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## ***Balance of Care for Children and Youth with Long Term Care Needs (Team Grant Project # 1.2)***

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## ***Presentation Outline***

- Background to Research Project 1.2
- Description of Project Stages
- Balance of Care Methodology and Children with Long Term Care Needs



## ***Background***

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### Children in Home and Community with Long Term Care Needs

- Defining “home and community” for children and youth
- Defining “Long Term Care” vs. “Complex Care Needs” vs. “Special Needs”



## ***Prevalence***

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### National Data

- 1991 Health and Activity Limitations Survey (HALS)
- 2001 Participation and Activity Limitation Survey (PALS)
- Romanow and Kirby



## ***Prevalence***

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### Provincial Data

- Increase in number of children receiving home care (Dick et al., 2001)
- Increase in acuity and complexity of needs for children in home and community care (To, 2001; Spalding et al., 2005)



## ***Shift to Home and Community Care***

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Most likely the number of children and youth requiring home and community care will continue to grow, as will the intensity and complexity of their needs

- Advances in medicine and technology
- Policy changes
- Ideas and Values



## ***Shift Based on Key Assumptions***

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- Home and community care...
  - More cost-effective compared to in-patient care
  - Allows for :
    - Enhanced consumer choice
    - Improves quality of life, psycho-social development, health outcomes



## ***But...***

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- Little systematic evidence
- Positive outcomes assume that children and families have access to needed care and “home” is safe and adequate – not always true



## ***Project Overview: Stage 1***

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- “Policy map”
  - Describe existing approaches to funding and delivery of home and community care for children and youth across Canada
- Methods
  - Analyze published documents and publicly available data (grey literature, websites etc.)
  - Supplemented with key informant interviews



## ***Stage 1 Highlights***

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- No real continuum – loosely linked services with multiple transitions
  - Between life stages, programs, agencies, providers, funding sources
  - Up to 20 different supports and services needed for some children when available



## ***Stage 1 Highlights***

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- Rural/urban disparities
- Human resource shortages
- Increasing demands on parents but lack of respite care
- Policy and health system design decisions are based on the needs of adults in all provinces
- New initiatives in delivery & funding



## ***Stage 1: Highlights***

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- Much remains to be known about differences in approaches to and patterns of home care across Canada (CIHI, 2000)
- Few studies that evaluate effectiveness
  - “Paediatric home care systematic review” (Parker et. al., 2006)
  - “Specialized home-based nursing services for children with acute & chronic illnesses” (Cooper et al., 2006 – Cochrane Library)



## ***Stage 2: Ontario Case Study***

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- Modification of Balance of Care model to fit unique needs of this population:
  - Skills and technology must be adjusted to small, growing bodies
  - Care must be adapted to varying developmental levels of child/family
  - Family the focus of care



## ***Stage 2: Ontario Case Study***

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- Partner with CCAC to estimate the costs of home and community care packages required for children and youth, and their families, at different levels of need.
- Develop case vignettes for children with long term care needs and their families
- Expert panel including parents in designing care packages



## ***Thank You***

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