

Why good policy makes a difference to
children with shorter lives.

The Northern Ireland perspective

**Joan Duncan - Paediatric Lead Nurse
Northern Health & Social Care Trust**

1. The Northern Ireland Context

Demographic statistics

- Total population 1.82 million¹
- 435,500 children (0-15 yrs)²
- 1300 children/young people with life limiting conditions³
- 500 children/young people with complex health needs⁴
- 150 child deaths every year⁵



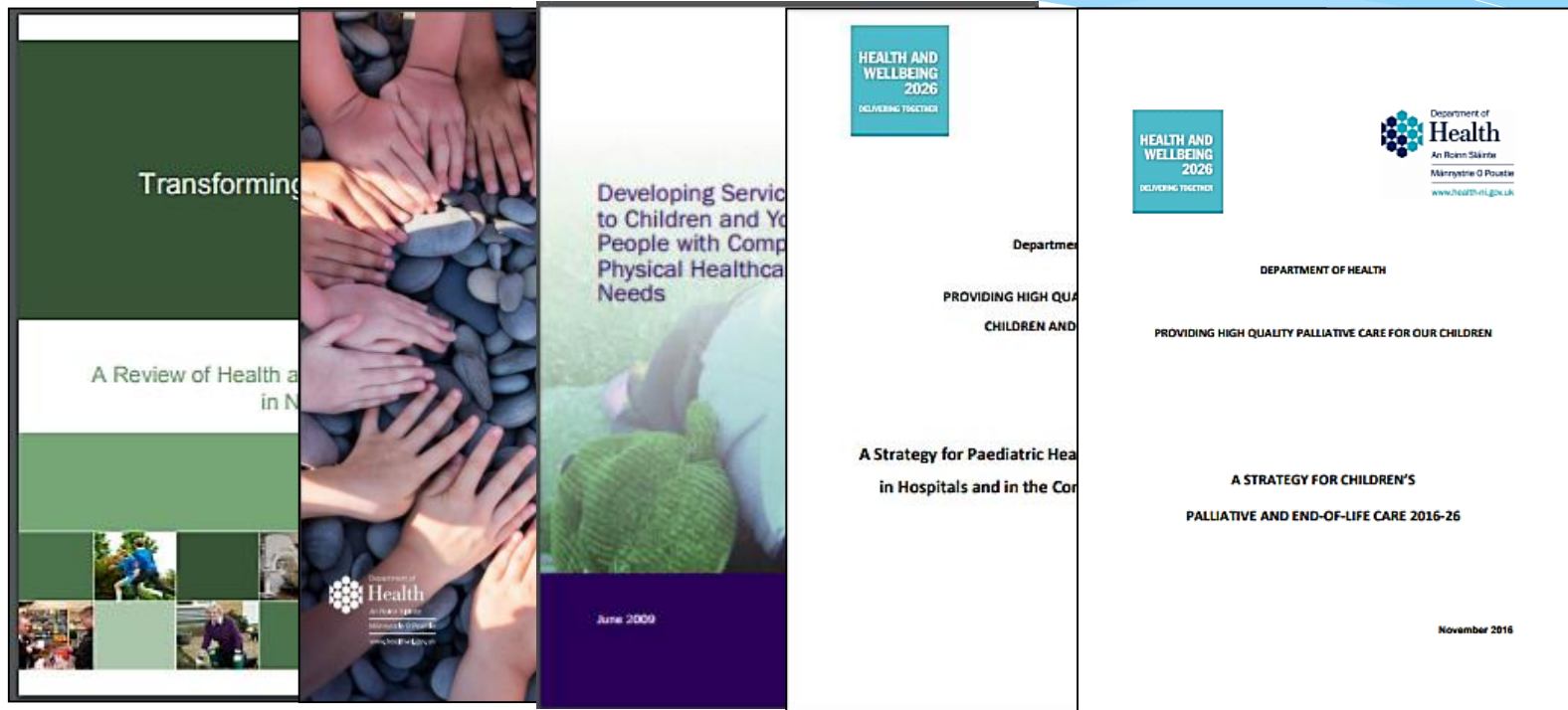
Map of N.Ireland depicting 5 HSC Trust areas

Current service delivery for children with palliative care needs

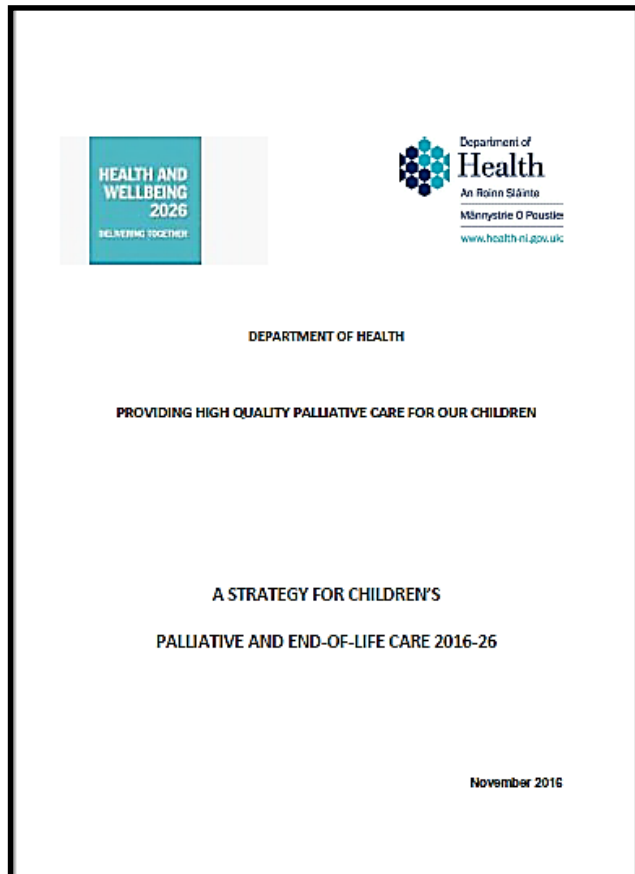


Professionals & services contributing to the care of children with palliative care needs in NI

2. The policy context



Children's Palliative and End of Life Strategy⁶



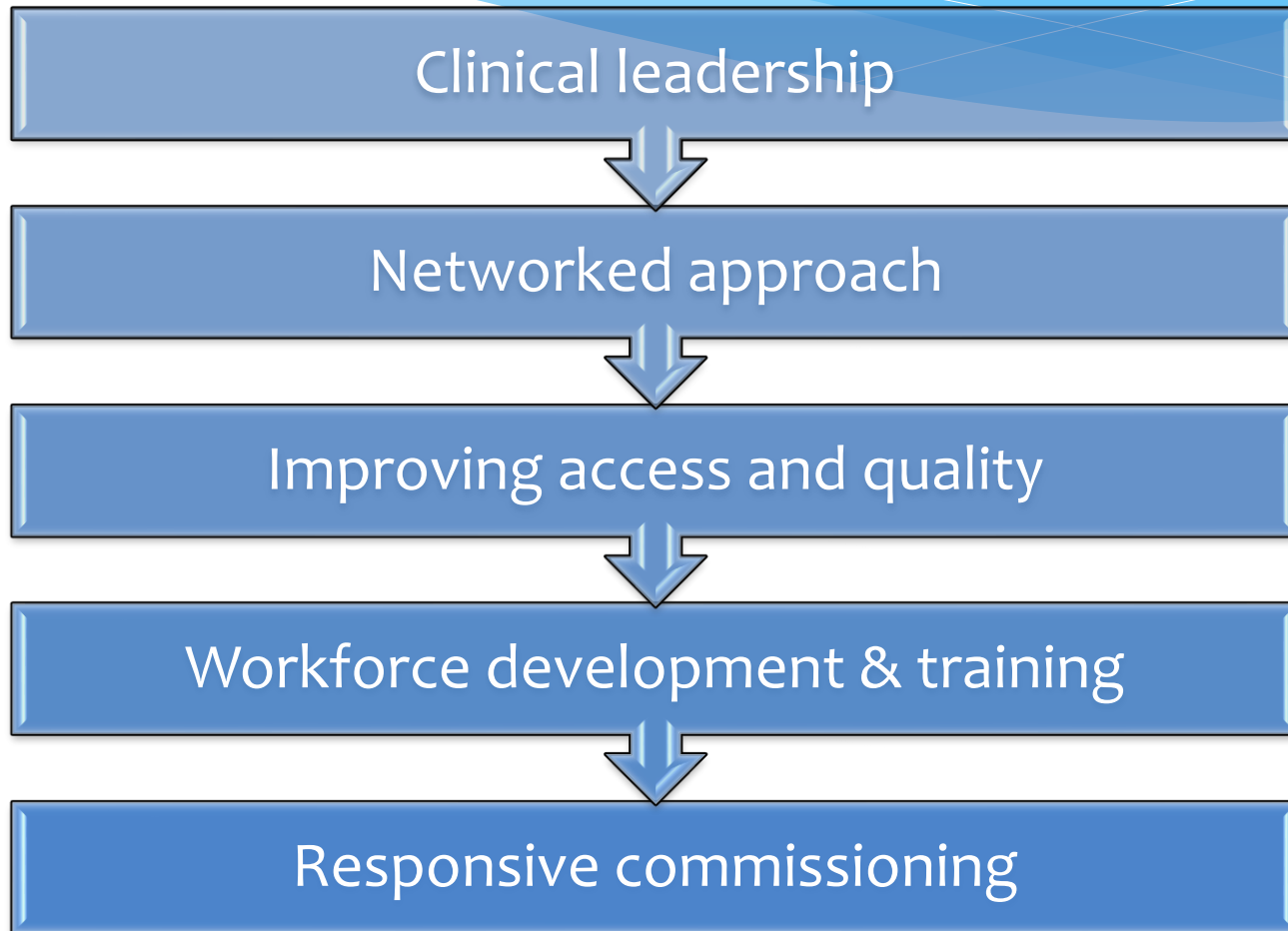
“No matter what the circumstances, every child deserves the best possible start in life and the support they need to achieve their full potential. From pre-birth up to young people in their late teens, this strategy encompasses everyone who requires paediatric palliative support, and those who are approaching the end of their lives.”

(P.4)

Key elements

- * Aim
 - * High quality, safe, sustainable and appropriate palliative and end of life care to ensure best outcome for child and family.
- * Outcome focused:
 - * 23 Objectives linked to new care model
- * New care model components:
 - * Support for families
 - * Holistic assessment and planning
 - * Right care, right place, right time
 - * Transition to adult services
 - * End of life care
 - * Bereavement care

Enabling the new model



3. Does good policy on its own make a difference?

- * The challenging context of care:
 - * Services under pressure,
 - * Financial constraint,
 - * Workforce issues,
 - * Lack of sitting Legislative Assembly since January 2107, and
 - * 'Brexit' around the corner.

What are our strengths?

- * Committed, motivated workforce within children's palliative care
- * Supportive strategies: articulate what we desire to achieve

Challenges?

- * Palliative care for children is not being optimised in the absence of strategy implementation.
- * We are still some way from achieving the aim of:
“High quality, safe sustainable and appropriate palliative and end of life care to ensure best outcome for child and family”⁶