

Children with Medical Complexity: Growing in number and in support needs

Esther Lee

Pediatrician, BCCH Complex Care Program & Canuck Place Children's Hospice

Brenda Lenahan

Co-director and founder, BC Complex Kids Society

MCFD CYSN Symposium

Tues. Nov 21, 2023 11am - 1pm



Disclosures

Esther Lee

- I have not been paid by any commercial companies for my services
- The presentation contain my own opinions and does not reflect that of my employer (PHSA)

Brenda Lenahan

- I have not been paid by any commercial companies for my services

Managing potential bias

Esther Lee & Brenda Lenahan

- We both have roles where we support families with children with medical complexity
- We are not discussing any products or medications

Objectives

1. Be aware of the definitions around children with medical complexity (CMC)
2. Understand the current literature on CMC
3. Be updated on the newer literature on CMC

Ultimate Objective: For you (caregiver and/or health professional) to be informed so you can give feedback to agencies making improvements for CMC – e.g., MCFD and many other agencies involved in CMC

Agenda

What we will talk about

- Definitions
- Literature
- What we have experience in

Part A

- Background and current literature & research
- Discussion

Part B

- New literature & research
- Discussion
- Q&A

Topics for discussion (same topics for part A and B)

- What points were new or surprising for you to hear?
What points made you feel seen?
- What areas are most urgent to address through policy changes in BC?
What will make the biggest difference for your family today and into the future?

A1. Background

- Definitions
- Numbers
- BCCH Complex Care & Slocan
- Care & System Map

Children with Medical Complexity: Definition



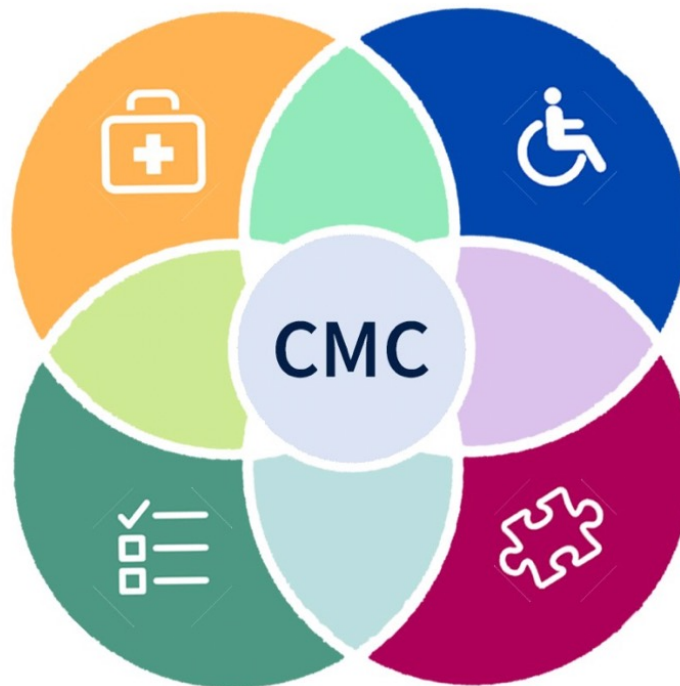
HEALTH CARE USE

- High resource utilization
- Necessitating involvement of multiple service providers



NEEDS

- Substantial family-identified needs
- Significant impact on family (e.g. financial burden)



FUNCTIONAL LIMITATIONS



- Severe
- Often associated with technology dependence

CHRONIC CONDITION(S)



- Diagnosed or unknown but suspected
- Severe and/or associated with medical fragility

Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529-538. doi:10.1542/peds.2010-0910
<https://sickkids.echoontario.ca/resources/complex-care/>

Slide courtesy of Grace Ng

Definitions - CMC vs...

- **Children with Special Health Care Needs (CSHCN) or Children with access and functional needs (CAFN - Chin 2020)** those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”
- **Other definitions**
 - Children with Disability;
 - Children with Complex Chronic Conditions
 - Children with Health Complexity
- **Children with Chronic Critical Illness (CCI)**
 - Children who need frequent prolonged hospitalization to critical care units

CSHCN

Children with
Special Health Care
Needs

Children with single
diagnosis e.g. autism,
intellectual or motor disability

Children with complex
or multiple disabilities

Technology-dependent
and / or unstable CMC

Children with
severe symptoms
and / or at end of life

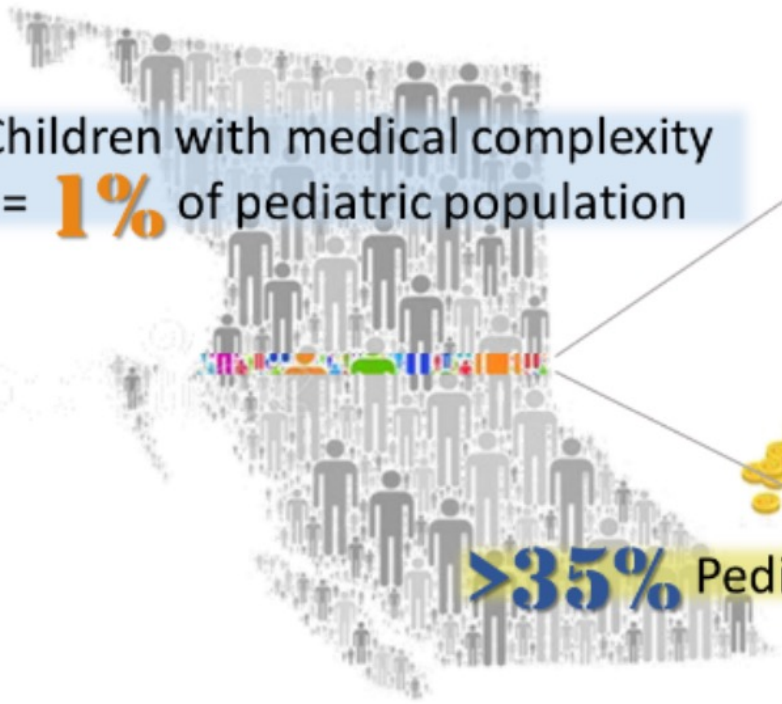
CMC

Children with
Medical Complexity


CCI

Children with Chronic
Critical Illness

Numbers



Children with medical complexity
= **1%** of pediatric population



>35% Pediatric health care costs

BC population:
2019: 5 million people
1 million (20%): children
= 10,000 (~1%) CMC
= 100,000 (~10%) CSCHN

BC Children's Hospital Complex Care Program

- BC's only pediatric complex care program
 - Other than diagnosis/disease specific programs (oncology, multiorgan transplant, craniofacial program, neuromuscular, neuromotor...)
 - Started in 2006 and grew organically
 - Physicians, nurses, and clerks
 - Provides
 - Collaborative care
 - Continuity
 - Care plan
 - Coordination of appointments
 - Care coordination
 - Shared decision making
 - Goal settings

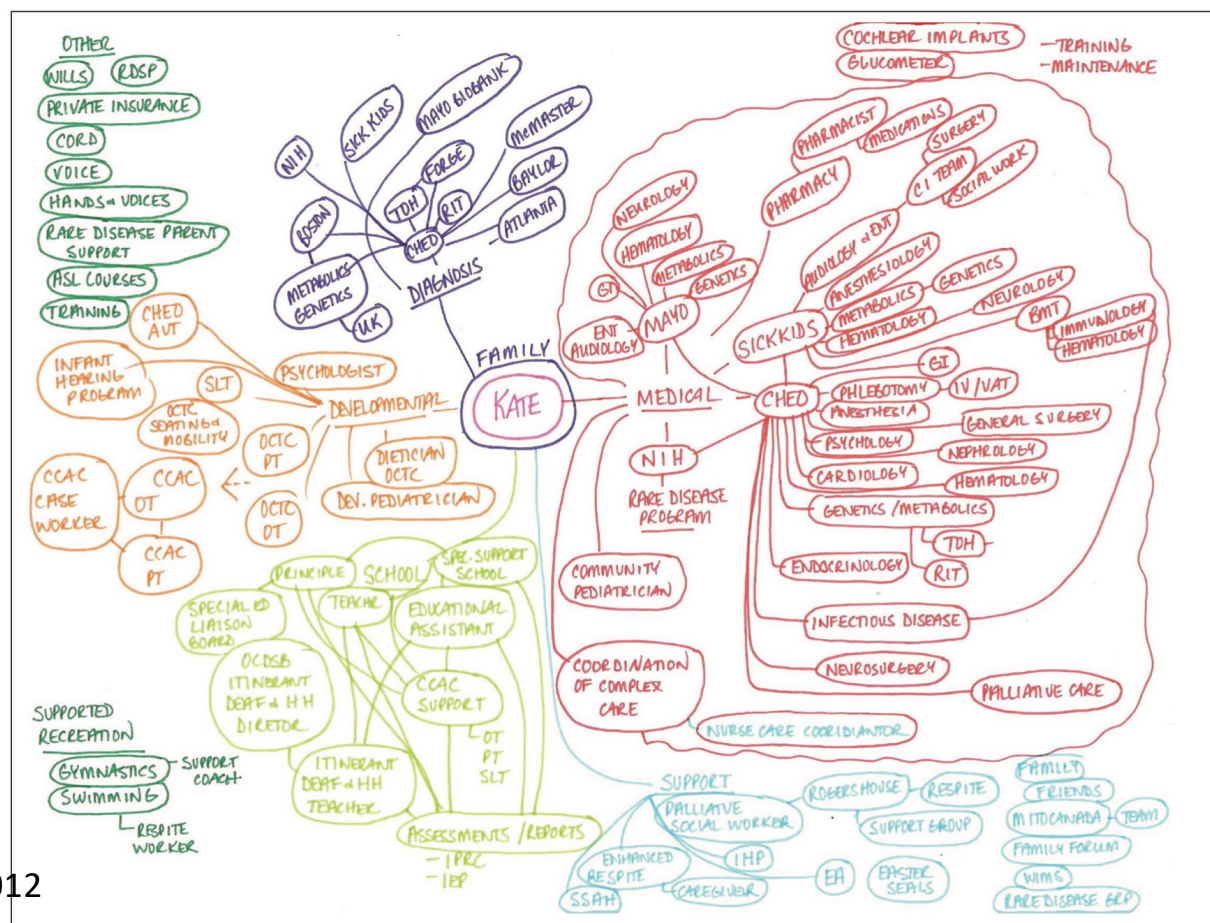


Slocan Site Redevelopment Program

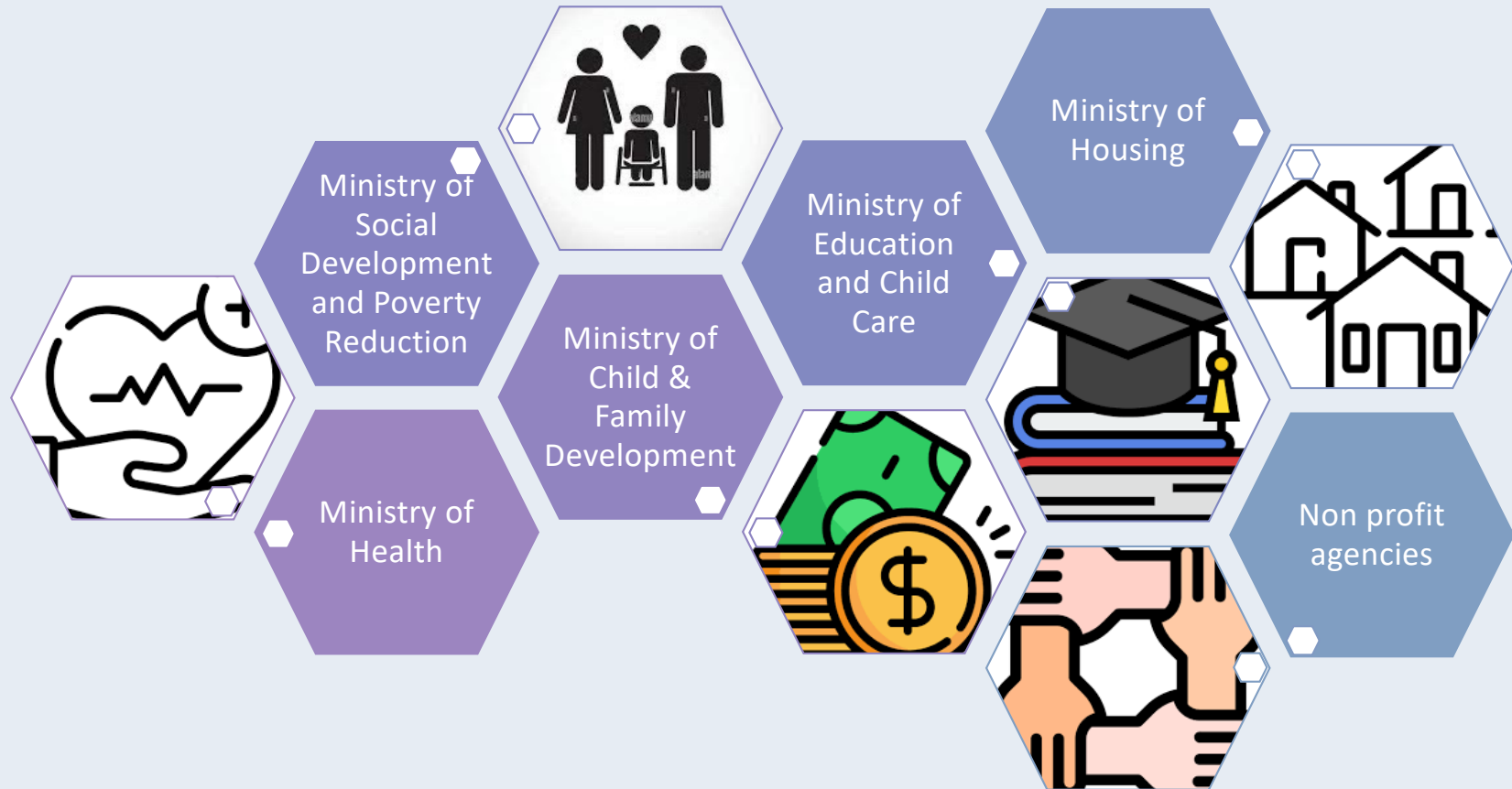
- Centre and Program for children with health complexity
- In planning stage: Ongoing close engagement with community, patients & caregivers, and clinical partners.
- To open ~2028
- Services
 - Care navigation and coordination
 - Training for children and families
 - Training for caregivers and care providers
 - Child and family suites
- <http://www.bcchildrens.ca/about/slocan>

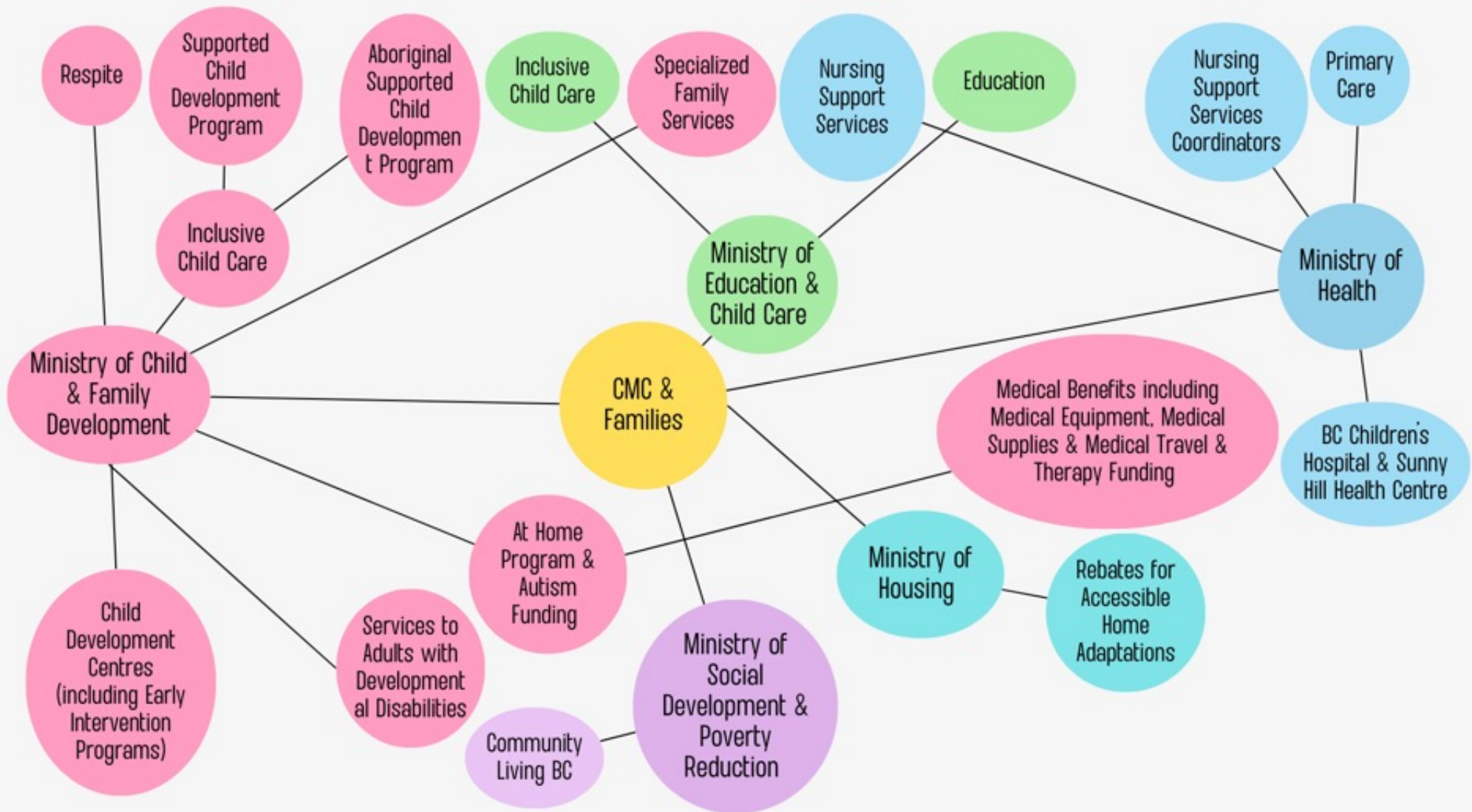


It takes a village



It takes a village - BC







HEALTH CARE USE

- High resource utilization
- Necessitating involvement of multiple service providers



FUNCTIONAL LIMITATIONS



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CHRONIC CONDITION(S)

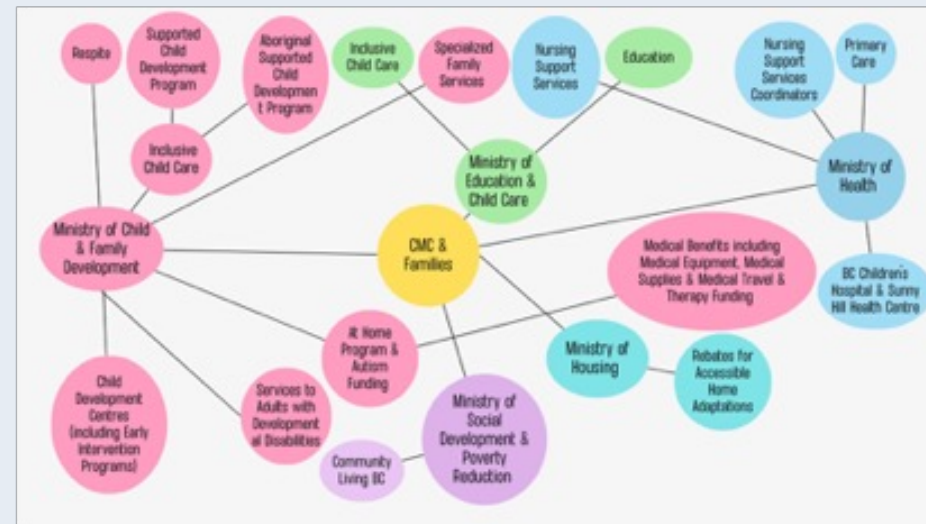
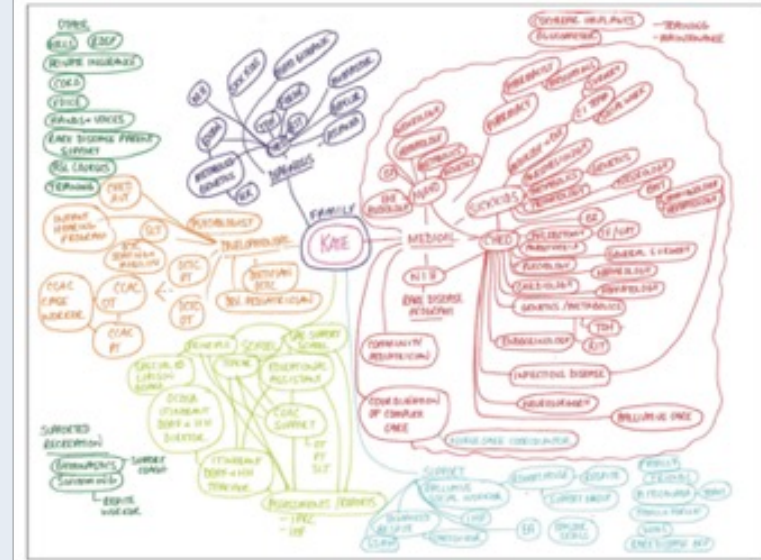


- Diagnosed or unknown but suspected
- Severe and/or associated with medical fragility



NEEDS

- Substantial family-identified needs
- Significant impact on family (e.g. financial burden)



A2. Current Literature

CAPHC 2018

CIHI 2020

Left Out RCY 2020

Alone and Afraid 2018

CAPHC Guideline for the Management of Medically Complex Children and Youth Through the Continuum of Care (2018)

Guideline developed by health professionals, researchers, and families

Goal is to standardize care for all Canadian children/youth and their families while improving safety, quality and ensuring accessible and equitable care.

https://www.childrenshealthcarecanada.ca/en/networks-and-hubs/Complex-Care/CAPHC-National-Complex-Care-Guideline-2018_final.pdf



CAPHC Guideline for the Management of Medically Complex Children and Youth Through the Continuum of Care

CAPHC Complex Care Community of Practice (CoP)
April 2018

CAPHC (2018)

Summary of Recommendations

Recommendation	Level of Evidence
1. Ensure that a process for clear identification of children and youth with medical complexity is in place to promote equity of services.	II, III
2. Build capacity within the healthcare system to deliver coordinated care that is holistic, comprehensive and family-centred to all children with medical complexity, closer to home	III
3. Identify a keyworker and care team for each child with medical complexity to facilitate service planning and care delivery in collaboration with the family/caregiver.	II, III
4. Develop and maintain a shared single care plan with common language and clear ownership for children with medical complexity that is accessible and updated in a timely manner.	II, III
5. Empower families by proactively supporting them to develop skills, competency and confidence to comprehensively care for their child and to advocate on behalf of their child.	II, III
6. Organizations providing services to children with medical complexity must have a strategy to transition between levels of healthcare and different care environments. (hospital – community – home – school- respite – adult services)	II, III

CAPHC (2018)

1. Ensure that a process for clear identification of children and youth with medical complexity is in place to promote equity of services.

II, III

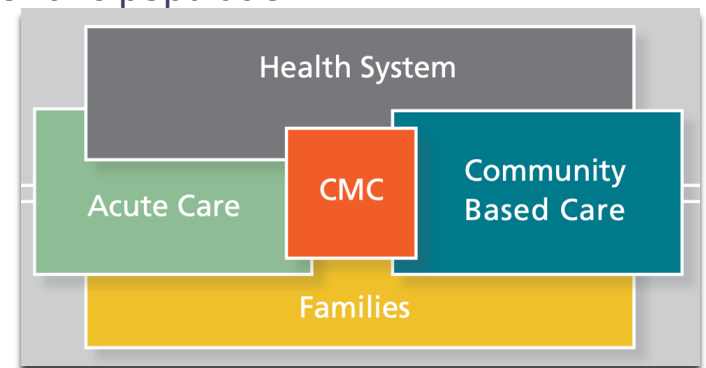
- It is recognized that other factors such as family identified needs, psychosocial domains may be independent factors that contribute to their complexity, yet the needs of these children may not be addressed depending on the local complex care program and their set criteria
- Health status of these children is dynamic; the health of these children changes over time and therefore the care needs also change both predictably and unpredictably. In establishing a program, there should be consideration for
 - a) flexibility in the process of intake and discharge to facilitate transitions in care support as needed,
 - b) explicit links with community providers who can provide care to stable CMC and
 - c) facilitated communication between hospital-based CMC programs and community providers; to meet the dynamic nature of care needs in CMC.

CAPHC (2018)

2. Build capacity within the healthcare system to deliver coordinated care that is holistic, comprehensive and family-centred to all children with medical complexity, closer to home

III

- 2.1 Develop, implement and sustain a supportive infrastructure for the care and services designed for CMC and their families.
- 2.2 Establish a governance model with well-defined objectives, goals and evaluation processes.
- 2.3 Develop a sustainability plan that identifies complex care as a priority and includes appropriate business planning practices.
- 2.4 Identify the education model required to meet the initial and ongoing education/training needs at all levels of care.
- 2.5 Identify and establish the standards of clinical delivery specific for this population.



CAPHC (2018)

3. Identify a keyworker and care team for each child with medical complexity to facilitate service planning and care delivery in collaboration with the family/caregiver.

II, III

3.1 The Key Worker role must be recognized and supported by the organization

3.2 Role, responsibilities and limitations of the Key Worker must be explicit

3.3 A defined model to support care delivery and transition management will include:

- Communication strategies to allow for interaction and collaboration of care giving team across all settings
- A clear process for identifying and addressing client needs, changes in status and changing goals

3.4 Model must include integration with services beyond those that are health related including but not limited to financial supports, schools, community activities, equipment and housing.

3.5 The Key Worker is a single point of contact for the family with the ability to work collaboratively creating linkages between acute care, home care, education and community agencies

3.6 The Key Worker represents the global interests and requirements of the child & family, which may include acute care, home care, education and community agencies and should facilitate engagement, coordination and communication among all providers and all settings.

3.7 The Key Worker should participate with the family in:

- Identifying and connecting with a primary care provider
- Setting child and family health goals
- Identifying non-clinical/community activities
- Identifying care needs
- Developing a comprehensive, child and family focused care plan with flexibility to adjust as goals and health care needs change
- Educating/coaching the family to strengthen their ability to advocate regarding their child's health needs/conditions

3.8 The Key Worker should facilitate and aid in planning for transitions in care:

CAPHC (2018)

4. Develop and maintain a shared single care plan with common language and clear ownership for children with medical complexity that is accessible and updated in a timely manner.

II, III

- 4.1 The care plan should be developed and maintained by the Key Worker with the input from the family and the healthcare team including the most responsible physician (either complex care clinic or primary care).
- 4.2 The care plan should be updated at clinic visits and after any major health status change.
- 4.3 The care plan should be inclusive of all the child's needs, clinical and non-clinical, including homecare, school, and community activities.
- 4.4 The care plan should include urgent care recommendation, resuscitation guidelines
- 4.5 The care plan should be part of the child's medical record.
- 4.6 The family, with the Key Worker will identify individuals and organizations that will have access to the care plan.

CAPHC (2018)

5. Empower families by proactively supporting them to develop skills, competency and confidence to comprehensively care for their child and to advocate on behalf of their child.

II, III

5.1 Parents and caregivers are provided with ample opportunity to learn about their child's condition and acquire the necessary skills to care for their child now and in the future.

5.2 Parents and caregivers are recognized as key members of their child's care team and their expertise should be acknowledged.

5.3 Families are engaged as partners in shared decision making and encouraged to make choices that are consistent with their values and goals.

5.4 Guidance and coaching on how to navigate the health, social, educational and developmental systems and access needed resources is provided, ideally by the Key Worker and healthcare team.

5.5 Parents and caregivers are supported in their home care management by health care providers, with differences in hospital care vs. home care acknowledged and incorporated into the care plan.

5.6 Resources and assistance are made available to families and caregivers. Care planning takes place with families and include suggestions for management of illness or complications that may occur.

5.7 Training and frameworks are in place to support health care providers in engaging meaningfully with families in this way.

5.8 Families are actively involved in program development at the system level.

CAPHC (2018)

6. Organizations providing services to children with medical complexity must have a strategy to transition between levels of healthcare and different care environments. (hospital – community – home – school- respite – adult services)

II, III

- 6.1 Organizations should develop standardized internal policies and structured processes, that include strategies for communication with other levels of care to support safe and effective transitions for children with medical complexity.
- 6.2 Discharge planning should be inclusive of community re-integration including home care, education and other social/ developmental environments where care may occur.
- 6.3 Planning will begin well in advance of a transition taking place; families should always be included in team meetings with the Key Worker about transition planning and should be involved in decisions about what will take place during in-hospital transitions and after they leave the hospital etc.
- 6.4 Hold at least one pre-discharge meeting for medical transitions with all parties involved to discuss concerns, answer questions, engage clients/families and caregivers in the care transition and understand the parents'/caregivers' perspectives on discharge readiness.
- 6.5 The Shared Care Plan should be reviewed and updated if necessary at each major transition in care.
- 6.6 A one-page summary of critical information about the child and family and their care plan should be developed and kept up to date for the family and made available to any health care professional who would need information on the child's needs.
- 6.7 Essential clinical information and /or resources are provided to the family and the identified circle of care upon discharge to support the clients' transition, and clients/families can ask questions.
- 6.8 Empower families through education about self-management; using teach back when providing information builds caregiver capacity.
- 6.9 Reconcile medications at care transitions and discharge and include in final transition plan. Identify ways for the client and/or caregiver to participate in the medication reconciliation process.
- 6.10 Care coordination must begin and be in place before discharge i.e. supplies and equipment appropriately set up in the home; transportation, caregivers (if applicable) etc.

Children and Youth with Medical Complexity in Canada (CIHI, 2020)



Children and Youth With Medical Complexity in Canada

https://secure.cihi.ca/free_products/children-youth-with-medical-complexity-report-en.pdf

CIHI, 2020

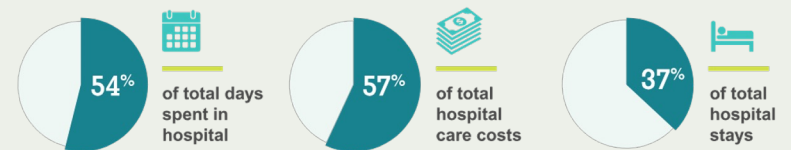
- 39% use 5+ meds, 32% medical technology
- 38% <5yrs, 23% older than 20, 51% male, distributed across income groups evenly
- 2/3 single condition (cancer, CVD, GI), 8%NI, 8%NI w/other conditions, 16% multiple conditions
- Children and youth received 44 hours per week of informal care. More than one-third had caregivers who were distressed.
- 1 in 3 use medical technology

This population's unique needs mean they require more health care compared with other children and youth



Acute care

■ Children and youth with medical complexity
□ Children and youth with other conditions



Specialty clinic

On average, children and youth with medical complexity

from Alberta visited specialty clinics



Medication

2 in 5 children and youth with medical complexity



Sources
Hospital Morbidity Database and National Ambulatory Care Reporting System, 2010–2011 to 2017–2018, and National Prescription Drug Utilization Information System, 2015–2016 to 2016–2017, Canadian Institute for Health Information.

© 2020 Canadian Institute for Health Information

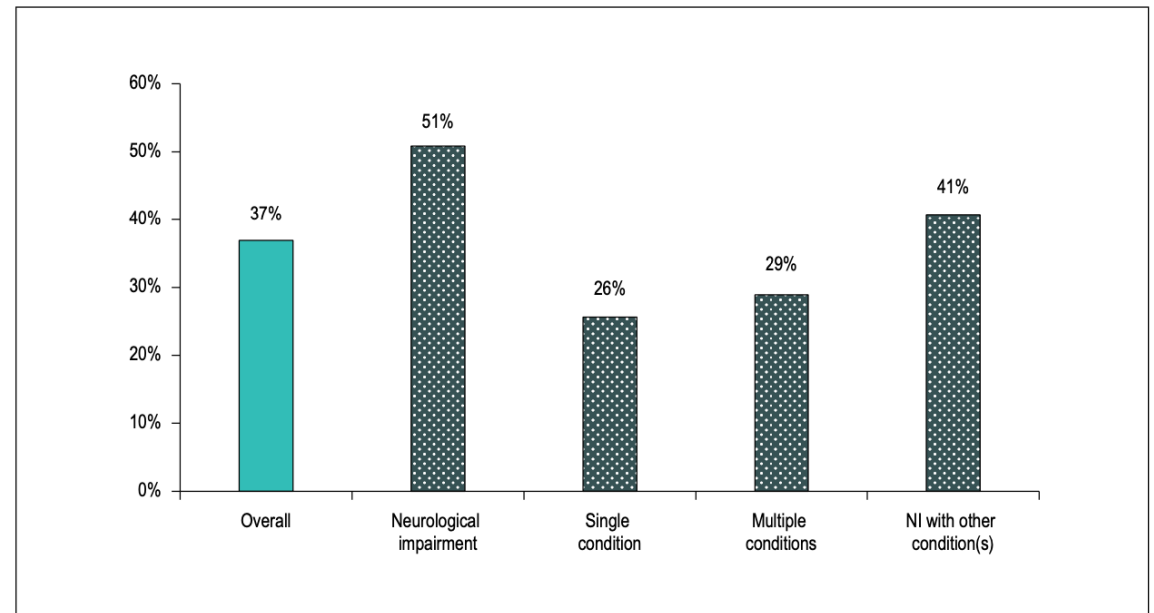
How to cite this document: Canadian Institute for Health Information. Children and youth with medical complexity in Canada [types of care infographic]. Ottawa, ON: CIHI; 2020.

Children and Youth with Medical Complexity in Canada (CIHI, 2020)

Over one-third of primary caregivers expressed distress

Of these primary caregivers, 37% expressed feelings of anger, distress or depression, or felt they were unable to continue in their caring activities. However, caregiver distress increased in those caring for children and youth with neurological impairment.

Figure 5 Distress among caregivers of children and youth with medical complexity receiving home care in the 2 years after the first hospital stay in 2015–2016, by type of medical complexity



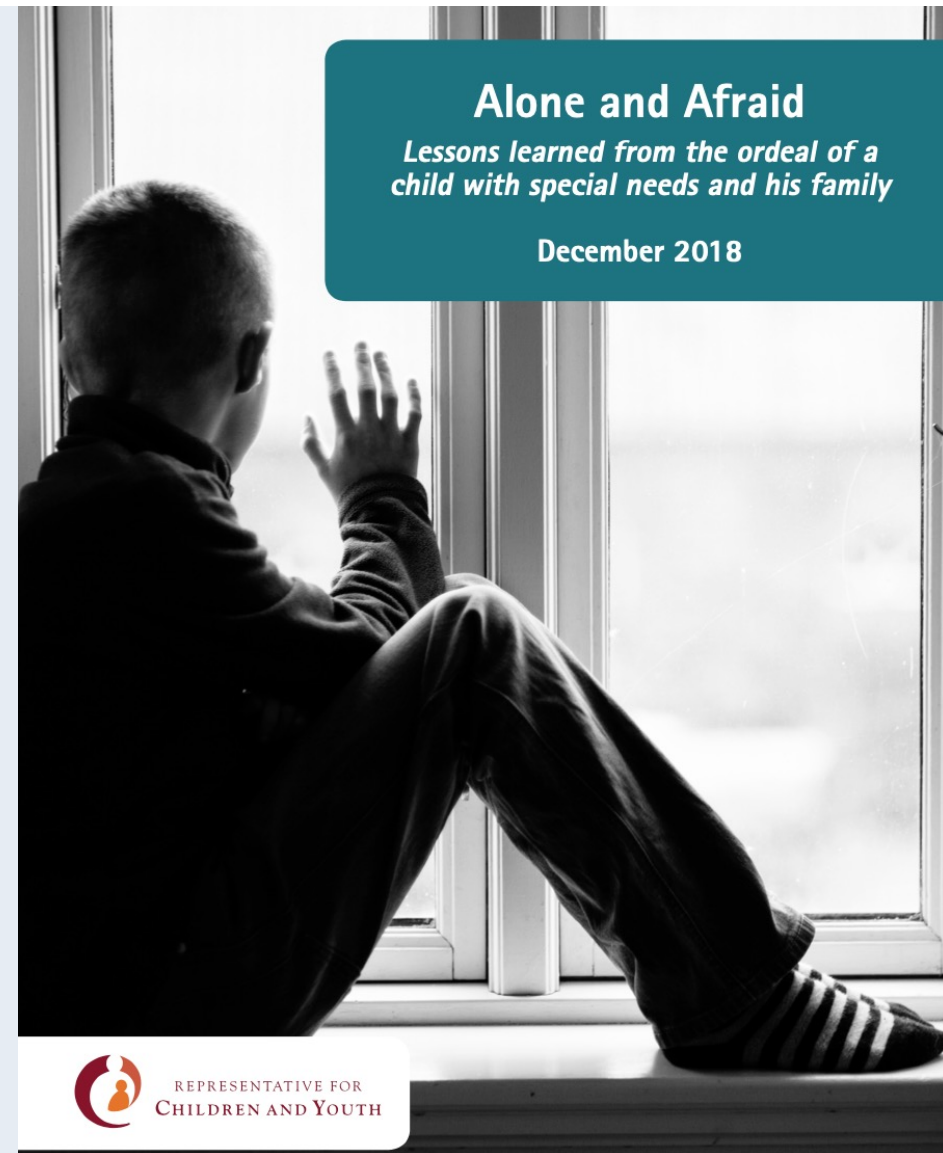
Children and Youth with Medical Complexity in Canada (CIHI, 2020)

- 37% of all hospital admissions, 1/6 of ED visits, and 54% of total hospital days.
- Key challenges highlighted for this group:
 - Most die in hospital at higher rate than ped population, limited palliative care
 - Multiple medications, rare, expensive meds, access difficult
 - Home care is limited, staff with pediatric expertise is not always available, long wait times, or do not qualify
 - Financial impact - one parent staying home, out of pocket expenses.
 - Major issues with transition to adult services

Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family (RCY, 2018)

- 11 key recommendations from the report
 - 1 – MCFD to undertake a comprehensive assessment of CYSN needs and service improvements
 - 3 – MCFD to take the lead in creating integrated service delivery with Ministries of Education and Health.

<https://rcybc.ca/reports-and-publications/reports/reviews-and-investigations/alone-and-afraid-lessons-learned-from-the-ordeal-of-a-child-with-special-needs-and-his-family/>



Left Out: Children and youth with special needs in the pandemic (RCY 2020)

- Highlights the issues families faced during the pandemic
- Call for transparent and consistent communication plan around benefits and relief programs.
- Call for flexible solutions to fit unique family needs.

https://rcybc.ca/wp-content/uploads/2020/12/CYSN_Report.pdf

Left Out: Children and youth with special needs in the pandemic

December 2020



Discussion - 1 of 2

Topics for discussion (same topics for part A and B)

- What points were new or surprising for you to hear?
What points made you feel seen?
- What areas are most urgent to address through policy changes in BC?
What will make the biggest difference for your family today and into the future?

B. New Literature

Still Left Out (2023)

BCCH Complex Care NKW and myBookletBC

COVID-19 and CMC

Medical traumatic stress

Disaster and CMC

Disability-based discrimination

~~Out of Pocket expenses~~

Still Left Out: Children and youth with special needs in the pandemic (RCY 2023)

- RCY Advocates working alongside families and caregivers continually engage with government and CYSN staff want to be helpful to families, but currently have limited or no options to offer.
- RCY estimates that as many as 80,000 B.C. children and youth with disabilities are currently not receiving any support.

<https://rcybc.ca/reports-and-publications/reports/still-left-out/>

Still Left Out: Children and youth with disabilities in B.C.

November 2023



BCCH Complex Care - Nurse Key Worker

Families' Feedback

[The NKW] makes sure we understand what was said and instructed by [clinician] when we are not sure. She understands and really cares for our family and helps us stay calm in very difficult situations.

The [CCP] knows more about my child than anybody. It's a relationship building over the years. We feel safe and understood when expressing our needs.

Since [the NKW] got involved, we haven't had to go to the [emergency room].

With the NKW involvement, I spend less time trying to understand who can and will talk to me. I don't worry that no one will call me back.



BCCH Complex Care - Nurse Key Worker

Outcomes

- **Families:** Timely access to single point of contact



- **Right Time:** More families able to receive complete care from our program, timely access to a provider who knows their child well & able to provide quality care coordination

- **Community providers:** Collaborate to support families close to home



- **Right Place:** Timely response to questions/concerns from our team, more capacity to work on collaboration & communication

- **Team:** Appropriate scope of practice



- **Right Provider:** Improved role differentiation: NKW doing RN scope activities, NP and MD doing NP/MD scope activities

Careplan - *myBookletBC.com*

myBooklet BC is a **child centric care plan** that emphasizes the **child's strengths and abilities** with content chosen by the child or family members

JULIA's MAKE ME HAPPY BOOK!

myBooklet BC: Partnership of families with children living with health complexity and a health professional student in completion of care plan

Judy YJ So¹; Lydia Kang²; Mandy Young³; Esther J. Lee, MD^{1,4,5}



The Impact of COVID-19 on British Columbia's Children with Medical Complexity and their Families

Jennifer L. Baumbusch, Ph.D., R.N.

Associate Professor
School of Nursing
University of British Columbia

Shawna R. Lamden-Bennett
Community Research Liaison

Jennifer E.V. Lloyd, Ph.D.
Research Associate
School of Nursing
University of British Columbia

Conclusion:

COVID-19 and its associated restrictions have had wide-ranging (mainly negative) consequences for BC's children with medical complexity and their families

Key findings



The Impact of COVID-19 on British Columbia's Children with Medical Complexity and their Families

Family & Community Life

- Respondents, mainly mothers, indicated that they are solely responsible for their medically complex child(ren)'s care the majority of the time.
- The majority of parents ($n=89$, 57.1%) reported that their own physical health is 'somewhat' or 'much' worse than one year ago.
- The majority of parents ($n=114$, 73.1%) reported that their own mental health and social well-being are 'somewhat' or 'much' worse than one year ago.
- Household income decreased, while unemployment and reliance on food security programs increased.

“Can you hear me OK?”: Caregivers of Children With Medical Complexity and Their Perspectives of Virtual Care During COVID-19


Vanessa C. Fong, PhD, Jennifer Baumbusch, RN, PhD, &
Koushambhi Khan, PhD

Virtual Care

“Can you hear me OK?”:
Caregivers of Children With
Medical Complexity and
Their Perspectives of Virtual
Care During COVID-19

- **Advantages and opportunities**
 - More convenient, safe, and higher in quality compared with in-person visits
 - Virtual care was also viewed as valuable in facilitating peer support and preventing social isolation during the pandemic.
- **Concerns and challenges**
 - Parents perceived virtual care to contribute to gaps in their child’s care and create additional stress and burden managing certain therapies (e. g., physiotherapy).
- **Parent choice and preference:**
 - Recognizing the unique and diverse needs of families by providing parents with choices when it comes to virtual care.

Experiences of medical traumatic stress in parents of children with medical complexity

Tammie Dewan^{1,2}  | Katie Birnie³ | Julie Drury | Isabel Jordan |
Megan Miller⁴ | Alexandra Neville⁵ | Melanie Noel⁵ | Alam Randhawa¹ |
Anna Zadunayski¹ | Jennifer Zwicker⁶

Experiences of medical traumatic stress in parents of children with medical complexity

Tammie Dewan^{1,2}  | Katie Birnie³
Megan Miller⁴ | Alexandra Neville⁵
Anna Zadunayski¹ | Jennifer Zwick

Key messages

- Recurrent exposure to pediatric medical traumatic stress (PMTS) places parents of children with medical complexity at risk of adverse mental health outcomes and future negative experiences.
- Systemic factors and their interaction in the healthcare setting contribute to parent feelings of powerlessness and vulnerability, which set the stage for PMTS to occur.
- Interactions and events that seem innocuous to healthcare providers may be perceived as traumatic by parents, necessitating a trauma-informed care approach.
- Dedicated and proactive mental health supports would help parents to identify and address the PMTS they have experienced and equip them to deal with future events.

Disaster support for families of children with medical complexity (CMC) and special healthcare needs: A rapid scoping review of communication strategies

- **Conclusion:** Two-way communication between providers and families with CMC is essential. Disaster planning must ensure equity, regardless of family location and language. We recommend that policy makers engage with parents and children to start this process.
- **Details:**
 - Pre-disaster, planning should include families, professionals, other stakeholders, and children themselves.
 - When a disaster is predicted, or occurring, healthcare providers should begin proactive outreach. A designated point person or care coordinator can fill this role.
 - Neighbours and peers are often first contacts in a disaster. Healthcare providers can use existing personal networks to support families during crises.
 - It is critical to re-establish care processes as soon as possible. This may involve using telehealth.
 - Priorities after a disaster are treating mental health issues, and returning to daily routines including school.

Perceived Disability-Based Discrimination in Health Care for Children With Medical Complexity

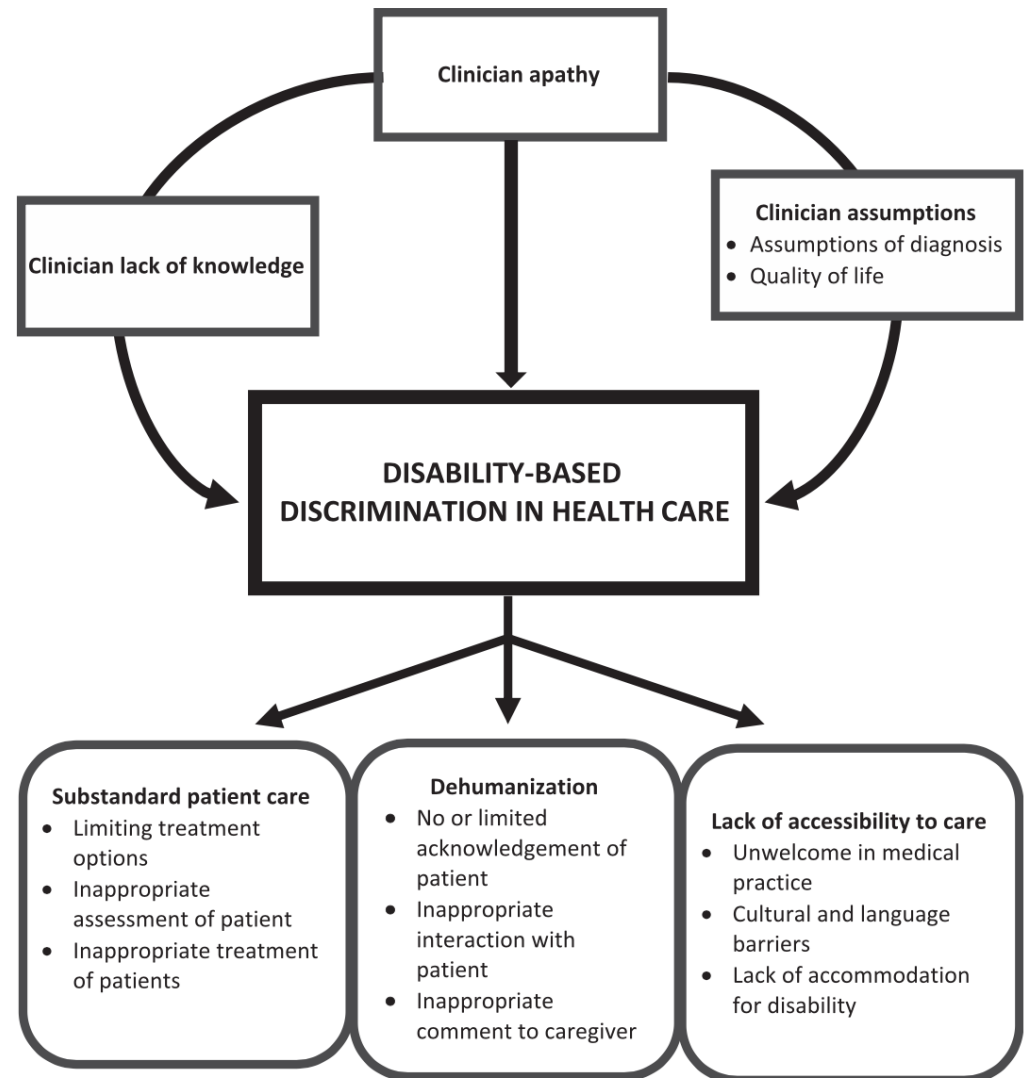
Stefanie G. Ames, MD, MS,^a Rebecca K. Delaney, PhD,^b Amy J. Houtrow, MD, PhD, MPH,^c Claudia Delgado-Corcoran, MD,^a Justin Alvey, MD,^a Melissa H. Watt, PhD,^b Nancy Murphy, MD^a

WHAT'S KNOWN ON THE SUBJECT: Disability-based discrimination in health care can lead to gaps in care and poor health outcomes for patients with disabilities. Evaluation of physicians has demonstrated a lack of confidence and skill in caring for patients with disabilities which may perpetuate disparities.

WHAT THIS STUDY ADDS: Caregivers of children with medical complexity report experiences of disability-based discrimination in the healthcare of their child. These experiences are driven by clinician knowledge, apathy, and assumptions, and manifest as lack of access to care, substandard care, and dehumanization.

Perceived Disability-Based Discrimination in Health Care for Children With Medical Complexity

Stefanie G. Ames, MD, MS,^a Rebecca K. Delaney, PhD,^b Amy J. Houtrow, MD, PhD, MPH,^c Claudia Delgado-Corcoran, MD,^a Justin Alvey, MD,^a Melissa H. Watt, PhD,^b Nancy Murphy, MD^a



Ames SG, Delaney RK, Houtrow AJ, et al. Perceived Disability-Based Discrimination in Health Care for Children With Medical Complexity. *Pediatrics*. 2023;152(1): e2022060975

Cliff or bridge: breaking up with the paediatric healthcare system

Jennifer Baumbusch, RN, PhD, FAAN, FCAN¹ 

- Transition from pediatric to adult health care system describe in various “break up” forms
 - The ‘Dear John’ letter
 - ‘It’s not you, it’s me’
 - Ghosting
 - What is needed: The Handover
- *“And our backpacks are full of trauma. My hope is that by sharing our experiences we can work together—families and healthcare professionals to build a system where families have a hand to hold on the other side.”*



Knowledge Translation Process - Modified with permission © [PENCRU](#).

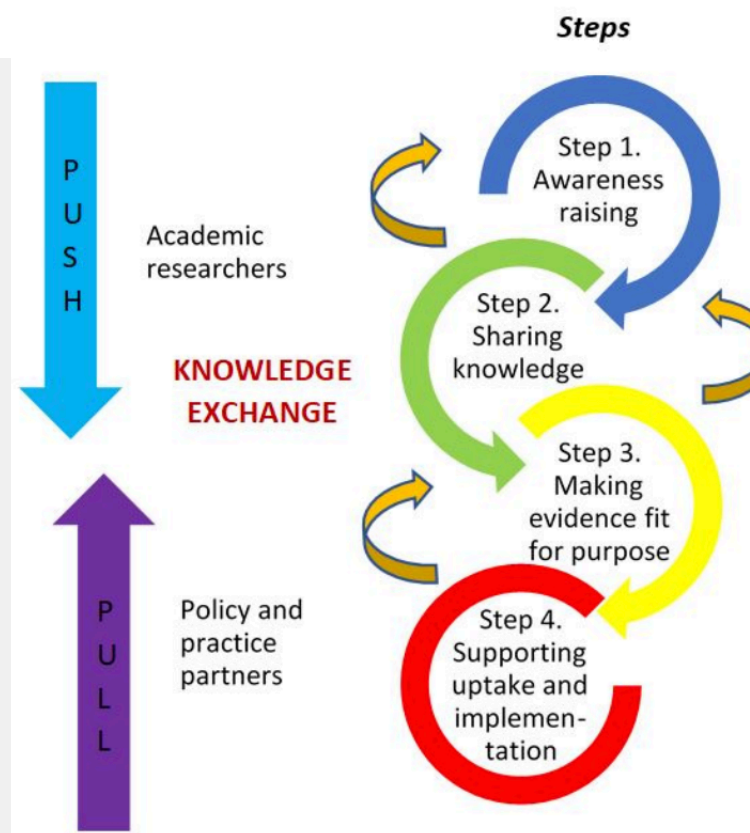


Figure 1. Fuse Knowledge Exchange model

Discussion - 2 of 2

Topics for discussion (same topics for part A and B)

- What points were new or surprising for you to hear?
What points made you feel seen?
- What areas are most urgent to address through policy changes in BC?
What will make the biggest difference for your family today and into the future?

Objectives Recap

1. Be aware of the definitions around children with medical complexity (CMC)
2. Understand the current literature on CMC
3. Be updated on the newer literature on CMC

Ultimate Objectives:

- For you (caregiver and/or health professional) to be informed so you can give feedback to agencies making improvements for CMC – e.g., MCFD and other agencies involved in CMC
- For you to see what the families and health professionals want and need for CMC is already published. We need to work all together to improve our system.

Feedback to improve the system

- <https://engage.gov.bc.ca/govtogetherbc>
 - MCFD CYSN
 - <https://engage.gov.bc.ca/children-youth-support-needs>
 - Other ministry opportunities
- Be involved in family groups
 - BC Complex Kids Society
 - Family Support Institute BC
 - BCEdAccess
 - InclusionBC
 - --> get invites on engagement opportunities

Acknowledgements and Thanks

- Slocan Site Redevelopment Program team
 - Tessa Diaczun and Elizabeth Stanford
- PHSA Communications
- Hema Patel, Montreal Children's Hospital
- Jennifer Baumbusch
- Mimi Kuan and Grace Ng
- BCCH Complex Care Program

References

Part A: Background and Current Literature

- Canadian Association of Paediatric Health Centres (CAPHC, now Children's Healthcare Canada CHC): **Guideline for the Management of Medically Complex Children and Youth Through the Continuum of Care.** (2018) https://www.childrenshealthcarecanada.ca/en/networks-and-hubs/Complex-Care/CAPHC-National-Complex-Care-Guideline-2018_final.pdf
- Canadian Institute for Health Information: **Children and Youth with Medical Complexity in Canada.** (2020) https://secure.cihi.ca/free_products/children-youth-with-medical-complexity-report-en.pdf
- Representative for Children and Youth: **Left Out: Children and youth with special needs in the pandemic** (2020) https://rcybc.ca/wp-content/uploads/2020/12/CYSN_Report.pdf
- Representative for Children and Youth: **Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family.** (2018) <https://rcybc.ca/reports-and-publications/reports/reviews-and-investigations/alone-and-afraid-lessons-learned-from-the-ordeal-of-a-child-with-special-needs-and-his-family/>
- Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics.* 2011;127(3):529-538. doi:10.1542/peds.2010-0910 <https://sickkids.echoontario.ca/resources/complex-care/>

Part B: New Research

- Representative for Children and Youth: **Still Left Out: Children and youth with special needs in the pandemic** (2023) <https://rcybc.ca/reports-and-publications/reports/still-left-out/>
- Baumbusch, Jennifer, Lamden-Bennett, Shawna, Lloyd, Jennifer. (2020) **The Impact of COVID-19 on British Columbia's Children with Medical Complexity and their Families.** <https://spice.nursing.ubc.ca/outreach/>
- Fong, Vanessa, et al. (2023). "Can you hear me OK?": Caregivers of Children with Medical Complexity and Their Perspectives of Virtual Care During COVID-19. *J Pediatr Health Care.* <https://doi.org/10.1016/j.pedhc.2023.08.008>. For a copy - email jennifer.baumbusch@ubc.ca
- Dewan, Tammie, et al. (2022). **Experiences of medical traumatic stress in parents of children with medical complexity.** <https://pubmed.ncbi.nlm.nih.gov/35947493/>
- Smith, Neale, et al (2021) **Communication in disasters to support families with children with medical complexity and special healthcare needs: A rapid scoping review** <https://sporevidencealliance.ca/key-activities/covid-19-evidence-synthesis/>
- Ames, Stephanie et al. (2023) **Perceived Disability-Based Discrimination in Health Care for Children With Medical Complexity.** <https://doi.org/10.1542/peds.2022-060975>
- Baumbusch, Jennifer. **Cliff or bridge: breaking up with the paediatric health care system.** (2023). *Paediatrics & Child Health.* <https://academic.oup.com/pch/advance-article/doi/10.1093/pch/pxad061/7259814>. For a copy - email jennifer.baumbusch@ubc.ca

Extra slides

Cost of Caregiving on Parents of Children With Medical Complexity and Life-Limiting Conditions

Jessica Shriver, MA, MS

- Shriver: Cost beyond money
- What are the \$\$\$
 - Upto \$3850-4043/month to caregivers for children in care (page 39 of Still Left Out)
 - **Median Annualized Cost per Child and Youth in Care with Support Needs** (<https://mcfcd.gov.bc.ca/reporting/services/children-and-youth-with-support-needs/performance-indicators>)
 - Median average - \$78,164
 - Median indigenous \$38,547
 - Median non-indigenous \$123,781

Shriver J. Cost of Caregiving on Parents of Children With Medical Complexity and Life- Limiting Conditions. Pediatrics. 2021;148(2): e2021050222

Out-of-pocket expenses reported by families of children with medical complexity

Christina Belza^{1,2,3}, , Eyal Cohen^{1,2,4,5,*}, Julia Orkin^{1,4,5}, Nora Fayed⁶, Nathalie Major⁷, Samantha Quartarone¹, Myla Moretti^{1,8,9}

- Study in Ontario
- Caregivers reported median OOP expenses of over \$8000.00 per year,
 - primarily due to costs associated with medically-associated childcare/homemaking (beyond routine costs), travel to medical appointments, inpatient hospitalizations and medical devices.
 - This amount translates into roughly 13% of the average household income in Canada of \$60,000 per year suggesting a substantial burden on families of CMC.
 - This is in addition to the variety of expenses that caregivers spend to care for healthy children.

Giving in Action Program Evaluation

Giving in Action, Receiving in Kind

A Summary Evaluation of Impact of the Giving in Action Society's "Family Independence Fund" and "Children with Special Needs Fund"

By Dr. Mike Evans, Dr. Rachele Hole and Dr. Tim Stainton

6/15/2014