
Building the Blocks for a Hospice in the Home (The Lego Project)

How one health care region in Ireland nurtured and co-ordinated existing community services to provide optimal, cost neutral community care at the end of a child's life.

Claire Quinn, Irish Hospice foundation, NUI Galway

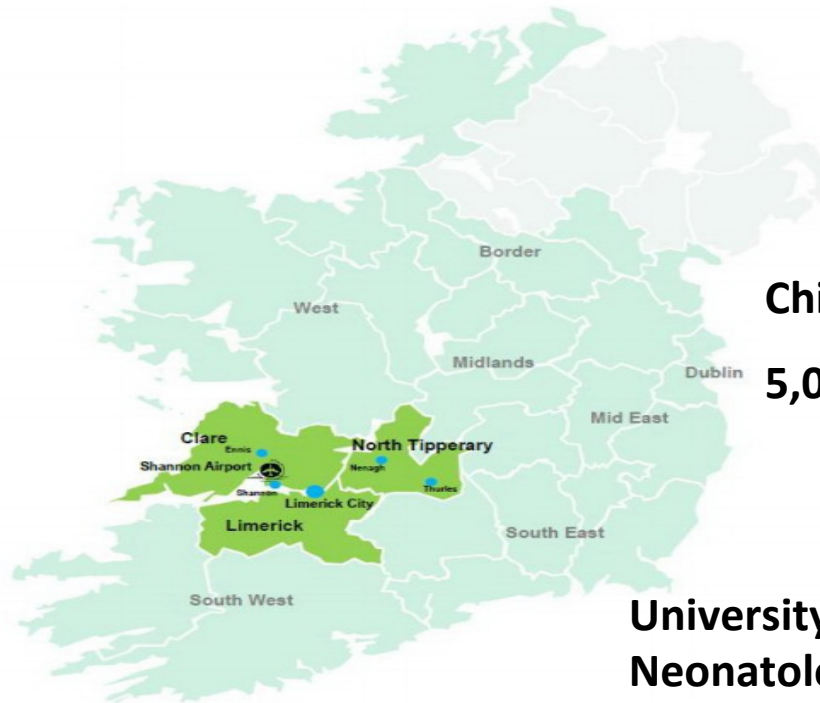
Siobhan Gallagher, University Hospital Limerick

National Policy 2010 - Ireland



- Palliative Care for Children with Life Limiting Conditions in Ireland
- ***“Hospice at Home teams should be developed by the Health Service Executive..”***
- Children with life limiting conditions who are at or approaching end of life, who/parent’s wish to die at home

Mid West Services



Childhood population 100,000 approx

5,000 deliveries per year approx

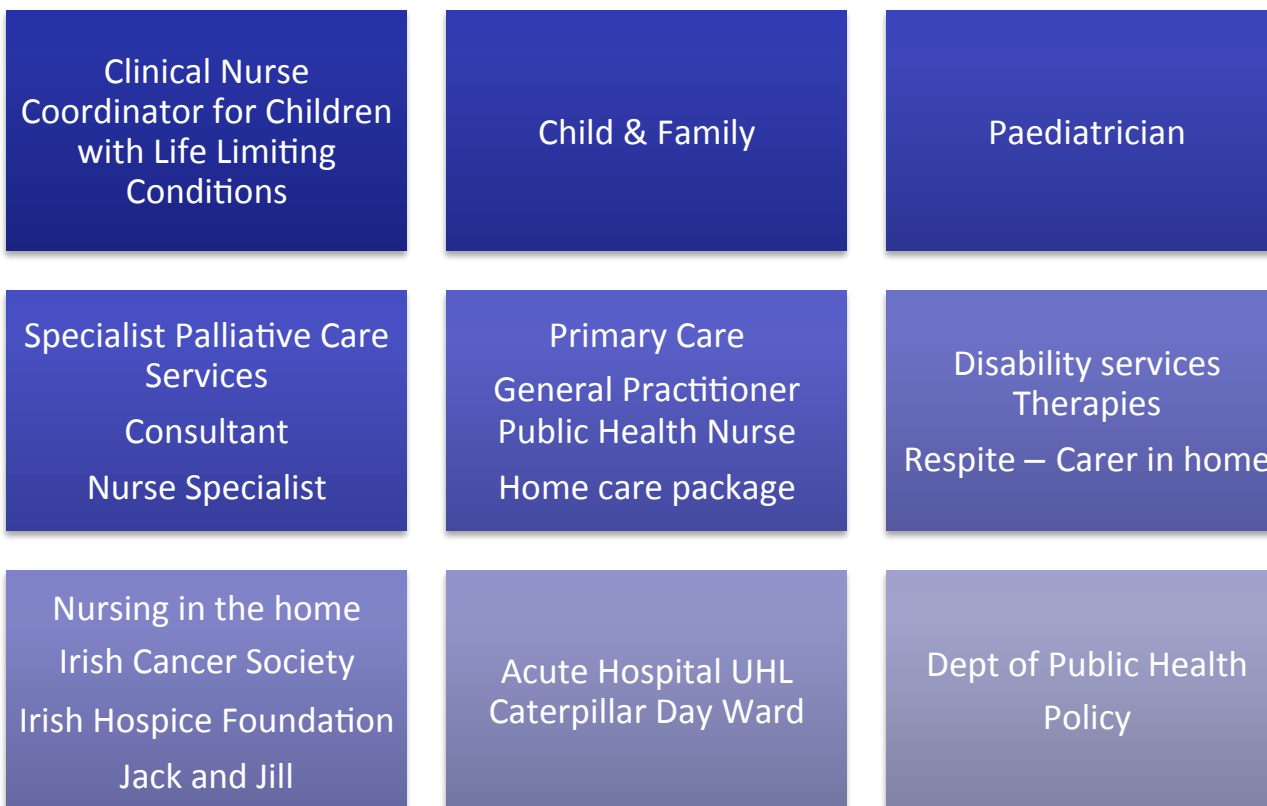
**University Hospital Limerick Group – Paediatrics/
Neonatology**

Specialist Palliative Care – Milford Care Centre

Regional Primary Care & Disability Services

**Clinical Nurse Coordinator for Children with Life Limiting
Conditions**

Building Blocks



Project Process

1. Steering Group Established

- Project coordinator appointed
- Literature review
- Benchmark current services
- Review best practice, experience elsewhere
- Parent participation

Project Process

2. Parent Participation

- 8 bereaved parents of 5 children with life limiting conditions who died at home took part
- Semi structured interviews with interview guide
- Interviews recorded, transcribed and analysed using Nvivo
- Focus on experience in the last month, particular last 24 hours of life, experiences of immediate and interim bereavement

Project Outcomes

Parent Participation

Themes Identified by Parents

Availability of **skilled** professionals **familiar** with the child and family

Communication between a link professional, parents and other service providers – Paediatrics, Specialist Palliative Care

Consistent professional with links to **Paediatric services**

Out of hours support

Hands on care by **skilled professionals at end of life**

Project outcomes

- Clinical Care Pathway developed
“The Child’s Journey”
 - Integrated, multidisciplinary, multiagency service
 - Referral Criteria
 - Care Plan in the home used by all agencies

Project Outcomes

Learning

- Enhancing communication between professionals, parents and other service providers
- Ensuring consistent links to acute paediatric services
- Facilitating co-ordinated out of hours support
- Providing hands on care by skilled professional at end of life
- Expert co-ordination ensured no extra cost to services
- Bereavement support

Project outcomes Challenges

- Availability of skilled Nurses
- Ongoing education and training
 - Individual, flexible, timely
- Out of hours support
- Sustainability

Conclusion

- “One off” project in a single geographical region
- Leadership and Partnership
- Existing services were coordinated at no extra cost to service
- Facilitate high quality Paediatric Palliative Care service in a community setting
- Could be replicated in other regions

Acknowledgements

- **Stephanie Staff, Project Coordinator**
- Members of the Steering Group, particular thanks...
 - **Hilary Noonan**, Clinical Nurse Coordinator for Children with Life Limiting Conditions
 - Margaret Naughton, Jack and Jill Liaison Nurse
 - Jacqueline Holmes, Director of Nursing, Milford Care Centre
 - Dr Mai Mannix, Director of Public Health, HSE Mid West
 - Padraig Doyle, Dr Keith Quintyne, Dr Marie Casey

Steering Group Membership

- Project Lead: Dr. Siobhan Gallagher: Consultant Paediatrician University Hospital Limerick, HSE Mid-West Community Services
- Stephanie Staff: Project Coordinator Hospice at Home for Children with Life Limiting Conditions
- Carmel Mc Loughlin: Disability Services Manager, HSE Mid-West
- Claire Quinn: Lecturer, NUI, Galway/Head of Research Laura Lynn Children's Hospice
- Dr Mai Mannix: Director of Public Health, HSE Mid-West
- Dr. Marian Conroy: Consultant Palliative Medicine Milford Care Centre, University Hospital Limerick
- Hilary Noonan: Clinical Nurse Coordinator for Children with Life Limiting Conditions, University Hospital Limerick, HSE Mid-West
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- Margaret Costello: Director of Public Health Nursing, HSE Mid-West
- Margaret Naughton: Liaison Nurse The Jack & Jill Children's Foundation
- Tony Murphy: Director of Clinical Services, Enable Ireland
- Aisling Ryan: Children's Services Manager, HSE Mid-West Children's Disability Services