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# ***Caring for Children, Youth and Families in Home and Community: Innovations and Best Practices from Across Canada***

## ***Setting the Context***

***Karen Spalding, RN, PhD.  
Associate Professor & Director – Master of Nursing  
School of Nursing, Ryerson University***

*CYHN is funded by SickKids Foundation.*

*The CRNCC is funded by the Social Sciences and Humanities Research Council of Canada and Ryerson University.*

# *Why The Care Needs of Children and Families are Unique*

- Skills and technology must be adjusted to small, growing bodies
- Care must be adapted to varying developmental levels of child/family
- Timely access to appropriate care crucial
- Family the focus of care



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# *Why We're Seeing Growing Needs in Home and Community*

- A range of converging factors mean that children requiring home and community care will continue to grow, as will the intensity and complexity of their needs



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# *Medical Advances*

- Advances in medicine and technology
  - Increased survival rates of children
  - Increased life expectancies of children with chronic conditions and life-threatening illnesses
  - Increase in multiple births



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# *Policy Change*

- Health system restructuring
  - Ongoing shift from hospitals/institutions to home and community
  - Discharge “quicker” and “sicker”
  - Regionalization of services
- More than a shift in “site” of care
  - Legislation; Entitlements (Beyond CHA)
  - Funding arrangements; Allocation mechanisms
  - Professional regulation; Working conditions



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# *Ideas and Values*

- Health outcomes and quality of life better in non-institutional settings due to family support, nurturing, and home environment
- Aid in “healing” through normative environment where psychological needs better met



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# *What We Know*

- Children account for up to 15% of home care clients (Kirby, 2002)
- 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)



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# *What We Assume*

- Home and community care...
  - More cost-efficient compared to in-patient care
  - Enhanced consumer choice, quality of life, psycho-social development, health outcome



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## *But ...*

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



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# *Problems and Gaps*

- Much remains to be known about differences in approaches to and patterns of home care across Canada (CIHI, 2000)
- Even less known about children
- 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)



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# *Filling the Gaps*

- Progress has been made
  - National research projects and scans
  - Collaborations across organizations to focus on the needs of children and families across the continuum of care
  - Symposium of 'best practices' and 'innovations' that will move us closer to solutions



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# National “Interfaces” Study (2002)

- Health Canada funded several studies on specific needs populations to examine the Continuum of Care
  - One population was children with special needs (excluding mental health)
  - Purpose - To assess current services for children and families, as well as options for developing an integrated continuum of care across service sectors

\*Spalding KL, Hayes VE, Williams AP, McKeever P. *Analysis of Interfaces Along the Continuum of Care. Technical Report 5: Services for Children with Special Needs and their Families.* Home Care and Pharmaceuticals Division, Health Policy and Communications Branch, Health Canada. 2002



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# *Interfaces: Key Findings*

- Non-system of Care
- 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



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# *Interfaces: Key Findings*

- Barriers to access
- Lack of service coordination and integration
- Rural/urban disparities
- Inadequate funding
- 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

# *Recommendations*

- Single or central point of access/entry
- Children & families need to have access to a minimum level of services including rural and isolated areas
- Develop means of linking services across ministries, departments, agencies and municipalities
- “Care coordinators” needed across continuum
- Flexibility in funding options



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# *Moving Forward*

- Children and Youth Home Care Network (CYHN)
  - Strategic Research Projects (Optimal and Outcomes)
  - Rotman Award for Innovation in Paediatric Home Care
  - Joint Initiatives (CHCA, CAPHC, CRNCC)
  - CRNCC/CYHN Symposium



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# *Building Partnerships*

- Canadian Home Care Association (CHCA)
  - Home Care Portrait - Pediatric Scan
- Canadian Association of Paediatric Health Centres (CAPHC)
  - “Finding Our Way Back Home: A National Resource on Promising Transition Practices”
  - Bridging the Gap Workshop
  - Continuum of Care Committee
- CRNCC – “From Ideas to Action”



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# *CYHN & CRNCC: Best Practices & Knowledge Transfer*

- Bringing frontline providers, consumers, researchers and decision makers together
- Forum to move ideas into action in an area of crucial and growing importance – our kids



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# *CYHN & CRNCC: Best Practices & Knowledge Transfer*

- Sharing best practices at all levels
  - Micro (individual level)
  - Meso (organization level)
  - Macro (system level)
- Integrate “lessons learned” into practice and policy making



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