Children's Rights Alliance

Submission to the National Paediatric Hospital Development Board in relation to the new National Children's Hospital

March 2009

Introduction

The Children's Rights Alliance is a coalition of over 90 NGOs working to secure the rights and needs of children in Ireland, by campaigning for the full introduction of the UN Convention on the Rights of the Child. The Alliance aims to improve the lives of all children, through securing the necessary changes in Ireland's laws, policies and services. The Children's Rights Alliance is grateful to the National Paediatric Hospital Development Board for the invitation to submit its views on the new National Children's Hospital.

Our submission is rooted in the UN Convention on the Rights of the Child, and seeks to ensure that the design of the new National Children's Hospital will have children's rights at its core. It has four sections:

- the principles that should underpin practice in the design phase
- the design process itself
- the functionality of the physical building and its environment
- planning for the future

A set of recommendations are made in each section, and summarised below.

Summary of recommendations:

- The National Children's Hospital must cater for **all children**, up to the age of 18
- **Children, parents**, support groups and all hospital staff must be engaged as **participants** in the process of hospital design
- **Tried and tested models of participation** should be used. Tokenistic consultation exercises will not work
- **Clinical staff and the design team** must be brought **together** as part of the design phase. Both groups need to develop a shared understanding of the project, its goals and its limits
- **Clinical leadership** is critical to ensuring medical staff buy-in to the new hospital design
- The hospital design must reflect the need for **smooth arrival at the hospital** for parents and children. This includes attention to car-parking, entrance design; and bathroom, pram and crèche facilities
- Design must ensure that children's journey through the hospital is smooth; and that **parents can stay comfortably with their children**, with access to basic services, like laundry and showers
- **Play and education facilities** are critical, and must be a key element of the design process
- **Religious and cultural sensitivities** must be respected within the hospital
- The National Children's Hospital must not be planned as a re-provision of existing services. It is a hospital for the future, and must **plan for future capacity** and future service provision.

1. Principles Underpinning Practice: UN Convention on the Rights of the Child

The Alliance believes that the principles of the UN Convention on the Rights of the Child must underpin all work undertaken in the field of children's health. These principles are not limited to the specifics of the "highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health" (Article 24), but also touch upon all aspects of a child's life in the hospital setting, including the voice of the child (Article 12), the best interests of the child (Article 3), the child's right not to be separated from his parents (Article 9), the child's right to rest, leisure, play and recreational activities (Article 31), and the right to education (Article 28).[1]

Article 1: Age of the Child

Most crucially, Article 1 of the UN Convention states that "a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier."[2] The National Children's Hospital should provide facilities and treatment for all children up to 18 years, consistent with the definition of a child in the *National Children's Strategy*, the key policy document relating to children,[3] and with the provisions in legislation affecting children such as the Child Care Act, 1991, and the Children Act, 2001. The age of 18 years should be the minimum cut-off point in the new hospital. In addition, flexibility is required in the case of a young people over 18 years who is developmentally delayed, it may be more appropriate that they continue to be cared for in a paediatric setting.

Currently, the three children's hospitals in Dublin have a formal cut-off age is 16 years, with some flexibility for children that are already within the system and deemed not ready to transfer to adult services. The new children's hospital provides an opportunity to address the anomaly in children's hospital services, and bring them in line with the national and international definitions of childhood, by providing services for all children up to 18 years. The decision to provide services to children up to age 18 will have design implications, in terms of capacity and design/decoration choices. Given this, the cut-off age must be defined at the earliest possible stage of the consultation process.

Providing services for children up to age 18 would go some way towards addressing the well-documented gap in adolescent health services in the existing children's hospitals.[4] While it is not the purpose of this submission to propose a new system of adolescent services, it is important to note that hospital services and design should be sympathetic to the changing needs of children as they grow older, for example, teenagers' desire for privacy should be recognised and respected.

Article 3: Best Interests of the Child

The design of the hospital must have the best interests of the child as its underpinning principle. All aspects of the hospital – from the basic design, to medical procedures and day-to-day practice and running of the hospital – must centre upon the needs of the child.

Article 12: Voice of the Child

A child who is capable of forming his or her own views should have the right to express those views freely, and those views should be given due weight according to the age and maturity of the child.[5] The voices of children – a mix of those that have been, or are in hospital, and those that have not – should play a key part in the design consultation. There are tried and tested participation

1 See the United Nations Convention on the Rights of the Child (1989) for the full text of these articles

2 United Nations Convention on the Rights of the Child (1989), p.2. Other international and national definitions of childhood and adolescence include: adolescence as a distinct developmental period in the age group 10-19 (World Health Organisation), adolescents are those between 13 and 18 years old (American Academy of Family Practice), a child is a person who has not yet attained his or her 18th year unless he or she has been married (recent Irish Mental Health legislation, which brings the definition in line with childcare legislation and with the age of majority).

3 Government of Ireland (2000), *The National Children's Strategy: Our Children - their Lives*, Dublin: Stationery Office

4 Council for Children's Hospital Care, (2005), *Background Information on Cut-off age for admission to the Children's Hospital*

5 United Nations Convention on the Rights of the Child (1989), p.4

techniques for engaging with children, which should be explored and adapted by those running the design process, to suit their particular needs.[6] Talking to children about what they want must be meaningful, and must include a feedback process whereby the children are informed where their views were taken on board, and provided with an explanation in cases where they were not.

Article 31: Right to Rest, Leisure, Play and Recreational Activities
"Play is a natural part of childhood, and a vital factor in the mental, social and emotional growth of children."[7] Play is also how children learn, how they develop relationships, how they understand risks and how they relax. It is a critical part of their lives, and even more so in the hospital setting, thus the provision of high-quality, appropriately staffed play facilities, designed in partnership with children, is essential.

Recommendations:

- The National Children's Hospital must cater for all children, up to the age of 18
- Children must be engaged as participants in the process of hospital design
- Developing appropriate play facilities, with sufficient staff, must be a central focus of the hospital design process.

2. The Design Process: involving children, families and staff

When you walk into the Children's Hospital at Montefiore, New York, the first thing you see is a glowing glass mural of the Milky Way. The swirl of cosmic blues and purples envelopes a white-hot centre marked with a tiny red dot. It reads, "You are here." Every inch of the hospital is loaded with information and inspiration about the universe, from the microscopic functions of life to the outer reaches of space. The effect is part high-tech classroom, part cutting-edge science museum, part futuristic playground. Combined, it is a powerful statement of what a children's hospital needs to be, in addition to its core function as a medical facility.[8]

From the outset the Evelina Children's Hospital in London wanted to be a hospital that didn't feel like a hospital, a place designed "by children for children."[9] Bright red rocket lifts, visible from inside and outside the hospital, carry people to a four-storey central conservatory. Floors are identified by their own colour and symbol, all based on the natural world and moving from the ocean and beach on the lower floors right through to the sky at the top. Play is a key activity at the hospital, symbolised by the 17 foot high helter-skelter slide in the outpatients department. That children were key contributors to the design is obvious from the finished hospital building. A Children's Board, made up of patients and local school children, were partners in the process, contributing their views on everything – from menus and furniture to building design.

Listen to children and parents
The examples above illustrate that hospitals are about more than sickness and health. How they make children feel – welcome, secure, happy and calm – is critical to their success. Children know what they like and they know what they want. Parents of sick children are experts in what could make their experience of their child's illness a better one. Constructively engaging both of these groups – parents and children – from the start of the planning and design process through to its conclusion is fundamental.[10]

6 Bristol Royal Hospital for Children and the Evelina Hospital for Children in London both engaged children in their design process. As have other hospitals around the world.
7 National Association of Hospital Play Staff (2004), *Improving the Patient Experience: Friendly Healthcare Environments for Children and Young People*
8 P. laBarre (2007), *Strategic Innovation: the Children's Hospital at Montefior*e, http://www.fastcompany.com/magazine/58/innovation.html?page=0%2C0 [accessed 19 March 2009]
9 See http://www.thegarret.org.uk/evelinaNow.htm for further information
10 Bristol Children's Hospital engaged children and parents in their design process, and have tried and tested methods that they may be willing to share with the NPHDB in its preparation for a participative process with children

Involve staff

Children and parents are not the only groups that need to be part of the design process, staff – at all levels – are key partners too. The hospital will be their workplace, and supporting them to develop a sense of ownership over it will help staff transition into the new building. Developing a participative process that includes staff on an ongoing basis is a key step in the hospital design phase.

At Bristol Royal Hospital for Children engaging clinical staff with the design team was a critical part of the ultimate success of the project.[11] The clinical team understood how the hospital needed to function in the day-to-day, the design team knew what could work in terms of how the hospital looked, felt and was structured. Both learned from one another in the early stages, and developed a shared vision for the hospital. Clinical leadership in the design process was seen as a key strength of the Bristol project.[12] A clinical steering group was set up, and made up part of the overall project board. Members of the clinical group in turn chaired groups focused on patient pathways (emergency, elective, and out-patient) through the hospital, and were tasked with developing resolutions where problems arose.

Chronic illness and condition support groups are additional voices that must be heard as part of the new hospital design consultation process.

Recommendations

- Children, parents, staff at all levels and chronic illness and condition support groups should be part of the design process from the outset to the project's conclusion
- Tried and tested models of participation should be used. Tokenistic consultation exercises will not work
- Clinical staff and the design team must be brought together as part of the design phase. Both groups need to develop a shared understanding of the project, its goals and its limits
- Clinical leadership is critical to ensuring that medical staff buy-in to the new hospital design.

3. Functionality of the Physical Building and its Environment: A hospital fit for children and families

A hospital fit for children and families must be built around their needs. Families should move through the hospital with ease; they should feel comfortable and looked after, safe, calm and welcome. Their needs – in terms of the child's health and the family's need to be together – should be easily met within the hospital environment, without fuss or distress. From nappy-changing facilities and making a cup of tea, to the journey from the car park to the ward, creating a family-centred environment must be a core design principle. This shift challenges traditional hospital organisation: it calls on hospitals to go from being doctor-centric, information-scarce institutions to being places that focus on responding to the needs and comfort of families, sharing information, and enlisting parents as partners in their children's health care.

With this in mind there are a number of things that must be considered:

Arrival

For children and parents, arriving at hospital is stressful. There are a number of practical design measures that could help to make this a more bearable experience:

11 Our journey so far', Presentation given by Geraldine Johnston, Divisional Manager, and Rebecca Mitchell, Project Manager, Bristol Royal Hospital for Children at the *Children in Hospital Ireland Annual Lecture*, November 2008

12 'Our journey so far', Presentation given by Geraldine Johnston, Divisional Manager, and Rebecca Mitchell, Project Manager, Bristol Royal Hospital for Children at the *Children in Hospital Ireland Annual Lecture*, November 2008

- Adequate car parking must be available. It should be free and accessible for parents and carers of children in the hospital. Bicycle parking should also be available for staff and visitors
- Pram and buggy parking should be available and accessible inside the hospital
- The entrance design should be welcoming, and instructions where to go should be clear. To address language issues and facilitate younger children, where possible, pictorial signs should accompany text
- Quality crèche facilities, with flexible opening hours, should be provided
- Bathrooms, with nappy-changing facilities, should be available directly inside the hospital entrance and throughout the building

Journey through the hospital

What children see on their way through the hospital is critical to their experience. Seeing another child in distress or waiting in a dark or unwelcoming space will deeply affect a child. The child's journey, as they move through the hospital – from A&E to a ward, from the ward to theatre, or from the in-patient department to a treatment room – should be smooth. Patient pathways should be developed, and tested, with the child's experience in mind. For example, travelling long distances through the hospital, especially for very sick children (those with low immune and high risk of infection) can be tiring and distressing. For very ill children accessing treatment which may be situation deep into the hospital building consideration should be given to providing an entry access point, in addition to the main door.

The design of the new children's hospital should ensure that that for a child, their environment will never trigger distress or fear. Instead, it should facilitate calm and homeliness, and be accessible and navigable for all children. All bedrooms must have natural light, and the view from children's windows is critical – that is what they see for most of the day; a garden or green space to look out on can help to relax or soothe children, and can make an enormous difference to a child's experience of the hospital environment. Special care should be taken when designing spaces where children and their families will be asked to wait for periods of time (for example, as part of treatment or waiting to see a consultant) these spaces should incorporate looking onto a green space (or perhaps a small aquarium).

- For very ill children where their treatment centre is located deep into the hospital building, the provision of an access point (additional to the main door) should be considered.
- All bedrooms must have natural light, and should have a view onto a garden or a green space.

Parents and families

Children in hospital need their parents' love, care and support. Parents and families want to spend as much time as possible with their child, during their stay at the hospital. The new children's hospital must be built to support parents and children to stay together, especially when children are very ill. Adequate facilities for parents are an essential design element to be considered. Ideally, facilities for parents should include:

- A bed for every parent to stay over with their child during their stay in hospital
- Accommodation facilities for those that live outside the Dublin area the night before a seriously ill child's appointment for hospital treatment. These facilities can be off-site but must be nearby
- Shower, clothes-washing and adequate storage facilities
- Kitchen facilities (for making coffee and tea) within short walking distance of each ward
- An affordable restaurant/canteen with flexible opening hours
- A garden or open green space for children and parents to sit in, or look at
- A private space close to each ward where parents can go to talk to one another or to make a phone call, without going too far away from their child
- An quiet/reflective space where parents can go if they have received bad news or simply to relax in silence

Experience in hospital:

Play

Play is central to children's learning and development, but above all it is an opportunity for children, alone or together, to have fun. Play facilities are critical in the new children's hospital, and hospital play staff will be a key part of the new hospital's workforce. The design process must specifically address play, and ensure the following:

- That appropriate and sufficient space is dedicated to play
- That play areas are safe and accessible
- That all play areas are sufficiently staffed
- That there is a balance between outdoor and indoor play
- That play is available throughout the hospital, including in spaces like the accident and emergency department, and the out-patients department; and that these areas also have dedicated play staff
- That there is a central play department, where all children in the hospital can come for special sessions, for example stress-reduction, one-to-one therapeutic play, and themed sessions
- That a qualified hospital play specialist is recruited to support the design of play facilities, to oversee their implementation, and to coordinate and implement play policy in the hospital.

Education

Children's education should face minimum disruption while they are in hospital. With the right facilities, tailored to the individual child's needs, children can continue to learn as they did outside of hospital. Given this, school facilities on-site are essential. But these school facilities differ greatly to the conventional school model; for example:

- The school calendar: for children in hospital school must be year-round, it cannot reflect the standard school calendar with its long summer break. Children are in hospital all summer, and this time provides them with the opportunity to catch up on work they may have missed during the year due to illness.
- Flexible teaching methods: teachers will need to –
    - move around the hospital, in addition to using a classroom
    - develop innovative approaches to teaching children with different levels of educational experience and ability to engage with learning
    - get to know children's educational needs quickly and respond to them

Religion and Culture

Children and families' religion and culture must be respected in their experience of the hospital as a place to visit and stay (for example in food provided, and washing and dressing facilities).

- A non-denominational reflective space for parents and relatives should be available in the hospital

Summary of recommendations:

- The hospital design must reflect the need for smooth *arrival* at the hospital for parents and children. This includes attention to car-parking, entrance design; and bathroom, pram and crèche facilities
- Design must ensure that children's *journey through the hospital* is smooth; and that parents can stay comfortably with their children, with access to basic services, like laundry and showers
- Play and education facilities are critical, and must be a key element of the design process
- Religious and cultural sensitivities must be respected within the hospital

4. Planning for the future

It is important to bear in mind that the planning process for the new National Children's Hospital is not simply planning for this year and next, but rather is about planning for the future – ten and twenty years on. Given the huge task facing designers and planners, and the high expectations and anticipation that surround the new hospital, it is important to acknowledge likely or potential future change, and to identify risks and concerns with building now for the future. Primarily, **scenario planning** must recognise likely change in demographics, and **must base its planning on children being all of those up to the age of 18.** Bristol Children's Hospital failed to plan for growth, and state it as one of the weaknesses of their project.

Designing and building a new National Children's Hospital is a once in a lifetime opportunity, and must be made the most of, thus:

- The National Children's Hospital must not be planned as a re-provision of existing services.
- It is a hospital for the future, and must plan for future capacity and future service provision.