



**Children
In Hospital**
Ireland (CIH)

**Pre-Budget submission to
the Oireachtas Joint
Committee on Social
Protection**



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In Hospital**
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Making hospital a happier place through play and advocacy

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Executive Summary

A new social payment is required to assist parents and carers with the non-medical financial costs arising from the prolonged and/or repeated hospital care of a child.

- Parents with children in hospital have **significant additional expenses**, while also facing **reduced earnings from employment**.
- The **existing social protection supports do not adequately respond** to the unique challenges faced by parents in this situation.
- Ireland's **National Action Plan** for the **EU Child Guarantee** makes **a commitment to easing the financial burden on parents with children in hospital**, in order to ensure that every child can have the best start in life.
- The Irish state has **obligations under the United Nations Convention on the Rights of the Child (UNCRC)** to **promote the best interest of the child** as a primary consideration in decision-making.
- The Irish state has obligations under the UNCRC to **provide meaningful assistance to parents** in their caregiving role.
- The **UN Committee on the Rights of the Child** has **identified social protection supports for parents as an important measure** to promote the right of the child to health.
- The **European Association for Children in Hospital (EACH) Charter** states that parents should not experience financial hardship when their child is in hospital
- The **public expenditure required to provide a new payment would be modest**. In any year, only a small minority of the total number of children who receive hospital care have prolonged stays and/or repeated attendances.
- It is estimated that it would cost **€20 million annually** to deliver an effective scheme. As a starting point, **if the state invested €1 million**, it would be possible to **provide a weekly payment of €230 to 700 families for up to six weeks**.

Introduction

Children in Hospital Ireland (CIH) welcome the opportunity to make a submission to the pre-budget scrutiny process by Oireachtas Joint Committee on Social Protection, Community and Rural Development and the Islands.

In this submission we highlight the non-medical financial costs which may be incurred by parents whose child requires prolonged and/or repeated hospital care. We make several policy proposals for how the social protection system can address these costs, through the introduction of a new payment, reforms to existing supports, and the commissioning of independent research.

The impact of the non-medical financial costs of hospital care on parents and families

Research carried out by CIH and published in its report, Childhood Illness, Financial Stress (2020), provides compelling evidence of the range of non-medical costs which may be incurred by parents whose child requires prolonged and/or repeated hospital care.

Children are not small adults - they need their primary caregiver to be with them on a full-time basis. Parents not only wish to be but also 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, compounding the financial difficulties they experience. This was evident in the findings of the CIH study.

- A large majority had experienced a fall in income, with their partners also faced with reduced earnings. The median weekly loss in income among respondents was €300, with partners losing a further €200 per week on average.
- 33% of parents surveyed had given up work to care for their sick child.
- 58% of parents reported a strong or extreme negative financial impact due to their child being in hospital.
- The majority indicated that they had serious concerns about their finances.
- 61% of parents reported taking on debt to meet non-medical costs, with 49% borrowing from friends or family.
- On a typical day, parents surveyed spent a median amount of €36 on food. Typically, cooking facilities are not available and parents, with limited opportunity to leave their sick child, must often purchase food on-site.
- Hospital visits were highlighted as another significant expense – Parents surveyed spent a median amount of €35 per day on travel and parking. Our research indicated significant disparities in these costs, with some parents spending several hundred euro to travel long distances.

The hospitalisation of a child also impacts on the mental and physical health and well-being of parents.

- Parents surveyed spent prolonged periods away from home during their child's hospital stay. While the median time away from home was 15 nights, several respondents were away for in excess of 150 nights.

- 86% of parents regularly slept in the hospital ward. Adequate rest is unlikely for parents in this situation, due to sleeping on chairs and on the floor and the level of medical activity continuing to take place during the night.
- CIH research has shown that one way in which parents reduce their food expenditure when in hospital is by not eating regular meals. In one case, a parent collapsed and was hospitalised, having not eaten for five days.
- Food available outside of core hospital hours is often unhealthy and lacking in nutrition.
- 21% of respondents accessed mental health services, with a further 38% in need of support but unable to access them due to cost, waiting times or accessibility issues. The median annual spend by parents on private mental health supports was €400.

Existing Financial Supports for Parents from Hospitals and Charities

The existing measures to reduce the financial burden on parents are inadequate. While some hospitals do offer concessions on parking or provide assistance with food or accommodation costs, there is no standardised approach across hospitals and it is often addressed on a case-by-case basis. It can be difficult for parents to access information about their entitlements through official sources, often relying on parent-to-parent knowledge exchange.

Medical social workers provide important support to families. CIH research indicates, however, that the medical social work departments in many hospitals do not have enough funding to adequately assist families in urgent need. Our research highlighted that the limited financial support that medical social workers have been able to offer in the past has been eroded over time with even their ability to provide food and parking vouchers having been curtailed.

Charities play a vital role in supporting parents, but have limited resources and can only support a small number of families at any one time. Many supports provided are also illness specific. Most organisations are unable to offer emergency funding and long waiting periods can apply

70% of parents surveyed reported that they received no financial support from from hospitals or charities during their child's stay. Only 6% received parking vouchers and 7% food concessions.

Existing Social Protection Supports for Parents

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/carers 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/carers 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.

The following restrictions apply

- If a child is hospitalised for more than six months, their parents are no longer eligible for these payments. This was extended from three months in Budget 2022.
- 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.

Due to these restrictions, parents whose child requires prolonged hospitalisation are not able to access targeted state supports. 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 rarely utilised by parents with children in hospital, stemming from the strict eligibility criteria.

The impact of these restrictions was recently highlighted in an unsuccessful appeal before the Supreme Court. In this instance, a child was born with a serious medical condition and required hospital care from birth. The child's father was unable to access Domiciliary Care Allowance for two and half years while the child remained in hospital. This is due to the requirement that the child must live at home with their parents to receive the payment. The father, as a result, did not receive any financial support from the state and was also unable to stay in paid employment, due to the parental care needs of the child in hospital.

While the court rejected the appeal, it acknowledged that parents are expected to provide an extensive amount of care when their child is in hospital. The court further noted that the limitations placed on entitlement to DCA represent a 'policy choice' by the Government to 'distinguish between classes of people'

This case further illustrates that the social protection system is not currently adequately equipped to respond to the specific needs of children in hospital and their parents. There is a clear need to move towards a specific social protection payment specifically designed to assist parents with the non-medical financial costs arising from the prolonged and/or repeated hospital care of a child.

Obligations of the state to promote children's rights and the role of parents

Children's rights are enshrined in the United Nations Convention on the Rights of the Child (UNCRC) and in Bunreacht na hÉireann.

The UNCRC recognises that children, due to their age and vulnerability, are entitled to specific additional rights, whilst reaffirming that they also have all the same basic human rights as adults. Core to the convention is the principle that the best interests of the child should be a primary consideration for state institutions when taking any action which impacts on children – when conflicting choices are available, the state is obliged to opt for the approach which best promotes the interests of the child.

The UNCRC has four general principles

- All rights guaranteed by the Convention must be available to all children without discrimination of any kind (Article 2)
- The best interests of the child must be a primary consideration in all actions concerning children (Article 3)
- Every child has the right to life, survival, and development (Article 6)
- The views of the child must be considered in all matters affecting him or her (Article 12)

The role of parents as the primary caregiver is emphasised throughout the convention. States have specific obligations to assist parents in this role including

- The requirement by states to respect parental rights, duties, and responsibilities (Article 5)
- The right of the child not to be separated from their parents unless it is in their best interest (Article 9)
- Provision of adequate assistance to support parents in their caregiving role (Article 18)
- Supporting parents and providing material assistance to ensure every child has a standard of living adequate for their physical, mental, and social development (Article 27)

The United Nations Committee of the Rights of the Child has considered this issue in general comments. General Comment 15 (GC-15) looks at Article 24 of the UNCRC – the right to the highest attainable standard of health. The committee consider health an inclusive right, calling for a holistic approach to respond to the social determinants of health.

GC-15 recognises the role of parents in promoting the right to health, calling for increased recognition of and support for the central caregiving role of parents. Measures called for include

- Social protection measures to promote the right to health, including subsidies, paid parental leave, and grants
- Counselling and mental health support for parents when their child is experiencing health issues
- State support to increase the capacity of the child to self-advocate for their right to health

Parents are the primary caregiver for their child. The rights, responsibilities, and duties of parents do not change or cannot be diluted when a child is in hospital. This is clearly affirmed in Article 2 – All rights are guaranteed for all children without discrimination. As per Article 3, all activities undertaken by institutions should hold the best interests of the child as the primary consideration. The state is required to provide care and protection to children. Furthermore, the state assumes specific responsibilities to support parents in their caregiving role, including through the provision of appropriate and material assistance. GC-15 expands on this, explicitly calling for targeted supports to assist parents and to promote the right to health.

The EU Child Guarantee requires member states to guarantee effective and free access to quality healthcare. Ireland's National Action Plan for the EU Child Guarantee makes a commitment to easing the financial burden on parents with children in hospital, starting with the removal of hospital charges. The stated aim of the plan is to ensure that hospital care is accessible and affordable, ensuring that every child can have the best start in life. It is necessary to address the non-medical financial costs if the obligations of the state under the guarantee are to be achieved.

The European Association for Children in Hospital (EACH) Charter identifies specific supports which should be provided for parents, including free hospital accommodation and that they should not incur a financial loss when their child is in hospital. The proposed supports echo the sentiments expressed in Articles 9 and 18 of the UNCRC, which seek to prevent family separation and to support parents in their caregiving role respectively.

The CIH research findings, as presented above, point to a shortcoming by the state. The best interest of the child is not being promoted if their parents are not receiving adequate support to fulfil their caregiving role. The financial, physical, and mental health impacts experienced by parents indicate a shortcoming by the state to adequately promote the rights of the child as required by Bunreacht na hÉireann, the UNCRC and the EU Child Guarantee.. In failing to provide support to alleviate these hardships, the state is not placing the best interests principle at the centre of its decision-making.

Moving towards a new social protection payment in Budget 2023

A new social payment is required to assist parents and carers with the non-medical financial costs arising from the prolonged and/or repeated hospital care of a child. The public expenditure required to provide a new payment would be modest. In any year, only a small minority of the total number of children who receive hospital care have prolonged stays and/or repeated attendances.

According to 2019 figures provided by Children's Health Ireland,

- 543 children spent in excess of 21 days in hospital, out of a total of 24,216 inpatient admissions.
- 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.
- 33 children required hospital stays from birth of 30 days or more.

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. This indicates that the number of children spending several months in hospital is minimal.

Whilst 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. 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.

As a starting point, **if the state invested €1 million, it would be possible to provide a weekly payment of €230 to 700 families for up to six weeks.**

There are precedents for similar supports

- The National Cancer Control Programme, through the Irish Cancer Society, provide a limited transport assistance fund for travel to cancer treatment.
- In July 2021, the Young Patient Family Fund was launched in Scotland, assisting parents and siblings with the travel, accommodation, and food costs arising from visiting a child in hospital. An initial sum of £5 million was allocated to this fund.
- Parents with children travelling from Northern Ireland to Children's Health Ireland @ Crumlin for treatment for congenital heart disease receive a daily subsistence payment from the NI health service.

Additional CIH Policy Proposals

As discussed, our headline policy proposal is the introduction of a new social protection payment to assist parents with the non-medical financial costs associated with prolonged and/or repeated hospital care of a child.

Further measures which should be taken are to

- Extend access to domiciliary care allowance and carer's allowance/carer's benefit to support parents whose child requires hospitalisation from birth.
- Extend access to domiciliary care allowance and carer's allowance/carer's benefit to parents whose child requires hospitalisation for more than six months.
- Extend access to domiciliary care allowance to children aged 16 and 17.
- Commission independent research to measure the full economic and social costs faced by household arising from childhood illness.
- Recognise and support the continued caregiving role of parents when a child is in hospital.

Testimonies from parents about the impact of the non-medical financial costs

"I'm trapped financially. I don't know how much longer I'll be able to manage"

"I feel guilty worrying about money because I'm so happy my children are well"

"Family helped as best they could but they also had bills to pay. There was no financial help we could apply for"

"I couldn't support my partner in the hospital. I had to work to pay our mortgage and keep our other children in school"

"To share our time between our child in hospital and our child at home we would have to travel three hours each way"

"We have to manage working, bills and learning to adapt all whilst looking after a sick child in hospital"

"Unexpected costs like the family car and the rising cost of food and fuel have started to eat into my budget"

"Bills still need to be paid at home. Childcare still has to be paid even when they don't attend"

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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

About the Network of Childhood Illness Organisations (NCIO)

This submission is supported by the members of the Network of Childhood Illness Organisations (NCIO). The NCIO has 15 member organisations representing a range of childhood illness and patient advocate groups. It works collaboratively to address the challenges faced by children and their families in the healthcare system.

www.ncio.ie



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