



Making hospital a happier place for children through play and advocacy

## **Submission to the Joint Committee on Disability Matters**

November 2020

## About Children in Hospital Ireland

[Children in Hospital Ireland](#) is a national organisation committed to promoting and ensuring the welfare of all children in hospital and their families. For 50 years, the organisation has been directly working with sick children.

## Introduction

Children in Hospital Ireland welcomes this opportunity to contribute to the consultation process, as a representative organization for sick children, including children with disabilities.

This submission focuses on several issues affecting both children with disabilities who must attend hospital, and their families. In some cases, this may be attending hospital for a specific once-off service (such as getting an MRI scan), while in other cases this may refer to attending outpatient visits regularly, or experiencing (a) prolonged inpatient stay(s).

Children in Hospital Ireland's submission focuses on the lived experiences of the families of children with disabilities. The content of the submission is based on information provided by the families of children with disabilities, as well as from social workers, hospital staff and members of the [Network of Childhood Illness Organisations](#).

A key piece of research which is referred to throughout the submission is the report [Childhood Illness, Financial Stress: The Hidden Costs of Hospital Care for Children](#) (*Childhood Illness, Financial Stress*), published by Children in Hospital Ireland in October 2020. The research was conducted using both surveys and interviews with the families of children who were in (or had recently been in) hospital, as well as with social workers, hospital staff and representatives from childhood illness organisations.

## Financial Issues for Parents of Children with Disabilities in Hospitals

### **No Statutory Payment**

Currently, there is no statutory payment specifically designed to help parents/guardians with the non-medical costs associated with hospital care for a child. The Domiciliary Care Allowance, Carer's Benefit, and Carer's Allowance - statutory payments which may normally support the family of a child with a disability - are all suspended if the child remains in hospital for longer than 13 weeks. As one parent of a child in hospital said, stopping the Domiciliary Care Allowance is "penalising those who have children in the hospital long-term".

### **Accommodation Costs**

Staying with your child in hospital is an accepted and necessary part of the care of a child in hospital and this is even more so for parents of a child with a disability. Children with reduced communication or additional needs will need their parents with them on a full time basis in hospital in order to ease anxiety for the child and help them to understand what is happening. However, by staying in hospital and caring for their child, significant additional costs are placed on parents and this is often alongside a significant reduction in income through loss of earnings.

Despite the removal of these statutory payments, families experience significant costs when they have a child in hospital. The report [\*Childhood Illness, Financial Stress\*](#) (Children in Hospital Ireland, 2020) interviewed families with children in hospital. It found that 96% of respondents stayed away from home overnight, to remain close to their child in hospital. Many parents stayed in their child's hospital room (for at least part of their hospital stay). As one parent explained

"I've slept on what's basically a yoga mat under a sink; you're getting in the nurses' way. How do you expect someone, anyone, to function... the sleep deprivation is a massive issue."

While some parents were able to avail of parents' accommodation in the hospital (averaging €18-30 per night) or a charity run property, these rooms are in limited supply. Other parents needed to stay with family/friends, in rented accommodation, in a B&B or hostel (averaging €125 per night), or a hotel (averaging €144 per night).

As one social worker summarised the need for parents to stay with/nearby their children in hospital

“We require that parents be here... Yet we’re forcing parents to pay even though they have to be here.”

### **Transport Costs**

Travel costs can be substantial for the parents of children attending hospital, particularly for those travelling to a different county for hospital care. This is compounded where parents must frequently commute between their child staying in the hospital, their job, and/or another child/children at home.

89% of parents interviewed in *Childhood Illness, Financial Stress* reported using a family car for transport to the hospital. Public transport is often not a viable option due to accessibility options or immunity issues

Parking costs vary greatly between hospitals. Where reduced fees for long-stay patients are available, information on these can be difficult to access. In addition, there is limited disabled parking available for parents who are bring a child with access issues to the hospital.

However, there are models of state support for children in ensuring accessible transport, which could be adapted to support the high travel costs associated with children with disabilities attending hospitals.

The Irish Department of Education provides school transport services for children with special educational needs and where this cannot be provided, a Special Transport Grant to help with the cost of making private transport arrangements may be available. While this example relates to education, a similar Transport Grant could be adapted for hospital visits.

Another model is the Hospital Travel Costs Scheme which operates through the NHS in Northern Ireland. This schemes offers support for travel to hospital in cases where children are referred for cardiac treatment in a hospital in the Republic of Ireland.

### **Other Additional Costs**

Other costs associated with a hospital stay including food, specially adapted clothes for the child, laundry costs and others, place significant stress and burden on parents of children with a disability. Please see *Childhood Illness, Financial Stress* for further details on the costs which families report.

## **Loss of income**

These costs are frequently compounded by a loss of income. *Childhood Illness, Financial Stress* found that 69% of respondents lost income as a result of their child's hospital care. In addition, 65% reported a reduction in their partner's income.

## **UNCRPD**

The right for children with disabilities and their parents to be together during hospitalisation is protected by several international and national conventions, including:

- Article 23.3 of the [United Nations Convention on the Rights of People with Disabilities](#) (UNCRPD) requires that  

‘States Parties shall ensure that children with disabilities have equal rights with respect to family life.’
- [United Nations Convention on the Rights of the Child](#) acknowledges the child's right to be with, and receive the care of, his/her parents, who are recognised as the child's primary caregivers (Articles 9 and 18).
- Article 21 of [The Council of Europe Guidelines on Child-friendly Healthcare](#) states that:  

“Child-friendly health care” includes [...] preventing the separation of the child from his or her family unless it is in the best interest of the child.’
- [Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014– 2020](#) and [First 5: A Whole-of-Government Strategy for Babies, Young Children and their Families 2019-2028](#) both include themes on the role of parents as the primary carers of the child, and the role of the State in providing services to enable and support parents in caring for their children.
- The [Constitution of Ireland](#) recognises the rights of the family ‘as the natural primary and fundamental unit group of society’ (Article 41.1.1<sup>o</sup>), explicitly recognises the ‘natural and imprescriptible rights’ of children (Article 42A.1) and the primary role of parents in safeguarding the welfare of their children (Article 42.1). In order for the parents of hospitalised children to protect their children's rights they must typically be with their child.

In order for family life to be respected, and for parents and children to be together, parents of children in hospital incur additional costs and potentially lose income, as discussed above.

Only a small number of families are affected by their children needing a prolonged or frequent stay in hospital due to their disability, or indeed due to an illness. However, 71% of parents/guardians who participated in our study, worry 'fairly often' or 'very often' about their finances due to their child's non-medical costs associated with hospital visits (*Childhood Illness, Financial Stress*, 2020).

Article 28.2(c) of the UNCRPD requires States Parties

"To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability related expenses, including adequate training, counselling, financial assistance and respite care"

The families of children with disabilities, who endure frequent and/or long-term stays in hospital, require such financial assistance from the State.

### **Recommendations**

Children in Hospital Ireland is recommending the following:

#### Statutory Payment

- The creation of a new Statutory Payment for the non-medical financial costs associated with having a child in hospital.

#### Social Welfare Reform

- Removal of restrictions on certain social welfare payments while a child is in hospital.
- Extension of entitlement to Domiciliary Care Allowance to those aged 16 and 17.

#### Parking and Travel Expenses

- Remove car parking charges for parents and carers of children in hospital.
- Explore options to assist with travel costs.

#### Accommodation Costs

- Ensure adequate provision of parents' accommodation and make this available free of charge.

### **Mental Health Services**

*Childhood Illness, Financial Stress* (2020) found that 21% of respondents sought mental health support for themselves due to the stress of having a sick child. Of families who sought mental health support, the average spent on mental health services in the past year was €801, with some paying as much as €1500 or €3000 over this period.

38% of respondents wished to access mental health supports for themselves, due to the stress of having a sick child, but could not. They were unable to access mental health supports due to either the cost, the waiting list for public service or their location.

An example of this issue is that one parent reported, in *Childhood Illness, Financial Stress*, that both they and their partner wanted mental health support, due to the stress of their child's medical condition. They were able to access temporary crisis care, but, due to the cost, they were unable to access the further mental health support they needed.

"The €60 it would cost for each of us each week, is not realistic for us at this time [... while] crisis counselling got us functioning again, we're both acutely aware that we're living on the edge."

## **UNCRPD**

Article 28.2(c) of the UNCRPD specifically includes a requirement for the State to provide assistance for counselling to the persons with disabilities and their families living in situations of poverty.

'To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability related expenses, including adequate training, counselling, financial assistance and respite care.'

## **Recommendation**

- Make counselling and psychosocial support accessible and affordable for parents of children in hospital.

## **Barriers to accessing supports**

Where state or hospital supports exist, parents frequently report difficulty in accessing the information about the supports. Parents are unsure where to turn to for the necessary advice. This problem is compounded by a lack of communication between different government Departments/agencies.

Moreover, where parents are aware of potential supports, they face further barriers to applying for them. In *Childhood Illness, Financial Stress (2020)*, many parents reported that they could not access potential supports because of the complexity of forms. They explained that the pressure of dealing with a sick child leaves little room for dealing with technical forms. One parent stated that:

“[It is] impossible to know what you should or can apply for, how to, when to... All these things are confusing at the best of times and increasingly difficult when in hospital and an emotional and physical wreck.”

These barriers seem particularly difficult for families with lower literacy levels or those who are recently arrived in Ireland. Moreover, as a social worker explained

“It’s only the families with incredible resilience and that have really high stamina that get payments.”

### **UNCRPD**

Article 9.2(f) of the UNCRPD states that States Parties shall also take appropriate measures:

- To promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;

### **Recommendation**

- Address issues which exclude some parents from social welfare payments, such as access to information, complexity of application forms, etc.

### **Waiting Lists**

There are currently long waiting lists for access to services, which are in many cases delaying those with disabilities from accessing the necessary diagnoses and appropriate supports and treatment.

For example, many of our stakeholders are reporting unacceptably long waits for services, including for MRIs, EEGs, Speech and Language Therapy, and surgical procedures. Timely investigations and diagnoses are vital for improving outcomes for children with disabilities.

## **UNCRPD**

Article 25(b) of the UNCRPD states that States Parties shall  
Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

The timely access to services is necessary for early identification and intervention, and in many cases to minimize and prevent further disabilities and later, more costly treatments.

### **Recommendation**

- Address the waiting lists for medical services to avoid stressful and damaging waits for children.

### **Transitioning to adult services**

As stated on the [HSE's website](#), "Transferring care to adult physicians should be 'a guided educational and therapeutic process, rather than an administrative event'". However, for many the transition from paediatric to adult hospital services can be uncertain, stressful and disruptive.

In many cases, adolescents with disabilities attend one hospital, but once they age-out of paediatric services, they need to begin attending two different adult hospitals to receive the specialist treatments they require. The care pathway from early adolescence must address issues such as self-advocacy, independent health care behaviour, and psychosocial supports including access to genetic counselling, advice on education and vocational planning, and general promotion of a healthy lifestyle.

In some cases/hospitals, adolescents with disabilities may be assigned a transition nurse to ease this process. However, this is not the case across all hospitals or specialities.

### **Recommendation**

- Put appropriate supports in place to ensure the smooth transition from child to adult services.

## Recommendations

As discussed above, Children in Hospital Ireland makes the following recommendations for the consideration of The Joint Committee on Disability Matters:

- The creation of a new Statutory Payment for the non-medical financial costs associated with having a child in hospital.
- Removal of restrictions on certain social welfare payments while a child is in hospital.
- Extension of entitlement to Domiciliary Care Allowance to those aged 16 and 17.
- Removal of car parking charges for the parents and carers of children in hospital.
- Explore options to assist with travel costs.
- Ensure adequate provision of parents' accommodation and make this available free of charge.
- Make counselling and psychosocial support accessible and affordable for the parents and siblings of children in hospital.
- Address issues which exclude some parents from social welfare payments, such as access to information, complexity of application forms, etc.
- Address the waiting lists for medical services.
- Put appropriate supports in place to ensure the smooth transition from child to adult services.

Children in Hospital Ireland asks that The Joint Committee on Disability Matters would consider the outlined matters when deciding their focus in their role as a Committee and their future work.

*President:* Professor Alif Nicholson, FRCPI, FRCPC *Secretary:* S Egan

*Directors:* M Burns, C Connaughton, P Kelly, C Kirrane, B O'Hare, K.Ryan, K.McAuley, C.Mason

Company limited by guarantee. Registered in Dublin, Ireland. Registered office as above. Registered Charity No.:20012632

Company Registration No. 297192. Charity No. 6632.

Supported by:

2020 Award Winner

