



**ombudsman
do leanaí
for children**

Waiting for Scoliosis Treatment: A Children's Rights Issue What has changed for children?

Statement from the Ombudsman for Children, Dr Niall Muldoon

Since July 2009, my office has received complaints from parents on behalf of their children who have scoliosis and in need of surgery. Over a sustained period of time, we had been alerted to the very long waiting times children were experiencing to access scoliosis spinal surgery.

I decided in March 2017 to publish a report on the experiences of these children and to share their stories on what it was like to wait for long periods of time for life changing surgery.

Following the publication of this report '*Waiting for Scoliosis Treatment: A Children's Rights Issue*' and after exhaustive advocacy by parents, and professionals alike there was a commitment by the government to address the systemic issues that were causing these waiting lists.

Since then my office has been tracking progress on the commitments made by the Minister for Health and the HSE. This included a commitment to address this issue once and for all to ensure that children diagnosed today with scoliosis and in need of surgery will not have to experience the excessive waiting times that previous children had to endure.

I have seen the actions taken and those proposed for the medium and long term.

I believe that these actions have generated some improvements such as increased surgeries, less children waiting for over 12 months for surgery, increased capacity and more resources.

I very much welcome the foundation that has been put in place to ensure sustainable changes such as inclusion of families in finding solutions, listening to children and most importantly the road map and governance structure set up through the Paediatrics Orthopaedic Implementation Group.

I particularly welcome that children with scoliosis were finally consulted about their experiences of waiting for scoliosis treatment and asked directly what could make things better for them. We supported the HSE in this participation project and welcome the

commitment to implement their recommendations into the wider strategic plan. But I am acutely aware that more has yet to be done.

A particular concern that remains is the issue of waiting lists for children who require an initial consultant assessment for scoliosis to determine the correct course of action for their condition. In August 2018 we were informed by the HSE that there were 138 children waiting for this assessment in Our Lady's Hospital Crumlin and in Temple Street Children's Hospital there were 39 children waiting for the same assessment. It is our understanding that this waiting list is managed in accordance with clinical need which is imperative to ensure that the child with the most urgent need receives urgent attention. Nevertheless, the psychological distress caused to a child and their family waiting for a prolonged period to hear as to whether or not they have scoliosis is unacceptable.

It is absolutely essential that a root cause analysis is undertaken to identify and address the issues contributing to this delay, as early detection is essential for early intervention. For example, we understand from our engagement with clinicians that there are significant delays accessing MRI scans which inhibits diagnosis.

In October 2017 Minister Harris announced a waiting list initiative so that no patient would be waiting longer than 15 months for an outpatient appointment. It is a grave concern to us that this target has not been met. In our report *'Waiting for Scoliosis Treatment: A Children's Rights Issue'* we called for child specific waiting lists with maximum waiting times which takes into account their particular vulnerabilities as children. We want to firmly reaffirm our position that this is essential to aid this group of children and indeed the development of paediatric services across all hospitals in Ireland.

Another key issue is those children and families who avail of surgery in other jurisdictions under the Treatment Abroad Scheme (TAS). Aftercare is hugely important in such cases and Irish based consultants have a key role in working collaboratively with their counterparts overseas to ensure children are actively supported when they return in terms of any necessary post-operative care.

Taking your child overseas for an operation is never the first choice for any parent as when your child is unwell we all prefer what is familiar and to be near our support network of friends and family. However, parents of children with scoliosis often make the decision to go overseas because of the on-going pain or discomfort their child may be experiencing while waiting for treatment here in Ireland. They make this decision in the best interest of their child. Therefore it is incumbent on all of the adults in the HSE to ensure that their decisions and actions regarding the provision of aftercare for children treated abroad are also made in the best interest of children.

I have met with numerous stakeholders on this matter including families, advocacy groups, the Minister for Health, Department of Health civil servants, the Children's Hospital Group,

consultants and hospital staff and management. My view is that there is an absolute commitment from all involved to address this matter in the best interest of children.

However, despite this and the positive movements to date I have decided to extend my watching brief for another year into 2019 to be assured that the actions as outlined in the Paediatrics Orthopaedic Implementation Group and the Scoliosis Co-Design 10 Point Action plan 2018/2019 are implemented and have the desired effect to making long lasting changes to the system for the benefit of children.

Key changes since our report 'Waiting for Scoliosis Treatment: A Children's Rights Issue'?

1. Decrease in number of children assessed as needing surgery, waiting for surgery

- In **April 2017** there were **312** children were waiting for scoliosis related surgeries across the three children's hospitals.
- By **August 2018** there are **138** children waiting for scoliosis related surgeries across the three children's hospitals.
- This means there was **174** less children waiting for scoliosis related surgeries

2. Key figures in relation to number of children with scoliosis that got surgeries

Overall increase in the number of children with scoliosis that got surgeries

- In **2016**, **224** surgeries took place
- In **2017**, **371** surgeries took place
- By August **2018** **246** surgeries took place with a projected total of **447** to be performed during 2018

3. Key figures in relation to children waiting for surgery

- At the end of **2017** there were **29** children waiting more than four months for scoliosis related surgeries
- Of these **23** families were offered operations abroad but did not wish to avail of this.

- By **June 2018**, there were **34*** children waiting more than four months for scoliosis related surgeries (*number of active patients waiting over 4 months for a scheduled date for an admission for a spinal procedure)

4. Key figures in relation to children waiting for an Outpatients Department assessment

- As of August 2018, there are **251** children waiting for a first-time consultant visit for spinal assessment in our Our Lady's Hospital Crumlin. It was reported that there were no children waiting over 2 years.
- As of August 2018, there are **39** children waiting for a first-time consultant visit for spinal assessment in Temple Street Children's University Hospital.

5. Decrease of waiting time targets from 18 months to 4 months

HSE target for surgery was reduced from 12 -18 months to 4 months which is more in line with international practice.

6. Key figures in relation to funding

9.3 million euros in additional funding allocated to paediatric orthopaedic services including scoliosis

7. Key facts in relation to improvements in staffing and resources

- New theatre opened in 2017 in Our Lady's Hospital Crumlin which provided an increase of 3 additional days surgery
- 25 staff members from different clinical and non-clinical areas in place to assist the multi-disciplinary team for scoliosis services as part of the approved 2018 National Service Plan.
- Pending appointments of two general paediatric orthopaedic surgeons by end 2018
- Clinical Co-ordinator appointed

- Project manager in place to co-ordinate surgeries abroad

Planning for sustained improvements

The reason the Ombudsman for Children's Office published our report '*Waiting for Scoliosis Treatment: A Children's Rights Issue*' last year was due to the lack of a concerted strategy by successive governments to address this issue once and for all. We are encouraged by the fact that there is now a dedicated implementation team and strategic plan and:

- An Orthopaedic Surgery Implementation group was established in 2018 to oversee the development and implementation of the 10 point plan.
- This plan was developed and recommended by the Scoliosis Co-Design group which includes families, advocacy groups and health professionals working together to make a difference.
- Scoliosis Co-Design 10 point Action Plan 2018/2019 was published in July 2018.
- In February 2018 two subgroups led by Orthopaedic Consultants from the children's hospital designed the outputs to deliver specific actions.
- A clinical integration strategy was developed to address the development of a central referrals system for all patients requiring paediatric services, including scoliosis.
- A new Scheduled and Unscheduled Care Performance Unit was established in the Department of Health with a remit to monitor the performance of access to scoliosis treatment.