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# Integrated Care Programme for Children

Dear Colleagues,

Following the publication of the National Model of Care in 2016, the Integrated Care Programme has the important task of developing a costed implementation plan for its implementation. Integration is the key word and, in this regard, three work streams have been developed. The acute care, the healthy child and the community care work streams are led respectively by Ms Eilish Hardiman, Dr Kevin Kelleher and Mr Bill Ebbitt. We hope to complete our work by May 2018 with a fully costed plan. This is a mammoth task but we are fully committed to meeting this deadline. Care pathways for children with congenital hearing loss and congenital muscle disorders are being developed, with parents and families affected central to these discussions.

The further support of the neonatal 24/7 transport system (which has been highly successful) and expansion of the paediatric transport system are essential elements of the

model of care implementation. The Waterford Paediatric Initiative focuses on a more consultant-delivered service and the targeted ultrasound service for infants at risk of developmental dysplasia of the hip will ensure an ultrasound service to screen for high risk cases of developmental dysplasia of the hips regardless of geographical location. All our work is sound-checked by the paediatric HSCP and nursing expert groups and the Clinical Advisory Group of the Faculty of Paediatrics.

We would like to thank Ms Grace Turner, Ms Siobhan Horkan and Ms Linda Power for all their hard work to date.

Kind regards

*Alf Nicholson*

Prof Alf Nicholson  
Clinical Lead, ICP for Children  
Consultant Paediatrician,  
Children's university Hospital, Temple Street

*John Murphy*

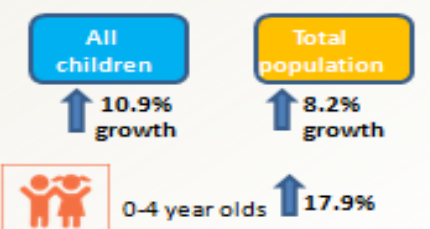
Prof John Murphy  
Clinical Lead, ICP for Children  
Consultant Neonatologist,  
National Maternity Hospital

## Children in Ireland – some facts



> 1 million children living in Ireland  
= 25% of the population

### 2006 – 2011 POPULATION GROWTH



### FOREIGN NATIONALS



### BIRTH & FERTILITY



69,267 births in Ireland in 2013  
5.5% were of low birth weight.



32.1 years Average age of all mothers with babies born in 2013

Ireland's total fertility rate is the highest among the EU-28 countries (Eurostat).

### CHILD MORTALITY

Overall CHILD mortality rate: 3.4 per 10,000  
Two thirds (65.6%) occurred in those aged less than 1 year (DCYA, 2012).  
2011 INFANT mortality rate: 3.6 per 1,000. This was below the EU-27 average of 4.2 per 1,000.

Largest single cause of child deaths was 'congenital malformations'

### CHRONIC DISEASE & OBESITY



One in ten 9-year-olds (11%) have a chronic illness or disability (Williams et al., 2009).



Over a quarter of Irish 9-year-olds are overweight or obese (Lavte & McCrory, 2011).



## Implementing a national model of care in an integrated way

### A model of care for children

The National Clinical Programme for Paediatrics and Neonatology, a joint clinical initiative between the Faculty of Paediatrics, Royal College of Physicians of Ireland and the Health Service Executive, has developed a national model of care for paediatric and neonatal healthcare services in Ireland.

The model of care addresses the changing healthcare needs in Ireland and describes a vision for high quality, accessible healthcare services for children in Ireland, from birth to adulthood. It spans a range of care settings from community services to tertiary and quaternary care. It sets out requirements in a range of paediatric subspecialties for infrastructure, staffing and processes, and the expected outcomes for children accessing each service. The model of care was approved by HSE Leadership in June 2016 and can be found online via HSE.ie.

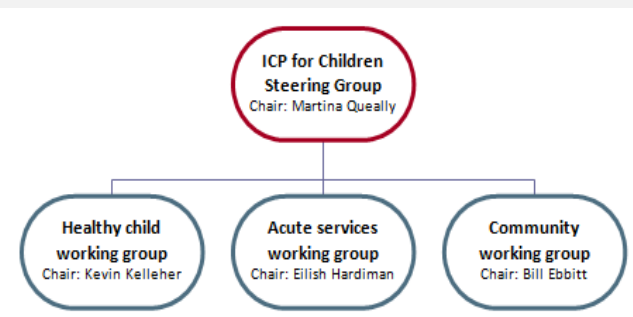


### Integrated implementation

The model of care must now be implemented, however, it cannot be implemented in the traditional service delivery 'silos'. It must be implemented in an integrated way to ensure that care follows the journey of a child from home to community and if necessary to the acute hospital, and back again. A seamless provision of child-centred care is required.

An implementation plan is being developed which will outline how the model of care should be implemented across community and hospital networks. This requires stakeholders to work together in an innovative integrated way, which has not previously happened in Ireland for children's services on a national scale.

The ICP for Children Steering Group has proposed to approach the implementation plan development through three working groups as follows:

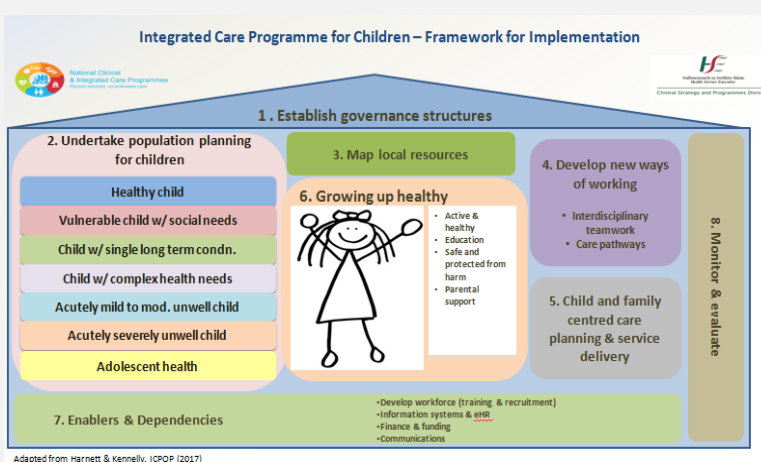


Additional expertise is being sought to support the development of the implementation plan (workforce planning, ICT, finance, health economics, population health) and expertise from within each of the divisions of mental health, social care, primary care, health and wellbeing and acute hospitals is also being sought to participate in the working groups.

There are challenges around the scale of the project and the different levels of readiness for implementation.

Workforce planning is more straightforward in some disciplines and service areas than others. The absence of an eHR system and fully integrated IT system poses significant challenges. Breaking down of traditional barriers is required, for example the provision of funding to a particular service rather than a patient journey. Enablers for integrated care are being considered, including ICT, workforce, finance and communications. An ICP for Children framework is being used as a focus for designing an integrated implementation plan at a local and national level.

## A framework for implementation



The Integrated Care Programme for Children has developed a framework for integrated implementation of the national model of care. It has 8 elements which present a roadmap for implementation nationally and locally. A population approach has been used, specifically through 'population segmentation'. The segmentation approach has been used to ensure health services are planned and delivered to all children based on need, not just those with a specific condition. This segmentation approach has been adapted from work done by Imperial College London. The ICP for Children recognised the need to address adolescent health so an additional segment was added for this important focus area.



### Paediatric Health and Social Care Expert Group (HSCP)

A paediatric health and social care professional (HSCP) expert group was formed in 2017 as part of the Integrated Care Programme for Children to provide a forum for HSCPs to inform and influence strategic direction and support the work of the integrated care programme and national clinical programme. The group will provide or source subject matter expertise, and assist in the development and review of guidelines and policies in line with national and international best practice. The group contains representatives from a range of professions working in acute, primary and community care settings.

The group is comprised of representatives from acute hospital and community services for each health and social care profession relevant for children. The chair of the group for 2017 was Claire Browne, dietitian manager, Temple Street. Claire will be succeeded by Margaret Mary Smith, neonatal speech and language therapist, Cork University Maternity Hospital. The group meet quarterly.

An important output of the group, supported by the Integrated Care Programme for Children and the Primary Care Division of the HSE, is the development of a competency framework for HSCPs working in paediatric services in all healthcare settings. Phase 1 of the project describes behavioural competencies under six domains:

- Principles of child health
- Communication
- Child- and family-centred
- Quality and safety
- Collaborative practice
- Professional and ethical practice

Phase 2 of the project will encompass the HSCP service standards required for children. The National Model of Care for Paediatric Healthcare Services will be used to guide this phase.

It is hoped that this document will be completed in the coming months. For further information on this group please contact Grace Turner [grace.turner@hse.ie](mailto:grace.turner@hse.ie) or Claire Browne [claire.browne@cuh.ie](mailto:claire.browne@cuh.ie).

### Nursing Expert Group – Children’s Services

The Integrated Care Programme for Children has established a Nursing Expert Group for Children’s services to support the work of the programme. The Nursing Expert Group provides a forum for nurses who provide care to children in the divisions of health and wellbeing, primary care, social care, mental health and acute hospitals. The purpose is to inform and influence the strategic direction of the ICP-C and the National Clinical Programme for Paediatrics and Neonatology (NCPNP), in line with the national model of care for paediatric healthcare services in Ireland, and taking into account the best interests of children and their families across the continuum of care, relevant national and international policy documents and reports and relevant national and international research, standards and evidence-based practice.

The objectives of the Nursing Expert Group – Children’s Services are:

- To influence and support the design, implementation and evaluation of programmes of work of the ICP-C and NCPNP
- To provide subject matter expertise to the ICP-C and NCPNP
- To assist in the development and review of guidelines and policies in line with national and international best practice
- To identify opportunities for collaboration and interdisciplinary and inter-agency working to improve the health and wellbeing of children
- To make recommendations to the NCPNP and ICP-C relating to nursing services for children

The group has representation from all settings providing nursing care to children including acute services, mental health, disability services and primary care.

The group is chaired by Suzanne Dempsey, chief director of nursing, Children’s Hospital Group. The group met five times throughout 2017.





## Targeted ultrasound service for developmental dysplasia of the hips

### Developmental Dysplasia of the Hip - New Service Development

The Integrated Care Programme for Children and the Healthy Childhood Programme are implementing additional ultrasound capacity in all maternity hospitals in Ireland to ensure that all babies who need an ultrasound to screen for Developmental Dysplasia of the Hip (DDH) can get it and at the right time.

All babies will get a clinical examination at birth and at their six-week check with either their GP or paediatrician. In addition, some (about 20%) babies will get an ultrasound as part of the targeted ultrasound screening programme. The programme specifies that babies who have a positive clinical examination should have an ultrasound before they are put in a harness and it should be within two weeks of birth (ideally by 3 days).

Also, all babies with one or more of the two risk factors should have an ultrasound at six weeks. The risk factors are:

- A first degree family history of DDH
- A baby that has been breech at or after 36 weeks gestation, regardless of the presentation at birth or final mode of delivery (if any baby in a pregnancy with more than one baby is breech then all

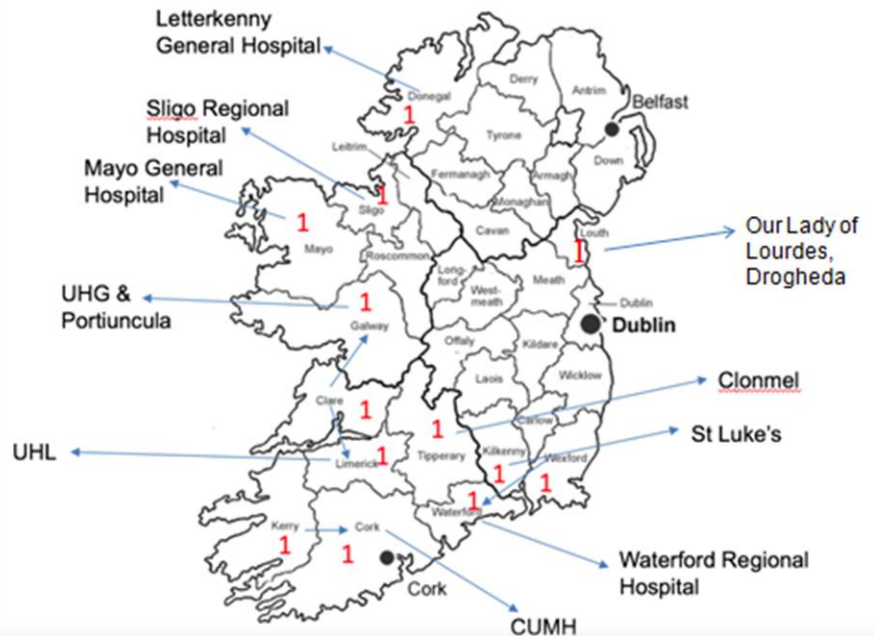
babies will be screened)

Before the project started not all hospitals could provide ultrasounds and those that could did not always have the capacity to do them on all babies that needed them or at the right time. Phase 1 of the implementation has been progressing this year. Helen McDonald, the project manager, has visited all of the hospitals and worked with each of the radiology units on their

implementation plan. Funding has been allocated to each unit for the additional staff required for them to provide the service as well as for training and some small equipment items. Limerick has been deferred to Phase 2 for operational reasons.

The preliminary work on Phase 2 sites has begun, pending allocation of funding for 2018.

### Phase 1 locations



## DDH training programme

The second DDH training programme ran in December 2017. This included a one-day refresher course for 15 participants and a three-day core training course which 39 people attended. This supplements the 32 people already trained on the 2016 course. All participants have trained in the Graf technique for taking and reading the ultrasounds, which is specified as the approach to use in the national DDH Screening programme. Both courses were delivered by Professor Graf, the clinician who developed the technique. He is an orthopaedic surgeon with a strong personal interest in improving outcomes for children. Prof. Graf brings over 30 years' clinical experience of using ultrasound to diagnose and guide treatment for DDH as well as an impressive publication record. We were also very lucky to have Dr Sally Scott teaching on the course. Dr. Scott is a retired Radiologist from England who was on the UK National Screening Committee subgroup on DDH and has been delivering training in the UK for many years. Both Dr Scott and Professor Graf have been very supportive of the work being done in Ireland to improve outcomes for children with DDH. The training course participants include radiologists, radiographers, orthopaedic surgeons and paediatricians. It provides a great opportunity for the participants to learn

from colleagues from other disciplines who are all interested in improving outcomes for children. The DDH project is developing a Network for people who have done the Graf training, which will be a peer support in the future for these highly skilled professionals.



L to R: Prof R Graf, Dr S Scott, Dr C Mason Mohan, Dr A Tarrant, Ms H McDonald, Mr J O'Beirne



## Waterford paediatric initiative

A project has been initiated in University Hospital Waterford to implement a consultant-delivered paediatric service. The project is in line with the 'Report of the National Task Force on Medical Staffing' (Hanly Report) which recommends a 'consultant-provided service' whereby consultants have a direct and substantial involvement in diagnosis, delivery of care and overall management of patients allowing important clinical decisions to be made faster and at a higher level. The model involves an improved ratio of consultants to non-consultant hospital doctors (NCHDs) and results in a new type of team in which there are more consultants providing 'hands-on' care and a higher proportion of NCHDs on training programmes.

Implementation of the project will bring significant benefits to children and their families. There will be increased access to senior decision makers resulting in decreased admissions and reduced length of stay. There will also be a greater provision of specialist clinics.

At the commencement of the project there were three consultant paediatricians (two permanent posts and one locum), eight paediatric registrars and eight senior house officers providing a service at University Hospital Waterford. The ratio of consultant to non-consultant hospital doctor in Waterford is 1:5.3. The National Clinical Programme for Paediatrics and Neonatology recommends rebalancing this ratio, and a ratio of 1:1.2 is proposed for University Hospital Waterford.

### Progress update

#### •First phase of recruitment:

Four consultant paediatrician posts were advertised in 2017 (one replacement post and three new posts). Three posts have been offered to successful candidates which will bring the total number of permanent consultant paediatricians to five.

#### •Second phase of recruitment:

Funding is available to recruit another four consultant paediatricians in 2018. Successful recruitment of these posts will bring the total number of permanent consultant paediatricians to nine.

#### •Third phase of recruitment:

Funding is required to recruit the final consultant paediatrician.

## Hepatitis B in the perinatal period

In 2017 a multidisciplinary working group developed a care pathway for pregnant women who are hepatitis B positive and the babies born to these mothers. The report has been developed to outline the best management of hepatitis B in the perinatal period. Roles and responsibilities of all relevant healthcare professionals have been defined.

We are delighted that the final version of the hepatitis B report has been approved by:

- Institute of Obstetricians and Gynaecologists
- Paediatrics Clinical Advisory Group
- Neonatology Clinical Advisory Group
- Child Health Steering Group

The report has now been submitted to the Health and Wellbeing Division for implementation. Implementation will require a national coordinator and local hospital coordinator.

## Permanent childhood hearing impairment – integrated care pathway

A multidisciplinary working group, chaired by Dr. Nick van der Spek and Dr Samantha Doyle, has been established to develop an integrated care pathway for the aetiological investigation and subsequent management of infants with permanent childhood hearing impairment (PCHI). The care pathway will build on the success of the Universal Newborn Hearing Screening (UNHS) programme and will seek to ensure that infants identified with hearing loss are investigated and managed according to nationally agreed standards.

The pathway is being co-designed with parent representatives and advocacy groups and will take into account:

- The best interests of children and their families
- Relevant national and international policy documents and reports.
- Relevant national and international research, standards and evidence-based practice.



## Integrated care pathway – Neuromuscular disorders

### Integrated Care Pathway for Children and Families with a Neuromuscular Disorder in Ireland

Children, adolescents and their families with a suspected or confirmed diagnosis of a neuromuscular disorder (NMD) require access to a broad range of healthcare services and supports in the community and acute hospital at any given point in time. The Integrated Care Programme for Children has been working on a specific project which aims to standardise the care journey of a child with NMD and their family from initial presentation to transition to adult services. The project was established to co-design an Integrated Care Pathway with parents, young adults with NMD and healthcare providers. This ICP project has involved working with parents and young adults with a neuromuscular disorder, healthcare professionals providing a range of services in different settings including a Clinical Lead Paediatric Neurologist and working with Muscular Dystrophy Ireland. These groups shared their particular experiences of services, their opinion with regard to what could be improved and ultimately collaborated and agreed a draft Integrated Care Pathway (ICP).

The core value of this ICP project is co-design in partnership with parents. The draft ICP has gone through a process of wide national consultation, which included a specific young adult consultation and a national families' consultation day. The ICP sets out a number of standards under eight themes as detailed below, which fall under three broad phases:

### Phase 1 – recognition/diagnosis

Early detection,  
recognition and onwards  
referral

Delivering the diagnosis  
in a supportive manner

Engaging appropriate  
community services and  
supports

### Phase 2 – ongoing care

Delivering integrated  
care

Delivering anticipatory  
care

Delivering child and  
family centred care

### Phase 3 - transition

Phased transition to adult services

Phased transition to end of life  
specialist services

The integrated care pathway has been amended following consultation and is now going through a process of approval. A number of practical resources such as leaflets and guides have been developed as part of this project to support implementation. Further resources are to be developed in 2018 to support the pathway. Once approved, the Integrated Care Pathway will be launched early in 2018. For further information on this group please contact Grace Turner (senior programme manager) [grace.turner@hse.ie](mailto:grace.turner@hse.ie) or Margaret Rafferty (project coordinator) [margaret.rafferty@hse.ie](mailto:margaret.rafferty@hse.ie)





## Integrated Care Programme for Children Steering Group

Name	Representing	Name	Representing
Claire Browne	Health and social care professionals	Aileen Killeen	Programme for Health Service Improvement
Susanna Byrne	Office of Nursing and Midwifery Services Division	Dr Cathal Morgan	Social Care Division
Dr Philip Dodd	ICP for Children Sponsor, National Clinical Advisor and Group Lead for Mental Health	Prof John Murphy	ICP for Children Clinical Lead
Suzanne Dempsey	Nursing operations representative	Prof Alf Nicholson	ICP for Children Clinical Lead
Dr David Hanlon	ICP for Children Sponsor, National Clinical Advisor and Group Lead for Primary Care	Dr Brendan O'Shea	Irish College of General Practitioners
Bill Ebbitt	Primary Care Division	Martina Queally	Chair of Group, CO CHO 6
Eilish Hardiman	Acute Hospital Division	Grace Turner	ICP for Children Senior Programme Manager
Siobhan Horkan	National Clinical Programme for Paediatrics and Neonatology	Aidan Waterstone	Tusla
Dr Kevin Kelleher	Health and Wellbeing Division		

### Further information...

For further information, or if you would like to get involved, contact Grace Turner, Senior Programme Manager, Integrated Care Programme for Children

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