Scoliosis Treatment for Ivy

Update on actions following an investigation into the effectiveness of the HSE multi-disciplinary planning process by Children's Health Ireland (CHI) at Temple Street in providing scoliosis treatment to Ivy.

October 2024

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Introduction

In June 2023 the Ombudsman for Children's Office (OCO) published an investigation into the effectiveness of the HSE multi-disciplinary planning process by Children's Health Ireland (CHI) at Temple Street in providing scoliosis treatment to Ivy* (17), who had been waiting for spinal fusion surgery since 2016 Our report made seven recommendations that CHI agreed to progress.

Since then, we have continued to engage with CHI, Ivy, her family and advocacy groups (Scoliosis Advocacy Network and Spina Bifida Hydrocephalus Ireland) and are now providing a progress update on those recommendations.

However, in doing so it is important to note that since Ivy's investigation was first published, grave concerns have emerged around the safety of some children with scoliosis being treated within CHI. Parallel to this, there have also been concerns about the administration by CHI of additional funding allocated by the Minster for Health to address issues involved in scoliosis treatment.

The efforts made by CHI in progressing our recommendations have been impacted by these revelations about practices and governance issues. These developments have also resulted in the breakdown of trust in the already fraught relationship between CHI and some of the advocacy groups and the children and families they represent. It is important to reference these developments in this progress report as they put into context the issues highlighted in "Ivy's" case and frame the ongoing concerns brought to the OCO by children and their families awaiting spinal surgery.

Post publication developments

In September 2023 it emerged that CHI had previously been made aware of concerns that unlicensed and unauthorised devices may have been implanted in some children during spinal surgeries. This is now subject to an external investigation by the Health Information and Quality Authority (HIQA). In response to this, CHI has commissioned two reviews, one internal and one external, which were collated into the *Report on Spinal Surgery for Patients with Spina Bifida in CHI at Temple Street.*[1]

This was provided to the HSE in August 2023 and led to its Chief Clinical Officer (CCO) commissioning an independent overarching external review of the issues by an international clinical expert.[2] Following this the Minister for Health established a Paediatric Spinal Task Force in March 2024.[3] Since then however, two of the major scoliosis advocacy groups have declined an invitation to participate. In July 2024, an audit requested by the Minister for Health revealed that 19 million euro, allocated in 2022, specifically to the area of Scoliosis and Spina Bifida treatment, may not have been spent as had been intended.[4]

Overview of the OCO investigation recommendations

In our investigation statement we recommended that CHI carry out an audit of the waiting list for children's scoliosis care to be assured that the information was 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 our investigation statement be shared with the HSE and other interested parties so there would be learning taken from Ivy's negative experiences. We also recommended CHI undertake an audit of the complaints handling policy and practices at CHI.

In response to our recommendations CHI identified a number of actions to address our concerns. Those actions and the recommendations that informed them will be outlined in this report.

1 https://www.childrenshealthireland.ie/news/report-on-spinal-surgery-for-patients-with-spina-bifida-in-children-health-ireland-at-temple-street-summary-of-findings-and-recommendations/

2 https://about.hse.ie/news/hse-commissions-external-review-aspects-orthopaedic-surgery-children-health-ireland-temple-street/

3 https://www.gov.ie/en/press-release/bb22d-statement-from-the-paediatric-spinal-taskforce-19-july-2024/

4 https://www.independent.ie/irish-news/money-was-steered-away-from-children-with-scoliosis-and-spina-bifida-parents-angry-at-misspent-19m-fund/a847048026.html

Update on Ivy

When we first heard of Ivy, she was 17 years old and had a complicated medical history. Ivy was born with neuromuscular scoliosis, cerebral palsy and she also suffered from hip dysplasia. Neuromuscular scoliosis is one of three main types of scoliosis that cause an irregular curvature of the spine. In this regard, 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. This was Ivy's experience. In 2016, spinal fusion surgery was being actively considered as her treatment plan at Temple Street Hospital, now 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. That delay, and the uncertainty about when and if surgery would occur, affected every aspect of Ivy's life, particularly her physical wellbeing, but also her mental health.

Ivy told us how her worsening condition meant her home had to be continuously modified to address her deteriorating ability and changing needs. She described how this impacted her ability to socialise with her peers and attend school. In the course of our investigation Ivy finally received her surgery in 2021. At that time, she told us that her levels of pain and discomfort were initially reduced and consequently the quality of her life improved. However, she and her family were informed that following the surgery performed on her spine, she would need further surgery for her hips.

Since 2021 Ivy and her father have sought clarification about the date for her hip surgery and under which consultant. CHI informed them that this was not a matter for CHI but rather her clinical team at the National Orthopaedic Hospital Cappagh. In October 2023, Ivy was advised by a new clinical team at Cappagh that her surgery was problematic and possibly no longer viable as the condition of her hips had worsened. Ivy and her family are understandably, devastated. Despite this, and with dignity and bravery, Ivy and her family are committed to continuing to highlight the difficulties experienced by children and young people in accessing timely and coordinated treatment for Scoliosis care.

Review of progress made on the agreed recommendations

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 Response to Recommendation 1

CHI explained that 'validation' is the process where patients on a waiting list are contacted to confirm if they are available, ready and willing to proceed with their child's hospital care. CHI say that waiting lists for inpatient and day case spinal surgeries are not routinely clinically validated as a standalone exercise. The OCO was assured that there is regular contact between the CHI Clinical Nurse Specialists (CNSs) and parents where they can raise queries on their child's medical condition, equipment needs, pre-operative assessment, timeline to surgery and more. According to CHI, there is no value in auditing waiting lists that are not routinely validated. They acknowledge that in Ivy's case formal clinical validation would have helped provide certainty about her clinical plan. To improve this, CHI say they have established a formal process for capturing contacts between clinical team members and families as they occur. This record includes details on the nature of any queries, response provided and actions taken. At 6 monthly intervals these records are cross checked with the waiting list for spinal fusion. Any families who have not made contact during this period will undergo validation at that point.

Recommendation 1 CHI agreed actions and update to OCO July 2024

Action	Action detail	Evidence reviewed by OCO	Status
1.	CNSs and medical secretaries to be given clear written guidance on escalation processes if waiting list concerns, including clinical deterioration, are raised with them	CHI have provided Standard Operating Procedures (SOP) for the following: 1. The management of patient/ family queries 2. The newly established Spinal Services Management Unit and for 3. Helpline Queries CHI have further provided patient sample's for: 1. Patient Spinal Service Helpline 2. CNS queries log 3. Sample non-clinical queries log	Complete
2.	CHI will develop a formal record and action process for capturing contact between family/ patients and nursing and non-clinical staff regarding updates or concerns re clinical condition.	CHI have provided the OCO with; 1. Scoliosis patient information leaflet 2. Pre-operative assessment leaflet 3. Halo traction information leaflet 4. Multi-Disciplinary Team (MDT) process information leaflet 5. Scoliosis discharge information leaflet 6. Website monthly data sample	Complete
3.	CHI will formalise the process to cross check spinal fusion waiting list with contact record every six months.	The OCO was provided with evidence of the new processes to support clinical validation.	Complete

Recommendation 2

"As proposed in the "Waiting List Action Plan 2022" we recommend that CHI at Temple Street reform the process where reviews of patient care can be initiated by the patient/family/caregiver/G P 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 CHI at Temple Street to engage with the HSE Deteriorating Patient Improvement Programme in this regard."

CHI response to Recommendation 2

According to CHI, the new processes to support clinical validation will also help to ensure that there is an effective and timely response to any deterioration experienced by children waiting for treatment.

CHI also say that as per action identifier 2 above, they have developed information materials for patients with details on who to contact for support within the hospital and advice for parents/ guardians on what to do if they're concerned about their child's condition.

Recommendation 2 CHI agreed actions OCO Update July 2024

Action	CHI Action detail	Evidence reviewed by OCO	Status
4.	CHI agreed to update/ formalise patient and family information materials regarding contact routes for scoliosis service concerns and/or clinical queries.	CHI have provided evidence as detailed above under action identifier 2.	Completed

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 Response to Recommendation 3

CHI agreed that all learnings should be shared with the HSE and all advocacy groups.

Recommendation 3 CHI agreed actions and update to OCO July 2024

Action	CHI Action detail	Evidence reviewed by OCO	Status
5.	CHI agree to share both the investigation statement and action plan with the Scoliosis Co-Design groups.	The Scoliosis Co-Design Group has not met since the publication of the investigation report. CHI have provided evidence of attempts to reconvene the Co-Design group which were not successful to date. Advocacy groups represented on the Co-Design Group have told us that they independently accessed the published investigation report and that they had lost confidence in Co-Design group process.	No progress has been made with the Co – Design Group an inactive forum.
6.	CHI advise of their intention to add updates to this action plan as a standing agenda item to Advocacy Group meetings until all actions are completed.	CHI have agreed to include the action plan as a standing item when the Co-Design Group reconvenes and at Advocacy Group meetings.	No progress has been made.
7.	CHI advise that learning from this investigation will be shared with all members of the Clinical Directorate responsible for developing transition plans to adult spinal services.	In this regard, CHI have provided the OCO with the following; 1. A Patient transfer protocol from CHI to the National Orthopaedic Hospital Cappagh (NOHC) 2. A Service Level Agreement (SLA) between both organisations	Complete

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

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 Response to Recommendation 4

Following our recommendations, says the Patient Feedback and Support Service has reviewed all access related complaints for the Orthopaedics Department in CHI.

CHI say 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 complaint handling guidance and mechanism, '*Your Service Your Say*'. CHI say they are satisfied that all new complaints regarding access to the Orthopaedics Service in CHI are responded to in accordance with the *"HSE Management of Service User Feedback Policy for Comments, Compliments and Complaints"* and escalated within CHI.

Recommendation 4 -CHI agreed actions and update to OCO July 2024

Action	CHI Action detail	Evidence reviewed by OCO	Status
8, 9 & 10.	CHI will review all open complaints relating to spinal services within CHI hospitals to ensure that they are being managed in line with expected quality standards. CHI will escalate all closed spinal orthopaedic complaints to the Director of QSRM for the next six months to ensure quality processes are working as intended. CHI will provide a report of open and newly closed spinal service complaints to the fortnightly orthopaedic meetings.	CHI have provided the OCO with a presentation detailing the review and analysis of all orthopaedic complaints for 2023. Furthermore, CHI further advise the following; "Any access related complaints were subsequently closed and no significant issues similar to that reported in the Ivy cases were identified. This information was shared with the then Director of Quality, Safety and Risk Management who was satisfied with the same. This Action was tracked through the CHI Operational Taskforce group and also closed out through this group.	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 Response to Recommendation 5

To ensure that good standards of quality, safety and best practice are maintained CHI say that an external clinical review of complex spinal surgeries was carried out on a small group of children with Spina Bifida over the past 3 years. The review involved expert clinicians in spinal surgery from a different jurisdiction examining CHI practices, procedures and patient outcomes in relation to those cases with a view to advising whether there are any patient safety-related issues and; whether improvements to CHI services are required.

CHI confirmed that this review included MDT processes and that all recommendations arising from this will be addressed.

Recommendation 5 CHI agreed actions and update OCO update July 2024

Action	Action detail	Evidence reviewed by OCO	Status
11 & 12.	CHI committed to ensuring that planned MDT processes were occurring on the intended schedule.	CHI say that MDTs happen on the 1st Friday of every month with Anaesthetists/General Paediatrics/Pre-Assessment/Spinal Surgeons /CNS and others as needed. Pre-operative MDT Orthopaedic meetings also happen every week , along with Surgical outcome review meetings. Those meetings are chaired by Clinical Specialty Lead. The OCO has received a copy of the external review report with the implementation plan in place to address recommendations with assigned Executive Owner.	Complete

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."

Recommendation 6 CHI agreed actions and update to OCO July 2024

Action	Action detail	Evidence reviewed by OCO	Status
13.	CHI said they were arranging to meet with Ivy in person to discuss the outcome of the investigation and acknowledge the learning and to answer any questions Ivy might have. The action plan would be given to Ivy in advance. before	Ivy and her father have confirmed that a meeting took place with representatives of CHI where an apology was offered for the handling of her medical care pathway through the hospital. Ivy told the OCO she felt the apology was somewhat of a formality that lacked an appreciation for her past and current circumstances. Ivy also said that CHI didn't offer to come to meet her so she had to travel by car for three hours, which she found very painful due to her condition. She further noted that no arrangements were made to facilitate parking in or near the hospital which caused great inconvenience as a wheelchair user. Ivy said she and her father raised the issue of her pending hip surgery and the lack of clarity about when, where and under whose care this would occur. They were told that this this was a matter that was between Ivy and adult services at Cappagh hospital.	Complete in principal, notwithstanding Ivy's experiences of same.

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 Response to Recommendation 7

We were advised by CHI that they are committed to ensuring that the standards and quality of its services are consistent across all sites. CHI say that, learning from this investigation and subsequent actions will be shared with CHI at Crumlin and the National Orthopaedic Hospital, Cappagh, the other two national locations who manage scoliosis waiting lists.

Recommendation 7 -CHI agreed actions and update -July 2024

Action	CHI Action detail	Evidence reviewed by OCO	Status
14.	CHI have committed to provide a report on this investigation and the CHI-wide actions arising from it to the *Board Quality and Patient Safety Committee*	CHI advise that the investigation report was provided to the *Board Quality and Patient Safety Committee* and they provided the OCO with; 1. A patient transfer protocol from CHI Temple Street to National Orthopaedic Hospital Cappagh (NOHC) 2. A Service Level Agreement (SLA) between both organisations	Completed

Conclusion

Typically, investigations conducted by the OCO result in public bodies recognising the adverse effect on a particular child, with efforts then made to provide redress. We have found that it is more difficult/challenging for public bodies to apply learnings from individual cases and apply them to other children in similar circumstances. In this case, we are satisfied that CHI have in the main engaged with and progressed 6 of the 7 the recommendations from Ivy's investigation

Unfortunately for Ivy, it appears she has not, and will not benefit from the progress that has since been made.

Furthermore, the OCO is acutely conscious that from the last published CHI figures in September 2024 there were 264 children (including 16 at NOCH Cappagh) waiting for spinal surgery across CHI hospitals.

In relation to Recommendation 3 and framed by the recent developments that have arisen since we first published our investigation, the Scoliosis Co-Design Group has not met and appears to have been totally inactive. While the work of the Paediatric Spinal Task Force has largely replaced the Co –Design Group, it is still important that CHI clarifies the position of the group. The OCO is particularly concerned that two of the advocacy groups on this Co-Design Group have told us that they the children and families they represent have completely lost trust in CHI.

The OCO urges CHI to re-establish good working relationships with those advocacy groups and families. Independent and impartial mediation might usefully be considered by all parties at this time in the best interests of the children concerned.

Finally, as we publish this progress report the Ombudsman for Children will continue to engage with the Minister and the HSE on behalf of these children. Through the OCO's complaint handling function we will continue to evaluate any further complaints brought to our attention in respect of Orthopaedic care provided at CHI.

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