

# The Changing Landscape of Pediatric Home and Community Care: Implications for Children, Families and Providers in Ontario

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Preliminary Provincial Findings

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# Pediatric Home Care: Policy Context

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- Ongoing shift from hospitals/institutions to home and community
  - Health system restructuring
  - Medical and technological advances
  - Changing social values
- Affects a range of special needs groups
  - Frail seniors, persons with disabilities or chronic illness, children with complex care needs



# Population of Special Needs Children Growing

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- More children, including those with Complex Care Needs (CCN), now require care in home
  - Advances in medicine and technology
  - Increase in survival rates of children (e.g. Cancer, ABI, CHD)
  - Increased life expectancies of children with chronic conditions and life-threatening illnesses (e.g. DMD, CF, CP)
  - Increase in multiple births
  - Persistent rates of low birth weight babies



# Children with Complex Care Needs (CCN)

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- I mechanical ventilators
- II prolonged intravenous
- III daily dependence on devices other than in I & II
- IV prolonged dependence on other devices and  
daily or near daily nursing care
- V chronically ill, not technology dependent and  
require same level of care as IV

Source: Toronto District Health Council, 2000.



# Recent Evidence

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- 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)
- Children account for 15% of home care clients (Kirby, 2002)
- Needs of other groups (e.g. frail seniors) also increasing (Hollander, 2002)



# Unique Needs of Children and Families

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- Places special demands upon health professionals, agencies and organizations
  - Skills and technology must be adjusted to small, growing bodies
  - Care must be adapted to varying developmental levels of child/family
  - Family, rather than the individual should be the focus of care



# Outcomes?

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- Are unique needs of children/family being met?
- What are implications of local, provincial variations?
- Are implications same for all groups: acute care substitution; long-term care; prevention and maintenance?
- Are cost-efficiencies really cost-shifting?
  - First rule of health economics: always easier to shift costs than to save costs



# National “Interfaces” Study\*

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- Lack of data
- Lack of consistency -- extensive variation
  - No standards, regulations, guidelines to local authorities on how to allocate resources for specific needs groups
  - Decisions made at local level by individual agencies and case managers

\*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. August, 2001



# Interfaces Findings (cont'd)

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- Limited strategic planning and analysis
- No real continuum – loosely linked programs and 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



# Ontario: Case Study

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- Background
  - Massive sweeping reform of home & community
  - 43 Community Care Access Centres (CCACs)
  - “Single” point of access (brokers)
  - Capped budgets
  - Introduction of “managed competition”
  - No entitlement to services



# Research Framework: Two Key Policy Dimensions

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- Dimension 1:  
Allocation decisions (under capped regional envelopes)
- Dimension 2:  
The public/private mix in service funding and delivery



# Dimension 1: Allocation

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- Regionalization of health care services aim to:
  - Break down the “silos”
  - Devolve decision-making “closer to home” to increase responsiveness, accountability, cost-efficiency
  - Improve continuity of care
  - Facilitate appropriate mix of services



# Integrated, Capped Budgets Change “Scope of Conflict”

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- Integrated budgets force shift from “distributive” to “re-distributive” policies
- Political theory suggests that decisions are a function of who participates, under what rules
- Those with power may cannibalize budgets of those with less power
- Tough resource allocation decisions “devolved” to CCACs



# The Ethical Dilemma in Allocation: "Fairness"

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- Given a small group with high needs and a larger group with real but moderate needs and a fixed budget...

What is equitable?

- Everyone gets the same amount ?
- High needs get what they need first, with lower needs group receiving what's left?
- High needs groups get nothing, so that resources can be used for maximum coverage?

# Dimension 2:

## The Public/Private Mix

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- Funding

- In-hospital services insured under Medicare (i.e.. publicly-funded)
- Services in home and community may be publicly funded if children deemed to be eligible, if services are available under capped CCAC budgets and service maximums



# Dimension 2 Research Questions: Funding

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- What impact do funding shifts (i.e. cutbacks, freezes) have on children and families in home and community?
- What services are accessible and publicly funded for children and families in home & community after discharge from hospital?

## Dimension 2:

# The Public/Private Mix

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- Delivery
  - Feasibility of market competition in delivering specialized services to small populations
  - Not-for-profit vs. for-profit providers
  - Incentives to cut costs at expense of quality?
  - Ability of consumers to judge “quality” and “safety” of care and are options available to “voice” concerns about service providers?



# Dimension 2 Research Question: Delivery

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- How does a managed competition environment in home care sector impact on the delivery of specialized services to small populations (access, costs)?



# Research Design

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- Multi-stage, multi-methods
  - Document analysis of Ontario data (e.g. CCAC annual reports, legislation, regulations)
  - Telephone survey of CCAC pediatric managers/directors
    - All 43 CCACs participated
  - Focus groups with family caregivers, case managers and service providers



# CCAC Survey

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## ■ Children's programs and services

- May include wide range of services (e.g. nursing, rehab, homemaking, respite, school, referral)
- All CCACs have school health program
- Variation in how CCACs interpret mandate for "children's services" (e.g. age range, respite, school)
- Children's services (nursing, therapy) not separate budget lines except for private school funding

## ■ Assessment

- Not standardized across province, CCAC/CM dependent
- Some CCACs use common assessment tools, others individualize to client



# CCAC Survey

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- Case management
  - Almost all CCACs have CM for children
  - Case management organization varies – by location, type of service (school/in-home)
  
- Providers
  - Contracted agencies expected to have specialized providers available but the ability of CCACs to monitor varies across province (due to HR issues)
  - Choice of level of provider (RPN, RN) determined by agency based on needs of child & consultation with CM

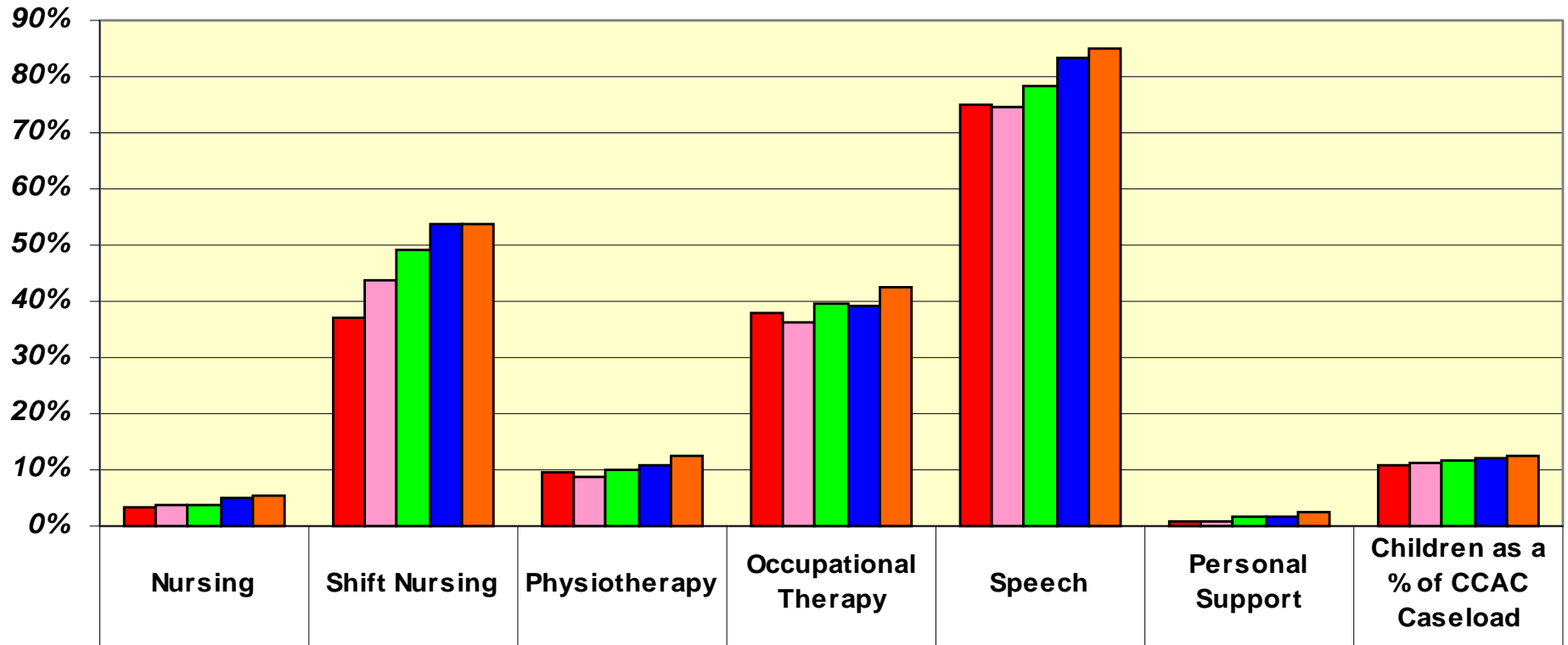


# Increasing Needs

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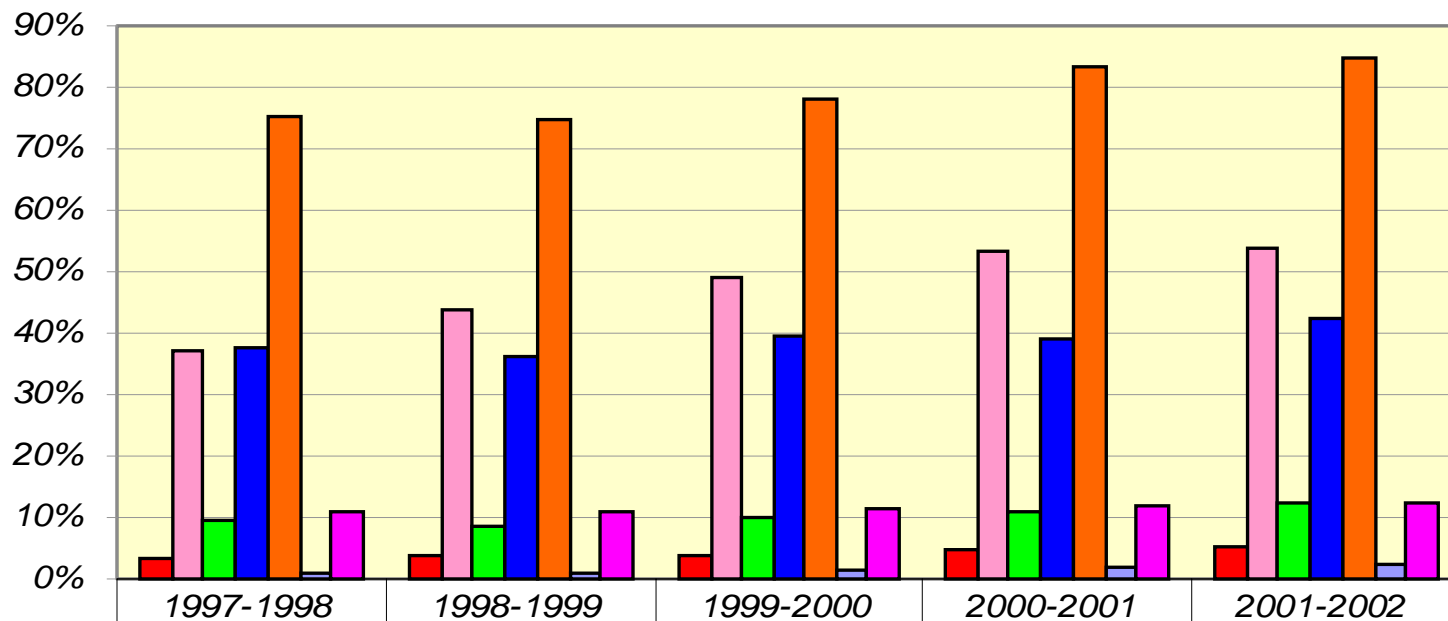
- Most CCACs have experienced:
  - Increasing demand for school health support services
  - Growing numbers of children with medically fragile needs now in community
  - Increasing acuity and complexity require professional services (nsg, rehab specialists)
  - Increasing demand for services from other areas including schools and daycare sites
  - Parents becoming more vocal advocates

## Proportion of CCAC Services & Caseload Utilized By Children 1997-1998 to 2001-2002



■ 1997-1998	3.47%	37.02%	9.50%	37.80%	75.01%	0.87%	11.00%
■ 1998-1999	3.75%	43.72%	8.68%	36.40%	74.63%	0.91%	11.14%
■ 1999-2000	3.67%	48.99%	9.98%	39.55%	78.13%	1.48%	11.47%
■ 2000-2001	4.88%	53.54%	10.86%	39.27%	83.43%	1.76%	11.94%
■ 2001-2002	5.28%	53.80%	12.49%	42.52%	84.89%	2.31%	12.61%

## Proportion of Caseload & Services Utilized by Children 1997/1998 to 2001/2002



<span style="color: red;">■</span> <i>Nursing</i>	3.47%	3.75%	3.67%	4.88%	5.28%
<span style="color: pink;">■</span> <i>Shift Nursing</i>	37.02%	43.72%	48.99%	53.54%	53.80%
<span style="color: green;">■</span> <i>Physiotherapy</i>	9.50%	8.68%	9.98%	10.86%	12.49%
<span style="color: blue;">■</span> <i>Occupational Therapy</i>	37.80%	36.40%	39.55%	39.27%	42.52%
<span style="color: orange;">■</span> <i>Speech</i>	75.01%	74.63%	78.13%	83.43%	84.89%
<span style="color: purple;">■</span> <i>Personal Support</i>	0.87%	0.91%	1.48%	1.76%	2.31%
<span style="color: magenta;">■</span> <i>Children as a % of CCAC Caseload</i>	11.00%	11.14%	11.47%	11.94%	12.61%

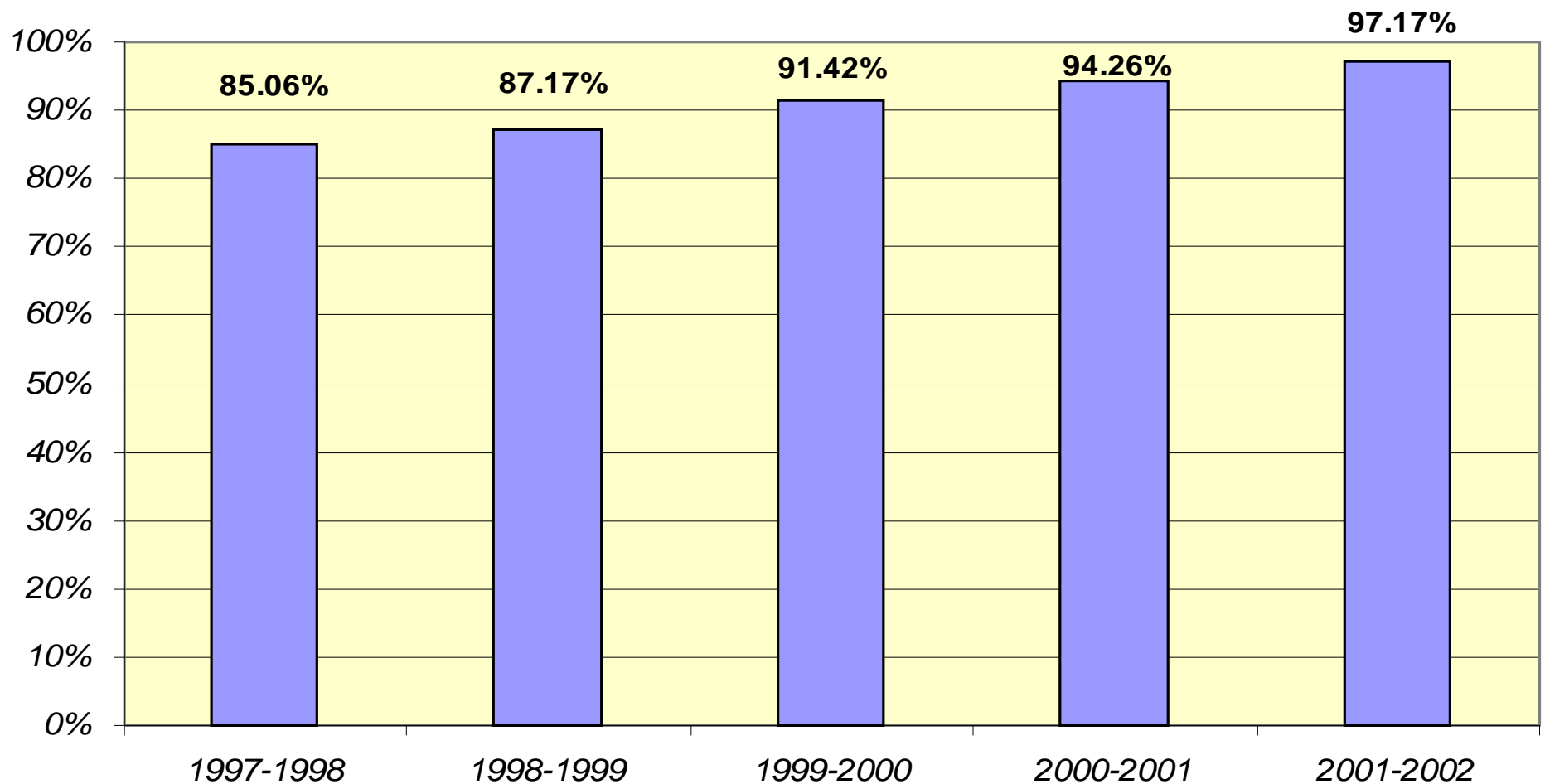


# Managing Needs

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- Range of strategies employed by CCACs:
  - Wait lists for school services more common
  - Block therapy – instead of continuing therapy, children receive “blocks” of 6 treatments, then back to wait list
  - Changing models of care – from intervention to consultation and education of caregivers (e.g. family, teacher)
  - More frequent case review to ensure goals of services are being met
  - Local collaborations (e.g. children’s treatment centres, school boards, hospitals)

## Percent of Pediatric CCAC Admissions from Referrals 1997/1998 to 2001/2002





# Challenges

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- Transaction costs increasing
  - Other agencies and ministries download provision and coordination of children's services to CCACs
  - RFP process has driven up provider costs particularly in areas of short supply
  - Overall volume given to some agencies decreased, resulting in loss of pediatric specialists



# CCAC Survey: The Bottom Line

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- Strong commitment to children to meet needs
- Children not doing as well as they used to but...
  - compared to other groups, respondents said children fare better due to access to other resources (e.g. enhanced respite and SSAH funding, programs from other ministries)
  - few children's services impacted by '01/'02 budget freeze
    - 13 CCACs had major reviews/cutbacks in children's services
    - 30 had little impact on children's services (limited to minor review)



# Focus Group: Parents of CCN Children

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- Despondency/permanent crisis mode
  - Difficult to “piece together” the services needed to care for their children
  - Services need to be more flexible to meet needs of entire family
- Huge stresses on families
  - Economic strains, family breakdown, personal illness
- Parents feel they have to repeat their stories over and over again



# Parents Views

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- CCACs have cut:
  - Service hours
  - Level of provider
  - Homemaking
- Parents forced to purchase privately (if they can)
  - Nursing costs now higher
  - Nurses working for private providers not permitted to work outside of contract
- To get services, families said they have moved between CCACs



# Parents' Views

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- Kids diagnosed as “palliative” get intensive levels of care
  - But when they survive & have same needs, service levels change as no longer diagnosed as “palliative”
- “Greatest fears”
  - Pre-school to school -- loss of “early years” (0-5 years)
  - High needs child “survives” to turn 21 so that respite, special services at home, school-based programs no longer available
  - Parents retire and lose employer insurance



# Focus Group: CCAC Case Managers

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- Good news -- children's services now have a higher profile
- Doing the best they can -- "filling the gaps" after other resources depleted -- family, insurance
- Finding alternatives: school health support services, special services at home, enhanced respite
- Innovative strategies and partnerships developed between community providers of children's services



# CCAC Case Managers' Views

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- Managing expectations
  - Need more realistic expectations – parents, doctors, hospitals, schools
  - “This monster” of high expectations created by system that “gave so much” so many years ago
  - Now focus is to teach others what to do to decrease reliance on “system”



# Focus Group: Providers

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- Increasing disparities between CCACs
  - E.g. eligibility, range of services, service caps
- No funding to plan and coordinate transition from hospital to home for CCN children
  - Utilizes great deal of provider resources
- Care pathways developed by providers at their own cost in good faith
  - Hope this “pays off” during next RFP process but no guarantees



## In Summary...

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- Children on the agenda
- Widespread commitment by individuals within children's services in the CCACs to providing best possible care within limited resources
- CCACs looking to develop innovative strategies (e.g. guidelines, partnerships) to continue to address needs



# Looking Forward

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- Recognition of increasing needs of children (and other groups)
- Frustration with current ability to meet children's needs on stretched resources
- Recognition that problems won't be solved through more cost-shifting, more blaming
- Strong commitment to find better ways

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