



Oireachtas Joint Committee on Disability Matters
Opening Statement by the Ombudsman for Children's Office
Wednesday 8th November 2023

Introduction

The Ombudsman for Children's Office would like to thank the Joint Committee on Disability Matters (Committee) for the invitation to appear today to discuss rights based care for children with disabilities. The Ombudsman for Children, Dr Niall Muldoon, sends his apologies that he is unable to attend this meeting due to a pre-existing work commitment.

As members of the Committee are aware, the Ombudsman for Children's Office (OCO) is an independent statutory body, which was established in 2004 under the Ombudsman for Children Act 2002. Under the 2002 Act, the OCO has two core statutory functions:

- to promote the rights and welfare of children up to 18 years of age; and
- to examine and investigate complaints made by or for children about the administrative actions of public bodies, schools and voluntary hospitals that have, or may have, adversely affected a child.

Rights based care for children with disabilities

You have invited us today to talk about our recent report called Nowhere to Turn.

By way of background, in 2020 we published an investigation into a little boy called Jack who suffered traumatic life changing injuries in a car accident when he was three years old. Following six months of intensive medical interventions, and despite having no medical requirement to be there, Jack was left in a hospital bed for over two and half years because the HSE and Tusla initially failed in their responsibilities separately and jointly to work together to support his family. When the family decided they could not care for him at home, the two state agencies again failed to find a suitable placement for him. Nearly three years on, we found positive progress has been made in respect of Jack himself and he thriving in a family environment, in school and with friends.

But unfortunately we found that the HSE failed to implement the broader key strategic recommendations from our Jack investigation. These include;

- developing an assessment process to determine the needs of children in similar circumstances
- to provide a specific support package for them.
- to ensure there is ring-fenced funding for these services and

- to ensure they have a range of placement options for medium and long term when they cannot return home

These failures have had a profound impact on the lives of children in Ireland.

Since our investigation we continue to receive complaints concerning children with complex disabilities whose parents are struggling to cope with their needs. These parents have requested support from the HSE, but that help and support has not been forthcoming or simply is not enough. Parents have told us how they have had to fight for supports for their children for years on end and that they feel, quite simply, they are no longer able to manage without proper backing from the State.

We have also heard from parents of children with challenging behaviour who are causing injury and harm to themselves and their siblings, and how as they grow older and physically stronger, it becomes harder to safely care for them. Some parents have felt they have no option but to leave their children in emergency departments or respite services in an effort to get them the services they need. In the most extreme cases, hospital staff told us about three children who spent 107, 205 and 368 days respectively in hospital when they didn't need to be there.

Parents themselves have also told us how they're too afraid to admit how exhausted and stressed they are because whenever they have, the HSE has referred them to Tusla and questioned their fitness to parent.

Other parents say they've referred themselves to Tusla, due to the impact on their other children, in the hope of triggering the support they need for the child with the complex issues. All these parents have presented as being loving, caring and deeply committed to their child. Even when a parent comes to the difficult decision that they can no longer care for their child full time, they have remained engaged and maintained an active caring role for them. We also spoke with HSE disability managers, nursing staff, school principals throughout the country who are all trying their best to make their concerns heard about these children and their families.

We produced *Nowhere to Turn* to highlight these issues as we cannot allow this to continue. As a country we should be hanging our heads, that these parents of our most vulnerable children are having to make these difficult choices. Can you imagine, for one moment, being in their shoes?

These same children are then left to languish in hospital beds and respite centres as there is simply nowhere for them to go.

The lack of inter-agency co-operation has been a constant frustration and challenge for children and their families. The HSE has too many siloed agencies and services within their own aegis (e.g. Disability Services, CAMHS, Primary Care) who do not, and apparently will not, work together to ensure the best interest of the children. It is crucial that they also do much better to cooperate with external agencies such as Tusla, An Garda Síochána and schools. Indeed the UN Committee on the Rights of the Child has recommended, in their concluding observations to the Government earlier this year, that *"the State party review the effectiveness of existing mechanisms for facilitating inter-agency coordination on activities affecting children, and identify measures to strengthen the monitoring and coordination of all activities related to the implementation of the convention across all sectors"*.^[1]

^[1] <https://www.gov.ie/en/press-release/9df69-united-nations-committee-on-the-rights-of-the-child-publish-its-concluding-observations-on-the-combined-fifth-and-sixth-periodic-reports-of-ireland/>

We understand there are discussions underway about introducing a statutory obligation for services to co-operate. We would therefore urge the HSE and all State agencies to start now in bringing about this much needed change in culture. Life got so much better for Jack when Tusla and HSE worked closely together to meet his needs. Therefore, this concept of working together and funding services jointly has been established and can and should be built upon across all other areas.

We made two recommendations:

1. The HSE to immediately implement all the outstanding recommendations from Jack's case. Not doing so is causing harm and distress to children and families.
2. The Minister for Children, Equality, Disability, Integration and Youth and the Minister of State for Disabilities to set up an independent monitoring mechanism alongside the upcoming Disability Action Plan 2024-2026 to hold the State to account for their support of these children.

Today's Committee hearing is about rights based care for children with disabilities. At the most basic level, every child under our constitution has a right to grow up within their family. If they cannot be cared for at home, then they are entitled to the best quality alternative care.

Mr. Justice Max Barrett made this comment in his determination of a recent High Court case about a teenage girl with a disability who had to stay in a single room in a regional hospital for close to sixty days as there was nowhere else for her to go: "The court recalls the promise, pointed to in the Proclamation of Independence, of a republic that would cherish all the children of the nation...the court cannot but observe that Miss X [could] be forgiven if she does not feel greatly cherished by the republic at this time."

We wholeheartedly agree with this sentiment and believe it is relevant for many other children in Ireland.

Conclusion

Thank you again for your invitation to meet you today on such a significant rights issues impacting on children. My colleague Mr. Colm Leonard and I are happy to take questions.