

# Children in Hospital Ireland

**Submission to the Joint Committee on  
Justice, Equality, Defence and Women's Rights**

**on**

**The Disability Bill 2004**

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## **1 Introduction to Children in Hospital Ireland**

Children in Hospital Ireland welcomes the opportunity to address the Joint Oireachtas Committee about the Disability Bill 2004. Children in Hospital Ireland is a National Organisation established in 1970 by parents of sick children to ensure all children in hospital are cared for appropriately. The organisation works collaboratively with parents, professionals and other organisations to champion sick children by promoting their welfare before, during and following hospitalisation. The services and activities are initiated through, and directed and supported by staff and resources from its Head Office in Dublin. As far as possible services are delivered locally by CHI volunteers. While not focusing on any illness or condition, Children in Hospital Ireland works on behalf of all sick children and their families.

## **2 Relevant Children in Hospital Ireland Publications**

Children in Hospital Ireland promotes the well-being of all sick children, before, during or following a hospitalisation. This is achieved through promoting the practices detailed in many of its publications, but specifically in the Charter for Children in Hospital and the Guidelines for the Care of Children with Special Needs in Hospital. In addition, Sick Children, Money Worries, a recent report based on research commissioned by Children in Hospital Ireland identified many inadequacies in the current provision of health care services encountered by families whose children are frequent users of the health services. Many of these children have disabling conditions and the identified inadequacies must be remedied through provisions in this bill. Copies of each of the above named documents have been included in the briefing packs provided for the members of the Joint Committee.

## **3 Acknowledging Children**

Children in Hospital Ireland understands that the Bill is concerned with the provision of services to people of all ages but we are greatly concerned that that it contains very little acknowledgement of the special needs of children with disabilities and their families. The bill does not acknowledge the supports that are required by carers, parents and families so that their disabled child can remain in their own home.

#### **4 Focus of Submission**

In this submission the focus is on the additional measures which Children in Hospital Ireland suggest should be incorporated into the Bill to protect the rights and meet the needs of children with a disability or special need. The focus is mainly, but not exclusively, on the requirements necessary for the provision of health services for these young people and their families.

#### **5 Defining Children and Disability**

Firstly the Bill must specifically address the fact that children are different from adults and the provision appropriate, accessible and responsive services must be informed by this difference. The Bill defines a child as a person under the age of eighteen years. In the context of children with certain disabilities and special needs this rigid definition is not appropriate. This Bill, dealing with people whose requirements for care may not mirror their chronological age must specify that the cut-off age for consideration for certain services has to be flexible to reflect this.

In Section 2, the words used to define disability "... a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the state by reason of an enduring physical, sensory mental or intellectual impairment" does not describe the experience of disability for children and their families. The image this definition conjures up – adults – immediately tends to disenfranchise children and families. This most vulnerable group of citizens, to date, have had to fight every inch of the way to have their needs understood. And then have had to fight even more to have those needs met.

In Section 6 the further definition of "substantial restriction" again is not a good fit for children who can have disabling conditions which could be episodic or while currently acute, reduce with time. There is no elaboration of how to interpret what constitutes a "service" which needs to be provided continually.

#### **6 Provision of Care**

The Bill must recognise that the provision of care, treatment or services to children is a different task than providing care, treatment or services to adults. It takes more staff to provide care to children with disabilities and more time is needed to adequately provide

this care. Insufficient staff numbers and insufficient time to administer required care and treatment, result in children with disabilities often being sidelined and excluded from participating. This goes against the philosophy of inclusion enshrined in recent Government policies such as the National Health Strategy and the National Children's Strategy. Lack of inclusion is detrimental to the well-being of the children in question. Ensuring that this does not happen needs to be built into the legislative framework.

## **7 Training and Skills of Personnel**

The Bill needs to specify that only staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families, conduct assessments or prepare service plans. Those conducting assessments must have training in consultation with and inclusion of the children and their carers in the assessment process. This is in line with Government policy as outlined in the National Children's Strategy.

It must be specified that all personnel, particularly the designated "access officer", who come in contact with children with disabilities and who provide any assistance, treatment or other service are knowledgeable and skilled in communicating and interacting with children with disability or special needs.

## **8 The Assessment and the Service Plan**

The protection of a child's right to early and appropriate interventions will hopefully allow children to maximise their full developmental potential. The needs assessment must include identifying and specifying how a child's disability has to be taken care of in hospitals and other care settings. The resultant "Service Statement" must include these directions for care and must be easily accessible to and consulted by everyone who provides a caring or therapeutic role in the child's life.

It is of paramount importance that the Disability Bill stipulates how gaps in provision between the requirements identified during the assessment and the provisions of service statement are to be addressed.

## **9 Hospitalisation of Children with Disabilities**

The Bill does not adequately protect the rights of children with disabilities who need recourse to the health care system. The hospitalisation of a child with a disability puts severe strains – both emotional and financial – on families. There are many inequities in the administration of the various services and entitlements. Because of time constraints may I refer you to the report *Sick Children, Money Worries* for a detailed analysis. Parents of children who have a child in hospital report extreme difficulties in accessing supports due to the lack of availability of information on what measures are available. The Disability Bill needs to specify that these inequities are removed and that information systems are improved. Removing inequities could include providing a personal medical card for any child with a disability, extending the list of qualifying conditions and illnesses covered under the Long Term Illness Scheme, standardising the assessment process for the Domiciliary Care Allowance and the Carer’s Allowance.

The Bill must also protect children from being inappropriately accommodated in Acute Hospitals when what they require is supported residential or respite care. Acute hospitals are not suitable for well children and both the rights of the child with the disability and the acutely ill children are not being met.

In relation to Sections 23, 24 and 25, the Bill needs to specify that Hospitals and other health care settings, particularly those providing facilities for children, are included under “public buildings” and need to be accessible for children with disabilities.

## **10 Codes of Practice**

It must be specified that any codes of practice being drawn up as outlined in Section 28 must include measures specifically addressing and relating to the needs of children with disabilities. The Bill must also specify that consultation with children and families and their support organisation informs the development of codes of practice.

## **11 Sectoral Plans**

Section 29 specifies that a number of Departments need to prepare Sectoral Plans. In its directions on the preparation of these plans, the Bill must stipulate that each sectoral plan includes the specific measures to be taken to provide services for children and young people with disabilities. Again, it must be specified that the development of

Sectoral Plans has to include consultation with children with disabilities, their families, carers and with support organisations.

## **12 Appeals and Complaints**

The processes for appeals and complaints are extensively set out. These processes and the personnel who administer them, should be independent of the services that are being challenged. In relation to the operation of the appeals and complaints procedures, Children in Hospital Ireland has concerns that the processes as described are lengthy and potentially expensive. This may deter families from pursuing a grievance. The processes need to be simplified.

The Bill comprehensively deals with the appeals and complaints procedures but is not as comprehensive on the provision of services. It would be interesting to know if any cost analysis has been carried out to determine whether the provision of appropriate and adequate services in the first place would outweigh the ongoing cost of implementing this comprehensive appeals and complaints procedures.

## **13 Excellence in Design**

In Part 6 the amendment detailing the operation of a Centre for Excellence in Design must be further amended to specifically ensure that children with disabilities are cared for in therapeutic and other environments which are designed, furnished, staffed and equipped to meet their needs. These needs include possibilities for play, recreation and education. The Bill must specify that the architecture and interior design must incorporate appropriate features for all age groups.

## **14 Monitoring and Evaluation**

Section 46 outlines a monitoring process to ensure compliance with directions on the employment of persons with a disability. Children in Hospital Ireland suggests that the Bill must also include a section which stipulates that a similar process be established to monitor and evaluate compliance with the directives addressing the needs of children. Childhood is short. In order to ensure that it will be effective in addressing the rights of children with disabilities, the Bill must specify that there be ongoing monitoring and evaluation of the provision of services for children with disabilities, which feeds back directly into policy and practice development.

## **15 In Conclusion**

Children in Hospital Ireland is grateful to have had the opportunity to address the committee. Should you like any further information or clarification we can be contacted as below. We would be delighted to talk to members of the committee at any time.

Let us remember, childhood is short. We have to get it right for children with disabilities. There will be no second chance to make it right. Children in Hospital Ireland urges that Joint Committee uses its best offices to ensure that the Disability Bill is appropriately amended so that the needs and rights of vulnerable children with disabilities and their families and carers are met.

Thank you for your attention