



## MORE THAN A NUMBER: Rights Based Review of Child Health Waiting Lists in Northern Ireland

### 1. Background

NICCY was established under the Commissioner for Children and Young People (NI) Order 2003. The principal aim of the Commissioner is to safeguard and promote the rights and best interests of children and young people in NI. In exercising these functions, the Commissioner must also have regard to all provisions of the United Nations Convention on the Rights of the Child (UNCRC). *'More Than A Number'* was conducted in accordance with the powers and functions set out in the Order. In particular, in line with statutory duties to 'keep under review the adequacy and effectiveness of law, practice and services provided for children and young people by relevant authorities, to advise Government and relevant authorities, and encourage children and young people and their parents / carers to communicate with the Commissioner and for their views to be sought.

### 2. NICCY's Report

The aim of *'More Than A Number'* was to inform and advise ongoing and future work plans to address the problem of growing health waiting lists, to ensure **children are visible** as part of this process and that their **rights are considered** at all stages.

The Review **presents official waiting list data** for children's health services not published as part of DoH statistical bulletins. It also includes the **voices of children** and their families on the impact that waiting is having on their health and quality of life, and on what they think needs to change about the system. Whilst carrying out this review, NICCY also engaged with **professionals and practitioners** working in and for child health services.

#### Key Statistics

**The report presents a concerning picture of the number and length of waits for services:**

First consultant led outpatient waiting times have increased year on year between 2017 and 2021, with **35,292** children waiting for a first appointment at April 2021.

Of the **17,194** patients waiting over a year for a first consultant led outpatient appointment at April 2021, **11,239** had been waiting between 1-2 yrs, **5,445** between 2- 4 years and **510** over 4 years.

Inpatient and day case waiting times have increased year on year between 2017 and 2021, with **9,481** children waiting for a first appointment at April 2021, with 62% (**6092**) waiting over 1 year, and **197** over 4 years.

**26,818** under 18s were waiting for access to one of the community child health services that HSCTs monitor as part of the Primary Target List. This List doesn't include key services such as ADHD.

## Overarching Findings from this Review

The waiting time statistics provided in NICCY's report has brought into sharp focus the **numbers and lengths of time children are waiting** for different types of healthcare treatment. The report also offers an insight into **what and how statistics are collected** across the system - generally, official publicly available waiting time statistics for children are limited, a reasonable level of disaggregated data was available on request for first consultant led outpatient and inpatient / day case services. However, there is a **complete absence** of regional monitoring or reporting of waiting times for the community child health system.

## HSC reform built around a 'whole system, child centred' approach

Worsening waiting times is a symptom of a system under strain and therefore reform and redesign of services will be the change required to make the most significant difference to waiting times. The ongoing **reform of the system must fully consider hospital and community-based child health services and how they intersect with primary care, social services and education.** These are vital components of an integrated and right based health and social care system.

To date, children's services have not been given sufficient attention as part of the reform process. The '**Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community in Northern Ireland 2016-2026**' sets out important improvements in relation to specific parts of the child health system. There has been no official progress update report published on this work and our review has found that some **limited transformation funding to progress actions** from the Strategy was made available in 2019 - three years after the Strategy was first published.

There are also three times more **paediatric posts vacant** for over 3 months in Northern Ireland compared to England, with workforce provision in rural areas a particular problem. A workforce plan is critical to addressing this.

## The Impact of delayed access to healthcare on children and families

Delay in access to healthcare has a profound impact on all aspects of a child's life and the wider family circle and the **impact worsens the longer they wait.** For the review, we spoke with children and families on waiting lists across different parts of the healthcare system but the impact and overarching issues they raised were similar.



Effects of delays in access to healthcare can have a considerable adverse effect on **children's**:

- **Health outcomes;**
- **Emotional and mental wellbeing;**
- **Educational attainment;**
- **Relationships with family and friends; and**
- **Quality of life.**

Parents want to see improvements in **information, communication, and coordination** by services – these are important basic minimum standards and are particularly important when waiting times for treatment and interventions are as troubling as they are.

## Recommendations

NICCY's report has 17 recommendations under 4 thematic areas which aim to bring greater visibility of children across hospital and community child health services as well as accountability in regard to **decision making, performance reporting and budget allocation** processes:

### 1. Achieving a Child Rights Based Health and Social Care System

'Think child rights' should be central to all decision-making processes on the design and reform of our healthcare system. Child Rights Proofing (conducting a child rights impact assessment) as NICCY recommends and on which we have provided information and tools is vital. The establishment of a new **Waiting List Management Unit** within the HSCB since August 2021 is welcome. However, the focus of the unit, at least initially, appears to be specific hospital elective care services only. It is **vital that this work includes children's services** and extend its reach to community as well as hospital-based child health services.

### 2. Enabling Processes and Structures

A full review of the child health system should be undertaken to ensure that health and social care reform is based on an up-to-date understanding of need across the system which should take account of existing plans and strategies. Improve the **visibility and accountability for child health across departments and agencies** by having high level dedicated posts in place to oversee commissioning, policy and service delivery, to include a Deputy Chief Medical Officer for Child Health.

In recognition of the fact that children and families are struggling now, and that it will take time to reduce waiting times and reform the system, we have made a specific recommendation for the establishment of **an interim regional waiting list management** process to better monitor children who are currently on hospital and community health service waiting lists - to include enhanced clinical triage, targets for review appointments and support for parents / carers.

### 3. Performance Management

The system needs to improve what information is collected and how it is used. Waiting times is one of a number of important indicators of progress in the system's ability to deliver a healthcare system that meets the needs of the population. Progress needs to be measured in **improved outcomes, increased satisfaction and quality of care** (through services being supported to achieve (at least) minimum service standards).

#### 4. Waiting Time Measures, Quarterly Reporting and Targets

Comprehensive waiting time data on hospital and community child health services should be developed as part of a broader performance management system. A range of **data users** should be involved in determining the information collected by the system. This more detailed data should be reported on as **part of the DoH statistical reporting schedule**. Consideration should be given to establishing **specific waiting time targets** for child health services.

#### Dissemination and Monitoring

NICCY's Review is significant because it reminds us that waiting lists are a **problem which affects children too** and that children's healthcare reform is essential. Children's unimpeded access to the healthcare is the basis of a prevention / early intervention approach and an essential part of providing **'every child with the best start in life'** in line with the Programme for Government outcomes and the Children and Young People Strategy.

We must strive to get to a point where all children and young people can get access to the right care, at the right time and in the right place and that **no child is left waiting months or years** in a queue to access services. Children have a **right to receive high quality care** without any unnecessary delay.

NICCY has asked the Department of Health Minister for a formal response to our Report recommendations by **30 April 2022** and has committed to publishing a **Monitoring Report** in **Autumn 2022**. This will set out our position on progress made against the report recommendations.

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A copy of the report is available from the NICCY website- <https://www.niccy.org/waitinglists>