National Paediatric Hospital

Submission from
Children in Hospital Ireland

to the
Executive and Board
of the
National Paediatric Hospital.

27 March 2009

Children in Hospital Ireland

Children in Hospital Ireland was founded in 1970 by a group of parents of hospitalised children who wanted to ensure that all sick children were cared for appropriately and with respect.

Since its formation Children in Hospital Ireland members have worked to offer a voice for all sick children and the organisation has played a major role in initiating and furthering change in how children are cared for in hospitals.

Children in Hospital Ireland actively helps and support parents and carers for sick children with practical advice and suggestions.

The organisation provides and manages a play service, PlayWell, in seventeen of the 26 hospitals throughout the country in which children are treated. Hundreds of trained and vetted volunteers organise arts and crafts, games and fun activities in wards, playrooms and other departments every week – they provide over 40,000 hours of play each year. The level of service and the number of hospital increases each year.

Children in Hospital Ireland also provides –

- Information and support to help families prepare for and deal with difficulties they may have before, during and following a child's stay in hospital.
- Advocacy for best health care for sick children.
- Publications and promotion of quality and working guidelines for the provision of health care to sick children, adolescents and children with special needs.
- National and local events for children in hospital.
- Education programmes for students, health professionals and the public.

As one of the country's leading children's charities, Children in Hospital Ireland is delighted to have been asked to make a submission to the Executive and Board of the National Children's Hospital. The organisation is delighted to offer its experience and expertise to the Executive and Board and looks forward to meeting to discuss this submission in the near future.

Children in Hospital Ireland; March 2009

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1 Introduction

Children in Hospital Ireland (CHI) was founded in 1970 and ever since has actively promoted the welfare of all sick children, especially those who require hospitalisation. CHI is an organisation with no vested interests or allegiances save to represent the best interests of sick children and their families. For many years CHI has called for a national review of paediatric services and for statutory guidelines for the care of children in hospital.

In 2001, CHI, welcomed mention of these measures in the National Health Strategy as an acknowledgement of the need. However, to date there has been no action on the development of statutory or any official guidance regarding the care of children in hospital and the review of paediatric services outside Dublin currently taking place is limited in scope. This is relevant to how the new hospital will function in the context of a national network for paediatric services.

CHI has also called for rationalisation of the children's hospitals services in the greater Dublin area for over two decades and welcomes the development of the new National Paediatric Hospital on the Mater Hospital Campus.

Concerns about the limitations of the site and about the benefits of co-location with an adult hospital have been expressed. It is hoped that during the course of the design phase of the new National Paediatric Hospital these concerns will be addressed.

However, in this submission CHI concentrates on the elements necessary to ensure a world class hospital which will be a centre of excellence, providing secondary services for the children of the Greater Dublin area and tertiary services for the children of the whole country. The services must be provided in a context and setting in which the holistic needs of the child are paramount: inclusive services for all children regardless of ability or disability

This hospital must meet more than minimum requirements. What is proposed must be visionary and must fit the needs of the populations it will serve. It must exceed what is regarded as today's highest standards and anticipate likely changes in society, technology, medical and nursing practice and government strategy over, at the very least, the next thirty years.

This document concentrates primarily on the physical aspects of the development of the hospital. Growing awareness of the importance of the psychological aspects of the care of sick and hospitalised children has led to the realisation that the provision of a clinical, sterile, medically orientated environment must not overshadow the emotional needs of the child. The hospital must provide an environment which is conducive to the promotion of health and the reduction of stress with the emotional and clinical needs being given appropriate attention.

Hospital care should change a child's routine as little as possible and provide as congenial an environment as a hospital and the child's illness permits.

2 Principles and Engagement in the Process

Children in Hospital Ireland strongly recommends all stages of the planning for the new hospital are measured against the principles and standards of the European Charter for Children in Hospital (The EACH Charter) and against the principles and articles of the UN Convention on the Rights of the Child.

Children in Hospital Ireland is a founding and active member of the Children's Rights Alliance and fully endorses the submission of the Alliance in its entirety, but with emphasis on, in particular, the Section on the Principles Underpinning Practice: UN Convention on the Rights of the Child and the Section on the Design Process: involving children, families and staff.

Engaging in robust consultation with all stakeholders will be crucial to the success of design process for the National Paediatric Hospital. Children in Hospital Ireland urges that the Executive and Board of the National Paediatric Hospital take measures to ensure that the those who represent the users of the hospital – children and families and the Chronic Illness and Condition Support Groups who represent them – are fully involved so that their expertise and experience can be made available and utilised. Children in Hospital Ireland is happy to place its own considerable experience and expertise, amassed through working in this area for almost 40 years, at the disposal of the Executive and Board of the National Paediatric Hospital.

3 Admissions Policy in the new National Paediatric Hospital.

The new National Paediatric Hospital must cater for the admission of child patients up to (at a minimum) the age of **18 years**. Bed numbers must reflect this. At present many of the adult hospitals in the Greater Dublin region admit children aged between twelve and 14 years upwards. The three children's hospitals do not routinely admit children over 15 or 16 years of age who have not been attending the hospital on an ongoing basis. This is significant in that current calculations on bed requirements rely an upper age limit of 15 of 16 years, broadly in line with current practices. However, in the new National Paediatric Hospital, these admission practices must change in line with the definition of children under the UN Convention on the Rights of the Child, the EACH Charter and in line with Government policy and recent Irish Legislation.

The new National Paediatric Hospital bed capacity must reflect this admissions policy and practice.

In addition, the hospital planning brief must incorporate an appropriate expansion capability for 10 years, 20 years and 30 years following its commissioning.

4 External Areas

All external approaches and areas must be inviting and welcoming for children.

5 Parking

Parking – free for all parents – must be on site and incorporated as an integral part of the hospital with easy access to all areas. Sufficient parking spaces must be available. Current research indicates that up to 1500 parking spaces will be required for the National Paediatric Hospital.

Dedicated spaces for those with mobility and other complex and special needs must be located adjacent to the entrance or entrances. Short term parking for set-down and pick-up must be available adjacent to the main entrance and out patients department. Short-term parking must be available for parents adjacent to the paediatric A&E entrance.

Approximately 60 designated parking spaces must be reserved for CHI's PlayWell and JustAsk volunteers.

6 Outdoor Play Space

Outdoor play, recreational and a variety of safe and secure green spaces (not necessarily at ground level) are an essential therapeutic factor in a children's hospital for both the children and their families. (Staff also require outdoor space for their well being.) Each child patient, irrespective of mobility restrictions, must to be able to access this outdoor space without difficulty, adjacent to where their care is being provided.

7 Access

Access by car is and will remain the preferred mode of transport for parents of and with sick children.

A **new traffic analysis** on access to the hospital must be undertaken to assess what changes are necessary to facilitate smooth access to the hospital from all areas of the city and from the main arterial routes into the city from around country. A traffic impact statement relating to the implications of the new hospital must be undertaken to assess the effect of the new hospital on the locality.

Ambulance and emergency access routes must also be assessed in the context of current road infrastructure.

A detailed and timetabled public transport development plan will need to be drawn up. The timelines will need to realistically indicate when essential infrastructure projects will be completed and how they will specifically service the new hospital.

8 Entry Points

The main entry point/reception area must be open, bright and interesting for children of all ages (0-18 years of age at a minimum) and for their parents. Staffed space for play, reading and quiet activities for children and information points for parents need to be located in this area.

Reception desks need to have low-level areas where children can see over without being lifted up. Reception desks also need to have interest panels and cubby-holes at child level with appropriate activities to distract and amuse.

Entrances to A&E and OPD or specialist clinics, if separate, must also incorporate the same features and facilities as at the main entrance area.

All entry/exit areas must have adequate seated waiting areas for parents waiting for pick up or taxis.

9 CHI Volunteer Centre

The CHI Volunteer Centre and JustAsk Help and Information Desk must be incorporated into the main entrance area. Currently CHI operates volunteer services in each of the

three children's hospitals with volunteer numbers in the region of 300. The organisation will transfer these services to the new hospital. The services will be upgraded and augmented in line with the changed environments. The Volunteer Centre needs to incorporate materials' storage space for both the JustAsk and the PlayWell Volunteer Services. The Centre also needs adequate office/administration space with a training room for up 40 people. The Volunteer Centre must have separate cloakroom and toilet facilities with lockable storage for volunteers' personal belongings.

10 Out Patients Department

The OPD may be the first introduction that children have to hospitals. Therefore, special care and imagination needs to go into the design of the department in order that the first impact is a positive one.

A staffed play area is essential to reduce the stress and apprehension for children and parents who are waiting. Hospital Play Staff need also to be on hand to provide preparatory and post-procedural therapeutic play. A staffed play area has the added benefit of reducing noise levels in the waiting area.

In addition to common waiting areas there must also be private and secluded waiting areas for families with children whose special circumstances, illness or condition required this facility.

The Out Patients Departments must be laid out in such a way that easy throughput is facilitated and difficulties in accessing all the specialities and services are eliminated.

Consultation and treatment rooms/areas need to be child friendly. Auditory and visual privacy requirements must be met.

Seating in the waiting areas must be flexible and suitable for all ages from young child to adult. Parents need to have full sized seating for comfort while waiting for prolonged periods. Waiting areas must be large enough to comfortably accommodate buggies.

Light refreshments must be on hand and waiting parents and their children must have access to more substantial catering if they are in the department for prolonged periods. A private room for breastfeeding mums must be located in the OPD area.

A separate appropriately appointed waiting area is necessary for teenagers.

The OPD area must have its own toilet and baby changing facilities.

11 Multidisciplinary Assessment Unit

A dedicated special needs multidisciplinary assessment unit must provide the complete range of resources and personnel necessary to facilitate care of the child and family.

12 Accident and Emergency Department and Ambulatory Care Centre

Facilities must be able to deal with all paediatric trauma and emergency cases presenting. State of the art services, utilities and systems must be installed to deal with major emergencies. Equipment and facilities must be appropriate to cater for children from 0 years of age up to 18 years of age. The department must also be able to receive and deal appropriately with **child and adolescent psychiatric** emergencies.

This will be the primary trauma and emergency department for the whole of the Greater Dublin Region. It will be the first port of call for a large percentage of this population and will receive referrals and transfers from the planned local ambulatory / emergency care centres. It should also serve as an expertise resource for all A&E departments around the country which receive child patients.

The A&E Department, like the OPD, may be the first introduction that children have to hospitals. Therefore, special care and imagination needs to go into the design of the department in order that the first impact is a positive one.

A staffed play area in A&E is essential for reducing stress and apprehension and for pre- and post-procedural therapeutic play which facilitates treatment.
The layout of the Accident and Emergency Department must facilitate the unimpeded fast-tracking of acutely ill and trauma children to appropriate resuscitation and treatment areas. Acutely ill children who are known patients of the hospital must be fast-tracked to the appropriate ward.

An unimpeded fast-track pathway to transfer children to the theatre and specialised care areas must also be designed in.

Less ill children and their parents need to have a welcoming and inviting waiting area with equipment and material to provide distraction such as aquariums and occupational and interactive material. Triage and assessment areas must be child friendly with adequate space for children to be accompanied by a parent. Investigations and treatment need to be carried out in the Department.

Isolation areas must also be child friendly, with adequate space to accommodate a parent.

Teenagers must have a separate waiting and treatment area.

There is a need for private areas where parents can speak to staff. There must also be a private area where distressed parents and other family members can be alone to talk together or to grieve following a trauma or bereavement.

There must be an appropriate number of single observation rooms where children can be monitored for a 23-hour (or longer) period in order to reduce short-term admissions

Dedicated refreshment, catering, breastfeeding, changing and toilet facilities must be provided in the A&E department.

13 Ambulatory Care Centre in the NPH

Ambulatory care will have to be provided in the new hospital as well as in the proposed satellite Ambulatory/Emergency Care Units. The hospital ambulatory care centre will need to have its own dedicated clinic space with access to fast testing and diagnostic facilities and to the provision of appropriate treatments and care.

14 Transit Areas

Corridors, stairs, lifts, lobbies and other transit areas need to be appropriately decorated – including low and high wall areas, floors and ceilings.

Signage and colour-coded (or theme-coded) wall and floor direction bands (or motifs) must be easily interpreted and unambiguous. Information points at junction areas would reduce confusion and reduce stress.

Doors and some walls and partitions need to have visibility panels at low level as well as at high level.

Corridor and Ward windows need to be to floor level so that children can see out.

15 In-patient Areas

In the new National Paediatric Hospital, all child patients must be cared for in single rooms. This is necessary for a number of reasons, not least infection control, the illness of the child in-patients and the need for privacy, dignity and respect. Traditional long corridor arrangements must be avoided for efficiencies. Line of sight observation is necessary for staff to monitor patients and for patients to have visual contact with staff. This could be achieved by having the rooms arranged in a circular or rectangular fashion around a central open area. This open area needs to include the nursing station and have space for play, eating, exercise, circulation and celebration.

Room size needs to comfortably and safely accommodate the child patient, parent or guardian and all the medical equipment necessary for care and treatment provision. Medical equipment and required treatment services must be built in to each room to ensure availability and to overcome the traditional problems of storage. Outlets for treatment equipment over beds and in treatment areas need to be discretely housed so as to minimise fear and stress.

The space provision for child/parent rooms must be in line with the best practice internationally.

Each room needs to have natural light and basic ensuite facilities. Space is needed for a child's own decoration and personal belongings and for the personal belongings of a parent staying with a child. (See also Parents Unit section below)

Accommodation for a parent or guardian must be incorporated into the fabric of the room. Room layout needs to be such that a parent can sleep there without compromising provision of care or safety. Parent beds can be freestanding, or flip-up or wall mounted. Where appropriate, additional accommodation needs to be provided for a parent/guardian away from their child's room, but on-site and within "dressing gown distance". (See also Parents Unit section below)

All furniture and equipment needs to be flexible and movable to facilitate provision of space for children of different ages and needs. Glass walls and "breakdown" walls between the rooms and the central open space can increase the sense of inclusion in the life of the hospital especially for children who have to remain in isolation. This flexibility between rooms would also address the problem of isolation experienced by parents. Where children need to be cared for in isolation, it is necessary to utilise design factors and technology so that these children can interact with others and participate in ward activities. All rooms need to have the most up-to-date future-proofed ICT connections.

Privacy can be maintained by providing integrated wall and window blinds which close from the bottom and which can be controlled by the children and their parents.

Children need to be cared for with children of similar age and/or developmental stage for example, groupings of babies, 3 to 6 year olds, 7 to 10 year olds, 11-14 year olds and 15 to 18 year olds.

All in-patient and treatment areas need to incorporate private space for personal communication and consultation between staff and parents and for parents to converse privately together. The care provided by a hospital must centre on the recognition of the child as a member of a family unit whose support is essential to the child's well-being. Parents should be encouraged and assisted to provide care and support to their child especially during stressful episodes and treatment rooms must have soundproofing. Parents need to be educated and supported to provide continuing care following their child's discharge.

All in-patient areas need to have separate areas/sitting rooms with refreshment facilities where parents can have privacy to relax, unwind and meet with other parents.

All in-patient areas require information points where parents can access information about the area and the hospital in general. State of the art technology must be utilised and future proofed.

All in-patient areas must have their own cleaning and hygiene centres with adequate and appropriate secure storage for materials and equipment

16 In-patient Play Areas

All inpatient area units need to have adequately staffed, equipped and appointed playrooms and play areas suitable for providing age appropriate play and recreation for children accommodated in the rooms. The play areas and rooms need to be adequately sized to allow access to children who have mobility difficulties or who are confined to bed. They also need to incorporate private space for preparatory, instructional and post procedural therapeutic play and for storage.

17 Day Treatment Areas

Increasingly care and treatment is provided on a day case basis. The above provisions for in-patient facilities apply and must be considered and adapted when designing space for day treatment areas. As the provision of treatment on a day case basis requires high levels of speedy activity for diagnostics and procedures, design elements need careful consideration.

Play space and Hospital Play Staff are needed in day areas to facilitate preparation and distraction for child patients. Waiting, toilet and catering and breastfeeding facilities need to be provided for children and parents.

Operational times for day areas or wards need to be maximised, without compromising care, to ensure the facilities can be used to reduce the need to admit children.

18 Intensive Care Units

Children in Intensive Care Units should be in single rooms which can accommodate a parent with out compromising safety and care. The unit must have a family room with bathroom and kitchen facilities. A staffed play centre with storage for appropriate materials to implement play programmes for a child in ICU must be included in the unit.

19 Baby Rooms

Each baby room needs to include sleeping and bathroom facilities for a parent beside their baby, incorporating the features outlined for in-patients above. In addition, each room must have access to supply of appropriate toys and stimulation equipment. Baby room areas need to have a common, well-equipped area, large enough to accommodate buggies, where parents can take their baby to parent and play. Because of the intensity of the experience for parents to be with their baby in hospital, baby areas also need to have a parent's sitting room where parents can relax, rest and meet with other parents

20 Neonatal Care / Special Care Units

Neonatal and Special Baby Units must provide an environment of quiet and calm where care can be delivered which will foster well being of baby and parents. The unit must be able to accommodate mother and father with baby to facilitate bonding and feeding. Sleeping and eating must be facilitated so that mother and father are supported adequately to participate in the care of their baby.

The neonatal / special care unit must incorporate single family rooms to accommodate babies who are stable but continue to require special care

In advance of the development of a co-located maternity hospital, the neonatal unit must develop professional, technological and physical pathways to the existing maternity hospitals. Links to maternity units around the country need to be upgraded in line with the delivery of an enhanced service.

21 Play Department

This is a children's hospital – play must be everywhere!

However, in addition to specific staffed provision in each in-patient area, out-patient area and in other departments, Hospital Play Staff need to have a central Play Department where all child patients can come for special sessions – for example, stress reduction in the multi-sensory room, one-to-one therapeutic play away from the in-patient areas, age-appropriate group and themed sessions etc.

The Play Department needs to accommodate and support a staff complement appropriate to the size and nature of the hospital – at capacity, forty to fifty staff members and managers. The Play Department must provide the Hospital Play Specialists with a base for administration and management, multidisciplinary consultations, programme planning, preparation, storage and maintenance of equipment etc.

The provision of easily accessible, safe and secure, green-space outdoor play areas adjacent to the central Play Department is essential.

22 Hospital School

Children in hospital, especially long stay patients and children requiring frequent admissions, need access to appropriate education to minimise the impact of the interruption to their schooling and to provide stimulation.

Staff need to be skilled in dealing appropriately with children with special educational needs. Staff also need access to specialist help in this area for assessment and advice on care and facilities required for children with special educational needs.

The new National Paediatric Hospital must be able to provide for all the second level educational needs of its patients as well and their primary level needs.

Technology must be available to assist the children and to facilitate links between the hospital and the child's own school and teachers.

23 Operating Theatres Area

The number and mix of theatres, anaesthetics areas, recovery and other areas must be sufficient to accommodate the surgical load from the secondary care and tertiary care elements of this major hospital. The theatres and associated spaces must also be able to accommodate the increased load arising from the transfer of a number of services which are currently being provided in adult hospitals. (See below Relocation of Paediatric Subspecialties) The need for children to have to travel abroad routinely for surgery must be eliminated. Travel for surgery must be only for the most rare of cases. The theatre area must be supported by adequate numbers of staffed intensive care and high dependency beds in order to minimise the need to cancel or postpone surgery.

The anaesthetic induction areas need to be large enough to accommodate an accompanying parent without compromising safety or the administration of anaesthesia.

Recovery rooms need to be large enough to accommodate an accompanying parent without compromising safety or care.

Décor in all theatre areas must be child friendly, distracting and soothing. A staffed therapeutic and distraction play area for all operating theatres is essential.

24 X-ray and Imaging Department

Décor and intelligent camouflage is necessary to minimise the scariness of large machinery. Space is needed to allow parents accompany a child for as long as possible during tests and treatments. A staffed therapeutic and distraction play area is essential these areas.

Both the Theatre Areas and the X-ray and Imaging Departments must be future proofed to accommodate the developing technologies which are coming on stream and to anticipate future innovations.

25 Therapeutic Departments

Physiotherapy, Occupational Therapy, Social Work, Psychology and other therapeutic Departments must all be located on site.

Adequate numbers of consultation rooms and office space must be provided for professionals working in these disciplines. (Consultation with the practitioners will provide the relevant information.)

Child and adolescent friendly décor is needed throughout these areas. Consultation rooms where staff can interact with children and speak privately to parents need to be sound proofed. Play areas need to be provided for the children to relax before or after therapeutic sessions. Visual and auditory privacy needs to be protected where appropriate.

Other therapeutic modalities such as Art, Drama, Music and Play Therapy, must also be catered for appropriately. Provision of a Hydrotherapy pool must be considered.

26 Teenage/Adolescent Unit

This is a key cohort of patients whose needs are constantly overlooked in the paediatric hospital setting. (See also Admissions Policy above) Adolescents and young people have needs which are distinct from those of both children and adults. To cater for these differing needs adolescents must be catered for in special units separate from children but within the new National Paediatric Hospital. These units can provide privacy and independence with opportunities for socialising, hobbies and homework. While fostering opportunities for independence, adolescents need to maintain links with and support from families and friends. Phone, internet and other electronic communications channels must be available to facilitate this.

With advances in care and treatments, the teenage patient population is increasingly significant and with special needs that must be addressed in the new National Paediatric Hospital. Young adult patients must be accommodated in an area/unit separate from younger patients. This area/unit must have specific appropriate design features. Gender separation must be considered and accommodated. This is necessary in order to ensure respect for privacy and personal needs related to both the physical and emotional changing and maturing processes being experienced by this cohort of patients. Age and size appropriate furniture, décor, bathroom, toileting and sanitary facilities need to be provided. Common play and recreation areas with limited kitchen facilities are also needed.

Accommodation needs to be provided in this unit (as for general in-patient areas above) for parents who need to stay with their child.

Where an adolescent patient is not being cared for in a dedicated Adolescent Unit, it is necessary that the in-patient area is able to appropriately provide for all their needs.

27 Children with Sensory Needs

Children with sensory impairment in hospital are at risk of isolation and deprivation of information normally assimilated by sight and hearing. This may add to their stress and staff need to have adequate training and skills to accomplish communication. They also need access to the latest assistive communications technology.

Hospital layout, signage and information must be accessible to children with auditory and visual impairments.

28 Multi- and Non-denominational Care and Ethnic, Religious and Cultural Needs

The spiritual needs of sick children and adolescents and their families should be supported through the availability of a chaplaincy/pastoral care unit. This unit must be able to provide private space for the representatives of the major religions. It must also incorporate a place of worship which can be used by different denominations. The hospital must ensure that families from non-Christian faiths are supported with access to the relevant spiritual advisors as appropriate. The hospital must also ensure that families of no faith are also supported by an appropriate care team.

The needs of sick children from minority groups including refugees, different religious and cultural backgrounds need to be understood and respected. The Hospital needs to be able to accommodate different cultural practices and provide interpreters where necessary.

29 Liaison/Transitional Care Unit

Transfer to adult services does not imply transfer to the co-located adult hospital. Adolescents with disabilities or chronic illness need to be supported through the transition from paediatric to adult services in the hospital of their choice. A resourced unit, staffed by skilled liaison personnel should be located in the Adolescent Unit and must develop relationships with adult services throughout the country. The unit must make the maximum use of communications technology to assist child patients make the transition to adult services with as little trauma as possible.

30 Patient and Family Entertainment Facilities.

Special events are a big part of hospital life for children, families and staff with events being organised during the year. The centre for Paediatric Health Sciences (see below) must incorporate conference facilities and lecture and seminar rooms. As the centre will be located in the Hospital, use can be made of the facilities for functions such as shows and entertainment for child patients and their families.

31 Child Psychiatry Unit

Here-to-fore the provision of mental health services for children and adolescents has been very lacking throughout the country, with none of the children's hospitals providing adequate facilities. This must be rectified in the new National Paediatric Hospital.

The current thinking in mental health care provision aims at reducing the stigmatisation that often accompanies mental illness. The new National Paediatric Hospital must include the provision of a child and adolescent psychiatric in-patient unit. This is essential to ensure the mental health needs of children and adolescents can be provided for as an integral element of this comprehensive children's hospital. Child and adolescent patients with mental illness have the right to be cared for in a paediatric setting where the ethos of care focuses on providing for their needs. Play and recreation areas as for all in-patient area and accommodation for parents are also necessary in this unit.

The Child and Adolescent Mental Health Centre must be the hub of a mental health service which also provides and supports care on an out-patient basis and which supports care in the community setting.

32 Relocation of Paediatric Sub-specialisms from Adult Hospitals

Here-to-fore a number of specific specialties have been delivered to children at other hospitals around the city. Chief among these are Neurosurgery, Cochlear Implantation, Renal Transplantation, Eye and Ear, Nose and Throat procedures, Plastic Surgery and Orthopaedics. These must be relocated to the new hospital. The physical building-space needs of these specialities must be included in the planning for the hospital.

33 Palliative Care

Consideration must be given to how palliative care is to be delivered. The physical configuration of space will depend on the models of care which are adopted by the hospital. However, as the goal of palliative care is to allow children to live their lives to the maximum to the end, palliative care facilities have to provide all that is necessary for

a child's life, particularly all forms of play. Family members must be accommodated with a child who is receiving palliative care. Quiet restful surroundings are required.

34 The Dying Child

When a child is dying it essential that rooms, which are separate and private, are available. Again the configuration is dependant on the models of care adopted. Rooms must be of sufficient size to accommodate parents and other family members where they can actively participate in the care of their child.

Support and advice must be available to parents to help them actively participate in the care of their child. The need for effective pain control is of great importance.

A home-hospital palliative care liaison unit must be made incorporated into the hospital to facilitate provision of medical and nursing support to parents who wish to care for their dying child at home. Channels of communication between community services and hospital services need to be excellent so that parents can easily return to the hospital or access any necessary information about their child's care.

35 Mortuary Facilities

When a child dies it is essential that parents and families be given the care, support and assistance necessary to cope with their grief. Information regarding the death should be given sympathetically in person to the families and family doctors should be informed of the death as soon as possible. Privacy is of the essence.

With all deaths, and especially with unexpected bereavement, privacy, support and advice are necessary along with access to their child's body. Appropriate facilities need to be provided where the wishes of parents regarding the laying-out and funeral arrangements for their dead child can be accommodated and supported.

36 Parents

Parents are part of their child's care team and need to be adequately supported in this role. Parents who overnight in the hospital need to have appropriate and comfortable furniture. In addition to overnight facilities in each child's room, sleeping facilities away from the child's bed, but on-site and at "dressing gown distance", are also required for a small percentage of parents. These rooms could be located in a "Parents Unit" and need to be large enough to accommodate a full sized parent bed, appropriate storage and bathroom facilities. In addition to providing alternative overnight facilities, these rooms must provide accommodation for a second parent or other family member whose presence is necessary because of the severity and complexity of the conditions which will be treated in the new National Paediatric Hospital.

For some parents, their child's condition or illness may mean that their lives are functionally transferred to the hospital, sometimes for months, to be with their child. To accommodate such parents, facilities which support parents to fulfil their work and family obligations must be incorporated into all inpatient areas and into the parent unit. For some families, hostel and hotel accommodation will be required and must be provided.

The Parent's Unit must also accommodate laundry facilities to cater for all resident parents. A parent's sitting room with kitchen facilities is also required where parents can

unwind and meet with other parents. In addition, parents also need access to private retreat areas where they can be alone when they need some space to reflect or grieve.

The unit must also accommodate parent education rooms where staff can educate, support and coach parents as required.

The parent's unit must have adequate storage lockers for clothes and other personal belongings which cannot be stored in their child's room. Parents of long-term child patients who are going home – with or without their child – for short periods, need storage for their belongings during the break period.

Family accommodation off site must be available for those with children living distant from the hospital who while not requiring admission need daily or frequent treatment in the hospital.

37 Food and Drink

The kitchen/catering services must have the capacity to safely provide for the special diets of all child patients with such requirements. Kitchen/catering safety systems must be put in place to ensure that cross contamination of food does not occur. Specially designated and separated equipment such as toasters must be made available where parents of children with special dietary requirements can prepare snacks as required.

The Dietetics Department must oversee the facilities and provision for special diets, for example those of children with Coeliac Disease, Diabetes and with metabolic disorders, to ensure that there is accurate awareness of special dietary requirements and availability of special foodstuffs.

Meals, snacks, tea, coffee and drinks need to be available to parents at all times. Kitchen facilities for making light meals and snacks and including a small eating area need to be incorporated into all in-patient areas and in the parents unit.

The hospital must ensure that canteen facilities are on-site, appropriate and adequate to provide a complete service to the parent and patient population and for the staff.
The opening times for a full canteen service need to reflect that parents may not always be able to go for meals at the conventional times. Child patients must be welcomed in canteen areas to reflect the importance of meals as a family and social activity.

Breast-feeding mothers need to be accommodated in all areas throughout the hospital

38 Parents Resource Room/Education Centre

Many parents of hospitalised children want to research their child's illness. The new National Paediatric Hospital must incorporate a staffed parent's resource room where they can do this in comfort and with assistance. Parents should be encouraged and assisted to provide care and support to their child especially during stressful episodes. The Resource Room/Education Centre must provide space for individual coaching and for group learning. Parents need to be educated and supported to provide continuing care following their child's discharge.

39 Hospital Shop/Retail Outlets

Resident parents in the new National Paediatric Hospital will require access to a variety of items and goods. Care must be taken to ensure that all retail franchises are tailored for

the hospital setting. Shops need to be appropriately positioned, not near the main entrance but close to A&E and OPD, where they are accessible to parents and visitors but not a source of temptation to children. Hospital shops need to be required to carry an appropriate stock of items requested by parents (nappies etc).

Careful thought must be given to ensure that food outlets, if included in the building, follow healthy eating guidelines.

An ATM and Change Machine must be provided on site.

40 Security and protection

The unrestricted access of parents and other visitors to children's wards must not be a danger to children's safety. Doors of wards must be appropriately secured. Staff caring for children must be alert to the presence of strangers by their knowledge of who are legitimate visitors. The presence of parents on the ward may act as a further deterrent to any intruder. Technology must also assist, for example, "smart" cards to allow access to car-parking, wards, catering and other facilities should be provided for parents. State of the art security systems must be built into the fabric of the hospital.

41 Advanced technology

Advanced technology needs to be used appropriately to assist parents and child patients. Each child's bed needs an ICT/broadband connection for access to the hospital intranet and to the Internet. Play and other common areas also need to have state-of-the-art ICT connections.

42 Crèche for siblings

Children in hospital are cared for as part of a family unit. Having a child in hospital can have a devastating impact on families. Often the care of siblings is a major challenge for parents. It is necessary that the hospital supports parents by assisting with the care of siblings through the provision of crèche/minding facilities. This facility must be available for parents whose children are in-patients or who are attending OPD, A&E and other departments

43 Shared Services – minimal use of adult facilities

The complete range of specialties, subspecialties and treatment modalities and services must be available in the new National Paediatric Hospital. If, in limited non-clinical circumstances, sharing of services takes place its must have absolutely no impact on care of the child patients. Children must not have to use any care facilities in the adult hospital except in the most rare of circumstances. In each case, the need to use the adult services must conform to criteria which protect the integrity of the children's hospital. (See also CHI's submission to Task Group re the location of the new hospital)

44 Shared Care/Outreach support centre

In order to maximise the benefits of shared care and outreach services, the hospital must incorporate a special education unit where health professionals from distant hospitals can be trained up to provide care locally for patients of the National Paediatric Hospital.

45 The Hospital in the Community

Emergency evacuation plans for the hospital, taking into account all the challenges and factors relating to co-location, current traffic flows and road layout, must be drawn up and assessed as part of the planning process.

How this co-located adult and children's hospital campus will participate in the emergency response plans for a major incident, taking into account the above mentioned challenges will have to be determined as part of the planning process.

46 Links with Community Services

Children should only be admitted to hospital if the care they require cannot be equally well provided at home or on a day basis. Their hospital stay should be a brief as possible. The importance of minimising the length of stay for children in hospital presumes the availability of locally based community backup services to provide the necessary support and skills to facilitate the care of sick children at home.

Community paediatricians should be available to provide secondary care and preventative programmes to children and families. A paediatric community nursing service is necessary to provide care to sick children after day care and discharge, who are referred by a GP, have a chronic illness or handicap or who are in need of terminal care. The GP provides a pivotal role in providing ongoing primary care to children and families and when necessary providing referral to specialist services. The planning of a seamless integrated health care service for children must define and support this crucial central role.

The interface between the hospital and community services must be managed by the hospital. The new National Paediatric Hospital must have a staffed liaison unit with established links to community paediatric, nursing and GP services. This unit must provide educational facilities where hospital specialists could provide training to those in the community to whom the care of child patients is being entrusted.

47 Health Promoting Hospital

The new National Paediatric Hospital should be a member of the Health Promoting Hospitals Network – a hub for promoting children's health in the Greater Dublin area and a resource for paediatric units around the country. Appropriate office and educational facilities need to be included in the design of the building. The unit should provide and facilitate hospital and community based child health promotion programmes including immunisation and vaccination, and accident prevention programmes. In collaboration with the hospital's multidisciplinary assessment unit, the HPH unit should identify, and monitor physical and intellectual child development problems identified in the inpatient population and in the local community. They should assist in the identification and care of children at risk, and offer guidance and support for parents.

48 Staffing and Staff Education Centre

Children should be cared for by medical and nursing staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families. Continuity of care should be ensured by the team caring for children. Recommendations from professional bodies representing clinical, medical and nursing staff should be adhered to in order to provide adequate cover in all areas of the hospital where children are treated.

As well as medical and nursing personnel, children in hospital also come into contact with a wide range of clinical and non-clinical therapeutic and other professional and technical staff. The hospital must have access to a Staff Education Centre with a suite of lecture theatres and seminar rooms located in the hospital's Centre of Paediatric Health

Sciences and Learning. (See below) Comprehensive induction and in-service training in dealing and communicating with sick children and their families can be provided to all staff –clinical and non-clinical - in this centre. Medical, nursing and other professional skills training will also be undertaken in this unit.

In order to ensure that staff are happy working in the new National Paediatric Hospital is will be necessary to provide first class staff facilities – appropriate numbers of well equipped staff rooms, changing, showering and toilet facilities. Staff also require common space for hospital staff groupings to meet for peer support, learning and socialising.

49 Centre of Paediatric Health Sciences and Learning incorporating Conference and Lecture Facilities

The new National Paediatric Hospital must be a centre of academic learning and research with links to universities throughout the country. This centre must take the lead in guiding the development of e-health and tele-health facilities for the whole hospital. The centre for Paediatric Health Sciences must incorporate conference facilities and lecture and seminar rooms.

50 Research Centre

The three existing hospitals have centres of research and learning which will have to be accommodated in the new National Paediatric Hospital. The NPH Research Centre will need to be incorporated on site in the new hospital to maximise the benefits accruing. The clinical research tradition should continue in the new hospital which will be a world class centre of excellence.

However, in addition to clinical and academic work, the Research Centre should also collect and monitor data relating to the use of the hospital to assist in the planning for the future. Statistics need to be compiled on age; through-put and bed occupancy; intensive care; parents staying overnight; A&E department; OPD, day care and ward attendants; children using the adult hospital facilities; children being nursed in the community and staffing qualification mixes.

The collection of information on demographic, geographical and illness factors in relation to the use of the hospital and the local health care services for children should lead to service development according to need. This would result in the integrated provision of services - primary, secondary, tertiary and community services and ensure seamless continuity of care from one to the other

Every child shall be protected from unnecessary medical treatment and investigation. This includes the right to refuse to participate in medical education and / or research.

51 In All Areas

The primary over-arching requirement for all areas of the hospital is that the needs of children as part of a family unit are paramount. To this end, the architecture, design, colour schemes, décor, and styling must be home-like and comfortable. Where it does not interfere with or compromise care, lighting should be soft. In addition to providing for child patients and parents, space to cater for visiting siblings and friends of patients must also be designed into the fabric of the building. Safe and secure outdoor green areas and useable balconies need to be available for child patients, parent and visitors.

All doorways/entrances and hospital areas including toilet and bathroom facilities must be fully accessible for all children and adults with disabilities and special needs. Access must be sufficient to cater for electric wheelchairs and standard beds.

Ward and patient rooms, doorways, corridors, bathrooms and all spaces in the new National Paediatric Hospital need to be adequately sized to accommodate mobility and communication aids and treatment equipment.

52 Management of the new National Paediatric Hospital.

A children's hospital is a place of constant change and flux involving numbers of patients, events and emergencies. The management of services and care in a major children's hospital is a complex, 24 hour a day function. In order to deal with clinical and operational issues in the shortest possible time, as they arise, it is essential to have both administrative and clinical managers on site. A management suite must be incorporated into the design of the hospital from the outset.

53 Governance

The Development Board and the Board of the new National Paediatric Hospital must be completely independent of the co-located hospital and include representation from the providers and users of the hospital's services and advocacy and support groups.

Although it is proposed that the new National Paediatric Hospital be co-located with an adult hospital, it must provide the complete range of services to tertiary level as would be expected in a major standalone children's hospital. In order to protect the integrity of the services provided the Governance and Governing Instrument of the new National Paediatric Hospital will be of paramount importance. The ownership of all hospital structures, ground level facilities and below ground services and facilities must rest with the National Paediatric Hospital.

CHI recommends that the new National Paediatric Hospital must include the complete range of clinical and diagnostic services and all the administrative functions necessary to support a major national hospital. However, if consideration is being given to whether some non-clinical, non-diagnostic back office services could be shared with the co-located hospital, rigorous analysis of the possible implications and impact on the delivery of services to sick children in the new National Paediatric Hospital must be carried out prior to any decisions being taken.

54 Conclusion

This submission is prepared by Children in Hospital Ireland to provide guidance and assistance to the executive of the new NPH, the Board and the design team in their development of the high level framework brief for the new National Paediatric Hospital.

Children in Hospital Ireland wishes the team well in their work and is committed to placing its experience and expertise at their disposal.

Children in Hospital Ireland. March 2009

55 Supporting documents

- The European Charter for Children in Hospital (the EACH Charter) (2002)
- Guidelines for the Care of Children with Special Needs in Hospital (2000)
- Sick Children, Money Worries. Children in Hospital Ireland (2004)
- Play Facilities for Child Patients in Irish Hospitals. (1993)
- Children Being Cared-for in Adult Wards. (1999)
- The Shape of Things to Come – Conference Papers. (1995)