale for decisions around the provision of care and support, rather than assessing the performance of individual health and social care services. Another example of differences in the regulation and monitoring processes can be seen in England and Scotland, where there are a number of agencies involved in assessing the safety and quality of health and social care services provided to children. In recent years, these agencies have worked together to undertake joint inspections in strategic areas, such as the delivery of integrated care and support.

### Service delivery

In a number of jurisdictions, reports showed that there were long waiting lists for services and a lack of services for children with additional needs. The review identified that this was particularly acute in children's social services and mental health services in America, England and Northern Ireland, where staff shortages and poor retention rates of experienced staff compounded the waiting times for children. Due to this, such services were often reactive and crisis-driven, rather than proactively meeting children's needs.

While there has been a focus on supporting children to transition between and out of health and social care services, timely and coordinated planning, the availability of appropriate follow-on care, and effective resource allocation, continues to be problematic across all jurisdictions. For example, the review identified that Australia did not have a systematic approach to supporting children who had been in care to transition into adulthood, and the findings for England highlight that for children with complex needs there is often a lack of suitable follow-on support when they reach adulthood.

### Health inequalities

The review also found that in a number of jurisdictions there are disparities among the health and wellbeing of indigenous and non-indigenous children. In New Zealand and Australia, the review found that indigenous children report significantly poorer outcomes across all health and wellbeing outcomes, are more likely to be living in poverty, and are more likely than their non-indigenous peers to be taken into care.

### Data collection

All jurisdictions reviewed gather data in relation to health and social care services provided to children, however, the focus of this data varies between jurisdictions. A number of jurisdictions, including Northern Ireland and New Zealand, have developed outcome-based frameworks to provide measurable indicators for child health and wellbeing. These frameworks seek to assess the impact that services are having on child health and wellbeing, and also the impact that policies and programmes have on the lives of children more generally. In contrast, the data gathered in America in relation to these services is mainly quantitative, and is used to inform the funding allocation to services. This focus makes it difficult to assess the impact of health and social care interventions and to identify whether services are achieving positive long-term outcomes for children.

## Summary of findings from evidence synthesis

Consistent with the findings from the international review are the key findings from the evidence synthesis of national and international literature. The findings from the evidence synthesis are documented under the four interlinked principles that will underpin all National Standards developed by HIQA. These themes are:

- a human rights-based approach

- safety and wellbeing
- accountability
- responsiveness.

## A human rights-based approach

In supporting a human rights-based approach, the evidence emphasises the importance of services and staff creating a culture of dignity and respect. Central to this culture are staff who take the time to develop a relationship with the child and their family, through listening to them and treating them in a non-discriminatory manner. A human rights-based approach ensures that children and their family can participate in decisions about their care and support, and their views are acted on. To do this, services must put structures and systems in place to support meaningful participation. The evidence emphasises the importance of respect, fairness and of valuing children as individuals in this process, as well as taking into account the strengths of families. It also highlights the importance of giving children power to influence the decisions that are made about their care and support, and to include families as partners in this process.

## Safety and wellbeing

In protecting and promoting a child's safety and wellbeing, the evidence highlights the importance of examining the child's health and wellbeing holistically, rather than simply responding to the presenting need. The evidence recognises that some children may be more vulnerable to poorer health and wellbeing outcomes for a range of reasons, including the complexity of their needs, their family and living circumstances. Additionally, when children are transitioning in and out of services, they are at increased risk of less focused and coordinated care. As such, the evidence highlights the importance of children receiving tailored care and support that mitigates these potential negative impacts on their health and wellbeing.

## Accountability

The evidence shows that in order for a service to be accountable to children and other stakeholders, it needs strong leadership and governance. Leaders and managers must work to strengthen and encourage their service's quality and culture, and to ensure that resources are deployed effectively to achieve high-quality and consistent services. The evidence highlighted that an accountable service works collaboratively with a wide range of professionals, organisations and services to ensure that children's needs are met effectively. Accountable services identify short, medium and long-term outcomes and measure the achievement of these outcomes using a range of agreed indicators.

## Responsiveness

The evidence sets out that a responsive service ensures that children are cared for and supported by staff who are skilled, trained and experienced. These staff communicate openly and honestly with colleagues in and outside their service, and with children, their families and advocates. The evidence shows that responsive staff use their professional judgement to ensure that children receive the care and support that is right for them and support families to act as advocates to ensure their needs are met. Staff regularly reflect on their practice to ensure it is meeting the diverse needs of children.

This document will inform the development of Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services in conjunction with:

- detailed discussions at meetings of the project Advisory Group and the Children’s Reference Group
- individual meetings with relevant informed and interested parties
- focus groups with:
    - children, young people and family members with experience of health and social care services
    - front-line staff and management in these and partner services
    - relevant advocacy groups
    - policy makers.

When the draft national standards are developed, a public consultation will be held. Submissions received during this consultation will be reviewed and carefully considered, and the draft national standards may be revised and improved based on the feedback received. The main amendments will be published in a related statement of outcomes document, outlining the stakeholder engagement, along with the final Overarching National Standards for the Care and Support of Children using Health and Social Care Services which will be available on the HIQA and MHC websites, www.hiqa.ie and www.mhcirl.ie.

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# Appendices:

## Appendix 1 – International experts contacted during the development of the evidence review

| Name | Role | Organisation | Jurisdiction |
|---|---|---|---|
| Ana Gardiner | Senior Health Policy Advisor | Council for Disabled Children | England |
| Dr. Brian Babington | CEO | Families Australia | Australia |
| Christine Irvine | Senior Policy and Information Officer | Northern Ireland Commissioner for Children and Young People | Northern Ireland |
| Henry Mathias | Head of Professional Practice and Standards | The Care Inspectorate | Scotland |
| Prof. Maria Brenner | Professor in Children's Nursing | School of Nursing and Midwifery, Trinity College Dublin | Ireland |
| Niamh Devlin | Senior Policy and Research Officer | Northern Ireland Commissioner for Children and Young People | Northern Ireland |
| Stella Conroy | Deputy CEO | Families Australia | Australia |

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