

Supporting new policy for children's palliative care services: lessons from the Irish Children's Palliative Care Programme (CPCP)

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Children's Palliative care in Ireland 2005-2018

The challenge:

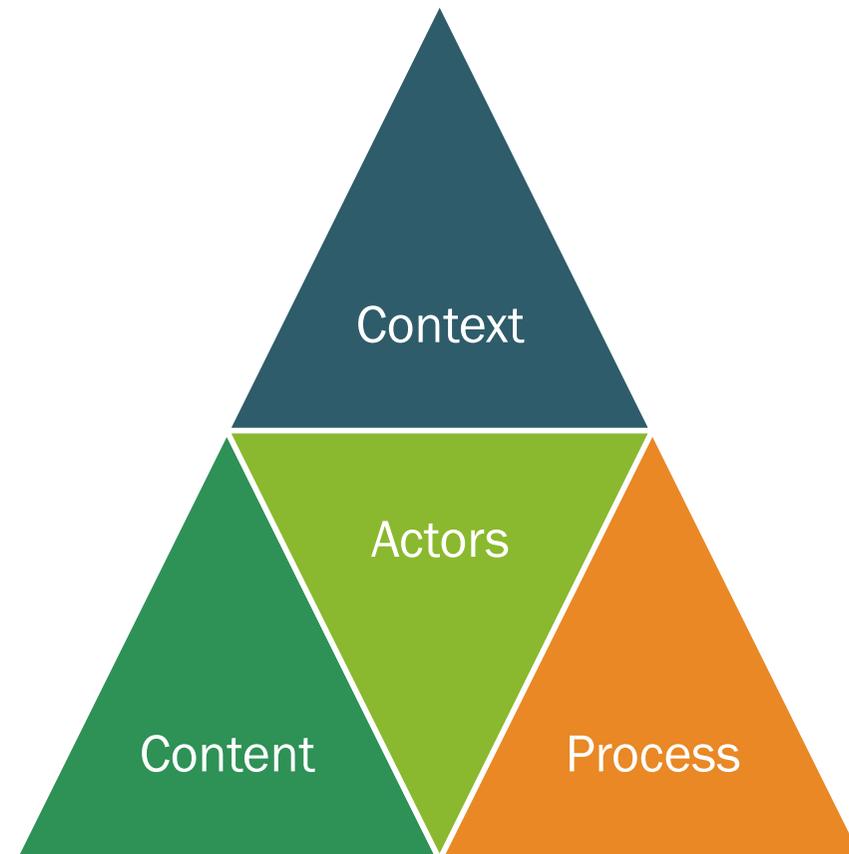
In 2005, there was an estimated **1,300**
(*later revised to **4,000***) children living with a life-limiting
condition in Ireland.
Around 350 die each year.

In 2005 to 2018 a national policy on children's palliative care
was developed and implement in Republic of Ireland.

What did we learn along the way?

How does policy usually get devised & implemented?

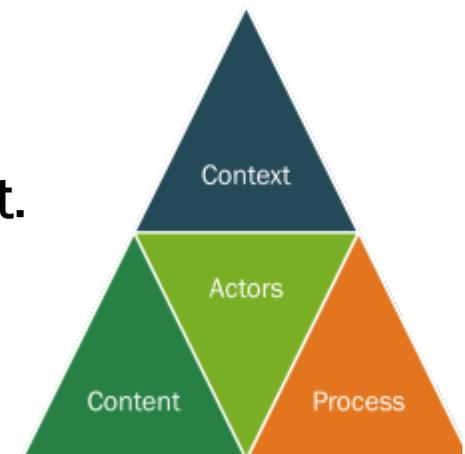
- Lots of models but simple one is Walt and Gilson (1994)
- Need AGREED content
- Need COMMITTED Actors
- Need a PROCESS
- Need conducive CONTEXT



Phase 1: 2001 - 2005

CONTEXT

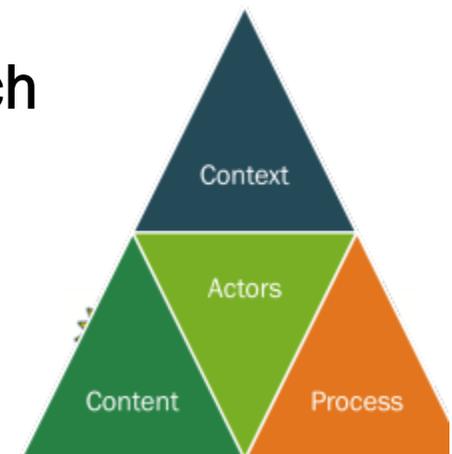
- **National policy on specialist palliative care for adults** existed - no such policy for children but identified as a need in adult 2001 policy.
- **Growing appreciation** that the needs of children in palliative/end of life phase were being neglected
- **No agreement** on what parents, children and health service needed to meet needs
- **Small group of 'actors'** – few charities (outside of Irish Hospice Foundation) and some specialist oncology/ academics/ paediatrics /adult palliative care
- Agreement to deliver a **consensus needs assessment**. (**CONTENT development**) . Funded by IHF (charity)



Phase 2: 2005-2010

Needs assessment 2005 – Consensus on CONTENT

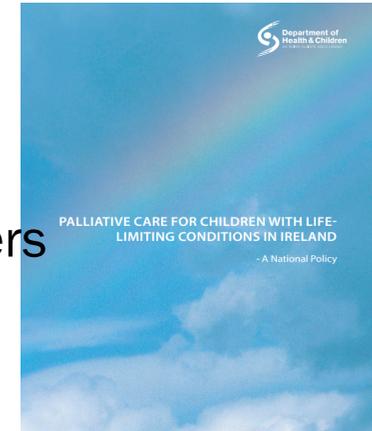
- very vulnerable children, particularly those who wished to be at home, were not getting the care and support they needed. Much greater appreciation among policy makers, paediatric community, health services and the public of the need of children and their families
- all staff needed basic and intermediate training in children's palliative care
- expertise was needed at national level and each region needed a specialist outreach nurse to coordinate care – there was a 'call to action'



National Policy – 2010

A perfect mix of **content**, **context** and **actors**

- Led by the Dept of Health with IHF participating with others
- Strong leadership within Dept of Health
- Wider range of actors involved
- **Critically this was led and therefore ‘owned’ by Department of Health – therefore now was State policy**
- **IHF made a commitment to seed fund a national programme of children’s palliative care to augment the poor services already there. Commitment was there, in principle, for Dept of Health/ HSE to take over after 3/5 years. (IHF role changes from campaigning to seed funding to allow development to happen)**



Phase 3| 2010-2016

CONTEXT

- 2011 – the biggest **recession** known to Ireland
- HSE total lockdown on new posts – **moratorium on recruitment**
- HSE still in early days of formation – **a lot of bureaucracy**
- Policy in place, funding in place but **difficult to recruit and keep momentum** – **PROCESS** impacted on delivery
- **No clear on role of nurses in community**
- **Critical enabler was commitment shown by HSE, IHF and all other key players** – all represented on NDC – **ACTORS** remained committed

Achievements| 2011–2016:

Building ~Capacity

- Employment of staff (consultant and 10 outreach nurses) 2011–Present: Delivery of level A and Level B training programmes in Crumlin Childrens Hospital
- 2016: Level C 3rd level CPC course opens in NUI, Galway
- 2012 onwards: Establishment of network of children's outreach nurses / clinical nurse coordinators, champion consultants and nurse managers (Network)
- 3rd International Children's Palliative Care Conference

Governance

- 2012: Common Governance Framework delivered
- 2011: National Development committee established (PROCESS)

Measuring progress

- 2014/15: Commissioning of national evaluation of 2010-2016 joint programme of investment (IHF & HSE)
- 2016: Publication of evaluation and move into next phase of CPC

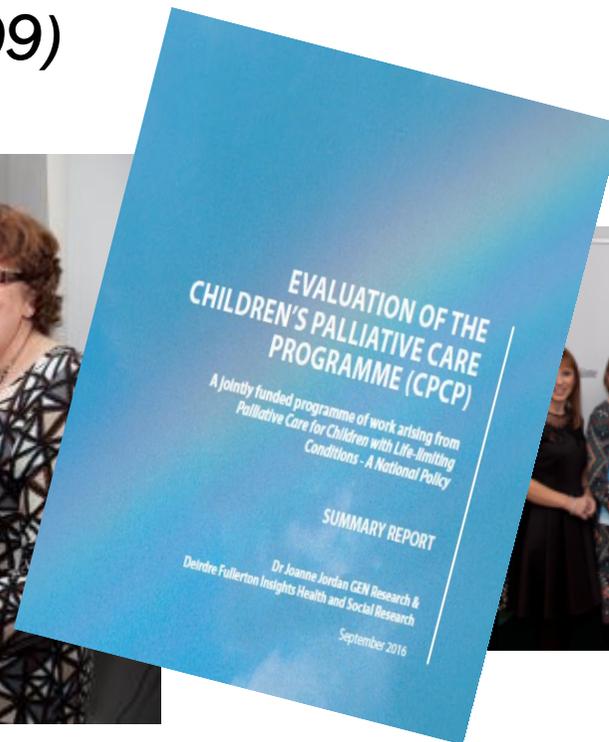


Evaluation of programme (Dec 2016)

Evaluation of the Children's Palliative Care Programme (CPCP)

A Jointly funded programme of work arising from *Palliative Care for Children with Life-limiting Conditions –*

A National Policy (2009)



Overview of evaluation outcome

- **Delivery of desired outcomes of the jointly funded CPC programme 2010-2016**
- **Improved quality of life for children with LLC and their families.** Service has been very positively evaluated and very well received by parent, families and healthcare staff
- **Improved co-ordination of services to children with LLCS** so they can be cared for in the home setting as far as possible.
- **An improved children's palliative care sector** as a whole with increased education on children's palliative care and appropriate engagement of the Community Nurse Coordinators in the provision of education / training.
- **Increased awareness of children's palliative care and of the new service** in both the public arena and health sector.

Challenges.....2018 onwards (Phase 4)

- Enduring needs in bereavement care, respite, care at end of life in the home and other areas.
- SUSTAINABILITY....
- PREVELANCE....
- WORKFORCE PLANNING....
- COMMITMENT...

Leadership lessons learned

- Long term view required – **may take 20 years**
- Need to foster commitment in key players who can make a difference (**ACTORS**). The **PROCESS** of engagement – research, joint committees, networking events is very important
- Achieving **CONSENSUS ON CONTENT** is critical - too many different direction results on chaos and discontent
- **CONTEXTS** change as fortunes change- need to be adaptable and able to respond to challenges and opportunities
- **There is a huge role for charities** (focused on children or end of life) to support the policy making process in a variety of ways. Maximise resources available to children palliative care.
- **CPC is complex and it needs collaboration.**

A close-up photograph of a white daisy flower with a bright yellow center, resting on a large green leaf. A small, red, textured felt heart is placed next to the flower. The background is dark and out of focus, showing some light-colored wooden elements. The text 'Thank you' is overlaid in white, sans-serif font on the right side of the image.

Thank
you