



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

Phone: 01 2903510

Email: info@childreninhospital.ie

Web: www.childreninhospital.ie

Thematic Report by Children in Hospital Ireland – Submitted to the United Nations Committee on the Rights of the Child

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Introduction

Children in Hospital Ireland (CIH) welcomes the opportunity to submit this thematic report to the United Nations Committee on the Rights of the Child.

In this report, we highlight significant issues related to the rights of children in hospital and children's right to access healthcare services in Ireland. Our comments and recommendation are made under sections A, F, G, and H.

This report was prepared by Children in Hospital Ireland, the national organisation which advocates for the rights and welfare of children before, during, and after hospitalisation. We are members of the European Association of Children in Hospital (EACH). Our work is guided by the EACH Charter, which uses a children's rights approach to advocate for improvements in the hospital experience and healthcare journey for children.

While this thematic report focuses on issues related to the rights of children in hospital and access to healthcare services in Ireland, we acknowledge the wide range of issues impacting upon children's right to health in Ireland. We support the parallel reports prepared by the Children's Rights Alliance, the Office of the Ombudsman for Children, and the Irish Human Rights and Equality Commission (IHREC). We also support the thematic report prepared by Mental Health Reform and the Children's Mental Health Coalition.

Children in Hospital Ireland would like to acknowledge the support of students from the School of Law, University College Dublin, in assisting with the development of this report.

A. General Measures of Implementation (arts. 4, 42 and 44 (6))

Incorporation of the Convention into national legislation (Article 4)

The UNCRC is currently not incorporated into Ireland's domestic legislation. This constrains its overall effectiveness.

Recommendation

The Committee is urged to recommend that the State commit to incorporating the Convention into national legislation.

F. Children with Disabilities (art. 23)

The Right of Children with Disabilities (Article 23)

Domiciliary Care Allowance (DCA) is a monthly payment for children aged under 16 with a severe disability who have significant additional needs. Recipients of this payment are automatically entitled to a medical card, giving them free access to healthcare services, and their primary caregiver can also access Carer's Allowance or Carer's Benefit.

When a child requires prolonged hospitalisation access to Domiciliary Care Allowance and to Carer's Allowance/Carer's Benefit 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 when a child is in hospital (see Section G for further information).

The following restrictions apply:

- 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 the child leaves hospital.
- Children aged 16 and 17 are not entitled to access Domiciliary Care Allowance.

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. 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'.¹

¹ <https://www.irishtimes.com/crime-law/courts/2022/07/04/supreme-court-dismisses-father-and-sons-appeal-over-care-allowance-while-child-was-hospitalised/>

Recommendation

The Committee is urged to recommend that the State remove the restrictions on accessing DCA for children in hospital and extend DCA to children aged 16 and 17.

G. Basic health and welfare (arts. 6, 18 (3), 24, 26, 27 (1)-(3) and 33)

Health and health services (Article 24)

Access to Healthcare

The healthcare system for children in Ireland is characterised by poor access, lengthy waiting lists, and underinvestment in crucial services, all of which negatively impact the promotion of the child's right to the enjoyment of the highest attainable standard of health. The Government has committed to *Sláintecare*, a ten-year programme to improve healthcare services in Ireland, but progress has been slow, with repeated delays. The *Sláintecare* Implementation Strategy has limited child-specific measures.

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 to delivering better outcomes for children and ensuring care is as cost effective as possible.

Ireland is an outlier among countries in Western Europe in that a significant number of children do not have access to GP and primary care services free of charge. The implementation of free GP care without a means test for all children under 18 has been repeatedly delayed: only those aged five or under currently benefit although it is anticipated that children aged six and seven will become eligible during 2022.

Ireland was ranked 22nd out of 35 European countries in the 2018 Health Consumer Powerhouse (HCP) study, but was ranked last for accessibility.² 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.³

Recommendation

² <https://healthpowerhouse.com/publications/#200118>

³ <https://www.ntpf.ie/home/nwld.htm>

The Committee is urged to recommend that the State accelerate progress towards the delivery of a universal healthcare system, set out a clear and realistic timeframe for the delivery of free GP care for all children, and to address waiting lists for services.

Non-medical financial costs and the role of parents

The promotion of children's right to health is also constrained by the non-medical financial costs which arise from childhood illness. These costs have a significant impact on the ability of parents to fulfil their caregiving role and support the attainment of the best possible health outcomes for their child.

Research carried out by Children in Hospital Ireland (CIH) and published in its report, *Childhood Illness, Financial Stress* (2020),⁴ 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.

Parents are required to be almost constantly present with their child in hospital and form a key part of the child's care team. It is in the best interest of the child that their parent, as the primary caregiver, is with them when they are in hospital. The involvement of parents during their child's treatment also contributes positively to stress reduction and reduced incidence of cross-infection and post-operative complications.^{5 6 7} The Convention recognises the child's right to be with and to receive the care of their parents, who are recognised as the child's primary caregivers (Article 9 and 18). Under the Convention, States are obliged to provide appropriate assistance to support parents in fulfilling their responsibilities towards their child (Article 18).

Parents, in seeking to fulfil their caregiving role when their child is in hospital, are limited in their ability to continue to participate in paid employment, with a resultant loss of income, thus compounding the financial difficulties they experience. According to parents surveyed in the CIH study, the median loss of income experienced was €300 per week. One-third of

⁴ https://childreninhospital.ie/wp-content/uploads/2021/09/Children-in-Hospital-Report_1-FINAL.pdf

⁵ Ministry of Health (1959) *The Welfare of Children in Hospital*, Platt Report. London: Her Majesty's Stationery Office.

⁶ Palmer SJ. (1993) 'Care of sick children by parents: a meaningful role', *Journal of Advanced Nursing*, Vol. 18, Issue 2.

⁷ Ygge B., Arnetz J. (2004) 'A Study of Parental Involvement in Pediatric Hospital Care: Implications for Clinical Practice', *Journal of Pediatric Nursing*, Vol. 19, No 3.

parents surveyed had given up paid employment to care for their sick child. 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. The financial impact is most acutely felt by families living in poverty. Families with a limited network of support, including families headed by a lone parent, those who are newly arrived in Ireland, and those experiencing homelessness, are disproportionately impacted by the financial pressure of having a child in hospital.

The hospitalisation of a child also impacts on the 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 said they had 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 background sound 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, which has implications for their health and well-being. Food available outside of core hospital hours is often unhealthy and lacking in nutrition.

Parents can also experience a negative impact on their mental health when a child is seriously ill, with many reporting difficulties in accessing adequate support. Of respondents to the CIH study, 21% said they had accessed mental health services, and a further 38% said they had needed such services but were unable to access them due to cost, waiting times or accessibility issues. The median annual spend by parents on the provision of private mental health supports was €400.

Given the evidenced health and social benefits for children arising from parental participation in their care, it indicates that the facilitation of parental presence during a child's hospitalisation is an important measure to promote the child's right to the highest possible standard of health.

One solution to this is for the State to provide financial support to parents in this situation. The existing supports offered through the Irish social protection system do not adequately respond to the unique situation faced by parents whose child requires prolonged and/or

repeated hospital care. The only payment potentially available to parents is the Additional 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. Furthermore it is not intended to be used on a continuing basis or to attend to basic needs, such as covering the cost of food or childcare.

The Committee has previously considered the financial impact of childhood illness on parents and families in its General Comment 15. This highlights the role of parents in promoting the right to health and calls for increased recognition of and support for the central care-giving role of parents. Measures called for include financial supports for parents, such as subsidies, paid parental leave, and grants.

Recommendation

The Committee is urged to recommend the development of a new social protection payment to assist families with the non-medical financial costs incurred when a child requires prolonged and/or frequent hospitalisation. This is necessary to facilitate a meaningful parental presence during hospital care and to promote the child's right to the highest possible standard of health.

Mental Health (Article 26)

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). There are significant shortcomings in Child and Adolescent Mental Health Services (CAMHS).

Implementation of Community CAMHS has not reached the stated targets, with a shortfall of 118 psychologists⁸ and only 73 community CAMHS teams,⁹ far below the target of 129. In 2021, there were 4,003 children on waiting lists for mental health services, with 405 waiting more than 12 months.¹⁰

There are only 72 CAMHS inpatient beds, based in Dublin, Cork, and Galway,¹¹ 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 Committee 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 care in an emergency department, or a children's hospital, or an adult inpatient unit.¹²

The development of 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, by ready access to emergency services and inpatient care in an appropriate setting.

Recommendation

⁸ <https://www.rte.ie/news/ireland/2022/0523/1300631-camhs-delays/>

⁹ <https://www.hse.ie/eng/staff/resources/our-workforce/resources/workforce-planning-report-mhs.pdf>

¹⁰ <https://www.hse.ie/eng/about/personal/pq/pq/2021-pq-responses/september-2021/pq-41553-21-bernarddurkan.pdf>

¹¹ <https://www.hse.ie/eng/about/personal/pq/pq/2021-pq-responses/october-2021/pq-49372-21-clairekerrane.pdf>

¹² <https://www.mhcirl.ie/sites/default/files/2021-06/MHC-Annual-Report-2020.pdf>

The Committee is urged to recommend that the State takes measures to ensure that all children under 18 years can access timely, high-quality and age-appropriate mental health service. The Committee is urged to recommend that the State commits to ensuring the adequate staffing in mental health services.

Additionally, the Committee is urged to recommend that the State should move to end the practice of children being admitted to adult inpatient psychiatric facilities. To achieve this, measure are required to ensure that CAMHS inpatient units are readily accessible, by increasing the bed capacity and staffing levels of such units. The Committee is urged to recommend that the state revise the General Scheme of the Mental Health (Amendment) Bill 2021 to ensure that the admission of children to adult psychiatric units is recognised as a short-term, transitional measure, rather than a practice placed on a statutory footing.

H. Education, leisure and cultural activities (arts. 28–31)

Leisure, recreation and cultural activities (Article 31)

In a hospital setting, play can have an important role for the child, providing a normalising experience in a stressful situation and increasing their resilience and ability to cope with their illness. Access to play for children in hospital can also aid treatment and recovery. The facilitation of play in hospital requires the input of trained and appropriately qualified Hospital Play Specialists.

There are, however, significant barriers which prevent the full attainment of this right when children are in hospital in Ireland. *Joining the Dots*, a 2018 report on an initiative to hear the views of children in hospital, indicated that 30% of 6–11 year old children in hospitals did not think that they had adequate things to do when in hospital; furthermore, an average of 34% of 12–17-year-olds said there was nothing to do in hospital for young people. The report also highlighted staff concerns about recreational facilities, highlighting that ‘there are not enough facilities for children of different ages’.¹³

Children in Hospital Ireland (CIH) carried out a survey of hospital play specialists in February 2022, revealing many of the challenges faced. This survey builds on CIH’s internal knowledge, informed by several decades of experience providing a volunteer-led hospital play service across the country.

The findings of the survey indicate that there is an under-investment in the provision of qualified hospital play specialists and that many smaller paediatric units have no play specialists. Whilst CIH provides a volunteer play service, this is not a substitute for trained professionals.

There is currently no hospital play specialist training course on the island of Ireland, with people required to travel to Britain to access training. This is despite a commitment made in the 2004 National Play Policy to develop a third-level course in Ireland, with a target date of

¹³ https://www.oco.ie/app/uploads/2018/06/JoiningtheDots_Report_June2018.pdf

2004. The majority of respondents to the CIH survey stated that there are inadequate opportunities for the on-going professional development of play specialists in Ireland.

Covid-19 measures have limited the type of play available to children in hospital. A majority of respondents reported that fewer play materials were available as well as more restrictions regarding which children can access play. There has also been an increase in 1:1 play. A significant concern raised by hospital play specialists, and shared by CIH, is the loss of many playrooms, which have been repurposed for other medical and administrative purposes. It is vital that these spaces be restored to their intended purpose.

Recommendation

The Committee is urged to recommend that the State develop a new National Play Strategy as soon as is feasible. The strategy should recognise the wide range of settings in which play can occur, including hospitals and care facilities, and place an obligation on providers to develop adequate and appropriate facilities and ensure adequate staffing to support the facilitation of play.

Who we are

Children in Hospital Ireland, 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. (See: www.childreninhospital.ie)

For queries please contact Fiachra Brennan, Policy Officer, Children in Hospital Ireland (Tel: 00 353 1 290 3510; Email: fiachra@childreninhospital.ie)

Children in Hospital Ireland

President: Professor Alf Nicholson, FRCPI, FRCPCH *Secretary:* S Egan

Directors: M Burns, C Connaughton, P Kelly, C Kirrane, B O'Hare, K Ryan, K McAuley, C Mason, C O'Dwyer, A O'Toole, M McSharry
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