# Building a Complex Care Service for Maine Kids

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**MaineHealth Pediatric Specialty Group**

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## Disclosures

- I have no relevant financial relationship(s) to disclose with ineligible companies whose primary business is producing, marketing, selling, re-selling, or distributing healthcare products used by or on patients.



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# Learning objectives

- Learn the history and current state of specialized pediatric complex care programs
- Review themes gathered from research with caregivers of medically complex kids in Maine
- Learn about services offered by the Program for Children with Medical Complexity (and geographic distribution of current patients)
- Discuss representative cases of medically complex kids in Maine
- Explore current and future challenges facing this patient population



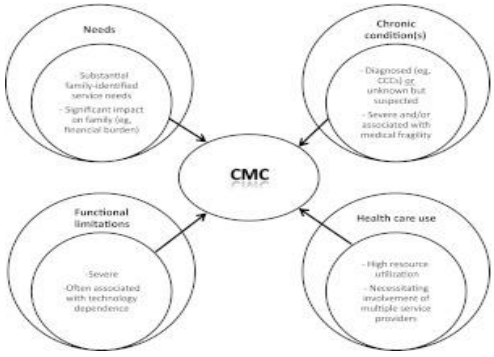
# History

- 1998: Definition of Children with Special Health Care Needs (CHSCN)
- CHSCN intended to be inclusive - includes those at risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type and/or amount beyond that required by children generally, about 15% of US kids
- Children with Medical Complexity (CMC) are a subgroup of CHSCN

Cohen E, Berry JG, Sanders L, Schor EL, Wise PH. Status Complexicus? The Emergence of Pediatric Complex Care. Pediatrics. 2018 Mar;141(Suppl 3):S202-S211. doi: 10.1542/peds.2017-1284E. PMID: 29496971.

# Formal definition of CMC

- Built on foundation of Complex Chronic Conditions (CCC) list built by Chris Feudtner, MD in 2000 (revised for ICD-10 in 2014) but not every child with a CCC diagnosis is a CMC!
- In 2011, Cohen et.al. proposed:




Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SK, Simon TD, Srivastava R. Children with medical complexity: an emerging population for clinical and research initiatives. Pediatrics. 2011 Mar;127(3):529-38. doi: 10.1542/peds.2010-0910. Epub 2011 Feb 21. PMID: 21339266; PMCID: PMC3387912.



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# Major risks CMC face

- Hospital readmission
- Total and preventable adverse effects
- Unnecessary variation in hospital care

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## CMC programs are usually based in children's hospitals

- Centering care within hospitals has limitations:
  - Hospital based metrics (e.g. readmission, ED utilization, etc.) may not be amenable to significant change
  - A significant portion of care for CMC occurs in community-based settings, (e.g. home health, outpatient medications)
  - Patients in rural areas face significant travel distances to specialized centers



## New England institutions with Complex Care programs

- Boston Children's Hospital
- MassGeneral Hospital for Children
- Children's Hospital at Dartmouth
- Hospital for Special Care, New Britain, CT

## Peer institutions with Complex Care programs

| Institution: | Pts: |
|---|---|
| • Children's Hospital at Dartmouth, Hanover, NH | 75 |
| • Janet Weis Children's Hospital at Geisinger, Danville, PA | 91 |



## What do families want from CMC programs?

- In a 2020 study at the University of Pittsburgh children's hospital, 2 themes emerged:
  - The value of having a clinician "quarterback" who is in-charge of their child's care and caregivers' go-to for questions and concerns
  - Wanting clinicians who are personally invested in and willing to "go above and beyond" for their child

Yu JA, Cook S, Imming C, Knezevich L, Ray K, Houtrow A, Rosenberg AR, Schenker Y. A Qualitative Study of Family Caregiver Perceptions of High-Quality Care at a Pediatric Complex Care Center. Acad Pediatr. 2022 Jan-Feb;22(1):107-115. doi: 10.1016/j.acap.2021.05.012. Epub 2021 May 19. PMID: 34020106; PMCID: PMC9979253.

# What do families want in Maine: our research

- From March 2022 – March 2023 semi-structured phone or video interviews conducted with 19 guardians of pediatric patients seen by 3 or more pediatric specialists, excluding oncology patients
- Salient themes identified using thematic analysis and placed at levels of the socio-ecological model (SEM)
- Interviews conducted until thematic saturation reached



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## Families of medically complex children in a rural area value **telehealth, peer support groups, and direct interaction** with their child

**Family Experiences of Care for Children with Medical Complexity in a Largely Rural Catchment Area: A Qualitative Study**

Logan Murray, MD; Danielle Doctor, MD; Amanda M. Payne, MSN; Sarah Gabrielson, MPH; Laura Amar Dolan, MD, MPH; Laura J. Faherty, MD, MPH, MSHP

### Introduction

- Multidisciplinary complex care programs are often found in large urban academic centers but are less common in rural areas
- Lack of access to complex care programs is an equity issue for rural families

### Methods

- From March 2022 – March 2023 semi-structured phone or video interviews conducted with 19 guardians of pediatric patients seen by 3 or more pediatric specialists, excluding oncology patients
- Salient themes identified using thematic analysis and placed at levels of the socio-ecological model (SEM)
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### Results

Guardians identified challenges at every level of the SEM.
**System:** Care communication is often fragmented and logistical barriers makes accessing care difficult.
**Community:** They expressed isolation in their communities both from resources and from families with similar experiences.
**Family:** Care plans are often unrealistic
**Individual:** Provider interactions sometimes lack compassion and empathy

**Guardian-generated solutions**

- Enhanced coordinated communication
- Increase use of telehealth and patient portals to improve communication and care
- Peer support groups
- Collaboration with guardians on care plans to ensure feasibility and sustainability
- Direct interaction with the child

### Discussion

- Telemedicine visits and easily accessible patient portals help bridge long geographic distances
- Peer support groups are desired but can be difficult to organize in rural areas
- Speaking directly to the child, even when there are communication barriers, is highly valued

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## Care communication is fragmented

- *"That communication piece just can be super challenging. Whenever she has to go outside the network to get care, that communication back and making sure everyone has the records takes a lot of our time to have to make sure everyone knows what they need to know when they need to know it."*
- **Family generated solutions:** Gather information from other providers and health systems in advance of office visits and include parents in communication with these other providers.
- *"I would expect that over time that we'll continue to refine those efforts, so that providers are communicating with each other that way and parents like myself are immediately in that loop. You know [with a] cc on an email, for example, you're understanding kind of what's going on."*



## Families face logistical barriers to getting to appointments

- *"Sometimes they want to see her more often than we're able to get her down there just because it's a big deal to get her ready, get her in a wheelchair, get the ramp out, get her out. During the winter we had a really hard time getting her from the house into the van and then travelling with her because it was cold outside."*
- **Family generated solutions: Utilize technology solutions such as telehealth and patient portal**
- *"We actually were able to just do the telehealth visit from our home which obviously was a lot easier. And I feel like those appointments work out great when you have a child with a lot of medical needs and it's not an easy process to pack them up and bring them to an office visit."*

## Families feel isolated

- *"I've been on this journey of being a special needs parent for a while. It's still difficult to navigate and to know what resources are out there." "I live more rural, there's nobody around me that has a child like mine."*
- **Family generated solutions: Create peer support groups where families can get help in person from people with similar experiences**
- *"I think one thing that would benefit families is having some type of like, support group of other family members who maybe have gone through similar circumstances."*



## Home care plans are unrealistic

- *"From the provider side, it's like, oh, well try these five things. But I don't think that folks have a real picture of what it's like to wake up and go to bed, to live through a day with a medically complex child. So those five things are really great, but three of them are likely unsustainable."*
- **Family generated solutions: Collaborate with families on care plans and incorporate their input**
- *"My daughter has had lab draws every 3 months. Well, we know at this point that it [her condition] is very well regulated. And so, you know, we kind of pushed back and said: can we have lab draws every 6 months?... And if so, maybe her buy in is going to be a little bit higher."*

## Child not treated respectfully/valued

- *"I think sometimes physicians forget that children are a lot smarter than they might perceive and they hear [and] they're like sponges. There have been conversations that were not so good about being like, Okay, is it time to bring her in and get her opinion, get her insight? This is happening to her."*
- **Family generated solutions: Interact directly with the child at every encounter**
- *"Speaking directly to my child, getting down on my child's level, my child was non-verbal. But we always expect our providers to presume competence and assume that my child, although she may not be able to answer back in a typical way, that she's understanding to some degree what's being told to her and experienced by her."*



## And so, to our program

- Our definition of eligible CMC:

Pediatric patients under the long-term care of 3 or more pediatric subspecialists, and/or living with medical equipment (such as G-tubes, NG-tubes, tracheostomy, etc.).

## Medical home vs consult service

- Geography of catchment area makes the decision for you
- Los Angeles: “Complex Care is the PCP, of course!”
- Salt Lake City: “We have patients from 3 states, they need their local PCPs. We’re consultants, using a mix of telehealth and families making long drives to see us.”



## Program goals

- Reduce ER visits
- Prevent or shorten hospitalizations
- Identify opportunities for more efficient or convenient provision of care
- Ensure that the family accesses all social, community, and medical support services to which they are entitled
- Meet each family’s goals to have a more satisfying life experience

Credit: program summary prepared by Elizabeth Murphy

# Program growth

- 1st inpatient consult 8/9/23
- 1st outpatient appointment 10/12/23
- Steady growth in both inpatient and outpatient volume
- 180 patients enrolled so far, total eligible in our service area is about 700
- Consults are coming from both inside and outside MaineHealth and from all over the state, ranging from Caribou to Kittery



# Services

- Create and regularly update a comprehensive summary of care/care plan for family and all care providers **(embedded in our consult/progress notes)**
- Assist with coordination of medical services including telephone triage available during regular business hours
- Partner/coordinate care with other facilities and programs such as different specialties or transitions between BBCH and Boston Children's Hospital
- Provide extra support during inpatient care and the care transition from inpatient to outpatient
- Provide nutrition management of tube feeding **(including pager access for nights, weekends, and holidays)**
- Identify sources of social support and community resources and assist with access
- Guide the transition from pediatric to adult care **(aspirational goal)**

# Team

**Elizabeth Murphy, Program Manager**
- Administrative guidance
- Program publicity and outreach
- Staff recruitment

**Logan Murray, MD – Co-Medical Director**
- Inpatient consults
- Ambulatory visits

**Amanda Payne, NP – APP – Co-Medical Director**
- Triage, care coordination
- Ambulatory visits

**Emily Sweeney, NP - APP**
- Triage, care coordination
- Ambulatory visits
- Inpatient rounding and support

**Jessica Rock, RN Manager**
- Triage, care coordination, rooming
- Recruitment and training of new staff
- Management of practice

**Robin Austin, RN Navigator**
- Triage, care coordination, rooming

**Kelly Falone, RD**
- Nutritional and feeding consultation
- Consultation for failure to thrive while eating by mouth
- Nutrition management of tube feedings
- Management of ketogenic diets

**Dana Orkin, RN (part of BBCH Nursing team)**
- Inpatient coordination
- Liaison with ambulatory team



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## Some recent cases we've had



## Multidisciplinary collaboration - SLP

- 13-month-old ex-23-week premature infant, meeting growth goals on 100% G-tube feeds
- Needs Modified Barium Swallow with Speech for clearance for liquids by mouth, scheduled in 1 month
- Problem: Taking nothing by mouth and refusing purees
- Strategy: Contacted SLP for additional recommendations:
  - Messy food play rather than offering with spoon
  - Provide hard solids he can gnaw on but not break off
  - Check in with family 1 week before study and reschedule if no interval progress

## Multidisciplinary collaboration – Community Case Mgr.

- 3-year-old new Mainer with CP, developmental delay, and seizure disorder living in motel
- Problem: Even when we could arrange transportation to ambulatory visits, family doesn't follow through
- Strategy: RN Manager arranged meeting with family and Community Case Manager at their home where they processed applications for specialized resources (Glickman Lauder Center), case worker attends ambulatory appointments, Complex Care has liaised with cultural broker as well



## Multidisciplinary collaboration – PCP & pediatric specialists

- 7-year-old ex-24-week with CP, seizure disorder, asthma, and chronic kidney disease
- Problem: Lives in NH, family with limited resources, misses follow-up appointments. This leads to preventable inpatient admissions
- Strategy: RN Manager coordinated with PCP and MaineHealth pediatric specialists so that patient could be seen by complex care, neurology, orthopedics, pulmonology, gastroenterology, and nephrology over 2 days

## Multidisciplinary collaboration – Palliative Care (PACT)

- Monthly standing meetings to discuss shared patients
- Cross-pollination of ideas and strategies



## Multidisciplinary collaboration - PCP

- 5-month-old with recent diagnosis of a mitochondrial metabolic disorder
- Complex Care RN triage line received call from parents 2 days after hospital discharge describing lethargy and poor feeding. RN recommended evaluation at PCP office
- Infant seen by local PCP (over 1.5 hours from Complex Care practice)
- PCP called after-hours pager to discuss with Complex Care physician to close the loop with advice to family and plans for upcoming weekend

# Current and future challenges



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# Major challenges – strict requirements to qualify for block nursing (MaineCare Benefits Manual Section 96)

A. **Level I**

A Member meets the medical eligibility requirements for Level I if he or she requires:

1. cuing 7 days per week for eating, toilet use, bathing, and dressing; **or**
2. limited assistance and a 1 person physical assist with at least 2 ADLs; **or**
3. limited assistance and a one person physical assist with at least 1 ADL plus physical assistance with at least 2 IADLs; **or**
4. any of the following nursing services, at least once per month, that are or otherwise would be performed by or under the supervision of a registered professional nurse:
   a. intraarterial, intravenous, intramuscular, or subcutaneous injection, or intravenous feeding, for treatment of unstable conditions requiring medical or nursing intervention; other than daily insulin injections for an individual whose diabetes is under control;
   b. nasogastric tube, gastrostomy, or jejunostomy feeding, for a new/recent (within past 30 days) or unstable condition;
   c. nasopharyngeal suctioning or tracheostomy care; however, care of a tracheostomy tube must be for a recent (within the last 30 days) or unstable condition;
   d. treatment and/or application of dressings when the physician has prescribed irrigation, the application of prescribed medication, or sterile dressings of stage III and IV decubitus ulcers, other widespread skin disorders (except psoriasis and eczema), or care of wounds, when the skills of a registered nurse are needed to provide safe and effective services (including, but not limited to, ulcers, 2nd or 3rd degree burns, open surgical sites, fistulas, tube sites, and tumor erosions);



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## Major challenges – lack of availability of block nurses

- Geographic limitations
- Certain placements are less favored by nurses



## Maine Paid Family Caregiving

- House Bill LD 346 required the Department of Health & Human Services to apply by July 1, 2024 to the Centers for Medicare & Medicaid Services (CMS) for a state plan amendment (SPA) to allow a parent of a child who is eligible for home health aide services under the MaineCare program to receive reimbursement for providing home health aide services to the child if they are a CNA.
- CMS responded that SPA not needed because MaineCare Benefits Manual Section 40 already permits this
- But there are challenges!

## Section 40 challenges

- MaineCare has informed Home care companies (Section 40 providers) in January 2025 that they can start hiring parents who are CNAs to be home care providers
- To date, no Section 40 providers have signed up to facilitate this routinely. 1 home care company has agreed to pilot with 2 families



## Advice from a Maine mother of child with medical complexity/advocate

- "Partner with families to recognize the faults of the current system and to break through them to enhance the strengths that each family has. Creating conditions that support these kids will support all kids. By investing in the well-being of kids and families, we're investing in the future."

  - Andrea Brooks Dole, 3/25/25

# Questions?



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