



**Children
In Hospital**
Ireland (CIH)

**Pre-Budget Submission
2024**

Children in Hospital Ireland (CIH Ireland) is a national organisation that works to support and advocate for the well-being of children, young people and their families before, during, and after hospitalisation.

Budget 2023 brought in welcome changes which contribute to our strategic aims to support children and their families. We welcome recent changes made to increase the Domiciliary Care Allowance and to extend the allowance for babies who remain in acute hospitals for up to six months from birth. However, while we welcome the increase in social welfare payments, it does not address the non-medical costs incurred by families who have a child who requires prolonged or frequent hospitalisation. Non-medical costs such as travel, parking, food and accommodation can create a huge financial burden and additional stress at what is already a difficult time for families. Research conducted by CIH Ireland identified that the median loss in income experienced by families was €300 per week [1].

CIH Ireland also welcomed the Waiting List Action plan for 2023 and the increased expenditure to address patient backlogs and reduce waiting lists. However, reduction targets have not been met so far in 2023 and we believe there is a further need for government to address hospital capacities and consultant shortages in Budget 2024 so that children have timely access to healthcare. This is in line with Article 24 of the UN Convention on the Rights of the Child [2], which states that children have the right to enjoy the highest attainable standard of health and access to healthcare services. It is the state's responsibility to ensure that no child is deprived of his or her right to access to such healthcare services.

Children in Hospital Ireland's core recommendation for Budget 2024 is to provide financial assistance to help families cope with the non-medical costs of child healthcare. Overall there are three key areas which need to be addressed in order to ensure children and their families receive the highest quality of care and are fully supported before, during and after hospitalisation.

Budget 2024 recommendations

- 1 Introduce a new social protection payment to assist parents with the non-medical financial costs arising from the prolonged or frequent hospital care of a child.**
- 2 Allocate a capped fund to subsidise the travel, accommodation, food, and childcare costs for families with children in hospital.**
- 3 Address wait lists and wait times so children have timely access to healthcare**

1

Support the non-medical costs associated with the hospital care of a child

CIH Ireland is calling for Budget 2024 to prioritise the investment to support the non-medical financial costs associated with the hospital care of a child. This will ensure that childhood illness does not contribute to poverty, disadvantage or social exclusion for the sick child, their siblings, or their family.

"While your child is in hospital your weekly budget basically doubles. It is like running two households at once"

Quote from parent

The existing statutory financial supports available through the social protection system do not adequately respond to the unique situation faced by parents whose child requires prolonged and/or repeated hospital care. While some families may be in receipt of domiciliary care allowance (DCA) and carer's benefit/carer's allowance, these payments are intended to assist parents with costs of caring for children with additional needs at home. When a child requires prolonged hospitalisation access to carer's benefit/carer's allowance, and domiciliary care allowance is restricted, as it is held that the cost of caring for the child is covered by the State. This fails to recognise the significant additional costs that parents are faced with.

Children in Hospital Ireland's research and report, *Childhood Illness, Financial Stress* (2020), provides compelling evidence of the range of non-medical financial costs which may be incurred by parents whose child requires prolonged and/or repeated hospital care. Significant costs faced by parents include travel, parking, food, accommodation, childcare for other children, and mental health supports for both the child and the family members.

The impact of these costs on families with a child who requires hospitalisation was further confirmed by the Northern Ireland Children's Health Coalition, who carried out research and published *The Hidden Costs of Having a Child in Hospital in Northern Ireland* [3]. "Caregivers reported significant financial ramifications of having a child who experienced inpatient care."

Childhood Illness, Financial Stress (CIH Ireland, 2020)

- The median loss in income experienced was €300 per week.
- One-third of parents surveyed had given up paid employment to care for their sick child.
- 61% reported that they had to take on debt to meet non-medical costs associated with having a child in hospital care.

To alleviate this, we recommend the **development of a social protection payment** to support parents and guardians with the non-medical costs that arise with long-term or frequent hospital care of a child. Parents should be entitled to the payment on a week-by-week basis. If a child requires a stay of more than four consecutive days their

parents should be eligible for the payment for that week, with that entitlement being extended if the child remains in hospital for additional weeks. Furthermore the payment should also be accessible to families that require frequent visits for ongoing treatment as these families are also impacted by significant costs. Applications could be made by parents to the Department of Social Protection with a medical sign-off required from the child's consultant.

2 Allocate a capped fund to subsidise the non-medical costs for families with children in hospital.

As an immediate measure, we recommend allocating a capped fund, on a pilot basis, to provide immediate assistance to families, which has proven to be a successful method of support within the UK. In 2021, the Scottish Government launched the Young Patients Family Fund [4]. The fund provides financial support for the families of inpatients from birth up to the age of 18 and covers costs such as food, travel and overnight accommodation where necessary. Claims can be made on a weekly basis when a child is in hospital and/or for up to three months after discharge. The Northern Ireland Children's Health Coalition has also called for a £4 million fund to assist families with a child who requires hospitalisation in the UK and Ireland [5]. In line with the current provision in Scotland and the proposal for Northern Ireland, we recommend allocating an initial €9.5 million for families to claim non-medical expenses incurred on a receipt basis. As this capped fund would be a pilot scheme, it should be monitored during 2024 and amended for budget 2025 based on demand.

CAYA - Irish Cancer Society

Research carried out by Children in Hospital Ireland and the Irish Cancer Society in 2022 reported that families could spend on average €201 per month on parking charges when taking their child to cancer treatment. Public transport is often not a viable option for these families, due to their child's compromised immune system. [6]

CIH Ireland supports the Irish Cancer Society's budget 2024 submission in their call for the government to address parking charges in hospitals across Ireland and support the families whose children require prolonged or repeat hospital care. [7]

[1] Childhood Illness, Financial Stress 2020. https://childreninhospital.ie/wp-content/uploads/2021/08/Children-in-Hospital-Report_1-FINAL.pdf

[2] <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>

[3] https://pure.ulster.ac.uk/ws/portalfiles/portal/121237275/Child_In_Hospital_Hidden_Costs_Report_v20.pdf

[4] <https://www.mygov.scot/young-patients-family-fund>

[5] <https://www.bbc.com/news/uk-northern-ireland-65939172>

[6] <https://childreninhospital.ie/wp-content/uploads/2022/08/Hospital-Parking-Charges-Report-Final.pdf>

[7] https://www.cancer.ie/sites/default/files/2023-05/2024%20Prebudget%20%26%20CAYA_both_digital.pdf

3

Address wait lists and wait times so children have timely access to healthcare

Wait times can have a significant impact on a child and can lead to the deterioration of their condition and reduce their quality of life. In some instances they may enter adulthood and still not have received the services they need. The National Treatment Purchase Fund (NTPF) has shown a significant increase in the number of children on waiting lists for inpatient treatments and day treatments since 2022. A slight decrease in the waiting list for child outpatient appointments has been noted with 87,209 on the list in June 2022 to 85,668 in June 2023 [8].

"The 2023 Waiting List Action Plan has reached its halfway point but is nowhere near achieving the reduction targets set for the end of the year."

IHCA President, Professor Robert Landers

With 44% of children waiting more than 6 months for an outpatient appointment in June 2023 [8] and 43% of children waiting more than 6 months on the inpatient/day cases waiting list [9], we are nowhere near the overall targets set out by Sláintecare to attain a maximum waiting list of 10 weeks for outpatient appointments and 12 weeks for inpatient/day cases [10]. Nor are we on track to achieving the targets set out by the 2023 Waiting List Action plan in which 90% of patients are waiting less than 9 months for an inpatient or day case procedure or 15 months for an outpatient procedure [11].

Wait times in emergency departments have also increased for children needing admissions during the first quarter of 2023, with an average wait time of 13.3 hours in comparison to 10.2 hours in 2022 [12]. According to the Irish Hospital Consultants Association "Such long waits for treatment are associated with worse patient outcomes and can lead to additional demands on healthcare resources due to the additional treatments required to manage symptoms." [13].

Recent figures by the HSE have also shown a continuing shortage of child inpatient psychiatric beds with a 40% drop in admissions to the four public Child and Adolescent Mental Health Services (Camhs) approved centres last year due to staff shortages.[14]. This is unacceptable. We call on the Government in Budget 2024 to urgently allocate expenditure to address the shortage of beds, lack of adequate facilities and consultant and staff vacancies.

To conclude, our core priority for Budget 2024, should be to address the non-medical costs associated with having a child in hospital. The best interest of the child is not being promoted if their parents/carers cannot fulfil their caregiving role. Parents/Carers need adequate support to sustain the financial implications of having a child in hospital.

In Budget 2024, there is a need for significant investment to accelerate the process of delivering high-quality healthcare services which enable children to lead active and healthy lives. Progress towards implementation of Sláintecare and The Waiting List Action Plan must be accelerated. Currently, the healthcare system for children in Ireland is characterised by poor access, lengthy waiting lists, and under investment in crucial services. Early intervention will help deliver better health outcomes for children and ensure their care is as cost-effective as possible. This will support both children and their families.

Every child and young person deserves, and has the right to timely access to healthcare.

[8] <https://www.ntpf.ie/home/pdf//2023/06/nationalnumbers/out-patient/National01.pdf>

[9] <https://www.ntpf.ie/home/pdf//2023/06/nationalnumbers/in-patient/National01.pdf>

[10] <https://www.hse.ie/eng/services/publications/serviceplans/national-service-plan-2023.pdf>

[11] <https://www.gov.ie/pdf/?file=https%3A%2F%2Fassets.gov.ie%2F249526%2F8b203212-06b9-4ddc-96f7-9938b0707e19.pdf#page=null>

[12] <https://www.rte.ie/news/health/2023/0523/1385106-wait-times/>

[13] <https://www.ihca.ie/news-and-publications/hospital-list-%E2%80%98long-waiters%E2%80%99-on-the-rise-again-as-increased-capacity-becomes-more-critical>

[14] <https://www.irishexaminer.com/news/arid-41189776.html>



**Children
In Hospital**
Ireland (CIH)

Suite 113 4-5 Burton Hall Road
Sandyford, Dublin 18

 01 290 3510

 childreninhospital.ie

 info@childreninhospital.ie

Company Registration No. 297192 | Charity No. 6632

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