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National Policy Framework for Children and Young People

Introduction

Children in Hospital Ireland (CIH) welcome the opportunity to make a submission to the consultation on the next National Policy Framework for Children and Young People in Ireland.

Children in Hospital Ireland (CIH) are calling for a national policy framework which prioritises

- The realisation of the full spectrum of rights which children are entitled to
- The provision of high quality and timely healthcare services which enable children to lead active and healthy lives
- Supporting the family unit when a child is in hospital and ensuring that childhood illness does not contribute to poverty, disadvantage or social exclusion for the sick child, their siblings, or their family
- Access to and adequate resourcing of play for children in hospital and in other healthcare settings

i. The Rights of the Child

The next national policy framework should prioritise the realisation of the full spectrum of rights which children are entitled to, as enshrined in the United Nations Convention on the Rights of the Child (UNCRC). The rights of children when they are in hospital is of particular concern for Children in Hospital Ireland (CIH). Children's rights do not change or cannot be diluted because a child is sick. Equally, the rights, responsibilities, and duties of parents, as the primary caregiver, should not be altered.

Through general comments, the United Nations Committee on the Rights of the Child has examined the right of the child 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. General Comment 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 through the provision of financial assistance and mental health supports.

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.

CIH Recommendations

- Recognise that children in hospital are entitled to the same rights as other children, including the right to participate in decision-making and have their voices heard
- Ensure that the rights of children in hospital are promoted and fully realised
- Support the family unit when a child is in hospital through financial assistance, paid parental leave, and the provision of counselling and mental health services for parents and siblings

ii. Access to high-quality healthcare

The next national policy framework should prioritise the provision of high quality and timely healthcare services which enable children to lead active and healthy lives. Currently, the healthcare system for children in Ireland is characterised by poor access, lengthy waiting lists, and underinvestment in crucial services.

Ireland is an outlier among countries in Western Europe – most children do not have access to GP and primary care services free of charge. The implementation of free GP care for children 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) study¹, but was ranked last for accessibility. Lengthy waiting lists are a significant contributor to this ranking. There are 96,088 children on waiting lists for treatment, assessments, and tests². Additionally, 2,625 children are waiting on support from Child and Adolescent Mental Health Services (CAMHS), with 171 waiting more than 12 months³.

Mental health services for children are inadequate, with successive governments failing to deliver on the recommendations of the 2006 strategy *A Vision for Change*. There are only 72 CAMHS inpatient beds nationally, based in Dublin, Cork, and Galway⁴; significantly below the target of 100 beds. Implementation of community CAMHS has not reached its targets, with a shortfall of 118 psychologists⁵ and only 73 community CAMHS teams⁶, far below the target of 129.

The admission of children to adult inpatient psychiatric facilities is a significant children's rights issue. Under the proposed changes to the Mental Health Act 2001, admissions of children to adult units will continue to be allowed. This practice has been identified by the UN Committee on the Rights of the Child as something which the state must take steps to end. This would also be in line with sentiments expressed in the National Healthcare Charter for Children and the EACH charter. Despite this, 27 children were admitted to adult units in 2020. There are only two high-

¹ <https://healthpowerhouse.com/publications/#200118>

² <https://www.ntpf.ie/home/nwld.htm>

³ <https://www.hse.ie/eng/services/publications/performance-reports/management-data-report-march-2021.pdf>

⁴ <https://www.hse.ie/eng/about/personal/pq/pg/2021-pq-responses/october-2021/pq-49372-21-claire-kerrane.pdf>

⁵ <https://www.hse.ie/eng/staff/resources/our-workforce/resources/workforce-planning-report-mhs.pdf>

⁶ <https://www.hse.ie/eng/about/personal/pq/pg/2021-pq-responses/september-2021/pq-41553-21-bernard-durkan.pdf>

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 unit⁷.

CIH Recommendations

- Ensure that the promotion of a child's right to health is a priority area for the upcoming policy framework
- Implement the recommendations contained within the *Sláintecare* plan to significantly reduce waiting lists for children and ensure timely access to treatment, assessments, and tests
- Implement the *Sharing the Vision* strategy to improve mental health services for children and young people
- Legislate to end the practice of children being admitted to adult psychiatric units

⁷ <https://www.mhcirl.ie/sites/default/files/2021-06/MHC-Annual-Report-2020.pdf>

iii. Supporting Children in hospital and their families

The next national policy framework should prioritise supporting the family unit when a child is in hospital. Interventions should seek 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.

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, 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.

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. 61% of parents surveyed took on debt to meet non-medical costs associated with having a child in hospital care.

The hospitalisation of a child also impacts on the mental and physical health and well-being of parents and siblings. 86% of parents surveyed 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. 21% of respondents accessed mental health services for themselves or for siblings of the child in hospital, with a further 38% in need of support but unable to access this due to cost, waiting times or accessibility issues. The median annual spend by parents on private mental health supports was €400.

⁸ https://childreninhospital.ie/wp-content/uploads/2021/09/Children-in-Hospital-Report_1-FINAL.pdf

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

CIH Recommendations

- Introduce a new social protection payment to assist parents with the non-medical financial costs arising from childhood illness
- Provide paid parental leave specifically for parents whose child requires prolonged and/or frequent hospital care
- Develop and resource counselling and mental health supports for parents with a child in hospital and their siblings
- Commission independent research to measure the full economic and social costs faced by households arising from childhood illness.
- Recognise and support the continued caregiving role of parents when a child is in hospital.

iv. Access to play in hospital

The next national policy framework should prioritise access to and adequate resourcing of play for children in hospital and in other healthcare settings. The right to play is enshrined in the UNCR. 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. There are, however, significant barriers which prevent the full attainment of this right when children are in hospital. 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.

There is an underinvestment in the provision of qualified hospital play specialists. Many smaller paediatric units have no play specialists at all. Whilst CIH provide 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 2004. 71% of survey respondents 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.

CIH Recommendations

- Update the 2004 *National Play Policy – Ready, Steady, Play* and include updated information on play available in a hospital setting
- Develop a third-level hospital play specialist course

- Invest in hospital play specialist staffing across all children's hospitals and regional paediatric units
- Working with Children's Health Ireland, the HSE, and hospital management to ensure all playrooms are restored to their intended purpose
- Invest in hospital play facilities and equipment across all children's hospitals and regional paediatric units

Attached:

Children in Hospital Ireland Submission to the Public Consultation on the next National Policy Framework for Children and Young People in Ireland

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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.

www.childreninhospital.ie

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