Scoliosis Treatment for Ivy

The effectiveness of the HSE multi-disciplinary planning process by Children's Health Ireland at Temple Street in providing scoliosis treatment.

June 2023

ombudsman
do leanaí
for children

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Abbreviations

CE	Chief Executive
CHI	Children's Health Ireland at Temple Street
HSE	Health Services Executive
OCO	Ombudsman for Children's Office
2002 ACT	Ombudsman for Children Act 2002
MRI	Magnetic Resonance Imaging
PE	Preliminary Examination
TOR	Terms of Reference
TAS	Treatment Abroad Scheme
UNCRC	United Nations Convention on the Rights of the Child

Executive Summary

Ivy

Our investigation centres on the case of Ivy (17) who had been waiting for spinal fusion surgery for scoliosis for five years since 2016. During this time, Ivy, who was born with cerebral palsy, experienced major deterioration in her spinal curvature, going from 30 to over 135 degrees. When Ivy and her family came to us, after previously raising their concerns a number of times with their GP, Ivy's consultant and Children's Health Ireland, they told us how the uncertainty surrounding her surgery impacted every aspect of Ivy's life, physically and mentally. They also explained the distress the whole family suffered because of Ivy's worsening spinal deformity and the impact on her overall health and ability to function and ability to attend school. Ivy eventually received surgery in 2021, significantly reducing her pain levels and improving her quality of life.

Overview of our Findings

When we investigated Ivy's case we found that the administrative actions of CHI had a negative impact on her life. What we found was that CHI failed to appropriately communicate with Ivy herself, and her family about her medical care planning. We found that the poor communication breached the hospitals own policies and procedures for managing waitlists and engaging with patients and their families. We also found that the hospital failed to properly address a complaint made by Ivy's father on her behalf about these matters.

Overview of Our Recommendations

We recommended CHI undertake an audit of the waiting list for children's scoliosis care, to be assured that the data and information is current, up to date and valid. We proposed that CHI reform the process where reviews of patient care can be initiated by the patient/family/caregiver/GP or others involved in the patient's care. We asked that this investigation statement be shared with the HSE and other interested parties so there would be learning taken from Ivy's negative experiences. Finally, we recommended CHI undertake an audit of the complaints handling policy and practices at CHI.

Our report is structured as follows;

- **Section 1** - Ivy's Story
- **Section 2** - The Complaint
- **Section 3** - The Investigation
- **Section 4** - Findings
- **Section 5** - OCO's Recommendations and Public Bodies' Responses
- **Appendix** - Relevant Law and Policy

Section 1: Ivy's Story

When we first heard of Ivy, she was 17 years old and had a complicated medical history. Ivy was born with cerebral palsy. She also suffers from hip dysplasia and neuromuscular scoliosis. This condition is one of three main types of scoliosis that cause an irregular curvature of the spine[1]. It is the second most common form of scoliosis and is associated with disorders of the nerve or muscular systems such as cerebral palsy, spina bifida, and spinal cord injury. Severe scoliosis can be disabling and with significant curvature of the spine, a person's chest space can be reduced which can impact the ability of the lungs to function [2]. This was Ivy's experience.

Ivy and her family were advised in 2016, that spinal fusion surgery was being considered as her medical treatment plan at Temple Street Hospital, now Children's Health Ireland (CHI). That surgery did not take place until January 2021. In that time Ivy experienced a major deterioration in her spinal curvature, from 30 degrees to over 135 degrees.

Her parents informed us of how the uncertainty about when, and if surgery would occur, affected every aspect of Ivy's life, particularly her physical wellbeing but also her state of mind. The family had raised this several times with their GP, Ivy's consultant and CHI. They went on to tell us about the distress experienced by the whole family at the progression of her spinal deformity and its impact on her overall health and functioning.

Ivy herself told us about the many hospital staff she had met over her time at CHI and her recognition of the difficult jobs they have in fulfilling their responsibilities to young people in similar circumstances as her own. Ivy expressed her appreciation and gratitude to the staff who were involved in her pre-operative care, her surgery and post-surgical care.

However, Ivy also spoke to us about how her condition worsened before her surgery, resulting in her home having to be continuously modified to address her deteriorating ability and changing needs. She went on to speak about how her worsening condition significantly impacted on her ability to socialise with her peers. Her deteriorating health resulted in her only being able to attend school for one, sometimes two days a week throughout her fifth year at school, 2018-2019. Ivy did receive her surgery in 2021 and she has told us that her levels of pain and discomfort have been reduced significantly as a result. She told us she is now able to engage better in both her family and broader social life. She even performs everyday tasks including attending to aspects of her intimate care. However, Ivy has informed that she will require further surgery for her hips and she and her father continue to engage with the relevant hospital about this surgery.

1 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).

2 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: The Complaint

In 2020 we received a complaint from Ivy's father on her behalf. That complaint was against Children's Health Ireland at Temple Street (CHI). As referenced above, Ivy has a complicated medical history having been born with cerebral palsy and suffering from hip dysplasia and neuromuscular scoliosis.

In 2016 Ivy and her father understood that spinal fusion surgery was being considered by her Consultant. That surgery did not take place until 2021 and in the intervening period Ivy experienced a significant deterioration in the curvature, from 30 degrees to over 135 degrees. During that time her father said that despite their repeated efforts, they were unable to get clear information from the hospital as to when she would receive surgical intervention.

Her father wrote to CHI in 2020 voicing his concerns about the delay and requesting a review of her case. He also sought clarity as to her future medical care planning when she turned 18. As he felt he was not provided with answers to his questions, Ivy's father contacted our Office and made a complaint.

Section 3: The Investigation

Our role is set out in the Ombudsman for Children Act, 2002. This states that we may investigate a public body, school or voluntary hospital where we believe that its administrative actions have or may have adversely affected a child. This means that we review complaints related to organisational actions or decisions to see whether they have already had, or might have a negative impact on a child.

The Act sets out the focus for our investigations. We aim to determine if a child has been adversely affected by a public service's administrative actions. The Act lists seven areas whereby organisational actions might be:

i. Taken without proper authority;
ii. Taken on irrelevant grounds;
iii. The result of negligence or carelessness;
iv. Based on erroneous or incomplete information;
v. Improperly discriminatory;
vi. Based on an undesirable administrative practice; or,
vii. Otherwise contrary to fair or sound administration

In July 2021 following our preliminary examination, we advised CHI that we intended to proceed to a statutory investigation with regard to the administrative actions of the hospital relating to its management of Ivy's medical care pathway.

As part of our investigation, we carried out a review of Ivy's CHI case files along with relevant policies and procedures provided by CHI. Interviews were subsequently conducted with Ivy, her parents and senior personnel from CHI including the CE, the Clinical Director and Ivy's consultants. Those meetings afforded CHI personnel an opportunity to comment and provide further information to assist our understanding of the matters under investigation.

Section 4: Findings

The Findings of our Investigations relate to whether Public Bodies' administrative actions have adversely affected Ivy. A summary of our findings against CHI are as follows;

Finding 1

We find that CHI at Temple Street have failed to adequately communicate with Ivy and her father between 2016 and 2020 with regard to her medical care planning and pathway. This became evident to Ivy in the context of the FOI request her father made in May 2020 and her subsequent removal and reinstatement on a CHI surgery waitlist in October and November 2020. This has caused considerable upset distress and anxiety for Ivy.

Finding 2

We find that CHI at Temple Street failed to administer {Ivy's} case in accordance with the procedures and principles set out in the National Inpatient, Day Case, and Planned Procedure (IDPP) Waiting List Management Protocol 2017. Nor is there a clear process shared with parents and GPs on how they can raise concerns about the deteriorating condition of their child while on the waiting list. This means that there was no clinical validation of Ivy's case which could have resulted in prioritisation of her case for clinical intervention. While we cannot say this would have resulted in earlier interventions but equally we cannot say that it would not.

Finding 3

We find that the CHI at Temple Street has failed to address the complaint made on behalf of {Ivy} on 20th May 2020 in accordance with the hospital's 2016 Complainants Management Policy. This failure denied {Ivy} and her family access to information about planning and decision making further to her care pathway at CHI. Subsequent revelations about the transfer of her case to adult services and the communication around the same was very distressing for (Ivy) at a time when her overall health was seriously compromised.

Finding 4

We find CHI at Temple Street has failed to consider in its responsibility to inform {Ivy} herself as to the status of the complaint made in respect of her on 20th May 2020. She advises this caused her upset and distress and she found the lack of engagement with her disrespectful.

Section 5: OCO's Recommendations and Public Bodies' Responses

Once we had completed our investigation and made findings, we also made a series of recommendations to CHI on how we felt things could be improved. Our recommendations and CHI's response to these recommendations, as well as their plan for implementing changes are set out below. While we will be conducting a review of the implementations of our recommendations in 12 months, based on the response from CHI and the plan they have provided us to ensure changes are made, the Ombudsman for Children's Office is satisfied with the outcome of this investigation to date.

Recommendation 1

As provided for in the refreshed National Outpatient Waiting List Management Protocol 2022, we recommend that CHI at Temple Street undertake an audit of the waiting list for children's scoliosis care, to be assured that the data and information is current, up to date and valid.

CHI Responses and actions

We were advised that validation is the process whereby patients on a waiting list are contacted to confirm if they are available, ready and willing to proceed with their hospital care. The inpatient and day case waiting list for spinal surgery is not routinely clinically validated as a standalone exercise as there is regular contact between Clinical Nurse Specialists within CHI and the parents of children waiting. Parents can contact the Clinical Nurse Specialists at any time regarding queries on their medical condition, equipment needs, pre-operative assessment, timeline to surgery and more.

Action identifier	Action detail	Action Owner	Action Timeline	Action status
1.	Clinical Nurse Specialists and medical secretaries to be given clear written guidance on escalation processes if waiting list concerns (including clinical deterioration) are raised with them.	Operations Lead CDA	31st May 2023	Complete

Given that this waiting list has not been routinely validated CHI does not believe that an audit of this process would be of value. CHI acknowledged that in the case in question formal clinical validation would have assisted in providing certainty regarding the clinical plan for this patient. In order to improve this going forward CHI committed to establishing a formal process for capturing contacts on care planning between clinical team members and families as they occur. This formal record will include details on the nature of any queries, response provided and actions undertaken. At 6 monthly intervals these records will be cross checked with the waiting list for spinal fusion. Any families which have not made contact, or where queries have not been closed off, will undergo clinical validation at that point.

Action identifier	Action detail	Action Owner	Action Timeline	Action status
2.	Develop formal record and action process for capturing contact between family/patient and clinical team members regarding updates or concerns in clinical condition.	Operations Lead CDA	31st May 2023	Complete
3.	Formalise process to cross check spinal fusion waiting list with contact record every six months.	Operations Lead CDA	31st May 2023	Complete

Recommendation 2

As proposed in the "Waiting List Action Plan 2022" we recommend that CHI at Temple Street reform the process wherein reviews of patient care can be initiated by the patient/family/caregiver/GP or other professionals involved in the patient's care. This should ensure an integration of information from any of these sources about a child's deteriorating condition while waiting for treatment and ensure this is clearly communicated and understood. It may be helpful for the CHI at Temple Street to engage with the HSE Deteriorating Patient Improvement Programme in this regard.

CHI responses and actions

CHI inform that patient safety is of utmost priority to them and they acknowledge that processes to ensure children remain safe while waiting are essential. They suggest that new processes to support clinical validation will also assist in ensuring that there is effective and timely response to any deterioration experienced by children waiting for treatment.

Action identifier	Action detail	Action Owner	Action Timeline	Action status
	See Action 2 above			

In addition to this, we are advised that patient information materials will be developed to enhance awareness on points of contact for support within the Orthopaedic service and also to advise on steps to take if a parent or guardian is concerned about their child's condition.

Action identifier	Action detail	Action Owner	Action Timeline	Action status
4.	Update/ formalise CHI patient and family information materials regarding contact routes with Spina bifida service concerns or clinical queries.	Patient Feedback and Support Services Lead	31st May 2023	Open - will be completed by 30th June 2023

Recommendation 3

We recommend that this investigation statement be shared with the HSE and the Scoliosis Co- Design Group so that any learning from Ivy's case can form part of an evaluation of the effectiveness of the MDT pathway for paediatric scoliosis care and the protocol for transition of adolescent patients to adult services.

CHI Responses and actions

We were advised that CHI fully agrees that all learning should be shared with the HSE and all advocacy groups.

Action identifier	Action detail	Action Owner	Action Timeline	Action status
5.	CHI will share both the investigation statement and action plan with the Scoliosis Co-Design group, the Scoliosis Advocacy Network, the Spina Bifida Hydrocephalus Paediatric Advocacy Group, and Spina Bifida Hydrocephalus Ireland.	Operations Lead CDA	31st May 2023	Open - will take place subsequent to meeting with family

CHI also agrees to provide progress updates on the improvement actions at our meetings with the advocacy groups.

Action identifier	Action detail	Action Owner	Action Timeline	Action status
6.	Add update to this action plan as a standing agenda item to Advocacy Group meetings until all actions are completed	Operations Lead CDA	31st May 2023	Open - subsequent to actions 4 & 5

CHI will further ensure that the learning from this investigation is shared with all teams involved in further developing transition pathways to adult services in spinal services.

Action identifier	Action detail	Action Owner	Action Timeline	Action status
7.	Ensure Learning from this investigation is formally shared with all members of the Clinical Directorate responsible for developing transition plans to adult spinal services	Clinical Director CD A	30th April 2023	Complete

Recommendation 4

We recommend the HSE National Quality Assurance Directorate undertake an audit of the complaints handling policy and practices at CHI Temple Street to include a review of how concerns are identified and reported onto hospital management and the HSE.

CHI Responses and actions

We are reminded that CHI was established as a new state entity in January 2019 involving the integration of three different hospitals and governance systems. In that context CHI advised that Patient Complaints handling has transitioned to the CHI Patient Feedback and Support Service (PFSS). This is the department in CHI which oversees Complaints Management as part of the Quality, Safety and Risk Management (QSRM) function.

Since this change in governance, CHI has confirmed there has been a substantial restructure and redesign of the Complaints Management Team and processes across CHI. Key Performance Indicators, Standard Operating Procedures, line management structure, data reporting and escalation processes have been reviewed and updated to ensure compliance with relevant standards and guidelines.

On receipt of our draft recommendations, the Patient Feedback and Support Service reviewed all access related complaints for the Orthopaedics Department in CHI.

We are informed that there are currently no open complaints relating to access to orthopaedic surgery or appointments which pre-date the PFSS transition in March 2022. All open complaints have been reviewed and CHI are satisfied that the response process is compliant with the HSE guidance 'Your Service Your Say'. CHI continued that they are satisfied that all new complaints received regarding access to the Orthopaedics Service in CHI are also responded to in accordance with the "HSE Management of Service User Feedback Policy for Comments, Compliments and Complaints" and escalated accordingly within CHI.

Action identifier	Action detail	Action Owner	Action Timeline	Action status
8.	Review all open complaints relating to spinal services in CHI to ensure that they are being managed in line with expected quality standards	Patient Feedback and Support Services Lead	30th April 2023	Complete
9.	Escalate all closed spinal orthopaedic complaints to DQSRM for the next six months to ensure quality processes are working as intended	Patient Feedback and Support Services Lead	31st October 2023	Open
10.	Provide report of open and newly closed spinal service complaints to the monthly Spina Bifida Services Review meeting	Patient Feedback and Support Services Lead	30th April 2023	Complete

Recommendation 5

We recommend that CHI Temple Street undertake a review of the Multi-Disciplinary Team process introduced in February 2022 to be assured of its effectiveness in coordinating and planning for patient care.

CHI Responses and actions

We are advised that actions taken to safeguard quality and safety are normal practice in healthcare and are ultimately in the best interest of the children and young people we treat. In order to ensure CHI maintain good standards of quality, safety and best practice CHI has requested an external clinical review of the spinal surgeries carried out on children with spina bifida over the past 3 years.

The review will involve expert clinicians in spinal surgery from a North American Hospital of excellence examining our practices, procedures and patient outcomes in relation to spina bifida spinal surgery with a view to advising whether there are any patient safety-related issues and whether improvements to our services are required.

We are advised that this review has commenced and it has been confirmed that MDT processes will be included in the review and that any recommendations arising from this will be addressed.

Action identifier	Action detail	Action Owner	Action Timeline	Action status
11.	Ensure that planned MDT process is occurring on the intended schedule	Clinical Director CD A	30th April 2023	Complete
12.	Ensure that the external Review of Clinical Outcomes in Complex Spinal Surgery in Children with Spina Bifida (October 2019 - October 2022) at Children's Health Ireland at Temple Street Hospital is fully supported to completion and any recommendations relating to MDT operation are actioned	Clinical Director CD A	31st May 2023	Open

Recommendation 6

We recommend that CHI should offer to re-engage with Ivy and her parents. The purpose of this should be to demonstrate an understanding of the learning that has been taken from this matter and to advise of the changes in practice with regard to the handling of concerns and complaints by parents and children.

CHI Responses and actions

CHI tell us that they will be arranging to meet with Ivy in person to discuss the outcome of the investigation and acknowledge the learning. The action plan on the recommendations will be provided in advance of that meeting and CHI would like to discuss this in more detail with Ivy in addition to answering any further queries she may have.

Action identifier	Action detail	Action Owner	Action Timeline	Action status
13.	Set up meetings with patient, and parents if the patient wishes, to discuss the investigation outcome and action plan.	Clinical Director CD A	31st May 2023	Complete

Recommendation 7

We recommend the Board of CHI formally consider whether the findings of this investigation and outcomes of the recommended audit and review are relevant to children waiting scoliosis treatment within their other services

CHI Responses and actions

In response to this recommendation CHI inform that as a single, and integrating, organisation they are committed to ensuring that the standards and quality of service are consistent across all sites. They continue that learning from our investigation will be actively shared across the CHI hospitals group.

Action identifier	Action detail	Action Owner	Action Timeline	Action status
14.	Provide a report on this investigation and the CHI-wide actions arising from it to the Board Quality and Patient Safety Committee	Clinical Director CD A	31st July 2023	Open - on agenda for 4th July 2023

Appendix

International Standards

The United Nations Convention on the Rights of the Child (1989) (UNCRC); The UNCRC is the principal international Children's Rights instrument adopted by the General Assembly of the United Nations in 1989. The UNCRC recognises children as autonomous rights holders and sets out the obligations of the state as a duty bearer. Although the UNCRC has not been incorporated into Irish law, Ireland ratified the UNCRC in 1992 and is subject to the treaty monitoring procedure. Noteworthy in this context being;

- Article 3 of the UNCRC enumerates the best interests' principle such that; "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration".
- Article 23 refers to children with a disability affirming that "Children with a mental or physical disability have the right to special care, education and training designed to help them to achieve the greatest possible self-reliance and to lead a full active life in society."
- Article 24 states; "Parties recognize 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."

National Policies and Procedures

- Treatment Abroad Scheme (TAS)
- The Health Information and Quality Authority (HIQA) -Better Safer Care Standards, (2013)
- The National Healthcare Charter for Children (2013)
- Better Outcomes, Brighter Futures (2014-2020): National Policy Framework for Children and Young People

CHI Local Policies and Procedures

- National Inpatient, Day Case, Planned Procedure (IDPP) Waiting List Management Protocol (2017)
- National Outpatient Waiting List Management Protocol (2022). Of Relevance;
- Waitlist Action Plan 2022.
- CHI Feedback and Complaints procedures (2016)
- Integrated Patient Registration and Management System the Integrated Patient Management System (IPMS) (2019)
- The Scoliosis Co-Design 10 Point Action Plan (2018/2019) (updated June 2019)
- Service Arrangements under Section 38 Health Act 2004- Revised October 2022.

Ombudsman for Children's Office
Millenium House
52–56 Great Strand Street
Dublin 1
D01 F5P8

T: 01 865 6800
F: 01 874 7333
E: oco@oco.ie
www.oco.ie
@OCO_Ireland