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

Maruzza Congress on Paediatric Palliative Care, Rome 2018
Building Blocks

Clinical Nurse Coordinator for Children with Life Limiting Conditions

Child & Family

Paediatrician

Specialist Palliative Care Services
Consultant Nurse Specialist

Primary Care
General Practitioner
Public Health Nurse
Home care package

Disability services
Therapies
Respite – Carer in home

Nursing in the home
Irish Cancer Society
Irish Hospice Foundation
Jack and Jill

Acute Hospital UHL
Caterpillar Day Ward

Dept of Public Health Policy
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

<table>
<thead>
<tr>
<th>Themes Identified by Parents</th>
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<td><strong>Availability</strong> of skilled professionals familiar with the child and family</td>
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<tr>
<td><strong>Communication</strong> between a link professional, parents and other service providers – Paediatrics, Specialist Palliative Care</td>
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<td><strong>Consistent professional</strong> with links to Paediatric services</td>
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<tr>
<td><strong>Out of hours support</strong></td>
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<tr>
<td><strong>Hands on care by skilled professionals at end of life</strong></td>
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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

- Jacqueline Holmes: Deputy Director of Nursing Milford Care Centre
- Jacqui Ellis: Team Leader Laura Lynn @ Home
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- 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