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

mhc
coimisiún meabhair - shláinte
mental health commission

Stakeholder Involvement Report

Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent statutory body 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.

Reporting to the Minister for Health and engaging with relevant Government Ministers and departments, 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 of Social Services 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 permanent international protection accommodation service centres, health services and children's social services against the national standards. Where necessary, HIQA investigates serious concerns about the health and welfare of people who use health services and children's social 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 and social care services, with the Department of Health and the HSE.

Visit www.hiqa.ie for more information.

About the Mental Health Commission

The Mental Health Commission (MHC) is an independent statutory body established under the provisions of 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 to its responsibilities under the 2001 Act, the MHC's remit was extended under the provisions of the Assisted-Decision Making (Capacity) Act 2015 to include the establishment of the Decision Support Service (DSS). The DSS supports adults who may require help, now or in the future, to exercise their right to make decisions about their personal welfare, property, or affairs. The main functions of the MHC are:

- **Registration and enforcement:** the MHC is responsible for establishing and maintaining a register of approved centres, which are hospitals that provide inpatient care and treatment for people with a mental illness or a mental disorder. As part of this registration, the MHC are responsible for enforcing associated statutory powers, such as attaching registration conditions.

- **Inspection:** inspecting approved centres annually and community mental health services and reporting on regulatory compliance and the quality of care, a function headed by the Inspector of Mental Health Services. In addition to individual inspection reports, the Inspector of Mental Health Services also carries out a national review of mental health services in the State.

- **Quality improvement:** developing and reviewing rules under the 2001 Act. Developing standards, codes of practice and good practice guidelines, to guide and enable those working in mental health services to provide high-quality care and treatment to service users. The MHC is also responsible for making rules that regulate specific types of treatment for mental illness,

including Electroconvulsive Therapy (ECT), restrictive practices such as seclusion and mechanical restraint and publish reports on these types of treatment regularly. The MHC also monitors the quality of service provision in approved centres and community services through inspection and reporting.

- **Mental Health Tribunals**: administering the independent review system of involuntary admissions to approved centres. This system requires that every order detaining a patient must be independently reviewed by a group of three people referred to as a mental health tribunal. The reviews are a core requirement in protecting and upholding patients' human rights.

Table of Contents

Overview of stakeholder engagement throughout the standards development process

1. Introduction and background

The Health Information and Quality Authority (HIQA) and the Mental Health Commission (MHC) have developed Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services. The draft national standards apply to all health and social care services caring for and supporting children. The standards aim to promote high-quality and safe care and support for children using health and social care services and quality improvements in that care and support by:

- Offering a common language for children and services to describe what high quality, safe and reliable health and social care services for children look like.
- Enabling a child-centred approach by focusing on outcomes for children and their families who are using services, and placing them at the centre of all that the service does
- Being accessible to children and families using services to understand what high-quality safe services should be and what they should expect from a well-run service.
- Creating a basis for services to measure the quality and safety of a service's performance against the standards, by identifying strengths and highlighting areas for improvement.
- Promoting day-to-day practice that is up to date, effective, consistent, and based on the best available evidence.
- Providing a framework for service providers to be accountable to people using their services, the public and funding agencies, by setting out how they should organise, deliver and improve the care and support they provide.

In 2019, HIQA and the MHC began developing the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services. These draft national standards were proposed during a scoping phase that was being carried out to develop a separate set of national standards specific to children's social services. During this scoping phase, HIQA met with a wide range of stakeholders who indicated that there was a need to develop a set of national standards that would apply to all health and social care services that work with children, in addition to specific standards for children's social services. These stakeholders included senior representatives from the Department of Health, Department of Children, Equality, Disability, Integration and Youth, the Health Service Executive (HSE), the Child and Family Agency (Tusla), the Ombudsman for Children's Office, and Children's Health Ireland, as well as front-line staff, children and families. They highlighted that children often need the support of more than one service and that an overarching set of standards for all health and social care

services working with children have the potential to improve the care and support experiences of children, by providing a common framework that promotes clarity, consistency and continuity within and between services.

The Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services developed by HIQA and the MHC applies to all health and social care services working with children, including:

- acute and community healthcare services, including homecare and support services
- inpatient and community mental health services
- residential and community services for children with disabilities
- children's social services, and
- general practitioners (GPs), community pharmacies and primary care services.

This approach puts the needs of children first, and provides a shared framework for all services to ensure that no matter what health or social care services a child is using, that there is a consistent and integrated response to their needs.

The draft national standards are informed by a review of the literature, two public consultations, and targeted focus groups and interviews with key stakeholders in the area of health and social care services providing care and support to children. The consultation with stakeholders set out in this document took place during 2020 and 2021.

The draft national standards have been informed by evidence presented in the *Evidence review to inform the development of Overarching National Standards for the Care and Support of Children Using Health and Social Care Services*.[1] This evidence base provides the results of an extensive programme of research conducted by HIQA and the MHC which consists of a review of children's health and social care services in Ireland, an international review of children's health and social care services in seven jurisdictions* and a literature review of relevant academic material. The evidence review is available at www.hiqa.ie and www.mhcirl.ie. All documents and publications were reviewed and assessed for inclusion in the evidence base to inform the development of the draft national standards.

The Project Team engaged extensively with children, young people, families, carers, and staff working in health and social care services, drawing on their expertise to inform the development of the draft standards at each stage of the process. While

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

the research undertaken ensured that the draft standards are evidence based, engagement with stakeholders ensured that the draft standards are appropriate to an Irish context. It also ensured that the draft standards maintain a clear focus on best outcomes for children and families and can be implemented in practice across the wide range of health and social care services that children interact with. This has resulted in draft standards written in language that is child friendly and that sets out what outcomes a child should expect and what a service needs to do to achieve these outcomes.

At the beginning of the standards development process, HIQA and the MHC established an Advisory Group and a Children's Reference Group. The Advisory Group was made up of a diverse range of interested and informed parties, including representatives from the Department of Health, the Department of Children, Equality, Disability, Integration and Youth, statutory bodies, advocacy groups, and regulatory bodies, as well as representatives from the Children's Reference Group. The Children's Reference Group was comprised of young people and family members with experience of health and social care services. This is the first time that HIQA set up such a group when developing national standards. Nominations to the group were sought through relevant organisations. The purpose of the Children's Reference Group was to help HIQA and the MHC understand the experience of children and families when they are using health and social care services and how these experiences affect them. They provided insight into the issues that are important to children and families using health and social care services so that this could be reflected in the content of the draft standards. The group ran in parallel to the Advisory Group and representatives of the group also attended Advisory Group meetings. Full details of the Advisory Group and Children's Reference Group can be found in Appendix A.

As well as focus groups, as set out in this document, HIQA and the MHC also undertook individual stakeholder meetings at key stages in the development of the draft standards. All focus groups were held online due to public health guidance at the time. A one-to-one telephone consultation was conducted where it was not possible for an individual to join a focus group.

The different methods of engagement, as outlined in this document, also provided an opportunity to raise awareness of the importance of the standards and to ensure buy-in from relevant stakeholders.

The following summary of stakeholder involvement outlines the process and outcome of the following consultation stages of the standards development:

Stakeholder involvement during standards development		
Scoping phase	Public scoping consultation survey September 2020	72 responses
	Focus groups and telephone consultations *(25 focus groups, three telephone consultations)* March – May 2021	156 participants
Public consultation	Public consultation survey on the draft standards September – October 2021	58 responses
	Focus groups on the draft standards *(13 focus groups, one interview)* October – November 2021	61 participants

At each stage of the process, members of the Advisory Group and the Children's Reference Group had an opportunity to input into the development of the draft standards. This included participation in scoping consultation discussions, providing feedback on the draft standards prior to public consultation, submitting a response to the public consultation on the draft standards, and providing further feedback on the revised draft standards following the public consultation. Additionally, following the public consultation, further engagement was undertaken with Advisory Group and Children's Reference Group members to further explore what is needed to support the implementation of the standards. Findings from this engagement are set out in Chapter 5 of this document.

2. Public Scoping Consultation

This chapter presents an overview of the analysis of responses received during the scoping consultation, undertaken at the initial stages of the standards development process, and how HIQA and the MHC used this information to inform the development of the draft standards.

2.1 Public Scoping Consultation Process

The public scoping consultation was managed by HIQA and ran for two weeks from 8 September 2020 to 23 September 2020. A consultation form was developed to assist people to respond to the consultation. Responses could be made via an online survey tool, and the form was available to download on www.hiqa.ie. Responses could also be emailed to a dedicated email address or posted to HIQA.

The consultation asked people with experience of health and social care services caring for and supporting children (including children, young people, family members, carers, advocates and staff) and the public for their views on the key areas that the standards should address. This consultation also asked for opinions on the important sources of information and evidence the Project Team should review, and the key organisations or individuals the team should engage with, in the development of the standards.

In total, 72 responses were received to the public scoping consultation. All responses were considered by the Project Team and used to inform the standards development process. Appendix B provides the list of organisations that responded to the public scoping consultation.

2.2 Results of the Public Scoping Consultation

Of the 72 responses, 29 people (40%) responded in a personal capacity and 43 people (60%) responded on behalf of an organisation. Of the 72 respondents:

- 43 (60%) stated that they were providing feedback as a staff member or other person working in children's health or social care services
- 4 (6%) stated they were providing feedback as a person who has used or is currently using children's health or social care services
- 25 (35%) stated they were commenting in an 'other' capacity.

Thirty-seven respondents (51%) gave details of their roles. Examples of the roles of respondents working in health and social care services included:

- Area director of nursing

- Chief executive officer
- Clinical director
- Director of children's services
- Information and advice officer
- National disability specialist
- Paediatric and mental health nurse
- Social worker.

2.3 Key areas that the standards should address

This question asked respondents 'What are the key areas that the standards should address?' All respondents answered this question. The key areas identified by respondents were reviewed by the Project Team and categorised into five themes. A sample of responses are outlined in Figure 1 below.

The key areas identified by respondents were presented to the Advisory Group and the Children's Reference Group at their first meetings. Together with the feedback received from the scoping focus groups, discussed in Chapter 3, and the findings from the evidence review, these key areas were considered by the Project Team as to how they might inform the content of the standards.

Figure 1. Responses to consultation question regarding key areas the standards should address

Rights-based approach

- Health and social care services should respect and protect children's rights as set out in the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).
- Children have a right to participate in their care and support and should be encouraged and supported to do so.
- All children should have equitable access to the services that they need.
- Services should have a complaints process that is accessible to children.

Integrated working

- Staff caring for and supporting children should consider the whole needs of the child and not just the needs the child presents to the service with.
- Collaboration and communication between services and staff is vital to ensure that the right service is delivered at the right time to each child.
- Transitions between services, including from children's services to adult services, should be carefully planned and coordinated so that children are prepared and supported as they move between services.

Prevention and early intervention

- Early identification and intervention are essential in ensuring timely access to services and preventing the problems experienced by children from becoming more serious.
- Promoting positive health and wellbeing for all children is key to preventing difficulties from arising and to minimising their impact when they do occur.

Partnership with families and communities

- Services and staff should support parents and siblings as well as the child presenting to the service.
- It is important to build parents' capacity to support their child's development.
- Services should work in partnership with existing services in communities to build on the expertise that is already there to support families.

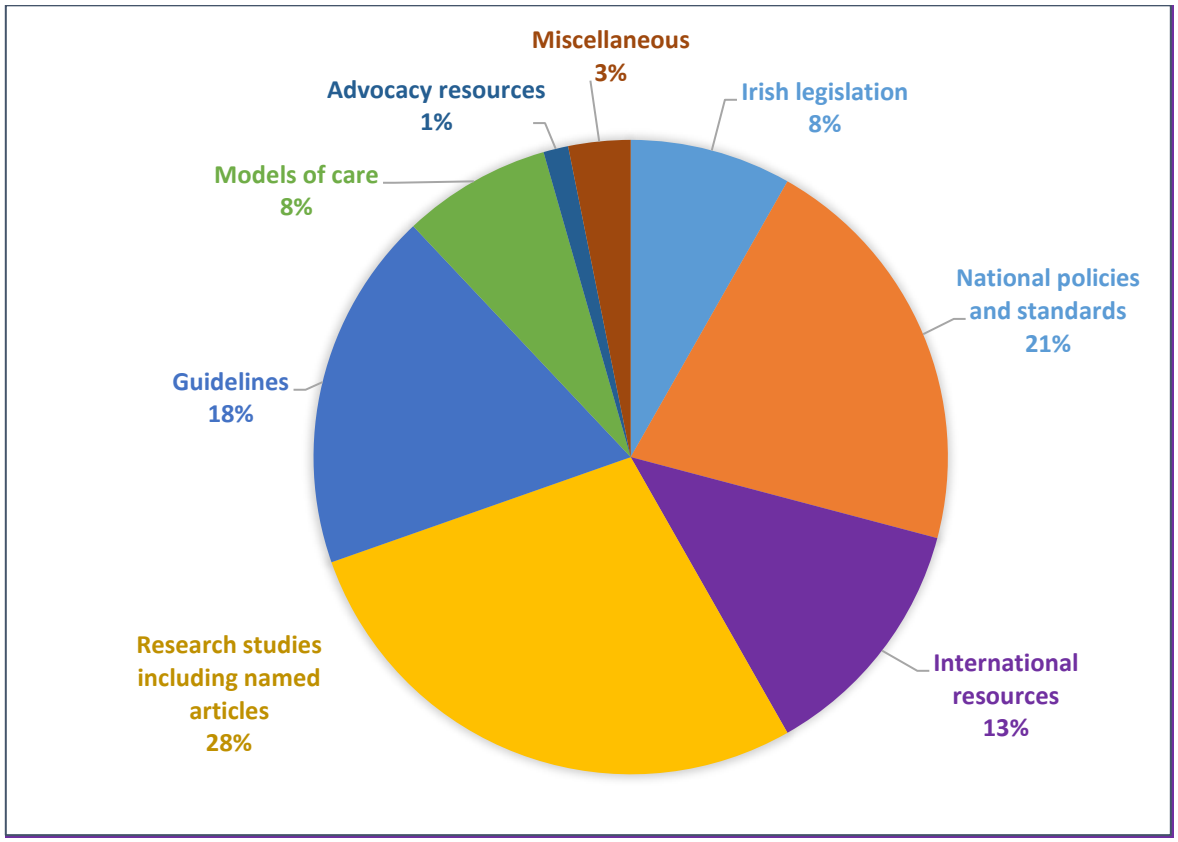
Good governance

- Proper planning and oversight of services and clear mechanisms of accountability are essential for a safe and effective service.
- Effective workforce planning and development is necessary to ensure that services have sufficient staffing levels and skill-mix to meet children's needs.
- A focus on measurable and demonstrable outcomes for children and their families is important to ensure that their needs are being met. Services and staff should assess the effectiveness of interventions on an ongoing basis.

2.4 Key sources of information to inform the standards

This question asked respondents 'What are the key sources of information that should be reviewed to inform the development of the standards?'. Sixty-nine respondents (96%) answered this question. Figure 2 provides an overview of the information sources suggested by respondents.

Figure 2. Responses to the consultation question regarding key sources of information to inform the standards



All information sources suggested by respondents were cross referenced with the sources already identified by the Project Team through HIQA's evidence synthesis process, and any new relevant sources were added to the evidence base to inform the development of the standards.

2.5 Key organisations or individuals to engage in the standards development process

This question asked respondents what key organisations or individuals the Project Team should engage with when developing the standards. Seventy respondents (97%) answered this question. While there were many organisations and individuals suggested, the most frequent suggestions were:

- Children and parents with experience of health, mental health, disability and social care services
- Health and social care professionals
- Child and Family Agency (Tusla)
- HSE – this included specific groups within the HSE, for example the Mental Health Engagement Office
- Advocacy groups – this included organisations such as the Children's Rights Alliance, Empowering People in Care (EPIC), and the National Advocacy Service for People with Disabilities
- Education providers
- Mental health services
- Disability services
- An Garda Síochána (Ireland's National Police Service).

The Project Team conducted a comparison between the organisations and individuals suggested by respondents and those included in the Project Team's stakeholder engagement plan for developing the standards. Where it was noted that there was a lack of representation from key groups or organisations, these were added to the stakeholder engagement plan to inform the development of the standards.

2.6 Future engagement

Respondents were asked if they would like to hear about opportunities to engage with HIQA in the future on the development of these standards. The majority of respondents (78%, or 56 people) stated that they would like to be contacted further. These respondents were added to the stakeholder database for the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services and stakeholders were notified about the commencement of the public consultation.

3. Focus group discussions during the scoping phase

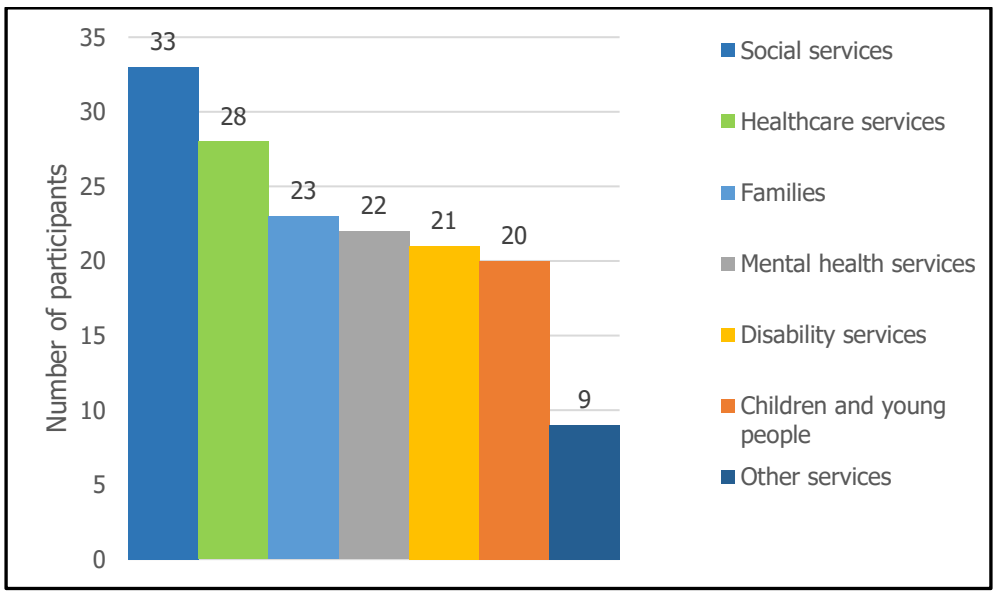
This chapter describes the process of collating and analysing the responses from focus group and telephone consultation participants that were undertaken to inform the development of the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services. This feedback was analysed against the four principles underpinning HIQA's standards development framework.[2]

3.1 Overview of the focus group process

Given that the draft overarching national standards apply to all health and social care services caring for and supporting children, the Project Team sought to ensure that as wide a range of relevant and interested stakeholders as possible had the opportunity to influence and inform the development of the standards. Focus groups were the primary method of consultation with these wide range of stakeholders at this stage of the process. A one-to-one telephone consultation was conducted where it was not possible for an individual to join a focus group.

During this stage of the standards development process, 25 focus groups and three telephone consultations were conducted, meeting with 156 participants in total. Focus group participants were identified through the scoping consultation and also through seeking nominations from relevant services and organisations. Focus groups were facilitated and documented by the Project Team. A breakdown of focus group and telephone consultation participants is illustrated in Figure 3.

Figure 3. Breakdown of focus group participants held during the scoping phase (n=156)



Focus groups with staff had representation from a wide range of health and social care services and included 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.

In order to facilitate children, young people and families to participate in the development of the standards, the Project Team worked with key staff members in a range of statutory and voluntary health and social care organisations working with children. These staff members assisted in a number of ways, including identifying participants for the focus groups, and assisting in the development of an informational flyer for these groups. They supported children and family members to understand the purpose of the focus groups. These focus groups were facilitated by staff with experience of working with children and families using health and social care services or by a member of the Project Team, where appropriate. At least one member of the Project Team attended each focus group to take notes, to provide information on the project, and to answer any questions.

Relevant briefing documents and flyers tailored to the needs of the group were sent to participants and or facilitators ahead of the focus group. These briefing documents outlined the purpose of the session, key questions for consideration, how feedback would be used, and provided assurance that feedback would not be attributable to any individual. The Project Team regularly reviewed the engagement with children, young people, families and staff to ensure as wide a range of perspectives as possible were included in the standards development process.

All of the feedback gathered during these focus groups was reviewed and considered by the Project Team to inform the development of the standards.

3.2 Feedback from focus groups during the scoping phase

The Project Team analysed all feedback received from the focus groups and telephone consultations conducted. Findings were collated under the four principles underpinning HIQA's standards development framework.[(2)] The principles are:

- a children's rights-based approach
- safety and wellbeing
- responsiveness
- accountability.

Overall, the findings from the focus groups undertaken during this stage of the standards development process reinforced the findings from the evidence review process.

These findings were presented to the Advisory Group and Children's Reference Group at their second meetings, together with an overview of the extensive stakeholder engagement. The following sections set out the feedback received from focus groups under each of the principles.

Principle 1: A Children's Rights-based Approach

As identified in the *Evidence review to inform the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services*, children have rights that are clearly stated and protected under current legislation in Ireland and human rights treaties which Ireland has agreed to uphold.(1) A children's rights-based approach means protecting and promoting children's rights when they are using health and social care services, including their right to be treated with dignity and respect, in a non-discriminatory manner, and to participate in their care and support.

The importance of staff recognising children as unique individuals and seeking to understand their wishes and aspirations was particularly important to children and young people who participated in the focus groups. Children using health and social care services appreciated when staff asked what their preferences were and how they wanted to engage with staff.

Participants across the focus groups felt that it was the role of health and social care services and staff to uphold the rights of children and to support children to understand their rights. Participants highlighted the importance of ensuring that children and families can participate meaningfully in decision-making about their care and support. They noted that each child's participation needs to be actively encouraged and supported in a way that respects the child's age, stage of development, and communication needs. These participants discussed the importance of providing children and families with information that is up to date, tailored to their needs and which supports them to make informed decisions.

Participants working in children's social services and disability services felt that services had improved in terms of facilitating children and families' involvement in care planning and goal setting. However, a number of children and parents with experience of mental health services, disability services and or children's social services felt that they were not always treated as partners in the decision-making process by staff. In addition, they highlighted situations where they were not provided with sufficient information or easily understandable information about their

needs or their care and support options. For example, a number of young people with experience of Child and Adolescent Mental Health Services (CAMHS) called for greater involvement of young people in decision-making about their treatment and highlighted the need for other therapeutic options, besides medication, to be discussed with them.

The importance of supporting each child's dignity and identity and treating them with respect was emphasised by focus group participants. A number of participants discussed the importance of services understanding the needs of marginalised communities and supporting their access to and engagement with services, for example through outreach and education. Children and young people emphasised the importance of racial and ethnic diversity within services, including among staff working in services and in advertisements about services, which allows them to feel seen and understood. They also highlighted the need for interpreters to be provided to support communication with parents whose first language is not English.

There was discussion across the focus groups about the importance of providing fair and equitable care and support to children regardless of geographic location or other circumstances. Participants felt that children should have the same access to, and quality of, services regardless of where they live or their needs or abilities. However, participants believed there was a 'postcode lottery' nationally, with inequality in the provision of services across the country. This point is discussed in further detail under Principle 4: Accountability.

Children and families spoke about their desire for services and staff to be sensitive to their needs and circumstances and to provide flexible options for appointments and access to services. A number of participants noted that the move to online appointments during the COVID-19 epidemic had removed barriers to attendance for some children and families, such as the time and inconvenience of travelling to appointments. While this did not suit every child's needs or preferences, participants stressed the importance of services providing appointments based on the needs of the child as opposed to the needs of the service.

Focus group participants discussed the need for services to have a clear and accessible feedback and complaints process for children. They noted that children's awareness of a complaints process, and their knowledge of how to use it, is key to ensuring that their voices can be heard and can inform service planning and development.

Principle 2: Safety and Wellbeing

Findings from the evidence review highlighted the importance of health and social care services focusing on the health and wellbeing of the child as a whole, rather

than simply responding to the presenting needs of the child.[1] The evidence identified that some children are more vulnerable to poorer health and wellbeing outcomes for a range of reasons, including the complexity of their needs, and their family and living circumstances. The evidence highlights the importance of children receiving tailored care and support that mitigates these potential negative impacts on their health and wellbeing. The views of focus group participants aligned with these findings.

Focus group participants felt that in order to provide effective care and support to children, services should approach each child's care holistically, looking at their overall health and wellbeing and their wider life circumstances, rather than focusing only on the need which they present to an individual service with. Participants noted that a child-centred approach requires staff to clearly identify each child's individual needs and apply tailored and timely interventions to meet these needs. When doing this, participants stressed the need for consideration to be given to the family's circumstances before tailoring these interventions.

Collaboration between professionals and coordination between services were recognised by participants as key to addressing children's needs in a holistic way. However, many participants felt that services often did not communicate and collaborate effectively. For example, 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. Some participants shared examples of good interagency and inter-professional working which delivered real benefits for children and families. Additional feedback in relation to interagency working is discussed further in Principle 4: Accountability.

Participants queried how a child's care and support can be effectively coordinated 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. Participants highlighted the need for health and social care services to move towards prevention and early intervention and away from crisis-driven responses. These participants set out the impact on children's safety and wellbeing and the distress experienced by children when their needs are not addressed in a timely manner. Additional points raised in relation to the planning and allocation of resources are discussed further in Principle 4: Accountability.

Focus group participants highlighted a number of issues that are important to parents and families. Children and families discussed the importance of staff working with them to identify their goals before tailoring interventions to meet their needs and aspirations. A number of staff participants discussed the importance of building

the capacity of parents so that they can in turn effectively care for and support their children. Parents noted the impact of a child's diagnosis on the family as a whole and highlighted the need for supports for parents and siblings of children with complex or long-term care needs in order to support their wellbeing and the wellbeing of the family as a whole.

Participants discussed the need for services to provide easily accessible information about what they do and how to access the service. In addition to having clear information on their website, they suggested outreach to schools and community organisations, the use of online and accessible platforms as well as booklets and child-friendly resources to communicate with and educate children and families. When engaged in a service, participants discussed the importance of families being provided with clear information and explicit signposting by staff to appropriate services to meet their child's needs. In most instances, staff and parents felt that information about services and the care pathways between services was not easily accessible to them and this hindered effective referrals. This lack of clear signposting also impacted the child and family's ability to navigate the health and social care system. A number of participants suggested that a central database or directory where staff and the public could access clear and up-to-date information on available services would be of benefit to professionals and families.

Participants stressed the need for advance planning and preparation for young people who will be moving from children's services to adult services. They 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. The need for well-considered and tailored aftercare planning for young people who will be leaving the care of the State was also stressed. Participants working in children's residential centres noted that fostering children's autonomy and life skills is important for young people's development and resilience and that staff have a responsibility in this regard. There was good practice reported in some healthcare settings where collaboration between some paediatric clinics and adult clinics 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. Participants discussed the age limit in accessing CAMHS, noting that new referrals of children aged 16 and above have to be made to the adult service, which many felt was inappropriate.

More broadly, many focus group participants 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.

Principle 3: Responsiveness

The evidence review identified key themes that describe a responsive service, where children are cared for and supported by skilled, trained and experienced staff.(1) These staff are open and clearly communicate with children, families, and their colleagues. Staff are able to exercise creativity and flexibility when meeting the needs of children to ensure they receive care and support that is right for them.

Focus group participants discussed the importance of services and staff being responsive to the needs of children, noting that staff should have the expertise to provide care and support tailored to a child's individual needs and circumstances. Most parents and children were complimentary of the quality of care they received from highly qualified and skilled staff. However, across the focus groups, participants highlighted that staff in health and social care services have high caseloads which affects their ability to provide care and support in a consistent and timely manner. In addition, they highlighted that children's social services and disability services do not always have the appropriate mix of disciplines to provide the right care and support to children with complex needs.

Participants highlighted the importance of staff being welcoming to children and families and treating them with fairness, respect and compassion. The importance of being able to build a meaningful relationship with key staff involved in their care and support was emphasised by children and young people. However, many participants reported that staff turnover, high caseloads, and increasing administrative burdens negatively impact on staff's ability to develop these relationships.

Participants discussed the need for effective workforce planning and increased staff resources to ensure that children's needs are responded to appropriately. Many participants highlighted inadequate staffing levels across health, mental health, disability and children's social services which prevents staff from meeting the needs of children in a timely way. They particularly highlighted the impact of high staff caseloads in children's social services and CAMHS, which they believed resulted in high staff turnover, unfilled vacancies and increased waiting lists for services. Increased incentives to attract and retain staff, as well as increased resourcing of services, was seen as vital to enable services to obtain and sustain the necessary staffing level and skill-mix to meet the needs of children.

Participants also highlighted that maternity and other leave is not covered in some services, and called for this to be addressed to ensure continuity of care for children and families. In addition, these participants highlighted that in situations where a staff member caring for a child will be changing, this should be communicated and managed with the child ahead of time, so that they have the opportunity to get to know the new staff member.

The need for services to support their staff to deliver effective care and support to children was stressed in many of the focus groups. Participants discussed the importance of staff being supported to develop their competencies through having time to engage in continuous professional development and reflective practice. They highlighted the importance of staff receiving regular supervision and support to reduce the risk of burnout, manage the personal impact of their work, and to ensure they are providing high-quality, safe and effective care to children.

Many participants discussed the fragmentation across health and social care services, noting that services work in silos and as a result staff within different services can duplicate referrals. They recognised the need for staff to work together in order to respond effectively to the needs of children, for example where a child is using more than one service, that staff coordinate their interventions, or where a child is moving from one service to another that staff coordinate the move to ensure a smooth transition. They highlighted that children can slip through the gaps where staff and services fail to communicate and felt that children are rushed out of one service before another has been secured. However, participants stressed that for a culture of coordination and collaboration between services to be fostered among staff, it needs to be driven from the highest level within organisations.

Principle 4: Accountability

As identified in the evidence review, accountable services ensure that children receive high-quality, safe care and support which is consistent, coordinated and focused on achieving good outcomes for children.[1] Accountable health and social care services have leaders and managers who strengthen the service's culture and support their staff to deliver on the service's vision. These services regularly assess the impact of their work on those that they are caring for and supporting. Accountable services work well with other relevant services to meet the child's whole needs.

Focus group participants acknowledged the need for services to work together to ensure that children's needs are met in a timely and coordinated way. To achieve this, many focus group participants emphasised the need for leaders and managers in organisations to strengthen the culture of collaboration within and between services through promoting and supporting interagency working and communication. At a high level, participants discussed the central role that education services play in each child's life, noting that there could be substantial benefits for children if links were strengthened between the education system, social services, disability services, mental health services, health promotion and justice.

Participants highlighted a number of challenges to effective interagency working including the lack of IT infrastructure to support information sharing between services, high staff turnover and long waiting lists for services.

A number of participants noted the benefits of joint working protocols between Tusla and An Garda Síochána and Tusla and the HSE which, when successfully implemented, ensure that services work with one another to utilise their knowledge and achieve a shared goal. However, a number of participants reported inconsistent implementation of the joint working protocol between Tusla and the HSE, as well as points of tension around who will fund interventions, leading to delays in decision-making in some cases. These participants suggested that an integrated funding stream between the HSE and Tusla could potentially reduce such tensions.

At a practice level, a number of participants highlighted examples of good interagency and inter-professional working which delivered real benefits 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[†] and Children and Young People's Services Committees (CYPSCs) in children's social services. However, with regard to Meitheal, a number of participants reported that implementation was inconsistent across areas and noted the important role of leadership and staff commitment in enabling successful implementation. A number of participants reported that the move to online meetings with the recent public health restrictions had removed a barrier to professional collaboration and facilitated attendance at interagency meetings.

Also in relation to interagency working, a number of participants felt there was a lack of transparency about staff roles and responsibilities within some services, which they felt 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. In addition, participants highlighted inflexible pathways between services, noting that services should accept referrals from a wider range of professionals.

Communication and information sharing between services was discussed as key to effective interagency working and participants discussed the need for services to put clear arrangements in place to support this. However, many participants highlighted inconsistent and inefficient communication practices across the health and social

[†] Meitheal is an early intervention approach that focuses on strengthening families and communities. Developed in Ireland, the approach coordinates a wide range of statutory services, including: children's social services; An Garda Síochána; health; education; and housing services, alongside community services to assist children and families who could benefit from the support of more than one service.

care sector. Staff, parents and children expressed frustration over poor communication between and within 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. A number of participants highlighted that data protection legislation, specifically the General Data Protection Regulation (GDPR), was often cited as a reason for not sharing information in relation to a child. The need for one lead person to assume coordination of a child's care across services was seen as essential to providing effective care and support. Parents suggested having a dedicated liaison person or key worker for each child that would help to bring services together, inform families of appropriate services and how to access them, and work towards making children and families feel heard by acting as the link between services. A number of staff participants expressed the view that the system as a whole, and individual services, require updated IT infrastructures to support sharing of information between services.

Participants stressed the need for transparency and equity in the planning and allocation of resources to meet a child's needs and that this should not be dependent on where they lived. Participants called for this inequity to be addressed to ensure that children have equal waiting times for services. Some participants noted that deprived communities should be 'over-resourced rather than under-resourced', given the higher prevalence of child and youth difficulties in these areas. Participants highlighted the inappropriate physical infrastructure of some services for children with disabilities and called for this to be addressed.

The topic of waiting lists for health and social care services was widely discussed by participants and highlighted as a key barrier to children accessing appropriate care and support in a timely manner. Participants discussed possible ways of addressing this such as increased funding of specialist services and effective planning and allocation of resources. As noted in feedback under Principle 3: Responsiveness, the need for improved workforce planning and development was emphasised by staff working in health and social care services. Staff shortages and high caseloads were viewed as placing an unsustainable burden on staff, which was leading to retention issues in key professions. Overall, focus group participants called for additional resources to match the health and social care needs of children across Ireland. This included increased staffing to reduce demanding caseloads and to enable staff to spend more time caring for and supporting children. Children with experience of mental health services and social care services called for the availability of staff outside of the typical 9am to 5pm Monday to Friday schedule, to address crisis situations and avoid inappropriate admissions to services.

Related to this, participants highlighted the need for health and social care services to move towards prevention and early intervention and away from crisis driven responses. They highlighted the strict criteria and high thresholds for 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. Participants stressed that resourcing early intervention would lead to improved outcomes for children and circumvent the need for more costly interventions in the long term. A number of participants highlighted the importance of community-based services in providing early intervention to children and their families in a holistic way. Participants discussed the expertise held within community-based services, noting their ability to perform outreach to seldom heard groups within the community. Increasing funding for services to care for and support children within the community was called for by focus group participants. Additionally, the expansion of community funding, supports and resources were viewed as a possible avenue to help alleviate waiting lists in CAMHS. For example, many participants felt that if mental health supports were offered more consistently and frequently within the community then there would not be such a strain on inpatient CAMHS.

Focus group participants stressed the importance of a culture of learning and quality improvement in services and noted the improvement seen in children's health and social services through the implementation of national standards, inspection programmes and regular audit. The importance of listening to feedback and responding to the opinions and voices of children and families was seen as central to delivering child centred and accountable services.

3.3 How this feedback informed the development of the standards

Notes from each of the focus groups and telephone consultations were read in their entirety by the Project Team. Each individual comment was assessed to determine whether it was within the scope of the standards and, if in scope, how it would be incorporated into the draft standards. Where feedback was out of scope of the standards, it was documented for discussion with key stakeholders to inform future service planning, as well as policy direction, and it was considered for possible inclusion in the development of implementation support tools. Feedback received from children's focus groups during this process was particularly helpful in informing the children's statements for each standard, as well as the associated features, reflecting what children and young people with experience of health and social care services felt was important.

4. Public Consultation

This chapter presents an overview of the analysis of the responses received during the public consultation, as well as the second round of focus groups undertaken during the public consultation process. The feedback from the public consultation and focus groups are presented together in this chapter as there was significant overlap in feedback received.

4.1 Introduction

As set out in chapters 2 and 3, feedback from the scoping consultation and focus groups informed the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services. During the public consultation on the draft national standards, respondents provided feedback on a range of issues that are outside the remit of HIQA and the MHC, but that are critical to the effective implementation of the standards and improvements within health and social care services working with children. The Project Team has discussed this feedback with the Advisory Group and with individual stakeholders with responsibility for developing policy and delivering services and will continue to engage with key stakeholders in this regard.

4.2 Overview of the public consultation process

The second public consultation was held when HIQA and the MHC published the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services. The six-week public consultation ran from 16 September 2021 to 28 October 2021 to gather feedback on the content and structure of the draft standards. Respondents were also asked to give feedback on what they felt was needed to support the implementation of the standards. The draft standards document was made publicly available to download on www.hiqa.ie and a consultation feedback form was developed to assist people to make submissions. Submissions could be made using an online survey tool, emailed to a dedicated email address, or posted to HIQA.

At the start of the second public consultation, the Project Team notified members of the Advisory Group about the consultation process and asked that they notify the organisations and groups they represent. The Project Team also contacted the Children's Reference Group, focus group participants, relevant health and social care professionals, advocacy groups and interested stakeholders by email to inform them of the process. The Project Team requested that they share information about the public consultation and encourage their colleagues, and children, young people, families and carers connected to their services or organisations, to participate in the process. In order to reach as wide a range of stakeholders as possible, the public

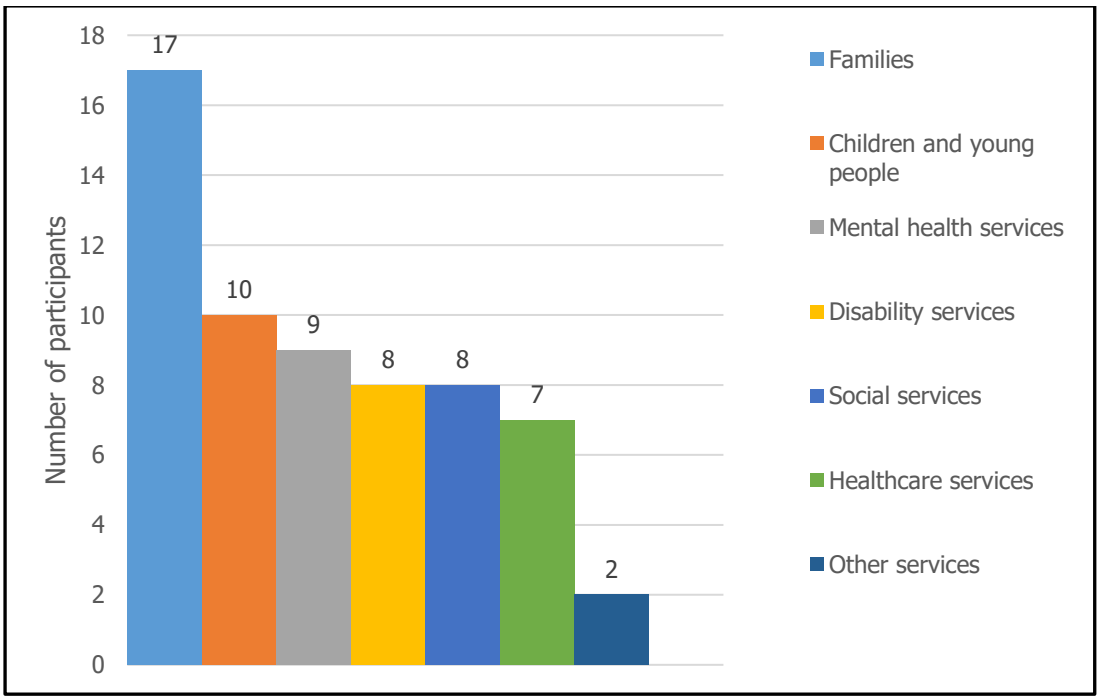
consultation was advertised in HIQA's newsletter and on both HIQA's and the MHC's websites. In addition, a press release about the public consultation was issued, and the consultation was advertised periodically via HIQA's and the MHC's social media channels, for example Twitter (now X), Facebook, LinkedIn and Instagram.

There were a total of 58 responses to the public consultation. All responses were considered and the draft standards were revised, where relevant. See Appendix C for list of organisations that responded to the public consultation.

During the public consultation process, the Project Team held a further 13 focus groups and one interview, meeting with 61 participants, to discuss the draft standards. As part of this process, the Project Team re-engaged with participants and facilitators from the focus groups conducted during the scoping stage of the standards. A number of these participants took part in the second round of focus groups. The Project Team also engaged with additional stakeholders to ensure as rounded an engagement as possible. A copy of the draft standards, as well as relevant briefing documents and flyers tailored to the needs of the group, were sent to participants and or facilitators ahead of the focus group. Due to public health restrictions as a result of COVID-19, all except one of these focus groups were held online.

A breakdown of focus group participants during the public consultation period can be seen in Figure 4.

Figure 4: Breakdown of focus group participants held during the public consultation (n=61)



All of the feedback gathered at the focus groups undertaken during the public consultation was reviewed and considered by the Project Team and, where relevant, incorporated into the revised draft standards.

4.3 Results of the public consultation responses

In submitting their feedback, respondents were asked if they were commenting on behalf of an organisation or as an individual. Of the 58 responses to the public consultation, 39 (67%) respondents responded on behalf of an organisation and 19 (33%) respondents responded in a personal capacity.

All 58 respondents gave further detail on what capacity they were responding in:

- 25 (43%) stated that they were providing feedback as a staff member or other person working in a health or social care service with children
- Two (3%) stated they were commenting as a person who has used or is currently using a health or social care service as a child
- 31 (53%) stated they were commenting in an 'other' capacity. These included staff from representative organisations, networks and advocacy groups working with children, and parents and relatives of children with experience of health and social care services.

Forty-eight (83%) respondents gave details of their roles. Examples of the roles of respondents included:

- Administrator in a domestic violence service
- Care leaver
- Director of a community care service
- Director of paediatric nursing
- Family member of a child using CAMHS
- Occupational therapist, CAMHS
- Paediatric clinical nurse specialist
- Principal social worker in a fostering service
- Programme manager in a disability service
- School principal
- Speech and language therapist, Children's Disability Network Team
- Staff member, homecare service.

The full list of organisations that made contributions to the public consultation are listed in Appendix C.

4.4 Feedback that applies to more than one standard

Throughout the public consultation, HIQA and the MHC received feedback that was relevant to a number of the principles and the standard statements rather than a specific standalone principle or standard statement. This section sets out this feedback and how HIQA and the MHC responded to it. This feedback relates to:

- Emphasis on supports for children with disabilities
- Alignment of the overarching national standards for children with the Draft National Standards for Children's Social Services.

Emphasis on supports for children with disabilities

Public consultation responses

A number of respondents requested that the standards place additional emphasis on the need for appropriate communication methods for children with varying communication abilities, as well as on the need to support such children to express their opinions and be involved in decision-making. These respondents also highlighted the need for more inclusive wording or phrases throughout the standards to include children with different communication needs. The example was given where the use of words like 'told' or 'voice' is not inclusive for children with speech and hearing difficulties.

Focus group responses

Similar to the public consultation responses, participants suggested minor wording changes in particular standards and features to further emphasise and clarify the need for services to provide information in a way that children and their families can understand.

HIQA and the MHC's response

In order to ensure that the language used throughout the standards is inclusive of children with a range of communication abilities and needs, the document was reviewed and the language amended where appropriate. For example, some of these changes include the use of word 'informed' instead of 'told' and the phrase 'to express my views' instead of 'to make my voice heard'.

Additional wording has been added to a number of standards and features to reflect the need to communicate with children in a way that meets their communication needs and abilities and to ensure they are supported to participate in their care and support. For example, additional wording was added to Standards 1.1 and 1.2 to reflect this. These standards now set out that children's rights are explained to them

in a way they can understand and that children are provided with information in a format they can understand to help them to participate in decisions about their care and support.

Alignment of the overarching national standards for children with the Draft National Standards for Children's Social Services

Public consultation responses

A submission from children's social services noted a number of differences between the overarching national standards for children and the Draft National Standards for Children's Social Services. They highlighted the importance of the two sets of standards being as closely aligned as possible for ease of use and consistency.

Focus group responses

This concern did not arise in the focus group discussions.

HIQA and the MHC's response

HIQA has developed the two sets of draft standards concurrently with each other to ensure they are well aligned, as the overarching national standards for children are the framework under which the Draft National Standards for Children's Social Services will sit. Following the public consultation on the draft overarching national standards for children, the two sets of standards were reviewed again and a number of wording changes were made to further align the standards, where appropriate. Differences between the two sets of draft national standards remain and reflect the differences in scope of the overarching national standards for children and the Draft National Standards for Children's Social Services.

4.5 Feedback on each principle

In this section of the feedback form, respondents were asked to provide feedback on each individual principle and the standard statements and features set out under the principle. Respondents were asked to consider the following questions as part of their review:

- Do you think all important areas have been covered in each standard statement or are there any areas that should be included or excluded?
- Are the features listed sufficient to assist staff working in health and social care services with children to meet the draft national standards?

The following sections outline feedback received, specific to each individual principle.

Principle 1: A Children's Rights-Based Approach

Public consultation responses

Of the 58 responses, 50 (86%) provided feedback on Principle 1.

The focus on children's rights and on the UNCRC within the draft national standards was very much welcomed by respondents. They felt that this principle, and the standards and features within it, were clear, comprehensive and covered all important aspects of a rights-based approach to the care and support of children.

"The standard statements cover the important aspects of children rights being heard, access to information and participation in decision-making."

Respondents welcomed the emphasis on supporting children's participation in decision-making regarding their care and support. However, some respondents were concerned about how infants, young children, children with developmental issues, or children who are non-verbal could be involved in decision-making.

"I wholeheartedly agree with the principles of the standards, but I am confused about how I would go about this in real life for someone who is, for example, 4 years old with severe ID, deaf, and visually impaired with no symbolic communication."

Many respondents welcomed the emphasis in this principle on the importance of equitable and accessible care and support for all children regardless of where they live, who they are or their needs or abilities. However, it was requested to amend the language in Standard 1.3 to reflect the reality that individual services, for example residential centres, may have a geographic or age remit and they would be unable to meet the standard as initially worded. Some respondents highlighted that to achieve equitable and accessible care and support for children, challenges such as limited staffing and resources, and the provision of appropriate infrastructure and supports to accommodate children with varying abilities and circumstances, would need to be addressed.

There was a positive response to the standard on feedback and complaints. A number of respondents highlighted that children's feedback to a service can be positive and felt that this should be reflected within the standard. They also noted that children can feel shy or nervous about giving feedback to staff and suggested that a mechanism whereby children can give feedback anonymously would encourage them to do so. Some respondents highlighted the importance of services having an appeals process where children and families can ask for their complaint to be looked at again. Others highlighted the importance of children and families

having access to independent advocacy services to support them when making a complaint.

Focus group responses

In line with feedback from the public consultation, participants strongly welcomed the focus on children's rights. Young people felt that it was very important that children understand their rights as they access health and social care services and welcomed that the standards set out that the rights of the child must be explained to them in a way that they can understand. A number of participants suggested that children's rights be highlighted further within the document by including a section on children's rights and the UNCRC at the beginning of the document. They noted that this would strengthen the emphasis on children's rights by highlighting their importance to health and social care services from the outset.

Participants welcomed the emphasis on supporting children to participate in decision-making about their care and support. However, a small number of parents and staff requested that a stronger emphasis be given in this principle to the role of parents in decision-making. These participants highlighted the complexities of involving children in decision-making when their insight may be impacted by disability or mental health difficulties. They noted that wording in feature 1.1.5 under this principle and feature 2.3.9 under the Principle of Safety and Wellbeing could be amended to reflect that parents should have a greater role in the decision-making process about their children's care and support at such times. However, the majority of parents, young people and staff felt that these features were important safeguards to protect children's rights, particularly children's best interests and that the correct balance had been struck throughout the standards between the participation of the child and the parent in decision-making.

HIQA and the MHC's response

In response to feedback from focus group participants regarding having an emphasis on children's rights at the outset of the document, a new section on the rights of children as set out within the UNCRC has been added to the beginning of the document before the overall introduction to the standards. This section also sets out that all organisations that provide care and support to children should endeavour to uphold these rights.

In response to points raised about how younger children, children with developmental issues and children who are non-verbal can be supported to participate in decision-making about their care and support in a meaningful way, additional text has been added to the overall introduction to this principle. The text highlights that every child's situation is different and emphasises the need for staff

to work collaboratively with the child and others to arrive at the best possible outcome for the child.

In relation to parents' role in decision-making about their child's care and support, HIQA and the MHC recognise the important role of parents in the decision-making process and this is clearly reflected in the standards, most notably under Principle 2: Safety and Wellbeing. As stakeholders highlighted, the standards must reflect and protect the rights of children who find themselves in a wide range of situations. Therefore references have been retained to situations where there are conflicts between the views of children and parents and between the views of parents and staff.

In relation to equitable access to care and support, clarifications were made to Standard 1.3 and to one of the features under this standard to reflect that some services have a geographic or age remit. The child statement in Standard 1.3 now sets out that "I am able to access the care and support I need without discrimination and as locally as possible to where I live." HIQA and the MHC acknowledge the need for additional resources, as well as improved infrastructure and supports in order to achieve equitable and accessible services for all children. As this is outside the scope and remit of these standards, such concerns have been documented by the Project Team and discussed with the Advisory Group in order to inform future policy development.

Regarding the feedback and complaints process, additional wording has been added to the features under Standard 1.4 to strengthen this process. The features now include that staff will support children to give feedback on the service, including raising concerns, making a complaint and or giving compliments; and that children and families are informed about independent advocacy services that can support them when making a complaint. Further emphasis on the need for a safe place and space for children when making a complaint has been incorporated, with the inclusion of the example of children being able to provide feedback anonymously. A new feature has been added, and additional wording added to an existing feature, to set out that if children and families are unhappy with the outcome of their complaint that they can request an explanation and that their complaint can be looked at again.

Principle 2: Safety and Wellbeing

Public consultation responses

Of the 58 respondents, 49 (84%) provided feedback on Principle 2.

Most respondents felt that the standards and features in this principle covered all important aspects of a child's care and support. They welcomed the emphasis on

children's and families' participation in care planning and decision-making, and the child-centred, holistic and joint working approach to supporting children to reach their potential.

"…In particular the statements support the development of a child-centred approach by services that takes account of all of the determinants of health and wellbeing and social, emotional and cognitive development. The features listed are broadly sufficient to assist staff working in health and social care services with children to meet the draft national standards."

The need for timely care and support to effectively meet the health and wellbeing needs of children was strongly reflected in the consultation feedback, with many respondents welcoming the references to the timely provision of care throughout the standards. A number of respondents requested additional references to timeliness within the standards and features to reflect the importance of a timely assessment of the child's needs, early preparation and support for young people transitioning from child to adult services, as well as a timely response to safety incidents and harm.

Respondents highlighted the widespread delays in care and support experienced by children due to long waiting lists. Staff shortages, and limited funding and investment in health and social care services within local communities, were noted as key barriers to a service's ability to meet children's needs in a timely and effective way, particularly children with complex needs.

A number of respondents requested that additional emphasis be placed within Standard 2.2 on the need for services and staff to build families' capacity to support their child's health, wellbeing and development needs.

A number of respondents highlighted the importance of discharge planning and supporting children and families at this critical stage. They noted that children and families need clear and comprehensible information regarding the reasons for discharge, and information on supports available within their community should they need it in the future, and requested that this be included in the standards.

In relation to safety, it was suggested that the service provider statement in Standard 2.6 be strengthened by including the need to apply learning from patient safety incidents and from other incidents in order to improve future policies and practices.

Focus group responses

Participants agreed that the standards covered the key aspects of safety and wellbeing for children. Young people in particular welcomed the emphasis on

coordinated and integrated care and the inclusion of the child and their family in decision-making.

Young people highlighted how children's goals and aspirations change as they grow and develop or as their health and wellbeing improves and felt that staff should regularly review children's goals to ensure that they have an up-to-date understanding of what is important to children. They requested that the wording be updated in Standard 2.2 to state that children are "regularly" asked about their goals by the staff caring for and supporting them.

A number of staff participants queried the wording of the service provider statement in Standard 2.2 which stated the service provider has arrangements in place to "ensure" each child reaches their potential. These participants noted that some families or children refuse to avail of the services offered despite the efforts made by staff and service providers. They felt the wording in this standard therefore poses an unrealistic expectation that the service provider cannot fully meet. They suggested the use of alternative wording such as to "support" each child to reach their potential.

A number of staff participants also queried the wording in feature 2.4.3 under Standard 2.4. This feature referred to staff taking the proper actions to protect children from 'serious harm.' They suggested the word 'serious' be removed to avoid confusion around what is considered serious harm to a child, highlighting that all forms of harm to a child should be taken seriously and addressed. They also suggested that an additional feature be added to this standard to recognise situations where a child's behaviour poses a risk to the child or to other children.

Participants discussed the need for proper planning and coordination to help young people manage the transition from child to adult services and welcomed that this was reflected in the standards. It was felt by a number of participants, however, that the standards needed to further emphasise that the transition should be a gradual and phased move from one to the other, to ensure a sensitive and smooth transition for children. Some staff participants highlighted that when they reach out to adult services, they are not always receptive to engage in an advance planning and preparation process.

HIQA and the MHC's response

To address feedback on the area of timeliness, wording in a number of features (2.1.1 and 2.5.1) and standard statements (2.5 and 2.6) have been updated to further reflect the need for 'timeliness' of care and support.

The importance of building families' capacity to care for and support their child has been emphasised further in Standard 2.2, with the child's statement and feature

2.2.1 updated so they now set out that services and staff support the child and their family to meet the child's health, wellbeing and development goals and needs.

To address staff concerns around the feasibility of services ensuring that children reach their potential, the wording of Standard 2.2 has been amended with the service provider statement outlining that services 'support' each child to reach their potential rather than 'ensure' that they do.

In response to the point raised by young people that their goals and aspirations grow and change over time, the word 'regularly' has been added to the child's statement in Standard 2.2 to emphasise the need for regular reviews of the child's goals.

To address feedback in relation to discharge planning, wording related to the discharge process has been amended under Standard 2.3, with the addition of a new feature and additional wording added to an existing feature. These features now set out that the child and their family understand the reasons for discharge and are provided with information about support services in their community that can help them in the future if they need it.

An additional feature has been added under Standard 2.4 to reflect situations where a child's behaviour poses a risk to themselves or others, that staff support them in understanding and managing their behaviour and emotions. To address staff feedback regarding the need to protect children from all forms of harm, the word 'serious' was removed from the phrase 'serious harm'.

To address feedback on the importance of a gradual and phased transition from children's services to adult services, additional wording has been added to feature 2.5.1. This feature now sets out that preparations begin well in advance of the move so that the change is gradual, and children are prepared for it.

In relation to the importance of applying learning from incidents, Standard 2.6 has been amended with the service provider statement now including that services '…will use learnings to inform future policies and practices'.

Principle 3: Responsiveness

Public consultation responses

Of the 58 respondents, 50 (86%) provided feedback on Principle 3.

Many of the respondents were very positive about this principle. They welcomed the focus on a holistic approach to care and support that is well coordinated by skilled and knowledgeable staff.

"The statements present a holistic approach to the needs of children and are underpinned by coordinated and responsive support."

Respondents welcomed the focus on continuous care and a positive and consistent relationship between staff and the child in the standards. However, a number of respondents working in acute settings highlighted that a consistent and continuing relationship with children, as set out in standard 3.1, would be difficult to achieve in their work given the nature of their services. In such services where care is episodic or time-limited they indicated that it is not feasible to develop consistent and continuous relationships with children and their families. They requested that the standards reflect that care and support can be once off or time-limited rather than ongoing.

Respondents welcomed the inclusion in the standards of staff taking the time to get to know a child's needs and circumstances. A number of respondents highlighted the importance of staff getting to know a child's "hopes", in order to provide the care and support that best suits the child and requested that this be reflected in the child's outcome statement in Standard 3.1. A submission from young people with experience of children's social services highlighted the importance of children being able to build trusting relationships with staff, who follow through on the commitments they make to children, and who demonstrate care and kindness. They also highlighted the importance of how 'endings' are managed for children.

In relation to Standard 3.2 on interagency working and coordinated care and support, a number of respondents commented on the need for joint working protocols for information sharing to enable a smooth transition when a child is moving between services and requested that this be reflected in the standards. Additionally, it was highlighted that services need to proactively identify and resolve barriers to multiagency working and optimise the coordination of care and support for children.

It was suggested that the standards would benefit from placing emphasis on the need for services to have mechanisms or processes in place to identify barriers to care for children from minority communities and to work proactively to address these barriers.

While respondents welcomed the standard statements and features set out under this principle, many noted the challenges to achieving them such as staff shortages, issues with staff retention, lack of staff supervision and limited resources. They highlighted that such challenges impede services from delivering quality, timely and responsive care and support to children.

"Agree with the standard statements in principle, however the reality of putting into practice will be difficult/impossible with current service resources."

Focus group responses

Similar to the feedback from the public consultation, focus group participants welcomed the standards set out under this principle and felt that they covered the important aspects in ensuring that services respond to the needs of children in a timely and coordinated way. Many of the participants agreed that current challenges in relation to staff retention, staff supervision and resources will need to be addressed in order to implement these standard statements. Funding for community services was also highlighted as necessary in the provision of appropriate and timely care. This was particularly stressed by staff working in disability and mental health services.

Children and young people noted how important it is for staff to be supportive and spend time with children to build good relationships with them and particularly welcomed the emphasis on consistent and continuous relationships with staff outlined in Standard 3.1. However, some staff participants, as in the public consultation feedback, questioned the feasibility of establishing continuous relationships with children given the episodic or time-limited nature of their services.

HIQA and the MHC's response

To address the feedback in relation to episodic care and the feasibility of staff developing continuous relationships with children, a definition of 'care and support' was added to the key terms. This definition recognises the range and type of support provided to children in different settings by different professionals to meet their health and wellbeing needs. The definition clarifies that care and support may be continuing or time-limited; preventative, supportive, palliative or curative; and provided in a range of different settings by different professionals. Thus, where feasible and appropriate, staff are expected to establish a continuous relationship with children in their care.

To address the points raised about the importance of staff considering children's "hopes" as well as their needs and circumstances in providing child-centred care and support, additional wording has been included in the child statement in Standard 3.1 to incorporate this. The child statement now sets out that staff spend time getting to know me as a child, including my needs, "goals" and circumstances "so that I get the care and support that best suits me."

Additional wording has been included in a number of features under Standard 3.1 and Standard 3.2 to reflect the points made by young people about the importance

of being able to build trusting relationships with staff, to experience kindness, and to have endings managed with care.

In response to feedback about the importance of services having protocols and arrangements in place to enable staff to share information and to coordinate care, a separate standard on information sharing has been created under Principle 4: Accountability. This standard (Standard 4.5) sets out that "the service provider has effective information management arrangements in place to enable services to plan, manage, and deliver child-centred, safe and effective care and support. This includes systems to share relevant information within and between services in an efficient and timely manner." Features related to use of information have been moved under the new standard and two additional features added. Together, the features set out that staff follow the proper policies and procedures when collecting, documenting and storing information about children and that they understand when and how to share information appropriately so that children get the care and support that they need.

In response to the point about the importance of services having a process or mechanism through which to identify and resolve barriers to care for marginalised groups, a new feature has been added under Standard 4.3 in the principle of Accountability. This feature sets out that children can be confident that services will recognise if it is difficult for them to get the care and support they need and will do all they can to help them so they can achieve the same outcomes as others. Additional wording has also been added to the introduction to the principle of Accountability to include that services work to identify any barriers to collaboration and communication between services and resolve them effectively.

HIQA and the MHC acknowledge the importance of sufficient staffing, adequate supervision of staff and staff retention to the development of stable relationships with children and families and to the provision of timely care and support. The importance of staff support and supervision is set out under Standard 3.3 and the need for effective workforce planning is set out under Standard 4.3. While limited resources and difficulties with staff recruitment and retention are outside the scope and remit of these standards, such concerns have been documented by the Project Team and discussed with the Advisory Group in order to inform future policy development.

Principle 4: Accountability

Public consultation responses

Of the 58 respondents, 48 (83%) provided feedback on Principle 4.

Overall, feedback on this principle was positive with many respondents highlighting that the standards will serve as a reference for service providers to check the quality of service they deliver. Further, they noted that the standards will assist service providers to understand their roles and responsibilities in promoting the safety and wellbeing of children to whom they provide care and support. Respondents welcomed the focus both here and in other principles on interagency working to ensure that children receive timely and coordinated care and support. They noted that good communication and collaboration between services, as set out under this principle and elsewhere in the standards, is crucial to the provision of coherent and consistent services to children and families.

The obligation of some services to submit statutory notifications to HIQA was highlighted and it was suggested that wording on this obligation be included.

The requirement for a lead person or a lead agency to coordinate a child's care and support across services, as set out in Standard 4.4, was welcomed by many respondents who felt this was essential to ensure that children receive integrated care and do not fall between services. However, a number of respondents, particularly staff and service providers, felt that this may be difficult to achieve given the current workload within services. A small number of respondents requested more guidance on how the lead person or lead agency should be decided on. Some respondents from children's social services noted that services covered by the standards are subject to different levels of regulation and monitoring. These respondents highlighted the need for fairness in inspections against the standards, recognising the limits of one service to compel the cooperation of another.

Many respondents welcomed the focus within this principle on the need for continuous quality improvement within services. A number of respondents noted, however, that the standards are quite broad and called for further details and guidelines on the frequency with which audits and reviews should be conducted. The importance of asking staff for their views on service improvement was highlighted and it was suggested that this should be reflected in the standards. The need for a feature on learning from incidents was also noted.

Focus group responses

In line with public consultation responses, young people and parents welcomed the focus on quality improvement and on regular reviews of services. They highlighted the importance of services being open and transparent and communicating with children and families about the changes they intend to make to the service following their feedback. These participants requested that a requirement to inform children and families how their views will be used and acted upon be included in Standard 4.2.

Similar to feedback from the public consultation, there were queries regarding the requirement for a lead person or a lead agency to coordinate a child's care and support across services. The majority of participants felt that a lead person or lead agency would facilitate effective service coordination and accountability. However, some participants working in children's social services felt that this had to be clearly defined to avoid the assumption that the statutory social worker would automatically take the lead in coordinating services. A number of other participants requested further specific information on how the lead person or lead agency would be decided and how this would look in different care settings, for example, when dealing with complex cases of mental health. Participants felt that for this to work, the lead person or lead agency must have the authority to make final decisions and to hold other services accountable.

Young people highlighted that the child's statement and the service provider statement in Standard 4.4 were not fully aligned, noting the need to include reference to the lead person or lead agency in the child's statement to ensure this alignment.

HIQA and the MHC's response

To address the point raised regarding the obligation of some services to submit statutory notifications, a new feature was added to Standard 4.1 setting out the need for services to follow proper policies and procedures for reporting incidents.

In response to feedback on the importance of services being transparent and accountable to children and families by providing them with information on how their feedback is being used, additional wording has been added to feature 4.2.2 under Standard 4.2. This feature now sets out that children and families will be told how their views will be used and the actions the service plans to take as a result.

In response to feedback from young people regarding the need to align the two statements of Standard 4.4, the wording of the child's statement has been updated, to include that children know the person or service in charge of organising all of the different services for them.

To strengthen the focus on continuous quality improvement within services, two new features were added to Standard 4.6 (previously Standard 4.5). The additional features set out that staff are asked for their views on how the service can be improved and that services learn from adverse events and incidents to make the service safer and better. Due to the broad range of services covered by these standards, it is not feasible to set specific parameters on how frequently services should conduct audits and reviews.

In response to feedback and queries regarding how the lead agency or lead person should be decided upon, HIQA and the MHC recognise that additional supports are required to facilitate interagency working, such as national and organisational policies and joint working protocols. While the development of such policies and protocols is outside the scope of these standards, these concerns have been documented by the Project Team and discussed with the Advisory Group in order to inform future policy development.

4.6 Feedback on the language and accessibility of the draft standards

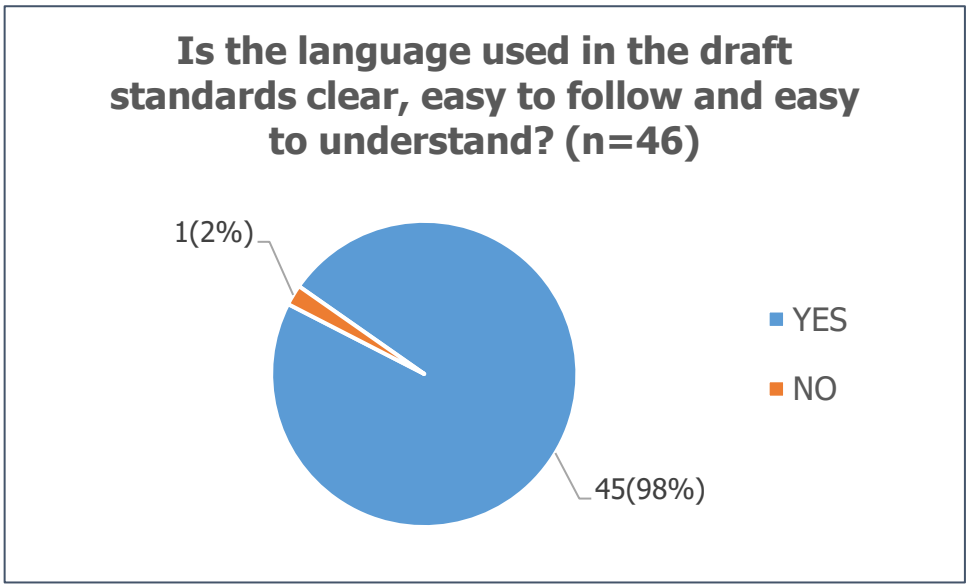
Questions 3.1(a), 3.1(b) and 3.2 sought feedback on the language and accessibility of the draft standards. This section of the document provides an overview of the responses received in relation to these questions.

Language used

Public consultation responses

Respondents were asked if the language used in the draft standards was clear, easy to follow and easy to understand. Forty-six (79%) of the 58 respondents answered this question. Figure 5 shows the number of 'Yes' or 'No' responses to this question.

Figure 5: Responses to public consultation regarding language used in the standards



Respondents commended the use of the child's voice within the standards. They noted that the child's perspective was well articulated in the standards and features and felt that this encouraged service providers to take the child's perspective meaningfully into consideration and increased the visibility of the child.

"The voice of the child is very strong and keeps the reader focused on what is important. The outcomes a child should expect and what a service provider must do to achieve this is very clear."

As noted in section 4.4, a number of respondents highlighted the need for more inclusive wording in places in the standards so as to include children with different communication needs and abilities.

In addition to this standards document, respondents recommended having supplementary documents that are in simplified, child-friendly and accessible formats. This would include for example, appropriate symbols and imagery for younger children, Braille, Irish Sign Language (ISL), audio formats and large prints.

Focus group responses

Focus group participants felt that the standards read well, were child focused and that the language was plain and accessible. Similar to the public consultation, participants welcomed the use of the voice of the child throughout the standards. Young people in particular felt that this made the standards child friendly and empowering to children.

However, in a focus group with parents and relatives with experience of health and social care services for children, a number of participants suggested that the language be more authoritative in the service provider sections. This would emphasise the responsibility and accountability of service providers in implementing the standards.

HIQA and the MHC's response

The standards were reviewed and where necessary, wording and phrasing changes were made to be more inclusive of children with disabilities.

HIQA and the MHC are committed to supporting services and staff to implement the standards through the development of guidance and tools. Suggestions for child-friendly and accessible documents to supplement the standards were considered as part of this. As a result, an animation and easy-to-read leaflet for children were developed and will be published alongside the standards.

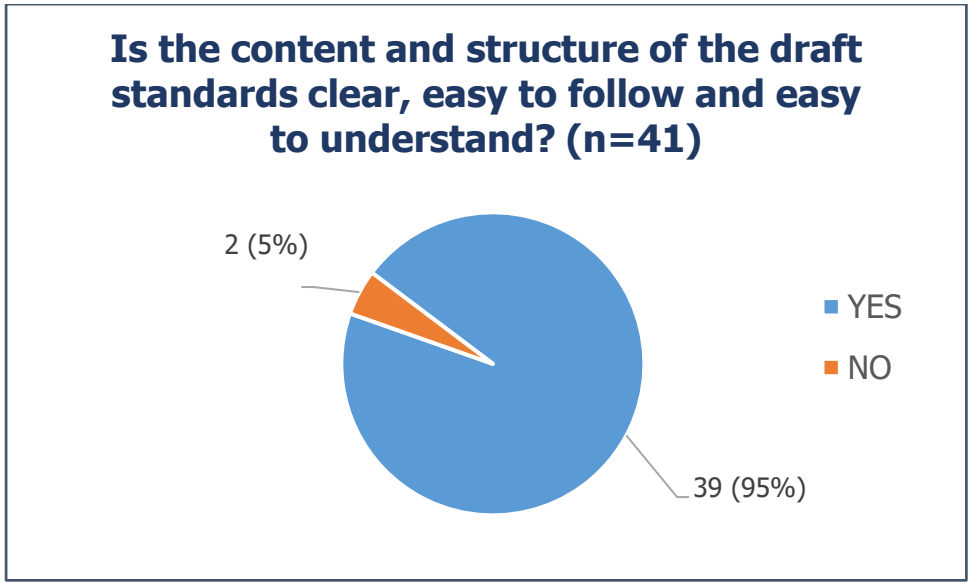
With regards to using more authoritative language in the service provider statements, HIQA and the MHC have carefully considered the language used throughout the document. The language used is consistent with other national standards such as the Draft National Standards for Children's Social Services. Therefore no changes were made in this regard.

Content and Structure

Public consultation responses

Respondents were asked if the content and structure of the draft standards was clear, easy to follow and easy to understand. Forty-one (71%) out of the 58 respondents answered this question. Figure 6 shows the number of 'Yes' or 'No' responses to this question.

Figure 6: Responses to public consultation regarding the content and structure of the standards



The majority of respondents welcomed the use of the child's statement focusing on the desired outcomes for the child, alongside the service provider statement stating the arrangements the service provider must have in place to achieve this outcome. However, a number of respondents wanted further details, particularly examples or scenarios, of how they can apply the standards in their service setting. Some felt they would benefit from a guidance section to help them achieve each standard. A small number of respondents noted that the document was long and suggested having an abridged version in addition to the full version.

Focus group responses

Participants agreed that the standards were comprehensive and well laid out. However, a number of staff participants suggested having more visuals throughout the document to make it more engaging. Children and young people noted that the standards were accessible and easy to follow. However, some suggested having a simpler and shorter version with more visuals for younger children.

HIQA and the MHC's response

HIQA and the MHC recognise that additional supports are needed to support services to implement the standards, for example the development of local policies and procedures commensurate with the standards. While the development of such policies and procedures is outside the scope of HIQA and the MHC, it is expected that organisations and services will develop such policies and procedures, setting out the detail necessary for services to implement the standards in practice.

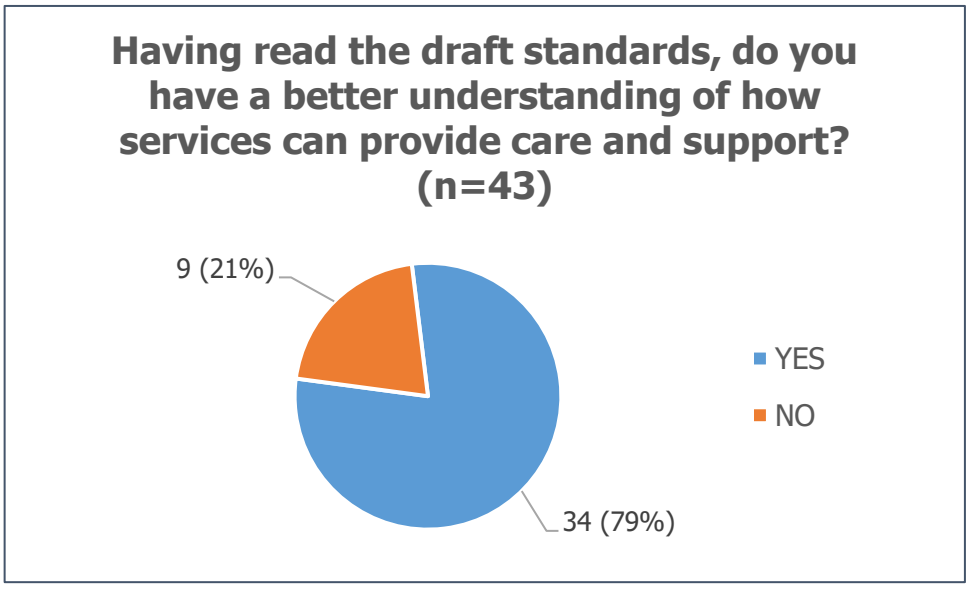
HIQA and the MHC are committed to supporting services to implement the standards through the development of guidance and tools. Learning and support material such as child-friendly, compact and easy-to-read documents were considered as part of this and an animation and easy-to-read leaflet for children were developed and will be published alongside the standards.

Understanding of how services can provide care and support

Public consultation responses

Respondents were asked if they had a better understanding of how services can provide care and support to children using health and social care services after reading these draft standards. Forty-three (74%) of the 58 respondents answered this question. The number of 'Yes' or 'No' responses to this question can be seen below in Figure 7.

Figure 7: Understanding of how services can provide care and support after reviewing the standards



The majority of respondents (79%) to this question agreed they had a better understanding of how they can provide care and support to children using health and social care services having read the standards. However, some noted that insufficient resources and staffing shortages will pose challenges for them in achieving these standards in practice.

"While the principles, standards, and features provide clear high-level service excellence guidance, the complexities within the system, capacity issues, staffing, and resourcing problems will play a significant role in achieving these standards."

A number of respondents added that a clear and robust implementation plan, clarity on interagency working, an inspection framework, and increased resources and government investment in services would help service providers to implement these standards. Those who responded negatively to this question felt there was a need for further clarity and specificity as to how these standards would work in their area of practice and called for examples and scenarios explaining how these standards would apply.

Focus group responses

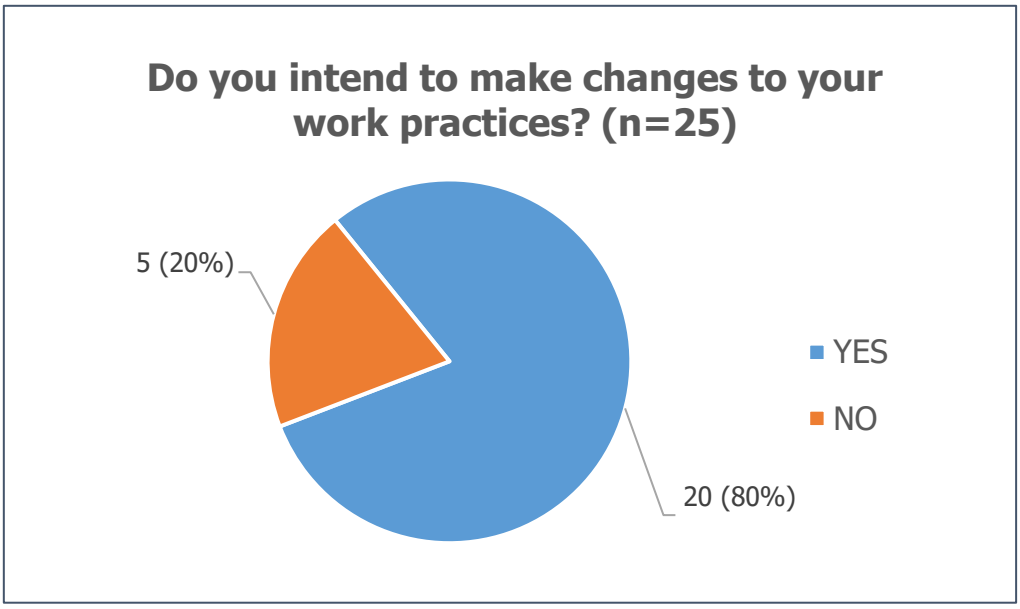
Similar to the public consultation feedback, focus group participants agreed that the standards are very comprehensive and well written. Most staff participants agreed that the standards set clear expectations of care.

Intention to Change

Public consultation responses

Respondents to the public consultation were asked to indicate if they intended to change their practice after reviewing the draft national standards. This was relevant to respondents working in a health or social care service with children. Twenty-five (43%) of the 58 respondents answered this question. The number of 'Yes' or 'No' responses to this question can be seen in Figure 8 below.

Figure 8: Participants who intend to make changes to their work practices



Those who indicated an intent to change their practice most commonly planned to incorporate the standards into their internal quality assurance approach, and to improve communication and collaboration with children and families in relation to care planning and decision-making.

However, insufficient resources, lack of managerial support and commitment, and inequitable geographical distribution of services were highlighted as issues that may affect change in practice.

Of those who indicated that they did not intend to change, many felt that they were already incorporating what the standards called for into their work practice and indicated that they intended to continue to do so.

Focus group responses

Responses from the staff focus group participants aligned with the written responses to the public consultation with similar challenges to changing practices highlighted.

4.7 Summary

Both the public consultation responses and feedback from focus group participants was reviewed and considered, and the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services were revised based on the feedback received, where relevant.

A summary of the feedback and subsequent changes to the draft national standards was presented to the Advisory Group and the Children's Reference Group at their

final meetings and final changes were made to the standards prior to their submission for internal approval.

5. Supporting implementation of the standards

HIQA and the MHC recognise that additional supports are required in order for services to implement the standards fully. An implementation science approach was applied to the development of tools and or resources to support services to put the standards into practice. This approach looks at the mechanisms of behaviour change and what is needed to support the successful implementation of any intervention. This approach allows HIQA and the MHC to identify, for example, if it is a knowledge gap or a behaviour change which needs to be addressed to support effective implementation, and to develop tailored tools and resources to meet the specific need.

At each stage of the development of the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services, the Project Team gathered stakeholder feedback to identify and understand potential barriers[+] to the implementation of the standards, in order to develop relevant tools to address these barriers.

Findings from the analysis of stakeholder feedback gathered throughout the standards development process identified a number of areas that require support. Some of these areas are within the remit of the HIQA and MHC Project Team, for example developing tools to support the implementation of the standards such as decision-making toolkits and guides that are accessible for children and families, while others are within the remit of HIQA's Chief Inspector, such as the development of an assessment and judgment framework for the standards setting out how services will be assessed against the standards. However, many of the areas identified are outside the remit of HIQA and the MHC, such as the development of a national policy on interagency working, and systems to support effective workforce planning and resourcing.

This chapter sets out the themes emerging from the analysis of stakeholder feedback on what is needed to support the implementation of the standards.

5.1 Themes emerging from stakeholder feedback

Interpreting and understanding the standards

Stakeholder feedback highlighted the need for support and guidance around the interpretation of the standards. Stakeholders suggested that local champions, with responsibility for raising awareness, disseminating information, and providing

[+] Barriers are defined as any factors that obstruct the capacity for health and social care services to implement evidence-based interventions.

guidance on the national standards, could aid implementation, particularly for front-line staff working in community-based services.

A small number of stakeholders suggested that HIQA and the MHC devise specific and tailored guidance for different service types, setting out the responsibilities of the service, including examples of standardised ways of implementing the national standards in practice. These stakeholders felt this would avoid variances in interpretation across different settings which could impact on evaluation and regulation.

Clarity on what monitoring will look like

Stakeholders sought clarity on how services would be inspected against these standards and how HIQA and MHC plan to measure achievement of the standards. Stakeholders noted that regulation of the standards would help to 'focus the mind', and suggested that regular information and consultation sessions with HIQA and the MHC throughout the inspection cycle where guidelines, support and advice were provided, would ensure compliance. Stakeholders noted the potential benefit of measuring or inspecting how multiple services interact to provide children care and support and proposed HIQA develop an inspection framework to inspect how services engage with one another.

Development of self-assessment tools

Stakeholder feedback indicated a strong demand for the development of self-assessment tools to enable services to assess their own compliance with the standards. Suggestions included self-audit checklists to enable organisations to evaluate how they adhere to the standards. Stakeholders also called for a quality improvement tool that would focus on whole service evaluation and incorporate multiple layers of feedback from service users and their families.

Interagency working

Stakeholder feedback from across mental health, social services, disability and healthcare sectors highlighted a need to promote and improve interagency working across services to ensure a child receives a holistic response to their needs. Stakeholder suggestions on how to improve interagency working included; a multidisciplinary approach to prevent services operating as silos, development of a focused work plan to enhance an interdepartmental and interagency approach, providing information on best practice in relation to information sharing and development of formal protocols for interagency working.

Stakeholders also suggested that the assignment of a key worker or lead person to coordinate a child's care and support across services would be extremely beneficial

and would help children and their families to navigate the health and social care system. They noted that this would reduce the need for children to repeat their history each time they access a service.

Related to this, analysis of stakeholder feedback indicated that services could be encouraged to conduct joint audits, and that HIQA and the MHC might be in a position to develop self-audit tools for interagency working to support this.

Effective communication and information sharing

Stakeholders from across mental health, social services, disability and healthcare sectors, were in agreement that communication and information sharing within and between services will be a challenge to implementing these standards. Stakeholders sought clarity around information sharing, particularly relating to how services can communicate with each other and share information about a child considering GDPR.

Resources and workforce planning

While outside the remit of HIQA and the MHC, stakeholder feedback at all stages of the standards development process highlighted the need for additional resources to support the implementation of the standards, both in the form of additional staff and an increased rolling budget to better plan for services in the longer-term. Stakeholders called for government commitment to increased funding for both staffing and other resources on an ongoing basis.

Stakeholders also highlighted the need for better workforce planning, including succession planning. It was noted that consistency in staffing would positively impact the experience of children and families using health and social care services.

Staff training

Stakeholder feedback indicated the need for staff to be suitably trained and provided with continuous professional development opportunities to keep up with new developments. Some stakeholders suggested that the standards be made part of mandatory training, while others proposed training regarding the standards be introduced at early career stage, for example, third level education. Stakeholder feedback also highlighted that live or pre-recorded webinars on the standards could be useful for training new staff, as well as increasing the reach of the standards.

Accessible information

The child-friendly language and emphasis on the child's perspective within the standards was welcomed by stakeholders. Feedback from stakeholders indicated that it was important that the child's perspective also be considered in the implementation of the standards and suggested that this could be done by

developing accessible documents, such as age appropriate simplified versions of the standards, as well as easy read, audio and visual versions. Additionally, stakeholders suggested that HIQA and the MHC devise a resource for children and families, based on these standards, outlining what they should expect from a service.

5.2 Additional work completed to support the national standards

HIQA and the MHC reviewed all stakeholder feedback gathered across each stage of the standards development process to identify what was needed to support the implementation of the standards into practice. Using these findings, the team engaged further with key stakeholders to identify appropriate information materials and tools to develop, within the remit of HIQA and the MHC. As a result, several resources were developed to support services to put the standards into practice, and to explain the key messages from the standards and what children should expect when they are using health and social care services. These materials include:

- an animation and an easy-to-read leaflet that supports young children to understand what the standards mean for them, as they journey through health and social care services
- a video of a family with experience of children's health and social care services, outlining the difference these standards will make to the lives of children and families, and
- a practical implementation guide to support staff in health, mental health and social care services to understand what national standards are, what they mean for their service and how to put them into practice.

The above resources will be available from the HIQA website www.hiqa.ie and the Mental Health Commission website www.mhcirl.ie when the standards are published. At present, the practical implementation guide is available for download from our website www.hiqa.ie.

6. Conclusion

HIQA and the MHC would again like to thank all those who contributed to the development of these draft standards through the Advisory Group, the Children's Reference Group, focus groups, and the public consultations, as well as individual stakeholder meetings. This involvement helped ensure that the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services are appropriate to the Irish context and can be implemented in practice. This will help contribute to the improvement of the care and support provided to children through the wide range of health and social care services they engage in.

References

1. Health Information and Quality Authority. *Evidence review to inform the development of Overarching National Standards for the Care and Support of Children using Health and Social Care Services*. Ireland: 2021. Available online from: https://www.hiqa.ie/reports-and-publications/standard/evidence-review-inform-development-overarching-national-standards

2. Health Information and Quality Authority. *Standards Development Framework: a principles-based approach*. Ireland: 2021. Available online from: https://www.hiqa.ie/reports-and-publications/guide/standards-development-framework-principles-based-approach

Appendix A — Membership of the Advisory Group, Children's Reference Group, and the HIQA and MHC Project Team

Advisory Group membership

Organisation	Name and title	Organisation type
Children's Reference Group	Representative(s) of Children's Reference Group *(see below)*	Organisations representing people who use services
Child and Family Agency (Tusla)	Kate Duggan, National Service Director	Social work agency
Children's Health Ireland	Eilish Hardiman, CEO	Statutory body
Children's Rights Alliance	Julie Ahern, Legal and Policy Manager** Mary Nicholson, Senior Policy Officer ~	Advocacy body
Department of Children, Equality, Disability, Integration and Youth	Kate Gillen, Social Work Specialist Michele Clarke, Chief Social Worker	Government department
Department of Health	Celeste O'Callaghan, Principal Officer, Paediatric and Acute Service Reform Deirdre Comiskey, Principal, Disability Services Unit* Michael Murchan, Assistant Principal Officer, Mental Health Unit	Government department

** Joined Advisory Group from November 2021.
~ Left the Advisory Group in November 2021.
* Joined Advisory Group from November 2020. Celeste O'Callaghan represented the Department of Health at the first Advisory Group meeting on 21 October 2020.

	Patrick Dolan[+], Principal Officer, Patient Safety Policy & Governance, National Patient Safety Office (NPSO) Susan Scally, Principal Officer, Social Care Division	
Health Information and Quality Authority	Eva Boyle, Head of Children's Services Rachel Flynn, Director of Health Information and Standards (Co-Chair)	Statutory body
Health Service Executive	Angela O'Neill, National Disability Specialist for Children and Families	Health service
Mental Health Commission	Gary Kiernan, Director of Regulation (Co-Chair) Elena Hamilton, Senior Regulatory Manager[±]	Statutory body
National Disability Authority	Áine Higgins Ní Chinnéide, Senior Standards Officer	Statutory body

[+] Joined Advisory Group from October 2021. Marita Kinsella represented the DoH at the second Advisory Group meeting on 21 June 2021.
[±] Left the Advisory Group in June 2021.

Children's Reference Group membership

Name	Nominating Organisation
Niamh O'Rourke	Head of Standards, Health Information and Quality Authority (Chair)
James Mohan	Children's Health Ireland
Joan Johnston	National Patient Forum
Mairie Cregan	Patients for Patient Safety Ireland
Mia Keaveney	Children's Health Ireland
Suzanne O'Brien	Empowering People in Care (EPIC)
Tammy Donaghy	Mental Health Commission
Tracey Holsgrove	RehabCare

Project Team, HIQA and MHC

Alison Connolly	Acting Head of Regulatory Practice and Standards, MHC
Carol McLoughlin	Standards Development Officer, HIQA[‡]
Cecil Worthington	Subject Matter Expert, HIQA
Davina Swan	Standards Development Lead, HIQA[§]
Deirdre Connolly	Standards Development Lead, HIQA[**]
Linda Weir	Standards Manager, HIQA
Louise O'Hara	Standards Development Officer, HIQA[††]
Sarah Fitzgerald	Standards Development Officer, HIQA[‡‡]
Shauna McCarthy	Standards Development Officer, HIQA
Sophia Egan	Standards Development Officer, HIQA[§§]

[‡] Carol McLoughlin left the Project Team in October 2020.
[§] Davina Swan joined the Project Team from October 2020.
[**] Deirdre Connolly left the Project Team in December 2020.
[††] Louise O'Hara joined the Project Team from August 2021.
[‡‡] Sarah Fitzgerald joined the Project Team from September 2020 to April 2021.
[§§] Sophia Egan joined the Project Team from May 2021.

Appendix B – Organisations that made submissions to the public scoping consultation (2020)

- An Garda Síochána, Garda National Protective Services Bureau
- Barnardos
- Child and Adolescent Mental Health Service (CAMHS), North Tipperary
- CAMHS, Mid-West Community Health Care
- Children and Young People's Services Committees (CYPSC), Co-ordinators' National Network
- Children in Hospital Ireland
- Children's Rights Alliance
- Cope Foundation
- Core Youth Service
- CORU
- Department of Children, Equality, Disability, Integration and Youth
- Department of Health, Social Care Division
- Empowering People in Care (EPIC)
- Enable Ireland
- Fostering Ireland
- Fresh Start
- Health Information and Quality Authority (HIQA), Children's Services Regulation Team
- Health Service Executive (HSE), National CAMHS Oversight
- HSE, National Mental Health Office
- HSE, Disability Services
- Inishowen Development Partnership
- Irish Aftercare Network
- Irish Association for Counselling & Psychotherapy
- Irish Association of Social Care Management (IASCM), a Special Interest Group (SIG) of Social Care Ireland
- Irish Association of Social Workers (IASW)
- Irish College of General Practitioners (ICGP)
- Irish Foster Care Association (IFCA)
- Irish Nurses and Midwives Organisation (INMO)
- Irish Wheelchair Association
- Jigsaw[***]
- National Disability Authority
- Rehab Group

[***] Submission made in March 2021.

- Spina Bifida Hydrocephalus Ireland
- St Patrick's Mental Health Services
- Tusla, Quality Assurance Directorate
- Tusla, Prevention, Partnership and Family Support Programme
- Tusla, Policy and Research Team
- Tusla, Senior Management Team
- Youth Advocates Programmes Ireland (YAP)[†††].

[†††] Submission made in March 2021.

Appendix C — Organisations that made submissions to the public consultation on the draft standards (2021)

- Acquired Brain Injury Ireland
- Advanced Community Care
- An Garda Siochána, Engagement through the Diversion Programme
- Association of Occupational Therapists of Ireland
- Association of Optometrists Ireland
- Barnardos
- Bluebird Care (Wexford)
- Brothers of Charity Services Ireland – West Region
- Care Leavers Network
- Children in Hospital Ireland
- Children's Rights Alliance
- Department of Digital Health, Children's Health Ireland
- Down Syndrome Ireland
- Enable Ireland
- Family Resource Centre National Forum
- Fostering First Ireland
- HIQA, Regulation Directorate
- HSE Community Health Organisation 9, Dublin North City and County
- HSE, National Oral Health Office
- HSE South East Community Healthcare (CHO5)
- Inishowen Development Partnership
- Irish Aftercare Network
- IASW
- IFCA
- INMO
- Irish Wheelchair Association
- Midlands Traveller and Roma Health Unit
- Mental Health Reform
- National Disability Authority
- National Federation of Voluntary Service Providers
- Office of Nursing and Midwifery Services Director
- Pavee Point Traveller and Roma Centre
- Reach Deaf Services
- Senior Children's Nursing Network, Children's Health Ireland
- St Patrick's Mental Health Services
- Tusla, Office of the Chief Social Worker

- Women and Children's Managed Clinical and Academic Network, Saolta University Health Care Group
- YAP, Parent Forum
- YAP, Youth Forum.

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

mhc
coimisiún meabhair - shláinte
mental health commission

Health Information and Quality Authority
George's Court
George's Lane
Smithfield
Dublin 7
D07 E98Y

+353 (0)1 814 7400
info@hiqa.ie
www.hiqa.ie

Mental Health Commission
Waterloo Exchange
Waterloo Rd
Dublin 4
D04 E5W7

+353 (01) 636 2400
info@mhcirl.ie
www.mhcirl.ie