



An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Key considerations to inform the National Policy Framework for Children and Young People 2023-2028





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### 1. Background

The Government is currently developing a successor framework to 'Better Outcomes, Brighter Futures (BOBF) National Policy Framework for Children and Young People 2014-2020' which will set out the vision and priorities for children and young people aged 0-24 years for the next five years. The original BOBF framework was the first comprehensive and overarching national policy framework for children and young people aged 0-24 years in Ireland. It was an ambitious, whole-of-government framework that prioritised children's rights and interests in policy-making. It emphasised a child centred, interagency and multidisciplinary approach to working across government, on horizontal and vertical levels. The successor framework, which will run from 2023-2028, will build on the work of the previous framework and aims to improve outcomes for children, young people and families living in Ireland by improving the systems and services that support them.

This successor framework is currently under development in the Department of Children, Equality, Disability, Integration and Youth (DCEDIY), and is expected to be published in March 2023. A public consultation on the framework was held in January 2022 and a blueprint for the framework, *Policy Framework for Children and* Young People 2023-2028 Blueprint, was published in August 2022. (2,3) The blueprint indicates that the framework will be set out under four principles (Equality, Support for Children and Young People, Delivering for Children and Young People, and Respect for the Views of Children and Young People), which are linked to general principles set out in the United Nations Convention on the Rights of the Child (UNCRC).(3) The new framework will include particular areas of focus called 'Spotlights'. These are areas of significant difficulty for children, which will require coordinated action across government in a focused, time-bound way. It is envisaged that an initial set of 'Spotlights' will be identified in the framework and further areas will be identified throughout the lifetime of the framework. For example, areas under consideration for Spotlights include mental health and wellbeing of children and young people (including play and recreation) and child and youth poverty.

A significant amount of research and stakeholder engagement has been conducted by the Health Information and Quality Authority (HIQA) and the Mental Health Commission (MHC) in recent years in the area of health and social care services working with children, in preparation for the development of national standards that will drive coherence and integration across health and social care services working with children.\* While good practice was identified through this research and engagement, a number of challenges were also identified that impact on the quality, safety and coordination of the care and support of children using health and social

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<sup>\*</sup>Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services were submitted for Ministerial approval in July 2022, and Draft National Standards for Children's Social Services were submitted for Ministerial approval in December 2021.

care services. This paper sets out key considerations that may assist in addressing these challenges and support the consistent implementation of national standards.

It is timely that the new framework is currently in development, as this provides an opportunity for HIQA and the MHC to share learnings from the development of the national standards that can be used to inform this important policy framework. To both inform the development of the framework and to highlight potential areas for attention as 'Spotlights', this paper will summarise the key findings from our research and stakeholder involvement for the development of national standards for health and social care services working with children. Specifically, this paper will set out, at a high level:

- the barriers and facilitators to quality improvement in the sector, such as the implementation of standards
- the policy considerations needed to address the barriers identified, in order to improve the quality, safety and coordination of care and support for children when they are using health and social care services.

#### 2. Methods

To inform the development of the *Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services*, HIQA and the MHC undertook an evidence review and engaged extensively with a wide range of stakeholders at every stage of the standards development process.

As a first step, a review of national, international and academic literature in relation to children's health and social care services was undertaken. This review took account of published research, investigations, and reviews of children's health and social care services in Ireland and in a number of international jurisdictions,<sup>†</sup> alongside legislation, standards, policy, guidelines and best practice in these jurisdictions and in Ireland. The *'Evidence review to inform the development of Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services'* is available on www.higa.ie and www.mhcirl.ie.<sup>(4)</sup>

HIQA and the MHC established an Advisory Group and a Children's Reference Group to inform the standards and to understand what would be needed to support the implementation of the standards into practice. The Advisory Group had representation from government departments, statutory bodies, advocacy groups and regulatory bodies. The Children's Reference Group was comprised of young people and family members with experience of health and social care services. The Children's Reference Group ran in parallel to the Advisory Group and provided insight

<sup>&</sup>lt;sup>†</sup> Northern Ireland, England, Scotland, Sweden, New Zealand, Australia and America

into the sector and feedback on the development of the standards. Representatives of the Children's Reference Group also attended the Advisory Group meetings.

HIQA and the MHC also held two public consultations to inform the standards. The first was a two-week scoping consultation held at the initial stages of the standards development process and the second was a national public consultation on a draft set of standards. The scoping consultation, carried out in 2020, asked stakeholders to identify the key areas that the standards should address. In total, there were 72 responses. The national public consultation on the draft standards was carried out in 2021. In addition to asking respondents for feedback on the draft standards, they were asked what was needed to support the implementation of these standards in the service they use or work in. Fifty-eight responses were received from this consultation, of which 39 were submitted on behalf of organisations.

In addition, HIQA and the MHC conducted focus groups and interviews with children, families and staff with experience of health and social care services working with children. In total, HIQA and the MHC held 38 focus groups and interviews, meeting with 217 participants. These focus groups informed the content of the standards and explored what would assist services to put the standards into practice. They included representation from people with experience of a wide range of health and social care services and included children; young adults with experience of health and social care services as children; families; carers; staff from primary care services, acute healthcare services, inpatient and community mental health services, residential and community disability services, Tusla and Tusla-funded services, An Garda Síochána, the National Educational Psychological Service; and inspectors from HIQA and the MHC.

A summary of how stakeholder views have informed the standards will be available to read in the *Stakeholder involvement report informing the development of the Draft Overarching National Standards for the Care and Support of Children using Health and Social C*are Services document, which will be published on the HIQA website, <a href="www.hiqa.ie">www.hiqa.ie</a>, alongside the approved National Overarching Children's Standards.

To validate and augment the findings from the initial evidence review and stakeholder engagement undertaken during the standards development process, an updated review of practice in Ireland and key international jurisdictions was conducted. This updated review focused on how barriers to implementation of standards identified in Ireland are being addressed in other jurisdictions in order to identify learnings for Ireland.

During the conduct of the evidence review and stakeholder consultation to inform the standards, a range of interdependent systemic challenges were identified which impact the care and support of children using health and social care services. For example, these included geographical distribution of services, long waiting lists for services, difficulties with staff recruitment and retention, and lack of systems and structures to support interagency working and transitions between services. Stakeholders from across health and social care services provided a wealth of insight into these challenges and their impact on the quality, consistency and coordination of care and support provided to children. The evidence review and stakeholder consultation also provided examples of good practice that support the safety, wellbeing and development of children using health and social care services. While many of the challenges identified were outside the scope of the standards, it was clear from the evidence that these challenges would significantly impact the ability of services to implement the standards in practice. The development of the successor framework to 'Better Outcomes, Brighter Futures' provides an opportunity to develop evidence-informed policy to address these challenges, and thereby support quality improvement in the sector and support services to implement the *Draft* Overarching National Standards for the Care and Support of Children using Health and Social Care Services.

# 3. Overview of children's health and social care system in Ireland

The governance, funding and delivery of health and social care services providing care and support to children in Ireland is complex. A number of government departments are responsible for the development of policy for children and overseeing the delivery of services to children. The primary responsibilities for child health and wellbeing lie with the Department of Health (DoH) and DCEDIY. 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). DCEDIY 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. 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 are two main statutory organisations involved in organising health and social care services that work with children: the HSE and Tusla. Both organisations deliver services to children through a wide range of public services, and also commission voluntary and private providers to deliver services on their behalf.

In addition, 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 HIQA, the MHC, the National Disability Authority (NDA) and the Office of Children's Ombudsman (OCO).

HIQA sets standards for health and social care services, including services provided to children, and inspects a range of services against these standards. HIQA monitors compliance with the standards in healthcare (hospital) services, child protection and welfare services, foster care services, children's residential centres and children's detention centres, and has a regulatory role in registering and monitoring residential services for children with disabilities and children's special care units. The MHC is responsible for promoting and encouraging high standards and good practices in the delivery of mental health services, including mental health services for children and adolescents. The MHC regulate approved mental health centres for children and adolescents with mental health issues. The NDA is an independent statutory body providing evidence-based advice and research to Government on disability policy and practice. The OCO investigate complaints about services provided to children by public organisations.

# 4. Key themes emerging from the evidence and key considerations for policy development

In Ireland, the importance of integrated care pathways and coordination of care and support between services to enable children to get the right care and support at the right time and in the right place has been recognised, and subsequent governments have made commitments to ensuring that children get this care and support. These commitments are outlined in a number of national policy documents, such as Sláintecare, the HSE's Paediatric Model of Care, the Department of Health's Sharing the Vision, and the HSE's Progressing Disability Services for Children and Young People. (5,6,7,8)

Nonetheless, a number of interdependent systemic challenges that impact on the quality, safety and coordination of care and support for children when they are using health and social care services emerged from the evidence gathered during the standards development process. These include challenges related to effective interagency working, supporting transitions from child to adult services, and issues related to service delivery. These will be outlined in this paper under the following themes:

- Improving interagency working
- Supporting effective transitions from child to adult services
- Supporting services to deliver timely and appropriate care and support.

Under each theme, considerations will be set out to address these challenges.

# 4.1 Improving interagency working

Effective interagency working and inter-professional working is crucial to ensure children receive well-integrated and coordinated health and social care. (4) The evidence review and stakeholder engagement undertaken to inform the development of the standards identified examples of good interagency and interprofessional working, which delivered integrated care to children and families. These included multidisciplinary teams and shared models of care in some healthcare settings, co-location of services in primary care centres or within local communities, and models of multiagency working such as Meitheal<sup>‡</sup> and Children and Young People's Services Committees (CYPSCs). However, the evidence review and stakeholder engagement highlighted many gaps and challenges to joint working between services.

The evidence review highlighted challenges in the delivery of coordinated health and social care services to children in Ireland. For example, the OCO has highlighted on a number of occasions the lack of coordination between the HSE and Tusla in caring for and supporting children with disabilities who are in the care of the State. (9,10,11) In 2020, the OCO published a report stating that despite some progress in the implementation of the *Joint Protocol for Interagency Collaboration between the Health Service Executive and Tusla*, coordination between these bodies is still an issue. (12,13) The OCO set out that the Government has an important role to play in ensuring the joint protocol is used effectively.

Feedback from stakeholders similarly highlighted the tendency of services to work in silos and a lack of formal working arrangements (including protocols, policies and procedures) to support different services to work together in a more coordinated and collaborative way to meet the needs of children and families. While a number of stakeholders noted the benefits of the joint working protocol between Tusla and the HSE which, when successfully implemented, ensure that services work with one another to utilise their knowledge and achieve a shared goal, they also reported inconsistent implementation of the protocol. Some stakeholders noted that having different funding streams for the HSE and Tusla led to tensions at times around who would fund interventions in complex cases, leading to delays in decision-making. Stakeholders also highlighted the need for leaders and managers in organisations to

<sup>&</sup>lt;sup>‡</sup> Meitheal is an early intervention approach that focuses on strengthening families and communities through activating a wide range of statutory services including children's social services, An Garda Síochána, health, education and housing services, alongside community services.

<sup>§</sup> CYPSCs are county-level committees that bring together the main statutory, community and voluntary providers of services to children and young people. They provide a forum for joint planning and coordination of activity to ensure that children, young people and their families receive improved and accessible services. Their role is to enhance interagency cooperation and to realise the national outcomes set out in *Better Outcomes, Brighter Futures National Policy Framework for Children and Young People, 2014-2020*.

strengthen a culture of collaboration within and between services through promoting and supporting interagency working and communication.

The evidence review and updated review of practice in Ireland and other jurisdictions showed that a number of jurisdictions, including England,\*\* Scotland and Northern Ireland, are using legislation to support an integrated approach to care and support, and to address disjointed and fragmented care. These jurisdictions have put the responsibility for 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 National Health Service (NHS) organisations and local authorities to deliver integrated care and support to children. While Ireland currently does not have legislation or national policy which compels cooperation or integrated working between public bodies with responsibility for the safety, health and wellbeing of children, the review of the 1991 Child Care Act highlighted the need for legislation in this area to support integrated working for children at risk or in the care of the State. (14) The original BOBF framework also identified cross-government and interagency collaboration and coordination as an area that needed to be strengthened in order to ensure that policies and services were made more effective in achieving better outcomes for all children and young people. (15) Further, the United Nations (UN) Committee on the Rights of the Child in their concluding observations on the combined fifth and sixth periodic reports of Ireland recommended that the State review the effectiveness of existing mechanisms for facilitating interagency coordination on activities affecting children.(16)

Communication and information-sharing between services is central to effective interagency working. However, in line with the evidence review and a number of recent reports reviewed, many stakeholders discussed inconsistent and inefficient communication practices across the health and social care sector. (14,17) Staff, parents and children who participated in focus groups expressed frustration over poor communication within and between services. For example, young people and parents seeing multiple professionals and or using multiple services expressed frustration at being continuously asked to re-tell their stories. In addition, parents of children with complex needs discussed carrying the responsibility for coordinating their child's care and sharing information across services, in order for their child's needs to be met. They stressed the need for services to work together and communicate effectively to reduce this burden on parents. A number of participants in the focus groups highlighted that data protection legislation, specifically the General Data Protection Regulation (GDPR), was often cited as a reason for not

<sup>\*\*</sup> England has recently passed the Health and Care Act 2022 which establishes a legislative framework which supports collaboration and partnership-working to integrate services for patients through the formalisation of integrated care systems.

sharing information in relation to a child. Stakeholders also highlighted the lack of IT infrastructure to support information sharing between services. One example of this is the use of paper discharge letters by inpatient Child and Adolescent Mental Health Services (CAMHS) and the delay in GPs receiving these letters, which means GPs are making treatment decisions based on patient self-reports in the interim. There is a need for digital enablement and a shared infrastructure for health and social care services to facilitate the timely, safe and secure sharing of information within and between services. (18)

HIQA has recently published a paper on key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland which makes a number of recommendations to improve the sharing of information between health and social care services. (18) These recommendations in a number of key and interdependent areas aim to bring Ireland into line with developments in other European countries. In the paper, HIQA has highlighted the need for legislation to support information sharing between health and social care services and to act as a catalyst for a more integrated health and social care sector. Regulations, guidelines, codes of practice and policy should be developed to support health and social care professionals to understand and implement this legislation. HIQA highlighted the need for appropriate ICT infrastructure, including the digitisation of health and social care records, to enable services to share information easily and for this to be underpinned by technical, security and data quality standards. HIQA also highlighted the need for clear rules for sharing information across all health and social care organisations and for making sure that organisations are following these rules. HIQA further noted the importance of ongoing engagement with health and social care professionals and the public in ensuring that developments in these areas are acceptable to, and meet the needs of, key stakeholders.

In January 2022, the Department of Health announced plans to develop new health information-specific legislation and in April 2022, the Minister for Health received Cabinet approval to develop the General Scheme of a Health Information Bill. The development of this Bill provides an opportunity to ensure clarity on information sharing within and between the HSE, Tusla and appropriate statutory bodies, and to support interagency working across services and organisations.

A number of stakeholders highlighted inflexible pathways between health and social care services, noting that services should accept referrals from a wider range of professionals. Additionally, a number of focus group participants felt there was a lack of transparency about staff roles and responsibilities within some services, which caused confusion about who to contact within services and uncertainty around referrals. In some cases, participants highlighted a lack of clarity around who holds responsibility over certain aspects of a child's care, especially for those with multiple

or complex needs. The evidence review and stakeholder engagement also highlighted that when children are transitioning in and out of services, they are at increased risk of less focused and coordinated care. For example, when children are discharged from acute services, there needs to be established and appropriate links to primary and community services.

Stakeholders noted that criteria to access services can be relatively strict, and their views align with findings in recent reports reviewed. (12,19,20,21) They noted that this was particularly an issue for children with dual-diagnoses, for example children with a disability and a mental health issue or children with an addiction and a mental health issue, who could be restricted to attending one service only or may be declined from both services. One example of this was the inability of children attending the School Age Disability Team<sup>††</sup> to also attend CAMHS due to CAMHS referral criteria. A number of parents reported that when their child's referral to CAMHS was accepted, they subsequently withdrew their child from the School Age Disability Team to ensure their child would be able to receive treatment from CAMHS. Parents felt that the two services should work together to ensure a holistic approach to their child's needs. This lack of integration of care and treatment for children with mental health needs has been highlighted in the recent CAMHS report which found a lack of coordination and joint working between primary care services, Children's Disability Network Teams, and CAMHS in many areas, with little sense of the child being at the centre of holistic mental health care provision. (22)

Similar operational challenges in relation to integrated working have been identified in other jurisdictions. While legislation is a key facilitator to supporting interagency cooperation in Scotland and Northern Ireland, there remains significant barriers to achieving interagency working at an operational level. The barriers in Scotland include a lack of resourcing, inadequate interagency communication, problems with data sharing, and poor understanding across the professions. In Northern Ireland, the health and social care system is still fragmented and working in silos. Northern Ireland is developing a new funding and planning model, 'Future Planning model', to address the operational challenges of planning and funding and to apply integrated care at the point of service delivery. Learnings from England, Scotland and Northern Ireland indicate that not only is it important to have legislation underpinning integrated working, the legislation must also inform all aspects of service delivery such as the structure of the system, governance and accountability practices, workforce planning, funding and service delivery planning.

Multidisciplinary teams can be a useful tool to support interagency and interprofessional cooperation and a number of jurisdictions have evaluated their effectiveness in different settings. For example, the IVO, the Swedish Health and

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<sup>&</sup>lt;sup>††</sup> School Age Disability Teams are multidisciplinary teams ran by the HSE which provide assessment and support services for children aged 5-18 years of age with developmental delays or disabilities.

Social Care Inspectorate, reviewed team meetings within and between mental health professionals.<sup>(23)</sup> It highlighted that an understanding of others' professional roles and responsibilities and having clear rules around information sharing were important for good communication and coordination among teams. A recent evaluation of Children Teams in New Zealand highlighted that for multidisciplinary teams to work effectively, the workforce must be adequately resourced and receive professional development.<sup>(24)</sup> It also noted that leadership and management should transcend multiple agencies to ensure that all agencies are working to the same objectives and aims.

Memoranda of understanding are another potentially useful tool to support interagency working. In Northern Ireland the *'Future Planning Model'* is exploring the use of memoranda of understanding, service-level agreements, lead provider contracts, alliance agreements or contracts, as well as charters to support the development of partnerships between professionals and organisations. <sup>(25)</sup> This includes Health and Social Care (HSC) Trusts, independent practitioners and the community and voluntary sector. Information-Sharing Protocols and Partnership Agreements are currently used within Family Support Hubs<sup>‡‡</sup> in Northern Ireland to promote effective interagency working. They outline what is expected from partner organisations and the policies and procedures that organisations must have in place to meet minimum governance requirements.

As highlighted in the evidence review, a wide range of standards have been developed in Ireland to drive improvement and assess the quality of care provided to children in health and social care settings, for example *National Standards for Special Care Units* and *National Standards for Residential Services for Children and Adults with Disabilities.* (26,27) Many of these standards are underpinned by regulations. However, as the regulations and standards are service-specific, they do not follow a child's pathway of care and support through the range of services they use. Furthermore, the systems to monitor the compliance of health and social care services with standards are complex and fragmented, with HIQA having a monitoring role in some services and a regulatory role in registering and monitoring others. HIQA and the MHC undertook the development of the Draft Overarching National Children's Standards to focus services on supporting a child's journey through the range of services that they use and to support services to take a holistic approach to meeting a child's needs.

In some jurisdictions, health and social care regulators have begun to inspect how services engage with each other in order to drive greater coordination and

<sup>&</sup>lt;sup>‡‡</sup> Family Support Hubs provide a range of early intervention and family support services across Northern Ireland. They promote cross-sectoral partnerships and provide an interface for services across the statutory, voluntary and community sectors, thereby enabling access to a wide range of services across Northern Ireland through a single access point.

integration between services. In England, since 2016, Ofsted and the Care Quality Commission have carried out a number of joint inspections on how local areas fulfil their duty to children and young people who have special educational needs or disabilities. These joint inspections are carried out in education, health and social care services, early years and specialist services. Similarly in Scotland, in 2017 the Care Inspectorate and Healthcare Improvement Scotland began undertaking joint inspections of Community Planning Partnerships to assess their effectiveness in commissioning and planning care in an integrated way.

#### Key considerations for the successor framework

Based on our learnings from the standards development process and the updated review of practice in Ireland and other jurisdictions, the following are considerations for the successor framework to facilitate and support better interagency and interprofessional working in the area of health and social care service provision for children:

- In line with a number of international jurisdictions such as Scotland, Northern Ireland and England, consideration should be given to the development of legislation on interagency working, to facilitate and support better interagency working in the area of health and social care service provision for children.
- > This legislation could provide a coherent long-term vision for interagency working between statutory bodies, set out specific joint planning structures that need to be established, and also set out organisational roles and responsibilities within this.
- ➤ The development of systems and structures, including policies and procedures, to establish formal working arrangements between and within services, to support staff to work together in a coordinated and collaborative way.
- ➤ Development of a programme of shared training for senior management in statutory organisations across health and social care to support them to implement and sustain interagency working and inter-professional working.
- Delivery of joint training for diverse front-line health and social care professionals to build inter-professional knowledge and understanding and foster good working relationships.
- ➤ Investment in and improvement of ICT infrastructures to facilitate effective collection, use and sharing of health and social care information.
- Clarity in the forthcoming Health Information Bill regarding information sharing within and between the HSE, Tusla, and appropriate statutory bodies.

- Development of organisational level protocols and memoranda of understanding to support the sharing of information between services.
- ➤ Conduct of joint internal audits to identify how services can improve the way in which they work together to meet children's needs, supported by self-audit tools for interagency working developed by national regulators.
- Undertake thematic inspections on interagency working to assess how services engage with one another to enhance the service and care pathway as experienced by the child.

#### 4.2 Supporting effective transitions from child to adult services

The risk of children not receiving timely, appropriate and joined-up care is exacerbated when children with continuing care and support needs are transitioning from children's services to adult services. (4) Stakeholders highlighted pockets of good practice within healthcare services in preparing and supporting young people who will be moving from paediatric services to adult services. They pointed to collaboration between some paediatric clinics and adult clinics which facilitated a young person's gradual transition from one to the other and this was pointed to as a model that would benefit young people if implemented more broadly in health and social care services. Nonetheless, the evidence review and stakeholder engagement highlighted that adequate preparation and planning for transition to adult services is not widespread. Stakeholders noted the difficulties experienced by young people engaged with CAMHS, paediatric healthcare services or children's disability services when they move to the very different environment of adult services and stressed the need for advance planning and preparation to ensure a sensitive and supportive transition for the young person.

The need for well-considered and tailored aftercare planning for young people who will be leaving the care of the State was highlighted in the evidence review and stressed by stakeholders. This has also been reflected in a recent OCO report which highlighted a number of concerns around aftercare planning for young people in care, including: delays in, and inadequate levels of, aftercare planning, failures to allocate aftercare workers, considerable variation in aftercare service provision nationally, and deficits in interagency cooperation in the provision of aftercare supports for children with disabilities. (28) The OCO and the Children's Rights Alliance have recommended that the State allocate sufficient resources to support appropriate levels of aftercare planning for all young people requiring aftercare and making aftercare supports and services available to all young people who need them. (28,29)

A number of stakeholders working in child and adolescent services highlighted that when they reach out to adult services to prepare young people for the transition, the adult services may not always engage in an advance planning and preparation process. Others discussed the age limit in accessing CAMHS, noting that new referrals of young people aged 16 and above have to be made to the adult service, which many felt was inappropriate. More broadly, many stakeholders expressed the view that most young people are not developmentally ready at 18 years of age to leave children's health and social care services and attend adult services and there were suggestions to extend children's services up to 25 years of age. Specifically in relation to mental health, this suggestion is in keeping with recommendations in 'Sharing the Vision' that the age of transition for young people moving from CAMHS to adult mental health services should be changed from 18 to 25 years of age. (8) Similar views in relation to children in care were expressed in the public consultation on the forthcoming National Policy Framework for Children and Young People 2023-2028. A report on the responses to the public consultation highlighted that a key message from respondents was that children in the care of the State should have the option to remain in care until 21 years of age. (2)

Other jurisdictions have taken different approaches to supporting young people transitioning from children's services to adult services. Australia and England both have government-supported transition strategies for young people moving from paediatric health services to adult health services. (30) While both countries suggest that planning for these transitions should take place as early as possible, they do not suggest an age at which the transition to adult care should happen. Rather, they recognise that effective transitions are not a 'one size fits all' process and must vary depending on the young person's clinical, social or emotional readiness and must accommodate disease-specific and individual-driven needs. They recognise that transition plans should vary by condition and be culturally sensitive.

A number of jurisdictions have funded the development and or piloting of transition support programmes for young people transitioning from children's services. In Northern Ireland, there are transition supports within schools for young people with disabilities to transition to adult life. When the young person is in Year 10 (aged 13-14 years), a transition plan is developed with the young person which outlines their goals and support needs for the future in relation to education, employment, housing, health, transport and leisure activities. The young person should be supported in the development of the plan by a multidisciplinary team which includes social services, their local GP or community nurse, teacher(s), educational psychologist, career adviser, parents or carers and anyone else of the young person's choosing. In England between 2008 and 2011, £19 million was invested in a Transition Support Programme to facilitate better transition for children and youth with complex conditions and disabilities. This represented once-off funding to 11 regions to develop local transition initiatives, many of which have been positively

evaluated.<sup>(32,33)</sup> However, after 2011 many of the local initiatives were not sustained due to lack of ongoing funding.

In New Zealand in 2019, the Government provided a budget for four years to Oranga Tamariki§§ for a four-year pilot to develop Transition Support Services (TSS) for children leaving care. (34) TSS is a relationship-based service and is premised on the recognition that support is needed past 18 years of age for children who have had a difficult start to life. It provides children over 15 years of age with a transition support worker to support them in planning for their future when they leave care. Additionally, TSS provides young people the opportunity to remain with a caregiver until they are 21 years of age. The service partners with 63 community organisations to deliver the service across New Zealand. In 2021, the Oranga Tamariki Evidence Centre published an evaluation of the TSS which strongly supported a continued development of the service. (35) It found that young people preferred to work with their transition support worker over their Oranga Tamariki social worker. It also found that regions with a dedicated transition coordinator from within Oranga Tamariki who liaised with community partners and facilitated transition planning meetings, worked better than regions without a coordinator. It highlighted that community partners need to be adequately funded to enable them to offer a competitive salary and professional development opportunities to staff, to facilitate the workforce stability required by a relationship-based service. Overall, the evaluation of the TSS confirmed the need for separate young person-centred services as a fundamental element of a successful transition process.

Scotland plans to introduce legislation to support young people with disabilities in the transition to adulthood. The 'Disabled Children and Young People Transitions to Adulthood Bill', which is at the early stages of the legislative process, will require local authorities to have transition plans in place for each child with a disability as they move into adulthood. It is also proposed that the Bill will require the Scottish Government to develop a National Transitions Strategy, setting out how they will improve opportunities for children and young people with disabilities and to have a Scottish Minister in charge of improving opportunities for children and young people moving into adulthood.

# Key considerations for the successor framework

Based on our learnings from the standards development process and the updated review of practice in Ireland and other jurisdictions, the following are considerations

<sup>§§</sup> Oranga Tamariki (The Ministry for Children) is the key organisation that holds responsibility for child wellbeing, specifically children at risk of harm and children in the care of the state in New Zealand.

for the successor framework to facilitate and support effective transitions for young people:

- ➤ In line with a number of international jurisdictions, consideration needs to be given to the development of a national policy and or legislation that facilitates and supports young people with continuing care and support needs to transition from child to adult services, in a way that is appropriate to their needs. This policy and or legislation could set out the responsibilities of the relevant children's services to:
  - assess the continuing care and support needs of young people at an early stage
  - develop a continuing care needs plan
  - advocate for the allocation of resources to support an appropriate transition, and
  - engage with relevant adult services in a timely way to plan for and support this transition.

It could also set out the responsibilities of the adult services to engage in the planning process and to support the young person in their transition between services.

- Consider the development of a funding model that facilitates the allocation of resources to health and social care services to ensure they can be flexible around the age at which a young person with continuing care and support needs transitions to adult services. In addition, in relation to CAMHS and children's social services:
  - extend the age at which young people with mental health difficulties are required to leave CAMHS and move to adult mental health services from 18 years of age up to 25 years of age
  - provide children in the care of the State with the option to remain in care up to age 21.
- ➤ Develop systems and structures, including policies and procedures, to establish formal working arrangements to plan for and support effective transitions from child to adult services.
- ➤ Build communication and collaboration between child and adult services to ensure that young people are prepared and supported to transition between services.

# 4.3 Supporting services to deliver timely and appropriate care and support

Timely, appropriate intervention is vital for children and young people to ensure their developmental needs are met and they are supported to reach their potential now and into the future. The evidence review and stakeholder engagement undertaken to inform the development of the standards identified a number of universally provided programmes which effectively promote and support children's health, wellbeing and development in their childhood years, for example the Early Childhood Care and Education (ECCE) Scheme, the HSE's Nurture programme, the school immunisations programme, and free GP visit cards for all children under six years of age. However, the evidence review and stakeholder engagement has also highlighted many gaps and challenges to achieving timely and appropriate intervention for children and young people in need of care and support.

The evidence review highlighted long waiting lists for health and social care services and the impact this has on the wellbeing and development of children and young people. Similarly, a recent OCO report to the UN Committee on the Rights of the Child has highlighted the difficulties and delays that many children with disabilities experience accessing general health services, and the long waiting lists for public mental health services experienced by children with mental health issues. (28) This was reflected in the recent CAMHS report which highlighted an increase in waiting lists for CAMHS since 2020 as well as a wide variation in the number of children on waiting lists and the length of those waiting lists across CHOs and internally within CHOs. (22) The OCO report recommended that the State implement measures, including allocation of additional resources, to reduce waiting lists and waiting times that adversely affect children's access to healthcare. (28) Likewise, HIQA's recent annual overview report on the inspection and regulation of children's social services has highlighted that many children continue to experience delays in receiving a service from Tusla or moving to a more appropriate service. (37) The UN Committee on the Rights of the Child in their recent report on Ireland has voiced concerns regarding the long waiting lists for children in need of hospital care, mental health services and disability services and supports. (16)

The topic of waiting lists for health and social care services was widely discussed by stakeholders who noted that staff shortages, high caseloads, and limited funding and investment in health and social care services within local communities, were key drivers. Stakeholders queried how services could meet a child's needs in a timely and effective way, or coordinate a child's care and support effectively between services, when long waiting lists impact on the delivery of the right care and support at the right time to meet children's needs. They highlighted the impact on children's safety and wellbeing and the distress experienced by children when their needs are not addressed in a timely manner. They also emphasised the need for health and

social care services to move towards prevention and early intervention and away from crisis-driven responses.

Stakeholders discussed insufficient staffing levels and high caseloads across health and social care services for children, and their views align with findings in recent reports reviewed. (12,19,22,38,39) They noted these issues were particularly acute within children's social services and CAMHS, causing recruitment and retention issues in these sectors. This was reflected in the recent CAMHS report which also noted particular difficulties with consultant psychiatrist staffing, and consequently with clinical governance in some teams, which increased the risk of "poor care" being provided to children. (22) Stakeholders also highlighted that in some instances staff leave is not covered in some services, leaving children and families with gaps in their care and support, and called for this to be addressed to ensure continuity of care for children and families.

The Committee on the Future of Healthcare Sláintecare report 2017 made a number of recommendations that, if implemented, would help to tackle these issues around access to services for children and young people. (6) The Committee identified that health and social care budgets need to be substantially increased to meet the needs of the population and that multi-annual budget cycles should be introduced to provide funding stability and predictability for service-providers to plan over the longer term. The OCO have recommended specific ring-fenced funding be allocated for children's mental health services and that multi-annual budgets for children's disability services be introduced to allow services to properly plan for anticipated and predictable needs. (28) The Sláintecare report also identified the need for a resource allocation model that would allow for equity of services across different geographic areas, taking into account population need, demographics, deprivation and other measures. Furthermore, it recommended a move from 'siloed' budgeting to having 'pooled' budgets across health and social care to support the integrated delivery of services. (6)

Other jurisdictions are also dealing with long waiting lists and staff shortages. Northern Ireland has recognised that a significant redesign and reform of their health and social care system is needed to reduce waiting times for services. The Government has set up a Waiting List Management Unit (WLMU) to improve waiting times and to support redesign of the system. This WLMU is developing a set of waiting time standards and working on improving the communication of waiting times to children and families.

Northern Ireland has also developed a 'Health and Social Care Workforce Strategy 2026'. (40) In supporting the implementation of the strategy, the Department of Health undertook a review of social workers in the areas of adult mental health, child protection, and services for looked after children. Arising from this review they made a number of recommendations including the need to develop a workforce plan,

improve the supply of social workers, increase recruitment and retention, implement workforce development and ensure strategic oversight to monitor workforce trends.

A number of jurisdictions are undertaking 'root and branch' reviews, with the aim of addressing structural issues in children's services, including proactively planning for future workforce needs. For example, in October 2022 Northern Ireland initiated an independent review of children's social care services. The scope of the review includes children's social services, disability services and CAMHS. The review team has highlighted the significance of the structural reconfiguration that is required within children's social care services, and the challenge of this work is further compounded by the current dissolution of the Northern Ireland Assembly. A similar root and branch review of children's social services was conducted in England and its findings published in May 2022. (41) To address workforce needs among social workers, this review made a number of recommendations including the introduction of a five-year early career framework to support social workers as well new national payscales to incentivise them to remain in post.

Geographical variation in the provision of health and social care services has been highlighted by the evidence review as a key challenge impacting children's access to appropriate services in a timely manner. Similarly, stakeholders discussed a 'postcode lottery' nationally, with inequality in the provision of health and social care services across the country. Children living in rural areas and in socio-economically disadvantaged areas were noted to experience poorer access to health and social care services. This was particularly the case for children with complex needs. Rural and smaller hospitals do not have the same opportunities for access to care, support and treatment that urban or larger hospitals do. Stakeholders also noted a lack of disability, mental health and primary care services in some geographic areas. They emphasised the importance of providing fair and equitable care and support to children, regardless of geographic location or other circumstances.

Stakeholders highlighted the strict criteria and high thresholds for initial access to specialist services, children's social services and CAMHS, which often results in children's difficulties worsening until their needs become more serious and entrenched. They stressed that resourcing early intervention would lead to improved outcomes for children and circumvent the need for more costly interventions in the long term. Children and staff with experience of mental health services and social services also called for the availability of staff outside of the typical 9 to 5, Monday to Friday schedule, to address crisis situations and avoid inappropriate admissions to services. A number of reports have similarly called for out-of-hours CAMHS facilities to be made available. (28,39,42,43,44)

In the area of mental health, a number of jurisdictions are increasingly directing attention towards prevention and early intervention to improve child wellbeing and reduce pressure on specialist mental health services. For example, Scotland and

Sweden have begun to look at the role of education and community services in improving identification of mental health issues among children and young people. In Sweden, a 2017 review of their CAMHS services noted the ideal position of educators in identifying concerns of child and adolescent mental health. (45) It noted that in order for professionals from outside mental health services to take on this role, they require supports and resources. Similarly, the Scottish Government takes the view 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. (46) A key part of this will be the delivery and progression of the Scottish Government's commitments regarding school counsellors and community wellbeing supports such as GPs and public health nurses. It is hoped that making these early intervention supports for children available can prevent children's difficulties escalating and reduce the number of referrals to specialist services. In keeping with this, respondents to the public consultation on the forthcoming National Policy Framework for Children and Young People 2023-2028 made a call for resources and supports to be provided to schools to support the mental health and wellbeing of students, for example access to effective mental health programmes, talk therapy, and access to mental health professionals such as counsellors.(2)

Scotland has also developed and expanded an NHS Mental Health Hub, so that it is available 24 hours a day and seven days a week to increase capacity for early intervention of individuals experiencing mental health issues. The NHS24 Mental Health Hub is a suite of different telephone services that are available to everyone in Scotland, including young people. In addition, a Distress Brief Intervention programme (DBI) has been rolled out on a national basis, providing rapid, accessible and focussed one-to-one support for people in distress. The DBI connects people over 16 years of age with local services in order to help them get through periods of distress or emotional pain. An evaluation of the programme found that it helped most individuals to manage and reduce their distress in the short-term and continued to benefit some individuals over the longer-term. <sup>(47)</sup> In line with these initiatives, to improve access to mental health supports for children in Ireland, the UN Committee on the Rights of the Child recommended that the State provide comprehensive mental health promotion, screening for mental health issues and early intervention services in schools at all levels and in communities. <sup>(16)</sup>

#### Key considerations for the successor framework

Based on our learnings from the standards development process and the updated review of practice in Ireland and other jurisdictions, the following are considerations for the successor framework to improve the quality and timeliness of health and social care service provision for children and young people:

- Consideration could be given to how to establish and resource a shared health and social care budget, provided on a rolling basis that will enable long-term, targeted planning, ensuring equitable access to well-resourced and staffed services.
- Promote collaboration between diverse budget holders to support planning and resourcing of integrated health and social care for children.
- ➤ Undertake joint financial and strategic planning to identify how services can improve the way in which they work together to identify, assess, plan for and meet children's needs.
- ➤ Ensure that high-quality information is gathered and used to inform service planning and resourcing.
- > Develop a national approach to workforce planning to address recruitment and retention issues, particularly in key sectors such as mental health and children's social services.
- > Increase incentives to attract and retain staff, to enable services to obtain and sustain the necessary staffing level and skill-mix to meet the needs of children.
- ➤ Implement measures, including review of waiting lists and allocation of resources, to reduce waiting times for specialist services. For example, the HSE funding for CAMHS could be increased to provide treatment for children with complex mental health needs.
- Establish out-of-hours services that operate at night and over the weekend in the areas of mental health and children's social services to address crisis situations and avoid inappropriate admissions to services.
- Provide mental health promotion activities and mental health supports within schools and local communities to support children and young people's wellbeing and to enable early intervention for those experiencing mental health difficulties.

#### 5. Conclusion

This paper brings together HIQA and the MHC's review of evidence and experiential learning for policy-makers to consider at a critical time in the development and implementation of the new children's policy framework. This paper sets out a number of systemic challenges and policy considerations to address these challenges

in order to improve the quality, safety and coordination of care and support for children when they are using health and social care services.

It outlines three key areas that important advances can be made in:

- improving interagency working
- supporting effective transitions from child to adult services; and
- addressing issues related to resourcing and staffing to improve service delivery.

Each of these three areas are interdependent, meaning that failure to address one could impede progress in other areas.

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