



ombudsman
do leanaí
for children

Waiting for Scoliosis Treatment

A Children's Rights Issue

MARCH
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ABBREVIATIONS

Health Service Executive	HSE
Ombudsman for Children's Office	OCO
Ombudsman for Children Act, 2002	2002 Act
Preliminary Examination	PE
European Convention on Human Rights	ECHR
European Convention on Human Rights Act 2003	2003 Act
United Nations Convention on the Rights of the Child	CRC
Our Lady's Children's Hospital Crumlin	OLCHC
Treatment Abroad Scheme	TAS
National Treatment Purchase Fund	NTPF
Children's Hospital Group	CHG

TABLE OF CONTENTS

Acknowledgments	2
Foreword	3
Section 1 Introduction	5
1.1 What is Scoliosis	7
1.2 How is Scoliosis Treated.....	7
Section 2 Implementing a child rights based approach	8
2.1 Relevant children’s rights standards	9
2.2 Relevant national policies.....	13
Section 3 Children’s views on waiting for Scoliosis surgery and its impact on their lives	14
<i>Harriet’s story</i>	15
<i>Delilah’s story</i>	18
<i>Jane’s story</i>	22
Section 4 Treatment for Scoliosis in Ireland	26
4.1 Current situation	27
Section 5 Waiting lists for Scoliosis: children’s rights perspective	30
Section 6 Recommendations	32

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We would like to thank the children and young people who gave us permission to use their stories. We would also like to acknowledge the significant efforts made by those involved in providing treatment services for children with scoliosis and note that many go beyond what is required of them to make sure that surgeries happen whenever possible.

We dedicate this report to children with scoliosis and to their parents who have had to advocate so strongly to vindicate their child's right to access essential medical services.



FOREWORD BY DR NIALL MULDOON

Children are not the same as adults. A year of illness or adversity for a child may be a quarter of their lives, or it may occur during a teenage growth spurt, amplifying the effects. An illness for a child may mean that they miss school, that they struggle to catch up or that they cannot do the same things that their friends can do.

The difficulties experienced by children and young people trying to access treatment for scoliosis has been well documented. Children have been left waiting for vital surgeries, parents and professionals advocating on their behalf have attracted attention, with investment and commitment following. Any improvement in waiting times for scoliosis treatment has been short-lived as the problem inevitably worsens and the cycle continues.

In this report we have examined the situation of children waiting for scoliosis treatment as a children's rights issue. We decided to prepare and publish this report to offer a real insight into the extent to which children's rights are being respected in the health sector in Ireland, in line with the Government's commitments on a national and international level.

This report raises huge concerns about the serious and ongoing violations of the rights of children waiting for scoliosis treatment. The powerful testimonies provided by the children and young people about their lived experiences make for chilling reading and, highlight the importance of listening to their views.

However, listening is not enough. There is an onus on us all to act and for the Government to fully and meaningfully address all of the issues raised.

Every child in Ireland has the right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. As Ombudsman for Children, I have a responsibility to promote that right.

Although this report has a specific focus, we have engaged in a broad analysis of children's rights in the healthcare context. It is clear that the international children's rights framework offers significant guidance to the Government on the general and specific measures that it must adopt to ensure that all

children's rights are recognised and protected. We hope that this report highlights the importance of applying this framework to all Government policy.

The new Article 42A.1 of the Irish Constitution, which was voted for by the people of Ireland recognises the child as a holder of rights. This will have little meaning unless we begin, as a society, to make children's rights real. To do this we must take immediate steps towards the full realisation of children's rights, and we must hold the State to account, where appropriate, to ensure those rights are vindicated.

Niall Muldoon



Dr Niall Muldoon

**Ombudsman
for Children**

Section 1

Introduction

There is a statutory duty on the Ombudsman for Children to promote the rights and welfare of children in a number of ways under Section 7 of the Ombudsman for Children Act, 2002 (2002 Act).¹ In light of that obligation, we are publishing this report with two main objectives:

- To highlight that waiting lists for paediatric spinal surgery have been and continue to be an issue of concern to children, directly affecting their lives and the enjoyment of their rights²; and
- To raise awareness of the principles and provisions of the United Nations Convention on the Rights of the Child (CRC) applicable in this context.³

Our primary reason for doing so is to highlight that as a party to the CRC, the Irish State must recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.

Since July 2009, the Ombudsman for Children's Office (OCO) has received complaints from parents on behalf of their children who have scoliosis. Over a sustained period of time, we have been alerted to the very long waiting times children are experiencing to access scoliosis spinal surgery. In this report we will address this issue from a children's rights perspective.

¹ As part of this duty a joint initiative, *Joining the Dots: Connecting Voices for Child-friendly Healthcare in Hospital*, is currently being undertaken by the Ombudsman for Children's Office and the Children's Hospital Group Board with the three children's hospitals in Dublin. The initiative will use a child rights framework to hear and take account of the views of children, young people, parents/guardians, hospital staff and management on a range of matters relating to the delivery of services to children and young people in hospital.

² Ombudsman for Children Act 2002, Section 7 (1)(e).

³ Ombudsman for Children Act 2002, Section 7 (1)(d).

As part of the preliminary examination (PE) of the complaints received, under the 2002 Act,⁴ we engaged with a number of key stakeholders including the HSE and Our Lady's Children's Hospital in Crumlin, where the majority of complex surgeries are carried out.

During the course of our involvement in these complaints, and in line with our policy of speedy local resolution where possible, surgeries were completed or scheduled for all the children on behalf of whom complaints were made.

However, in our examinations, we concluded that the delays children experienced were primarily related to either the prioritisation of children on surgery waiting lists, which is a decision based on clinical judgement, or how resources and staff are allocated. As these issues are beyond our remit for investigation, complaints were closed at the conclusion of the PE stage and did not progress to investigation.⁵

Nevertheless, following the closure of these complaints, we became aware, through parents who contacted the Office as well as through our own enquiries, and information in the public domain, that children are still facing significant waiting times for spinal surgery to treat scoliosis. In fact, waiting lists for paediatric spinal surgeries have continued to increase despite initiatives introduced to address them. We are also concerned, as is a matter of public record, that the target of the HSE and the Department of Health in relation to waiting times for paediatric spinal surgeries has been set at 15 to 18 months.

⁴ Ombudsman for Children Act 2002, Sections 8 and 9.

⁵ See Ombudsman for Children Act 2002, section 9(3)(a) and section 11(1)(c) and 11(1)(d).

Although we could not investigate the complaints received, we strongly believe that this is a significant children's rights issue, which remains of concern to this Office and children themselves. It is for this reason that we decided to prepare and publish this report with the aim of highlighting the situation of children waiting for scoliosis treatment as a children's rights issue. However, since this is not a report of a PE or a review of the PEs carried out by this Office, we have been careful, having regard to the secrecy provisions of the Ombudsman for Children Act 2002, not to use information obtained in the course of a PE. All of the factual information in this report is information that is already in the public domain and is referenced as such.

There has been widespread coverage of this issue in the public domain, including in parliamentary debates, highlighting the experiences of children and their parents who have been so seriously affected by the unacceptable waiting times for scoliosis surgery. In preparing this report, we also made direct contact with three young people who have been affected by the long waiting times for their spinal surgeries to hear from them about the impact this has had on their lives. Both the parents and the young people who have been in contact with the OCO have described the significant pain of the condition, the worsening effects of increasing spinal curvature while awaiting surgery and the emotional and mental impact of the physical appearance associated with the condition.

In line with our obligations under the CRC, the Irish Government has a duty to fulfil children's right to health by undertaking measures, to the maximum extent of its available resources. This includes adopting appropriate legislative, administrative, budgetary and other measures towards the full realisation of this right⁶.

⁶ See in particular, Articles 4 and 24 of the CRC.

The physical and psychological effects that children suffer as a result of violations of their socio-economic rights, including the right to health, are particularly stark due to their age and lower level of physical and mental development.⁷ According to a leading expert in this area:

*'This is true both in relation to (a) the immediate impact that violations of the right to health may have on a child's physical and psychological state, and (b) the long-term detrimental effects on the child's development and future capacity for autonomy resulting from such a violation.'*⁸

Furthermore, the exclusion of children from democratic processes that determine policies and budgetary allocations heightens the duty on the Ombudsman for Children to highlight the rights and welfare of children and to hold Government to account to ensure that children's rights and interests are recognised and upheld.⁹

As explained above, the aim of this report is to highlight the situation of children waiting for scoliosis treatment as a children's rights issue. By doing so, we are very conscious that there are many other situations where the economic, social and cultural rights of children are not respected, protected or fulfilled by the Irish State. We hope that the analysis provided in this report highlights the importance of applying a child rights framework to all Government policy. This is particularly important to breathe life into the statement in Article 42A.1 of the Irish Constitution, inserted after the Children's referendum in 2012, which firmly recognises the child as a holder of rights and the State as the body responsible for the vindication of those rights.

⁷ A. Nolan, *Socio-Economic Rights, Democracy and the Courts* (Oxford: Hart Publishing, 2014) at p. 15.

⁸ *Ibid.*

⁹ *Ibid.*, at p.7.

1.1

What is Scoliosis?

Scoliosis is a condition causing a side-to-side curvature of the spine. It can occur due to congenital, developmental or degenerative problems, but most cases of scoliosis do not have a known cause. These cases are called idiopathic scoliosis.

Scoliosis can be present at birth, or can develop from infant age through to adulthood. However, in the majority of cases, curve progression can be greatest during adolescence and scoliosis that develops during this period of childhood will often progress more significantly.

The effects of scoliosis depend on the severity of the condition (the curvature of the spine). Severe scoliosis can be disabling and in cases of significant curvature of the spine, a person's chest space may be reduced which can affect the ability of the lungs to function. Scoliosis can be extremely painful and may cause visible physical deformity.

1.2

How is Scoliosis treated?

Treatment of scoliosis depends on the patient's type and specific level of scoliosis and can range from no treatment and/or monitoring, or bracing in less serious cases, to elective orthopaedic spinal surgery in more serious cases.

International best practice indicates that children should be operated on within 3–6 months of it being clinically determined that surgery is required.¹⁰ Research also shows that children with a curvature over 70 degrees, often as a result of lengthy surgical waiting lists, do not do as well post-surgery as those under 70 degrees.¹¹

As children grow, scoliosis can develop significantly and curvature of the spine can increase rapidly in a short space of time. In circumstances where the curvature is increasing, the sooner treatment is initiated the less significant, challenging, costly and risky it will be.

Surgery for paediatric scoliosis is a complicated procedure and requires pre-operative processes such as an MRI, as well as a significant number of professionals (including anaesthetists, consultant surgeons and specialised theatre nurses) to be involved and co-ordinated. Suitable surgery space is also required, as is post-operative, in-patient care and subsequent out-patient review.

¹⁰ H. Ahn, H. Kreder, N. Mahomed, D. Beaton and J. G. Wright, *Empirically derived maximal acceptable wait time for surgery to treat adolescent idiopathic scoliosis* (2011) available at: <https://www.ncbi.nlm.nih.gov/pubmed/21543302> (accessed 27/01/2017).

¹¹ R. C. Tarrant, J. M. Queally, P. F. O'Loughlin, P. Sheeran, D. P. Moore and P. J. Kiely, "Preoperative curves of greater magnitude (>70°) in adolescent idiopathic scoliosis are associated with increased surgical complexity, higher cost of surgical treatment and a delayed return to function" (2016) *Irish Journal of Medical Science* (accessed: 30/01/2017).

Section 2

Implementing a child rights based approach

Since 2009, the Ombudsman for Children's Office (OCO) has received a number of complaints from parents who are concerned about the length of time their children have been waiting for spinal surgery. A common denominator to these parents' complaints is the deteriorating effect the lengthy waiting times have had on their children's lives.

The continuous stream of complaints we have received about the waiting lists for paediatric spinal surgery over a period of eight years is evidence that the situation hasn't been resolved and remains an issue of concern for children. While we cannot publish the information which we obtained from public bodies for the purpose of this report, the information presented, including the range of explanations provided as to why this situation remains unresolved, is a matter of public record. These include: loss of operating capacity due to cut-backs¹²; no availability of anaesthetic cover¹³; increase in the referrals for spinal review and a consequent increase in surgical demand¹⁴; no theatre time available¹⁵; no theatre nurses available¹⁶; lack of qualified

consultant orthopaedic surgeons¹⁷; the need to double the capacity for scoliosis surgery in Our Lady's Children's Hospital Crumlin (OLCHC).¹⁸

The aim of this report is to highlight the situation of children waiting for scoliosis treatment as a children's rights issue and to bring attention to the importance of applying a child rights framework to Government policy. Section 7 of the Ombudsman for Children's Act, 2002 provides that the statutory function of the OCO shall include encouraging public bodies, schools and voluntary hospitals to develop policies, practices and procedures designed to promote the rights and welfare of children. There is also a prescribed role to promote public awareness of matters relating to the rights and welfare of children and how those rights can be enforced, including the principles and provisions of the United Nations Convention on the Rights of the Child (CRC).

¹² See Irish Times, June 2009 at <http://www.irishtimes.com/news/fears-over-crumlin-waiting-lists-1.842211> (accessed: 27/01/2017).

¹³ See Irish Medical Times, 17 September 2009 at <http://www.imt.ie/blogs/hospital-medicine/crumlin-to-clear-scoliosis-surgery-list-by-february-17-09-2009/>; and Irish Medical Times, 20 March 2009 at <http://www.imt.ie/news/hospitals-to-meet-hse-on-waiting-lists-20-03-2009/> (accessed: 27/01/2017). According to the Dublin critical care paediatric ICU report published in 2008, which looked at the facilities in Temple Street, Tallaght and Crumlin hospitals, major structural deficiencies in the service remained.

¹⁴ Dáil Éireann Debate, Wednesday 5 November 2014 at <http://oireachtasdebates.oireachtas.ie/debates%20authoring/debate-swebpack.nsf/takes/dail2014110500034> (accessed: 27/01/2017).

¹⁵ Dáil Éireann Debate, Thursday 3 December 2015 at <http://oireachtasdebates.oireachtas.ie/debates%20authoring/debate-swebpack.nsf/takes/dail2015120300008> (accessed: 27/01/2017).

¹⁶ *Ibid.*

¹⁷ *Ibid.*

¹⁸ *Ibid.*

2.1

Relevant Children's Rights Standards

The principal children's rights instrument is the CRC, which was adopted by the General Assembly of the United Nations on the 20 November 1989. This was a landmark development as the CRC is widely considered to be the gold standard for a children's rights approach.

It is a comprehensive document which recognises children as autonomous rights holders in all areas of their lives — including in the family, school and the community — and their fundamental rights to health and healthcare (Article 24), to play and leisure (Article 31) and an adequate standard of living (Article 27) for example, as well as making specific provision for children in vulnerable circumstances, such as children with disabilities (Article 22).¹⁹ The CRC also sets out the obligations of the State as a duty bearer,²⁰ as well as recognising the important role of parents and carers to support children to exercise their rights (Articles 5 and 18).²¹

Although the CRC has not been directly incorporated into Irish law²², Ireland has positively affirmed the existence of socio-economic rights through its ratification of the CRC in 1992, as well as other international legal instruments.²³ In the area of international relations, Ireland has also confirmed its commitment to the indivisible nature of all human rights: civil, political,

¹⁹ See U. Kilkelly, "Children's Rights in Ireland: Ireland's Relationship with the CRC" in S. Egan (ed.), *International Human Rights Perspectives from Ireland* (Dublin: Bloomsbury Professional, 2015) at p. 200.

²⁰ Committee on the Rights of the Child, *General Measures of Implementation of the Convention on the Rights of the Child* (2003) UN Doc. CRC/GC/2003/5 at para 1.

²¹ U. Kilkelly, "Children's Rights in Ireland: Ireland's Relationship with the CRC" in S. Egan (ed.), *International Human Rights Perspectives from Ireland* (Dublin: Bloomsbury Professional, 2015) at p. 199.

²² Article 29(6) of the Constitution states that "[n]o international agreement shall be part of the domestic law of the State save as may be determined by the Oireachtas."

²³ In particular, the International Covenant on Economic, Social and Cultural Rights. See L. Thornton, *Socio-Economic Rights and Ireland* in S. Egan (ed.), "International Human Rights: Perspectives from Ireland" (Dublin: Bloomsbury Professional, 2015) at p. 104.

economic, social and cultural.²⁴ Therefore, the State must undertake all appropriate legislative, budgetary and other measures, to the maximum extent of its available resources, to progress the full realisation of the children's rights principles enshrined in the CRC.²⁵

Ireland also became one of the first states to ratify the 3rd Optional Protocol to the CRC on a Communications Procedure in September 2014.²⁶ This mechanism was designed to strengthen children's rights and allows individuals, groups of children and their representatives to bring complaints to the UN Committee on the Rights of the Child (Committee) in respect of alleged violations of their rights under the CRC and its Optional Protocols. It presents a new avenue for children to have their views heard and to vindicate their rights.²⁷

The Committee is a group of 18 international children's rights experts established under the CRC who report to the United Nations General Assembly. The Committee monitors the implementation of the CRC and provides substantial guidance and clarity in relation to the interpretation and content of children's rights principles. Such guidance can provide important considerations on how the right of the child to the highest attainable standard of health can be implemented in Irish law and policy.

At a European level, the Guidelines on child-friendly healthcare were adopted by the Council of Europe in 2011 with a view to embedding a child-rights approach to the provision of health services and administrative decision-making more generally.²⁸ These

²⁴ L. Thornton, *Socio-Economic Rights and Ireland* in S. Egan (ed.), "International Human Rights: Perspectives from Ireland" (Dublin: Bloomsbury Professional, 2015) at pp. 104, 195.

²⁵ See in particular, Article 4 CRC.

²⁶ Minister Charlie Flanagan ratifies a key UN Protocol to strengthen the rights of Irish children (2014) at <https://www.dfa.ie/news-and-media/press-releases/press-release-archive/2014/september/minister-charlie-flanagan-ratifies-a-key-un-protoc/>.

²⁷ E. Quinn, *Ireland to ratify complaints mechanism under UN Convention on the Rights of the Child* (2014) at <http://humanrights.ie/tag/un-committee-on-the-rights-of-the-child/>.

²⁸ Guidelines on child-friendly health care (Adopted by the Committee of Ministers on 21 September 2011 at the 1121st meeting of the Ministers' Deputies).

Guidelines serve as a practical tool for governments in adapting their health care systems to the specific rights, interests and needs of children and note that the implementation of child-friendly healthcare requires ‘*an alignment of motivation, thinking and action at three different levels: policy making, service planning and individual care*’.²⁹

Ireland ratified the European Convention on Human Rights (ECHR) in 1953 and it has been indirectly incorporated into domestic law by the European Convention on Human Rights Act 2003 (2003 Act). Although the ECHR does not contain a direct provision relating to children, the European Court of Human Rights has developed a practice of interpreting and applying substantive Convention rights in light of the children’s rights principles contained in the CRC.³⁰ In particular, much of the Court’s case-law establishes the importance of the ‘best interests principle’, as set out in Article 3 CRC and described further below.³¹ This is significant as Section 4 of the 2003 Act requires all organs of the State to conduct their activities in a manner that is compatible with Ireland’s ECHR obligations.³²

Implementing a Child Rights-Based Approach

Article 24 of the CRC states that children have the ‘right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health’. There is international consensus that children are entitled to special care and assistance to ensure the implementation of these rights, and children in difficult conditions need particular consideration.³³

The Committee has identified four CRC provisions as general principles, integral to the implementation of all other rights:³⁴

- o **Article 2** provides that all children must be able to enjoy their rights without discrimination of any kind, irrespective of their circumstances or those of their parents/guardians;
- o **Article 3** requires that the child’s best interests are a primary consideration in all actions and decisions concerning them. The Committee has established that this is a three-fold concept – it is a substantive right, an interpretive legal principle and a rule of procedure. This principle has been interpreted as establishing that it is not possible to present a course of action as being in the best interests of the child if it runs counter to a relevant right of the child.³⁵
- o **Article 6** recognises the child’s right to life, survival and development. This

²⁹ *Ibid.*, at pp 5, 18.

³⁰ C. Smyth, “Children, Direct Provision and the European Convention on Human Rights” in S. Egan, L. Thornton and J. Walsh (eds.), *Ireland and the European Convention on Human Rights: 60 Years and Beyond* (Dublin: Bloomsbury Professional, 2014) at p. 175. See also, Application No. 8786/08, *Rahimi v. Greece*, 5 April 2011.

³¹ U. Kilkelly, “The Best of Both Worlds for Children’s Rights? Interpreting the European Convention on Human Rights in Light of the UN Convention on the Rights of the Child” (2001) 23(2) *Human Rights Quarterly* 308 at p. 324.

³² See M. L. Paris, *The European Convention on Human Rights: Implementation Mechanisms and Compliance* in S. Egan (ed.), “International Human Rights: Perspectives from Ireland” (Dublin: Bloomsbury Professional, 2015) at p. 103.

³³ Guidelines on child-friendly health care (Adopted by the Committee of Ministers on 21 September 2011 at the 1121st meeting of the Ministers’ Deputies) at p. 6.

³⁴ Committee on the Rights of the Child (1991), *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*.

³⁵ C. Smyth, “Children, Direct Provision and the European Convention on Human Rights” in S. Egan, L. Thornton and J. Walsh (eds.), *Ireland and the European Convention on Human Rights: 60 Years and Beyond* (Dublin: Bloomsbury Professional, 2014) at pp. 175-176. See also, Committee on the Rights of the Child, *General Comment No 14 on the right of the child to have his or her best interests taken as a primary consideration* (2013) UN Doc. CRC/C/GC/14 at p. 4.

obliges states to provide optimal conditions for childhood³⁶ and according to the Committee can only be implemented in a holistic manner, by the enforcement of all other children's rights, as well as through respect for the responsibilities of parents and the provision of quality services;³⁷ and

- o **Article 12** enshrines children's right to freely express their views in all matters involving or affecting them, and for these views to be given due weight in line with their age and maturity. The child's capacity to form his/her own views must be assessed on a case by case basis.³⁸

These core principles should be central to all decisions affecting children's health and development, including resource allocation and the development and implementation of policies and interventions that affect the underlying determinants of their health.³⁹

According to the Committee, the effective implementation of children's rights requires states to adopt a range of general measures such as: the provision of specialised training to those working with and for children; raising awareness of rights among children and their parents/guardians; collecting disaggregated data; and making effective remedies available where the rights of children have been breached.⁴⁰ In addition to these general measures of implementation, more specific steps must also be taken to ensure a rights-based approach to the provision of healthcare services.

Firstly, the passage of time carries particular danger as a slow determination of a child's

interests or rights could delay access to supports and services vital to his/her development. For this reason, the Committee has noted that procedures and processes relating to children must be prioritised and completed in the shortest time possible. This requires all decisions concerning children's right to health and healthcare services to be handled carefully and expeditiously, and reviewed at reasonable intervals in terms of the child's perception of time, evolving capacities and development.⁴¹

Secondly, the Guidelines on child-friendly healthcare recommend for member states to pay particular attention to the investment in services for children and families.⁴² Guidance from the Committee also highlights the specific obligation on the Government to ensure that there are functioning children's health facilities, goods, services and programmes in sufficient quantity in Ireland, including sufficient hospitals, clinics, health practitioners, mobile teams and facilities, community health workers, equipment and essential drugs to provide health care to all children within the State.⁴³ In accordance with General Comment No. 15, the Irish Government is required to take immediate action to implement its obligations to respect, protect and fulfil the right to health of children waiting for paediatric scoliosis surgery to the maximum extent of available resources.

"Available resources" not only refers to financial resources but also to human and organisational resources. This includes planning, financing and implementing children's health policies, programmes and services in a sustainable manner.⁴⁴ Where available resources are demonstrably inadequate, the Irish Government is still required to undertake targeted measures

³⁶ R. Hodgkin and P. Newell, *Implementation Handbook for the Convention on the Rights of the Child* (Geneva: UNICEF, 2007) at p. 93.

³⁷ Committee on the Rights of the Child, *General Comment No. 7: Implementing Child Rights in Early Childhood* (2005) UN Doc. CRC/C/GC/7 at p. 6.

³⁸ Committee on the Rights of the Child, *General Comment No 12: The Child's Right to be Heard* (2009) UN Doc. CRC/C/GC/12 at p. 11.

³⁹ U. Kilkelly and E. Savage, *Child-friendly Healthcare: A report commissioned by the Ombudsman for Children* (Dublin: Ombudsman for Children's Office, 2013) at p. 20.

⁴⁰ Committee on the Rights of the Child, *General Comment No. 5: General Measures of Implementation* (2003) UN Doc. CRC/C/2003/5.

⁴¹ See the Committee on the Rights of the Child, *General Comment No 14 on the right of the child to have his or her best interests taken as a primary consideration* (2013) UN Doc. CRC/C/GC/14 at p. 15.

⁴² Guidelines on child-friendly health care (Adopted by the Committee of Ministers on 21 September 2011 at the 1121st meeting of the Ministers' Deputies) at p. 6.

⁴³ Committee on the Rights of the Child, *General comment No. 15 on the right of the child to the enjoyment of the highest attainable standard of health* (2013) UN Doc. CRC/C/GC/15 at p. 22.

⁴⁴ Committee on the Rights of the Child, *General comment No. 15 on the right of the child to the enjoyment of the highest attainable standard of health* (2013) UN Doc. CRC/C/GC/15 at pp. 16-17.

to move as expeditiously and effectively as possible towards the full realization of children's right to health. Irrespective of resources, the Government has an obligation not to take any retrogressive steps that could hamper children's enjoyment of their rights.⁴⁵ Accordingly, policy, programmes and services related to scoliosis must be planned, designed, financed and implemented in a sustainable manner.⁴⁶ Taking into account children's best interests as a primary consideration is also crucial when weighing up competing budget allocation and spending priorities.

In February 2016, the Committee published its 'Concluding Observations' on Ireland's record on children's rights.⁴⁷ It called on Ireland to adopt 'a child rights approach in the formulation of the State budget by implementing a tracking system for the allocation and use of resources for children throughout the budget at all levels of government'.⁴⁸ The Committee has also recommended for the Government to:

- conduct a comprehensive assessment of the budget needs of children and increase the budget allocated to social sectors, addressing disparities through the application of indicators relating to the rights of the child;
- ensure that resources allocated for the protection and promotion of the rights of the child are adequate;
- define specific budgetary lines for children with disabilities who may require affirmative social measures, and ensure

that those budgetary lines are protected in situations of economic crisis; and

- include child rights impact assessments in the framework for integrated social impact assessments, to ensure that fiscal and budgetary decisions are compliant with obligations under the Convention.⁴⁹

The Committee has emphasised that national human rights institutions, including Children's Ombudsman, have an important role to play in ensuring the realisation of the right to health, including by reviewing and promoting accountability and advocating systemic change.⁵⁰ To improve compliance with the international standards in place, it is important to assess the current state of implementation, paying particular attention to specific situations where children's right to health is violated.

⁴⁵ Committee on Economic, Social and Cultural Rights, *General Comment No. 3: The Nature of State Parties Obligations* (1991) UN Doc. E/1991/23 at para 9.

⁴⁶ Committee on the Rights of the Child, *General comment No. 15 on the right of the child to the enjoyment of the highest attainable standard of health* (2013) UN Doc. CRC/C/GC/15 at pp. 16-17.

⁴⁷ Committee on the Rights of the Child, *Concluding observations on the combined third and fourth periodic reports of Ireland* (2016) UN Doc. CRC/C/IRL/CO/3-4.

⁴⁸ Committee on the Rights of the Child, *Concluding observations on the combined third and fourth periodic reports of Ireland* (2016) UN Doc. CRC/C/IRL/CO/3-4 at pp. 13-14. See also, Committee on the Rights of the Child, *General comment No. 19 on public budgeting for the realization of children's rights* (2016) UN Doc. CRC/C/GC/19. In its Concluding Observations, the Committee has reflected on its detailed analysis in General Comment No. 19 and applied it specifically to the Irish context.

⁴⁹ Committee on the Rights of the Child, *Concluding observations on the combined third and fourth periodic reports of Ireland* (2016) UN Doc. CRC/C/IRL/CO/3-4 at pp. 13-14.

⁵⁰ Committee on the Rights of the Child, *The Role of Independent National Human Rights Institutions in the Promotion and Protection of the Rights of the Child* (2002) UN Doc. CRC/GC/2002/2 and Committee on the Rights of the Child, *General Comment No. 5: General measures of implementation of the Convention on the Rights of the Child* (2003) UN Doc. CRC/GC/2003/5.

2.2

Relevant National Policies

With respect to children's health policy in Ireland, most initiatives have been general in nature and focused either on specific health issues affecting children (eg. obesity) or on health matters affecting particular groups of children (eg. Traveller health). While there have been a number of important commitments made as set out below, it is clear that a broad-based, integrated policy framework is necessary to guide the development of child-friendly healthcare in Ireland.⁵¹

Better Outcomes, Brighter Futures

Outcome 1 of Better Outcomes, Brighter Futures, the national policy framework for children & young people 2014 – 2020, is focused on furthering Ireland's implementation of the CRC, including Article 24 on the right to the enjoyment of the highest attainable standard of health and to have access to health services.⁵²

The framework specifically highlights the importance of good quality primary healthcare services, backed up by additional targeted services, to support all children to learn, grow, have a healthy life and productive relationships.⁵³ As a result, the Government has recognised the following:

- Access to quality, affordable and early intervention services that support children and young people in leading a full and varied life is critical to overall wellbeing and development;

⁵¹ U. Kilkelly and E. Savage, *Child-friendly Healthcare: A report commissioned by the Ombudsman for Children* (Dublin: Ombudsman for Children's Office, 2013) at pp. 37-43.

⁵² Department of Children and Youth Affairs, *Better Outcomes, Brighter Futures: The national policy framework for children & young people 2014 - 2020* at http://dcya.gov.ie/documents/cypp_framework/BetterOutcomesBetterFutureReport.pdf at p. 48.

⁵³ *Ibid.* at p. ix.

- Children and young people with poor physical health may need support to develop the skills required to maximise their independence and develop their capacity to contribute to society;
- For those with a long-term illness, appropriate support arrangements should be put in place.⁵⁴

The Government has also committed to strengthen the participation of children and young people in decision-making for health and wellbeing at a community level.⁵⁵

National Healthcare Charter for Children

The National Healthcare Charter for Children, You and Your Health Service, was published in 2013 and adopts a child-centred and rights-based approach to children's healthcare. It sets out the expectations and rights of children, parents, carers and health professionals for the delivery of healthcare services and is focused on the following principles: access; dignity and respect; safe and effective services; communication and information; participation; privacy; improving health; and accountability.⁵⁶ With proper commitment to resources, training and awareness-raising measures, this Charter has been recognised as having genuine potential to influence the extent to which healthcare services operate in line with children's rights standards in Ireland.⁵⁷

⁵⁴ *Ibid.* at p. 52.

⁵⁵ *Ibid.* at p. 58.

⁵⁶ Health Service Executive, Patient Safety First and Department of Health, *The National Healthcare Charter You and Your Health Service* at http://www.hse.ie/eng/services/yourhealthservice/hcharter/National_Healthcare_Charter.pdf.

⁵⁷ U. Kilkelly and E. Savage, *Child-friendly Healthcare: A report commissioned by the Ombudsman for Children* (Dublin: Ombudsman for Children's Office, 2013) at p. 43.

Section 3

Children's views on waiting for Scoliosis surgery and its impact on their lives

Under the Ombudsman for Children Act 2002, the Ombudsman for Children's Office has an obligation to give due weight to the views of the child in accordance with their age and understanding. With that in mind, and considering the commitment made by Government in the Better Outcomes, Brighter Futures (BOBF) policy to promote a culture that listens to and involves children and young people, the testimonies of three young people who experienced long waiting times for their scoliosis surgeries are included in this report.

Harriet's Story

My scoliosis was idiopathic, it had come on around the time I was 12 in 2011. My friends noticed my walk and I felt that my hips were sticking out. I told my mum and we went to the hospital in Galway for an x-ray. We found out that I had a 10/12 degree curvature of my spine. The doctor said not to worry too much about it as some curvature of the spine was normal. A few months later when I went back, I can still remember the doctor saying that things hadn't behaved as had been expected. They said that I grew rapidly and that it was too fast on one side. I was referred to Crumlin hospital.

I had an appointment in May 2012. It was a whole year before I was seen again. When I arrived for my appointment in May 2013 my consultant was really unhappy with how long it had taken to see me again and the delays that were happening in seeing patients. It was then that my mum and me began to feel that my treatment might not all happen straightforwardly. We knew I needed surgery after that meeting, my curvature had increased to 50 or 60 degrees by that time but Crumlin couldn't tell me when I would have my surgery because of the waiting list. From the moment I was put on the waiting list I knew that I wouldn't have surgery in the timeframe they said was best for people with scoliosis.

During that time things were getting progressively worse. Living with scoliosis was really hard, physically and emotionally. While I was on the waiting list I wasn't on prescribed painkillers, it was just the most powerful over the counter stuff. There was also no advice on what to do to manage the scoliosis and the pain. I was eating paracetamol.

I was told to exercise and keep up my dancing as that would help before and after the surgery, but it got harder and harder to do. Everything that I did, whether going shopping with my friends or doing a dance event, I had to pay the price a few days later with the pain. I was missing school; I was in too much pain and had to just stay in bed sometimes. Other days I would go in for a half-day, I'd come home and collapse and that would be me done, I'd have to go to bed. School were great, keeping me involved and giving me my work, but there is only so much that you can do when you aren't in school.

“I was in too much pain and just had to stay in bed sometimes...”

To explain, I was totally deformed, I was all off to one side. If I was lying on my side in bed, my rib cage would touch my hip on one side. The back pain wasn't even the worst, my chest hurt a lot. My doctor said it was referred pain which meant that other parts of my body were getting hurt because my body was leaning on them. That just totally freaked me out. The girl who I ended up sharing my room with in Crumlin, her organs were being crushed for the same reason. You are always thinking worst-case scenario, you know, that you might end up in a wheelchair if something goes wrong. It's not fair to live like that when there is a treatment for it.

But despite how painful it was, I struggled more mentally. It was exhausting. To look at my spine, it was very strange and clothes were a big problem for me at that time. And then there was the waiting and not knowing. I'm an English and Drama student, I love performing and I like having things rehearsed and knowing what's going to happen. This felt like the opposite. It wrecked my head. I remember in transition year we were going to Barcelona and all my friends were counting down the days on a phone app, but I didn't bother having the app on my phone, I just didn't know if I would be able to go.

One thing that helped me was that my brother's friend had had the surgery when she was younger and she talked to me. I had never heard it from a patient's view before, only from the doctors. To hear what was going to happen from someone who had been through it, that was really helpful. That might actually be something that helps people, pairing a patient up with a past patient. I've done it now for other girls and I've made friends, some of who I've never met before because we've opened up to each other about scoliosis and shared experiences online.

The lowest point of all for me was in August 2014. I was going into fifth year and I didn't know if I was going to be going to be able to do my leaving cert when I should, or if I'd end up going to college in a wheelchair. I had an appointment in Crumlin. At first, the idea of surgery had really frightened me, I would faint or have panic attacks at appointments, but by then I just wanted it over with, my curve was 70 degrees. But the consultant told me there was no timeframe for my surgery, it could be two weeks or it could be 5 years. I just started crying.

Then, just a couple of weeks later I was called for surgery. When my mum told me and I threw up with the fear. After 17 months waiting, two weeks to prepare.

The staff were great before surgery. But sometimes they would be explaining things about the surgery to me and I just didn't want to know, I just blocked it out. I knew that they would be putting rods into my back and some screws as well. I didn't get much sleep that night before, but the morning of the surgery they brought me down, gave me anaesthetic and that was that until I woke up.

It's hard to explain the feeling, I had been off to one side for so long but when I woke up I felt that I had been straight all my life and that now, all of a sudden when I woke up I was crooked, like everything was backwards. It took a long time to feel normal.

During physio at the hospital was the first time I looked in the mirror after surgery I just started roaring crying, I couldn't comprehend how I looked and that this was my body and that it was straight.

My curvature is 10 degrees now and it hasn't moved, thank god. I was told by the consultant that the surgery couldn't have gone any better. When they open you up, they pull you to see how far you'll straighten naturally before they force it and put in the rods. They told me they had never seen someone straighten so much themselves.

I had to go for physio after the surgery and every day I got a bit more flexible. I feel grand now and work out at the gym in college to help. I can't remember what it felt like to have the curve. I have sciatica; it's common with scoliosis patients because your spine has been lying on your nerves for so long. I'm on painkillers, but it's a small price to pay.

I had my two year surgery anniversary there in October. People said to me it seems like yesterday, but for me it feels like ages ago, I guess it's like I've had a new life since then. I feel like I was born again. After all that, doing the leaving cert and getting to college, that was massive for me.

It still baffles me though. They were absolutely brilliant in the hospital, I can't say enough about all the staff in Crumlin, and I could tell they were frustrated, but it took so long. Me and my mum felt that the knowledge and skills were there, the willingness was there, but it was just that the money wasn't there. That was the most annoying thing. I knew the longer I waited, the worse it was for my scoliosis. There is very little you can do for someone waiting for surgery, only so much you can say. The scoliosis is always there until you have the surgery.

Delilah's Story

I was diagnosed when I was 8 years old, in 2011. We didn't know about it until I fell off the swing we have on a tree in the back garden. My mum is a nurse and she was looking at my back to see if I had injured myself and she noticed that something wasn't right with my spine. We went to the Lourdes in Drogheda and they diagnosed me with scoliosis and referred me to the consultant in Crumlin.

I think I was already about a 40 degree curve at that time. The first treatment the consultant advised was to refer me to go get a brace. They knew straight away that I would need the surgery at some point but they wanted to stabilise things and for me to get older and not be growing as much before I had the surgery.

I was 8 years old and so at first I thought it might be kind of cool to have a brace, but it didn't end up that way. First, I waited 6 months for the brace but they ended up making me the wrong type. I wore it for about 6 months until my next appointment in Crumlin. The second the consultant saw it on me he told me to take it off and that it was not doing any good. He referred me for another one which was the right type but that was a year after I had been told to get it.

My brace was very uncomfortable and I would often have bruising or bleeding which they told me was very uncommon. In primary school, I would have to go out of class to take the brace off because it was so painful. My friend had to come with me because it had straps and I needed help.

There was a tiny bit of improvement but once I started growing things went downhill and the curvature increased by a lot. My hips were sore and I had internal pain all the time and it was getting worse. It got more difficult to do things. I was hunched, you could see it, my back, my shoulders, legs and hips, they were all out of place and I was bent sideways. It's a big thing when you are young, how you see yourself. I knew the longer I waited, the worse it could get, I just didn't realise how bad it would get and how serious the operations I would end up having would be.

Emotionally it was draining, constantly feeling like I couldn't do stuff, missing activities, missing school. At one point, I went to a physio who specialises in scoliosis, but they said

that there was nothing they could do, I was too advanced and I just needed the surgery.

“...there was nothing they could do, I was too advanced and I just needed the surgery”

I had appointments every 6 months. At one of these, in 2014, when I was 12, I was told to throw the brace away, that it was no good for me anymore and that I would just have to go for the operation. I was told I was now on the surgery waiting list. We had known I would need surgery from the start so I was prepared for getting the news. But then we just waited to hear when I would actually have the surgery. I was always thinking maybe it will be this month, but it never was, that was so frustrating.

My parents were annoyed as well, they felt that there was no forward planning; all along, the hospital knew I would have surgery but they waited until it became critical before putting me on the surgery waiting list. We feel that it would have made more sense if I had been on the waiting list from the start, when I was 8, I was always going to need it. We would call Crumlin a lot to find out where things were at, but would never get any definite news about how long I'd be waiting. My parents even contacted politicians to try and get things sorted. We had to do all this just to try and get things moving.

About a year after that, I was finally told that I was going to have the surgery, the only thing that nearly disappointed me about getting the news was that I would have to go to England for it, but by that point I just wanted it done. In autumn 2015 we were asked if we would consider going to Stanmore (the hospital in England) for surgery as they were sending children over there. Although it wasn't perfect we straight away said yes. We met with the consultant and staff from Stanmore. The consultant had been a surgeon to the royal family! We were one of the first to accept the offer of going over so we'd be one of the first surgeries. We had waited a long, long time and then after being told I could have the surgery in Stanmore it was only a month and half until the surgery.

It was just me and my dad who went over. We were fortunate because we had relatives in London who we could stay with for a night before I went to hospital and after surgery as I wasn't

allowed fly for a while. Some people turned down going to Stanmore and I think the costs of going over there was part of the reason. The HSE pay for some but not all of the costs and it hasn't been easy to get all that sorted.

By the time I had the operation my spinal curve was 90 to 100 degrees, which is a lot. Because of that, I didn't know if I would be having a one part or two-part surgery and they wouldn't know until they saw inside me. It ended up that I needed a two-part surgery because of how severe my curve was. That was disappointing because I would have to stay in hospital about a week longer and because, if they had done it earlier, I could have had a one-part operation, which would have been easier and less painful.

They were big operations. They opened me up and then they had to move my organs to one side so that they could work on one part my spine. They also had to cut away some of my ribs. Then they had to wait a week before operating on the other part of my spine. I was prepared for that but the thing that surprised me was that they had to put a chest drain in me between surgeries because they had to collapse my lungs. Out of everything they did, that was the most horrible part. I don't think I'm the best with pain, so it wasn't the best experience! But some of the nurses and staff were lovely and I guess, sometimes the people make the place. When I was around people to keep me away from the thoughts and the pain it wasn't that bad... but sometimes it could be very severe, I remember crying and not wanting to move when all the physiotherapists were trying to get me out of the bed after the second surgery.

When I first stood up after the operation I was very shocked. I felt very off-balance, standing straight for the first time in years, if not ever, it was strange. I don't remember looking in the mirror afterwards but I grew two inches because of the operation, suddenly I was taller than my sisters. We have a bit of a competition about height so I was happily surprised by that!

It wasn't great coming back getting services. We never get anything from Crumlin without having to ask. We had a follow up in Crumlin after the operation when the team from Stanmore came over but even that didn't go perfectly as they didn't have the x-rays that we had taken to review things. We were meant to find out if I could go swimming and cycling on my holidays to France. That was annoying!

In Stanmore they thought that physio would be waiting for me. They told me that once I was healed I should start getting physio in Ireland straight away. After years of having a curve in my spine the muscles around my back and shoulders need to be worked on. But I still don't have physio in Ireland, I'm still in pain and my muscles spasm a lot. I've actually only just been told that I'll be

getting some physio next week. Everything's very slow and you have to cause a fuss.

From what I saw in England compared to here, there is a big difference in the treatment you get and when you get it. I was definitely the worst over there at the time. The waiting list here is insane. It's upsetting. They need to sort it out. Don't wait till someone is at 80 or 90 degrees to put them on the waiting list, think long term. As well, it costs more money the bigger the surgeries are. It doesn't make sense.

“The waiting list here is insane. It's upsetting. They need to sort it out.”

The surgery itself was a success and my spine is straight, I just wish that once I got back I got sorted, got my physio and aftercare so I could move on. It is still affecting me. Since I got back to school from the operation, I've done about five full days of school because of the pain. When I had the operation, they told me to expect to be back doing full days by the end of the school year in May. I started 2nd year in September and I thought again that I'd be sorted and be back full time, but it's November and I'm still the same, missing part of school nearly every day.

The point of me going to England was that I felt that I could get it over and done with and move on with my life. Nearly a year later I still haven't had physio and I'm still missing out.

Jane's Story

When we were on holidays in summer 2013 my mum noticed that I was leaning and that one of my hips stuck out more than the other. So, when we got home we went to the GP and he told me that I had scoliosis and referred me for an x-ray. Actually, when I was told I had scoliosis it made a bit of sense to us as I had always had a bit of back pain when I was playing sports. That was September 2013 and I was at 50 degrees already so I was referred to Crumlin.

I had my first appointment in November 2013 and they put me on the waiting list for surgery that day. Anything over 50 degrees needs surgery. I was 12 at the time and it didn't really register with me what I had or what was going to happen, nothing like how I felt near the end anyway. It was idiopathic scoliosis, so we don't know how or why it developed, it just did, that's how it was explained to me.

I didn't know anyone else who was getting or who had had the surgery or scoliosis. It was isolating. I feel like if there was a community built around scoliosis to exchange tips and stories it would help everybody. Your parents and the hospital can help to a certain extent, but you are the only one who has to go into school or look at yourself every day.

Mum had gone on Facebook and found pages like scoliosis Ireland and found parents and people who had the surgery for tips, we didn't even know what scoliosis was before I had it. We had to kind of figure it out ourselves. Since my operation, Crumlin have put parents and kids from the area in touch with my mum to help explaining and reassuring about things. That could have eased a lot of pressure on me if we had have had that.

At first, we were told that it would be August 2014 when I would have my surgery, so we had our hopes set for that and even in June of that year, they were still telling me August, but that rolled around and nothing. And it went on and on like that, being pushed out by a month and then another month every time I would go up for an assessment. They would explain that emergency cases were being done, or someone else had been moved up the list, or there was no theatre time. My friends would ask me every time I went up and every time I had to say it's next month now. You'd get your hopes up every month, until

by the end when they'd say it should be next month I'd just say to myself, ok, I know it's not going to happen.

They need to sort out the waiting list and figure out why it's taking so long for people to get to the point of surgery. It's only gotten worse in reality. It's ridiculous that they haven't found a solution to it yet. They need to sort themselves out. When I used to Google things about scoliosis, I'd see kids in America and other places getting their surgery a few months after being diagnosed.

During that time, my scoliosis was getting worse and worse, by June 2014 it was 78 degrees. I had a curve in my upper back that was arched and another curve in my lower back that was more like normal scoliosis. At that stage, I had given up hockey, running and dancing and all the other stuff that I did. It was a lot for a 13 year old to deal with.

By September 2014, I was over 96 degrees, up from 50 in one year. I had gone from very little pain, to pain all the time, having to carry paracetamol in my school bag. I'd come home and basically be crippled and just have to lie down or sit against something warm to help with the pain. And then, at the very end of it, just before my surgery my ribs had begun to enclose in on my lungs so I was having trouble breathing and I had a lot of indigestion because my food pipe was bent with my back. It was getting really bad.

“In the hospital they would use the word *deformity* in front of me a lot.”



On top of that, mentally and emotionally I was starting to hit early puberty and I was feeling like I didn't look like anyone else because my hip stuck out, I had a lump on my back, my shoulder was uneven and I leaned to my left and was very collapsed on myself. It made me very self-conscious and it was draining to feel that way. My whole upper body was squished into itself so my clothes didn't fit right, I didn't like wearing tight clothes that would show off my back problem and I didn't like looking in the mirror because I knew I looked weird.

In the hospital, they would use the word deformity in front of me a lot. I know that's what it is, but when you're a 13 or 14 it's not nice to have adults talk like that and say things like 'your deformity has got significantly worse' right in front of you. The consultant was good at talking to me and explaining, but he

wasn't always available when we went up, so we wouldn't always see him and when we didn't it wasn't always as easy for me, it could be very formal and 'doctory' and, ironically, I felt a bit out of place in a children's hospital!

I was told in February 2015 that I was going to have my operation and the date was set for March. Because my curve was so bad by that point I was going to need two surgeries. Initially I just thought it would end up being another 'it'll happen next month' thing but as the date came closer we started to feel like it was actually gonna happen this time. We went up the night before my operation, but even then, we didn't know for sure, if we had a bed because they couldn't tell us until we got there. We were just praying that it would go ahead. Thankfully, they did and I had my first surgery the next day. It felt surreal, we had waited so long and now it was happening, it kind of goes by you in a blur.

“The whole waiting process made me very sad all the time...”



Then I was a week in hospital before the spinal fusion surgery. That week in hospital was not fun. It was painful, especially the chest pump. I spent most of it asleep.

The ward that I was in was very run down for a spinal injury ward. There were no facilities for parents to stay on the ward and there were two children in each room, which is a bit uncomfortable. There were three broken wheelchairs on the ward to share between all the kids. There was one shower and three toilets. I couldn't eat much but the food was just not nice or very healthy. At night, there were only two nurses on duty to look after children who couldn't even sit up on their own let alone go to the toilet or whatever. The nurses were fantastic though and took great care of me.

When I woke up after the second operation I had a big cry. I had this moment when I reached down my body and I felt my rib area and they weren't sticking out and then I reached down where my hip was and it wasn't sticking out and then I started balling. It had been so long since I had seen myself not deformed, twisted, sore, and broken. There was also so much relief and happiness that it had finally happened after a year of waiting and complaining and giving out to people.

The surgery went really well and they got a better result than I could have hoped for. I was a 108 degrees at surgery and they got it down to 18 degrees. I couldn't be happier with that, but it could have been even less had they done the surgery a year or so before that.

The recovery took a while. I went to physio for about a year after coming out of hospital. They gave me shoulder and core exercises to get me back on my feet. I did get a lot of pain in the months after the operation as my muscles were still stretching back to where they were meant to be and that kind of thing. But 2016 has been a good year for the pain, I still get the occasional backache or whatever but it's better.

I'm basically back to normal and how I should be but there are some issues and restrictions. One of my shoulder blades sticks out I think that's because my ribs are a bit deformed from it happening while I was still growing. They removed 4 discs in my vertebrae to make sure the bones would fuse together and not go back to the way it was, but that has meant that I don't have as much flexibility. I have to keep my back straight because I can't bend my back any other way, so things like tying my shoes is a bit weird and I can't relax into a couch, little things like that. It's not painful, it's just restrictive, I'm all one solid object in my upper body.

At the time, I was just so relieved to have the operation done but now looking back it's annoying and makes me angry. My operation could have been so much simpler and better. I wouldn't have been out of school for months afterwards. I wouldn't have been in hospital as long. I wouldn't have taken a bed that someone else could have used. I wouldn't have had the chest pump while I was in hospital and I wouldn't have taken up two theatre dates instead of just one. I have two giant scars now, one from my ribs to my belly button and one down my back, whereas if they had done it a year earlier I would have been left with just a tiny scar on the middle of my back, less pain, less time recovering and have more movement in my back now.

But really, I'll deal with all that, I'm just glad I don't have scoliosis anymore. It's not something I think about much a lot and I forget it's happened sometimes until something or someone reminds you. But the whole waiting process made me very sad all the time, I didn't like leaving the house or looking in the mirror. I felt trapped in my own head, nobody else I knew looked like me, it's only me that sticks out, so when I came back and I was fixed it was very liberating, I was finally like everyone else. It was like someone flipped a switch. I was out, I was wearing the clothes I wanted to wear, I was hanging out with friends and going to discos. Everything I felt like I couldn't do cause of scoliosis. The surgery gave me a new lease on life, I could start afresh, I basically felt like a new person.

Section 4

Treatment for Scoliosis in Ireland

In Ireland, the majority of children with scoliosis who require orthopaedic spinal surgeries are treated in Our Ladies Children's Hospital Crumlin (OLCHC), including those requiring the most complicated and serious procedures.

OLCHC has an agreed capacity to carry out 58 spinal surgeries (major procedures) per year as part of its annual Service Level Agreement (SLA) with the HSE.⁵⁸ However, in 2014 the Department of Health acknowledged, '*when we consider projected demand, we can see that it will be necessary to increase the number of cases carried out per year [in OLCHC] from approximately 58 to 120*'.⁵⁹ Similarly, according to orthopaedic surgeon, Pat Kiely, 200 paediatric spinal surgeries should be carried out in Ireland every year to meet the needs of children with scoliosis, and Crumlin alone should be doing 120 cases a year to match the demand.⁶⁰

Smaller numbers of surgeries also occur, or have occurred in the Adelaide and Meath Hospital Dublin (incorporating the National Children's Hospital), University Hospital Galway, University Hospital Cork, Cappagh National Orthopaedic Hospital and Children's University Hospital Temple Street. A number of other hospitals outside of the Irish public health system have undertaken surgeries as part of a HSE initiative to manage the scoliosis waiting list.

⁵⁸ See Dáil Éireann Debate, Wednesday 5 November 2014 at <http://oireachtasdebates.oireachtas.ie/debates%20authoring/debate-swebpack.nsf/takes/dail2014110500034> (accessed 27/01/2017).

⁵⁹ *Ibid.*

⁶⁰ See Irish Daily Mail, Monday 23 February 2015 at <http://straightaheadireland.ie/wp-content/uploads/2014/03/daily-mail-feb-23-2015.pdf> (accessed 27/01/2017); See also Dáil Éireann Debate, Wednesday 5 November 2014 at <http://oireachtasdebates.oireachtas.ie/debates%20authoring/debateswebpack.nsf/takes/dail2014110500034> (accessed 27/01/2017).

In addition to the hospitals involved, the HSE (in particular the HSE Acute Hospitals Division), the Children's Hospital Group, the Treatment Abroad Scheme (TAS) and the National Treatment Purchase Fund (NTPF) have, or have had roles in the funding, planning and oversight of paediatric scoliosis treatment in Ireland.

The NTPF sets a timeframe of five months (20 weeks) for children, from the date that a decision to operate on the child is made, to the delivery of that operation.⁶¹ However, as illustrated in the next Section, children in Ireland have been experiencing significant waiting times for scoliosis surgery, of up to 15 to 18 months, in some cases. The OCO is of the view that the target set by the HSE that no child will be waiting longer than 18 months for spinal surgery⁶² is totally detached from the reality of this condition, and the suffering it causes to children. This target falls significantly short of the NTPF timeframe of 20 weeks and completely ignores the 3-6 months target recommended by international best practice.⁶³

⁶¹ See <http://www.ntpf.ie/home/about.htm> (accessed 27/01/2017). The NTPF is an independent statutory body established by the Minister for Health, which collates data on waiting lists. Public hospitals must ensure they meet the maximum waiting time guarantees for their patients. For children requiring admission to hospital the maximum wait time is 20 weeks. See Dáil Éireann Debate, Wednesday 5 November 2014 at <http://oireachtasdebates.oireachtas.ie/debates%20authoring/debateswebpack.nsf/takes/dail2014110500034> (accessed 27/01/2017).

⁶² See Irish Examiner, Saturday 16 May 2015 at <http://www.irishexaminer.com/ireland/private-hospitals-tackling-waiting-lists-says-varadkar-331009.html> (accessed: 27/01/2017).

⁶³ H. Ahn, H. Kreder, N. Mahomed, D. Beaton and J. G. Wright, *Empirically derived maximal acceptable wait time for surgery to treat adolescent idiopathic scoliosis* (2011) available at: <https://www.ncbi.nlm.nih.gov/pubmed/21543302> (accessed 27/01/2017).

4.1

Current Situation

The HSE National Service Plan 2015 committed to increase the provision of scoliosis surgery for children to meet the demand,⁶⁴ and the Acute Hospital Division Operational Plan 2015, offered to put in place a comprehensive solution.⁶⁵ Additional funding of €1.042m was allocated under the 2015 Service Plan to increase capacity at OLCHC⁶⁶ and in June 2016, the construction of the new theatre in OLCHC was completed.⁶⁷

However, despite the additional resources provided in 2015, the number of surgeries undertaken in OLCHC still fell short of what was required to deal with demand.⁶⁸ In order to address waiting times in the interim, patients from OLCHC were transferred to other hospitals where capacity was available and where that was clinically appropriate. These included Temple Street, Cappagh, Tallaght and the Blackrock Clinic. External capacity was also identified at the Royal National Orthopaedic Hospital at Stanmore in the UK.⁶⁹

In 2016, the OCO continued to be contacted by parents regarding the long waiting list for paediatric spinal surgery. In June 2016, we were contacted by the parent of a boy with idiopathic scoliosis who had been on the surgery waiting list since August 2015. During this time his curve had progressed, was

putting pressure on his lungs and his ribs were beginning to rotate. Although he was classified as a critical case, there was still no date for his surgery. Because of the severity of the curvature of his spine, he had to undergo halo traction for a period prior to his surgery, which subsequently occurred in late 2016⁷⁰.

The HSE National Service Plan 2016⁷¹, the Acute Hospitals Division Operational Plan 2016⁷² and the Children's Hospital Group (CHG) Operational Plan 2016⁷³, all commit to develop and enhance Paediatric Scoliosis Services in OLCHC to address ongoing capacity deficits, including the specific provision of support for the new theatre capacity.⁷⁴ Under the HSE National Service Plan 2016, further resources of €0.987m were allocated for Orthopaedics and Trauma to address waiting lists in OLCHC.⁷⁵ However, the opening of the new orthopaedic theatre is dependent on the recruitment of additional theatre nurses, which according to the CHG, has presented a challenge.⁷⁶ Throughout 2016, the new orthopaedic theatre was ready but not operational.

In September 2016, the HSE launched its Winter Initiative 2016/2017, which includes €2m provided specifically for scoliosis surgeries.⁷⁷ However, despite the additional resources, the number of patients aged 18 or under waiting

⁶⁴ HSE, *National Service Plan 2015* (2014) at <http://www.hse.ie/eng/services/publications/corporate/NSP2015.pdf> (accessed: 27/01/2017).

⁶⁵ Acute Hospital Division Operational Plan 2015 at <http://www.lenus.ie/hse/bitstream/10147/552508/1/acutesopplan15.pdf> (accessed: 27/01/2017).

⁶⁶ Dáil Éireann, Written answers, Thursday 19 January 2017 at <https://www.kildarestreet.com/wrans/?id=2017-01-19a.543> (accessed: 27/01/2017).

⁶⁷ The Irish Times, 8 February 2017, at <http://www.irishtimes.com/news/health/hse-totally-dysfunctional-says-blackrock-clinic-founder-1.2968005> (accessed: 13/03/2017).

⁶⁸ Dáil Éireann, Seanad debates, Wednesday 22 April 2015 at <https://www.kildarestreet.com/sendebates/?id=2015-04-22a.8> (accessed: 27/01/2017).

⁶⁹ See Dáil Éireann, Seanad debates, Wednesday 22 April 2015 at <https://www.kildarestreet.com/sendebates/?id=2015-04-22a.8> (accessed: 27/01/2017).

⁷⁰ While this information was brought to the attention of the OCO, it was not subject of a PE.

⁷¹ Health Service Executive, *National Service Plan 2016* (2015) at <http://www.hse.ie/eng/services/publications/serviceplans/nsp16.pdf> (accessed: 27/01/2017).

⁷² Acute Hospital Division Operational Plan 2015 at <http://www.lenus.ie/hse/bitstream/10147/552508/1/acutesopplan15.pdf> (accessed: 27/01/2017).

⁷³ HSE, *Children's Hospital Group Operational Plan 2016* (2016) at <http://www.hse.ie/eng/services/publications/serviceplans/serviceplan2016/OpPls16/ChldHosOpPls16.pdf> (accessed: 27/01/2017).

⁷⁴ Dáil Éireann, Written answers, Thursday 2 June 2016 at <https://www.kildarestreet.com/wrans/?id=2016-06-02a.33> (accessed: 27/01/2017).

⁷⁵ Dáil Éireann, Written answers, Thursday 19 January 2017 at <https://www.kildarestreet.com/wrans/?id=2017-01-19a.543> (accessed: 27/01/2017).

⁷⁶ Dáil Éireann, Written answers, Thursday 19 January 2017 at <https://www.kildarestreet.com/wrans/?id=2017-01-19a.543> (accessed: 27/01/2017).

⁷⁷ Dáil Éireann, Written answers, Thursday 19 January 2017 at <https://www.kildarestreet.com/wrans/?id=2017-01-19a.543> (accessed: 27/01/2017).

for scoliosis surgery in hospitals in Ireland, had increased from 230 at the end of September 2016⁷⁸ to 236 at the end of December 2016.⁷⁹

In January 2017, the HSE announced as key achievements of its waiting list action plan 2016⁸⁰ that:

- 24 paediatric scoliosis patients waiting more than 18 months had either been treated or would have a treatment plan in the Blackrock Clinic in Dublin within the coming weeks; and all other paediatric scoliosis patients breaching 18 months had a treatment plan at Crumlin;
- 23 adolescent scoliosis patients breaching 18 months were clinically reviewed in the Mater Misericordiae University Hospital's spinal unit. Any patients requiring surgery had either been treated or were scheduled for treatment that month.

According to the Minister for Health, the focus of the new waiting list action plans for 2017 is to ensure that by the end of October 2017, no patient will be waiting more than 15 months on the inpatient/day-case waiting list, or on the outpatient waiting list.⁸¹ It has been documented that some children with scoliosis are waiting for over two years for their first appointment, and in some cases are not getting post-operative reviews for three years.⁸² The OCO is of the view that child-specific waiting lists should be published⁸³

⁷⁸ The Journal, 13 November 2016 at <http://www.thejournal.ie/scoliosis-waiting-lists-ireland-2-3069483-Nov2016/> (accessed: 7/02/2017).

⁷⁹ The Journal, 7 February 2017 at <http://www.thejournal.ie/scoliosis-waiting-lists-ireland-3-3191575-Jan2017/> (accessed: 7/02/2017).

⁸⁰ Inpatient and Day Case Waiting Lists (2017) at <https://hse.ie/eng/services/news/media/pressrel/inpatient-and-day-case-waiting-lists.html> (accessed: 7/02/2017).

⁸¹ Irish Medical Times, *New waits initiatives announced for 2017* (2017) at <http://www.imt.ie/news/new-waits-initiatives-announced-for-2017-12-01-2017/> (accessed: 7/02/2017).

⁸² The Journal, 13 November 2016 at <http://www.thejournal.ie/scoliosis-waiting-lists-ireland-2-3069483-Nov2016/> (accessed 13/03/2017).

⁸³ Figures from the National Treatment Purchase Fund indicate that at the end of January 2017, 3,289 children were waiting for over 18 months for an outpatient appointment. However, it appears that accessible, accurate and comprehensive information in relation to waiting lists for children accessing health services in Ireland are cur-

for all healthcare services in Ireland. Targets for maximum waiting times for out-patient appointments should be established with reports which monitor these targets published quarterly.

The Minister for Health, Simon Harris, has also announced that the new operating theatre for the treatment of scoliosis will open at Crumlin Children's Hospital in April 2017 and will carry out 194 spinal operations this year.⁸⁴ However, the Hospital is still in the process of a recruitment drive to attract new theatre nurses with the necessary paediatric training and an orthopaedic surgeon post in Crumlin hospital will only be filled in June.⁸⁵ The Minister has confirmed that children on waiting lists must be treated within the scheduled wait time or have their case outsourced to private clinics for treatment.⁸⁶ Minister Harris recently stated in the Dáil:

*'...even as we speak, HSE officials are in Stanmore in the UK looking at the possibility of utilising a facility there to help to deal with....a backlog in terms of procedures, especially in treating scoliosis. We can open an additional theatre here or there or hire additional consultants and use other hospitals...to provide support. However, if we are serious about radically reducing the waiting times, we are going to need to do something above and beyond the norm to get the lists to a level where they are sustainable.'*⁸⁷

Research and international best practice, unequivocally show that delays in surgery for children with scoliosis who qualify for surgical

rently unavailable in the public domain. See Dáil Debate, Wednesday, 8 March 2017 at <https://www.kildarestreet.com/debates/?id=2017-03-08a.429> (accessed 13/03/2017).

⁸⁴ The Journal, 7 February 2017 at <http://www.thejournal.ie/hse-waiting-lists-3226537-Feb2017/> (accessed 13/03/2017).

⁸⁵ Dáil Debate, Wednesday, 8 March 2017 at <https://www.kildarestreet.com/wrans/?id=2017-03-08a.219&s=speaker%3A414> (accessed 13/03/2017).

⁸⁶ The Journal, 7 February 2017 at <http://www.thejournal.ie/hse-waiting-lists-3226537-Feb2017/> (accessed 13/03/2017).

⁸⁷ Dáil Debate, Wednesday, 8 March 2017 at <https://www.kildarestreet.com/debates/?id=2017-03-08a.429> (accessed 13/03/2017).

treatment are associated with increased operative time, longer fusion levels, need for combined procedures, and potential for complications.⁸⁸ Furthermore, Irish-led research shows that children with idiopathic scoliosis and a curvature over 70 degrees, often as a result of lengthy surgical waiting lists, do not do as well post-surgery as those under 70 degrees.⁸⁹ These cases are associated with increased surgical complexity and higher cost of surgical treatment, as well as delayed post-operative return to school or other full-time education.⁹⁰

There have been significant delays in publishing the promised HSE action plan on scoliosis. We understand that the HSE will deliver on this commitment in the coming weeks.⁹¹ The HSE director general Tony O'Brien has committed that by the end of this year, no child will wait longer than four months for a paediatric scoliosis procedure. This report makes a number of recommendations which should be taken into account by Government to ensure access to timely access to treatment for scoliosis patients. However, the recommendations also place this issue in the broader context of the child's right to the highest attainable standard of health.

In accordance with Article 24 CRC, every child in Ireland waiting for paediatric orthopaedic surgery for scoliosis is entitled to the enjoyment of the highest attainable standard

88 S. Fallatah, M. Sait, F. Almutairi, "The Effect of Waiting for Surgery on Patients with Adolescent Idiopathic Scoliosis" (2015) 4 *Journal of Spine* 224.

89 R. C. Tarrant, J. M. Queally, P. F. O'Loughlin, P. Sheeran, D. P. Moore and P. J. Kiely, "Preoperative curves of greater magnitude (>70°) in adolescent idiopathic scoliosis are associated with increased surgical complexity, higher cost of surgical treatment and a delayed return to function" (2016) *Irish Journal of Medical Science* (accessed on 30 January 2017).

90 *Ibid.* According to OLCCH orthopaedic surgeon Pat Kiely, a long-term, sustainable solution would require, one centre, with one theatre dedicated to spinal deformity surgery rather than multiple centres doing small amounts. See *Irish Daily Mail*, Monday 23 February 2015 at <http://straightaheadireland.ie/wp-content/uploads/2014/03/daily-mail-feb-23-2015.pdf> (accessed 27/01/2017).

91 *Dáil Debate*, Wednesday, 8 March 2017 at <https://www.kildarestreet.com/wrans/?id=2017-03-08a.219&s=speaker%3A414> (accessed 13/03/2017). See also *Dáil Debate*, Thursday, 9 February 2017 at <https://www.kildarestreet.com/debates/?id=2017-02-09a.5> (accessed 13/03/2017) and *Dáil Debate*, Wednesday, 8 March 2017 at <https://www.kildarestreet.com/debates/?id=2017-03-08a.429> (accessed 13/03/2017).

of health and to facilities for the treatment of this illness and for the rehabilitation of their health. In particular, the Government is under an obligation to adopt a child rights-based approach to all decisions affecting the health and development of children with scoliosis and to take special measures to ensure the implementation of their rights, including through the allocation of sufficient and sustainable resources and the development of child-friendly healthcare services.

However, the lived experiences of this vulnerable group of children over the last decade illustrate how the lack of adequate Government action has led to consistent breaches of their right to health. The constant pain associated with the condition, the deteriorating effects of an increasing curvature of the spine, the growing visible physical deformity, the emotional and mental distress suffered and in some cases the inability of children's internal organs to cope has directly and negatively affected these children's right to health in and of itself (Article 24 CRC). Their enjoyment of other human rights has also been affected, including their right to a standard of living adequate for their physical, mental, spiritual, moral and social development (Article 27 CRC), their right to education (Article 28 CRC), their right to play and recreational activities (Article 31 CRC), and in some cases their right to survival and development (Article 6 CRC).

Many children with scoliosis in Ireland have been denied orthopaedic spinal surgery for up to 18 months because of factors that range from a lack of resources and operational capacity, to a lack of availability of anaesthetists, theatre nurses, and funding from the HSE. The involvement of the OCO with complaints over a sustained period of time has found that, despite a number of short-term measures and some temporary improvements in waiting list times, the number of patients waiting significant periods of time for scoliosis treatment has continued to increase.

Section 5

Waiting lists for Scoliosis: a children's rights perspective

As outlined in this report, while initiatives have been put in place as a response to the waiting lists, these have not successfully addressed the long term human and capital resource issues that continue to impact on the ability of those involved to plan and deliver successful operations, in a timely manner, which would best meet the needs of children with scoliosis. While short term initiatives have had some success, it is a matter of serious concern to the OCO that the longer term initiatives have not materialised, despite being identified a number of years ago. This situation is not in compliance with international obligations under Article 24 of the CRC.

It has been established that children are often affected in different ways from adults, both psychologically and physically, by violations of their right to health due to their stage of development.⁹² However, the testimonies and other information set out above confirm that the Government has failed to fully discharge its obligation to provide children with timely access to essential health services for the treatment of scoliosis. It has also been demonstrated that, in practice, such delays can result in children being left in limbo and can have long-term detrimental effects on their development and future capacity for autonomy.

The importance of transparent decision-making in how resources are rationed has become increasingly important in recent years.⁹³ However, there has been reluctance in Irish law, policy and political debates to define economic, social and cultural rights, such as health care

provision, as legal entitlements.⁹⁴ Public policy and debate in the area of health must give consideration to providing a robust legal guarantee for equal access to healthcare. In February 2014, the Constitutional Convention recommended that socio-economic and cultural rights are provided express Constitutional protection.⁹⁵ As far as this Office is aware, there has been no action taken by Government in relation to this recommendation to date.⁹⁶

The main argument put forward by the Oireachtas and the Courts against such Constitutional protection is the separation of powers doctrine - that the power to determine how the State collects and distributes revenue and resources is vested in the Oireachtas. However, Ireland has accepted the indivisible nature of all human rights at an international level and it is time to take these human rights obligations seriously. Guidance from UN Committees charged with monitoring

⁹⁴ See L. Thornton, *Socio-Economic Rights and Ireland* in S. Egan (ed.), "International Human Rights: Perspectives from Ireland" (Dublin: Bloomsbury Professional, 2015) at p. 187.

⁹⁵ Constitutional Convention, Eighth Report on the Convention on the Constitution (2014). In May 2015, a Private Members Bill to give constitutional protection to economic, social and cultural rights, (using the language of international human rights law) was opposed by Government (Thirty-Fourth Amendment to the Constitution (Economic, Social and Cultural Rights) Bill 2014. See Dáil Éireann Debate, 19 May 2015 at <http://oireachtasdebates.oireachtas.ie/debates%20authoring/debateswebpack.nsf/takes/dail2015051900051>. A second Private Members Bill on inserting the protection of social, economic and cultural rights into the Constitution is currently being put forward by the Independents 4 Change party and is at second stage. See <https://www.oireachtas.ie/viewdoc.asp?DocID=33063&&CatID=59>.

⁹⁶ The Minister of State at the Department of the Taoiseach, Deputy Paul Kehoe, noted in January 2016 that the recommendation of the Constitutional Convention for socio-economic rights to be expressly enumerated in the Constitution raises substantial questions that need consideration, including questions about the suitability of providing protection of these rights at a Constitutional level, the separation of powers doctrine and resource issues. See <http://oireachtasdebates.oireachtas.ie/debates%20authoring/debateswebpack.nsf/takes/dail2016011400039>.

⁹² A. Nolan, *Socio-Economic Rights, Democracy and the Courts* (Oxford: Hart Publishing, 2014) at p. 15.

⁹³ D. Madden, *Medicine, Ethics and the Law in Ireland* (Dublin: Bloomsbury Professional, 2016) at p. 42.

international treaties (such as the CRC), show that it is possible to frame legislative and Constitutional protection for such rights in a way that ensures they are closely aligned with the separation of powers doctrine.

The obligation to undertake all measures, to the maximum extent of available resources, to progress the full realisation of the children's rights principles enshrined in the CRC has been interpreted 'as a call for prioritisation of children within the state budget so as to ensure appropriate levels of service delivery'.⁹⁷ The Special Rapporteur on Child Protection recently stated that 'Ireland must "take all necessary measures" to improve healthcare services, including through increased public spending'.⁹⁸ As outlined above, the Committee on the Rights of the Child has been very clear about the link between budgets and resources and the realisation of children's rights. It has stated as follows:

*Implementation of the human rights of children must not be seen as a charitable process, bestowing favours on children...No State can tell whether it is fulfilling children's economic, social and cultural rights 'to the maximum extent of available...resources' as it is required to do under article 4 [of the CRC], unless it can identify the proportion of national and other budgets allocated to the social sector and, within that, to children, both directly and indirectly*⁹⁹

Accountability is also well established as an important principle of human rights. Ensuring accountability requires continuous monitoring by Government and Civil Society and includes budget analysis. While children are members of families and societies, we need to focus

⁹⁷ See E. G. Thukral, "Budget for Children" in A. Nolan, R. O'Connell and C. Harvey (eds.) *Human Rights and Public Finance*, (Oxford: Hart Publishing, 2013) at p. 147.

⁹⁸ G. Shannon, *Ninth Report of the Special Rapporteur on Child Protection: A Report Submitted to the Oireachtas (2016)* at <https://www.dcy.gov.ie/documents/publications/201611189thReportoftheSpecialRapporteuronChildProtection.pdf> at p. 21.

⁹⁹ Committee on the Rights of the Child, *General Measures of Implementation of the Convention on the Rights of the Child (2003)* UN Doc. CRC/GC/2003/5.

our attention on their distinct citizenship and ensure their inclusion in governance. Disaggregating specific spending for children would ensure that children are prioritised within the state budget so that policy commitments translate into the allocation of resources and appropriate levels of service delivery to protect children's rights.¹⁰⁰ Attention must be paid to the Committee's Concluding Observations on Ireland and its most recent General Comment No. 19 on public budgeting for the realisation of children's rights. While we acknowledge that it is essential that a balance be struck between competing demands on finite resources,¹⁰¹ the Government has recognised that children are entitled to special care, protection and assistance through its ratification of the CRC and other legal instruments and must implement its obligations in this regard. This is the basis for the recommendations made below specifically relating to children waiting for scoliosis treatment.

The powerful accounts from the young people who have shared their experiences of waiting for surgery in this report highlight the importance of the right of the child to have their views heard. However, there is also a duty to ensure that those views are taken into account in matters affecting them, in accordance with their age and maturity. It is important the children who are affected by scoliosis waiting lists are listened to and the negative effect this has had on their lives is taken into account by Government in formulating solutions. In the context of initiatives announced by Government most recently to address the backlog of children waiting for scoliosis treatment, it is important to listen to individual children and their families about the impact of having to travel abroad for this essential surgery, having regard to their particular circumstances.

¹⁰⁰ See E. G. Thukral, "Budget for Children" in A. Nolan, R. O'Connell and C. Harvey (eds.) *Human Rights and Public Finance*, (Oxford: Hart Publishing, 2013).

¹⁰¹ Ireland's submission, *Calls for comments – Advanced version for the Committee on the Rights of the Child Draft General Comment - Article 4 (2015)* at www.ohchr.org (accessed: 13/03/2017).

Section 6

Recommendations

1.

The realisation of the right to health of children waiting for scoliosis paediatric orthopaedic surgery should be prioritised by Government action as a matter of urgency. No child with scoliosis should have to wait in excess of 4 months from when the need for surgery is clinically determined. This is in accordance with Government commitments recently made and in line with international best practice. Barriers to achieving this should be reviewed and eliminated.

2.

The Department of Health should commission and publish a situational analysis of existing practices, issues and infrastructure for the delivery of paediatric scoliosis surgery services in Ireland. This situational analysis should:

- assess the institutional capacity and the availability of human, financial, and technical resources. Specific deficits in resources should be identified.
- Carry out a clinical review of services and set national and regional priorities for the treatment and aftercare of scoliosis and strategies for their achievement.
- Budgeted action plans and operational strategies should be established and published with specific timeframes.

3.

The Government and service providers should promote and facilitate the effective participation of children in improving their health, in taking part in decision-making related to their care, in planning health care activities and evaluating their results, according to their age and maturity.

4.

National Standards of Practice, specific to respecting children's rights within health services, should be developed and implemented. Child-specific waiting lists should be published for all healthcare services in Ireland. Targets for maximum waiting times for out-patient appointments should be established. Reports which monitor these targets should be published quarterly.

5.

The Government should develop and implement a comprehensive and broadly-based national policy framework on child-friendly healthcare, taking account of International and European best practice and human rights standards. This should be done in consultation with children themselves and guided by the key principles of the CRC and by General Comment No. 15 on the right of the child to the enjoyment of the highest attainable standard of health.

6.

To promote accountability for children's health, this national policy framework must include a transparent mechanism to ensure that a cyclical process of planning, implementation, monitoring and evaluation takes place.

7.

A national policy on child-friendly healthcare should include a specific strategy to build inter-sectoral alliances across the healthcare sector, to develop consensus and build and sustain momentum towards the implementation of children's rights in healthcare settings. This collaborative network should include senior figures from the healthcare sector, a wide range of children's health experts and professional groups, law and policy makers, healthcare managers, statutory agencies, patient and advocacy groups and interdisciplinary researchers.

8.

An expert group should be established across the healthcare sector to advise Government in relation to the development of this national policy and an accountability mechanism. The expert group should publish progress reports and report to the Joint Oireachtas Committee on Health.

9.

The development of a national policy on child-friendly healthcare should be accompanied by awareness-raising measures, designed to promote children's rights in healthcare among children, their families, practitioners, managers and policy-makers.

10.

The Government should fully implement the Committee's recommendations in its Concluding Observations on Ireland's implementation of the CRC, particularly with regard to child-friendly budgeting. Although these recommendations apply to all budgetary decisions made by Government, the Department of Health should publish specific timelines for their implementation in the health sector.



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