

CHILD-FRIENDLY HEALTHCARE

A REPORT COMMISSIONED BY
THE OMBUDSMAN FOR CHILDREN

Prof Ursula Kilkelly, Faculty of Law, UCC &

Prof Eileen Savage, School of Nursing and Midwifery, UCC

November 2013

• the right to a name and nationality

• the right to practise their religion

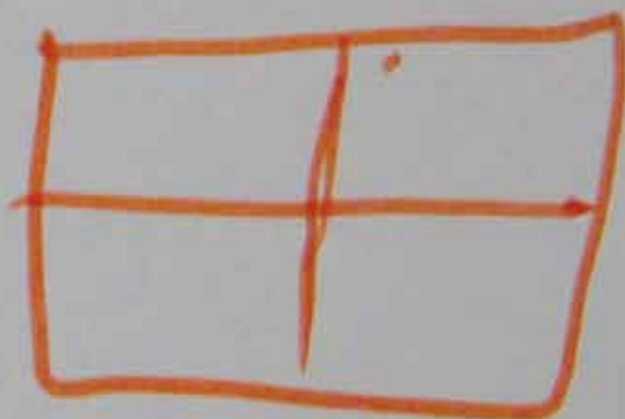
• the right to get information

do do with health

do do with health

should be fun

hospital



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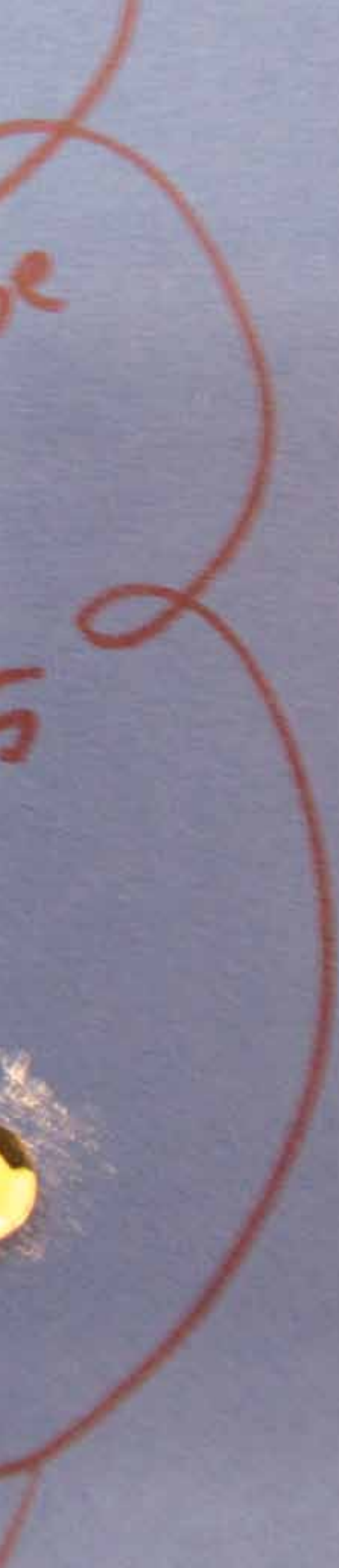
Prof Eileen Savage, School of Nursing and Midwifery, UCC

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ACKNOWLEDGEMENTS

The right to
special
education and
training if they
need it!

People in special care
would need a special
School because if they
could not go to school
they would not be able
to take care of themselves
or keep them self healthy

Acknowledgements

This report is the result of research undertaken by an inter-disciplinary research team at University College Cork on behalf of the Ombudsman for Children. The four members of the research team were:

- Professor Ursula Kilkelly, Faculty of Law, University College Cork (PI)
- Professor Eileen Savage, School of Nursing and Midwifery, University College Cork (PI)
- Professor Jonathan Hourihane, Department of Paediatrics and Child Health, University College Cork
- Dawn Farrell, School of Nursing and Midwifery, University College Cork.

We would like to thank the Ombudsman for Children's Office – especially Ombudsman for Children, Emily Logan and her colleagues Karen McAuley and Nikki Gallagher - for the opportunity to undertake this research and for the support we received in bringing it to publication.

The research was mainly a desk-based study, but it also involved engagement with a range of health professionals, managers and researchers who work in healthcare in Ireland and other countries. Many people gave very willingly of their time and offered us the benefit of their advice and experience about how to translate children's rights into practice in healthcare settings. This report is enriched by their contributions. We are especially grateful to our colleagues on the research team – Jonathan Hourihane and Dawn Farrell – for the value of their respective contributions and to everyone who contributed to this research. All mistakes remain our own.

Ursula Kilkelly & Eileen Savage

Cork, 1 November 2013

List 7/6/11

By, Ailona Farrelly

What i'd like hospitals to be like.....

FOREWORD

- 1) That the Doctor would tell the children before the parents.
- 2) That the Doctor would be nice to the patient.
- 3) That you could choose what food you get.
- 4) That the Doctor explains things clearly.



Foreword

As Ombudsman for Children, my role, and statutory responsibility, is to promote and monitor the rights and welfare of children under 18 living in Ireland. Among my positive obligations in this regard – as provided for by the Ombudsman for Children Act, 2002 – are to undertake research on any matter relating to the rights and welfare of children and to promote awareness of how matters relating to children’s rights and welfare can be enforced.

Healthcare is an issue that necessarily affects every child in Ireland and, by extension, their parents, carers and families. For many children, their interaction with the healthcare system may be limited to occasional visits to their GP. For some children with particular health conditions, their engagement with healthcare services may be a more regular occurrence; while for other children with certain chronic illnesses, healthcare services and their relationships with professionals will be a significant and integral part of their daily lives.

It is not surprising, therefore, that the UN Convention on the Rights of the Child (UNCRC), which Ireland ratified in 1992, should include a focus on children’s healthcare. Article 24(1) states that every child has the right to ‘the highest attainable standard of health and to facilities for the treatment of illness and the rehabilitation of health’. Article 24(1) further provides that State Parties to the Convention ‘shall strive to ensure that no child is deprived of his or her right of access to such healthcare services.’ During its most recent review of Ireland’s progress towards implementing its commitments under the UNCRC, the UN Committee on the Rights of the Child in 2006 expressed concern about a number of issues relating to children’s healthcare, including the absence of statutory guidelines safeguarding access to and the quality of healthcare services, in particular for children in vulnerable situations. In light of its concerns, the Committee recommended the adoption of ‘all-inclusive legislation that addresses the health needs of children’. It also recommended that the Government provide targeted resources and statutory guidelines to ensure that the quality and availability of healthcare services are maintained nationwide and, furthermore, that the resources allocated to existing healthcare services for children be used in a strategic and coordinated manner.

Since 2006, there have been a number of notable public policy developments concerning children’s healthcare in Ireland. Notwithstanding such developments, there is still neither a statutory basis nor a national policy framework dedicated to children’s healthcare in Ireland. As this current research commissioned by my Office highlights, such a legislative and policy framework is merited as it could usefully guide the development and delivery of healthcare services for children into the future and inform a process to mainstream a culture of respect for children’s rights in healthcare settings.

Undertaken by Professor Ursula Kilkelly and Professor Eileen Savage of University College Cork, the main purpose of this research has been to identify how ‘child-friendly healthcare’ can be fostered in and across healthcare settings attended by children and young people under 18 years living in Ireland.

With reference to international standards, and in particular to the UN Convention on the Rights of the Child and the Council of Europe’s Guidelines on Child-friendly Healthcare, this research underscores that a child-friendly approach to healthcare policy and service provision requires us not only to progress the realisation of children’s right to healthcare, but also to respect and protect children’s rights in healthcare. Among these rights are core children’s rights principles, namely: the rights of all children not to be discriminated against, to have their best interests treated as a primary consideration in all actions concerning them, and to have their views taken into account in all decisions affecting them. As the researchers point out, many other children’s rights under the UNCRC also come into play in the context of children’s healthcare, including their right to enjoy regular contact with their parents unless it is contrary to their best interests, their right to privacy, their right to be protected from all forms of harm, their right to information, their right to education, and their right to rest, play and leisure.

The question of how children’s rights can not only be promoted and protected, but enforced in healthcare settings used by children is also addressed in this research report, with reference to initiatives being implemented in other jurisdictions, children’s documented experiences of healthcare services and practices among healthcare professionals.

Drawing on the research evidence, Professor Kilkelly and Professor Savage identify several core 'building blocks' for progressing child-friendly healthcare in Ireland. They include: developing a national policy on child-friendly healthcare; setting standards on the rights of children in healthcare settings; raising awareness among parents and children and providing training to healthcare professionals on children's rights in healthcare; and conducting situational analyses of current practices in Ireland with a view to highlighting and sharing good practices, which are consistent with child-friendly healthcare. In addition, the research findings emphasise that progressing a child-friendly approach across the healthcare system and within all healthcare settings attended by children requires a collaborative, coordinated and integrated approach involving leadership at different levels of the healthcare system and within different healthcare settings as well as constructive dialogue involving policy-makers, healthcare professionals, children and their parents/carers. A final key building block concerns the need to take into account the views and experiences of children. As this current research points out, while this is already happening to some extent in the context of health professionals' engagement with children at an individual level, it has yet to become established as a core value of the Irish healthcare system.

The findings of this research will inform future work by my Office to support the development of child-friendly healthcare in Ireland. In publishing this report, it is my hope that the research will also be a useful foundation resource for all those with responsibilities and roles to play in fostering a culture of respect for children's rights in healthcare in Ireland.

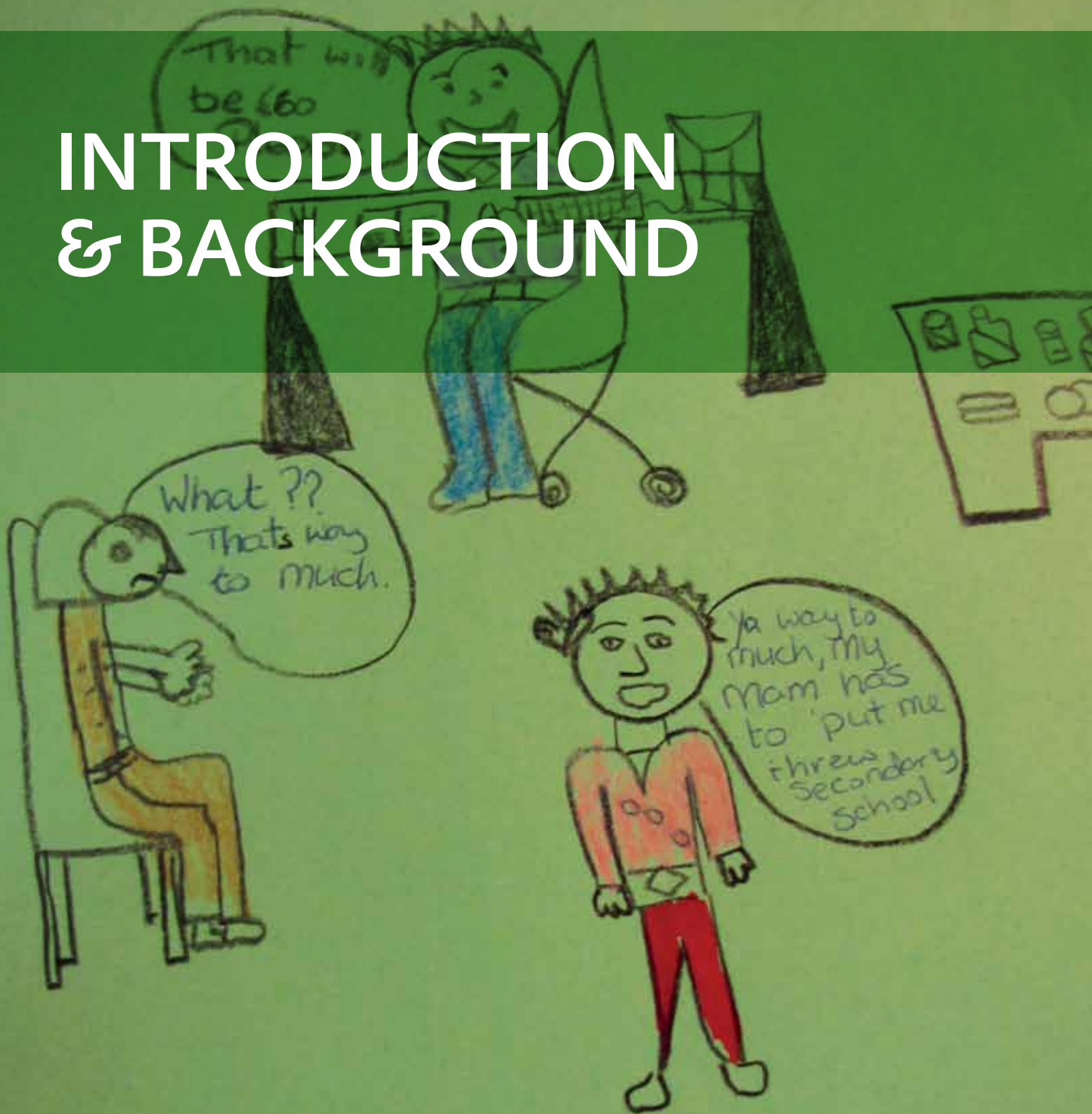
Emily Logan
Ombudsman for Children

an
one
treat
a week



a proper
dinner ✓

INTRODUCTION & BACKGROUND



Introduction to children's rights in healthcare

The United Nations Convention on the Rights of the Child (CRC) is an international legal instrument that sets out the rights of children – defined as all those under 18 years. Ireland ratified the Convention in 1992 and under Article 4, Government is required to take measures to promote, protect and fulfil children's rights (Committee on the Rights of the Child, General Comment No. 15, 2013: 71). The Convention is a comprehensive document and among its provisions are Article 24, which recognises the child's right to the highest attainable standard of healthcare and to facilities for the treatment of illness and rehabilitation of health. According to the Committee on the Rights of the Child, this requires that children receive 'quality health services' which at the primary level are in sufficient quantity and quality, functional, within the physical and financial reach of all sections of the child population, and acceptable to all... Secondary and tertiary level care should also be made available, to the extent possible, with functional referral systems linking communities and families at all levels of the health system (General Comment No. 15, 2013: 25).

Beyond Article 24, the Committee on the Rights of the Child has stressed the importance of viewing children's health as indivisible from and inter-connected to the child's other rights.¹ The Convention's four general principles are particularly important in this context. These principles are: non-discrimination – that children are entitled to enjoy all rights without discrimination under Article 2; best interests - that the child's best interest are a primary consideration in all actions concerning the child under Article 3; the right to life, survival and development under Article 6, and the right of the child to express his/her views and have them given due weight in all matters affecting the child in accordance with the child's age and maturity under Article 12 (Committee on the Rights of the Child, General Comment No. 15, 2013: 8-19). The Committee has highlighted the importance of a broad based approach to children's health, acknowledging that different developmental stages will require different health priorities, and requiring account to be taken of the life cycle and the social determinants of health (para. 20-22). It has also noted the importance of responding to and understanding children's evolving capacities as the child moves towards independent decision-making (para. 20-22). Article 12 of the Convention requires that

children be facilitated and supported to participate in individual decisions about their healthcare and in the development and implementation of healthcare policy and healthcare services (Committee on the Rights of the Child, General Comment No.12, 2009: 98-104). It also requires children's views to be taken into account on all aspects of health provisions, including, for example, what services are needed, how and where they are best provided, barriers to accessing or using services, the quality of the services and the attitudes of health professionals, how to strengthen children's capacities to take increasing levels of responsibility for their own health and development, and how to involve them more effectively in the provision of services, as peer educators (Committee on the Rights of the Child, General Comment No. 15, 2013: 19).

In addition to respecting the child's right to health, the healthcare process and setting must also be child-friendly. The Council of Europe Guidelines on Child-friendly Healthcare define such an approach as one which 'places children's rights, needs and resources at the centre of health care activities' (2011: para. 2). Bearing in mind that children do not leave their rights at the door of the hospital, doctor's surgery or clinic, regard must be had, for example, to the child's right to family support and care (Art 18), to education (Arts 28 and 29), to play and leisure (Art 31), to protection from harm (Art 19) and to privacy (Art 8). An holistic approach to children's rights to and in health thus requires a healthcare system that connects health rights to the child's other rights. Taking the Convention's general principles into account requires healthcare to which children have equal access, that meets the needs and best interests of individual children, that recognises their evolving development and capacity and takes account of their views. Moreover, healthcare that is consistent with children's rights respects the dignity of children, secures their right to be protected from harm and promotes their right to be supported by family and other carers. The right to education, to play and leisure and to privacy are crucially important in the healthcare context also.

Although the Convention applies to every child under 18 years, the same approach is not appropriate for all children given that children's needs change depending on their age, stage of development, state of health and other circumstance Committee on the Rights of the Child, General Comment No. 15, 2013: 20-22). The vulnerability of especially young children in the healthcare system explains the focus on the needs of this group but as the Committee on the Rights of the Child notes, however,

¹ The Committee adopted the World Health Organisation definition of health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. (Committee on the Rights of the Child, General Comment No. 15, 2013: 4).

states have tended to ignore the need to provide health services that are sensitive to the particular needs and rights of adolescents (Committee on the Rights of the Child, General Comment No 4, 2003: 4). Compliance with the Convention thus means that different facilities, attitudes, behaviours and practices will be appropriate for older teenagers than for young children (para. 41).

The importance of the healthcare setting as a place where children's rights are respected is highlighted by the fact that all children will come into contact with the healthcare system at some point in their lives. Children meet healthcare professionals – themselves a very diverse group – in a wide variety of settings when they access primary, secondary and tertiary care, and they go through this process with their parents and carers, and sometimes alone. Focusing on children's rights in healthcare thus presents a clear opportunity to ensure respect for children's rights in their everyday lives. Ensuring that this experience is a positive one, where the child feels respected and listened to, where his/her needs are met and he/she feels supported, will serve to underpin respect for the child's rights more generally. Through this experience, children learn the importance of respecting others and the value of being respected. Protecting the rights of children in the healthcare setting means not only that they receive treatment that makes them better or improves the quality of their lives, it also means that their broader needs, as children, are met throughout that process. In this way, healthcare that is child-friendly is better healthcare for children, and this has an important multiplier effect that can benefit families and indeed society as a whole (Council of Europe, Guidelines on Child-Friendly Healthcare, 2011: 14).

Parents and families are immensely important to children and in healthcare they play a vital role offering children support, advocacy and reassurance. Child-friendly healthcare supports the bonds between children and their families, reflecting the important role that the family plays in the protection of children's rights in healthcare (para. 21). In many instances, parents or other carers will be primary advocates for their children, communicating with healthcare professionals on their behalf and taking responsibility for decision-making. In this way, parents play an important role in ensuring that their children's interests are met and that their rights to health and healthcare are fully protected. This can be a challenging time for parents and they need to be supported in the fulfilment of their responsibilities in this area (Committee on the Rights of the Child, General Comment No. 15, 2013: 78).

Government is responsible for putting in place the law and policy framework and the systems and structures that ensure healthcare is consistent with the Convention on the Rights of the Child (Article 4). In this regard, the Committee on the Rights of the Child has highlighted the importance of a clear policy framework setting out the priorities and the measures necessary to provide, protect and fulfil children's rights in practice (General Comment No. 15, 2013: 71-74). Healthcare professionals, meanwhile, are instrumental to the protection of children's rights in practice and they too have responsibilities to protect, promote and fulfil children's rights. For many healthcare professionals – particularly those who are specially trained - focusing on children's needs and rights is an integral part of their work. Even still, and particularly for those working in the mainstream healthcare system, ensuring a child-friendly approach can be challenging due to a lack of resources, time and supports (Kilkelly and Donnelly 2006). Although these are difficult barriers to overcome at an institutional level, ensuring child-friendly healthcare on an individual level is not difficult – at its simplest, the kind face of a doctor or nurse can ease the worries of a child in pain. More generally, where priorities are set out clearly in a national policy framework, like the one recommended in this research, this will provide direction to the healthcare system and prompt the kind of co-ordinated action which, informed by the experience of healthcare professionals, and the input of parents and children, is necessary to enable children's rights to be fully respected.

Research (documented in chapter 2 below) shows that there is an amount of good practice in Ireland with respect to child-friendly healthcare. Healthcare professionals - both in specialist and general practice - are attuned to the specific needs and circumstances of children and promote their rights in and to healthcare. Champions of the child-friendly approach can also be found in organisations like Children in Hospital Ireland and the many other charities, professional groups and individuals who work to ensure that children receive the best quality healthcare and that their rights are protected. At the same time, progress in the implementation of child-friendly healthcare has been slow. Good practice frequently goes unnoticed, other than by the children themselves and their parents/carers and families, and the opportunity to celebrate it and replicate it in the system more widely is thereby lost.

Research (see chapter 2) has documented the characteristics that children would like in a healthcare professional, i.e. those who respect children, use language they can understand and show empathy and humour in their relationships with them. Evidence of a child-friendly approach to healthcare is strongest among those who are specialised in children's health. Yet, greater numbers of children encounter professionals and managers who work in the general healthcare system, who may be less aware of the impact of their work on the rights of individual children or of the importance of a child-friendly approach. For this reason, the mainstreaming of good practice throughout the healthcare system presents an opportunity to protect children's rights more widely. To this end, the voices of those who champion children's rights in Irish healthcare need a wider audience and greater awareness needs to be raised among decision-makers of the benefits and importance of respecting children's rights in healthcare.

This Research

This research arose out of an invitation to tender issued by the Ombudsman for Children's Office in 2011 and awarded to the UCC team following a competitive process. The project was a desk-based study designed to bring together all of the available evidence on children's healthcare that serves to promote and protect children's rights in healthcare, and more broadly, to develop and sustain a children's rights culture in the healthcare setting. As the tender outlined, the research was to identify the available evidence on the extent to which children's rights are currently being realised in the healthcare setting, and to provide a theory and evidence base for a proposed programme of work to be undertaken by the Ombudsman for Children's Office for the promotion of children's rights in healthcare in Ireland.

Aims and Objectives

As specified by the invitation to tender, the broad aim of the research was to identify standards of good practice in fostering a culture of respect for children's rights in primary, secondary and tertiary healthcare settings attended by children and young people under 18 years. Specific objectives of the research were:

- to identify professional attitudes, behaviours and practices across healthcare settings attended by children, which demonstrate and promote respect for children and their rights;

- to source any existing national and international guidelines, practice standards, policies, procedures and/or other supports relevant to the promotion of a culture of respect for children and their rights across healthcare settings;
- to identify examples of good practices in Ireland and in other countries which have been demonstrated to support a culture of respect for children and their rights in healthcare settings;
- to appraise and synthesize the evidence to inform recommendations for good practices worthy of mainstreaming in relevant healthcare settings in Ireland in the interests of strengthening a culture of respect for children and their rights in these settings.

As the invitation to tender also outlined, the research aimed to:

- be solution-focused by identifying approaches, policies and mechanisms that could be mainstreamed in primary and secondary healthcare settings in Ireland.
- provide the theoretical and evidence base to underpin and support a piece of work by the Ombudsman for Children with children and young people to focus on encouraging and promoting a culture of respect for children and their rights in healthcare settings.

Methodology

The research combined desk-based research with some empirical research – principally through interviews with key personnel nationally and internationally – in order to ensure that the research aims were met to the fullest extent possible. This next section outlines the methods used.

Design

International children's rights standards on healthcare (notably the CRC and both the Concluding Observations (Ireland), the General Comments of the Committee on the Rights of the Child and the Council of Europe Guidelines on Child-friendly Healthcare) provided the backdrop to this project. The principal method used was desk-based, secondary research undertaken using principles and procedures of Systematic Review methodology guided by the Centre for Systematic Reviews and Dissemination (CRD 2009) for identifying and synthesising best available evidence for healthcare practice. The overarching and central focus of this

research was to glean from research and other data the good practices that foster a culture of respect for children's rights in primary, secondary and tertiary healthcare settings. The systematic approach to this research involved four strands:

1. **Empirical strand:** review of national and international studies;
2. **Expert strand:** review of professional opinion, experiences or consensus;
3. **User strand:** review of perspectives of children attending healthcare settings;
4. **Organisational Cultural strand:** review of accessible/available websites of healthcare settings/organisations attended by children in Ireland, and of a select number of international websites of healthcare settings/organisation.

Criteria for Including Evidence

Evidence for each of the four strands related to professional attitudes, behaviours and/or practices was included provided that it explicitly demonstrated good practices in fostering a culture of respect for children and their rights in primary or secondary healthcare settings attended by children under 18 years. On this basis, evidence that merely provided data on practice/service shortfalls (and did not offer any qualitative analysis) was excluded.

1 **Empirical strand** – This included published primary or secondary studies conducted in Ireland or elsewhere on how and to what extent children's rights are protected and promoted in healthcare settings. Studies sampling professionals, children and/or parents or other relevant stakeholders were included. This included research that explored children's involvement in clinical decision-making, healthcare policy and reform, and children as service users. It extended beyond the child's experience as a service user and examined how healthcare services are organized and delivered, and how accessible and appropriate they are to children's needs and rights. Any design that fell within qualitative or quantitative research approaches was included.

2 **Expert strand** – Commentaries and reports representing the views of experts were included. Experts included frontline professionals, managers and policymakers working in healthcare settings; guideline/standard developers and evaluators or other relevant stakeholders including NGOs like Children in Hospital (Ireland), Action for Sick Children (Scotland);

the European Association of Children in Hospitals and others. It involved published guidelines, standards, policies and position papers from bodies like the Medical Council of Ireland, the Royal College of Surgeons, An Bord Altranais and the Health Service Executive. This also included the guidance of international organisations like the World Health Organisation, the Committee on the Rights of the Child and the Council of Europe. This strand also involved contacting a select number of experts both nationally and internationally, identified as having a current or past major strategic and/or operational role in promoting a culture of respect for children and their rights across various healthcare settings. It included those involved in or associated with the implementation of models of best practice or similar initiatives in other jurisdictions.

3 **User strand** – This included perspectives of children in Ireland that are in the public domain e.g. personal stories or experiences posted on accessible websites/newsletters of hospitals or other healthcare settings. Parents' perspectives on respecting children and their rights were also reviewed from these sources, if available. The views of children as healthcare users were also sourced in the Empirical Strand.

4 **Organisational Culture Strand** – this included websites of child healthcare settings/ organisations in Ireland and a select number of international websites (see search strategy below) that communicate a culture of child-friendly/centred initiatives relevant to respecting children and their rights. Flagship children's hospitals and other similar community-based healthcare initiatives were also researched here.

Search Strategy

Electronic databases were searched for primary and secondary studies, and for evidence from Experts in the field, including grey literature. EBSCOhost Online Research Databases were used to simultaneously search relevant health and psychosocial databases (*Academic Search Complete, CINAHL, MEDLINE, PsycINFO, PsycARTICLES, Psychology and Behavioural Science Collection, SocINDEX, and UK/Eire Reference Centre*). From the legal perspective, specialist databases (*Westlaw, HEINONLINE*) allowed the search of children's rights and medical law journals.

Cochrane Library was searched to further identify secondary research evidence in healthcare (eg systematic reviews) within the Cochrane Database of Systematic Reviews, DARE (Database of Abstracts &

Reviews of Effectiveness) and HTA (Health Technology Assessment Database).

Guideline Websites were searched – Australian National Health and Medical Research Council Clinical Practice Guidelines, Canadian Medical Association Infobase of Clinical Practice Guidelines, eGuidelines (UK), Guideline Clearing House (US), G-I-N (Guidelines International Network), New Zealand Guidelines Group, NLH (National Library of Guidelines (UK), NICE (National Institute for Health and Clinical Excellence, UK), SIGN (Scottish Intercollegiate Guidelines Network); Committee on the Rights of the Child; WHO.

Irish Websites of Child Healthcare Settings – The HSE website link on ‘Find a Health Service’ was used to search the websites of Children’s Hospitals, General hospitals with paediatric services, and primary care settings if available/accessible. The purpose of this search was to source any available evidence on (i) children’s comments/views on healthcare received (user strand) e.g. in newsletters, or children’s fora; (ii) organisation culture on promoting child friendly or centred initiatives.

International Websites of Child Healthcare Settings and Children’s Rights – a select number of websites were searched in countries identified as ranking the quality of child health services (eg US News and World Best Ranked Children’s Hospital) or known to be implementing programmes that support children’s rights in healthcare. A search filter was established to include key terms and their variations. All potentially eligible studies, papers, websites etc. identified in the search strategy were reviewed by two members of the research team to determine whether they met the inclusion criteria described above. The search was limited to all records published or available from 1989, reflecting possible developments since the adoption of the Convention on the Rights of the Child.

Policy and Recent Developments – throughout the study, attention is paid to policy developments such as the National Standards for Safer Better Healthcare, the Healthy Ireland Framework and the National Healthcare Charter for Children. Account was also taken of developments concerning the new National Children’s Hospital and policy flowing from this decision.

Data Analysis and Synthesis

Analysis and synthesis involved two broad sets of data directly relevant to respecting children’s rights in healthcare – studies relevant to promoting a culture of respect for children in healthcare and models of good practice for protecting children’s rights in healthcare. A record was made of specific examples of good practice in Ireland and in other countries which have been demonstrated to support a culture of respect for children and their rights in healthcare settings. The analysis and synthesis was conducted against a backdrop of international law on children’s rights in healthcare and the national law and policy framework for children’s health and child health services.

The Report

The results of this research are presented in the following five chapters. Chapter 1 introduces the subject of children’s rights in healthcare and sets out the framework that guides the remainder of the report. Chapter 2 presents the available research evidence on the extent to which children’s rights are respected in healthcare. It synthesises existing studies completed in Ireland and other countries and identifies the factors relevant to a child-friendly approach to healthcare. Chapter 3 presents the law and policy framework in Ireland and highlights the gaps that exist in this area. Chapter 4 describes the models of practice, rolling out internationally, designed to promote children’s rights in healthcare. Finally, Chapter 5 draws conclusions from all of the evidence presented as to what works best to promote children’s rights in healthcare. It then recommends the steps that should be taken to advance the development of child-friendly healthcare in Ireland.

CHAPTER 1

CHILDREN'S RIGHTS IN HEALTHCARE



WHEN TALKING
TO CHILDREN
BE GENTLE

Introduction

The purpose of this chapter is to introduce children's rights in healthcare and to describe what is meant by a child-friendly approach in this area. It identifies why children's rights are important in this context and explains the steps that need to be taken to protect, promote and fulfil children's rights in healthcare.

The chapter draws on international children's rights standards including, in particular, the UN Convention on the Rights of the Child, the international treaty to which Ireland is a party, commentary from the UN Committee on the Rights of the Child (the body which monitors the Convention), the UN Human Rights Council Resolution on the rights of the child to the enjoyment of the highest attainable standard of health and the Guidelines on Child-Friendly Healthcare, adopted by the Council of Europe in September 2011. These instruments articulate the elements of an approach to healthcare that promotes and respects children's rights.

Children's Rights In Healthcare

The rights of children are set out in the Convention on the Rights of the Child (CRC), which was adopted by the United Nations in 1989 and ratified by Ireland on 28 September 1992. The CRC is a universal blueprint for the care of children, defined as everyone under 18 years, which sets out the minimum standards of treatment to which all children are entitled. As one of the most far reaching and comprehensive human rights treaties, the CRC recognises that children are autonomous rights-holders, while at the same time acknowledging that children are a vulnerable group who need the support of adults to enjoy their rights and to develop and fulfil their potential. CRC provisions include the right to protection from harm (Article 19), to have basic rights such as education, healthcare and play respected (Articles 28, 24 and 31) and to ensure that the best interests of the child are a primary consideration in all actions (Article 3). The Convention embodies an approach to children's needs that respects their inherent dignity and evolving capacity (Article 5) while affirming the importance of the family to children (Preamble, Article 18; see Kilkelly, 2007).

Healthcare Rights

The Convention contains two key provisions concerning children's healthcare. These are:

- Article 6, which recognises the right of the child to life, survival and development, and

- Article 24, which deals with health and healthcare. Paragraph (1) provides for the right of the child to the 'highest attainable standard of health and to facilities for the treatment of illness and the rehabilitation of health'. It requires that states 'strive to ensure that no child is deprived of his or her right of access to such health care services'. Paragraph (2) requires states to pursue full implementation of this right and to take appropriate measures to diminish infant and child mortality; ensure the provision of necessary medical assistance and healthcare to all children with emphasis on the development of primary healthcare; to combat disease and malnutrition, including within the framework of primary healthcare, to ensure appropriate pre-natal and post-natal healthcare for mothers; to ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents; and to develop preventive health care, guidance for parents and family planning education and services.

Emerging from these two provisions is the strong emphasis on primary health care, prevention and healthcare information and awareness. Similarly important is the emphasis on the role of the family in supporting the protection of the child's rights in the healthcare setting. Finally, it is important to note how the Convention connects the child's rights to health and healthcare to children's development and to the social determinants of health more generally (Committee on the Rights of the Child, General Comment No. 15, 2013: 20-22; Council of Europe, Guidelines on Child Friendly Healthcare, 2011).

Ireland's Progress in the Implementation of Article 24

When Ireland's progress in the implementation of these rights was first considered by the Committee on the Rights of the Child in 1998 concerns were expressed with regard to specific aspects of the child's right to health care including the low rate of breast-feeding (1998: 18), the incidence of teenage suicide and the lack of adequate programmes addressing adolescent health-related problems like drug and alcohol abuse and early pregnancies (1998: 19). More generally, the Committee noted that there was no national policy to ensure the rights of children with disabilities and it criticised the lack of adequate programmes and services addressing the mental health of children and their families (1998: 20).

In 2006, when Ireland's second report was considered, the Committee on the Rights of the Child expressed concern about an even wider variety of issues relevant to healthcare. In particular, it noted the lack of a comprehensive framework for primary care and the absence of statutory guidelines safeguarding the quality of and access to health care services in line with Article 24, in particular for children in vulnerable situations (2006: 44). Issues raised in 1998 were repeated again including concerns about the inadequacy of programmes and services relating to the mental health of children (2006: 46), the high level of alcohol consumption by adolescents (2006: 48), the apparent link between underage substance abuse and the suicide rate (2006: 50) and insufficient access by young people to necessary information on reproductive health (2006: 52). Following on from its concerns about health issues, the Committee addressed its recommendations to the area of children's healthcare. In particular, it recommended the adoption of 'all-inclusive legislation that addresses the health needs of children' (2006: 45). It also called on the Government to provide both targeted resources and statutory guidelines to ensure the quality and availability of these services and that the resources used for existing health care services for children are used in a strategic and co-ordinated manner.

General Principles

The Convention has four provisions that act as 'general principles' (Committee on the Rights of the Child, 1991: 15). These are:

- Article 6, the right to life, survival and development (mentioned above);
- Article 2, the principle that children are entitled to enjoy their Convention rights without discrimination of any kind;
- Article 3, the requirement that the best interests of the child must be a primary consideration in all actions taken concerning the child, and
- Article 12, that the child is entitled to have a say in all matters affecting him/her and to have his/her views given due weight in accordance with age and maturity.

These provisions have a particularly important status as guiding Convention principles. The three latter principles in particular serve to inform the implementation of the Convention in all areas of the child's life, including in the healthcare setting. For this reason, they are discussed here in more detail.

Non-Discrimination

Article 2 prohibits discrimination in the enjoyment of all Convention rights and taken together with Article 24 it means that children are entitled to enjoy the right to healthcare regardless of their differing circumstances or those of their parents. The fact that Article 2 expressly prohibits discrimination on the grounds of either 'origin' or 'property' makes it clear that children should not be deprived of adequate health or healthcare due to their economic or social status or where they live. According to the Committee on the Rights of the Child, states should identify factors that disadvantage certain groups of children and address those factors when developing laws, regulations, policies, programmes and services for children's health, and work towards ensuring equity (Committee on the Rights of the Child, General Comment No. 15, 2013: 11; Office of the High Commission for Human Rights, 2012: 19).

Disparities in children's access to healthcare were raised by the Committee on the Rights of the Child when it considered Ireland's efforts to implement the Convention in 1998 (Committee on the Rights of the Child, 1998: 14). It attracted the Committee's attention again when it considered Ireland's second report in 2006 (Committee on the Rights of the Child, 2006: 45) and it was raised by several states during the Universal Periodic Review process in 2011 (Human Rights Council, 2011: 106.32-57).

Best Interests of the Child

Article 3 of the CRC provides that in all actions concerning children the best interests of the child must be a primary consideration. This fundamental principle of the Convention requires a child-focused approach to decision-making affecting children to be observed in all health-related decisions concerning individual children or children as a group (Committee on the Rights of the Child, General Comment No. 15, 2013: 12). According to the Committee on the Rights of the Child, states must place children's best interests 'at the centre of all decisions affecting their health and development' including decisions about treatment, allocation of resources and the development and implementation of policies and interventions that affect the underlying determinants of their health' (para. 13).

Article 3 requires that children's healthcare meets the needs of the individual child and it serves as a reminder to those with responsibility for children's care that children's interests must come first. At the individual level, this requires that decisions made about a child's health and healthcare must be informed by what would best serve that child's interests and the Committee on the Rights of the Child has recommended that states should develop 'procedures and criteria to provide guidance to health workers for assessing the best interests of the child in the area of health' (Committee on the Rights of the Child, General Comment No. 15, 2013: 14). According to the UN High Commissioner for Human Rights, 'individual children's best interests should be based on best public health practices grounded in evidence, children's ascertainable wishes and feelings (art.12), their physical, emotional and educational needs, age, sex, background, relationship with caregivers and other relevant characteristics (Office of High Commissioner for Human Rights, 2012: 20). More generally, Article 3 highlights that national policy and the organisation of healthcare services must take due account of the interests of all children as a group (Committee on the Rights of the Child, General Comment No. 7, 2005: 13; General Comment No. 15, 2013: 12).

The determination of 'best interests' can be difficult where adults have differing and often subjective views about what is best for children. The indivisibility of children's rights requires an approach that focuses on the child in his/her family, social and environmental context, rather than solely on the child's medical or clinical needs (Committee on the Rights of the Child, General Comment No. 15, 2013: 7). Compliance with Article 3 also requires an inclusive approach which incorporates the views and perspectives of children (12). According to the Committee, deliberate steps must be taken to ensure the best interests of the child are taken into account. It is an essential part of this process that those determining a child's best interests hear the views of children and take them into account (Committee on the Rights of the Child, General Comment No. 12, 2009: 74). In this way, ensuring that the best interests of the child are a primary factor in actions concerning the child brings the child (either directly or through representation or advocacy) to the fore in the decision-making process. Parents have a clear role to play here and where the child is ill or very young, this will be particularly important (Council of Europe, Guidelines on Child friendly Healthcare, 2011: 24).

Participation

Article 12 of the CRC provides that the child who is capable of forming a view has a right to express that view in all matters affecting him/her, with due account being given to the child's views in line with the child's age and maturity. According to the Committee on the Rights of the Child, this provision addresses the social and legal status of the child – as a subject of rights with less than full autonomy – and it marks out as a core value of the Convention that every child has the right to be heard (Committee on the Rights of the Child, General Comment No. 12, 2009: 5). The Article 12 principle is relevant to children's healthcare in at least two ways: the first concerns the involvement of the child in individual, clinical decision-making and the second involves taking children's views into account in matters of healthcare policy and in the planning, delivery and improvement of healthcare services (para. 98).

In relation to the former, the Committee on the Rights of the Child has pointed out that children should be included in decision-making processes in line with their evolving capacities (General Comment No. 12, 2009: 100). However, views about the limits of children's capacity can mean that they are not always given the opportunity to be involved in a meaningful way in decisions about their healthcare. In some cases, such as with very sick or young children, their parents may undertake this role on their behalf. However, even very young children are capable of expressing their views if adults, including healthcare professionals, develop the skills to listen to them (para. 21). Children of all ages are similarly capable of understanding information if it is given to them in accessible language and style. According to the Committee, information on health promotion, health status and treatment options should be provided to children and their carers in a language and format that is accessible and clearly understandable to them (General Comment No. 15, 2013: 114).

Children's participation rights promote children's involvement in the process of decision-making, rather than their right to decide or to determine the outcome of decision-making processes affecting them. Moreover, because children's needs and evolving capacities vary, there is no single, right approach to promoting and providing for a child's participation in healthcare decision-making. How and to what extent children are involved directly will depend on the age of the child, the child's personal circumstances and his/her wishes, among other factors. What is most consistent across different age groups is that children want to be listened

to, they want more information about their healthcare and they want to understand the information they are given (Council of Europe, Guidelines on Child Friendly Healthcare, 2011). Thus although older children are likely to be involved in decision-making about their healthcare on an equal basis with their parents, and some may want complete autonomy, many others will choose to rely on the support of parents and healthcare professionals to guide them through. The process of how this is achieved will vary from child to child.

With respect to children's participation in the broader context, it is clear that children of all ages have much to contribute to the development and implementation of healthcare policy and the way in which services are designed and delivered to them (Committee on the Rights of the Child, General Comment No. 15, 2013: 19). Respect for children's right to be heard requires their views and perspectives to be heard and taken into account in this context also and, for this reason, the Committee on the Rights of the Child has recommended that states introduce measures enabling children to 'contribute their views and experiences to the planning and programming of services for their health and development' (General Comment No. 12, 2009: 104; General Comment No. 15, 2013: 19).

Children's Rights to Family, Education, Play and Protection

It is well established that children's rights are indivisible, meaning that individual rights cannot be viewed in isolation; instead they create an holistic framework for the treatment of children that aims to protect their rights in all areas of their lives. It is important to note therefore that, apart from the provisions set out above, many other Convention rights are relevant in the healthcare setting. Of particular importance are the provisions that recognise the role that parents play in the support and care of their children. These are set out in the Preamble to the Convention, in Article 5, which recognises the role of parents in guiding children to exercise their rights, and in Article 18, which recognises that parents are the child's primary care givers and that the best interests of the child are their primary concern (Kilkelly, 2007). In addition, Article 18(2) entitles parents to state support in the fulfilment of their duties towards their children, making it clear that, although parents have the primary responsibility, it is the state's overriding duty to support them to this end. The relationship between children and their parents is protected by Article 9 of the CRC, which ensures that separation shall only occur where it is determined to be in the child's best interests.

A range of other substantive provisions are relevant in the healthcare setting including: the child's right to protection from harm (under Article 19), the child's right to education (Articles 28 and 29), the child's right to play, rest and leisure (Article 31) and the child's right to privacy (Article 8). Together, all of these provisions provide a framework for children's healthcare that meets children's needs and interests, that takes account of their status as individuals, and that is informed by the broader social context of children's lives. More recently, this children's rights framework has been developed into a model for child-friendly healthcare. Explanation of this model now follows.

Child-Friendly Healthcare

According to the Council of Europe Guidelines on Child-Friendly Healthcare (2011), child-friendly healthcare is an approach that is consistent with the rights of children and is informed by the core principles of dignity, participation, equitable access to healthcare and the best interests of the child. It aims to integrate the rights of children into healthcare policy, the delivery of services and the treatment of children in various healthcare settings. According to the Guidelines, child-friendly healthcare is informed by a commitment to children's rights to good health and healthcare, to respect for their dignity as individuals in their own right, and for their right to have a say about how they are treated both medically and by the healthcare service as a whole.

Child-friendly healthcare requires a healthcare system that respects the child's rights including:

- The right to access and enjoy healthcare without discrimination (Article 2);
- The duty to ensure that the child's best interests are a primary consideration in all actions concerning the child and that the child receives the care and protection necessary for his/her wellbeing (Articles 3 and 20);
- The right to life, survival and development (Article 6);
- The right to express his/her views and have those views taken into account in all matters affecting the child in line with his/her age and maturity (Article 12);
- The right to enjoy regular contact with his/her parents unless that is contrary to the child's best interests (Articles 9, 18 CRC);
- The right to privacy (Article 16);
- The right to be protected from harm (Article 19);

- The right to education (Articles 28, 29);
- The right to play, rest and leisure and to participate fully in artistic and cultural life (Article 31);
- The right to express opinions including the freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice (Article 13);
- The right to access information and material from a diversity of sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health (Article 17);
- The right to be protected from all forms of exploitation and harm (Article 36);
- The right to manifest religious beliefs (Article 14); and for children from minority groups have the right to enjoy their own culture, to profess and practise their own religion, or to use their own language (Article 30).

As the Guidelines make clear, child-friendly healthcare takes full account of the importance of families in children's healthcare and the need to view and treat children within this wider context. The Guidelines assume that the needs of children and their families are at the heart of all healthcare services and that services are designed to ensure that the child and his/her family receive a whole range of interventions as appropriate.

Children are not an homogenous group: the needs of babies vary dramatically from those of toddlers, whereas teenagers face very different challenges and both require different services and service delivery methods to meet their needs. Healthcare that is child-friendly thus needs to encompass the diversity of circumstances in which children need healthcare and how it is provided must be appropriate to the stage of development and the understanding of the child as well as the needs of the child or young person. The Committee on the Rights of the Child has recognised that older children or adolescents have particular needs in accessing healthcare that have not traditionally been given full consideration (Committee on the Rights of the Child, General Comment No 4, 2003: 3). According to the Committee (2003: 39) and the World Health Organisation, healthcare for young people must be provided through points of delivery that are equitable, accessible, and acceptable to young people. Issues of privacy, access to information, fear of stigma and the right to age appropriate facilities are hugely important

concerns for this group, as is their active involvement in the assessment and provision of healthcare services. Child-friendly healthcare must thus have a youth-friendly dimension.

The Merits Of Child-Friendly Healthcare

According to the Guidelines on Child-Friendly Healthcare, the child-friendly approach has many advantages, the first of which is that it is consistent with and focused on respect for children's rights in healthcare. The second advantage of the child-friendly approach is that it presents a coherent and co-ordinated framework as to how healthcare should be delivered to children. It encapsulates the need to put in place a comprehensive range of services which both promote and protect children's health, coupled with timely, accessible and affordable services when problems occur. Third, child-friendly healthcare can improve the quality of the healthcare experience because when using services, all component parts required to achieve a good outcome should be in place and work well together. Related to this, there is some evidence to suggest that child friendly health care offers some benefits in terms of improving child health outcomes. This evidence mainly relates to child friendly initiatives specific to surgical procedures with reference to psychological outcomes and includes a reduction in children's anxiety levels and negative responses to surgery through therapeutic play (LI et al. 2007) or alleviation of pre-operative anxiety through the use of a child friendly storybook designed for children undergoing tonsillectomy (Tunney & Boore 2011). In a review of the literature, Moore and Kirk (2010) commented that most research to date on the benefits of child participation in health care has focused on processes of care rather than on clinical health outcomes. However, their review on young people's participation in decision making identified some positive psychosocial outcomes such as improved self-esteem and positive self-regard. Fourth, the child-friendly approach ensures that children are able to participate in decisions concerning them and encouraged to provide feedback on their experience of services. This should lead to improved services for all children. In summary, then, child-friendly healthcare is a way of working, a process, which secures better healthcare to children in a manner consistent with their rights. It is a hallmark of quality healthcare for children in that it is informed by their best interests, takes account of their views and is child-centred in its approach throughout. Although further research is required to establish long-term outcomes of child participation in healthcare and/or

child-friendly healthcare, including both clinical (i.e. physical) and psychosocial outcomes, initial research in this area suggests real potential here too.

Implementing Child-Friendly Healthcare

Translating children's rights into practice in healthcare requires the adoption of various measures designed to ensure that all children's health services and programmes comply with the criteria of availability, accessibility, acceptability and quality (Committee on the Rights of the Child, General Comment No. 15, 2013: 112). According to Article 4 of the CRC, implementation of the Convention requires the adoption of legislative, administrative and other measures and the maximum expenditure of available resources. Moreover, Article 3(3) of the CRC requires the establishment of institutions, services and facilities for the care and protection of children and systems that collect data about children's lives are vital to monitor progress and ensure on-going improvement. States are encouraged to develop measurable indicators to assist in monitoring and evaluating progress in the implementation of children's right to health (Committee on the Rights of the Child, General Comment No. 15, 2013: 107) and children's views must be incorporated into the evaluation process (Committee on the Rights of the Child, General Comment No. 5, 2003: 48-50; General Comment No. 15, 2013: 19). Indeed, the Committee has recommended that states engage in a 'cyclical process of planning, implementation, monitoring and evaluation', involving 'the meaningful participation of children' in this process (2013: 108).

Child-friendly healthcare requires a framework for the delivery of healthcare services that meet the needs and fulfil the rights of children. According to the Council of Europe Guidelines, it is necessary to integrate the rights of children with respect to health and health care into a practical framework that 'drives cultural change and consequent improvement in all services which contribute to the health and well-being of children' (2011: 20). The approach should be applicable 'at the level of policy/planning development, at the service-delivery level and at the level of individual children and families' (2011: 20). In addition to meeting children's needs, the child-friendly approach thus requires good co-ordination and continuity of care and is connected to organising healthcare services in a way that ensures effectiveness, efficiency and equity so that the right service is available for the right child, at the right time and at the right cost (2011: 29).

Beyond the organisation of healthcare services, implementing child-friendly healthcare depends to a large extent on the attitudes, skills and competence of those who provide healthcare services at all levels. Although there is frequently considerable knowledge and expertise among child health specialists about child-friendly healthcare, mainstreaming the child-friendly approach remains a challenge.

The scope and nature of training for healthcare professionals influences the extent to which children are treated as individuals, with the capacity to understand information about their health and healthcare and to participate in healthcare decision-making (Committee on the Rights of the Child, General Comment No. 15, 2013: 116). For this reason, the Committee on the Rights of the Child has recommended that all healthcare professionals receive systematic training on children's rights in healthcare and child development (General Comment No. 5, 2003: 66-70; General Comment No. 12 2009: 49; General Comment No. 15, 2013: 52, 116)). The breadth of this recommendation reflects the need to mainstream awareness about children's rights and the child-friendly approach among 'all healthcare professionals' in all parts of the healthcare system. In this regard, it is also important to raise awareness of children's rights in healthcare among policy makers and healthcare managers so that those who set national and local priorities are sensitive to the needs and rights of the children and families.

Parents are key advocates for the interests of children in the healthcare system and they play an important role in ensuring the protection of children's rights in this setting. The Convention requires that parents are facilitated and supported in this role by increasing their awareness of children's rights in healthcare and by providing them with practical assistance (see Article 18 of the CRC). Raising awareness about children's rights in healthcare among children themselves is also vital to securing the development of a child-friendly approach to children's healthcare (see Article 42 of the CRC).

Mainstreaming Child-Friendly Healthcare

Finally, in this chapter, it is important to consider the circumstances in which children access healthcare and the various settings in which children's healthcare is delivered. For this purpose, healthcare services can be divided into those which provide specialist healthcare to children and those which provide general healthcare to the entire community. At the community level, where the vast majority of children interact with the healthcare

system, children are rarely seen by children’s specialists and will instead be treated by those without specialist training in children’s health or healthcare. Although there is often experience and expertise in child-friendly healthcare at a community level, more frequently those who have specialised in children’s healthcare work are to be found in secondary and tertiary care services. This means that most children will be treated by doctors and other healthcare professionals without this specialism. Limited resources will often mean that it is not feasible for healthcare services to be delivered to children by specialists alone. For example, even where play specialists are employed in a hospital setting they will not be available 24 hours a day. It is thus unrealistic to expect the same degree of expertise from a health professional working in a community setting as would be expected from a specialist who works only with children, in a dedicated child-friendly environment. What is critical, then, is to establish broad minimum standards which all health professionals can meet, with the expectation that even greater protection for children’s rights in healthcare will be realised gradually across the healthcare system. In this way, mainstreaming child-friendly healthcare throughout the healthcare system to the maximum extent possible should be the principal objective.

Conclusions

This chapter has outlined the merits of a child-friendly approach to healthcare and has set out the details of such an approach and how it can be achieved. In summary, the child-friendly approach requires that:

- Healthcare policy and the organisation and delivery of health services recognise the importance of children’s rights in healthcare and promote the best interests of children individually and collectively in all actions that affect them. The policy framework and the structure of the healthcare system must respect the child’s rights to family support, protection from harm, access to education and secure enjoyment of their rights to rest, play and leisure;
- Decision-making on matters that affect the child is informed by children’s views and perspectives. Children’s views should be taken into account in clinical decisions and in the development of healthcare policy and services;
- Services are organised and implemented in a manner that recognises children’s special needs, circumstances and vulnerabilities, with reference to their evolving capacity and changing needs and in the broader social and family context.

This chapter has also identified that, in accordance with international standards, various elements are necessary to achieve child-friendly healthcare, including:

- A clear national policy framework for children’s healthcare;
- Awareness raising and training among healthcare professionals, managers and policy makers about the merits of child-friendly healthcare;
- Mainstreaming of the child-friendly approach among all healthcare professionals;
- Supports for parents/carers to help them to fulfil their role supporting children to access healthcare and participate fully in the healthcare process;
- Awareness of child-friendly healthcare among parents/carers, as well as children themselves.

Overall, it is clear that respect for a broad range of children’s rights is necessary to underpin the child-friendly approach to healthcare, and that a variety of steps must be taken to achieve child-friendly healthcare in practice. The next chapters address these issues further by documenting the research on children’s experiences of healthcare (Chapter 2), addressing the current policy landscape (Chapter 3) and identifying models for respecting children’s rights in healthcare (Chapter 4). Notwithstanding the whole range of rights that make up child-friendly healthcare, Chapters 2 and 4 focus on particular aspects of the child-friendly approach that have emerged as dominant in both research and practice. This explains why children’s rights to information, to participate in decision-making and to enjoy the support of their families appear dominant in these discussions even though other rights are equally important.

being take seriously

CHAPTER 2

CHILDREN'S EXPERIENCES OF HEALTHCARE: A REVIEW OF RESEARCH

(When I go to the
doctor I would like
them to take me

Seriously.



Introduction

The aim of this chapter is to present a summary of the available research evidence on children's experiences of healthcare, as well as the perspectives of healthcare professionals, with a view to identifying how child-friendly healthcare can become a reality. This chapter draws on international studies on children's rights in healthcare and on a number of studies undertaken in Ireland. There are few general studies on children's rights in healthcare. Much of the research undertaken to date has focused on the extent to which children participate in healthcare decision-making. This explains the emphasis in this chapter on the issues of information and communication, although the related issues regarding the behaviour and attitudes of healthcare professionals and children's perspectives on the healthcare environment are also discussed.

The Healthcare Environment

Few studies have sought to document children's experiences of and perspectives on the healthcare environment. However, in 2011, 2,257 children aged between 12 and 18 years from 22 European countries were surveyed about their experiences of healthcare and what was important to them about their treatment by healthcare professionals (Kilkelly, 2011). The survey presents a useful snapshot of children's everyday experiences of healthcare and children's views on the healthcare environment, as well as the nature of healthcare settings, facilities and spaces. It is considered here together with other available research on these issues.

Organisation of Healthcare Services

Chapter 1 above highlighted that the child-friendly approach to healthcare requires healthcare services to be organised in a way that ensures that they meet children's needs and take their circumstances into account. Research findings have indicated that a number of key areas are important to children in service planning: service organisation and access; care delivery processes; staffing (qualifications and communication style); and environment. With respect to service organisation and access, children want accessible, flexible and integrated services that allow for continuity of care. In addition, they want wider access to information about health matters and related services made available to them (the need for community drop-in centres was highlighted in one review (NCB 2005)). A specific call for fairness and equality has been made by young people with

intellectual disabilities (Hoole and Morgan 2010). In relation to the process of delivering care, the provision of information and shared decision-making has been identified as important (NCB 2012). In addition, children have highlighted that services need to be holistic and to include emotional and social care, not just physical aspects of care; this point has been made specifically with regard to general and acute healthcare services (Koller et al. 2010; NCB 2005).

The Council of Europe study asked children how far they had to travel to their appointment and how long they had to wait to be seen. The children reported different experiences. Most children travelled a short distance (the journey taking less than 30 minutes) to get to their appointment although over 20% of children said that the journey was either a 'medium' distance (taking between 30 and 60 minutes to get there) or a long distance away (taking more than one hour). Once children got to their appointment, children had mixed experiences of how long they had to wait before being seen. Although the majority (40.8%) of respondents said that the waiting time was short, i.e. that they were seen in a few minutes, almost one third (28.9%) said that the wait was medium in length, whereas a further 13.6% reported that they had to wait a long time. The length of waiting time was of particular concern to children in Ireland who were involved in the study (a period of 1 ½ to 2 ½ hours was cited).

Healthcare Facilities

The evidence points to a number of facilities and resources that children would like to see built into service planning. Play and recreation resources and activities have been highlighted as important to children across a range of healthcare settings (NCB 2012; Lambert et al. 2010a; Koller et al. 2010; NCB 2005; Boylan 2004). This is an area reported to be inadequate by children in Ireland and elsewhere (Migone et al. 2008; Kilkelly, 2011). Play is a vital part of the child-friendly approach to healthcare in that it aims to secure healthcare services to children in a manner that respects their rights. The necessity of ensuring that play specialists are available to every Irish hospital that treats children has been an ongoing campaign of Children in Hospital Ireland. Although there is little published research on the role of play specialists in promoting a culture of respect for children's rights in healthcare settings, there is evidence that organised and supervised play activities by play specialists fosters a child-friendly environment and helps to alleviate children's distress and anxieties in relation to procedures such as day surgery

(Fereday and Darbyshire, 2008). Their work clearly promotes the delivery of healthcare to children through play and is an excellent example of child-friendly healthcare.

Developmentally-appropriate facilities such as separate adolescent units, bright and colourful décor and age appropriate furniture have been identified by children as key concerns in healthcare (NCB, 2012; Lambert et al. 2010a; NCB 2005; Boylan 2004). For example, children's (5-8 years) views on the design of the new children's hospital in Ireland include some important child-focused recommendations such as the inclusion of quiet reading areas; stepping stone paths leading to play areas; open spaces to allow for physical activities e.g. jumping and dancing, and information and communication technology for playing games (Lambert et al. 2010a). Children's recommendations for child-friendly facilities and resources also address the nature of their clinical care. Older children, in particular, have called for healthcare settings to be designed in ways that promote their privacy during consultations and treatment procedures (NCB 2012; Tylee et al 2007; NCB 2005; Boylan 2004). The need for distinct child-friendly settings for different categories of children is also applicable to younger children in the Irish context (Lambert et al. 2010a).

Waiting Areas

Children have reported mixed experiences of healthcare waiting areas. In the Council of Europe study, the vast majority of children (80.1%) said that the waiting area was a good place to wait, while others complained that the waiting rooms were not sufficiently child-friendly. Children were critical of the lack of age appropriate toys and games in waiting areas, noting that the needs of babies and toddlers tend to be catered for, but not those of teenagers (Kilkelly and Donnelly, 2006). For children, the availability of ways to pass the time while they are waiting to see a healthcare professional is very important, not least because it is linked to the fact that children may find these experiences stressful, especially when they are anxious or in pain. In this respect, many (37.5%) of the children who participated in the Council of Europe survey reported being bored while they waited for their healthcare appointment, while 19.9% of children felt anxious and a further 7.9% said that they were in pain. The importance of having child-friendly activities available to help pass the time more easily has been raised in the Irish context also (Kilkelly and Donnelly, 2006; Coyne et al, 2006).

Hospital Settings

Children consider the physical nature of the healthcare setting to be very important and various studies have highlighted that healthcare settings need to take into account the needs and perspectives of children of different ages (Kilkelly and Donnelly, 2006; Lambert et al, 2010; Kilkelly, 2011; NCB 2012). Irish children involved in the Council of Europe study explained that hospitals and paediatric units should:

- Include places to relax;
- Not be too cramped and include individual rooms;
- Have rooms with windows;
- Have comfortable and clean beds;
- Have television with lots of channels, DVDs, computer and other games, a games room and internet access;
- Enable parents/families to stay with their children;
- Provide good food;
- Have outside spaces if possible;
- Smell better;
- Provide storage space for children to put their possessions.

Children have identified the importance of enjoying family support while in hospital and during medical treatment (Kilkelly, 2011; NCB 2012). For children, having family members with them helps them to feel safe and secure and they have expressed concern that the distance between home and hospital might limit the scope for their families to be with them (Kilkelly, 2011). While children recognise that it may not always be feasible for parents to be present while they are receiving treatment, they agree that they should have the opportunity to have their parents and family members with them, whenever possible, as their presence is comforting to children. According to children, steps could be taken to facilitate parents and family members to be with or nearby their children during treatment.

Healthcare Professionals: Behaviour And Attitudes

Children's Experiences and Views

Children are acutely aware of the role of the healthcare professional and various studies have documented the importance of the professional's behaviour and attitudes

in ensuring child-friendly healthcare. Studies have found that children clearly connect their experience of a quality healthcare service with the qualities of healthcare professionals. In this regard, they want staff to be knowledgeable, skilled, competent, and to have expertise specific to a child's health condition or problem (NCB 2012; Robinson 2010). Children's relationships with their professionals are important to them and the evidence clearly points to children wanting professionals that are friendly, good communicators, good listeners, empathetic and non-judgemental (NCB 2012; Robinson 2010; Mainey et al. 2009; Coad and Shaw 2008; Dogra 2005; NCB 2005; Boylan 2004). Significantly, children consider that these qualities are important for others working in the healthcare system, like receptionists (NCB, 2005). Research has recorded children's views that the 'ideal' healthcare professional is kind and friendly (Kilkelly and Donnelly, 2006; Coyne et al, 2006; Mitchell-Lowe and Eggleston 2009; Kilkelly, 2011; NCB 2012) and they especially appreciate healthcare professionals who are not serious all the time, and who have a sense of humour that they can share either through less formal dress or their manner (Kilkelly and Donnelly, 2006). Overwhelmingly, children want healthcare professionals to be sympathetic towards them (Kilkelly and Donnelly 2006; 2011) and they want healthcare professionals who empathise with them and their situation and show some appreciation of what they are going through (NCB 2012; Buckley and Savage 2010; Coyne et al. 2006; Smith and Callery 2005).

Perspectives of Healthcare Professionals

Communicating with children in the healthcare context requires healthcare professionals to exercise 'interpersonal sensitivity' i.e. affective behaviours that pay attention to, and interest in, the child's feelings and concerns (Levetown et al. 2008). Based on a review of evidence of clinical communication in paediatric settings, Levetown et al. offer practical behavioural advice to healthcare professionals to ensure effective communication with children. Among these are to begin conversation with a broad, non-threatening topic; to pay attention to body language and tone of voice; to listen actively; to use creative communication tools such as drawings and games; to talk with the child not at them and to use language that they can understand. These elements are a vital part of translating child-friendly healthcare into practice by connecting with children through language and approach.

Being Informed By Healthcare Professionals: Information And Communication

Children's Experiences and Views

Children have consistently highlighted the importance of information and communication in the healthcare setting and attached special importance to being prepared for treatment, being able to understand what the healthcare professional is saying and being able to ask questions. Information is recognised as a pre-requisite to the child's effective participation in healthcare decision-making (Committee on the Rights of the Child, 2010: 25), and so is essential to promote the child's rights in healthcare. Moreover, children themselves have made the connection between not being afraid or in pain and their need for information and communication. For example, children readily identify that having things (eg proposed treatment) explained to them in advance makes them less afraid (Kilkelly & Donnelly, 2006; NCB 2012) and so information is thus vital to ensure a child-friendly approach to healthcare. Not surprisingly, 80.9% of children surveyed by the Council of Europe considered it important that children receive information about what is going to happen to them in the healthcare setting (Kilkelly, 2011).

Few studies have explored information sharing practices with children in healthcare. However, research has shown that children want information on what to expect especially in relation to procedures and medical treatments. According to research (NCB 2012; Coyne and Gallagher 2011; Migone, Nicholas and Lennon 2008; Coyne et al. 2006; Kilkelly and Donnelly, 2006) children are not always satisfied with the information received from healthcare professionals in a variety of contexts. In 2006, for example, Kilkelly and Donnelly found that children aged 5 to 11 years were generally dissatisfied with how they were informed about impending procedures such as injections and x-rays. Although there was some evidence of procedures being explained, including the reasons for these, the practice of informing children was sketchy and unplanned. Similarly, Buckley and Savage (2010) explored the pre-operative information needs of children (6 to 9 years) undergoing tonsillectomy in one general teaching hospital in Ireland. Children, who were interviewed on the eve of surgery, spoke of having received little information in advance of admission for surgery. The research identified that as a consequence of children having limited information, they tended to construct inaccurate representations of what might happen and these could be frightening. For example, one child had heard from school friends that

the operation meant “they were going to cut open my belly and stick their hand up and take out my tonsils” (2005). A more positive picture was found in an Irish survey of children, parents and professionals (Migone et al. 2008) where most of the 50 children surveyed agreed that staff had ‘properly’ explained procedures and treatments. However, data from professionals showed that only 50% of nurses and 59% of doctors encouraged children to ask questions. Asking children questions about information they receive is important to assessing whether or not they understand this information and its implications for them.

As to what how information is presented to them, children are clear that they need information that is easily understood through the use of plain language and props (NCB 2012). Children themselves appreciate that this takes time that is not always available to healthcare professionals who work under pressure. At the same time, they identify ‘not being rushed’ as an important element of the child-friendly approach to healthcare (Kilkelly, 2011).

Children have identified the importance of professionals using child-friendly terminology when medical or healthcare information is being communicated to them. Studies have found that the use of ‘simple’ language in the child’s own terms and the avoidance of medical ‘jargon’ better enables children to understand health information communicated to them (Mitchell-Lowe and Eggleston 2009; Kilkelly and Donnelly 2006; Coyne 2006). However, it is evident that as children get older, they want information in terminology that goes beyond ‘baby terms’, for example, ‘ametop’ instead of ‘magic cream’ (Gibson et al. 2010).

There is little evidence publicly available of children receiving information using props such as child-friendly information leaflets or booklets; CD-rom, or web based interactive programmes. Children in Hospital Ireland, a children’s health charity, provides important resources on its website – with information for mainly younger children and for parents – including leaflets, reading lists and interactive games.

Perspectives of Healthcare Professionals

According to Jaaniste et al. (2007), healthcare professionals often experience uncertainty about informing children in relation to medical procedures. These researchers set out a framework for providing children with health related information: content – what to tell them; format – how to convey information;

personnel – who provides information; and timing – when to provide information. However, providing information to children in a way that is accessible and relevant to children’s needs can be challenging and a number of Irish studies have found that in practice communication with children is poor (Buckley and Savage 2010; Lambert, Glacken and McCarron 2010b; Savage and Callery 2007; Kilkelly and Donnelly 2006; Coyne et al. 2006).

One recent Irish study sought to develop and implement a child-friendly pre-operative preparation programme (O’Shea, Kelleher and Cummins 2010). Pre-admission preparation involved a visit by children and their parents to the children’s unit and to the operating theatre. Children received an information session using a video and booklet centred around two life-size doll characters, Roby and Molly. The principles of information sharing, play and fun underpinned this preparation programme. Evidence from countries outside Ireland suggests increasing efforts at developing child-friendly information for children using a range of methods. In particular, there has been a growing interest in recent years in developing interactive multimedia methods of communicating information to children about their health, mostly with respect to chronic conditions (Jones et al. 2010; Moulton et al. 2009; Duff et al, 2006; McPherson et al. 2006; Davis et al 2004). Generally, children have viewed this method of receiving information favourably and there has been some evidence of positive behavioural (e.g. sense of control over illness; coping strategies) and clinical (e.g. reduced hospitalisations/unscheduled emergency visits; fewer medication courses) outcomes noted in these studies.

Healthcare professionals have themselves identified the challenges associated with the effective communication of information to children. In particular, they have expressed concern that structural or system problems – inadequate time, little or no training, lack of accessible and comprehensive information and too few paediatric staff – affect their ability to convey information to children in a child-friendly manner (Ameratunga et al. 2010; Kilkelly and Donnelly, 2006). Training and education have a vital role to play by supporting health professionals to develop and maintain necessary skills here. The only review of health and medical curricula undertaken in Ireland to date was undertaken in 2005, when it was found that there was a lack of training in communication skills among some health professionals (Kilkelly and Donnelly, 2006). The situation has undoubtedly improved since that time,

with increased attention now being paid in both third level education and ongoing professional development to the importance of the child's right to information and the development of skills to communicate effectively with children. However, ensuring that all healthcare professionals who come into contact with children (and not just paediatric specialists) are appropriately trained and sensitive to the needs of children in this area is a key issue that has yet to be fully addressed.

Perspectives of Parents/Carers

Parents and carers have an important role to play in ensuring children receive and understand information about their health and healthcare. Information can be conveyed directly or indirectly, through their parents or carers, and every child will have different needs and capacities in this respect meaning that the adult's role may also vary. In some instances, parents may seek to prevent the communication of information to their children on the ground that it may cause them distress, or because they might not be able to handle the enormity of its implications. Research has identified that in some cases, parents believe themselves to be better placed to communicate directly with the healthcare professional (Kilkelly and Donnelly, 2006). Particular difficulties have been documented in life threatening clinical cases such as childhood cancer (Zwaanswijk et al. 2011; Young et al. 2003), as well as the more general situation where parents perceive that children should be protected from what they might perceive as negative information or bad news (Coyne and Gallagher 2011; Kilkelly and Donnelly, 2006; Runeson et al. 2002; Tates et al. 2002). In such cases, the healthcare professional will be required to use his/her skills and experience to work with parents to ensure that the child's need for information is met. At the same time, it is important for healthcare professionals to remain alert to the needs of parents in this context (Kilkelly and Donnelly, 2006) and creating an awareness among parents about children's need for information about their healthcare is vital.

Being Heard By Healthcare Professionals

It is an important part of child-friendly healthcare that children are supported and facilitated to participate in healthcare decision-making. Information (discussed above) is the starting point of this process, but creating the space in which children are heard by healthcare professionals, can ask questions and express concerns is also critical.

Experience and Views of Children

A range of studies have identified that children are largely marginalised from the decision-making process across a range of healthcare settings including in hospital inpatient units (Lambert et al. 2008 & 2010b; LeFrancois 2007; Coyne et al. 2006), outpatient departments (Savage and Callery 2007) and community contexts (Kilkelly and Donnelly 2006; Tates et al. 2002). Lambert et al's study (2010b, 2008) identified that children could be either 'passive bystanders' in the healthcare process, when communication was focused entirely on their parents, or 'active participants', when healthcare professionals communicated directly with them, although many children oscillate between these two positions depending on their needs. Other research has found that the communication style of healthcare professionals in hospital settings – where conversations and interrogative questioning were used – contributed to the largely marginalised position of children (Savage and Callery 2007). These researchers found that parents' accounts of their children's health (cystic fibrosis) were often privileged over those of their children, and some children spoke of healthcare professionals not believing what they had to say.

Studies have shown that children's preferences about their level of involvement during consultations can vary according to age. Younger children often prefer their parents to communicate to health professionals on their behalf, whereas older children mostly prefer to take the lead (Gibson et al. 2010; Garth, Murphy and Reddihough 2009; Savage and Callery 2007; Kilkelly and Donnelly 2006; Coyne et al. 2006).

Perspectives of Healthcare Professionals

Studies on the perspectives of health professionals have found age and cognitive ability to be factors used to determine children's level of involvement in consultations (Garth et al. 2009; Martenson and Fagerskiold 2007; Kilkelly and Donnelly 2006). At the same time, research has found that young children have a greater capacity to communicate about their health and well-being than adults (professionals and parents) are willing to believe (Garth et al. 2009; Savage and Callery 2007; Alderson and Montgomery 1996). Moreover, the attitudes of some professionals towards children with mental health problems (NCB 2012; Day 2008) or intellectual disabilities (Garth et al. 2009; Cavet and Sloper 2004) reflect the belief that these children are cognitively less able to be consulted, compared to other children of similar ages. The reality that one size

does not fit all is reinforced by the fact that additional factors - illness experiences, social experiences of communicating with adults and a willingness to be involved - may influence the level of involvement that children want during consultations (Gibson et al. 2010; Alderson, Sutcliffe and Curtis 2006) making this a dynamic process. Training and education is essential to equip healthcare professionals with the skills to deal with the variety of situations that may arise and to ensure that they can respond appropriately to the needs of the child in each individual case (Committee on the Rights of the Child, 2003; 2013: 52, 116)

Participation In Healthcare Decision-Making

Child-friendly healthcare requires that children receive necessary and appropriate information on their healthcare, are able to ask questions and are heard by healthcare professionals with responsibility for their care. The extent to which these elements are present in children's healthcare is connected to the broader issue of children's participation in healthcare decision-making.

Children's Experiences and Views

Studies have reached mixed conclusions as to the extent to which children are being enabled to participate in their healthcare decision-making (NCB 2012; Moore and Kirk 2010; Coyne 2008; Martenson and Fagerskiold 2007; Worrall-Davies and Marino-Francis 2008). In one Irish study, hospitalised children (aged 7-18 years) differentiated between making 'small' (those relating to everyday aspects of care, like diet and medication) and 'serious' decisions (relating to surgery for example) (Coyne et al 2006; Coyne and Gallagher 2011). Children had mixed views as to whether they wanted greater autonomy in making the serious decisions - almost half of the children preferred that their parents and healthcare professionals would make the serious decisions, whereas others would have liked these decisions to be shared or to have made the decisions themselves.

These findings suggest that children's participation in decision-making is a matter of degree and, in line with child-friendly healthcare, there is a need for a flexible and individualised approach that meets the needs, choices and desires of the children concerned. As to how to put this element of the child-friendly approach into practice, the first step is to identify the factors that prevent children from participating fully in healthcare decision-making. According to a wide range of studies, the following issues prevent children having full

involvement in decision-making: poor communication skills among professionals; use of medical jargon rather than child-friendly language; lack of information as a basis for making decisions; lack of time and appropriate facilities; ignoring or disregarding children's preferences; professional and parental attitudes and beliefs about age and competence of children (Moore and Kirk 2010; Kelsey, Abelson-Mitchell, and Skirton 2007; Runeson Martenson, and Enskar 2007; Kilkelly and Donnelly, 2006).

Aside from the issue of information, addressed above, these problems may at first glance appear to be inter-linked and complex to resolve. However, on reflection, many of the obstacles can be addressed by creating an awareness of the importance of children's participation and an enhanced understanding of children's capacity to play a role in decision-making. The knowledge and skills of the healthcare professional can easily be enhanced and developed through education and skills-based learning. The fact that much of this learning takes place in the clinical setting, i.e. in the workplace rather than the classroom, makes it vital to ensure that the setting (including the physical environment) is focused on providing healthcare that is child-friendly. Play specialists who facilitate and promote good practice in hospital settings, for example, are crucial to ensure the mainstreaming of the child-friendly approach.

It is also important to support parents to fully understand children's needs and capacity to play a role in their own healthcare. Parents' primary concern is their child's welfare and they may not always be aware of the importance of involving children in the decision-making process. Research has identified that parents can also struggle sometimes to have their voices heard above the controlling influences of healthcare professionals (Hallstrom and Elander 2004). It is important thus to promote communication between all three groups - children, parents and health professionals - with a view to increasing awareness about the child's right to participate in decision-making, the benefits to them of doing so and ways in which participation can be promoted and enhanced. The research shows that what children seek is accessible information and safe spaces in which they can express themselves freely and be supported to better understand their health and healthcare. The vast majority of children want their parents to have a role in that process, in line with their evolving capacity, and it is for both parents and healthcare professionals to work together to promote children's ability to contribute in a meaningful way

to decisions about their healthcare (Alderson and Montgomery 1996). Addressing the attitudes, roles and competencies of all three groups is thus necessary to maximise the child-friendly approach to healthcare. Promoting a better understanding between all three groups is also important in this regard.

Involvement In The Evaluation Of Healthcare Policy And Feedback On Services

In contrast to the growing body of knowledge on children's participation in clinical consultations and decision-making regarding their health, there is less known about the role of children in health service planning, governance, and policy formulation.

The Council of Europe survey sought children's views on follow-up and working together in the healthcare system and here a majority (50.4%) said that no-one had asked them about their experience or followed up with them in any way after their appointment (Kilkelly, 2011). Children were also asked about participation in healthcare policy making. A large proportion (47.2%) said that they would like to have a say about children's healthcare in their area, although a large proportion (29.6%) were not sure. When asked how they would like to participate in such discussions, the most popular answer was by speaking directly to a person face to face, although other avenues – including school - were also popular.

In recent years, attention has focused on the 'service user' in the healthcare context and the idea of children being recognised as service users in healthcare is slowly gaining momentum internationally. This is partly due to international obligations under Article 12 of the CRC, and partly due to a wider political agenda concerning democratization, citizenship and choice all of which are applicable to all service users (OCC 2013; Coad and Shaw 2008). The available evidence on engaging with children as service users relates mostly to health service planning, especially children's views and expectations of services. A growth of interest in this area is particularly notable in the UK (OCC 2013; Koller et al. 2010; Hoole and Morgan, 2010; Robinson 2010; Mainey, Ellis and Lewis 2009; Coad and Shaw 2008; Day 2008; NCB 2005; Dogra 2005; Boylan 2004); only two Irish studies of relevance were located (Lambert et al. 2010a; Migone

et al. 2008).² These reviews or studies collectively draw on children's views across a range of services – acute hospital care, long-term care; community, mental health, and intellectual disability.

The need to respect children by meeting their needs across all components of the healthcare system (organisation and access; care delivery processes; staffing qualifications and communication style; and environment) has been highlighted by, for example, reviews of evidence from the UK (NCB 2012 and 2005), and a UK national survey, 'Children's Voices' (Boylan 2004). In order to promote respect for children and their rights, health services need to be planned and implemented in accordance with children's own identified needs. In reality, this aspiration is far from realised (OCC 2013; Hoole and Morgan 2010; Coad and Shaw 2008; Dogra 2005) and there is little substantive evidence on the long term impact that children's views have on changing and improving services to meet their needs. If children are to be respected as service users, however, it is important to go beyond recording their views about services and their recommendations for how services should be changed. Although this is an important baseline, respect for children's rights in healthcare, and indeed the spirit of service user involvement, requires that children are supported to actively engage in the design and delivery of both services and policy. Research indicates that children and young people themselves want to play a more active role in shaping health services for them and have strong views on what good health services for them and their peers should look like (NCB 2012). As Article 12 of the CRC makes clear, children's views must not only be heard but taken into account in matters that affect them. Children's participation at this level has begun, including through initiatives in the UK (NCB 2013), Northern Ireland (Godfrey 2003) and Ireland (Owens 2010; Burke et al. 2010). However, work is at an early stage of development and a concerted, coordinated approach is needed if provision for children to be heard at this level is to become mainstreamed.

Conclusion

This chapter presented the research evidence on children's experiences of healthcare with a view to highlighting good practice in the implementation of

² Although Irish studies presented in previous sections provide data that could inform service planning and development at a broad organisational level, they were not specifically designed with this in mind, hence their exclusion from this section on service user involvement.

children's rights in this area. Although there is emerging evidence about the engagement of children as service-users, this is at a very early stage of development, including in Ireland, and the potential of engagement with children in this area has yet to be fully explored. There are also gaps in knowledge concerning children's views about their rights and needs in healthcare at other levels; for example, children have not been asked how healthcare should be organised in Ireland to best meet their needs or what Government and healthcare providers can do to promote greater respect for their rights in healthcare.

There is now ample evidence about issues such as the role of healthcare professionals and parents in relation to the ability of children to access information and to engage in healthcare decision-making processes. Children want information about their healthcare that they can understand and they want health professionals who are able to communicate with them in a child-friendly manner. Research indicates that as yet, practice on the ground in Ireland remains very mixed, although children have recorded positive experience of professionals who have specialised by training or experience in children's healthcare. While this is very welcome, the majority of children will not encounter these specialists who usually work in tertiary services; they will more commonly be seen by general practitioners in primary and secondary care who may or may not have the requisite skills, experience or competencies to ensure that the approach is a child-friendly one. Research has identified the barriers to implementing child-friendly healthcare and good practice is beginning to emerge in relation to how to engage with children in healthcare processes. Some professional bodies and third level institutions already incorporate these approaches into education and training. However, this needs to be undertaken by healthcare professionals on an on-going basis if child-friendly healthcare is to be fully mainstreamed throughout the healthcare system. Moreover, although important, changing the attitudes and practices of individual professionals will produce only limited success in the promotion of children's rights in healthcare unless it is part of a systems-wide programme of cultural change. Promoting leadership and supporting the champions of the child-friendly approach to healthcare are both key to successfully changing organisational culture. In practice, this can be complex and contested terrain especially if such efforts come without a clear programme of action – derived from national child health policy – that is shared by all those (professionals,

management, administrators and policy-makers) working with and for children in health services. The current policy landscape is examined in the next chapter while the role of leadership, which is also crucial here (Scott et al. 2003), is explored in Chapter 4, together with other measures designed to promote the child-friendly approach.

nice people



nice people



things that help you

nice smile



nice chair



~~nice~~ bed



nice food



to sit on



to play with



CHAPTER 3

THE LAW AND POLICY FRAMEWORK FOR CHILDREN'S HEALTHCARE

They need
support
and nice stuff
to be happy
and stuff to use
+

DVD'S



Introduction

The importance of coherent policy to the achievement of child-friendly healthcare in practice is clearly articulated in a multitude of international instruments. Article 4 of the CRC requires the implementation of the Convention through multiple means including the adoption of legislative and other provisions. For the Committee on the Rights of the Child (2003, 2005), national policy is central to the implementation of children's rights, including in healthcare (2013). The Guidelines on Child-Friendly Healthcare note that implementation of child-friendly healthcare requires 'an alignment of motivation, thinking and action at three different levels: policy making, service planning and individual care' (at 56). Moreover, the Guidelines recommend that member states 'facilitate the incorporation and, where appropriate, the adaptation of the child-friendly health care approach into policies, service planning and practice, coupled with the development of relevant measures to monitor implementation'(57). International standards thus make a strong case for the adoption of a comprehensive national legal and policy framework to guide the delivery of children's healthcare. Consistent with this, Ireland was criticised in 1998 for failing to put in place a comprehensive framework for primary care (Committee on the Rights of the Child: 1998) and in 2006, the Committee on the Rights of the Child recommended that Ireland adopt all inclusive legislation in order to address the health needs of children (Committee on the Rights of the Child, 2006).

Against this backdrop, the aim of this chapter is to consider the current framework of law and policy for children's healthcare in Ireland. Although the traditional picture has been one of fragmentation and a lack of focus on children's healthcare, several recent developments indicate a positive move towards a more integrated and child-focused approach to healthcare for children.

Key Developments In Law And Policy

A range of different legal and policy initiatives have addressed healthcare, children's health and general children's issues in the last decade. Legal developments have been limited to the age of consent to medical treatment. With respect to health policy, some of these initiatives are general in nature, in that they set out plans for the population at large; some deal with specific healthcare contexts (e.g. primary care, acute hospital care) or address the needs of specific subgroups of the population (e.g. Travellers);

while others deal with discrete issues or aspects of children's health such as obesity, development surveillance, tertiary services and palliative care. A range of policy initiatives have also been developed to deal with issues affecting children, including the National Children's Strategy 2000-2010 and the emerging Children and Young People's Policy Framework. Although welcome, these initiatives fall short of the broad-based policy framework necessary to guide the development of child-friendly healthcare in Ireland. The following section outlines some of the key developments in law and policy concerning children's healthcare. It explains why these developments have not produced a coherent law and policy framework in this area and why such a policy framework for children's healthcare is necessary.

Legal Framework

There is little statutory provision for children's healthcare or governing healthcare decision-making in Ireland. Currently, the law provides that children over 16 years can consent to medical treatment,³ but the law is silent on the rights of children under 16 years to receive information or to be involved in the decision-making process. Further ambiguity is added by the fact that mental health law defines children as those under 18 years⁴ and because the Constitution has been interpreted to recognise that parents have a right to their children's healthcare information up to the child's 18th birthday.⁵ As a result, the law does not currently give clear guidance to healthcare professionals as to the role of parents when the child is entitled to consent⁶ and it provides little support for health professionals seeking to treat children as individual rights-holders. It is not yet clear whether the constitutional amendment, passed by referendum on 10 November 2012 and giving constitutional expression to the rights of all children, will have any impact on this situation. The amendment contains an important general statement in Article 42A.1, that the State 'recognises and affirms the natural and imprescriptible rights of all children and shall, as far as practicable, by its laws protect and vindicate those rights'. This could be used to support children's rights

3 See section 23, Non-Fatal Offences against the Person Act 1997.

4 The Mental Health Act 2001 for example defines a child as under 18 years casting doubt on the child's capacity to consent to medical treatment in this area.

5 See *McK v Information Commissioner* [2006] IESC 2.

6 *McK v Information Commissioner* [2006] IESC 2. On these issues, see Law Reform Commission Consultation Paper on Children and the Law: Medical Treatment. Dublin: Law Reform Commission, 2009. LRC CP59-2009.

in the healthcare context, both generally and in order to address the current gaps that prevent children's rights from being fully realised in this context.⁷

Currently, however, children's healthcare has no statutory basis and the rights of children to and in healthcare have no formal legal protection. The absence of a coherent legal framework means that those developing and delivering healthcare services for children do so without the guidance that legislation provides.

National Consent Policy

A National Consent Policy was approved in April 2013 reaffirming first, the role of consent in ensuring respect for the position of users of healthcare services as rights holders (1:2) and second, the requirement of consent as a legal obligation under Irish and international law (1:4). From this perspective, the Policy may be viewed as adopting a rights-based approach to decision-making about healthcare. In line with the principle of non-discrimination, it therefore extends to all service users – adults and children - and all health and social care interventions including research (1:1). Further, the Policy provides guidance on how to ensure the rights-based implementation of applicable Irish law on free and informed consent and, specifically, respect for the rights of services users in healthcare decision-making, including the rights to self-determination, information and privacy.

The Policy is divided into four parts: General Principles; Children and Minors; Research; and Do Not Attempt Resuscitation. There is express reference to children within each of the four parts - for example, Part 3 acknowledges children's rights to participate in research affecting them (at 70-73). The second part is necessarily child-focused: it provides particular guidance for ensuring children's rights in decision-making about health and social services. In this respect, the introduction to the section affirms the legal obligations to ensure the best interests of the child are paramount and assure respect for children's views on all matters affecting them (2:1). This necessarily includes respect for children's broader rights, for example, children's rights information (at 24), age/maturity direction guidance and privacy (at 52). The Policy also affirms the principle of non-discrimination by expressly acknowledging

the applicability of these rights to all children including children with disabilities (at 48). Indeed, it provides particular guidance for ensuring the rights of specific groups of children - the minor parent and children in the care of HSE (at 57) – as well as ensuring children's rights on specific matters such as mental health services (at 59) and sexual health services (at 60).

Framed by the relevant Irish law, therefore, Part 2 provides guidance on how to ensure children's rights are respected in decision-making. This extends to all children, whether they are entitled to consent under law or not. The Policy, for example, provides guidelines for assessing the maturity of children under 16 to consent to health or social care interventions without the knowledge or consent of parents or legal guardians (at 53). Importantly, it also provides guidance for ensuring respect for children's rights where children refuse health or social care services. For mature minors, for example, the guidance places emphasis on the importance of child-friendly decision-making: assuring a safe space for children to freely express their views. However, if the intervention is deemed to be in the best interests of the child, the Policy affirms the legal guardian/parent must be informed and if no consensus is reached, legal advice should be sought (at 54). For older children between 16 and 18 years entitled to consent to surgical, medical or dental treatment (under the law set out above), the Policy proposes that 'in general such refusal should be respected in the same way as for adults' (at 55). The Policy therefore ensures respect for children's autonomy and provides guidance for facilitating '...where possible, the child's right to make his or her own decisions' (at 48). In this respect, the Policy can be considered to bring Ireland into line with international standards on children's rights and it provides welcome guidance to professionals as to how to support children's participation in decision-making in healthcare. It stops short, however, of providing the certainty and security of legislation, the adoption of which must remain a priority.

National Health Policy

Health Policy from 2000 to date

The last two decades have witnessed the development of health policy dealing *inter alia* with *Health Promotion* (2000), *Primary Care* (2001), *Health Service Transformation* (2006) and *Service User Involvement* (2008). In summary, although there has been no shortage of healthcare policy, notably since 2000, it has mainly addressed health or the reform of the

⁷ There has been limited litigation in this area. See *Ryan v AG* [1965] IESC 1; [1965] IR 294 (the fluoride water case) and a series of cases regarding the treatment of children with disabilities which had health implications. See for example, *O'Donoghue v Minister for Health* [1996] 2 IR 20.

healthcare system with limited references to children, children's health or child-friendly healthcare. *Primary Care – a New Direction* was not specific to children but clearly envisaged a model of care with many similar priorities to child-friendly healthcare, including an interdisciplinary team-based approach to service provision with integration between primary care and secondary and specialist services. The broad based Health Strategy – *Quality and Fairness* – picked up on commitments to well-being and health in the *National Children's Strategy* (2000, 136). It viewed children as interacting with various levels of the health system and it identified a number of actions to address shortcomings in child health and healthcare services.

Policy on Service User Involvement

In 2008, the HSE adopted *Engaging Children in Planning Design, Development, Delivery and Evaluation of Services* as an Action Plan to incorporate the views of children into the design, delivery and evaluation of HSE services. In particular, it aimed to create the conditions for children to participate in decision-making relating to their health, including their use of services and it commits to ensuring outcomes result from this participation and that its quality and impact will be monitored. It made further commitments to involve children in staff recruitment, to build on good practice with respect to engaging with children and to invest in cultural change and training in this area.

More generally, one of the most significant developments in recent health policy has been the adoption of the *National Strategy for Service User Involvement (SUI) in the Irish Health Service 2008 to 2013*. For children, it is significant that the SUI strategy linked to the *National Children's Strategy* (2000) and in so doing, identified one of its seven goals as undertaking work that involves children and young people. The implementation of the Strategy is the responsibility of the National Advocacy Unit, which currently falls under the Quality and Patient Safety Directorate in the HSE.⁸ There has been considerable activity in this area in recent years including the publication of *Your Service Your Say, a Framework Document on Service User Involvement and Primary Care* (HSE, 2011). Further developments in this area are reported below under the National Children's Health policy heading.

8 See <http://www.hse.ie/eng/about/Who/qualityandpatientsafety>.

Government for National Recovery 2011-2016

The latest Programme for Government includes a commitment to review Government's plans for reform of the Irish health system and health services. A central commitment in the programme is to introduce a system of Universal Health Insurance (UHI) for the whole population by 2016 so as to secure 'equal access to care for all' and ensure that there is 'no discrimination between patients on the grounds of income or insurance status' (2011:31). Significant structural and governance reforms are envisaged in advance of the introduction of the proposed UHI system, including the return of HSE functions to the Minister for Health and the Department of Health.⁹ Commitments have been made to progress the establishment of primary care teams and primary care centres in line with *Primary Care – A New Direction* (2000). The 2014 budget contained a commitment to introduce free GP care to children under five years.¹⁰

These and other proposed reforms to the health system and health services will, if implemented, impact directly and indirectly on access to healthcare by children and health services for children. Similarly, two recent developments in national health policy provide some additional context for initiatives that have a more dedicated focus on children's healthcare.

National Standards for Safer Better Healthcare

The *National Standards for Safer Better Healthcare* published by the Health Information and Quality Authority (HIQA) in June 2012 apply to healthcare services provided or funded by the HSE (excluding mental health services). Designed with the express intent of supporting health service providers to improve the quality and safety of the care they provide, the Standards are grouped around eight themes, namely: person-centred care and support; effective care and support; safe care and support; better health and well-being; leadership, governance and management; workforce; use of resources; and use of information.

Although the Standards are neither focused on children nor explicitly rights-based, they incorporate several principles that if implemented effectively across

9 Preliminary measures in this regard include the Health Service Executive (Governance) Act, which came into force in July 2013 and which provides for the establishment on an interim basis of a new Directorate within the HSE that will replace the former HSE Board and be directly accountable to the Minister for Health via its Director General.

10 'Minister Reilly announces free GP care for children aged 5 and under as part of Budget 2014', Press Release, 15 October 2013, available at <http://www.dohc.ie/press/releases/2013/20131015.html>

healthcare services and settings used by children could support efforts to advance a culture of respect for children's rights in these areas. The Standards set out under the theme of Person-Centred Care and Support offer a particularly clear example of this (HIQA, 2012:19ff.):

- The planning, design and delivery of services are informed by service users' identified needs and preferences;
- Service users have equitable access to healthcare services based on their assessed needs;
- Service users experience healthcare which respects their diversity and protects their rights;
- Service users are enabled to participate in making informed decisions about their care;
- Service users' dignity, privacy and autonomy are respected and promoted;
- Service providers promote a culture of kindness, consideration and respect;
- Service users' complaints and concerns are responded to promptly, openly and effectively with clear communication and support provided throughout the process;
- Service users are supported in maintaining and improving their own health and wellbeing.

Although children are mentioned as a specific group of 'service users' in the *Standards*, it is in respect of particular issues, namely the matter of informed consent (and the need for "effective arrangements" to be in place to "protect the best interests of children ... who lack the capacity to give informed consent" (HIQA, 2012: 28)) and the protection of children from abuse (and the need to put "specific arrangements" in place to "protect children and vulnerable adults from all forms of abuse while healthcare is being provided" (HIQA, 2012:68)).

HIQA has a statutory function to monitor compliance with the National Standards and can undertake investigations into the safety, quality and standard of healthcare services. HIQA has indicated that it plans to develop 'a structured programme' of monitoring compliance, which will commence following an initial period supporting service providers with implementing the Standards and involve taking a 'monitoring for improvement approach' (HIQA, 2012: 12).

Healthy Ireland Framework 2013-2025

In March 2013, the Government launched *Healthy Ireland*, a framework that aims to improve health and wellbeing in Ireland through a suite of actions to be implemented between period 2013 and 2025. The framework has four goals, namely to:

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

The actions designed to give effect to these goals are structured around six broad themes: governance and policy; partnerships and cross-sectoral work; empowering people and communities; health and health reform; research and evidence; and monitoring, reporting and evaluation. The Cabinet Committee on Social Policy will oversee delivery of the framework, the Health and Wellbeing Programme in the Department of Health will have responsibility for strategic planning and coordinating implementation of actions under the framework, and a multi-stakeholder Healthy Ireland Council will act as a national advisory forum to support implementation of the framework across different sectors. It is envisaged that a cross-sectoral approach will be taken by Government and public services at national and local levels to delivering the framework, that the private and voluntary sectors will be encouraged to participate, and that communities, families and individuals will be supported to play an active role.

The framework is anchored in an holistic view of health and wellbeing – health and wellbeing are defined in positive terms, as more than the absence of disease; account is taken of different facets of health and different life stages; health is viewed in individual and societal terms; multiple factors that influence health and wellbeing are noted (e.g. socio-economic circumstances, education, employment, and housing); and promotion, prevention and intervention measures are considered within the framework of actions identified to support improvements in population health and wellbeing.

In the context of this broad population health framework, children and child health feature in four ways. Firstly, as many of the preliminary indicators

under each of the four goals suggest, the framework concerns children in so far as it concerns the population as a whole (e.g. increasing the proportion of the population undertaking regular physical activity). Secondly, the framework considers childhood as a life stage and supporting health in childhood as a key area for intervention on the basis that it is not only in the interests of children as children, but also as future adults as well as of society as a whole. In this context, several of the indicators concern children generally (e.g. increasing immunisation rates among children and increasing the proportion of children reaching a 'good level of development at age five'). Thirdly, there are indicators that focus on specific health issues as they relate to children (e.g. tackling levels of obesity and smoking among children and young people). And finally, there are a number of indicators that focus on particular groups of children whose health is more at risk due to, among other things, disparities in provision (e.g. reducing 'the gap in low birth rates between children from the lowest and highest socio-economic groups').

While *Healthy Ireland* is clearly not a national policy framework on child health and healthcare, the proposed actions and preliminary indicators set out in it suggest that, if implemented, the framework may impact positively on children's health. It is anticipated that an "outcomes framework" detailing specific indicators in respect of each goal in *Healthy Ireland* will be produced by the end of 2013 and this may offer further information to support a more in-depth assessment as regards the extent to which the framework has the potential to address key issues affecting children's health and healthcare.

Children's Health Policy

Until very recently, children's health policy in Ireland focused either on specific health issues affecting children (e.g. palliative care, obesity) or on health matters affecting particular groups of children (e.g. Traveller health). Arguably, *Healthy Ireland*, the population health and wellbeing framework described above, follows this trend. While the framework takes an holistic view of health and wellbeing and, accordingly, a number of the proposed measures concern all children as a sub-group of the overall population, many of the areas for action relating to children focus on particular health issues (e.g. tackling levels of obesity and smoking among children and young people) or on disparities that are adversely affecting particular groups of children (e.g. rates of lower birth weights among children in lower socio-economic groups).

At the same time, there are clear signs that attention is turning to the need to develop a broader policy framework for children and related to this a model of care for children's health. In addition, there have been a number of developments, including preliminary work on significant capital projects, that are consistent with a policy perspective that considers issues in terms of 'child health' rather than as being relevant to either 'children' or 'health'. This shift in emphasis has been supported by the recent work of the Paediatric and Neonatology Clinical Programme and the National Advocacy Unit of the HSE.

National Children's Hospital

Published in 2006, *Children's Health First* (McKinsey and Company) considered the strategic organisation of tertiary paediatric services in Ireland that would be 'in the best interests of children'. Informed by international best practice and entailing interviews with leading physicians and administrators, the report recommended one national, tertiary paediatric centre based in Dublin and its co-location with an adult academic hospital. The publication of this report was followed by a number of well documented developments, which saw work on the establishment of a new national children's hospital being commenced and then delayed. Principal among these was An Bórd Pleanála's decision not to grant planning permission for the construction of the proposed hospital on the site of the Mater Hospital. Following consideration of the implications of this decision, an expert group appointed by the Minister for Health and chaired by Dr Frank Dolphin recommended that a new national children's hospital be built on a site at St. James's Hospital. This recommendation was approved by Cabinet in early November 2012 and in April 2013 Dr Jim Browne was appointed Chair of the Children's Hospital Group Board with Eilish Hardiman being appointed CEO of the Children's Hospital Group in September 2013. The main role of the Board is to oversee the operational integration of the three existing children's hospitals in Dublin ahead of completion of the new National Children's Hospital and to play a key role in ensuring that the new hospital is designed to the highest standards and completed as soon as possible. In August 2013, the Minister for Health announced the appointment of a Chair and other members to a reconfigured National Paediatric Hospital Development Board, with responsibility for the design, planning, building and equipping of the new hospital. At the time of writing, it is anticipated that construction of the hospital will be complete by 2019, at the earliest.¹¹

¹¹ See the details of all these announcements at <http://www.dohc.ie/press/releases/>

Relocation of the National Maternity Hospital, Holles Street

In May 2013, the Minister for Health announced the Government's plan to relocate the National Maternity Hospital, Holles Street to the St. Vincent's University Hospital Campus. The proposed relocation is in keeping with a recommendation made by KPMG in its 2008 Independent Review of Maternity and Gynaecology Services in the Greater Dublin Area Report that maternity hospitals should be co-located with adult acute services so as to facilitate access by hospital-based maternity services to a full range of medical and surgical specialities and clinical support services.

It is envisaged that the new purpose built hospital will have the capacity to accommodate up to 10,000 births per year and that accommodation at the new hospital will include a High Dependency Unity, a Neo-Natal Intensive Care Unity, and a Special Care Baby Unit as well as providing for a range of national specialities and services such as an early pregnancy assessment unit, an emergency assessment area and day services.

An indicative sum of €150 million has been approved in the HSE's capital plan to enable the project to proceed. It is foreseen that construction of the new National Maternity Hospital will commence in late 2016 with a view to it being completed by 2018.

Paediatric and Neonatology Clinical Programme

The Paediatric and Neonatology Clinical Programme was established in June 2011 under the auspices of the HSE's Clinical Strategy and Programmes Directorate.¹² During 2011 and 2012, the Programme's National Leads undertook a review of paediatric and neonatology services, which included an extensive consultation process and a formal site visit to every paediatric department in the country (Murphy, Nicholson and Turner 2013). The review identified the following needs:

- an increased focus on health promotion, support for parenting and improving child and young person well-being;
- greater child, young person and family involvement in planning child and adolescent services;
- data reflecting the quality of service provision and quality metrics essential for continual quality improvement (p 7).

Based on their observations during the site visits the authors recommended, among other things:

- that the new National Children's Hospital become a hub for paediatric care nationally, with a national model of integrated care being developed to avoid a 'magnet effect'
- the need to look at different models of acute care delivery, and
 - the development of a National Service Framework for children and young people in Ireland (akin to the NSF developed in Scotland, Wales and Northern Ireland) (pp 7-8).

Arising from the review process, the National Leads identified ten 'pillars' to help underpin the future care of children and young people in Ireland. They are to:

- involve and empower parents and patient groups in decisions;
- focus on quality improvement;
- improve access to scheduled care for children;
- establish a consultant-delivered paediatric service;
- improve primary care for children;
- develop a national model of care for newborns;
- develop a retrieval service for newborn and paediatric retrieval;
- plan for the future using predictive analytics;
- set national service standards for paediatric departments and insist on accurate data collection of a minimal dataset;
- focus on health promotion, prevention and screening (8-9).

It is envisaged that, in due course, the findings of and recommendations arising from this review process would inform the development of a national model of care for all children in Ireland.

National Healthcare Charter for Children

In 2008, the Department of Health and the HSE committed to the development of a National Healthcare Charter. Entitled *You and Your Health Service*, the National Healthcare Charter was devised with input from interested parties (HSE, 2012). Feedback on the Charter highlighted that, while it might be suitable for adult services, it was less readily applicable to

¹² For more information see <http://www.hse.ie/eng/about/Who/clinical/natclinprog/paediatricsandneonatologyprogramme/about.html>

paediatric care. In response, the National Clinical Programme for Paediatrics, in collaboration with the HSE's National Advocacy Unit and a parents' reference group, commenced work to adapt the Charter for paediatric services and put a draft of this Charter out for consultation at the end of 2012.

The National Healthcare Charter for Children, published in November 2013, adopts a child-centred and child-rights approach to children's healthcare, in setting out the expectations and rights of children, parents/carers and health professionals for the delivery of healthcare services. The initiative has genuine potential to influence the extent to which healthcare services operate in line with children's rights standards and could, if the commitment of resources, training and awareness raising materialises, represent a significant advance towards child-friendly healthcare in Ireland. Its drafters considered it important for the Charter's effective implementation that it follow the accepted style and approach of the 'adult' Charter. Regardless, it is important that the Children's Charter is informed by children's rights principles and values. This combined approach may bring about a wider acceptance and implementation of both documents, with enhanced possibility that the child-focused standards in the Charter will become mainstream.

National Children's Policy

The principal policy development in recent years in Ireland was the adoption in 2000 of the *National Children's Strategy*.

The National Children's Strategy – Our Children Their Lives 2000–2010

The *National Children's Strategy* put in place a set of broad based policy objectives relating to children and required that all the actions taken under the Strategy are child-centred, family-oriented, equitable, inclusive, integrated and action-orientated. The whole-child perspective underpins the Strategy and its three goals.

- **Goal 1:** Children will have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity;
- **Goal 2:** Children's lives will be better understood and benefit from evaluation, research and information on their needs, rights and effectiveness of services;
- **Goal 3:** Children will receive quality supports and services to promote all aspects of their development.

Agenda for Children's Services

Further policy initiatives followed the three goals of the National Children's Strategy including the *Agenda for Children's Services: A Policy Handbook* published in 2007 as the first national policy framework for children's health and social services in Ireland. It sets out the strategic direction and key goals of public policy in relation to a wide range of children's services and aims to be a 'working tool' designed to assist policy-makers, service managers, and front-line staff to meet the needs of children and their families in ways that are evidence based, accessible, effective and sustainable. The Handbook recognises that a joined-up approach is critical to ensuring the strategic direction of public policy relating to children's health and social services in Ireland and proposes the establishment of local Children's Services Committees, which include membership from local agencies and organisations working on behalf of children, as the bodies responsible for integrated planning and service delivery.

Children and Young People's Policy Framework

Under the Department of Children and Youth Affairs, established in 2011, a new five year Framework is being developed to cover the period from 2014 to 2018 to build on the National Children's Strategy. Informed by a large consultation with children and young people (DCYA, 2012), the Framework is intended as an overarching document under which policy and services for children and young people will be developed and implemented. Its development has been informed by the advice of the National Children's Advisory Council, which represents a range of statutory and non-statutory organisations working with children and young people, the views of the National Children's Strategy Implementation Group which includes nominees of Government departments and State agencies which develop policies and deliver services for children and young people and input from the public. The Framework is expected to be published later in 2013 and so it is not yet known whether and to what extent health and healthcare will feature. It is notable, however, that the preceding Strategy did not address children's health in line with the prevailing view at the time that this was more properly dealt with in the context of health policy (Kilkelly, 2008). Given the importance of health and healthcare to children's lives, and the interconnected nature of these issues to children's other rights and interests, it is essential that the national policy framework incorporate policy imperatives around child-friendly healthcare in line with an holistic children's rights approach (OCO, 2012).

Conclusions

It is clear that there has been good progress made in advancing child health policy and standard setting in Ireland, especially in recent months. Significant among these developments are: the adoption of the Consent Policy, which deals with a precise but particularly important area of healthcare; the developments around paediatric services; and the development of the National Healthcare Charter for Children. Together, these developments represent a significant advance in the orientation of healthcare services around children's needs and rights. The key challenge here is to ensure that the initiatives are inter-connected and that, where appropriate, they combine to present a coherent vision for children's healthcare in Ireland. Investment in training and awareness raising activities will not only support the Charter's implementation; if inclusive of the National Consent Framework, it will also help to maximize the potential of both documents to promote a greater child-focused approach to healthcare and healthcare services.

Linkages must also be made with the new National Policy Framework being developed by DCYA to advance policy on children's services more generally. Regardless of whether the DCYA Framework addresses health priorities, it is vital – given the level of fragmentation that has previously existed here – that it links up with developments in the health sector (the Charter, the Consent Framework and developments around paediatric services linked to the national children's hospital) if the potential for change is to be fully realized. All the policy instruments highlighted here have potential to provide clear guidance for healthcare professionals who have previously operated without national standards or policy. If brought together, the various documents could produce a comprehensive plan to deliver child-friendly healthcare offering guidance for healthcare professionals and managers, but also crucially for children and families. Drawing on existing policy outlined in this chapter, and both the international standards in Chapter 1 and research evidence in Chapter 2, it is recommended that the policy contains the following elements:

1. **Vision:** the vision of the national policy must be to achieve a broad based system of healthcare for children that meets their needs, fulfils their rights and best interests and takes into account their capacity.
2. **Goals and Aims:** the goals and aims of the policy must be closely linked to the achievement of this vision and should be based on the Convention on the Rights of the Child and the Council of Europe Guidelines on Child-friendly Healthcare. The goals and aims must

include the development of cross-departmental collaboration, improved linkages between local and national services and between general and specialist healthcare services and they must encapsulate holistic, broad based and evidence-informed approaches to children's healthcare.

3. **Principles and Values:** in addition to the principles and values specific to child-friendly healthcare, a policy on children's healthcare should be underpinned by the same underlying principles that inform the national policy on health. These include: participation, equity, transparency, monitoring and accountability. In addition, they must be informed by children's rights including principles of non-discrimination, best interests and the right of the child to have his/her views taken into account. The importance to the child of his/her family must also be recognised.
4. **Approach:** the approach taken to the development of a new national policy framework on children's healthcare is vital to ensure that it raises public awareness about the importance and merits of child-friendly healthcare, that it builds understanding about this approach and capacity to implement it among all healthcare professionals who care for children, and to ensure it is informed by a range of approaches to children's healthcare, including those involved in the provision of general (in addition to specialist) healthcare services. To this end, the approach to the development of the policy must be inclusive, participative, holistic and broad-based. It must incorporate the experiences of children and their families to ensure that it formulates a broad-based vision for children's healthcare.
5. **Supporting Change:** it is vital that the process of developing the framework pays attention to the change in culture that is necessary to achieve child-friendly healthcare. Key to this is the widespread capacity building that is required to implement the policy framework throughout the healthcare system, including among decision-makers in children's healthcare at all levels.
6. **Outcomes:** the policy framework must set out well-defined and objective indicators that are capable of measuring progress in a transparent manner (WHO 2004).¹³ Evaluation processes must be established to

¹³ A detailed account on the process of developing a national child health policy is available in the WHO (2004) document at: http://www.emro.who.int/cah/PDF/Development%20of%20National%20Child%20Health%20Policy_English%202004.pdf

ensure that they are informed by good practice, with a specific role for children themselves. The discussion in the next Chapter on models of good practice should be helpful in this respect.

7. **Monitoring, Inspection and Complaints:** It is vital to ensure timely implementation of the national policy framework that the policy on children's healthcare set out mechanisms to provide for monitoring and inspection of children's healthcare services to ensure principles are being adhered to and outcomes achieved. Child-friendly healthcare requires that these mechanisms involve children themselves and are undertaken by independent bodies with expertise and awareness of children's rights in healthcare. Finally, the policy must make provision for an independent complaints mechanism to ensure that complaints can be responded to promptly and effectively.

A case can also be made for the need to address these goals and priorities in legislation. Following on from the recommendation of the UN Committee on the Rights of the Child, for example, a broad national legislative framework is required to bring statutory clarity to the many issues concerned here. The Government's commitment to review the Law Reform Commission's recommendations is welcome in this respect (Programme for Government 2011: 21) and the need for a comprehensive review of the law regarding children's healthcare is given further impetus by the success of the 2012 constitutional amendment.

Overall, therefore, what is required to promote children's rights in healthcare is a national-level response, in the form of a legislative and policy framework that sets out a coherent vision as well as practical principles and priorities to guide the full implementation of a child-friendly approach to healthcare.

CHAPTER 4

RESPECTING CHILDREN'S RIGHTS IN HEALTHCARE: MODELS OF GOOD PRACTICE



Introduction

Chapters 2 and 3 of this Report identified the standards of child-friendly healthcare and the research evidence on how to make rights a reality for children in the healthcare setting. Chapter 4 identified the importance of putting a coherent law and policy framework in place to underpin reform towards more effective respect for children's rights in practice. The challenge of developing and implementing a national system of child-friendly healthcare system is perhaps new to Ireland, but it is not new to other countries where various initiatives have been underway in the development of models of good practice that support respect for children's rights in healthcare settings. In this chapter, we present a range of these models, sourced from published or grey literature;¹⁴ additional insights were gleaned from interviews with healthcare experts involved in the development and roll out of some models. The term 'model' is used broadly to represent practice initiatives that are available to healthcare professionals, service managers, policy makers and others for application in healthcare settings when working with and for children. In selecting models for inclusion in this report, only those models of best practice that are explicitly aimed at implementing children's rights through the development of child-friendly standards, resources, or campaigns for practice are included. We especially sought to include models that would empower health professionals to promote the rights of children in healthcare – although it is notable that we found no information on initiatives focused on education or training of healthcare professionals - and we avoided those that we considered likely to create onerous but meaningless exercises of measurement or monitoring. Of course, there are no guarantees that any particular model will apply neatly to the Irish healthcare system but the ones identified here have been proven to have significant merit and so are worthy of careful consideration.

To this end, we located one international model (i.e. rolled out across a number of countries), and a number of models being implemented in individual countries (Australia, New Zealand, Canada and Scotland). We did not locate any models from Ireland that met the specific inclusion criteria in terms of implementing children's rights through the development of child-friendly standards, resources, or campaigns for practice. In

¹⁴ Most models in this chapter were sourced from the grey literature. Grey literature, also known as the grey or hidden web, refers to papers, reports, technical notes or other documents produced and published by governmental agencies, academic institutions and other groups (e.g. professional organisations; Charity groups; Health Service Organisation websites) that are not distributed or indexed by commercial publishers. Many of these documents are difficult to locate and obtain.

particular, although there are several positive initiatives underway in Ireland, we were unable to identify any evidence evaluating their effectiveness and so they are not included for this reason.

For each model presented in this chapter, details on its substantive content or focus as well as the processes of development, implementation, evaluation, and associated outcomes, where available, are presented.

International Model

Self-evaluation Model and Tool on the Respect of Children's Rights in Hospital

In 2004, a Task Force on 'Health Promotion for Children and Adolescents in and by Hospitals and Health Services' (HPH-CA) was established as an initiative of the International Network of Health Promoting Hospitals and Health Services (WHO). The Task Force currently involves 15 members from various countries including England, Scotland, Italy, Norway, Austria, Estonia, Portugal, Croatia, Estonia, Spain, Greece, Hungary, Canada, Australia, and the USA. One of the first activities of the Task Force was to conduct an exploratory survey involving 114 children's hospitals and departments throughout 22 European countries. This survey highlighted gaps in the Children's Rights in Hospital Charters adopted, and a lack of tools to assess children's rights in those hospitals that had adopted Charters.

In response, in 2009, the Task Force developed and implemented a Self-Evaluation Model and Tool (SEMT) on the Respect of Children's Rights in Hospital (Task Force HPH-CA, 2009). The SEMT was developed in collaboration with experts from relevant agencies and organizations with reference to the Convention on the Rights of the Child (CRC), the European Association of Children in Hospital (EACH)¹⁵ Charter and other relevant documents.¹⁶

¹⁵ EACH is an umbrella organization for the member organisation involved in the welfare of all children before, during or after a hospital stay. In 1993 the EACH was established to help realise a list of rights, since known as the EACH Charter. In 2001 more detailed explanations were added to the EACH Charter in the form of the Annotations. At present 13 national associations are members of EACH. 5 Associations are associated members.

¹⁶ A broadly similar model known as the Child-Friendly Health Care Initiative (CFAI) was piloted in 5 sites across European countries which commenced over 10 years ago (Southall et al. 2000). Due to limited funding the project ended (sourced during interview with Mr. Andrew Clarke who worked on the project). Further information on the CFAI is available from Nicholson S. and Clarke A. (2005) Child Friendly Healthcare: a Manual for Health Workers. Accessed at: http://www.cfhiuk.org/publications/cfhi_manual.htm.

The four principles of the CRC serve as a theoretical basis for the SEMT: (i) non-discrimination (Art. 2); (ii) best interest of the child (Art. 3.1); (iii) life, survival and development (Art. 6); (iv) respect for the views of the child (Art. 12). The SEMT focuses on three areas of rights:

Right to the highest attainable standard of healthcare:

- Children's healthcare provision should take into consideration all dimensions of health, including physical, mental, social, cultural and spiritual;
- Children have the right to access health services without discrimination;
- Children shall be admitted to hospital only if the care they require cannot be equally well provided and effective at home or on a day basis;
- Children have the right to have full opportunity for play, rest, leisure, recreation and education suited to their age and condition and to be in an environment designed, furnished, staffed and equipped to meet their needs.

Right to information and participation in all decisions involving their healthcare:

- Children have the right to be informed in a manner appropriate to their age, developmental level and understanding;
- Children have the right to express freely their opinions on any issue that involves them and the right to be heard and have their views be taken into consideration in a way consistent with their age and maturity.

Right to protection from all forms of violence:

- Children have the right to be protected from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse;
- Children have the right not to be separated from their parents/guardians/caregivers against their will during their stay in hospital;
- Children have the right to privacy;
- Children have the right to a dignified death;
- Children have the right not to feel pain;
- Children have the right not to be submitted to clinical research or experimentation projects and to have the possibility to withdraw during the process of research (Simonelli et al. 2010, p. 11).

The SEMT is used in a cyclical process of quality improvement involving four phases: (i) mapping the reality of existing practices (i.e. gaps in children's rights in practice) through the implementation of the SEMT; (ii) planning the improvement, through the identification of a set of standards for the respect of children's rights in hospital; (iii) making improvement, through the implementation of specific actions; (iv) evaluating the change, by monitoring progress and gaps.

A select group of 17 hospitals was involved in piloting the SEMT in 2009 and this was managed by four working groups made up of the members of the Task Force and eight external participants, including experts from UNICEF and the Care Quality Commission in England. Each working group was associated with a single task, namely overall monitoring of the implementation of the SEMT; coordinating scientific debate; capacity building, and child participation. Local processes of implementing the SEMT varied across sites. Teams varied in size and participating personnel although they usually included managers, clinicians, children and young people and parents/carers. Work methodologies also varied, and included joint group discussions, the establishment of an ad hoc Steering Committee, Working Groups, one-to-one interviews, discussion between participating hospitals, informal discussions ward by ward and audits with staff, children and young people and carers. The SEMT was implemented in participating hospitals using existing/available resources.

In its Final Report on the implementation process of the SEMT (Simonelli et al., 2010), the Task Force noted this model and tool to be a useful approach to assessing, improving, and evaluating practices on respecting children's rights in hospital settings. Some important, positive features of successfully implementing the SEMT were:

- discussion and focus groups involving multidisciplinary teams, children and their parents;
- sharing of information about practices within and between hospitals at local, national and international level;
- strong motivation among staff, and
- hospital management that leads or strongly supports the process.

The Final Report provides specific examples of good practices and actions for improvement arising out of the SEMT implementation process. These include:

- access by adolescents to child friendly services, including mental health services;
- putting in place protocols between hospital and community services;
- using an interactive internet based programme connecting hospitalised children to their school, and
- providing children with a virtual/online tour of the hospital prior to admission.

Some examples of actions identified for improvement included:

- raise awareness of all stakeholders;
- prepare a child-friendly version of the Charter on Children's Rights;
- extend 'child-friendly' environment to all hospital wards;
- carry out patient satisfaction surveys upon discharge;
- provide continuous training for staff and students on communicating with patients of all ages; and
- put in place child-friendly complaints mechanisms.

The Task Force reported that the area of rights found to be most challenging for hospitals to deal with was children's "right to information and participation in all decisions involving their healthcare" (Simonelli et al. 2010, p. 44). Following implementation of the SEMT, this area was where the least progress was achieved overall. A lack of communication skills and training on specific issues concerning children's rights in healthcare was identified by most hospitals, and there was evidence that children and young people were not adequately involved in their treatment plans, or facilitated to participate in other aspects of their hospitalisation experiences (including the self-evaluation process). The Task Force reported "a pressing need to raise awareness amongst staff about the importance of communicating with children and their parents and to give staff the adequate skills to do this in the most effective way" (p.44). These evaluation data echo the evidence presented in earlier chapters of this Report.

Key messages articulated by the Task Force in its Final Report are first, that it is feasible to roll out comparable self-evaluation processes across countries and across health systems and second,

that this collaborative approach whereby good practices, challenges and work methodologies are shared is likely to yield more significant results than would be the case for single hospital initiatives. A website¹⁷ provides details of the SEMT process and related Task Force activities. Resource material can also be accessed through this website, including local reports from participating hospitals.

Experts¹⁸ involved in the implementation of the SEMT or associated with its work interviewed for this study described its positive benefits. In particular, they highlighted that the process of implementing the SEMT was successful in raising awareness among healthcare professionals about the CRC and respecting children's rights in healthcare. Prior to this, the Experts reported that healthcare professionals generally worked from a biomedical framework when working with children, with little awareness of children's rights in healthcare across a broader spectrum of care and experiences. To be successful, the Experts observed, rights have to be at the core of changing practices, and children's views need to be central to what needs to be changed and how. A limitation of the Task Force's initial implementation of the SEMT was that the model was largely developed by adults and implemented by adults. This limitation is now being addressed through greater involvement with children. For example, in Alder Hey Children's Hospital, a planned action has been put in place for children to complete self-evaluation surveys, targeting as many or a high representation of children in specific clinical contexts. Of late, this has included surveys of the total population of children attending cardiac services (inpatient & outpatient settings) over a one month period and children attending ENT (very large caseload) over a one week period. In terms of gaining commitment from healthcare professionals who undertake this work, experience has shown that all surveys have been processed once a number of criteria are met – one being that the survey is requested by clinical team following which they sign up for the whole process. This means that they 'own' the process and have agreed to implement changes and process these for Membership with Investing in Children, the UK based

17 http://www.hphnet.org/index.php?option=com_content&view=article&id=294%3Ahp-for-children-a-adolescents-in-a-by-hospitals-&catid=20&Itemid=95

18 Two interviews were conducted. Experts that participated in the first interview were: Ana Guerriero (Task Force Co-ordinator), Ms. Liz McArthur (Alder Hey Children's NHS Foundation Trust); and Mr. Liam Cairns (Investing in Children, UK). A second interview was conducted with Professor Les White (Task Force Member, and led the implementation of SEMT in Australia).

child participation organisation.¹⁹ The Experts noted that in that their experience the process of membership or accreditation was a 'major driving force' in getting health service managers to buy into changing practices towards quality improvements in child health services. However, the SEMT process is not integrated into any accreditation system, as yet.

In Australia, the SEMT has been implemented in Sydney Children's Hospital (led by Prof. L. White, then CEO of the Hospital). Following an initial survey using the SEMT, a Charter was developed and then disseminated throughout the hospital by means of posters; it was also sent individually to all families and staff (see Australia below). There are now 15 hospitals (mix of children's hospitals and children's services within general hospitals) involved and one community setting. Other agencies are seeking to get involved e.g. community services and disabilities services. According to Professor White, the SEMT has become a 'magnet' for change with a growing number of 'allies'.

Taken together, some key messages communicated by the Experts about the successful implementation of the SEMT at local health service level included:

- the importance of seeking the views of children;
- the need for organisation-wide information and communication about respecting children's rights in healthcare;
- starting with the implementing process and following with policies and procedures;
- focusing on what can be achieved with recognition that not everything can be achieved;
- leadership, including the use of local champions (ie staff at unit level); support from management – otherwise the process will not work.

Manual on Children's Rights in Hospital and Health Services

With the development of the SEMT process, it became evident to the Task Force that there was need to improve further the technical tools used to assess and improve the respect of children's rights in hospital (HPH-CA, 2012). In line with the Health Promoting Hospitals Standards and Principles on Health Promotion, the Task Force decided to prepare a set of assessment tools on children's

rights in hospital for different stakeholders. In particular, self-evaluation tools (questionnaires) were prepared for healthcare managers, healthcare professionals and evaluation tools (also questionnaires) were prepared for children aged between 6 and 11 years, children and adolescents aged between 12-18 and for parents/carers.

The Task Force's explicit aim is to ensure that child health promotion is an 'integral part of the everyday practice in hospitals and other health services' (2012, p. 4) and mainstreaming – of child health and of children's rights – as key goals of children's healthcare services – is thus a priority. The tools have three broad aims - to ensure that children's 'assets, their empowerment for health and the development of their human potential' are consistently and effectively utilised in health services, that child rights are 'recognised as a key component of and a fundamental contributor to effective health promotion', by collecting and disseminating knowledge, case-studies and evidence on the practical value of respecting child rights in health settings, and that child participation in terms of the effective and equal involvement in the assessment, planning and improvement of healthcare delivered in hospitals and health services is promoted (2012, p. 4).

According to the Task Force, the aim of the Manual is to provide tools, which can be used in an 'improvement programme cycle within hospitals and health services, aimed at advancing the respect, protection and fulfilment of children's rights within those institutions' (2012, p.4) It is recognised that the tools will not be applicable in the same way in all settings across Europe and beyond and their further adaption – to make them relevant across societies and cultures – will be required. In this way, hospitals and health services are invited to adapt them to best fit their needs and features. Feedback and collaboration on the application and adaption of the Manual is specifically invited.

National Models

Australia and New Zealand

Standards for the Care of Children and Adolescents in Health Services²⁰

In 2008, an expert multidisciplinary working group in Australasia developed the above Standards and an

¹⁹ Investing in Children is a UK organization concerned with the rights of children and young people.

²⁰ Standards are available on the Royal Australasian College of Physician's Website – Accessed at: <http://www.wcha.asn.au/>

associated *Audit Tool*.²¹ The group had representation from The Royal Australasian College of Physicians (RACP) Paediatrics & Child Health Division; The Association for the Wellbeing of Children in Healthcare & Children's Hospitals Australasia and with the support of professional associations or societies. A combination of empirical evidence, published good practice standards, and expert consensus were used to inform the Standards. Both the Standards and associated audit tool are underpinned by the CRC.

To guide the process, good practice principles of the International Society for Quality in Health Care (ISQua), International Principles for Health Care Standards and the Australian Productivity Commission principles for standards development were used. Feedback from stakeholders was sought through extensive consultation on the draft Standards, followed by pilot-testing of the revised Standards in six health services of varying sizes and locations in Australia.

The principal goal of the Standards is to ensure that quality care is provided in an environment that is safe and appropriate for the age and stage of development of the child or adolescent. Particular emphasis is placed on the need to provide separate facilities for children and adolescents in all healthcare settings in which they receive care. The Standards are designed to apply to any Australian health service where children or adolescents are cared for in either the hospital setting (e.g. inpatient wards; emergency departments, outpatients) or the primary care setting (e.g. community health centres; child health centres). Some individual standards are specific to inpatient settings, and are therefore not applicable to the primary care sector.

The Standards provide over 40 detailed recommendations in the areas of: recognising and respecting children's rights (e.g. being treated sensitively and with dignity; informed and involved in decision making); the provision of child, adolescent, and family friendly facilities (e.g. designated paediatric areas; facilities for parents to stay); the availability of developmental and age appropriate equipment (e.g. furniture; toys; games); and the need for appropriately qualified staff (i.e. specifically trained to meet their physical, psychosocial, developmental, communication and cultural needs).

21 Available at the Royal Australasian College of Physician's website: <http://www.racp.edu.au/page/policy-and-advocacy/paediatrics-and-child-health>

Hill *et al.* (2011), recently describing the process of developing and pilot testing the Standards, noted that the inclusion of many diverse stakeholders and the engagement of jurisdictions in the process have resulted in a set of constructive tools that are practical and easy to implement. The Standards are intended to be a framework for guiding care and for actively directing health service providers to examine existing practices, policies, and guidelines in place to ensure that children are care for in a safe and appropriate environment. The authors noted ongoing advocacy as being crucial to raising awareness about the Standards and to ensuring that they are utilised. They also recommended that all health services commit to continuous quality improvement, including participation in national accreditation programmes that include regular assessment of the adequacy of child and adolescent health services against these Standards. However, in Australia, health services can vary from state to state in terms of seeking accreditation and even those services that are accredited by the ACHS²² Evaluation and Quality Improvement Program (EQuIP), in-depth review is not mandatory.

Charter on the Rights of Children and Young People in Healthcare Services in Australia and New Zealand²³

In 2010, a Charter specific to implementing the rights of children and young people in healthcare services in Australia (and New Zealand) was launched following a collaborative project by the Children's Hospital Australasia (CHA)²⁴ and the Association for the Wellbeing of Children in Healthcare (AWCH).²⁵ The Charter was developed over a period of two years and is informed by the Australian Charter of Healthcare Rights; the New Zealand Code of Health and Disability Services Consumer Rights; and the Charter of the European Association for Children in Hospital (EACH). The need for the Charter arose out of a self-evaluation survey across health services in Australia as part of the mapping phase of implementing the SEMT (see above). While these findings demonstrated both commitment and practice in the respect of children's rights, areas

22 Australian Council on Healthcare Standards

23 Children's Hospital Australasia and Association for the Well-being of Children in hospital (2010). Charter on the Rights of Children and Young People in Healthcare Services in Australia Accessed at: <http://www.wcha.asn.au/>

24 Non-profit body whose vision is to enhance the health and well-being of children and young people and which is achieved by supporting member hospitals, and health services in Australia and New Zealand.

25 National organization advocating for the needs of children, young people and families within the health care system in Australia.

for improvement were also identified, in particular, the absence of a Charter on the Rights of Children and Young People in Healthcare Services in Australia.

The Charter is underpinned by three principles: (i) the primary consideration of the child's or young person's best interests; (ii) hearing and taking seriously all children and young people; (iii) the family is the fundamental group in children's and young people's lives. The Charter is applicable to all healthcare settings that children and young people access including health promotion and health education activities. There are three versions of the Charter – one for children, one for young people, and one for health service providers.

A total of eleven rights are stated in the Charter, and each statement is supported by an explanatory note. The Charter states that every child and young person has the right to:

- Consideration of their best interests as the primary concern of all involved in his/her care;
- Express their views, and to be heard and taken seriously.
- The highest attainable standard of healthcare;
- Respect for themselves as a whole person, as well as respect for their family and the family's individual characteristics, beliefs, culture and contexts;
- Be nurtured by their parents and family, and to have family relationships supported by the service in which the child or young person is receiving healthcare;
- Information, in a form that is understandable to them;
- Participate in decision-making and, as appropriate to their capabilities, to make decisions about their care;
- Be kept safe from all forms of harm;
- Have their privacy respected;
- Participate in education, play, creative activities and recreation, even if this is difficult due to their illness or disability;
- Continuity of healthcare, including well-planned care that takes them beyond the paediatric context.

Having developed and launched the Charter, work is now underway to promote, implement, and monitor its effectiveness. This is at a very early stage with consultations with various stakeholders underway.²⁶

²⁶ Les White, personal communication, see above.

The Charter on the Rights of Young People in Healthcare Services developed in Australia is also being implemented in New Zealand.²⁷ Prior to developing the Charter, Standards were developed. However, it appears that the Charter now represents the work in progress toward implementing a culture of respecting children's rights in healthcare settings in New Zealand.²⁸ A notable feature of developments towards respecting children's and young people's rights in New Zealand is that a Report to Standards New Zealand was published (McGachie 2004) based on focus group consultations with 51 young people between 13 and 25 years.²⁹ The overall thrust of this Report is that young people wanted the right to be involved in all matters pertaining to themselves and to be the gatekeeper to family involvement. They also wanted staff to be knowledgeable and well educated on youth culture and able to relate to young people.

Canada

Population health children's rights awareness campaign

This Model, underpinned by the CRC, represents a local community action research project aimed at raising awareness about children's rights to highest standard of health care. Article 42 of the CRC, which requires that the principles and provisions of the Convention are made widely to both adults and children, was a driving force for this project (Mitchell 2000).

The campaign began with the establishment of a Regional Steering Committee on the CRC with representation from children and youths, practitioners, policy and decision-makers, non-governmental organizations, academics, business and public relations professionals. A public education campaign was then rolled out in the region to promote greater awareness of the CRC among children and youth participants, as well as policy makers, practitioners, and the general public. This included advertising (e.g. press, television and radio, city transit buses) by a public relations company. In addition, Child's Rights Symposia, hosted by children and youths, were organised.

²⁷ Accessed at: <http://www.scoop.co.nz/stories/PO1105/S00191/rights-of-children-and-young-people-in-healthcare-charter.htm>

²⁸ Email contact was made with The Paediatric Society, New Zealand to inquire about the current status of implementing the Standards. The authors were forwarded the Charter in response to our email inquiry.

²⁹ Accessed at: www.paediatrics.org.nz/files/.../SNZYouthConsultationReport.pdf

According to Mitchell (2000), this community based Model represents a practical approach to implementing children's rights in healthcare through stakeholder partnerships, public promotion, and child and youth participation. However, achieving progress beyond campaigning can be a challenge because various stakeholders such as practitioners and policy makers differ in their understandings of childhood and its implications for children's rights (personal communication, during interview).³⁰ According to Mitchell, the political debate on child healthcare in Canada is far removed from the lived experiences of most children and young people and Canada still has a long way to go in implementing a children's right approach to healthcare (Mitchell, 2000).

United Kingdom

Children and Young People's Healthcare Rights – A Resource Pack³¹

This *Resource Pack* on children's and young people's healthcare rights represents a model of good practice in terms of supporting and empowering children and young people to exercise their rights in healthcare settings. Launched in 2008, the Resource Pack was developed by Action for Sick Children in Scotland over a period of four years (2002-2006). The **EACH Charter, underpinned by the CRC, was the basis for awareness-raising about children's rights during the workshops. In developing the Resource Pack, almost 9,000 children, young people, families, carers, healthcare and other professionals and voluntary/community groups were consulted in a series of workshop sessions.**

The *Resource Pack* aims to ensure that children, young people and their families are made aware of their healthcare rights at times of illness. It provides a structured approach to discussing healthcare services and healthcare rights with children and young people in either education or community settings, such as Scouts, Guides, and other youth groups. The *Resource Pack* contains three sets of workshops for children aged five years and over; children aged eight to 12 years; and young people aged 12 years and over. For each age group, there are between three and six workshops. The *Resource Pack* provides guidance to trainers on

facilitating each workshop session with reference to trainer notes (sample questions and discussion points); a specific objective, a focused learning point, resource materials required, learning activities to be undertaken, and suggested reading. Two DVDs produced by children are also available: one is a short film as an example of one method of encouraging children to learn about their rights; and a second that uses animation as a learning tool. The *Resource Pack* contains information about how to make and use animation as part of learning.

The first three workshops for children aged five years and over aim to: encourage the children to talk about what happens when they are unwell; to introduce children to hospital contexts and the people who work there; and to introduce children to the idea of expressing their views about what happens to them in hospital or other healthcare context. The second set of workshops for children aged 8 to 12 years aims to: further explore their understandings, concerns, and experiences of being unwell and going into hospital; inform them of their rights within the healthcare system; check their understandings of their rights and responsibilities, and to think through and discuss decisions made; and explore the range of different services available to them. Age-appropriate hand-outs and materials are available for use during these workshop sessions. In addition, ideas for discussion and questions around the EACH charter points are provided. The third set of workshops for young people aged 12 years and over aim to: facilitate them to think about the meaning of health, how to protect their health, and what services are available to them, and issues around equality and inequality in healthcare. In addition, there is a workshop that aims to develop young people's understandings of the need for rights and how to exercise these rights. The sixth and final workshop for this age group concerns reaching consensus about priorities within a group setting and raising awareness of the EACH Charter and health rights in Scotland. Guidelines, examples and appropriate supplementary materials are provided for each of these workshops.³²

Conclusion

When considered alongside the evidence presented in earlier chapters, it is encouraging to note the wealth of activity in other jurisdictions towards child-friendly healthcare. It is perhaps notable that countries leading in this area are linked to the international project associated

³⁰ We interviewed Professor R. Mitchell, a children's rights advocate and academic at Faculty of Social Sciences (Child and Youth Studies, Ontario).

³¹ Action for Sick Children Scotland (2010) Children and young people's healthcare rights: A resource pack Accessed at <http://lx.iriss.org.uk/content/children-and-young-peoples-healthcare-rights-resource-pack>

³² Further information on this Resource Pack can be obtained from Ms. Amy Joss, Project Officer, at: amy.joss@virginmedia.com

with the Self-Evaluation Model and Tool on the Respect of Children's Rights in Hospital (SEMT) and the more recent Manual and to the development of Charters as significant awareness raising tools. Taken together, these analyses of models of practice suggest that promoting a culture of respecting children's rights in healthcare settings is feasible and achievable. However, it requires an approach that is multi-layered, targeting all levels of the health system – horizontally (primary, secondary, and tertiary) and vertically (service delivery in healthcare settings, service planning, and policy formulation). Although capacity building and awareness raising among healthcare professionals is undoubtedly achieved through these initiatives, it is perhaps surprising that there is so little focus on education and training within the initiatives themselves.

In summary, it is clear from these models that the critical building blocks for child-friendly healthcare are: building inter-sectoral alliances; raising awareness of children's rights in healthcare (all layers of health system including professionals, management and policy-makers; the general public, children themselves); undertaking situation analyses of current practices; developing and implementing standards on the rights of children and young people in healthcare settings; and the active support of health sector management. Leadership, itself a building block, is needed as a vital pillar to support the remaining 'building blocks'. Lastly, and most importantly, hearing the views and experiences of children and using them as the basis for action is what matters most to progressing and realising a vision for respecting children's rights in healthcare settings. The next chapter considers how this learning can be applied towards the development of child-friendly healthcare in Ireland.

A Doctor Who is Kind
A Doctor Who Really Helps
A Doctor Who Gives you sweets
A Doctor Who cares
A Doctor Who Takes your opinion
A Doctor Who Tells the Real

This Makes A Good Doctor



CONCLUSIONS AND NEXT STEPS



The principal aim of this project was to identify, by means of desk based research, standards of good practice in fostering a culture of respect for children's rights in primary and secondary healthcare settings attended by children and young people under 18 years. The research was set within the context of international law on the rights of the child, notably the United Nations Convention on the Rights of the Child and the Council of Europe Guidelines on Child-friendly Healthcare (chapter 1); the available research evidence on children's experiences of healthcare and professional attitudes, behaviours and practices on respecting children's rights in healthcare settings (chapter 2); and the law and policy framework in Ireland (chapter 3). In chapter 4, some current models of practice developed to support child-friendly healthcare were outlined.

The Report aims to present a vision for children's rights in healthcare and how child-friendly healthcare can be achieved in Ireland. It is intended as an accessible and practical source of information to guide the Ombudsman for Children's Office as it develops a programme of work in this area. The Report concludes by recommending solution-focused approaches, policies and mechanisms that, the research suggests, can serve to promote a culture of respect for children's rights that can be mainstreamed throughout healthcare settings in Ireland.

In the absence of substantial evidence comparing various approaches to promoting a culture of respect for children and their rights in healthcare, or evaluating the impact of any given approach, it is difficult to conclude that any one model of practice for the promotion of children's rights in healthcare is superior to another. However, drawing on the research evidence, international law and guidance and the lessons to be learned from colleagues around the world who are working to develop and implement such approaches, we consider the following 'building blocks' to be necessary for developing and implementing a framework for child-friendly healthcare in Ireland:

- Development of national policy on child-friendly healthcare;
- Building inter-sectoral alliances;
- Raising awareness about children's rights in healthcare, including education and training for healthcare professionals;
- Situational analysis of current practices;
- Standards on the rights of children in healthcare settings;

- Leadership;
- Management support;
- Listening and responding to children.

All of these actions are inter-linked and mutually dependent. Leadership is crucial to ensure that these processes result in a healthcare system that meets the needs of all children and ensuring children's participation will ensure that what emerges is consistent with their rights and builds on their experiences. The various steps are now explained in more detail.

National Policy Framework on Children's Healthcare

Chapter 1 identified clearly that under the Convention on the Rights of the Child, Ireland has a duty to take steps to adopt and implement a national policy framework to ensure the rights of children are respected in healthcare settings. The Council of Europe Guidelines on Child-friendly Healthcare articulate in more detail why and how this should be done. There has been good progress in recent months in the development of children's health policy, including some important initiatives which are informed by children's rights principles. The Consent Policy Framework provides guidance where there was previously none and should help to ensure that decision-making involving children adheres to children's rights standards as well as bringing about greater consistency and clarity in this area. The National Healthcare Charter for Children provides a child-focused, and indeed child rights focused, statement of what children and their families can expect from the healthcare system.

As Chapter 3 outlines, these are positive initiatives which, together with the new Children's Policy Framework from the Department of Children and Youth Affairs, have real potential to advance the goal of ensuring that healthcare in Ireland is child-friendly. At the same time, they fall short of a comprehensive law and policy framework which, the evidence suggests, is required to ensure the implementation of child-friendly healthcare in practice. As Chapter 1 explains, the process of developing this new framework must link in with existing policy on children and health, draw on the wealth of expertise of healthcare professionals in Ireland and be informed by the extensive experience of children themselves. Like the Charter, it must be based on the Convention on the Rights of the Child and in particular be informed by the CRC's general principles: non-discrimination, regard for the best interests of the

child and the child's right to have his/her views taken into account in matters that affect him/her. The drafting of the policy must take place through a transparent and inclusive process of engagement with everyone in the healthcare system to achieve consensus about how children's rights values can be translated into practice in the design of a child-friendly model of healthcare.

Building Intersectoral Alliances

Evidence points to the importance of inter-sectoral alliances in the promotion of children's rights in healthcare. Such alliance-building brings together organisations and individuals with experience and expertise of healthcare towards a strong and collective power base that can work to influence social change in promoting a culture of respect for children's rights in healthcare. It reflects the empowerment of healthcare professionals – those with frontline and direct experience of the merits and the challenges of child-friendly healthcare – and supports the leadership of professional and child advocacy organisations in achieving a child-friendly approach to healthcare. The availability of existing models of good practice in other countries makes it possible to draw on others' experiences through international collaboration.

In Ireland, while co-operation is clearly improving and consensus emerging around child-friendly healthcare, there is a need to build inter-sectoral alliances across the healthcare sector, between different professionals and professional groups and involving law and policy makers, healthcare managers, statutory agencies, patient and advocacy groups and inter-disciplinary researchers. Building such a collaborative network would help to raise awareness, develop consensus and build and sustain momentum towards the implementation of children's rights in healthcare settings. A network of this kind could also facilitate the sharing of experiences of and approaches to the implementation of children's rights in healthcare. It could support 'buy-in' across the health sector through the development of relationships and strategic partnerships and could help to provide the leadership and infrastructure supportive of a child-friendly healthcare model. The involvement of senior figures from the healthcare system and a wide range of children's health experts would serve to ensure that positive developments are championed at a political and management level among policy makers, health service executives and managers, ultimately promoting a children's rights culture among the healthcare sector and the health professionals who work in it.

Raising Awareness About Children's Rights In Healthcare

Guidance from the Committee on the Rights of the Child, research and those involved in promoting children's rights in healthcare in other countries have highlighted the relationship between children's rights awareness and the realisation of children's rights in practice. Accordingly, raising awareness about children's rights in healthcare will need to be an important part of any action plan in this area and involve local, regional and national activities, including in the implementation of the National Healthcare Charter for Children. This needs to take place on at least two levels: general awareness raising about children's rights in healthcare to improve understanding among children and adults in this area, and ongoing professional training on children's rights in healthcare, including the development of specific skills necessary to meet the information and communication needs of children in healthcare settings. This should include both dedicated training for child health specialists, but it should also take the form of continuing professional development for all healthcare professionals. The extent to which this training already forms part of the educational curriculum at third level means that many of the professional bodies are already well placed here. More generally, examples of education and awareness raising initiatives from other countries (noted in Chapter 4) include: holding regional and national conferences (relevant to all stakeholders); convening public meetings; working through the media; advertising on billboards, public buses etc; targeting social settings that children attend e.g. schools; youth organisations etc. Initiatives have also served to develop information materials on child-friendly healthcare and to disseminate them throughout healthcare organisations and practice settings, targeting professionals, managers, policy makers, as well as children and their families as service users with a view to raising awareness about the merits and substance of a child-friendly approach.

Situational Analysis Of Current Practices

Situational analysis of current practices, often described as auditing children's rights in practice, is fundamental to developing a model of practice for promoting a culture of rights for children in healthcare. Although children's rights auditing has taken place in Ireland – including studies commissioned by the Ombudsman for Children's Office (eg Kilkelly 2007a) – little activity of this kind has been undertaken in healthcare except within the narrow context of children's participation in healthcare decision-making (see Chapter 3). The review of paediatric

and neonatology services is significant in this respect ((Murphy, Nicholson and Turner 2013) notwithstanding that it was not an assessment of children's rights in these settings. The experience of other countries indicates that a situational analysis must be multifaceted involving multiple stakeholders, notably healthcare professionals and children and their families, to ensure compatibility with children's rights standards. Typically, such processes involve the collection of baseline data on: existing practices; potential and feasibility of developing practices; and attitudes, beliefs and commitments to respecting children's rights. Collectively, these data inform understanding of a child-friendly approach to healthcare. Baseline data may be collected in combinations of ways - for example, surveys; individual/focus group interviews; review of practice initiative repositories; and desk based research to review national and international evidence. This Report therefore serves as important baseline data, but other suggestions also follow.

It was noted throughout this Report that much good practice is already in place in the healthcare system with many professionals offering healthcare that meets the specific needs of children (Murphy, Nicholson and Turner, 2013). Little of this work is celebrated, however, and there are few highly visible champions of children's rights in the healthcare system. This could be addressed in a number of ways. Firstly, the good practice currently underway in the healthcare system could be documented so as to usefully highlight examples of the child-friendly approach to healthcare. Children and young people, their advocates and healthcare professionals should be encouraged to record their positive experiences with a view to bringing this information into the public domain. At another level, healthcare professionals could be supported to develop one or other of the tools already developed for this purpose (see chapter 4).

Currently, no repository for good practice in children's healthcare exists in Ireland, making it difficult for healthcare professionals and organisations to share their experiences and learn from each other. A situational analysis could thus produce such a repository of good practices and could be undertaken by the professional bodies. Such a process could help to identify the education and training needs of staff and it could also serve to identify successful initiatives suitable for mainstreaming throughout the system. This is likely to have good 'buy-in' factor because of the sense of pride associated with this type of positive recognition.

This process could also be used to identify and champion those who practice child-friendly healthcare and who

are committed to its mainstreaming throughout the healthcare system. Supporting champions to provide leadership to the sector and to act as advocates for change at local and national levels would be a positive step.

Setting Children's Rights Standards in Healthcare

The analysis of models of practice in chapter 4 clearly points to standard setting as one of the key ways of translating the language of children's rights into tangible indicators that have practical application. The idea of standard setting for clinical practice is not new to health professionals in Ireland and there are requirements to follow Standards of Practice set out by professional bodies and other agencies such as the Health Information and Quality Authority (HIQA). However, the fact that there are no standards specific to respecting children's rights within the broad scope of health services used by children in Ireland suggests that there is a gap to fill here.

Standards and associated documents/manuals already being implemented in other countries could be used as a base to develop a working set of Standards for the Irish context. Those that have been successfully implemented in terms of respecting children in healthcare settings are clearly underpinned by the CRC, thereby reinforcing the rights of children in and to healthcare. The Manual and Tools for Assessment and Improvement from the Health Promoting Hospitals and Health Services Child and Adolescent Task Force is an excellent example of the kind of measure that has multiple purposes; it documents a baseline of children's healthcare experiences by engaging with all stakeholders, including children themselves, and it enables professionals and management to monitor progress while raising awareness among all the parties about children's rights and the child-friendly healthcare approach. While other monitoring is ongoing and/or being developed consideration should be given to adapting the HFH-CA Tool for use in children's health services at both national and local level. In this regard, the self-assessment Tool could be adapted to inform the implementation of the new National Healthcare Charter for Children developed by the HSE.

The development of Standards is not an end in itself, however, and research shows that work in this area must be a cyclical process moving from development to implementation and on to evaluation, as evident from chapter 4. To be feasible, this needs to have practical application in the routine day to day working lives of

healthcare professionals, not least because lengthy and labour intensive approaches are less likely to enjoy 'buy-in' from health professionals. Standards should be incrementally introduced in specific settings like hospitals, before being rolled out throughout the healthcare system.

Leadership

Leadership is a pillar of support for each of the above building blocks. An overwhelming message arising out of chapter 4 is that, without leadership, efforts at shifting healthcare systems and individual healthcare settings towards a culture of respecting children and their rights will not work.

National leaders from among the healthcare professions are hugely important, and many of these could form part of the strategic alliance outlined above. Local champions are also vital to support the operational implementation of Standards on the ground in healthcare settings. This involves open consultation and dialogue with all relevant stakeholders in any given healthcare setting, which may be an organisation wide initiative or simply confined to one unit/department or area within an organisation, which in some services might be the approach to take to 'break the ice' or to move an organisation in small steps – 'start small, think big' perspective. Typically, this small step approach might commence in an area where a genuine interest is expressed in getting involved in a child-friendly approach to healthcare. It is worth keeping in mind that even though such an approach may be viewed as a good initiative by many staff, at least in theory, not everyone will buy into this practice. However, expert opinion, gleaned for this project from other countries, suggests that changing organisation wide culture *does* happen even with small beginnings.

The establishment of the Department of Children and Youth Affairs has ensured increased visibility and political priority is given to children's services. As part of this, a new agency is being established – the Child and Family Agency – which will move responsibility for children's care and protection from the HSE. It would appear that responsibility for children's health will remain with the HSE/Department of Health and with the National Advocacy Unit within the Quality and Patient Safety Directorate, as well as the *Paediatric and Neonatology Clinical Programmes* team more specifically. Consideration should be given to putting in place a unit dedicated to child-friendly healthcare within the HSE/Department of Health, given that this is where much

of the expertise and leadership now lies. Links with children's services – with the Child and Family Agency and the Department of Children and Youth Affairs – will be an increasingly important part of this function and consideration might also be given to establishing a high level group to ensure an integrated approach to child-friendly healthcare across relevant services and government departments.

Management Support

Strongly related to the issue of leadership is the issue of management support. Research shows that even excellent initiatives have little potential for success without the support and buy-in from health service management at all levels (some managers may in fact be the leaders). Management support is important to facilitating changes in practice for example, through training and education (on or off 'work based learning' as needed); organisation wide dialogue and consultation; facilitating inter-agency collaboration and sharing of practice initiatives; and committing to the provision of quality healthcare services that are child-friendly. A strategic alliance could bring together leaders from among healthcare professionals directly involved in providing healthcare to children with senior management who have overall political responsibility for delivering healthcare. Management must support a vision of child-friendly healthcare by engaging with healthcare professionals and listening and responding to children themselves with respect to the planning, design, delivery, evaluation, and reform of child-friendly healthcare.

Listening And Responding To Children

None of the above steps will achieve the goal of child-friendly healthcare without listening and responding to the views and experiences of children. This research suggests that although the profile and status of children's rights continues to grow internationally, challenges remain at a national level (Kilkelly 2007a). In the healthcare sector, research identifies good practice in health professionals' engagement with children on an individual level. However, this has not yet emerged as a core value of the healthcare system. The findings from this Report indicate that unless children are viewed as central to their healthcare throughout the healthcare system, respect for their rights will remain rhetoric. Giving unequivocal expression to the duty to hear and take account of children's views in a national policy framework on children's healthcare is a vital

first step. However, the policy must also articulate a range of ways in which this is to be achieved in practice, including raising awareness among children and adults about the importance of taking children's views into account; providing training for healthcare professionals on communicating with children; and putting in place effective channels of communication to feed children's experiences and perspectives into the process of healthcare reform. Parents are also vital to this process.

Conclusion

Health and healthcare are essential to children, their development and their well-being. Implementing children's rights in healthcare is essential to a system of healthcare that meets children's needs and takes account of their specific circumstances. Reflecting on all the positive initiatives, developments, processes and approaches set out in this Report, the inseparable nature of children's rights and healthcare is enduring. The challenges of promoting child-friendly healthcare must be met by a series of complex strategic and operational initiatives, many of which are already underway in Ireland in 2013. Based on the UN Convention on the Rights of the Child, the challenge of mainstreaming the child-friendly healthcare approach must be led by identifiable champions and advocates, including the many healthcare professionals that work daily with children as well as children themselves. The 'building blocks' offered here are recommended as the 'next steps' towards child-friendly healthcare in Ireland. Respecting children's rights in healthcare, including listening to and responding to their views, is becoming a reality in the healthcare settings of other countries. There is no reason why Ireland cannot do likewise.

REFERENCES



A

Action for Sick Children Scotland. (2010). *Children and Young People's Healthcare Rights: A Resource Pack*. Scotland: Action for Sick Children. Available at <http://lx.iriss.org.uk/content/children-and-young-peoples-healthcare-rights-resource-pack>

Alderson, P., & Montgomery, J. (1996). *Health Care Choices. Making Decisions with Children*, London: Institute for Public Policy Research.

Alderson, P., Sutcliffe, K., & Curtis, K. (2006). Children as partners with adults in their medical care. *Archives of Disease in Childhood*, 91, 300–303.

Ameratunga, S., Abel, S., Tin Tin, S., Asiasiga, L., Milne, S., & Crengle, S. (2010). Children admitted to hospital following unintentional injury: perspectives of health service providers in Aotearoa/New Zealand. *BioMedCentral Health Services Research*, 10, 333.

B

Boylan, P. (2004). *Children's Voices Project. Feedback from Children and Young People about their Experience and Expectations of Healthcare*. Commission for Health Improvement. National Health Service. Available at: http://www.cqc.org.uk/_db/_documents/o4o12717.pdf

Buckley, A., & Savage, E. (2010). Preoperative information needs of children undergoing tonsillectomy. *Journal of Clinical Nursing*, 19, 2879–2887.

Burke, K., Owens, S. & Ghatge, D. (2010). *Learning from Experience to Inform the Future: Findings Emerging from the Initial Phase of the Children's Services Committee in Ireland*. Centre for Effective Services. Available at: <http://www.effectiveservices.org/images/uploads/file/publications/Learning%20from%20the%20past%20to%20inform%20the%20future.pdf>

C

Cavet, J., & Sloper, P. (2004). Participation of disabled children in individual decisions about their lives and in public decisions about service development. *Children & Society Volume*, 18, 278–290.

Children's Hospital Australasia and the Association for the Wellbeing of Children in Healthcare. (2010). *Charter of the Rights of Children and Young People in Healthcare Services in Australia*. Australia: Children's Hospital Australasia. Available at <http://www.wcha.asn.au/>

Children's Rights Alliance. (2006). *From Rhetoric to Rights Second Shadow Report to the United Nations Committee on the Rights of the Child*. Dublin: Children's Rights Alliance.

Coad, J.E., & Shaw, K.L. (2008). Is children's choice in health care rhetoric or reality? A scoping review. *Journal of Advanced Nursing*, 64, 318–327.

Coad, J., Flay, J., Aspinall, M., Bilverstone, B., Coxhead, E., & Hones, B. (2008). Evaluating the impact of involving young people in developing children's services in an acute hospital trust. *Journal of Clinical Nursing*, 17, 3115–3122.

Council of Europe. (2011). *Guidelines on Child-Friendly Health*. Available at: http://www.coe.int/t/dghl/standardsetting/childjustice/Guidelines%20on%20child-friendly%20justice%20and%20their%20explanatory%20memorandum%20_4_.pdf

Coyne, I. (2006). Consultation with children in hospital: children, parents' and nurses' perspectives. *Journal of Clinical Nursing*, 15, 61–71.

Coyne, I., Hayes, E., Gallagher, P., & Regan, G. (2006). *Giving Children a Voice: Investigation of Children's Experiences of Participation in Consultation & Decision – Making in Irish Hospitals*. Dublin: Office of the Minister for Children.

Coyne, I.T. (2008). Children's participation in consultations and decision-making at health service level: a critical review of the literature. *International Journal of Nursing Studies*, 45, 1682–1689.

Coyne, I., & Gallagher, P. (2011). Participation in communication and decision-making: children and young people's experiences in a hospital setting. *Journal of Clinical Nursing*, doi: 10.1111/j.1365-2702.2010.03582.x

D

Day, C. (2008). Children's and young people's involvement and participation in mental health care. *Child and Adolescent Mental Health*, 13, 2–8.

Davis, M.A., Quittner, A.L., & Stack, C. (2004). Controlled evaluation of the STARTBRIGHT CDROM program for children and adolescents with cystic fibrosis. *Journal of Pediatric Psychology*, 29, 259–267.

- Department of Children and Young People. (2012). *Life as a Child and Young Person in Ireland: Report of a National Consultation*. Dublin: Stationery Office.
- Department of Health. (1991). *Child Care Act*. Dublin: Stationery Office.
- Department of Health. (2001). *Mental Health Act. No. 25*. Dublin: Stationery Office.
- Department of Health. (2004). *Health Act*. Dublin: Stationery Office.
- Department of Health. (2007). *Healthy Lives –Brighter Futures: the Strategy for Children’s and Young People’s Health*. Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_094399.pdf
- Department of Health and Children. (2000). *The National Children’s Strategy – Our Children their Lives*. Dublin: Stationery Office.
- Department of Health and Children. (2000). *The National Health Promotion Strategy, 2000-2005*. Dublin: Stationery Office.
- Department of Health and Children. (2001). *Primary Care: A New Direction*. Dublin: Stationery Office.
- Department of Health and Children. (2001). *Quality and Fairness – A Health System for You*. Dublin: Stationery Office.
- Department of Health and Children. (2006). *Quality and Fairness – A Health System for You, Action Plan Progress Report 2005*. Dublin: Government of Ireland. Available at: http://www.dohc.ie/publications/qualityandfairness_progress.html
- Department of Health and Children. (2007). *Quality and Fairness – A Health System for You, Action Plan Progress Report 2006*. Dublin: Government of Ireland. Available at: http://www.dohc.ie/publications/action_plan_progress_report_2006.html?lang=en
- Department of Health and Children. (2008). *National Strategy for Service User Involvement in the Irish Health Service 2008-2013*, Dublin: Department of Health and Children. Available at: http://www.hse.ie/eng/services/Publications/Your_Service_Your_Say_Consumer_Affairs/Strategy/Service_User_Involvement.pdf
- Department of Health. (2013). *Healthy Ireland. A Framework for Improved Health and Wellbeing 2013-2025*. Dublin: The Stationery Office.
- Department of Justice, Equality and Law Reform (2001). *The Children Act 2001*. Dublin: The Stationery Office.
- Department of the Taoiseach (2011). *Programme for Government 2011*. Available at: http://www.taoiseach.gov.ie/eng/Publications/Publications_2011/Programme_for_Government_2011.pdf
- Denyer, S., Keenaghan, C., Armstrong, M., Quinlan, A., Cullen, C., & Gilhooly, B. eds. (2001). *Get Connected – Developing an Adolescent Friendly Health Service*. Dublin: National Conjoint Child Health Committee. Available at: http://www.hse.ie/eng/services/Publications/services/Children/Get_Connected_Developing_an_Adolescent_Friendly_Health_Service.pdf
- Dogra, N. (2005). What do children and young people want from mental health services? *Current Opinions in Psychiatry*, 18, 370-373.
- Duff, A., Ball, R., Wolfe, S., Blyth, H., & Brownlee, K. (2006). Betterland: an interactive CD-ROM guide for children with cystic fibrosis. *Paediatric Nursing*, 18, 30-33.
- E**
- European Association of Children in Hospital. (2002). *The EACH Charter and Annotations, EACH*. Available at: <http://www.each-for-sick-children.org/each-charter/charter-and-annotations>
- F**
- Fereday, J. & Darbyshire, P. (2008) Making the wait easier: Evaluating the role of supervised play in a surgical admission area. *Neonatal, Paediatric and Child Health Nursing*, 11(1), 4-9.
- Franck, L., Noble, G., & McEvoy, M. (2008). Enquiring minds want to know: Topics requested by users of a children’s health information website. *Patient Education and Counselling*, 72, 168-171.
- Freeman, M. (1983). *The Rights and Wrongs of Children* (Continuum International Publishing).

G

Garth, B., Murphy, G.C., & Reddihough, D.S. (2009). Perceptions of participation: Child patients with a disability in the doctor-parent-child partnership. *Patient Education and Counselling*, 74, 45-52.

Gibson, F., Aldiss, S., Horstman, M., Kumpunen, S. & Richardson, A. (2010). Children and young people's experiences of cancer care: A qualitative research study using participatory methods. *International Journal of Nursing Studies*, 47, 1397-1407.

Godfrey, A. (2003). Children's service planning: The process and implications for wider partnership working. *Child Care in Practice*, 9, 181-198.

Gray, N.J., Klein, J.D., Noyce, P.R., Sesselberg, T.S., & Cantrill, J.A. (2005). Health information-seeking behaviour in adolescence: the place of the internet. *Social Science and Medicine*, 60, 1467-1478.

H

Hallstrom, I., & Elander, G. (2004). Decision-making during hospitalization: parents' and children's involvement. *Journal of Clinical Nursing*, 13, 367-375.

Hanafin, S., & Brooks, A.M. (2005). *The Development of a National Set of Child Well-being Indicators in Ireland: Executive Summary*. Dublin: The National Children's Office. Available at: <http://www.childrensdatabase.ie/viewdoc.asp?Docid=27&CatID=13&mn=&StartDate=01+January+2005>

Health Information and Quality Authority. (2012). *National Standards for Safer Better Healthcare*. Available at <http://www.hiqa.ie>

Health Service Executive. (2005). *Best Health for Children Revisited: Report from the National Core Child Health Programme Review Group to the Health Service Executive*, Available at: <http://www.lenus.ie/hse/handle/10147/44901>

Health Service Executive. (2006). *HSE Transformation Programme 2007-2010*. Dublin: Health Service Executive. Available at: <http://www.hse.ie/eng/services/Publications/corporate/transformation.pdf>

Health Service Executive. (2008). *Engaging Children in Planning Design, Development, Delivery and Evaluation of Services*. Available at: http://www.childandfamilyresearch.ie/sites/www.childandfamilyresearch.ie/files/hse_policy_on_engaging_children_in_planning_design_development_delivery_and_evaluation_of_services.pdf

Health Service Executive. (2010). *National Service Plan 2010*. Dublin: Health Service Executive. Available at: <http://www.hse.ie/eng/services/Publications/corporate/National%20Service%20Plan%202010.pdf>

Health Service Executive. (2010). *Working with Children and Young People: A Guide for Frontline Staff*. Dublin: Health Service Executive. Available at: <http://www.hse.ie/eng/services/sys/Documentation/WorkingwithChildren.pdf>

Health Service Executive. (2011). *Service User Involvement and Primary Care: Framework Document 2011*. Available at: http://www.hse.ie/eng/services/sys/Documentation/involve/sui_framework.pdf

Health Service Executive. (2012). *National Healthcare Charter. Your Service Your Say*. Available at: http://www.hse.ie/eng/services/yourhealthservice/hcharter/National_Healthcare_Charter.pdf

Hill, M., Pawsey, M., Cutler, A., Holt, J.L., & Goldfeld, S.R. (2011). Consensus standards for the care of children and adolescents in Australian health services. *The Medical Journal of Australia*, 94, 78-82.

Hoole, L. & Morgan, S. (2010). 'It's only right that we get involved': service-user perspectives on involvement in learning disability services. *British Journal of Learning Disabilities*, 39, 5-10.

Hunt, P., & Backman, G. (2008). Health systems and the right to the highest attainable standard of health. *Critical Concepts*, 10, 81-92.

I

Illback, R. J., & Bates, T. (2010). Transforming youth mental health services and supports in Ireland. *Early Intervention in Psychiatry*, 5, 22-27.

International Network for Health Promoting Hospitals and Healthcare Services (2012), *Children's Rights in Hospitals and Health Services: Manuals and tools for Assessment and Improvement*, edited by A. Guerrero.

Irish Society for quality and Safety in Healthcare. (2010). *Measuring the Patients' Experiences of Health Services*. Available at: www.isqsh.ie

J

Jaaniste, T., Hayes, B. & Von Baeyer, C.L. (2007). Providing children with information about forthcoming medical procedures: a review and synthesis. *Clinical Psychology Science and Practice*, 14, 124-143.

Jones, J.K., Kamani, S.A., Bush, P.J., Hennessy, K.A., Marfatia, A., & Shad, A.T. (2010). Development and evaluation of an educational interactive CD-ROM for teens with cancer. *Pediatric Blood Cancer*, 55, 512-519.

K

Kelsey, J., Abelson-Mitchell, N., & Skirton, H. (2007). Perceptions of young people about making in the acute healthcare environment. *Paediatric Nursing*, 19, 14-18.

Kilkelly, U. (2001). The best of both worlds for children's rights? Interpreting the European Convention on Human Rights in the light of the UN Convention on the Rights of the Child. *Human Rights Quarterly*, 23, 308-326.

Kilkelly, U., & Donnelly, M. (2006). *The Child's Right to be heard in the Healthcare Setting: Perspectives of Children, Parents and Health Professionals*. Dublin: Office of the Minister for Children.

Kilkelly, U. (2007) 'Children's Rights and the Family: Myth and Reality' *Studies* volume 97 number 385 7-18.

Kilkelly, U. (2007a) *Barriers to the Realisation of Children's Rights in Ireland*. Dublin: Ombudsman for Children's Office.

Kilkelly, U. (2008). *Children's Rights in Ireland: Law, Policy and Practice*. Dublin: Tottel Publishing.

Kilkelly, U. (2011) *Child Friendly Healthcare: The Views and Experiences of Children and Young People in the Council of Europe*. Strasbourg: Council of Europe.

Kilkelly, U. & Donnelly, M. (2011). Participation in healthcare: The views and experiences of children and young people'. *International Journal of Children's Rights*, 19(1), 107.

Koller, D., Nicholas, D., Gearing, R., & Kalfa, O. (2010). Paediatric pandemic planning: a children's perspectives and recommendations. *Health and Social Care in the Community*, 18, 396-377

L

Law Reform Commission. (2009). *Consultation Paper on Children and the Law: Medical Treatment*. LRC CP59-2009. Dublin: Law Reform Commission.

Lambert, V., Glacken, M., & McCarron, M. (2008). 'Visible-ness': the nature communication for children admitted to a specialist children's hospital in the Republic of Ireland. *Journal of Clinical Nursing*, 17, 3092-3102.

Lambert, V., Coad, J., Hicks, P., Glacken, M. (2010a). *Physical Places and Social Spaces for Young Children in Hospital*, Dublin: National Paediatric Hospital Project

Lambert, V., Glacken, M., & McCarron, M. (2010b). Communication between children and health professionals in a child hospital setting: a child transitional communication model. *Journal of Advanced Nursing*, 67, 569-582.

LeFrancois, B.A. (2007). Children's participation rights: voicing opinions in inpatient care. *Child and Adolescent Mental Health*, 12, 94-97.

Levetown, M. & The Committee on Bioethics. (2008). Communicating with children and families: from everyday interactions to skill in conveying distressing information. *American Academy of Pediatrics*, 121, e1441-e1460.

LI H.C.W., Lopez, V. & Lee T.L.I. (2007). Effects of therapeutic play on outcomes of school aged children undergoing day surgery. *Research in Nursing & Health*, 30, 320-332.

M

McGachie, C. (2004). *A Report to Standards New Zealand*. Available at: <http://www.paediatrics.org.nz/files/DHB%20Scorecards/SNZYouthConsultationReport.pdf>

Mainey, A., Ellis, A., Lewis, J. (2009). *Children's Views of Services a Rapid Review*. London: National Children's Bureau

Martenson, E.K., & Fagerskiold, A.M. (2007). A review of children's decision-making competence in health care. *Journal of Clinical Nursing*, 17, 3131-3141.

- McKenna, V., Barry, M., & Friel, S. (2004). *Review of the National Health Promotion Strategy 2004*. Dublin: Department of Health and Children. Available at: http://www.nuigalway.ie/health_promotion/documents/General_Staff_Publications/2005_rep_mckenna_hp_strategy_2004.pdf
- McKinsey & Company. (2006). *Children's Health First: International Best Practice in Tertiary Paediatric Services: Implications for the Strategic Organisation of Tertiary Paediatric Services in Ireland*. Available at: http://www.hse.ie/eng/about/21c/National_Paediatric_Hospital/
- McPherson, A.C., Glazebrook, C., Forster, D., James, C., & Smyth, A. (2006). A randomized, controlled trial of an interactive educational computer package for children with asthma. *Pediatrics*, 117, 1046- 1054.
- Midlands Health Board. (1999). *Best Health for Children - Developing a Partnership with Families*. Available at: <http://www.lenus.ie/hse/handle/10147/45180>
- Migone, M., McNicholas, F., & Lennon, R. (2008). Are we following the European charter? Children, parents and staff perceptions. *Child: Care, Health and Development*, 34, 409-417.
- Mitchell, R.C. (2000). Implementing children's rights in British Columbia using the population health framework. *The International Journal of Children's Rights*, 8, 333-349.
- Mitchell, R.C. (2011). Human rights and health promotion: A Canada fit for children? *International Journal of Child, Youth and Family Studies*
- Mitchell-Lowe, M. & Eggleston, M. (2009). Children as consumer participants of child and adolescent mental health services. *Australasian Psychiatry*, 17, 287-290.
- Moore, L. & Kirk, S. (2010). Literature Review of children's and young people's participation in decisions relating to healthcare. *Journal of Clinical Nursing*, 19, 2215-2225.
- Moult, B., Stephenson, P., Geddes, N. & Webb, J. (2009). From pamphlets to podcasts: Health information at Great Ormond Street Hospital for children NHS Trust. *Journal of Visual Communication in Medicine*, 32 (2), 43-47.
- Murphy, J. Nicholson, A. and Turner, G. (2013), *National Clinical Programme for Paediatrics and Neonatology. Review of Paediatric and Neonatology Services and a Framework for Future Development*. Dublin: HSE.
- N**
- National Children's Bureau. (2005). *Children and Young People's Views on Health and Health Services: A Review of the Evidence*. London: National Children's Bureau.
- National Children's Office (2000). *Report of the Public Consultation for the National Children's Strategy*, Dublin: The Stationery Office. Available at: <http://www.dcy.gov.ie/viewdoc.asp?DocID=68>
- National Children's Office. (2005). *Young Voices – Guidelines on How to Involve Children and Young People in your Work*. Dublin: Minister of Children.
- National Paediatric Development Board. (2010). *National Model of Care for Paediatric Healthcare Services in Ireland*. Available at: <http://www.newchildrenshospital.ie/index.cfm/page/modelofcare2>
- Nicholson, S., & Clarke, A. (2005). *Child Friendly Healthcare: a Manual for Health Workers*. Maternal & Child Health Advocacy International. Available at: http://www.cfhiuk.org/publications/cfhi_manual.htm.
- O**
- Ombudsman for Children (2012) Advice of the Ombudsman for Children on the Children and Young Person's Policy Framework 2012-2017.
- Office for the Minister of Children. (2007). *The Agenda for Children's Services: A Policy Handbook*. Dublin: Stationery Office. Available at: http://www.dcy.gov.ie/documents/publications/CS_handbook%5BENGLISH%5Dlowres.pdf
- O' Shea, M., Cummin, A., & Kelleher, A. (2010). Setting up pre-admission visits for children undergoing day surgery: a practice development initiative. *Journal of Perioperative Practice*, 20, 203-206.
- Owens, S. (2010). *An Introductory Guide to the Key Terms and Interagency Initiatives in Use in the Children's Services Committees in Ireland*. Centre for Effective Services. Available at: <http://www.effectiveservices.org/ces-projects/poo2-working-together-for-children-initiative-childrens-services-committees>

P

Paediatric Society of New Zealand. (2002). *New Zealand Standards for the Wellbeing of Children and Adolescents receiving Healthcare*. Available at: <http://www.paediatrics.org.nz/files/DHB%20Scorecards/standardswellbeinglongdocmay02.pdf>

Pillinger, J. (2010). *Formative Evaluation of the Joint Community Participation in Primary Care Initiative*. Report prepared for Health Service Executive. Available at: <http://www.hse.ie/eng/services/ysys/Documentation/CommunityParticipationPrimaryCare.pdf>

R

Robinson, S. (2010). Children and young people's views of health professionals in England. *Journal of Child Health Care*, 14, 310-326.

Runeson, I., Hallstrom, I., Elander, G. & Hermeren, G. (2002). Children's participation in the decision-making process during hospitalization: an observational study. *Nursing Ethics*, 9, 583-598.

Runeson, I., Martenson, E., & Enskar, K. (2007). Children's knowledge and degree of participation in decision making when undergoing a clinical diagnostic procedure. *Pediatric Nursing*, 33, 505-511.

S

Savage, E., & Callery, P. (2007). Clinic consultations with children and parents on the dietary management of cystic fibrosis. *Social Science & Medicine*, 64, 363-374.

Savage, E. (2007). The contribution of specialist nurses to the management of cystic fibrosis in Ireland. *Journal of Children's and Young People's Nursing*, 1, 180-185.

Scott, T., Mannion, R., Davies, H.T.O. & Marshall, M.N. (2003). Implementing culture change in health care: theory and practice. *International Journal for Quality in Health Care*, 15, 111-118.

Simonelli, F., Guerreiro, A., & Task Force on Health Promotion for Children and Adolescents in and by Hospitals and Health Services. (2010). *The Respect of Children's Rights in Hospital: An Initiative of the International Network of Health Promoting Hospitals and Health Services* (Final Report of the implementation process of the implementation of the *Self-evaluation Model and Tool on the Respect for Children's Rights in Hospital*). International Network of Health Promoting

Hospitals and Health Services – WHO Collaborative Centre. Available at: http://www.hphnet.org/index.php?option=com_content&view=article&id=1551%3Ahp-for-children-a-adolescents-in-a-by-hospitals-&catid=20&Itemid=95

Smith, L. & Callery, P. (2005). Children's account of their pre-operative information needs. *Journal of Clinical Nursing*, 14, 230-238.

T

Tates, K., Meeuwesen, L., Elbers, E. & Bensing, J. (2002). 'I've come for his throat': roles and identities in doctor-parent-child communication. *Child Care Health and Development*, 28, 109-116.

The Royal Australasian College of Physicians, Association for the Wellbeing of Children in Healthcare & Children's Hospital Australasia. (2008). *Standards for the Care of Children and Adolescents in Health Services*. Available at: <http://www.wcha.asn.au/>

The Scottish Government (2007). *Delivering a Healthy Future: An Action Framework for Children and Young People's Health in Scotland*. Available at: <http://www.scotland.gov.uk/Publications/2007/02/14154246/12>

Tylee, T; Haller, D.M., Graham, T., Churchill, R., Sanci, L.A., (2007). Youth-friendly primary-care services: how are we doing and what more needs to be done? *The Lancet* 269, 1565-73.

Tunney A. & Boore J. (2013). The effectiveness of a storybook in lessening anxiety in children undergoing tonsillectomy and adenoidectomy in Northern Ireland doi:10.3109/01460862.2013.834398

U

United Nations General Assembly (1989). *Convention on the Rights of the Child*. Geneva: United Nations.

UN Committee on the Rights of the Child, *General Guidelines Regarding the Form and Content of Initial Reports to be Submitted by States Parties under Article 44, Paragraph 1(a) of the Convention*, CRC/C/5/1991

UN Committee on the Rights of the Child, *Concluding Observations: Ireland*, CRC/C/15/Add.85 4 February 1998.

UN Committee on the Rights of the Child, *Concluding Observations: Ireland*, CRC/C/IRL/CO2 29 September 2006.

United Nations Committee on the Rights of the Child. General Comment No 4. *Adolescent Health*. CRC/C/GC/4/2003.

United Nations Committee on the Rights of the Child. General Comment No 5. *General Measures of Implementation*. CRC/C/GC/5/2003.

United Nations Committee on the Rights of the Child. General Comment No. 12. *The Right of the Child to be Heard*. CRC/C/GC/12/2009.

United Nations Committee on the Rights of the Child, General Comment No. 15, *The Right of the Child to the Enjoyment of the Highest Attainable Standard of Health*. CRC/C/GC/15/2013.

United Nations Office of the High Commission for Human Rights, *Report to the Human Rights Council on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health*. A/HRC/22/31, 2012

W

Wales, S., Crisp, J., Moran, P., Perrin, M., & Scott, E. (2008). Assessing communication between health professionals, children and families. *Journal of Children's and Young People's Nursing*, 2, 77-83.

Williams, J., Greene, S., McNally, S., Murray, A., & Quail, A (2010) *Growing up in Ireland: National Longitudinal Study of Children, The Infants and their Families*. Dublin: Stationery Office. Available at; <http://www.drugsandalcohol.ie/14301/>

World Health Organisation. (2004). *Development of National Child Health Policy. Phase 1: The Situation Analysis*. Available at: <http://www.emro.who.int/cah/childhealthpolicy-situationanalysis.htm>

Worrall-Davies, A. & Marino-Francis, F. (2008). Eliciting children's and young people's views of child and adolescent mental health services: A systematic review of best practice. *Child and Adolescent Mental Health*, 13, 9-15.

Y

Young, B., Dixon-Woods, M., Windridge, K., & Heney, D. (2003). Managing communication with young people who have a potentially life threatening chronic illness: Qualitative study of patients and parents. *British Medical Journal*, 326, 1-5.

Z

Zwaanswijk, M., Tates, K., van Dulmen, S., Hoogerbrugge, P.M., Kamps, W.A., Beishuizen, A., & Bensing, J.M. (2011). Communicating with child patients in pediatric oncology consultations: a vignette study on child patients', parents' and survivors' communication preferences. *Psycho-Oncology*, 20, 269-277.

APPENDIX 1

A funny

doctor is good

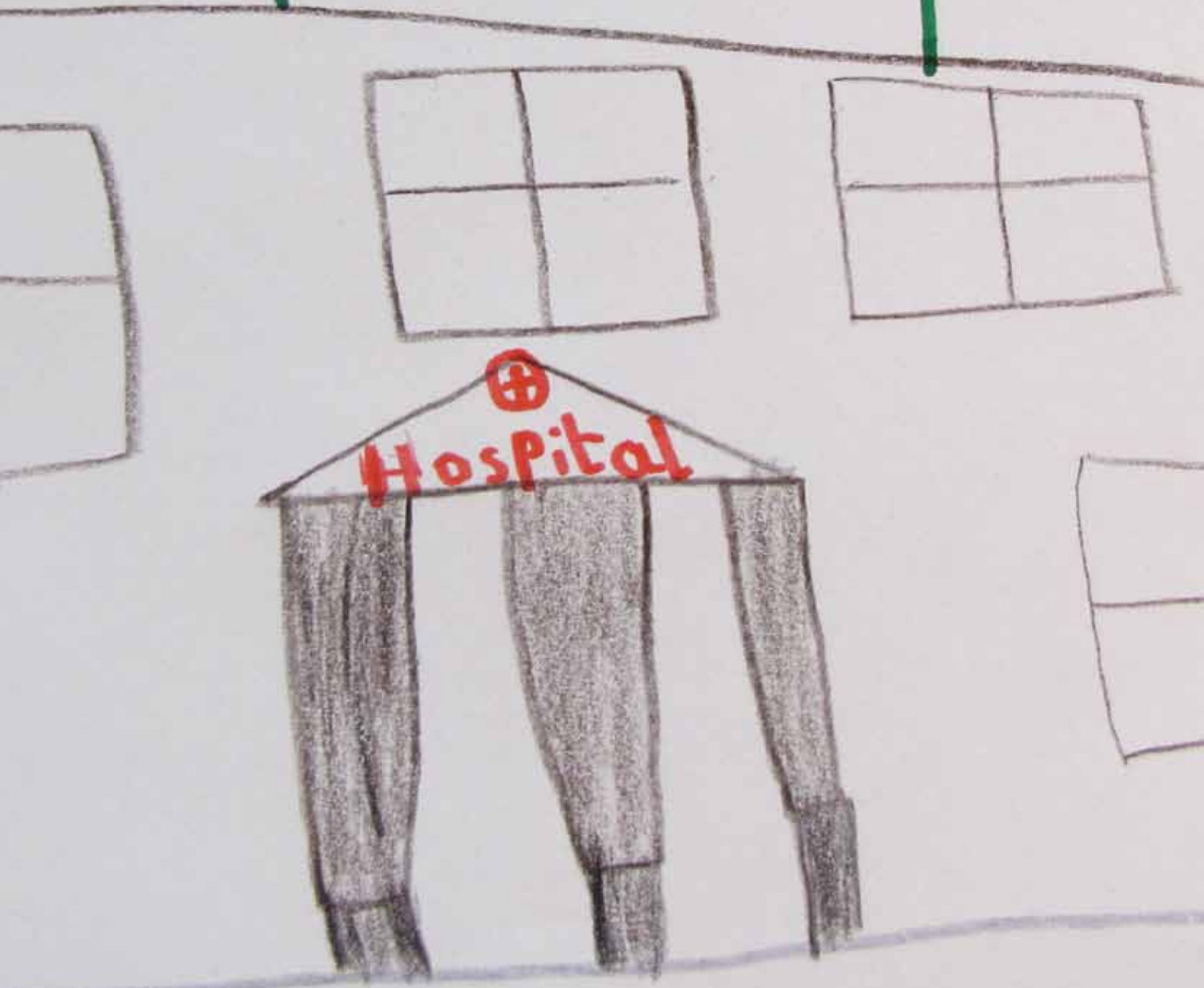
医生

Appendix 1: 'Building blocks' for a Practice Model Promoting a Culture of Respecting Children's Rights in Healthcare

NATIONAL POLICY FOR CHILD-FRIENDLY HEALTHCARE		
WHAT WORKS? →	WHY?	→ HOW?
Building Inter-sectoral Alliances	<ul style="list-style-type: none"> » Strong infrastructure of support and leadership » Promotes 'buy-in' from diverse stakeholders including policy makers and management » Strong and collective power base to influence social and cultural change » Joined-up thinking 	<ul style="list-style-type: none"> » Align with 'key' organisations and groups in Ireland » Engage with policy-makers (e.g. Government & HSE, private and voluntary) » Link in with International initiatives & leaders » Set up a National Steering Group
Awareness Raising on Children's Rights	<ul style="list-style-type: none"> » Gets 'everybody' thinking about children's rights and what this means in healthcare » Challenges traditional assumptions about children as passive & incompetent. 	<ul style="list-style-type: none"> » National & regional conferences » Media publicity » Public meetings & workshops » Meetings & Workshops in healthcare organisations; schools; youth clubs etc. » Dissemination of information in written format
Situation Analysis of Current Practices	<ul style="list-style-type: none"> » Establishes good practice » Audits current position on rights compliance in healthcare settings » Establishes needs, strengths & challenges » Provides context & knowledge for planning 	<ul style="list-style-type: none"> » Research the evidence – home & abroad » Survey existing practices (primary & secondary settings); » Involve children – their experiences & what rights are important to them? » Interview policy makers & health service managers
Setting & Implementing Standards	<ul style="list-style-type: none"> » A child-friendly framework for practice » Process of continuous quality improvement that can link to accreditation processes » Potential to link practices to child health services and evaluation of outcomes 	<ul style="list-style-type: none"> » Frame within CRC and relevant Irish policy » Draw on existing Standards from abroad » Develop through consensus & Pilot » Keep it simple & feasible for application
Management Support	<ul style="list-style-type: none"> » Provides infra-structure and resources to make change possible 	<ul style="list-style-type: none"> » Education and training of staff » Facilitate organisational wide consultation » Secure resources based on identified needs » Putting children's rights on agendas » Giving children a 'voice' at all levels – practice, planning, policy
LISTENING & RESPONDING TO CHILDREN		

We spend
our money
on car
parks

No Children's
ward go to
Dublin



More
You should
Yoon
Could
ful.



