

The importance of adequate health surveillance for children with Down syndrome

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Credit: Down Syndrome Ireland

Researchers at the Department of Paediatrics at Trinity's School of Medicine and Children's Health Ireland (CHI) at Tallaght University Hospital have established a unique 'one-stop' health surveillance clinic

for children with Down syndrome.

Down [syndrome](#) (or Trisomy 21) is the most common chromosomal abnormality, making up 8% of all registered such cases Europe-wide. In Ireland, one baby with Down syndrome is born out of 444 live births, that is about 110 babies each year. Management of this condition has improved over the decades, in part due to the implementation of healthcare programs that are designed to improve both life expectancy and quality of life for those with Down syndrome.

Clinicians in CHI in Tallaght who look after patients with Down syndrome noted that many of the services for patients in the Mid-Leinster area were largely provided by non-statutory bodies. This is because traditionally, care had been provided by religious and charitable organizations who were dedicated to a single type of disability, resulting in the access to and coordination of services being both variable and fraught with logistical difficulties.

Researchers at CHI, Tallaght had an ambitious aim; for 100% of [children](#) with Down syndrome at CHI Tallaght to receive care that was in accordance with the detailed Irish and UK guidelines. The collaborative group included Clinical Nurse Specialist Fiona McGrane, who was instrumental in setting up the new service. With [financial support](#) from the National Children's Hospital Foundation and the National Children's Research Centre, the group set up twice monthly 'one stop' multidisciplinary [health](#) surveillance clinics catering for 270 children with Down syndrome. This clinic involved care by a clinical nurse specialist, as well as same day appointments with audiology and phlebotomy.

The Trinity and CHI Tallaght research team undertook a research audit of the service and found that compliance to guidelines improved with each iteration of the clinic. Parental satisfaction was 100% when

surveyed, and there are now plans to expand the clinic to include Nutrition & Dietetics and Play Therapy, as well as to include interdisciplinary services such as cardiology, respiratory and mental health in due course.

Professor Eleanor Molloy, Professor and Chair of Paediatrics and Child Health in the Department of Paediatrics, School of Medicine, Trinity and senior author of the study acknowledged the collaborative efforts of the whole team, including Clinical Nurse Specialist Fiona McGrane and Paediatrician Dr. Joanne Balfe, in bring the project to fruition. She said: "As well as showing significant improvements to the adherence to guidelines, there was also considerable improvement in implementing health promotion strategies, such as providing information on immunisations. Our project provides a framework which would be potentially emulated and used in other medical conditions. This type of clinic is therefore a template for other conditions in children with complex health care needs."

Commenting on the research, Nicola Hart from Down Syndrome Ireland said: "Children with Down syndrome often have multiple health needs. It makes sense from the family perspective to reduce the number of hospital visits by having a multidisciplinary clinic and coordinated appointments, and our members are very appreciative of the clinic at CHI, Tallaght University Hospital. The clinic gets consistently positive feedback from our members who have visited or phoned for advice, and we would like to sincerely thank all involved. This approach to meeting the healthcare needs of children with Down syndrome is clearly working, and we will continue to lobby for additional clinics to be set up in other parts of the country to meet the medical needs of people with Down syndrome across their lifespan. This and other research coming from the clinic is very welcome. It will help to inform best practice not just for those attending, but for children who have Down syndrome in other parts of Ireland and around the world."

This research, "Implementation of a health surveillance clinic for children with Down syndrome," was published in February 2021 in the *Archives of Diseases in Childhood—Education and Practice*.

More information: Niamh C Lagan et al. Implementation of a health surveillance clinic for children with Down syndrome, *Archives of disease in childhood - Education & practice edition* (2020). [DOI: 10.1136/archdischild-2019-317126](https://doi.org/10.1136/archdischild-2019-317126)

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