

Supporting children in hospital

Budget 2023 submission



Making hospital a happier place through play and advocacy

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Children in Hospital Ireland (CIH) is calling for Budget 2023 to prioritise the investment in high-quality healthcare for all children and to ensure that parents and families are not faced with an excessive financial burden as a result of non-medical financial costs associated with the hospital care of a child.

Access to healthcare is a children's rights issue – Article 24 of the United Nations Convention on the Rights of the Child (UNCRC) states that every child 'has the right to enjoy the highest possible standard of health, to access health and other related services and to facilities for the treatment of illness and rehabilitation of health'.

The total investment package required in Budget 2023 is €386.6 million, with significant expenditure required by the Department of Health and the Department of Social Protection.

Our submission proposes two packages of investment:

High-quality healthcare for all children

- **€100 million** to progress the roll-out of free GP care for all children
- **€48 million** to expand primary and community-based care services, reducing pressure on acute services
- €16 million to move towards the delivery of the recommended number of CAMHS beds and the full resourcing of community CAMHS teams
- €150 million to reduce waiting lists for treatments, assessments, and tests, with a focus on long-term capital investment in community-based services to deliver lasting positive outcomes for children and their families

Total Package - €314 million

Reducing the financial burden on families

- **€20 million** to introduce a new social protection payment to assist parents with the non-medical financial costs of hospital care
- **€30 million** to extend Domiciliary Care Allowance to children aged 16 and 17
- **€11.2 million** to increase Domiciliary Care Allowance by **€20** per month
- **€9.5 million** initial funding to develop a scheme to subside the travel, accommodation, food, and childcare costs for families with children in hospital
- €500,000 initial funding to support the removal of hospital parking charges for parents of children who require prolonged stays or frequent visits

Total Package - €72.6 million

Investment in high-quality healthcare for all - €314 million

The overall package of investment required in Budget 2023 for healthcare services delivery is €314 million*

- €100 million to progress the roll-out of free GP for all children
- **€48 million** to expand primary and community-based care services, reducing pressure on acute services
- **€16 million** to move towards the delivery of the recommended number of CAMHS beds and the full resourcing of community CAMHS teams
- **€150 million** to reduce waiting lists for treatments, assessments, and tests, with a focus on long-term capital investment in community-based services to deliver lasting positive outcomes for children and their families

Total Package - €314 million

*Based on the recommendations made in the Sláintecare (2017) report

In Budget 2023, 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 Sharing the Vision must be accelerated. Currently, the healthcare system for children in Ireland is characterised by poor access, lengthy waiting lists, and underinvestment in crucial services.

Children are particularly impacted by lengthy waiting lists, as they have rapidly evolving needs. Failure to access the supports they require in a timely manner can have a long-term detrimental impact on their development. In some instances they may enter adulthood and still not have received the services they need.

Early intervention is essential, helping to deliver better outcomes for children and ensure care is as cost effective as possible.

Ireland is an outlier among countries in Western Europe – a significant number of children do not have access to GP and primary care services free of charge. The implementation of free GP care for all children under 18 has been repeatedly delayed, with only those under six currently benefitting.

Ireland was ranked 22nd out of 35 European countries in the 2018 Health Consumer Powerhouse (HCP) study, but was ranked last for accessibility[1]. Lengthy waiting lists are a significant contributor to this ranking. As of June 2022, there are 100,770 children on waiting lists for treatment, assessments, and tests[2]. Additionally, 4,003 children are waiting on support from Child and Adolescent Mental Health Services (CAMHS), with 405 waiting more than 12 months[3].

In line with many other countries Ireland is experiencing a significant increase in mental health issues among young people, particularly in the wake of the Covid-19 pandemic. Mental health services for children are inadequate, with successive governments failing to deliver on the recommendations of A Vision for Change policy (2006) and its successor Sharing the Vision (2020). Implementation of Community CAMHS has not reached its targets, with a shortfall of 118 psychologists[4]and only 73 community CAMHS teams[5], far below the target of 129.

There are only 72 CAMHS inpatient beds nationally, based in Dublin, Cork, and Galway[6], significantly below the target of 100 beds. The admission of children to adult inpatient psychiatric facilities is a continued practice and a pressing children's rights issue which must be addressed. This has been identified by the UN Committee on the Rights of the Child as something which the State must take steps to end. Despite this, 27 children were admitted to adult units in 2020. There are only two high observation CAMHS beds, both in Dublin. CAMHS units generally do not take out-of-hours admissions, with children in crisis only able to access an emergency department, a children's hospital, or an adult inpatient unit[7].

Investment in the full range of CAMHS services is essential to ensure that children's mental health needs are catered for both by community-based services and, in the case of acute illness, ready access to emergency services and inpatient care in an appropriate setting.

Notes

- [1] https://healthpowerhouse.com/publications/#200118
- [2] https://www.ntpf.ie/home/nwld.htm
- [3] https://www.rte.ie/news/ireland/2022/0523/1300631-camhs-delays/
- $\label{thm:constraint} \begin{tabular}{ll} [5] https://www.hse.ie/eng/about/personalpq/pq/2021-pq-responses/september-2021/pq-41553-21-bernarddurkan.pdf \end{tabular}$
- [6] https://www.hse.ie/eng/about/personalpq/pq/2021-pq-responses/october-2021/pq-49372-21-claire kerrane.pdf and the second of the properties of the prope
- [7] https://www.mhcirl.ie/sites/default/files/2021-06/MHC-Annual-Report-2020.pdf

Reducing the financial burden on families - €72.6 million

Children in Hospital Ireland call for an overall package of investment of €72.6 million in Budget 2023 to alleviate the financial burden on families with sick children

- **€20 million[9]** to introduce a new social protection payment to assist parents the non-medical financial costs arising from the prolonged or frequent hospital care of a child
- €30 million[10] to extend Domiciliary Care Allowance to children aged 16 and 17
- **€11.2 million[11]** to increase Domiciliary Care Allowance by **€20** per month
- €9.5 million[12] initial funding to develop a scheme to subside the travel, accommodation, food, and childcare costs for families with children in hospital
- €500,000 initial funding to support the removal of hospital parking charges for parents of children who require prolonged stays or frequent visits

Total Package - €72.6 million

Government interventions are required in Budget 2023 to ensure that childhood illness does not contribute to poverty, disadvantage or social exclusion for the sick child, their siblings, or their family.

Research carried out by Children in Hospital Ireland (CIH) and published in its report, Childhood Illness, Financial Stress (2020)[8], 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 and parking, food, accommodation, childcare for other children, and mental health supports.

"I feel guilty worrying about money because I'm so happy my children are well" - Quote from a parent

Parents are required to be almost constantly present with their child in hospital and form a key part of the child's care team. This restricts their ability to participate in paid employment, with a resultant loss of income, thus compounding the financial difficulties they experience. According to parents surveyed, 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.

"While your child is in hospital your weekly budget basically doubles. It is like running two households at once"– Quote from a parent

The non-medical costs have a significant impact on the entire family unit, with 58% of parents reporting a significant negative financial impact on the household finances and 61% reporting that they had to take on debt to meet non-medical costs associated with having a child in hospital care.

"I'm trapped financially. I don't know how much longer I'll be able to manage" - Quote from a parent

The non-medical financial costs experienced by parents with children in hospital weaken the financial stability of the family unit, with adverse consequences for the sick child, their parents, and other children within the household. These costs contribute to the likelihood of the family experiencing poverty, disadvantage or social exclusion. There is also a cumulative and long-lasting effect where the debt incurred continues to impact on family finances for many years after the child has been in hospital. The existing social protection supports do not adequately respond to the unique situation faced by parents whose child requires prolonged and/or repeated hospital care.

In addition to the issues raised above, families who are in receipt of domiciliary care allowance (DCA) and carer's benefit/carer's allowance may have their access to these supports significantly restricted when their child requires prolonged hospitalisation as it is held that the cost of caring for the child is covered by the State.

- If a child is hospitalised for more than six months, their parents are no longer eligible for these payments.
- Parents who apply for these payments when their child enters hospital, or if they require hospitalisation from birth, cannot receive them until they leave.
- Children aged 16 and 17 are not entitled to access domiciliary care allowance.

These restrictions reflect a failure to recognise the significant additional costs and loss of income that parents are faced with when their child needs hospital care.

The only other payment potentially available to parents is the Exceptional Needs Payment, designed to assist in meeting once-off, exceptional expenditure which cannot be covered by weekly income. CIH research indicates that this scheme is largely inaccessible for parents with children in hospital, stemming from the strict eligibility criteria.

This financial burden faced by parents is a significant children's rights issue. The United Nations Convention on the Rights of the Child (UNCRC) places specific obligations on states to provide adequate assistance to support parents in their caregiving role.

The Committee on the Rights of the Child (Com-CRC) has called for a holistic approach to respond to the social determinants of health and for states to recognise and support the central caregiving role of parents. Measures called for include financial supports for parents, such as subsidies, paid parental leave, and grants.

Notes

- [8] https://childreninhospital.ie/wp-content/uploads/2021/09/Children-in-Hospital-Report_1-FINAL.pdf
- [9] See appendix one
- [10] https://www.kildarestreet.com/wrans/?id=2021-11-16a.927
- [11]https://www.oireachtas.ie/en/debates/question/2022-06-28/640/#pq_640
- [12] With the level of investment, the government could provide a meaningful level of support to 4,000 families with children in hospital.

Appendix One - Costs associated with introducing a new social protection payment

Although it is difficult to accurately determine the costs associated with providing a payment without access to all the available information, CIH estimate it would cost approximately €20 million per annum. This figure accounts for variation in the demand for the payment – most would require support for a few weeks, with a minority requiring support throughout the year.

CIH believe a simple, accessible scheme could be developed, with parents 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 via the hospital administration office, with a medical sign-off required from the child's consultant.

There were 24,216 inpatient admissions to the Children's Health Ireland hospitals in 2019. The majority of these admissions were short and not part of ongoing treatment needs. As such most families would not qualify for the payment.

2019 figures obtained from Children's Health Ireland point to the number of families who would be reached by the payment.

- 5,460 children spent more than four consecutive days in hospital
- 1,022 children spent more than 14 consecutive days in hospital
- 543 children spent more than 21 consecutive days in hospital
- 351 children spent more than 28 consecutive days in hospital
- 1,980 children required ten or more hospital visits, out of a total of 334,500 engagements with the services of Children's Health Ireland.

According to the Department of Social Protection, the extension to DCA announced in Budget 2022 to include children who spend between three and six months in hospital is estimated to benefit 170 children.

These figures all indicate that the number of children spending several months in hospital is minimal. Only a small minority of families would require this payment throughout the year. As such, the cost to the exchequer would be modest.

About Children in Hospital Ireland (CIH)

Children in Hospital Ireland (CIH), founded in 1970, seeks to promote the well-being of children within the healthcare system in Ireland in particular, before, during and after hospitalisation. It advocates for reform and improvement in the healthcare system so that the child's right to child-centred health services may be fully realised. It provides a volunteer-led play and recreation service in 14 hospitals across Ireland. www.childreninhospital.ie

Children in Hospital Ireland

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