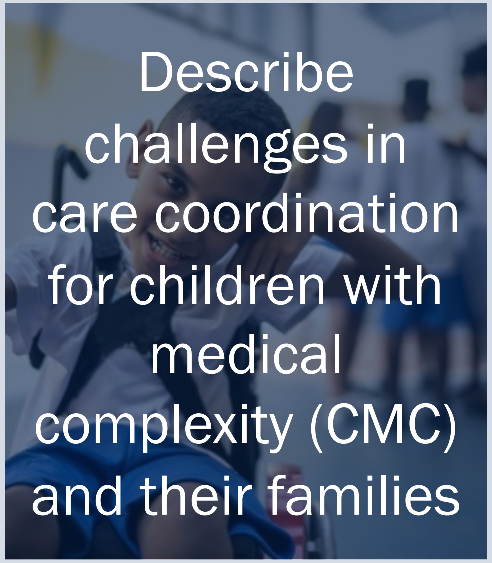
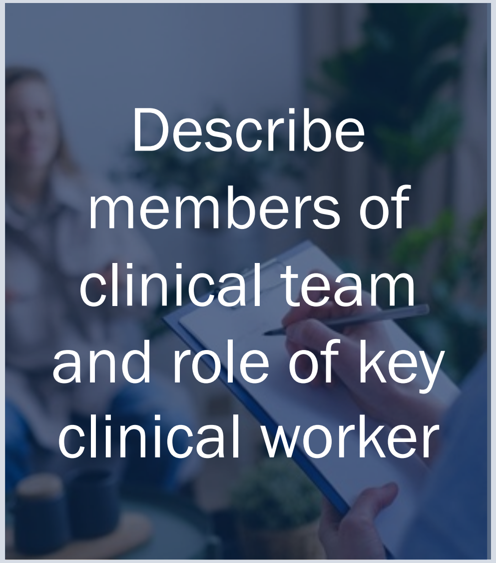
Care Coordination and Care Plans

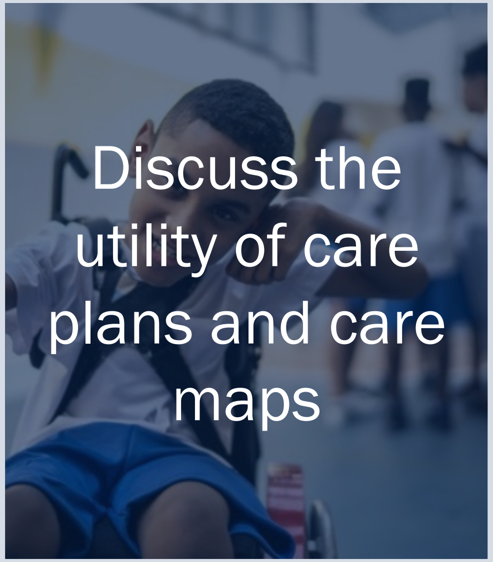
Michelle Ho, NP - Paeds

Sherri Adams, NP - Paeds

Learning Objectives


Describe challenges in care coordination for children with medical complexity (CMC) and their families


Describe members of clinical team and role of key clinical worker


Discuss the utility of care plans and care maps


Review an approach to transition to adult care for CMC

Children with Medical Complexity (CMC): A Definitional Framework

HEALTH CARE USE

- High resource utilization
- Necessitating involvement of multiple service providers

FUNCTIONAL LIMITATIONS

- Severe
- Often associated with technology dependence

NEEDS

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

CHRONIC CONDITION(S)

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

Cohen, E. et al., Pediatrics 2011

Children with Medical Complexity

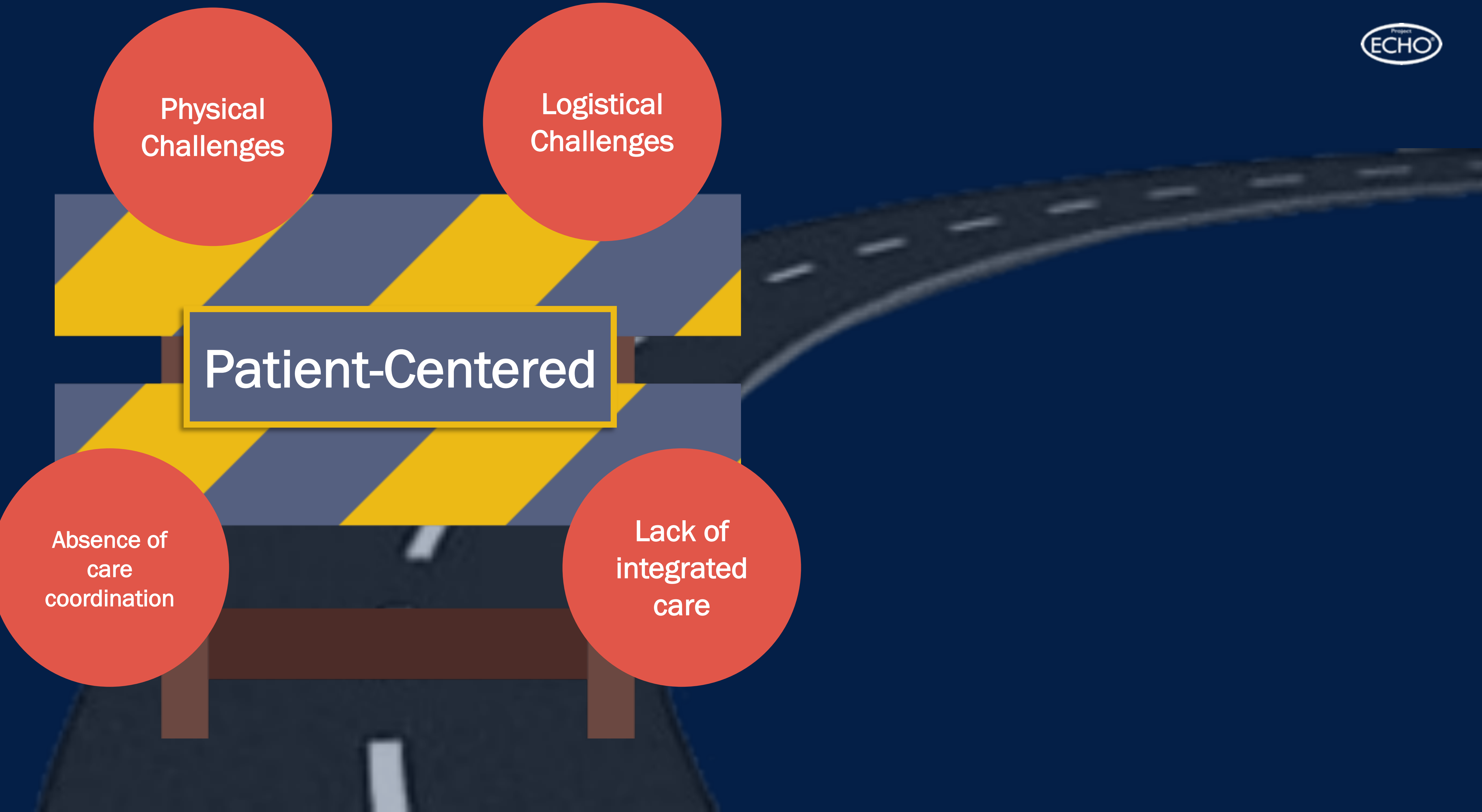
Improved health care coordination models help CMC and their families:

- Get the care that they need
- Reduce the opportunity for health care error
- Improves their care experience

BARRIERS

BARRIERS

- Patient-centered barriers
- Family-centered barriers
- Barriers related to the health-care system



Physical Challenges

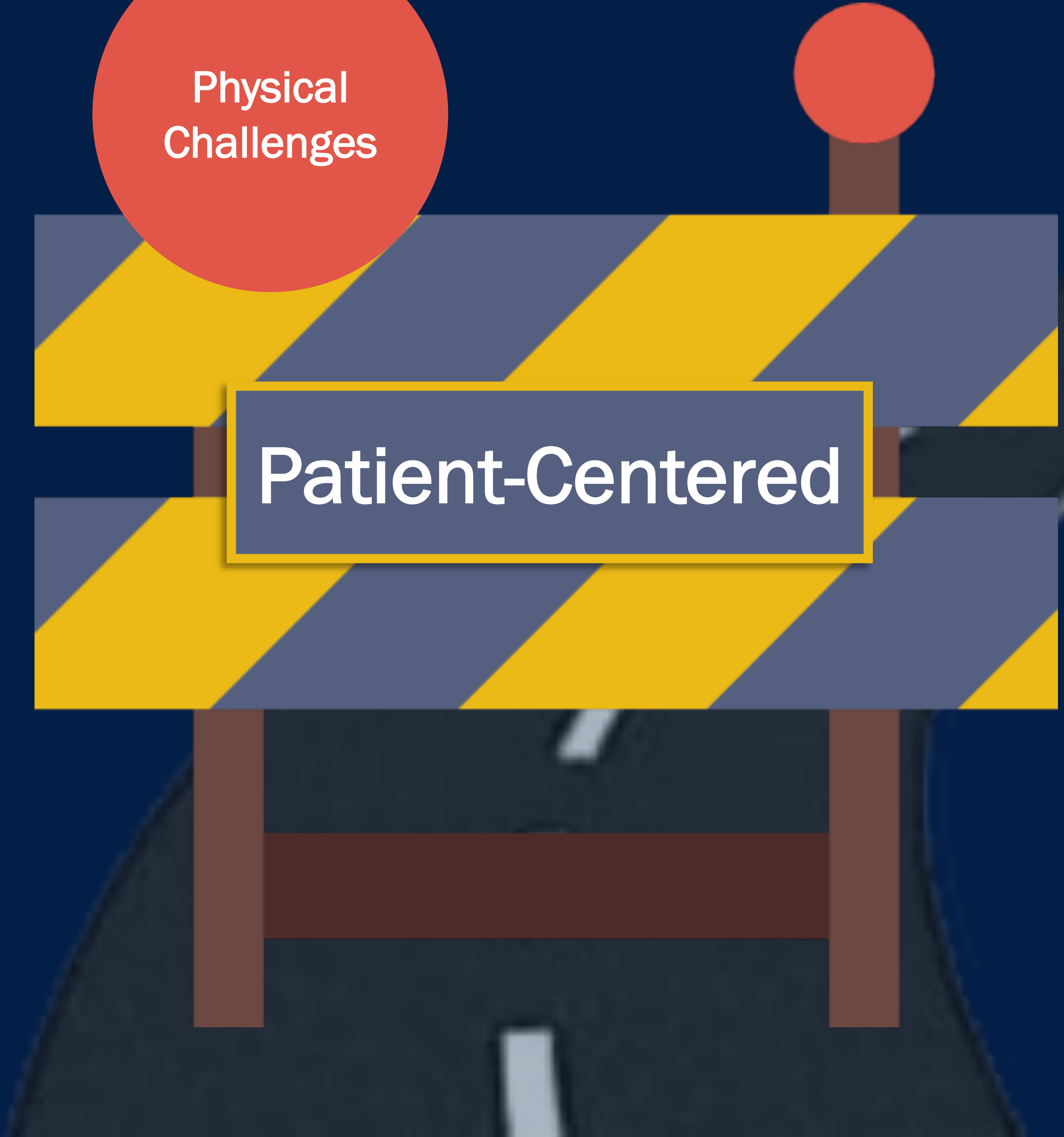
Logistical Challenges

Patient-Centered

Absence of care coordination

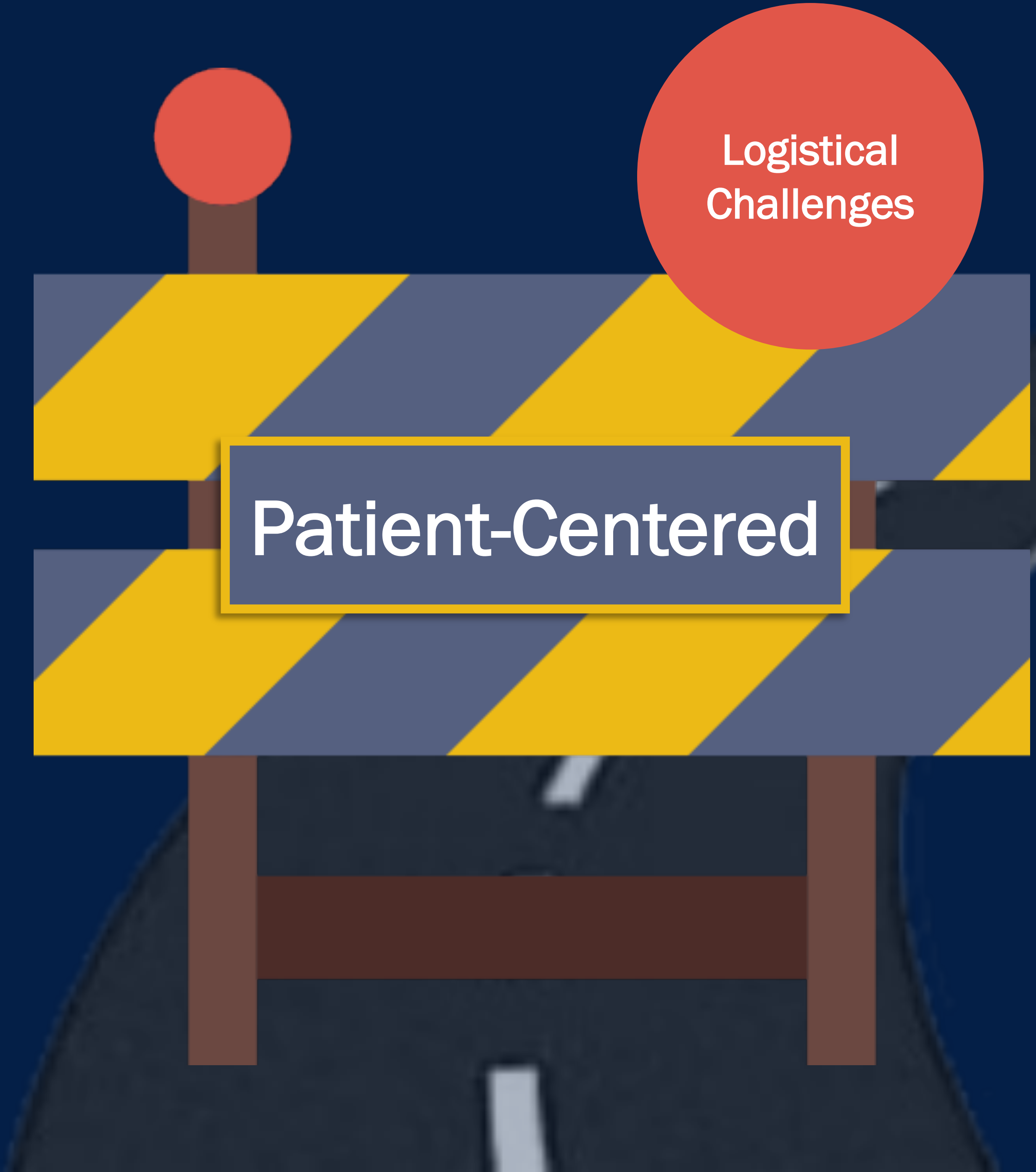
Lack of integrated care

Physical Challenges



Patient-Centered

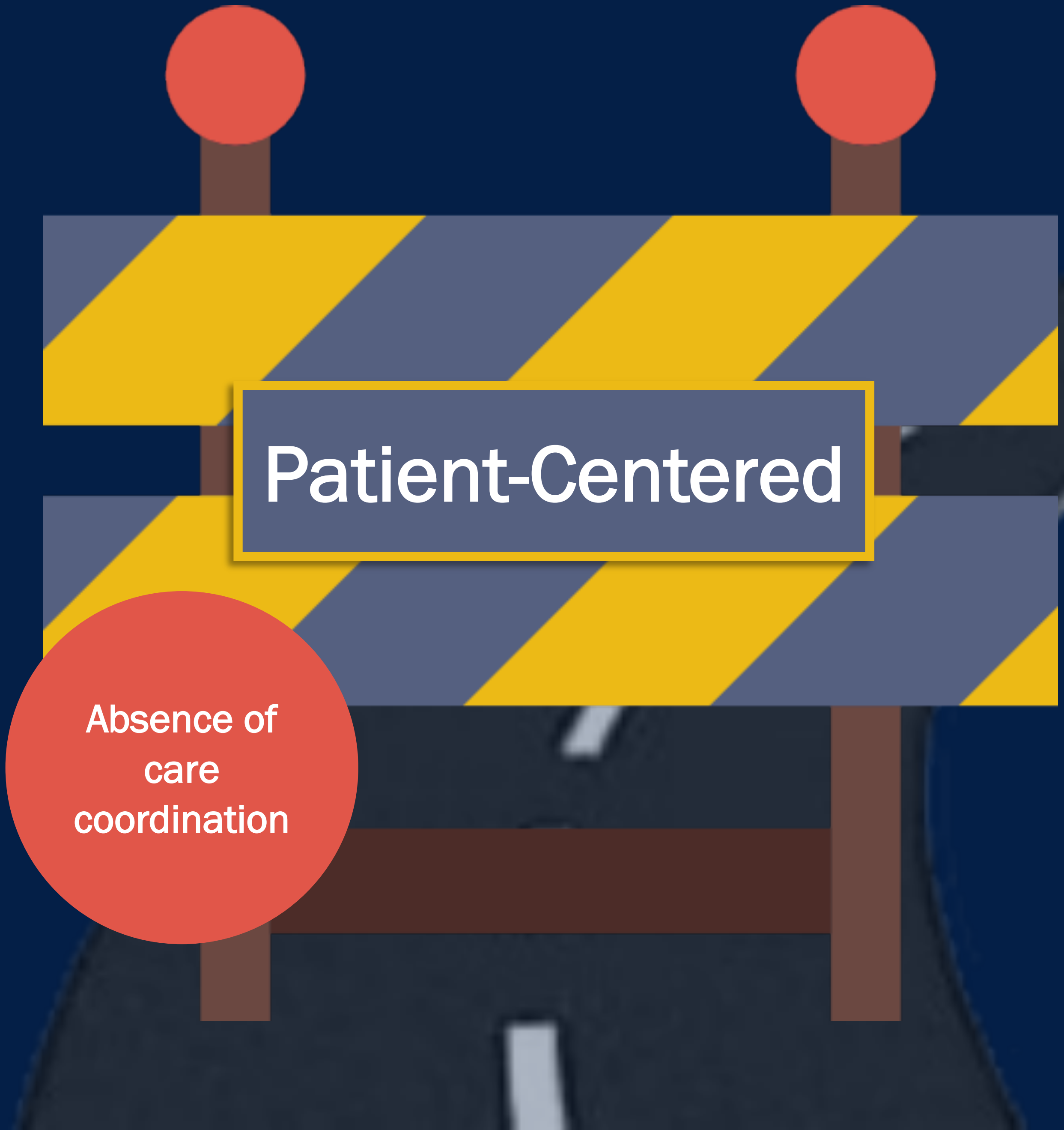
- Medical equipment
- Accessibility



Logistical Challenges

Patient-Centered

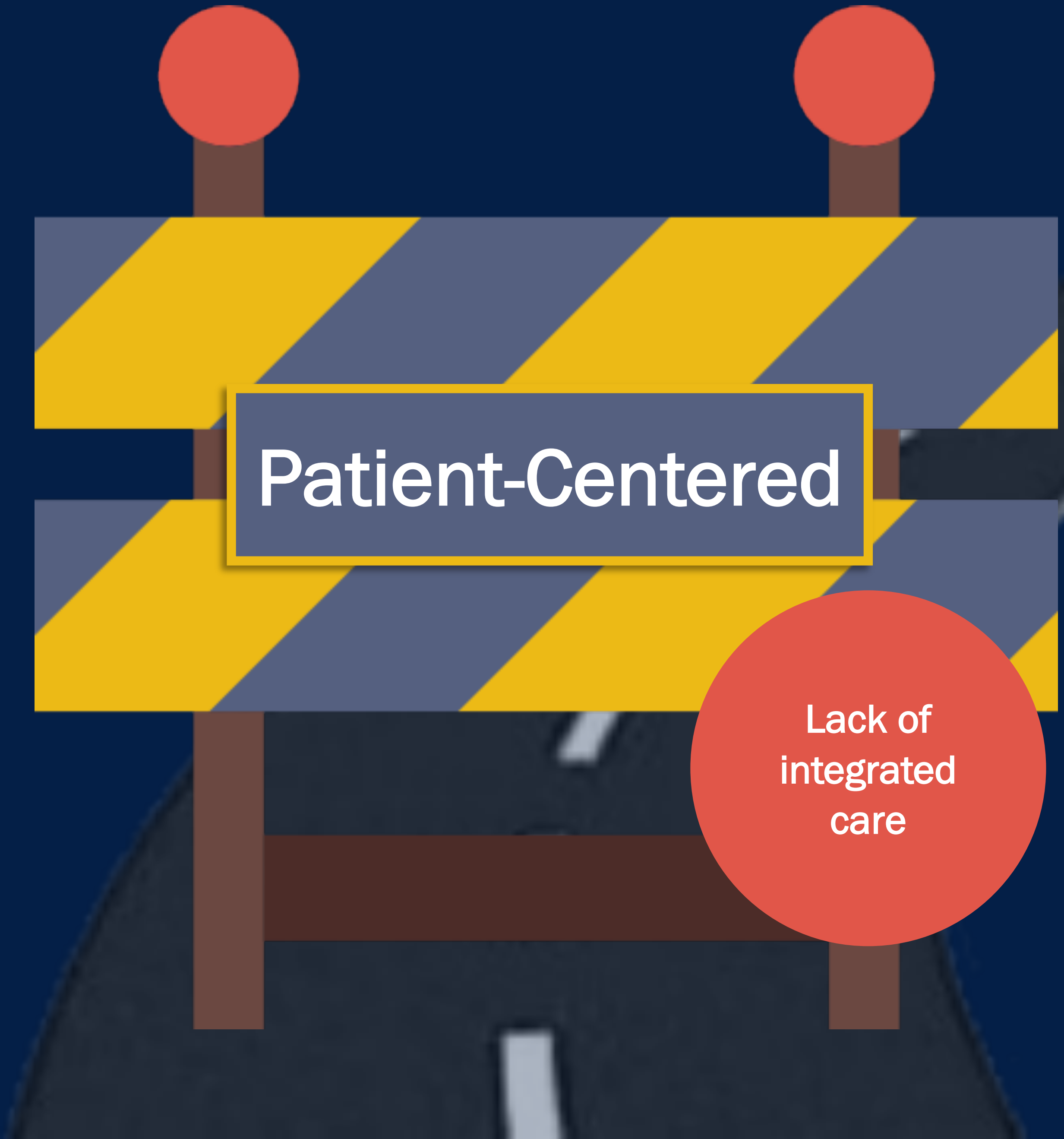
- Travel to appointments
- Interruptions to provide care
- Vehicle to support safe transportation
- Constant visualization of the child, may require another adult



Patient-Centered

Absence of care coordination

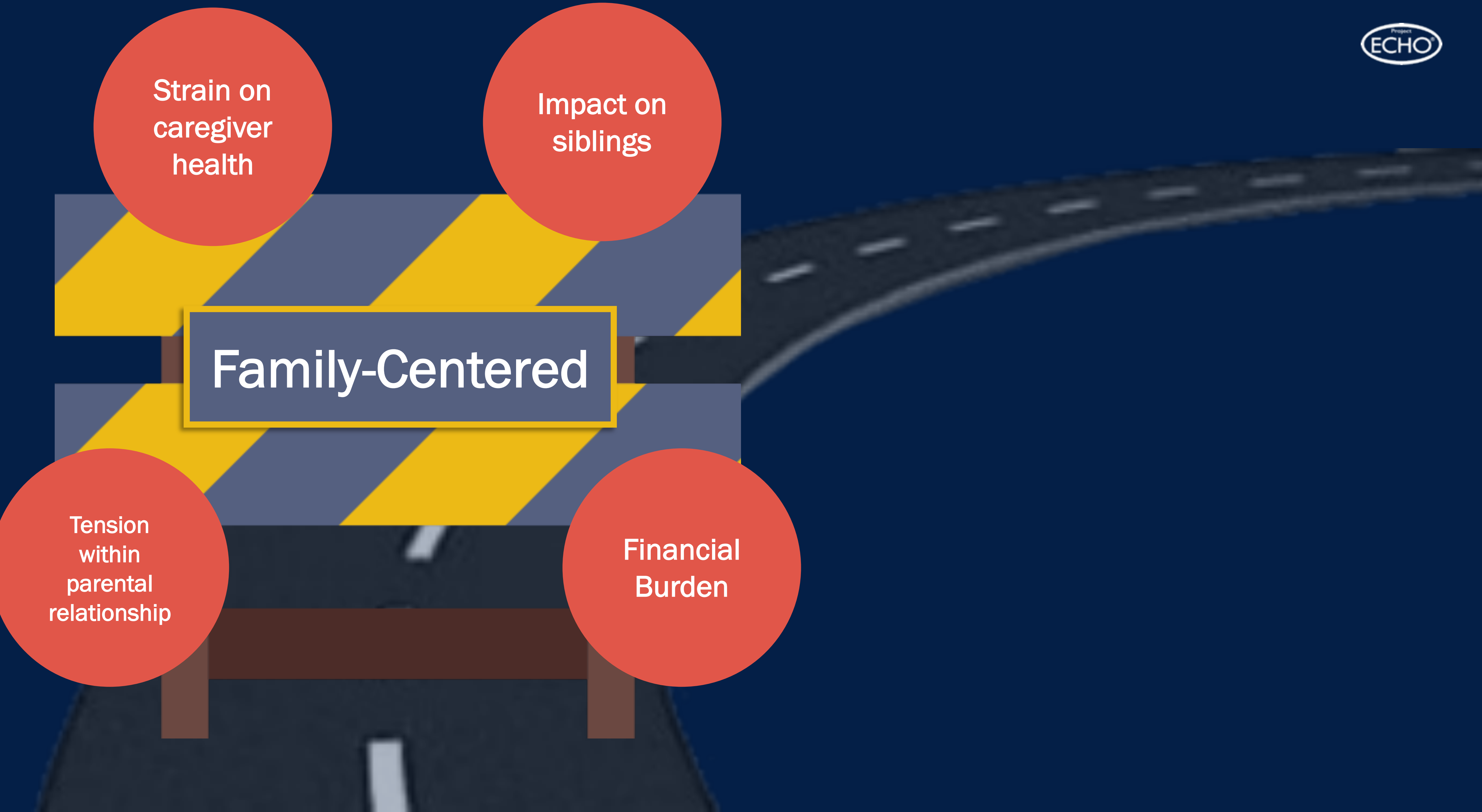
- Lack of streamlined goals of care
- Poor communication between providers and teams
- Multiple appointments



Patient-Centered

Lack of integrated care

Between primary care, tertiary care, home care, and community-based settings.



Family-Centered

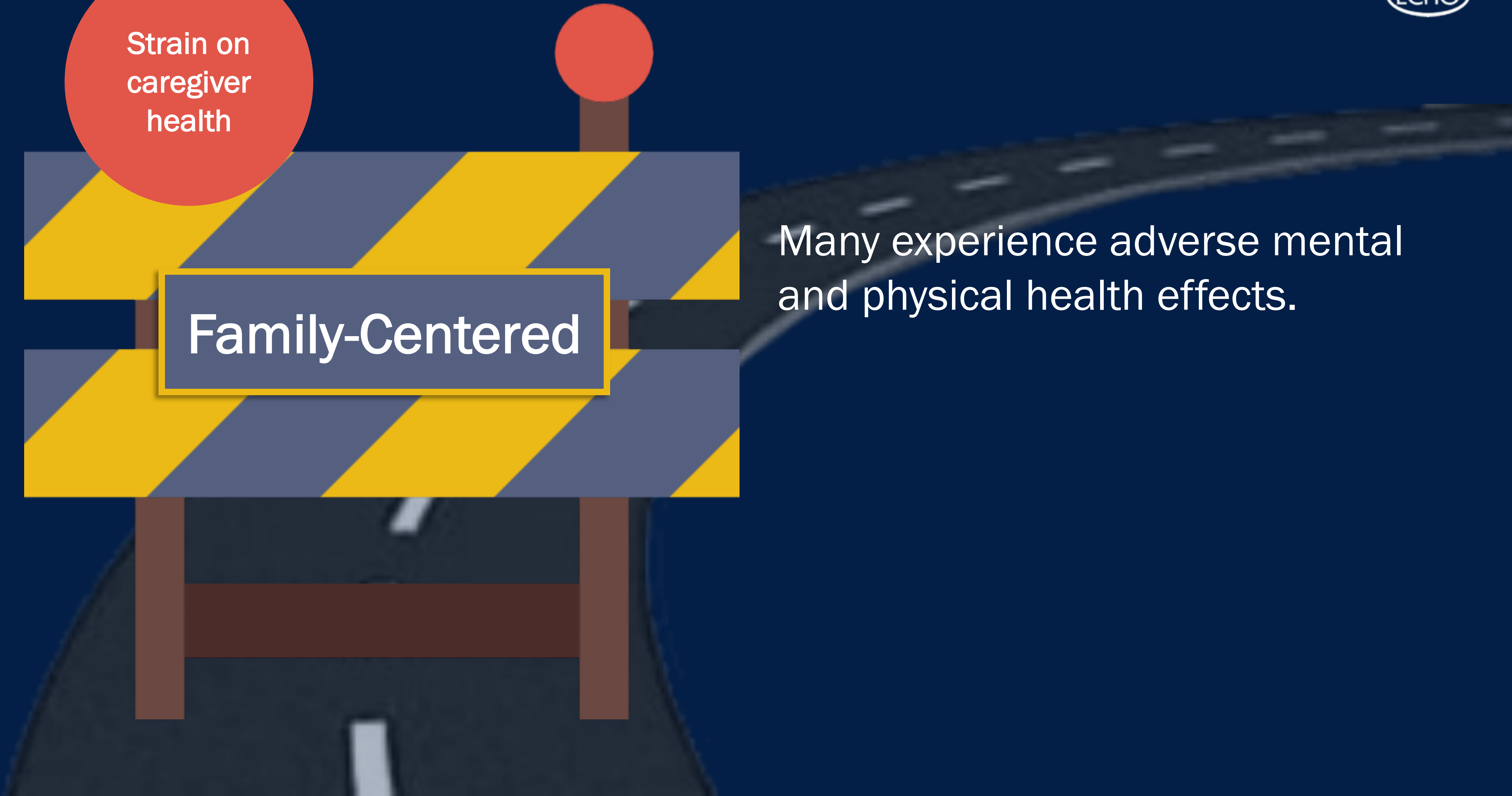
Strain on caregiver health

Impact on siblings

Tension within parental relationship

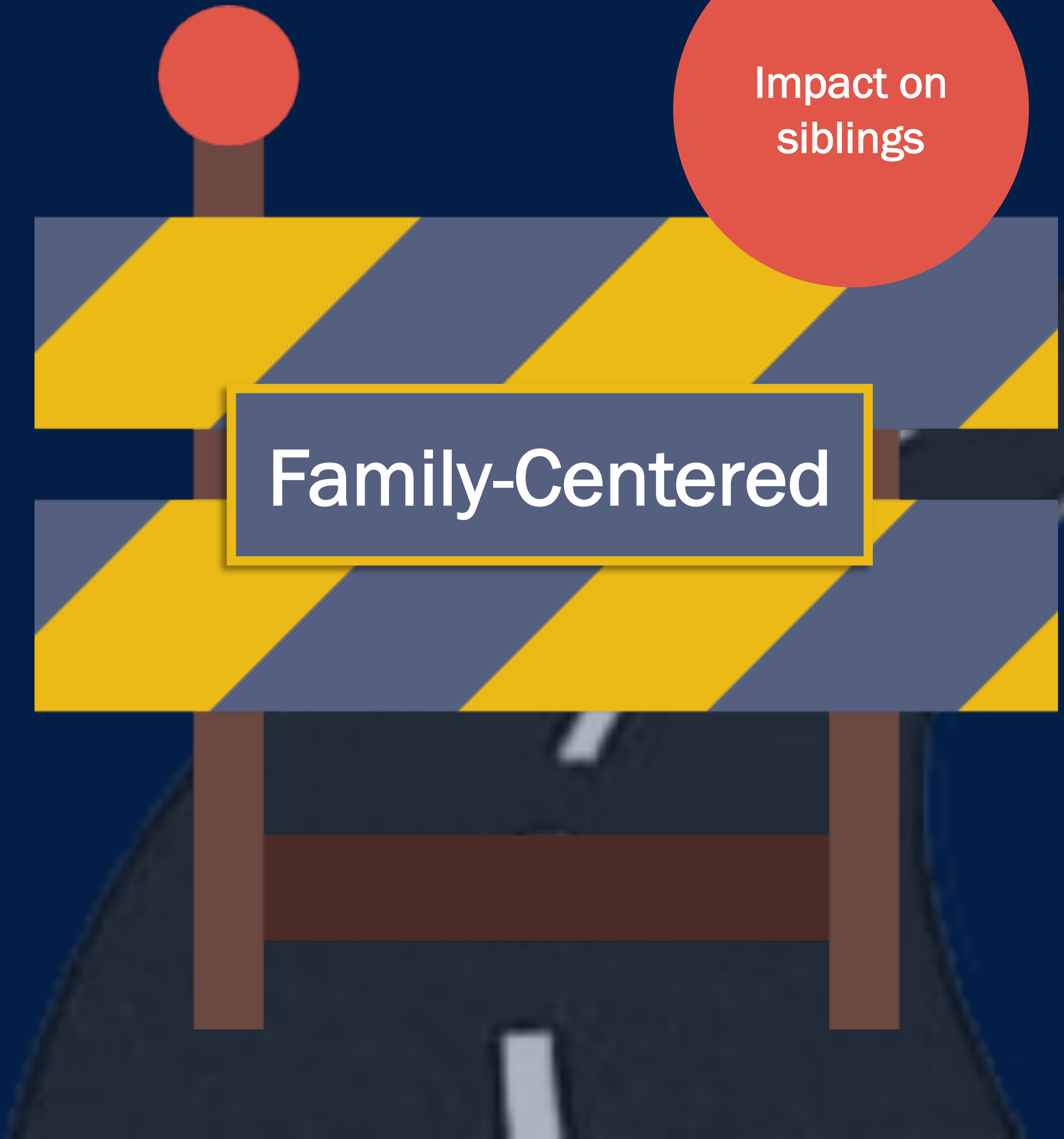
Financial Burden

Strain on caregiver health



Family-Centered

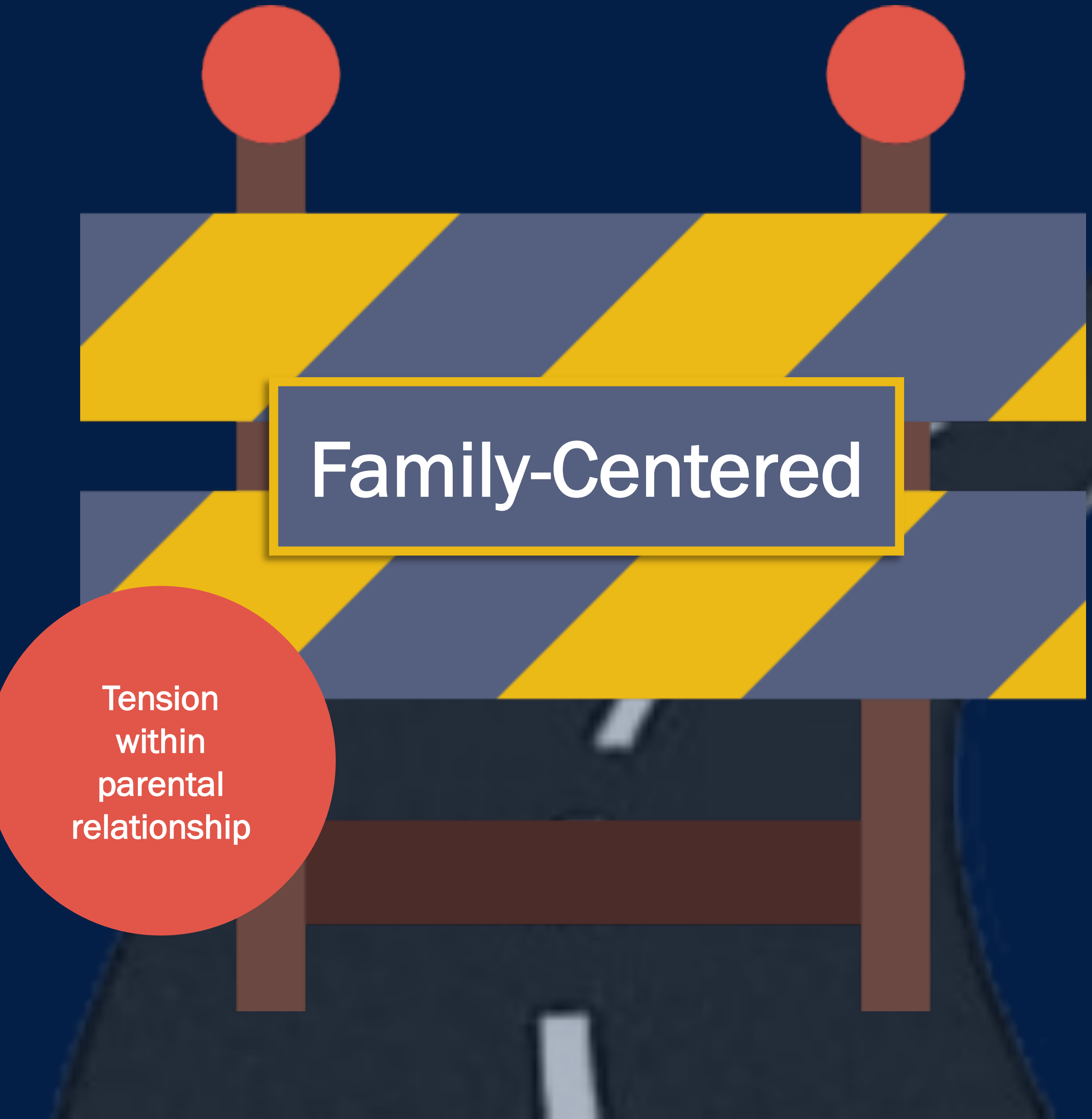
Many experience adverse mental and physical health effects.



Family-Centered

Impact on siblings

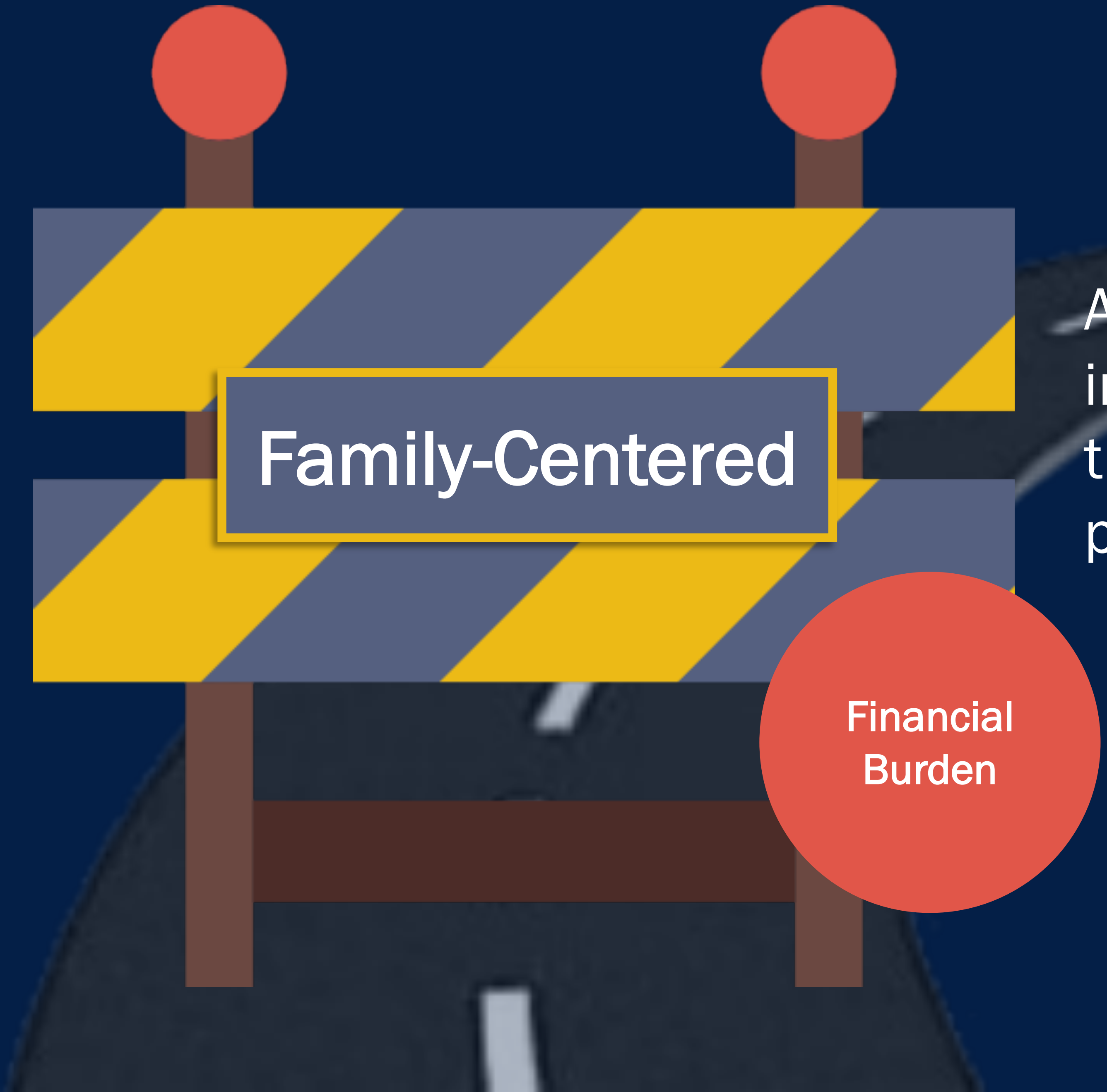
Increased absenteeism from school, reduced participation in extracurricular activities, behavioural issues, and an unpredictable daily routine.



Family-Centered

Tension within parental relationship

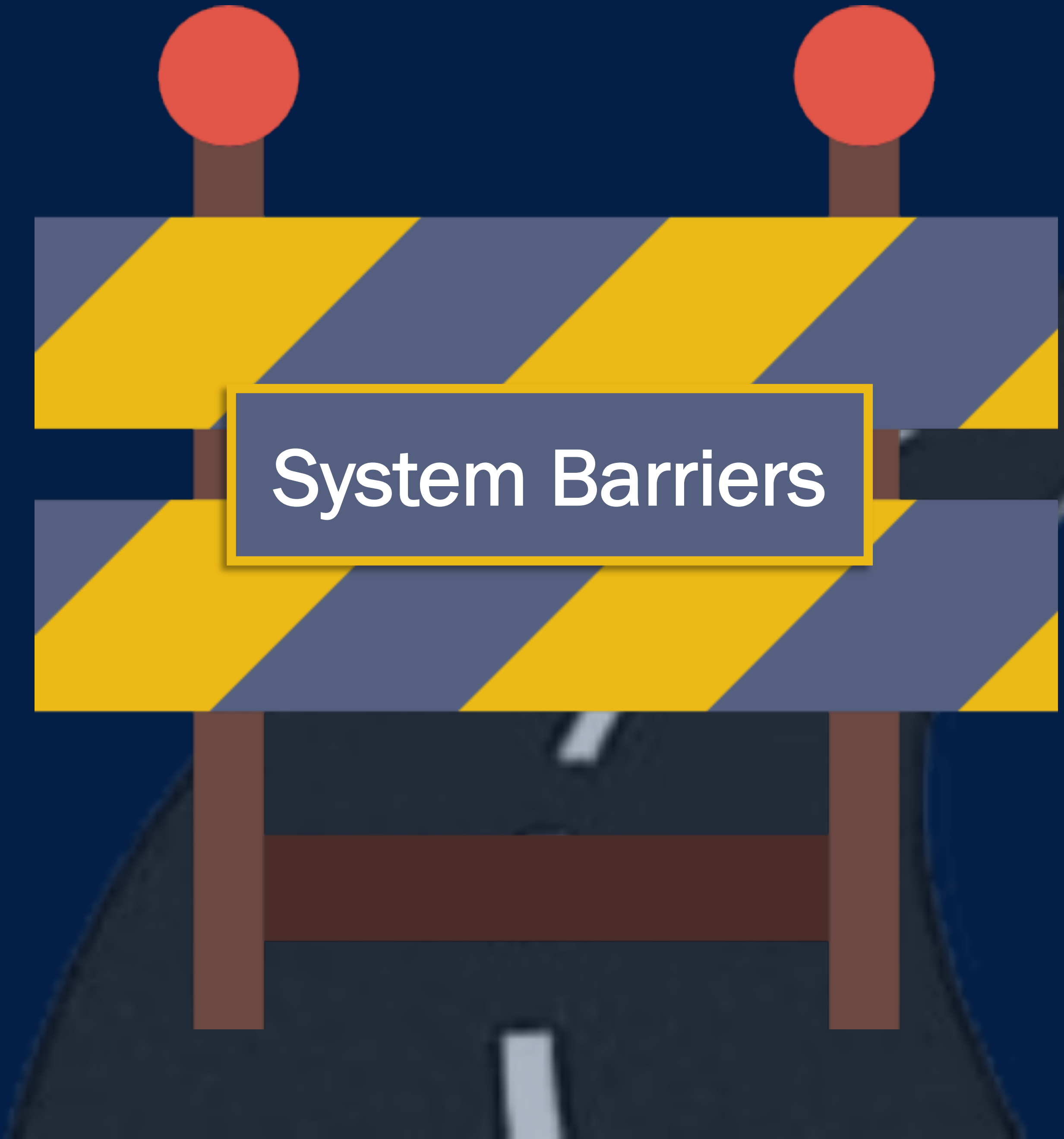
Stresses and worries,, advocating for their child, financial concerns, and caring for other siblings can place strain on the relationship.



Family-Centered

Financial Burden

Additional costs and reduced income as parents may change their working arrangements to provide care for their child.



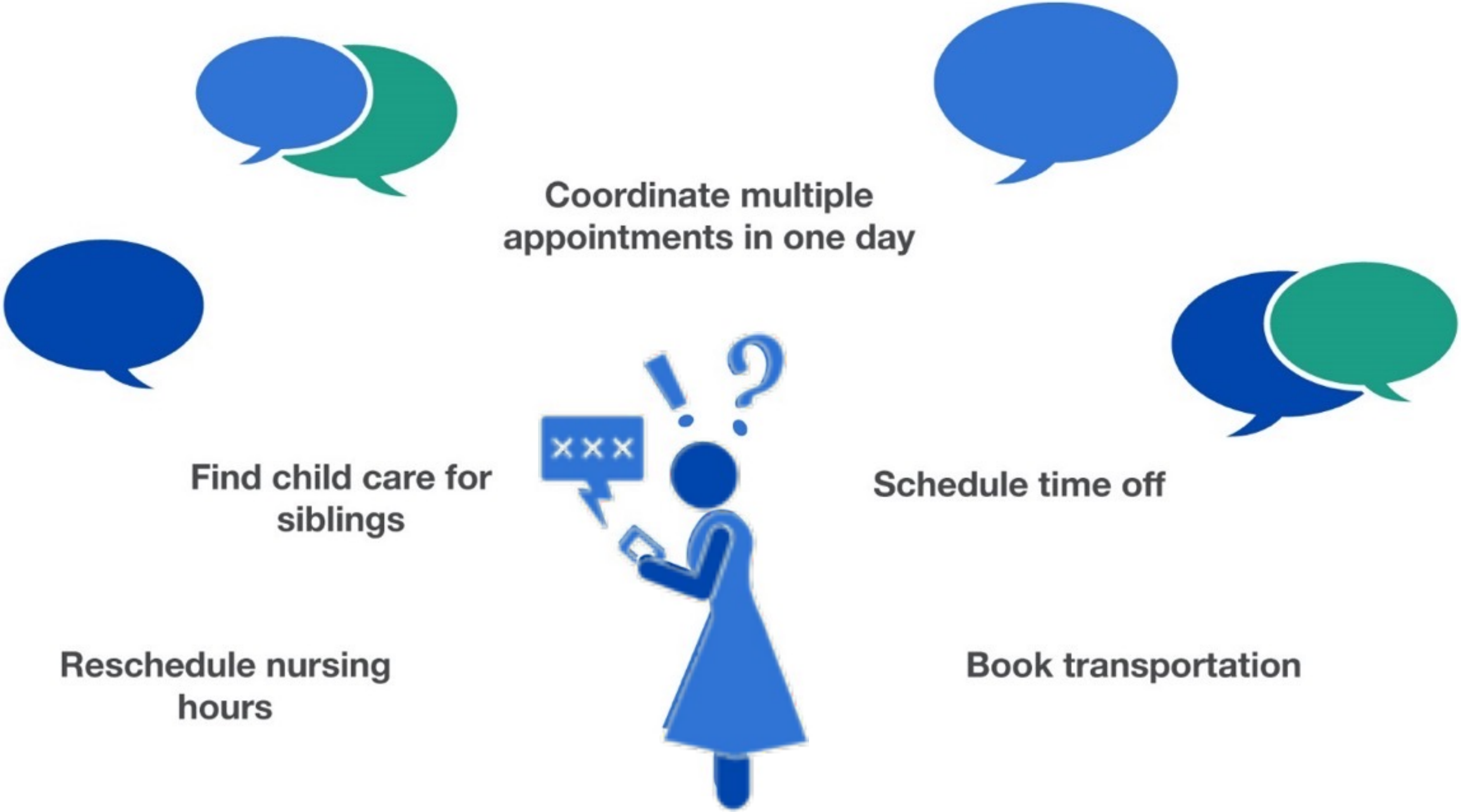
System Barriers

- Lack of communication and integrated programs.
- Lack of family-centred care and partnership.
- Lack of communication between different professionals.
- Limited funding for Complex Care programs.
- Lack of transition programs from paediatric to adult care.

- Scheduling Clinic Appts.
- Travel & Parking
- Registration & Check-in
- Waiting Room
- Multiple Care Provider Appts
- Investigations
- Travel Home

A Family's Journey through a Hospital Visit

Source: Kids Health Alliance



Coordinate multiple appointments in one day

Find child care for siblings

Schedule time off

Reschedule nursing hours

Book transportation

A Family’s Journey through a Hospital Visit

Scheduling Clinic Appts.

Travel & Parking

Registration & Check-in

Waiting Room

Multiple Care Provider Appts

Investigations

Travel Home

Source: Kids Health Alliance

Ensure all bags and equipment are packed in the car

Appointment times too early for out-of-town patients

Long commutes; must stop for suctioning

High cost of parking

Lack of accessible parking spots

A Family’s Journey through a Hospital Visit

Scheduling Clinic Appts.

Travel & Parking

Registration & Check-in

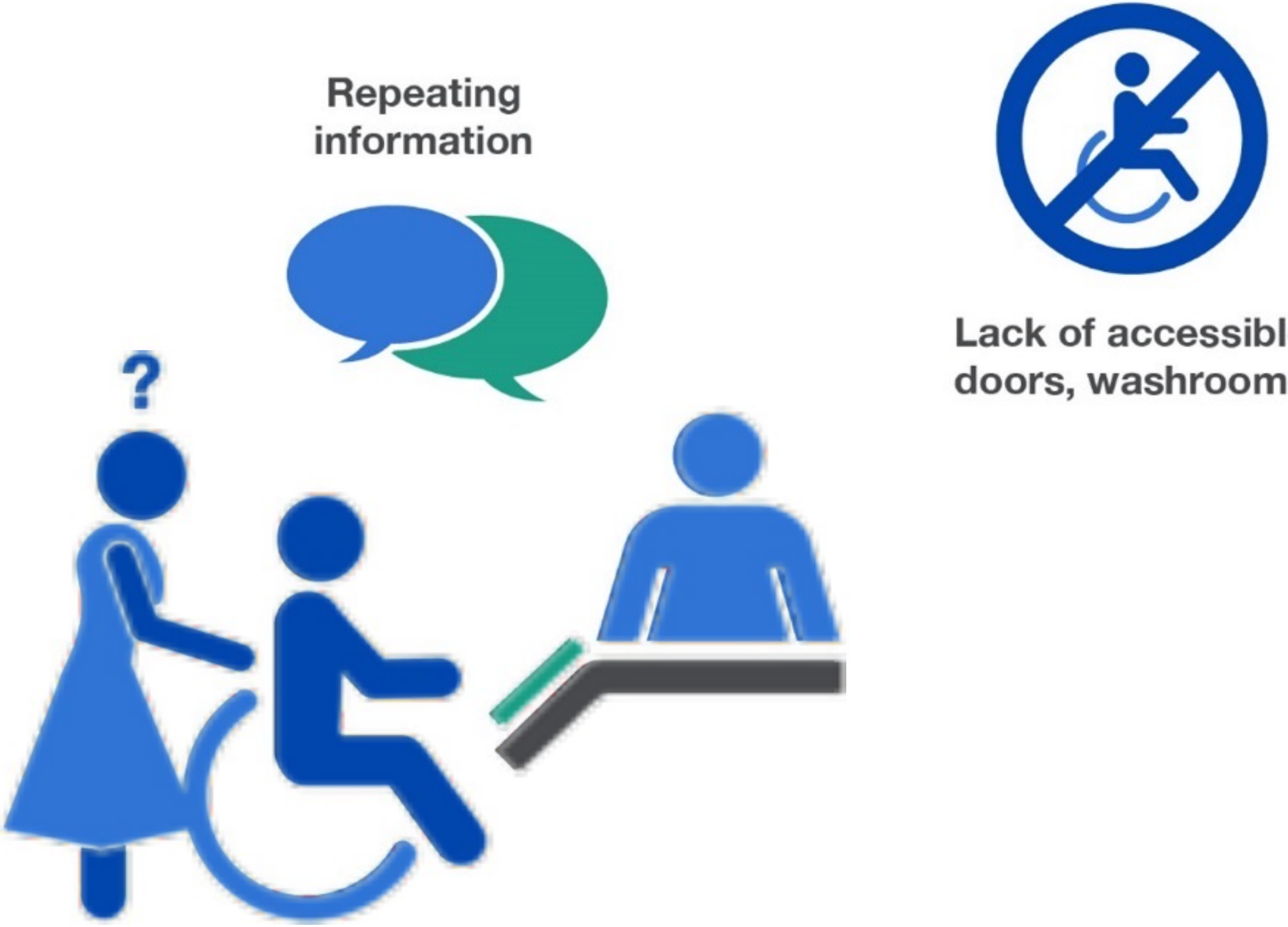
Waiting Room

Multiple Care Provider Appts

Investigations

Travel Home

Source: Kids Health Alliance



Repeating information

Lack of accessible doors, washrooms

Difficulty finding clinic location

A Family’s Journey through a Hospital Visit

Scheduling Clinic Appts.

Travel & Parking

Registration & Check-in

Waiting Room

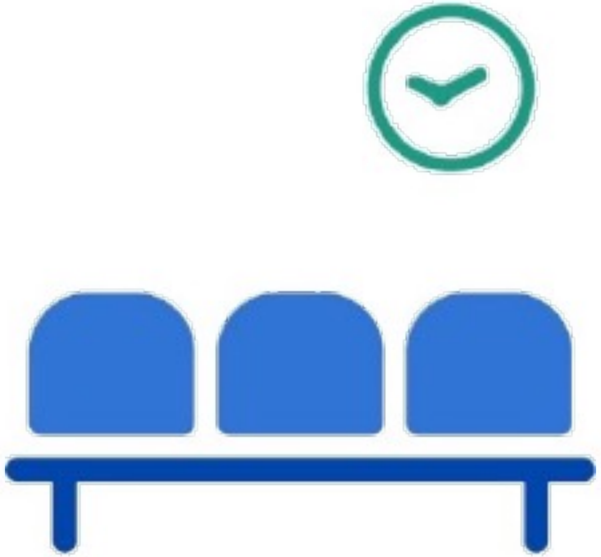
Multiple Care Provider Appts

Investigations

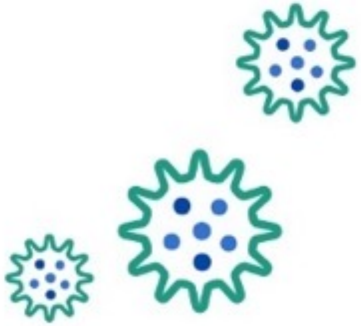
Travel Home

Source: Kids Health Alliance

Long wait



Exposure to illness and infection



Agitation from multiple stimuli

Lack of accessible space

A Family’s Journey through a Hospital Visit

Scheduling Clinic Appts.

Travel & Parking

Registration & Check-in

Waiting Room

Multiple Care Provider Appts

Investigations

Travel Home

Source: Kids Health Alliance

Waiting for doctors or specialists to arrive

Unprepared students

Repeating the story to multiple providers

A Family's Journey through a Hospital Visit

Scheduling Clinic Appts.

Travel & Parking

Registration & Check-in

Waiting Room

Multiple Care Provider Appts

Investigations

Travel Home

Anxious about results

Long wait

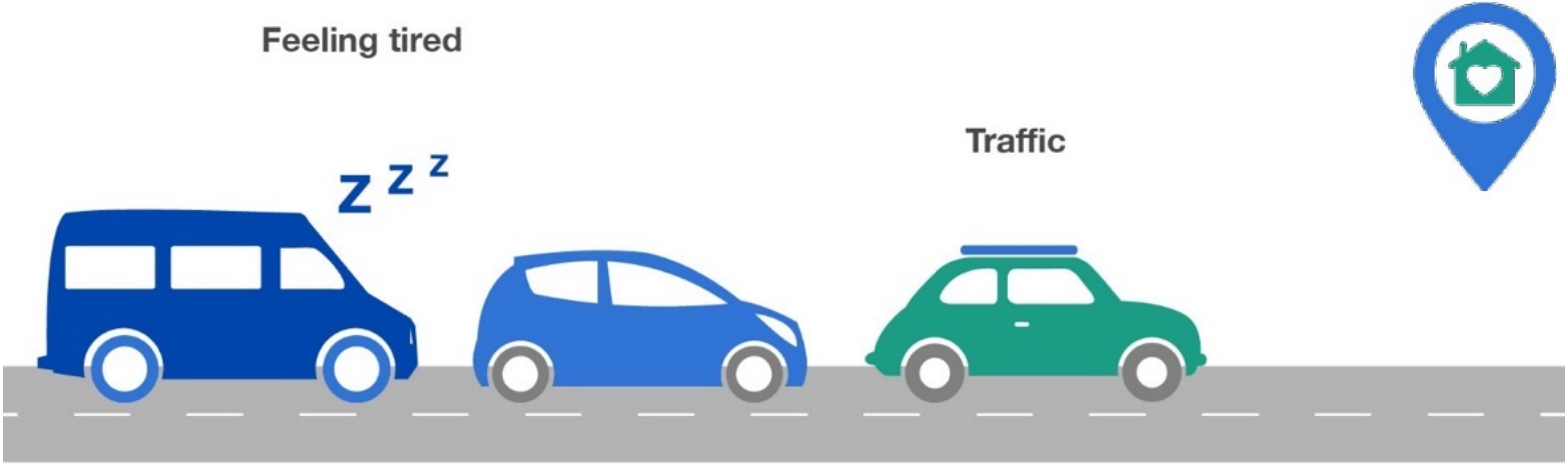
Confusion with requisitions

Issues with rescheduling appointments

A Family's Journey through a Hospital Visit

- Scheduling Clinic Appts.
- Travel & Parking
- Registration & Check-in
- Waiting Room
- Multiple Care Provider Appts
- Investigations
- Travel Home

Source: Kids Health Alliance



Feeling tired

Traffic

A Family's Journey through a Hospital Visit

Scheduling Clinic Appts.

Travel & Parking

Registration & Check-in

Waiting Room

Multiple Care Provider Appts

Investigations

Travel Home

Source: Kids Health Alliance

What are the objectives of a Complex Care program?

Complex Care Program

- INTEGRATED CARE
- COORDINATE CARE
- FACILITATE COMMUNICATION
- DELIVER PROACTIVE CARE
- ADVOCATE FOR CHILDREN AND FAMILIES
- DEVELOP CLEAR GOALS OF CARE
- SUPPORT HOLISTIC CARE FOR THE WHOLE FAMILY

CCKO Functions of a Complex Care Clinic and Program Standard

INTEGRATED CARE

Contrast to
“fragmented,
episodic care”

Coordinated
across team,
organizations,
systems

Encompasses
unique child and
family needs and
preferences

COORDINATE CARE

Led by key clinical worker

Partnership with child and family

FACILITATE COMMUNICATION

Key worker facilitates access and communication

Complex Care Plan

DELIVER PROACTIVE CARE

Active identification of potential concerns and determining activities that will reduce the incidence or severity of the 'potential problem'

Screening, early intervention

ADOVCATE FOR CHILDREN AND FAMILIES

Empower and support children and families over time, fostering their strengths without creating dependence.

Promote building capacity within the child/youth and family, and community teams

DEVELOP GOALS OF CARE WITH THE CHILD AND FAMILY

Determining a child and family's overarching goals allows the health-care team to help meet these goals.

SUPPORT HOLISTIC CARE FOR THE WHOLE FAMILY

Understand the child/youth and family structure and current services in place as well as the strengths and needs of each child/youth and their family.

Who are members of a Complex Care Team?

Members of the Complex Care Team

Nurse Practitioner (key clinical worker)

Paediatrician

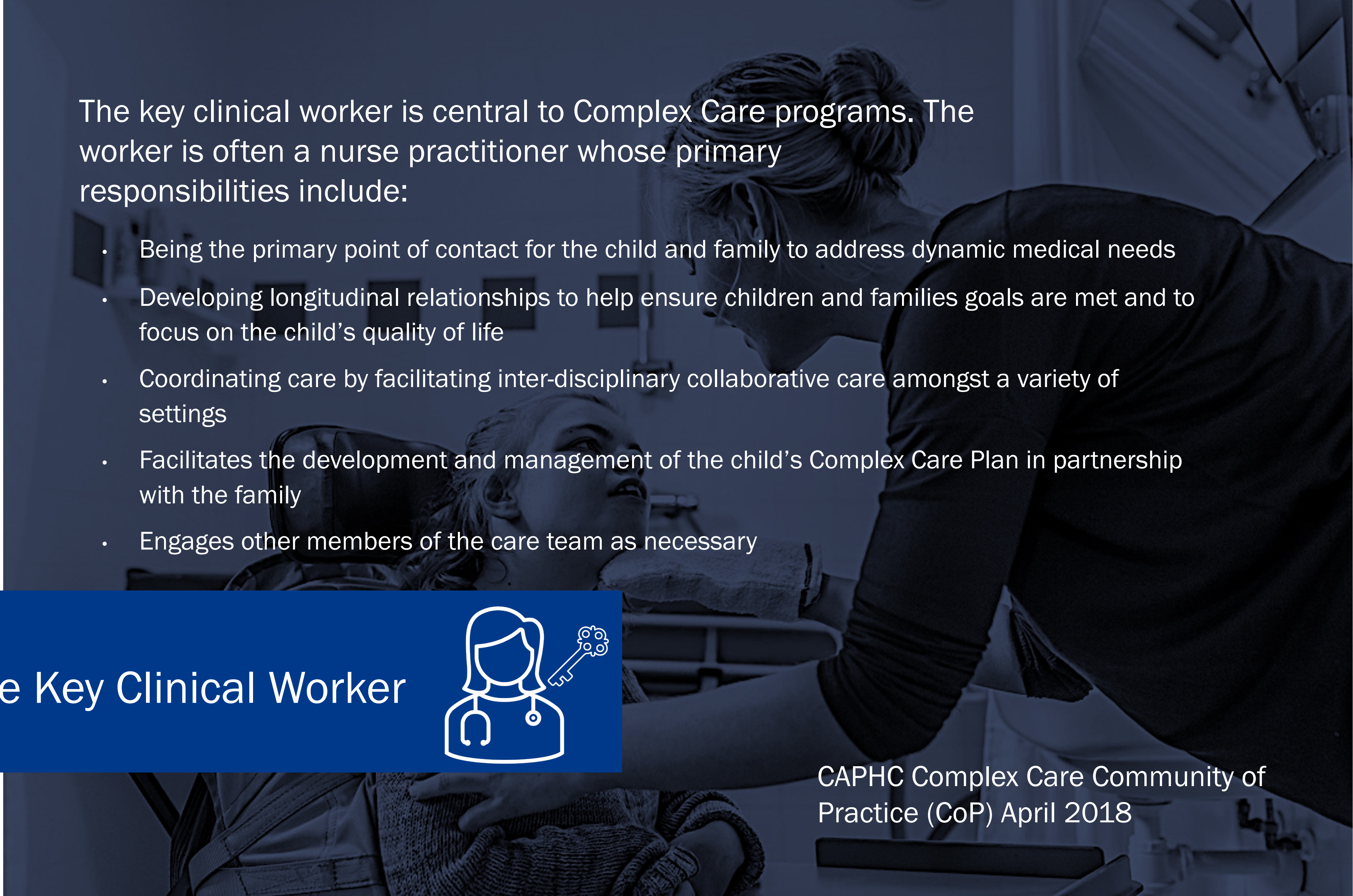
Registered Dietitian

Home and Community Care Support Services Coordinator

Social Worker

Program Coordinator

Role of the Key Clinical Worker



The key clinical worker is central to Complex Care programs. The worker is often a nurse practitioner whose primary responsibilities include:

- Being the primary point of contact for the child and family to address dynamic medical needs
- Developing longitudinal relationships to help ensure children and families goals are met and to focus on the child's quality of life
- Coordinating care by facilitating inter-disciplinary collaborative care amongst a variety of settings
- Facilitates the development and management of the child's Complex Care Plan in partnership with the family
- Engages other members of the care team as necessary

CAPHC Complex Care Community of Practice (CoP) April 2018

What is a care plan/shared plan of care?

Care Plans for CMC

- A written document that outlines major medical information and care needs for a specific child

- “A comprehensive compiling of the information, in partnership with the family, needed to support coordination of care for the multiple needs of an individual child or youth, and his or her family”

https://downloads.aap.org/AAP/PDF/Medical%20Home/Shared%20Plan%20of%20Care2.pdf

What do they do?

- Improve family-clinician relationships by enhancing/validating information exchange
- Support provision of family-centered care
- Provide information that enhances the care relevant to both medical and social needs of CMC
- Component of care coordination

Adams S, Cohen E, Mahant S, Friedman JN, MacCulloch R, Nicholas DB. Exploring the usefulness of comprehensive care plans for children with medical complexity (CMC): a qualitative study. BMC Pediatr. 2013;13:10 4

Lion KC, Mangione-Smith R, Britto MT. Individualized plans of care to improve outcomes among children and adults with chronic illness: a systematic review. Care Manag J. 2014;15(1):11–25

Mann, E., Pyevich, M., Eyck, P.T. *et al.* Impact of Shared Plans of Care on Healthcare Utilization by Children with Special Healthcare Needs and Mental Health Diagnoses. *Matern Child Health J* **25**, 584–589 (2021). https://doi.org/10.1007/s10995-020-03101-3

Adams *et al. BMC Pediatrics* 2013, **13**:10
http://www.biomedcentral.com/1471-2431/13/10

BMC Pediatrics

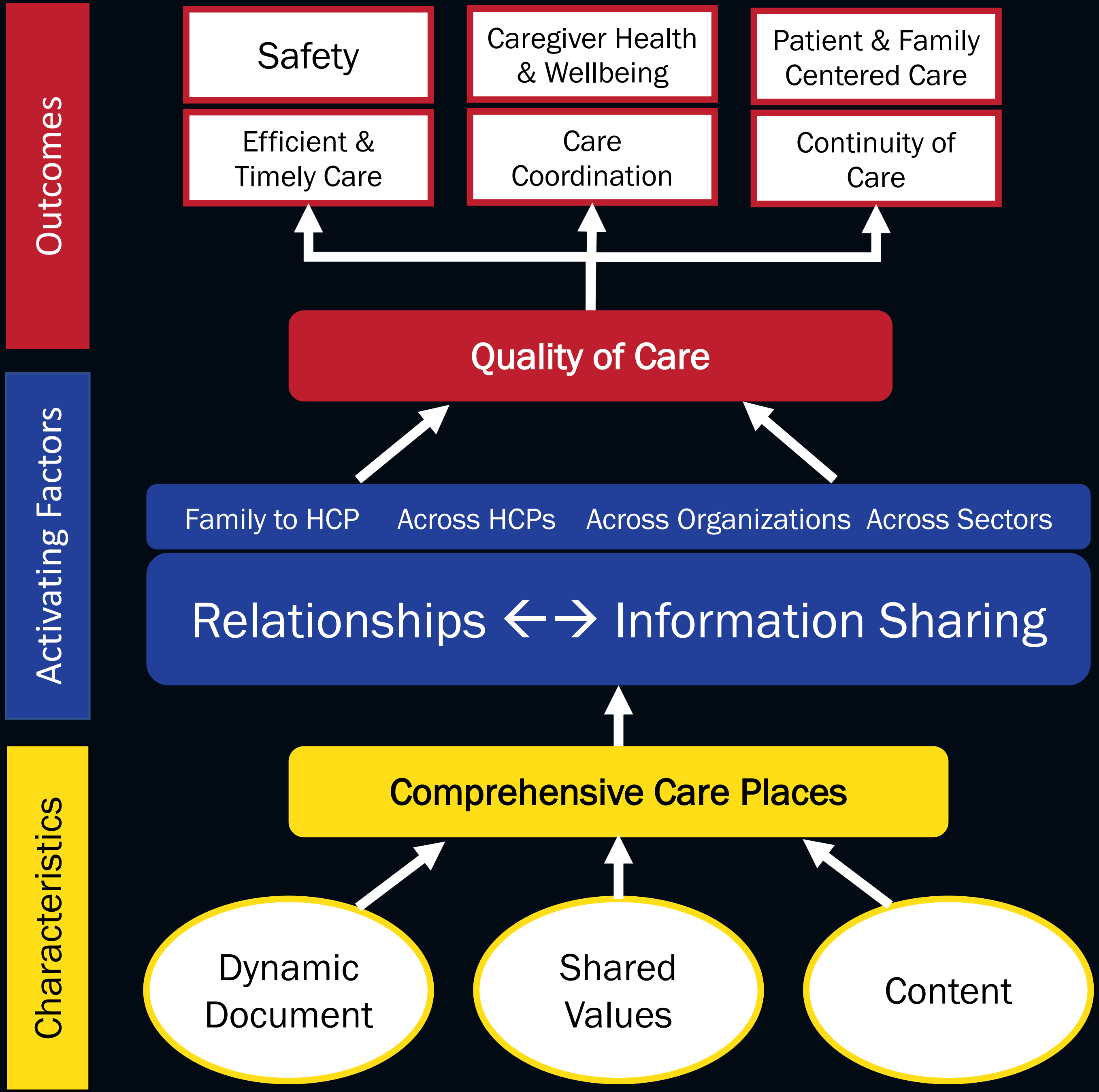
RESEARCH ARTICLE **Open Access**

Exploring the usefulness of comprehensive care plans for children with medical complexity (CMC): a qualitative study

Sherri Adams[1,2*], Eyal Cohen[1,3,4,5], Sanjay Mahant[1,3], Jeremy N Friedman[1,3], Radha MacCulloch[6]
and David B Nicholas[7]

To explore how parents and Health Care Providers (HCPs) of CMC perceive the usefulness of a care plan

Interviewed 15 parents
Focus Groups 15 HCPs



Outcomes

Safety

Caregiver Health & Wellbeing

Patient & Family Centered Care

Efficient & Timely Care

Care Coordination

Continuity of Care

Activating Factors

Quality of Care

Family to HCP Across HCPs Across Organizations Across Sectors

Relationships ←→ Information Sharing

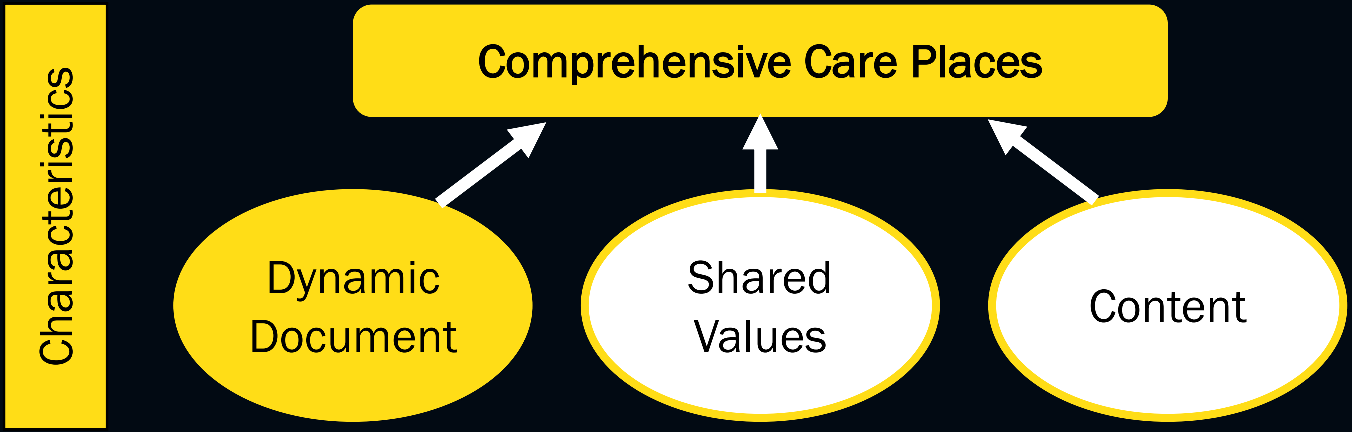
Characteristics

Comprehensive Care Places

Dynamic Document

Shared Values

Content



Characteristics

Comprehensive Care Places

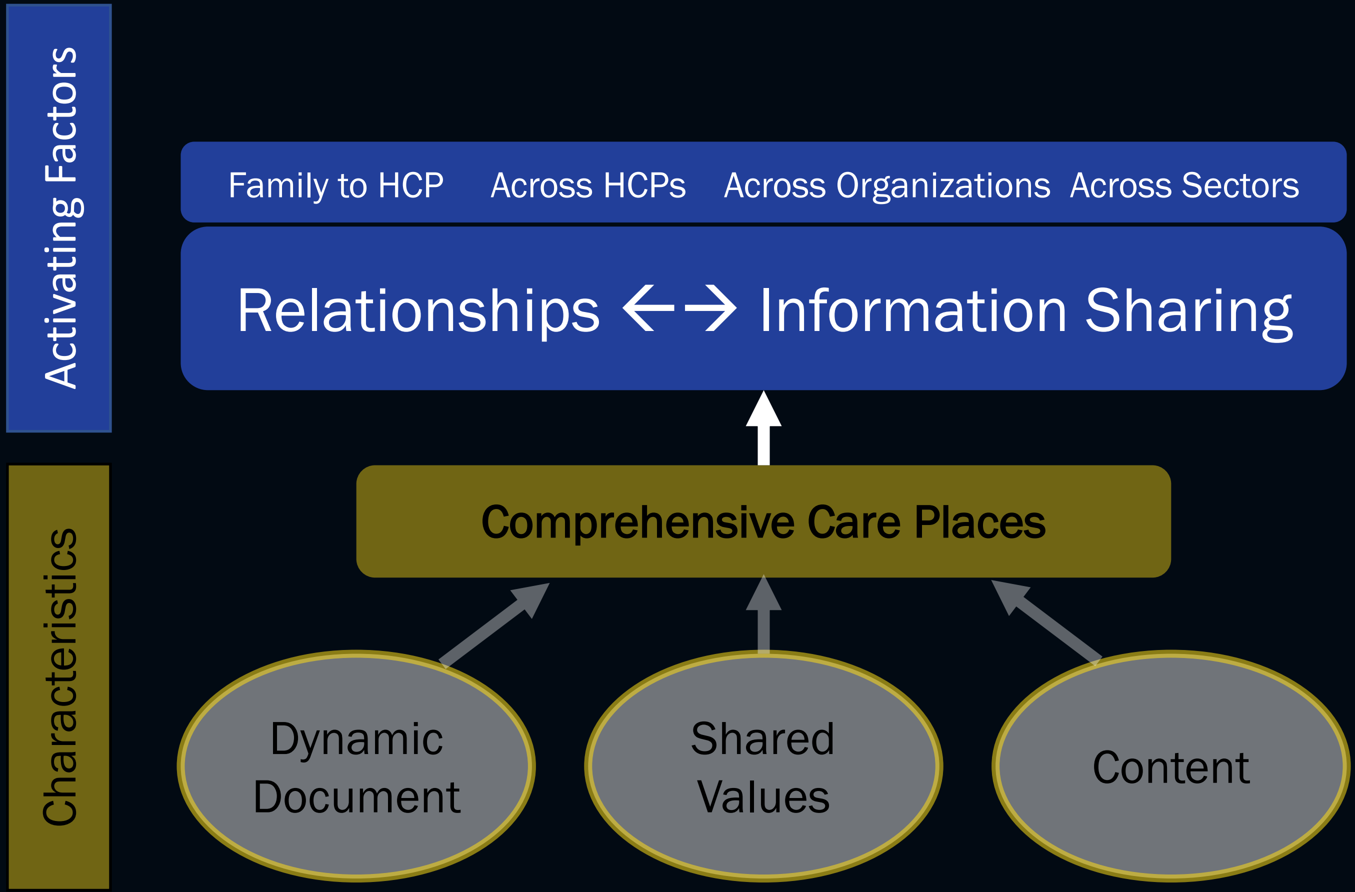
Dynamic Document

Shared Values

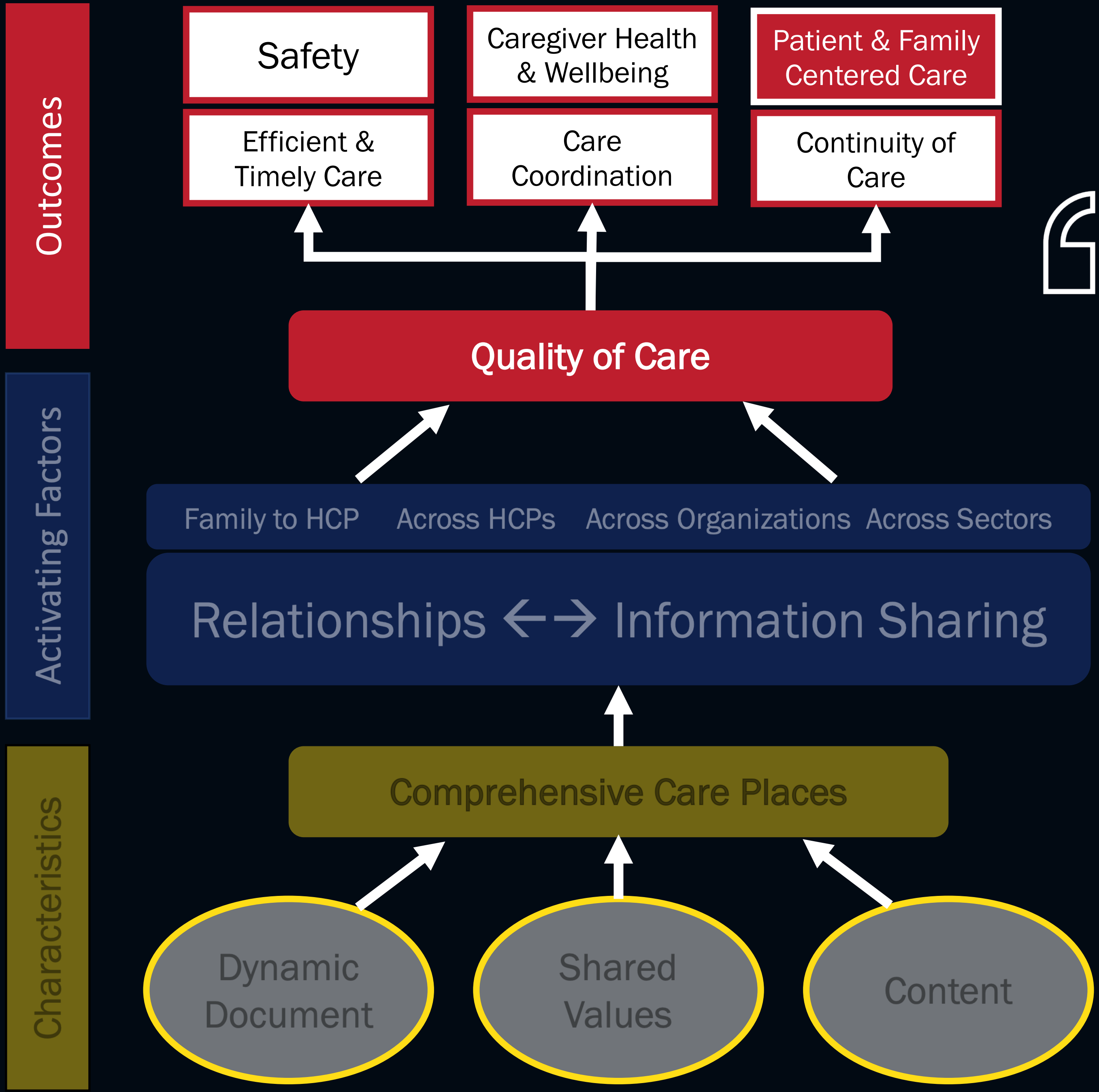
Content

> *I think it’s a comprehensive road map, or Google map, Coles [Cliff] notes version for complex patients, instead of a thick chart. That summarizes where you’re at, and where you’re going, and who to contact…*
>
> (Heath care provider)

Credibility



> *"I had this underlying anxiety that they weren't going to listen to me, how am I going to get them to understand me. Okay, screaming isn't working, what can I do to have them listen? That's gone. [The care plan] sort of levels out the playing field. We're both talking the same language. I may not have medical training, but I have this, I have this piece of paper. And we're speaking the same language. And it gives me a level of comfort, it gives me a level of security."*
>
> (Mother)



Outcomes

Safety

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Quality of Care

Activating Factors

Family to HCP   Across HCPs   Across Organizations   Across Sectors

Relationships ←→ Information Sharing

Characteristics

Comprehensive Care Places

Dynamic Document

Shared Values

Content

> *“There is another benefit I wanted to add. When we are in the hospital and we see doctors for the first time […] they start asking the parents questions. And I can’t tell you how many times I’ve had to give her medical history with all its gory details. And it’s extremely stressful for me. So this [the care plan] saves me from having to deal with that. […] We all go through so much as parents, and we suffer a lot physically, emotionally, psychologically. So this document saves me.”* (Parent)

(Parent)

Adams *et al. BMC Pediatrics* 2013, **13**:10
http://www.biomedcentral.com/1471-2431/13/10

BMC Pediatrics

RESEARCH ARTICLE **Open Access**

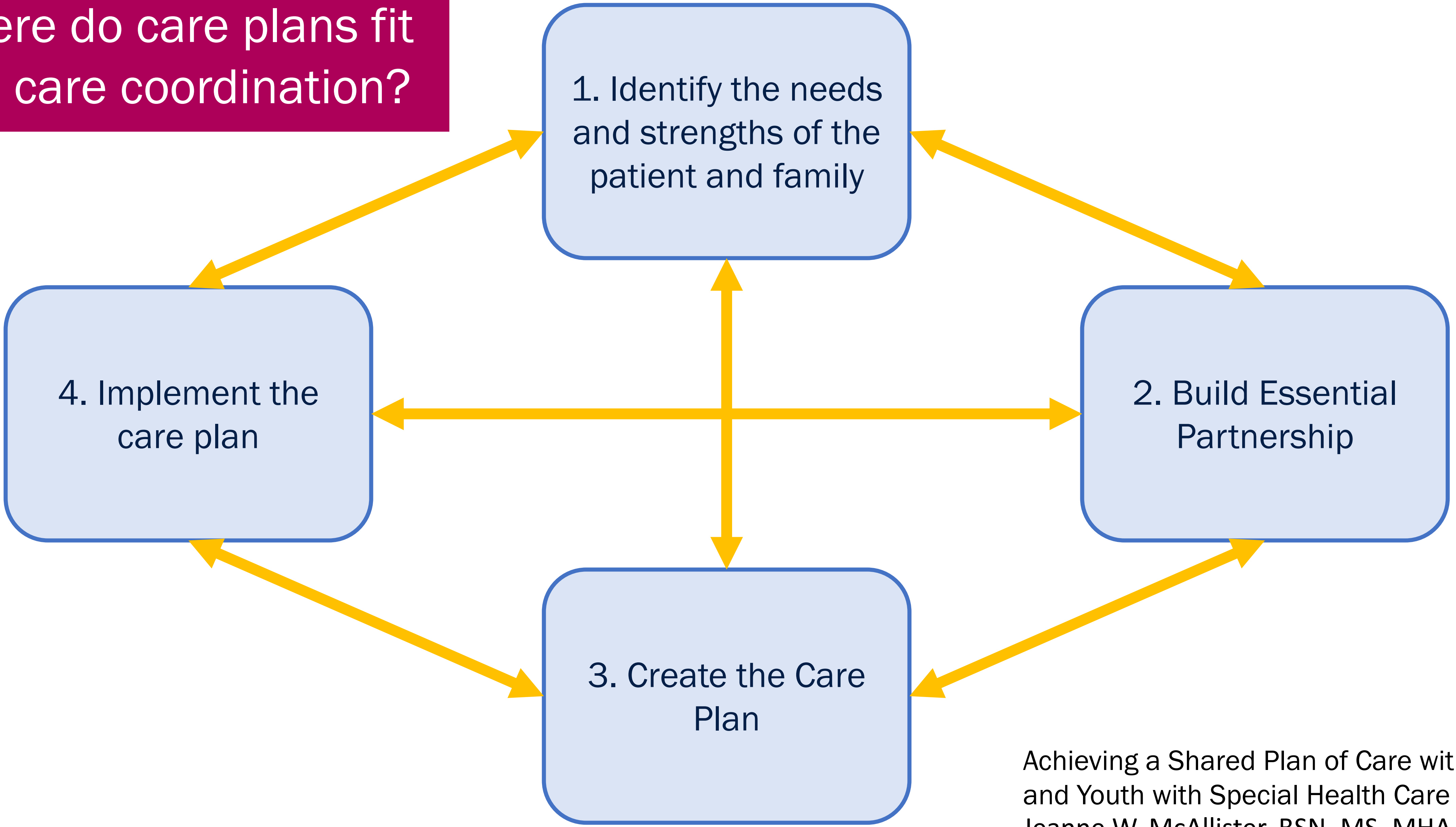
Exploring the usefulness of comprehensive care plans for children with medical complexity (CMC): a qualitative study

Sherri Adams[1,2*], Eyal Cohen[1,3,4,5], Sanjay Mahant[1,3], Jeremy N Friedman[1,3], Radha MacCulloch[6] and David B Nicholas[7]

Findings

- Care plans are a tool to build trust and relationships
- Family empowerment and credibility
- Starting point for HCPs
- United advocate

Where do care plans fit into care coordination?



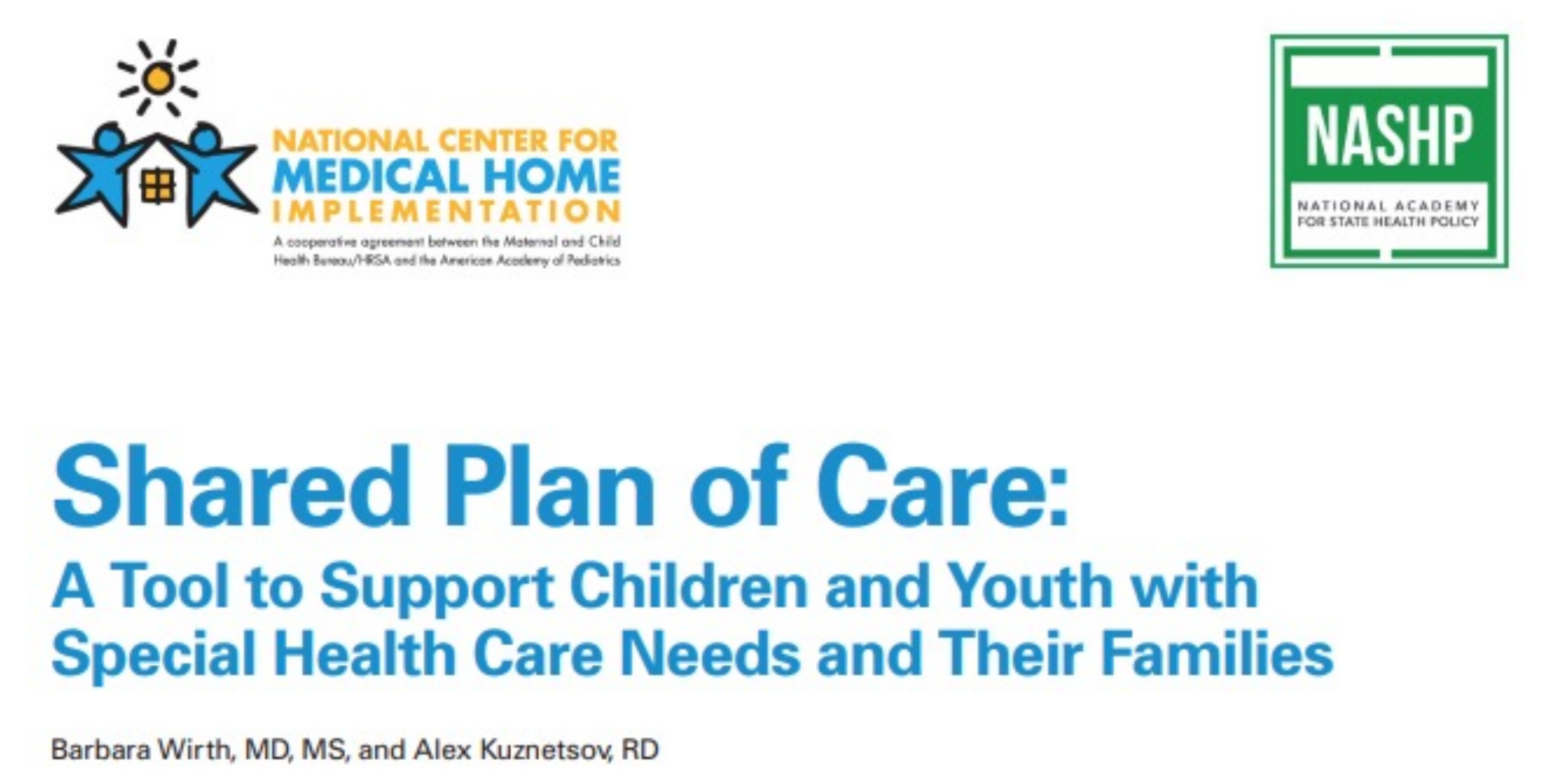
1. Identify the needs and strengths of the patient and family

2. Build Essential Partnership

3. Create the Care Plan

4. Implement the care plan

Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs
Jeanne W. McAllister, BSN, MS, MHA, 2014



NATIONAL CENTER FOR
MEDICAL HOME
IMPLEMENTATION
A cooperative agreement between the Maternal and Child Health Bureau/HRSA and the American Academy of Pediatrics

NASHP
NATIONAL ACADEMY FOR STATE HEALTH POLICY

Shared Plan of Care:

A Tool to Support Children and Youth with Special Health Care Needs and Their Families

Barbara Wirth, MD, MS, and Alex Kuznetsov, RD

This report outlines the principles for the shared plan of care model and recommends core content for an integrated and comprehensive shared plan of care for children, youth, and their families.

Provincial
Council for
Maternal and
Child Health

building a brighter future

Complex Care for Kids Ontario Standard: Medical Care Plan

Version Date: May 9, 2017

Provincial Council for Maternal and Child Health
building a brighter future

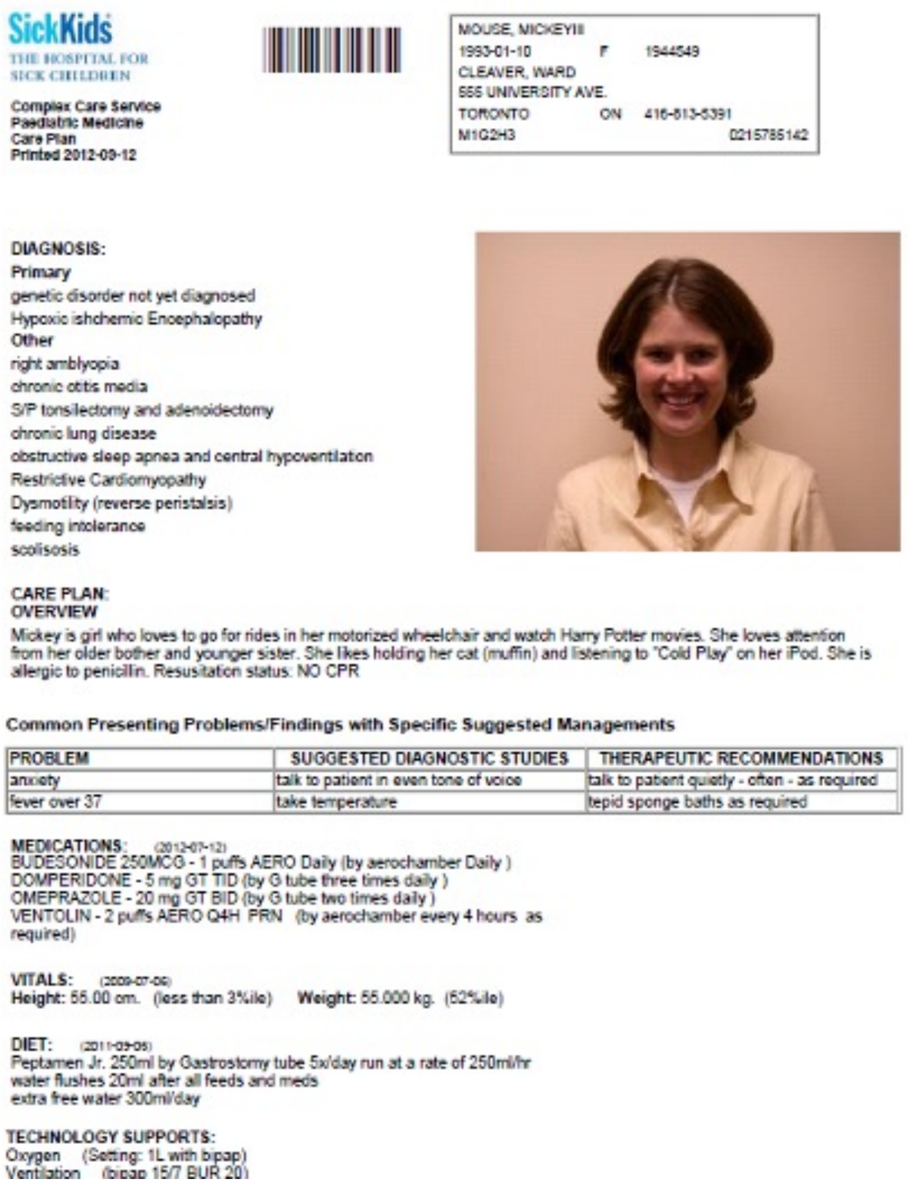
Medical Care Plan Standards: Content Short Form

The following are standard data elements to be included in a medical care plan:

- ☐ Child Identification **PHOTO**
- ☐ Allergies/Reaction/Alerts
- ☐ Caregiver Names and contact
- ☐ Legal Guardian and contact
- ☐ Advance Directives (indicate documented decisions)
- ☐ Diagnosis
- ☐ Short Non-medical Description of the child
- ☐ Complex Care primary contacts: clinical key worker[2], physician

- ☐ ER Management
- ☐ Medication List
  - ☐ Scheduled and PRN Medication
  - ☐ Parenteral and/or G-tube feeds
- ☐ Growth parameters and unusual 'normals' in vital signs or physique

- ☐ Communication
- ☐ Technology/Technology Support
- ☐ Current issues (systems based)
- ☐ Adaptive seating
- ☐ Mobility aids
- ☐ What I want for my child (Commonly known as 'Patient care goals') → Consider action list
- ☐ Immunizations
- ☐ Signature (or electronic trail) of person updating content medical care plan Last updated (electronic trail sufficient if present)
- ☐ Contact List
  - ☐ Family Physician/Paediatrician
  - ☐ List of Physicians and Programs Followed at Tertiary Hospital or Community
  - ☐ Special Needs Strategy: Coordinated Service Planning Care Coordinator
  - ☐ LHIN Care Coordinators



SickKids
THE HOSPITAL FOR
SICK CHILDREN

Complex Care Service
Paediatric Medicine
Care Plan
Printed 2012-09-12

MOUSE, MICKEYIII
1993-01-10 F 1944549
CLEAVER, WARD
555 UNIVERSITY AVE.
TORONTO ON 416-813-5391
M1G2H3 0215785142

DIAGNOSIS:
Primary
genetic disorder not yet diagnosed
Hypoxic ishchemic Encephalopathy
Other
right amblyopia
chronic otitis media
S/P tonsilectomy and adenoidectomy
chronic lung disease
obstructive sleep apnea and central hypoventilation
Restrictive Cardiomyopathy
Dysmotility (reverse peristalsis)
feeding intolerance
scolisosis

CARE PLAN:
OVERVIEW

Mickey is girl who loves to go for rides in her motorized wheelchair and watch Harry Potter movies. She loves attention from her older bother and younger sister. She likes holding her cat (muffin) and listening to "Cold Play" on her iPod. She is allergic to penicillin. Resusitation status: NO CPR

Common Presenting Problems/Findings with Specific Suggested Managements

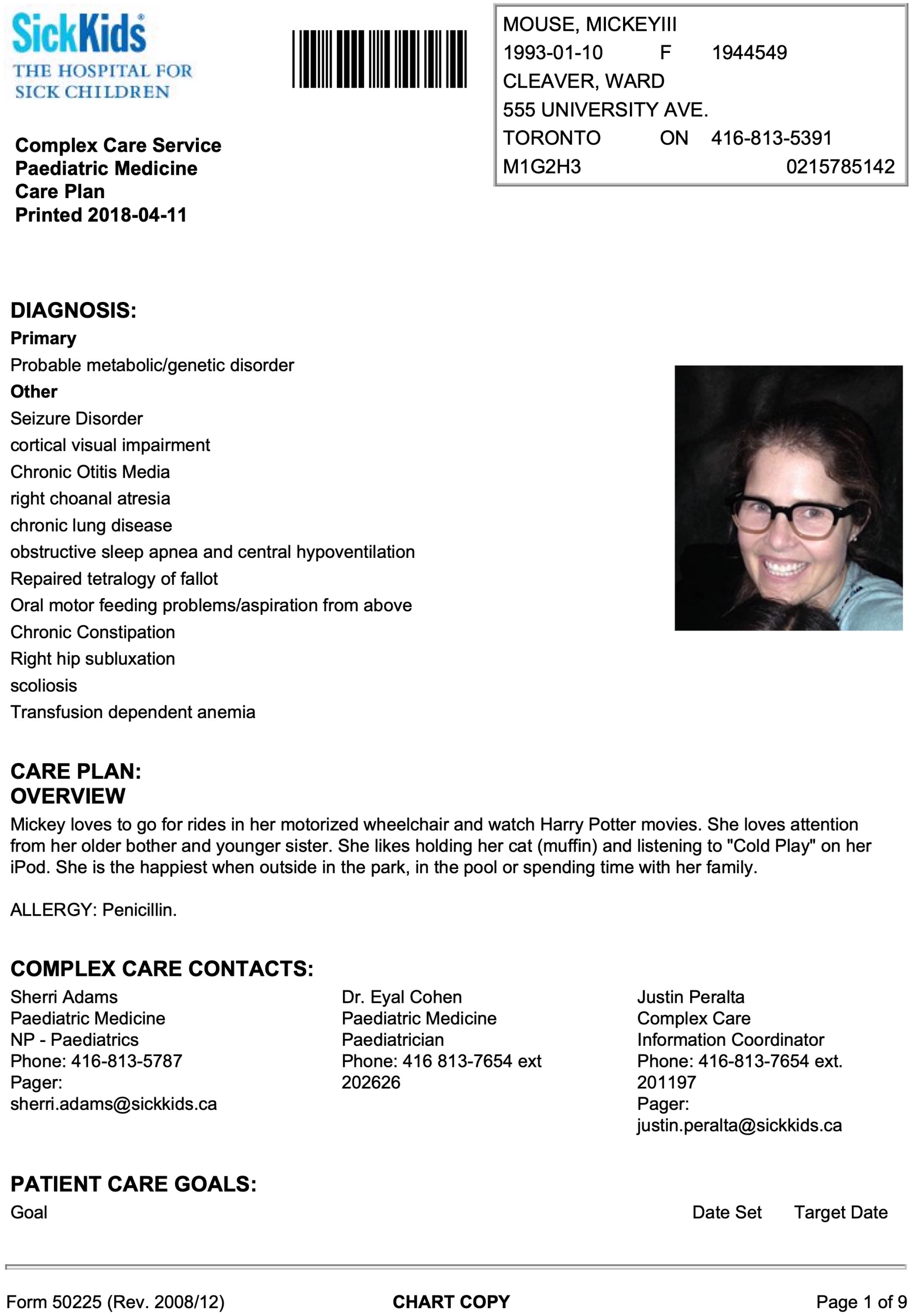
PROBLEM	SUGGESTED DIAGNOSTIC STUDIES	THERAPEUTIC RECOMMENDATIONS
anxiety	talk to patient in even tone of voice	talk to patient quietly - often - as required
fever over 37	take temperature	tepid sponge baths as required

MEDICATIONS: (2012-07-12)
BUDESONIDE 250MCG - 1 puffs AERO Daily (by aerochamber Daily)
DOMPERIDONE - 5 mg GT TID (by G tube three times daily)
OMEPRAZOLE - 20 mg GT BID (by G tube two times daily)
VENTOLIN - 2 puffs AERO Q4H PRN (by aerochamber every 4 hours as required)

VITALS: (2009-07-06)
Height: 55.00 cm. (less than 3%ile) **Weight:** 55.000 kg. (52%ile)

DIET: (2011-09-06)
Peptamen Jr. 250ml by Gastrostomy tube 5x/day run at a rate of 250ml/hr
water flushes 20ml after all feeds and meds
extra free water 300ml/day

TECHNOLOGY SUPPORTS:
Oxygen (Setting: 1L with bipap)
Ventilation (bipap 15/7 BUR 20)



SickKids
THE HOSPITAL FOR
SICK CHILDREN

Complex Care Service
Paediatric Medicine
Care Plan
Printed 2018-04-11

MOUSE, MICKEYIII
1993-01-10 F 1944549
CLEAVER, WARD
555 UNIVERSITY AVE.
TORONTO ON 416-813-5391
M1G2H3 0215785142

DIAGNOSIS:

Primary
Probable metabolic/genetic disorder
Other
Seizure Disorder
cortical visual impairment
Chronic Otitis Media
right choanal atresia
chronic lung disease
obstructive sleep apnea and central hypoventilation
Repaired tetralogy of fallot
Oral motor feeding problems/aspiration from above
Chronic Constipation
Right hip subluxation
scoliosis
Transfusion dependent anemia

CARE PLAN:
OVERVIEW

Mickey loves to go for rides in her motorized wheelchair and watch Harry Potter movies. She loves attention from her older bother and younger sister. She likes holding her cat (muffin) and listening to "Cold Play" on her iPod. She is the happiest when outside in the park, in the pool or spending time with her family.

ALLERGY: Penicillin.

COMPLEX CARE CONTACTS:

Sherri Adams
Paediatric Medicine
NP - Paediatrics
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Pager:
sherri.adams@sickkids.ca

Dr. Eyal Cohen
Paediatric Medicine
Paediatrician
Phone: 416 813-7654 ext 202626

Justin Peralta
Complex Care
Information Coordinator
Phone: 416-813-7654 ext. 201197
Pager:
justin.peralta@sickkids.ca

PATIENT CARE GOALS:

Goal	Date Set	Target Date

Provincial Council for Maternal and Child Health
building a brighter future

Medical Care Plan Standards: Process Short Form

The following are process standards for the development, sharing, maintenance, and use of medical care plans:

1 Child/family enrolled in the complex care program have a medical care plan

2 Clinical key worker is responsible for the development and maintenance of the medical care plan in partnership with child/parent/and care team

3 Child/parent approves the information included in the medical care plan

4 Parents coached and educated in the purpose and use of the medical care plans

5 Most up-to-date medical care plan is made available in the child's medical record

6 The child/parent receives a copy of the medical care plan and works with the clinical key worker to identify the individuals/teams (hospital and community) required to receive the medical care plan

7 Medical care plans shared with identified care team (hospital and community) members and parent

8 Medical care plans reviewed and updated, as required, after each regularly scheduled complex care clinic visit, hospital admission, or as urgent changes arise

FAQs

What platforms are used to create the care plan?

Where does the care plan live?

How is it shared?

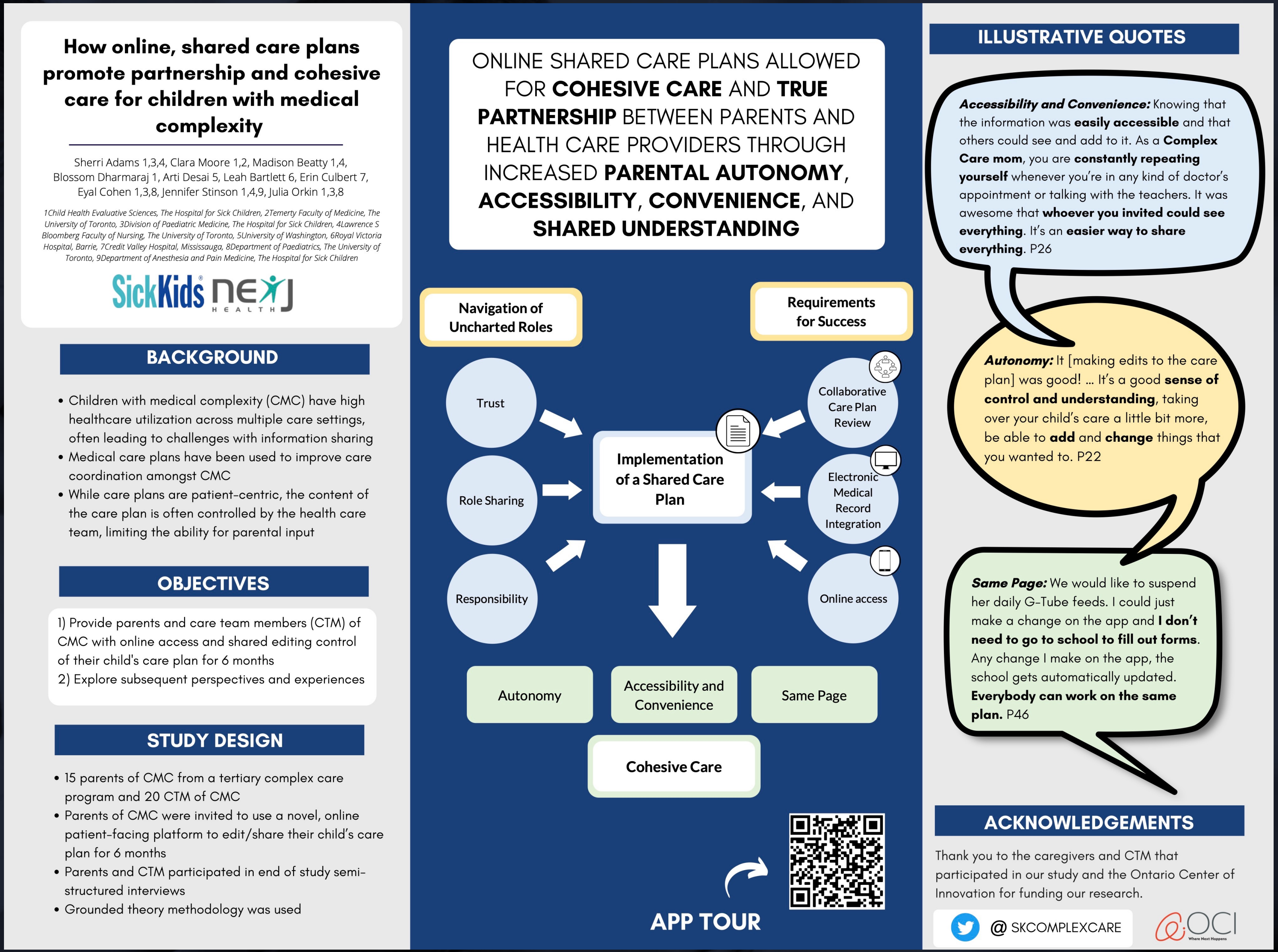
Who has access to it?

How is it used by the family?

How is it used by the care team?

Future Directions

- Sharing platforms
- Caregiver participation



How online, shared care plans promote partnership and cohesive care for children with medical complexity

Sherri Adams 1,3,4, Clara Moore 1,2, Madison Beatty 1,4,
Blossom Dharmaraj 1, Arti Desai 5, Leah Bartlett 6, Erin Culbert 7,
Eyal Cohen 1,3,8, Jennifer Stinson 1,4,9, Julia Orkin 1,3,8

1Child Health Evaluative Sciences, The Hospital for Sick Children, 2Temerty Faculty of Medicine, The University of Toronto, 3Division of Paediatric Medicine, The Hospital for Sick Children, 4Lawrence S Bloomberg Faculty of Nursing, The University of Toronto, 5University of Washington, 6Royal Victoria Hospital, Barrie, 7Credit Valley Hospital, Mississauga, 8Department of Paediatrics, The University of Toronto, 9Department of Anesthesia and Pain Medicine, The Hospital for Sick Children

BACKGROUND

- Children with medical complexity (CMC) have high healthcare utilization across multiple care settings, often leading to challenges with information sharing
- Medical care plans have been used to improve care coordination amongst CMC
- While care plans are patient-centric, the content of the care plan is often controlled by the health care team, limiting the ability for parental input

OBJECTIVES

1) Provide parents and care team members (CTM) of CMC with online access and shared editing control of their child's care plan for 6 months
2) Explore subsequent perspectives and experiences

STUDY DESIGN

- 15 parents of CMC from a tertiary complex care program and 20 CTM of CMC
- Parents of CMC were invited to use a novel, online patient-facing platform to edit/share their child's care plan for 6 months
- Parents and CTM participated in end of study semi-structured interviews
- Grounded theory methodology was used

ONLINE SHARED CARE PLANS ALLOWED FOR **COHESIVE CARE** AND **TRUE PARTNERSHIP** BETWEEN PARENTS AND HEALTH CARE PROVIDERS THROUGH INCREASED **PARENTAL AUTONOMY**, **ACCESSIBILITY**, **CONVENIENCE**, AND **SHARED UNDERSTANDING**

Navigation of Uncharted Roles

- Trust
- Role Sharing
- Responsibility

Requirements for Success

- Collaborative Care Plan Review
- Electronic Medical Record Integration
- Online access

Implementation of a Shared Care Plan

- Autonomy
- Accessibility and Convenience
- Same Page

Cohesive Care

APP TOUR

ILLUSTRATIVE QUOTES

Accessibility and Convenience: Knowing that the information was **easily accessible** and that others could see and add to it. As a **Complex Care mom**, you are **constantly repeating yourself** whenever you're in any kind of doctor's appointment or talking with the teachers. It was awesome that **whoever you invited could see everything**. It's an **easier way to share everything**. P26

Autonomy: It [making edits to the care plan] was good! … It's a good **sense of control and understanding**, taking over your child's care a little bit more, be able to **add** and **change** things that you wanted to. P22

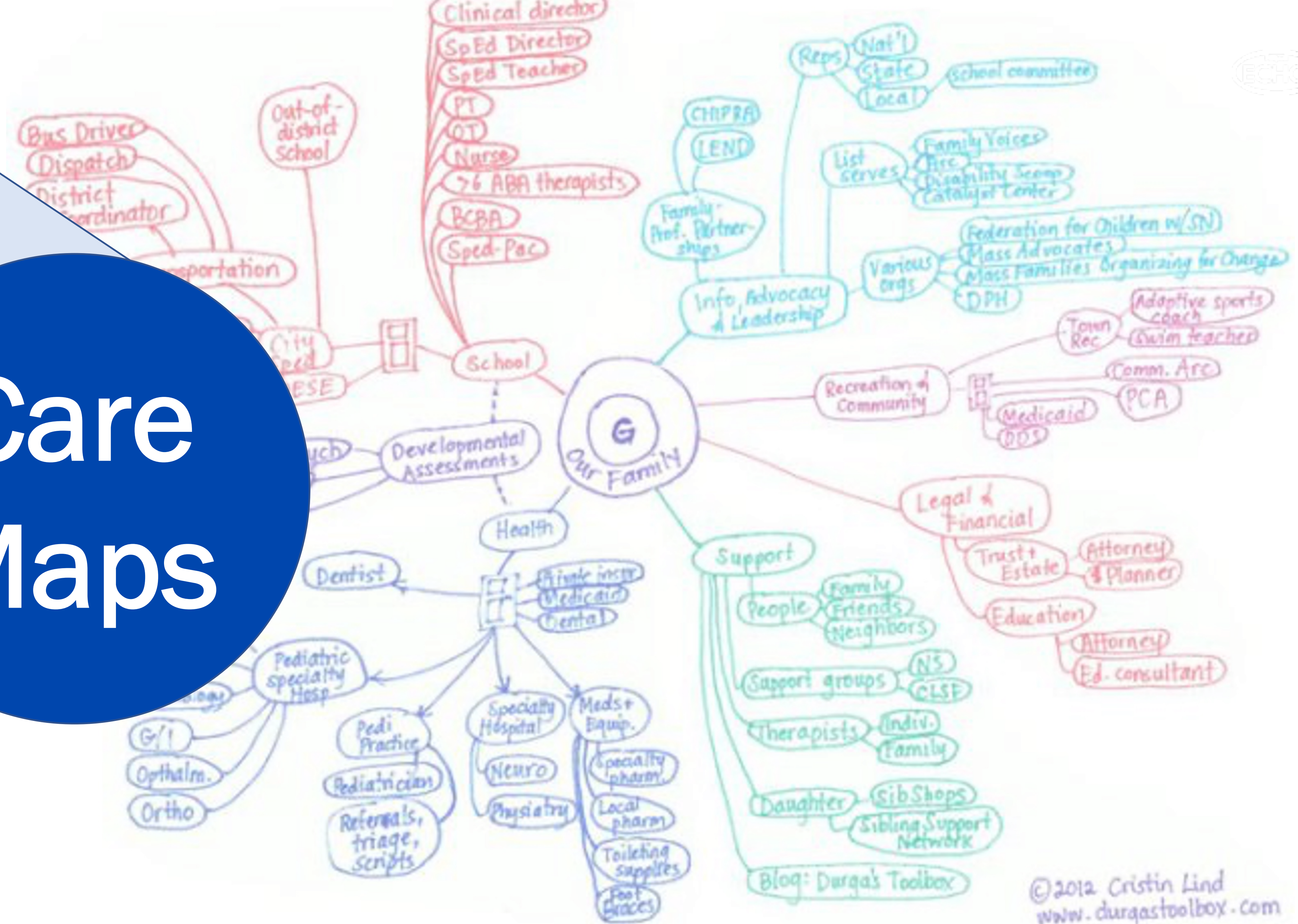
Same Page: We would like to suspend her daily G-Tube feeds. I could just make a change on the app and **I don't need to go to school to fill out forms**. Any change I make on the app, the school gets automatically updated. **Everybody can work on the same plan.** P46

ACKNOWLEDGEMENTS

Thank you to the caregivers and CTM that participated in our study and the Ontario Center of Innovation for funding our research.

@ SKCOMPLEXCARE

Care Maps



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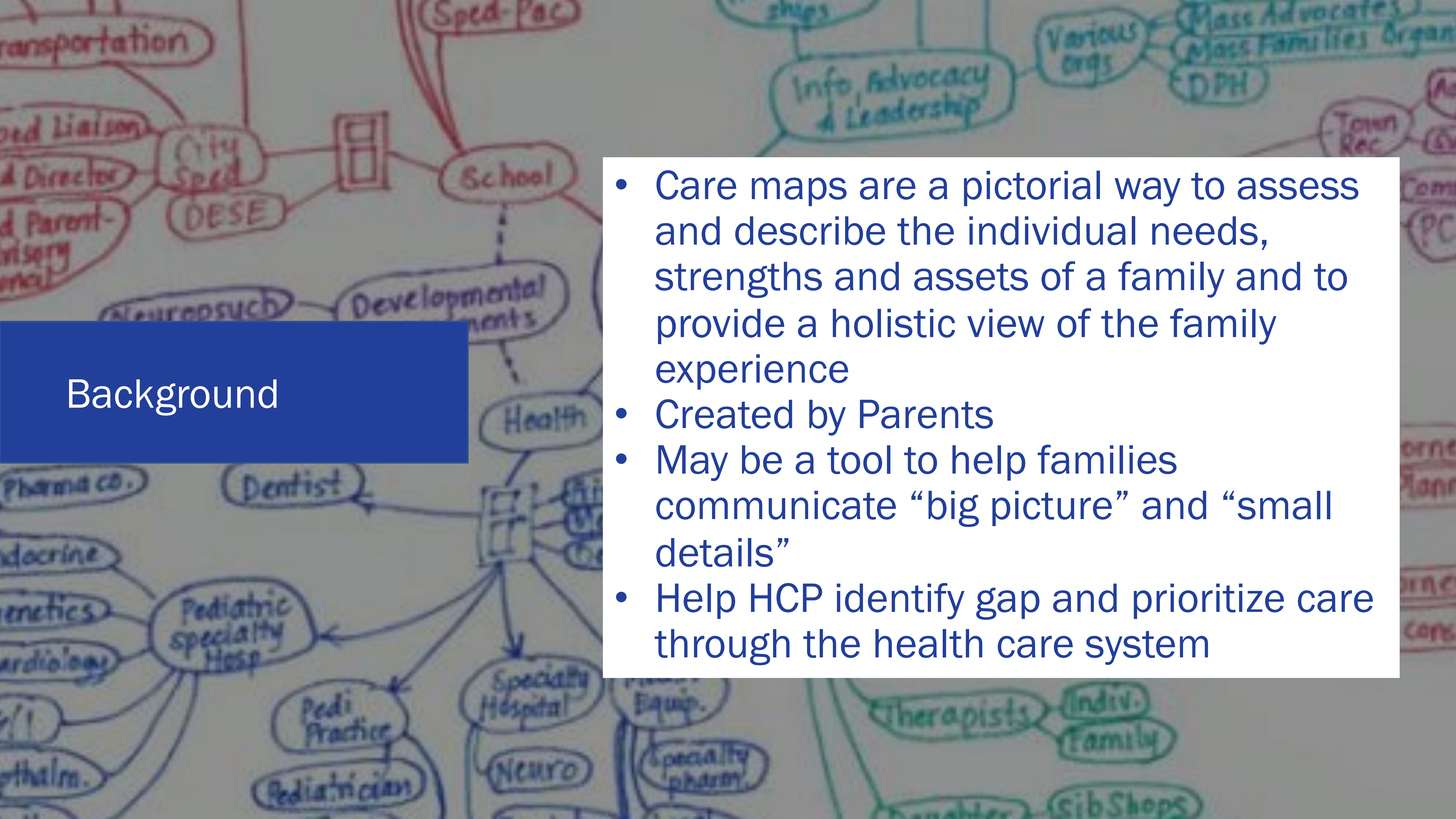
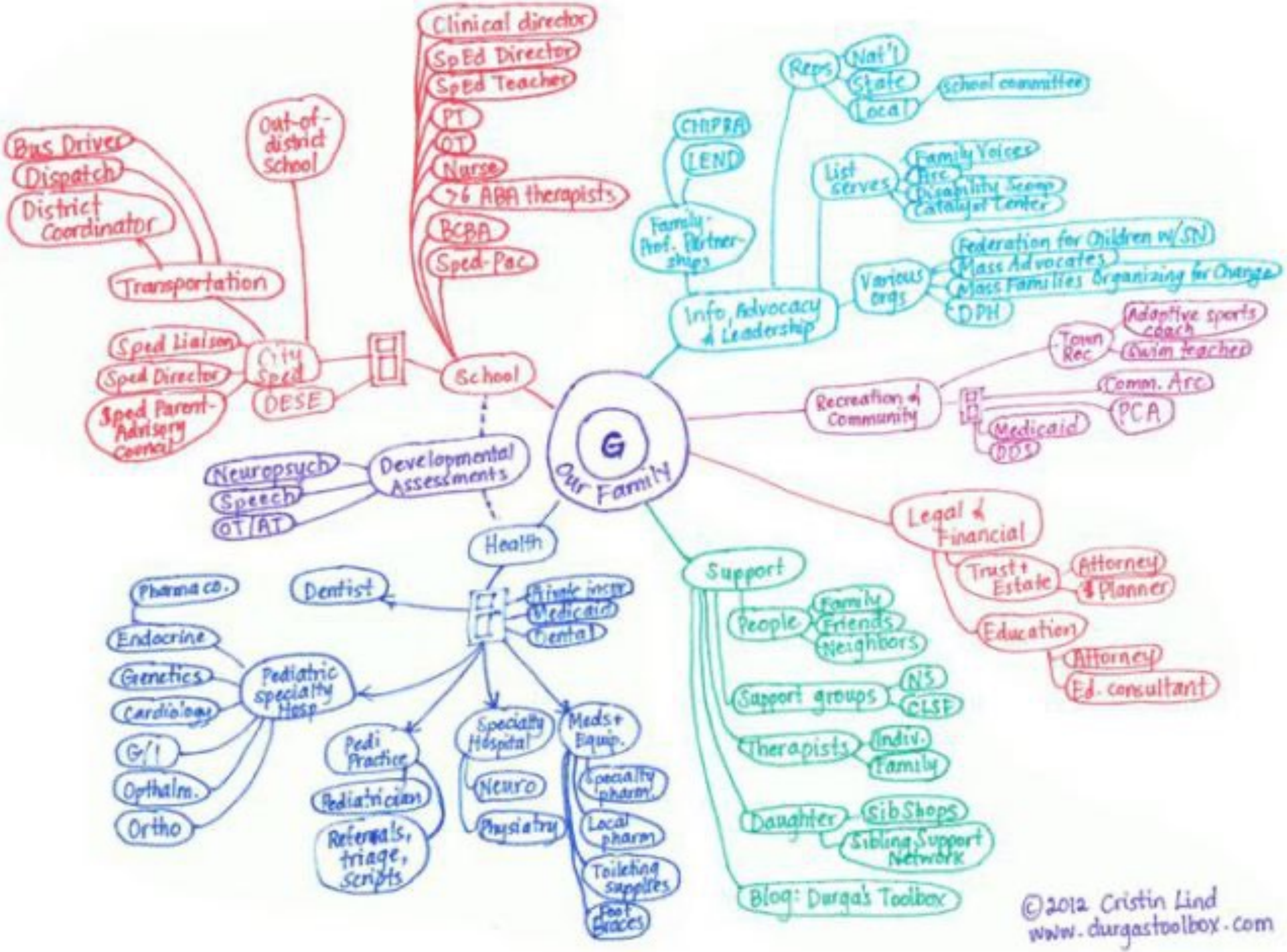


Background

- Care maps are a pictorial way to assess and describe the individual needs, strengths and assets of a family and to provide a holistic view of the family experience
- Created by Parents
- May be a tool to help families communicate “big picture” and “small details”
- Help HCP identify gap and prioritize care through the health care system



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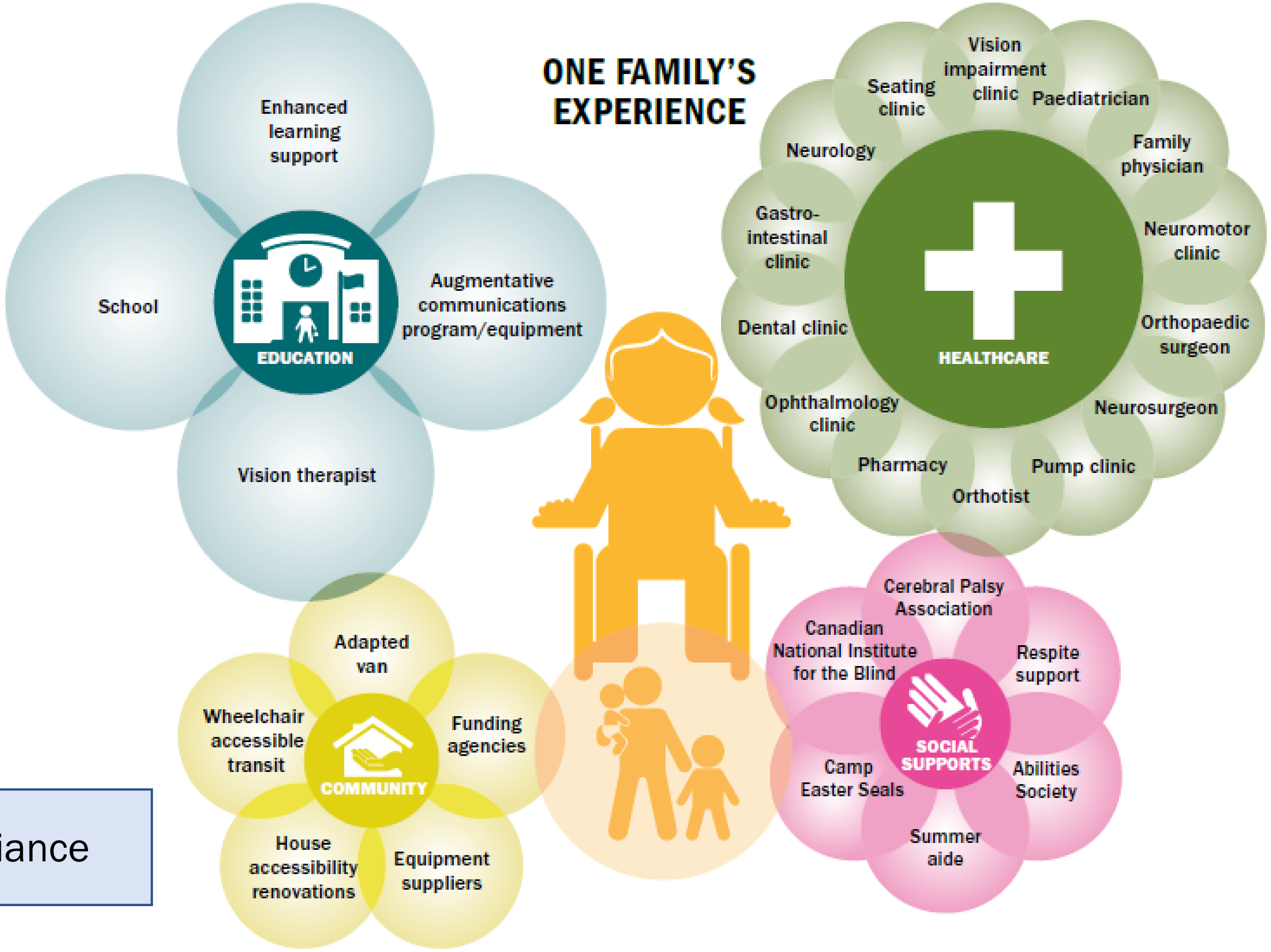
Navigating a complex system

The caregiving ecosystem for children and youth is more complex than for adults



ONE FAMILY'S EXPERIENCE

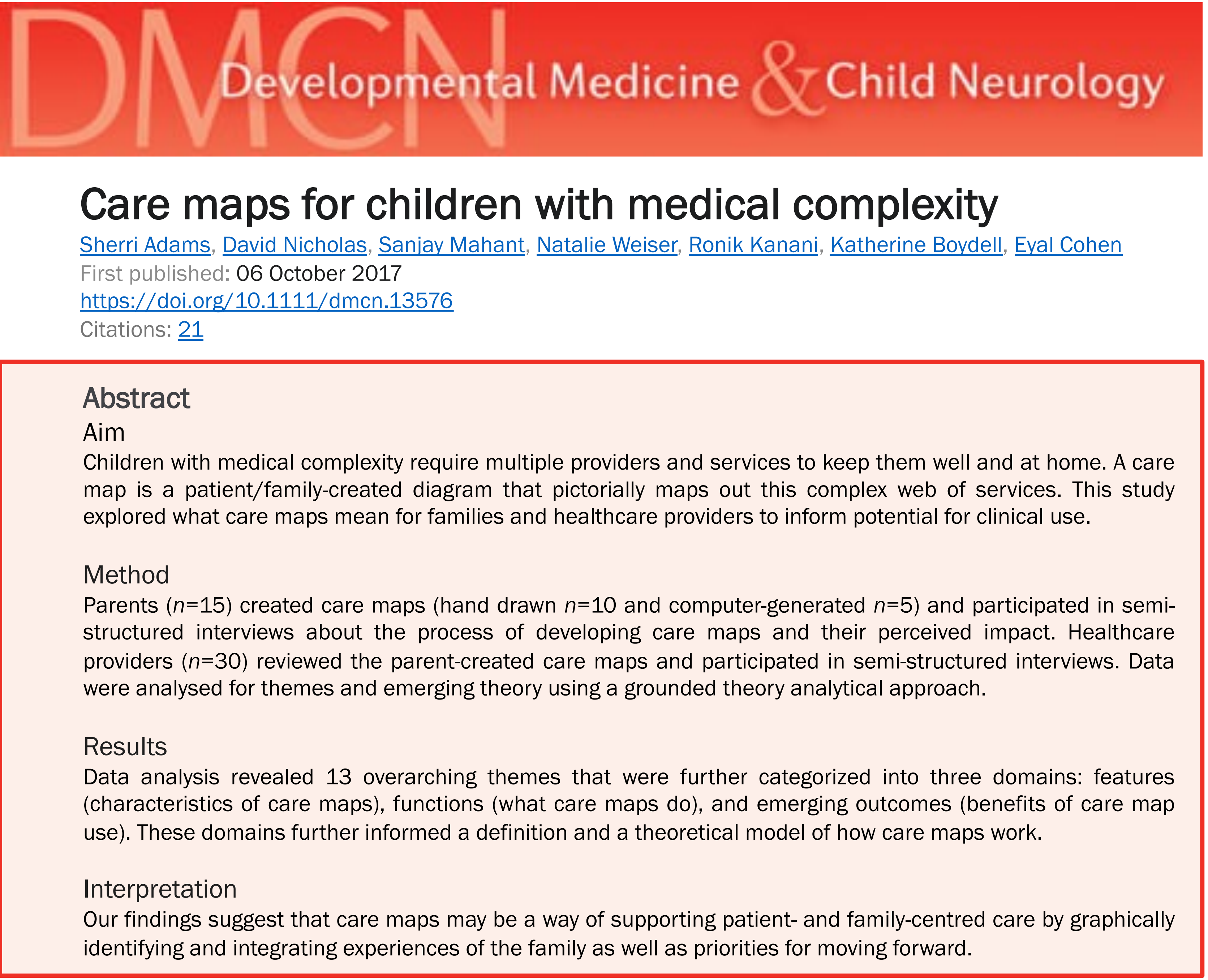
EDUCATION
- Enhanced learning support
- Augmentative communications program/equipment
- Vision therapist
- School

HEALTHCARE
- Vision impairment clinic
- Paediatrician
- Family physician
- Neuromotor clinic
- Orthopaedic surgeon
- Neurosurgeon
- Pump clinic
- Orthotist
- Pharmacy
- Ophthalmology clinic
- Dental clinic
- Gastro-intestinal clinic
- Neurology
- Seating clinic

COMMUNITY
- Adapted van
- Funding agencies
- Equipment suppliers
- House accessibility renovations
- Wheelchair accessible transit

SOCIAL SUPPORTS
- Cerebral Palsy Association
- Respite support
- Abilities Society
- Summer aide
- Camp Easter Seals
- Canadian National Institute for the Blind

Source: Kids Health Alliance



DMCN Developmental Medicine & Child Neurology

Care maps for children with medical complexity

Sherri Adams, David Nicholas, Sanjay Mahant, Natalie Weiser, Ronik Kanani, Katherine Boydell, Eyal Cohen

First published: 06 October 2017
https://doi.org/10.1111/dmcn.13576
Citations: 21

Abstract

Aim

Children with medical complexity require multiple providers and services to keep them well and at home. A care map is a patient/family-created diagram that pictorially maps out this complex web of services. This study explored what care maps mean for families and healthcare providers to inform potential for clinical use.

Method

Parents (*n*=15) created care maps (hand drawn *n*=10 and computer-generated *n*=5) and participated in semi-structured interviews about the process of developing care maps and their perceived impact. Healthcare providers (*n*=30) reviewed the parent-created care maps and participated in semi-structured interviews. Data were analysed for themes and emerging theory using a grounded theory analytical approach.

Results

Data analysis revealed 13 overarching themes that were further categorized into three domains: features (characteristics of care maps), functions (what care maps do), and emerging outcomes (benefits of care map use). These domains further informed a definition and a theoretical model of how care maps work.

Interpretation

Our findings suggest that care maps may be a way of supporting patient- and family-centred care by graphically identifying and integrating experiences of the family as well as priorities for moving forward.

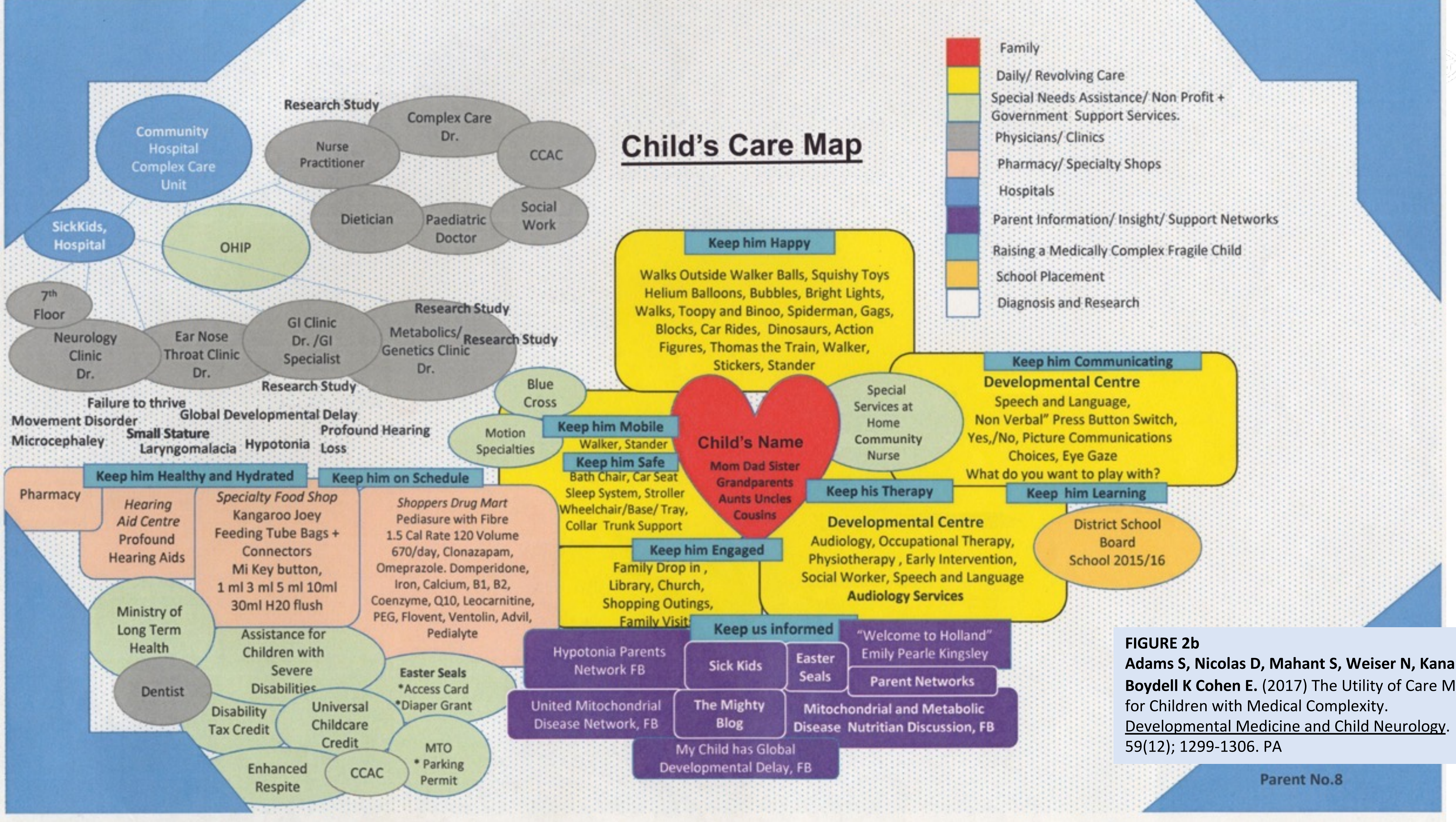


FIGURE 2b

Adams S, Nicolas D, Mahant S, Weiser N, Kanani R, Boydell K Cohen E. (2017) The Utility of Care Maps for Children with Medical Complexity. Developmental Medicine and Child Neurology. 59(12); 1299-1306. PA

Co-Creation, Development and Evaluation of Online Care Maps for Children with Medical Complexity (CMC)

Sherri Adams (1,2,3), Blossom G. Dharmaraj (2), Madison Beatty (2), Clara Moore (2), Arti Desai (4), Leah Bartlett (5), Erin Culbert (6), Eyal Cohen (1,2,7), Jennifer Stinson (2,3,8), and Julia Orkin (1,2,7)

Affiliations: (1) Division of Pediatric Medicine, SickKids, Toronto, Canada, (2) SickKids Research Institute, Toronto, Canada, (3) University of Toronto, Lawrence S Bloomberg Faculty of Nursing, (4) University of Washington, Seattle, Washington, USA, (5) Royal Victoria Hospital, Barrie, Canada, (6) Credit Valley Hospital, Mississauga, Canada, (7) University of Toronto, Department of Pediatrics, (8) Department of Anesthesia and Pain Medicine, SickKids, Toronto, Canada.

AN ONLINE CARE MAP PROVIDED INSIGHT AND VALUE TO PARENTS AND CARE TEAM MEMBERS

Transition to Adult Care

Implications to inform policy and practice: Transitioning of YMC to Adult Care

Provincial Council for Maternal and Child Health
building a brighter future

Review

Lin Li*, Marissa Bird, Nancy Carter, Jenny Ploeg, Jan Willem Gorter and Patricia H. Strachan

Experiences of youth with medical complexity and their families during the transition to adulthood: a meta-ethnography

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

ELSEVIER

Transition to adult care for youth with medical complexity: Assessing needs and setting priorities for a health care improvement initiative

Lin Li, RN, BFA, BScN [a,b,*], Anna Polanski, RN(EC), MN-NP (Paediatrics) [a,c], Audrey Lim, MD, FRCPC, MSc [b,d], Patricia H. Strachan, RN, PhD [a]

> Transition to me equals sheer fear…It’s like jumping off a cliff. And if you’re really well prepared – you might have a parachute or a trampoline along the way for a short respite period there…
>
> (Parent)

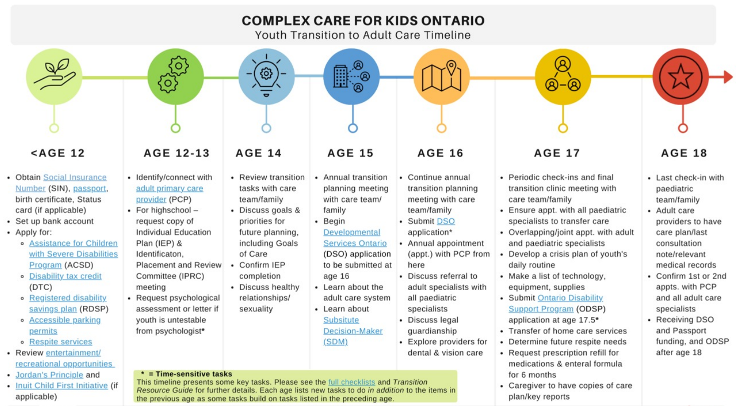
Schultz RJ. Parental experiences transitioning their adolescent with epilepsy and cognitive impairments to adult health care. (2013). *Journal of Paediatric Healthcare*, 27:359–66.

> “It was like after all those years we had depended on the (pediatric) hospital to help us, and now we had the impression that we were on our own. No one knew us, we were nothing. We were a number.
>
> (Parent)

Davies H, Rennick J, Majnemer A. (2011). Transition from pediatric to adult health care for young adults with neurological disorders: parental perspectives. *Canadian Journal of Neuroscience Nursing*, 33:32–9.

Content of the Transition Toolkit

Timeline



COMPLEX CARE FOR KIDS ONTARIO
Youth Transition to Adult Care Timeline

<AGE 12
- Obtain Social Insurance Number (SIN), passport, birth certificate, Status card (if applicable)
- Set up bank account
- Apply for:
  - Assistance for Children with Severe Disabilities Program (ACSD)
  - Disability tax credit (DTC)
  - Registered disability savings plan (RDSP)
  - Accessible parking permits
  - Respite services
- Review entertainment/ recreational opportunities
- Jordan's Principle and
- Inuit Child First Initiative (if applicable)

AGE 12-13
- Identify/connect with adult primary care provider (PCP)
- For highschool – request copy of Individual Education Plan (IEP) & Identificaton, Placement and Review Committee (IPRC) meeting
- Request psychological assessment or letter if youth is untestable from psychologist*

AGE 14
- Review transition tasks with care team/family
- Discuss goals & priorities for future planning, including Goals of Care
- Confirm IEP completion
- Discuss healthy relationships/ sexuality

AGE 15
- Annual transition planning meeting with care team/ family
- Begin Developmental Services Ontario (DSO) application to be submitted at age 16
- Learn about the adult care system
- Learn about Subsitute Decision-Maker (SDM)

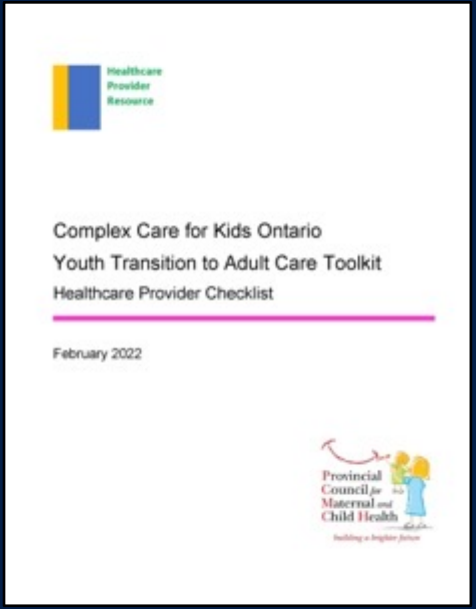
AGE 16
- Continue annual transition planning meeting with care team/family
- Submit DSO application*
- Annual appointment (appt.) with PCP from here
- Discuss referral to adult specialists with all paediatric specialists
- Discuss legal guardianship
- Explore providers for dental & vision care

AGE 17
- Periodic check-ins and final transition clinic meeting with care team/family
- Ensure appt. with all paediatric specialists to transfer care
- Overlapping/joint appt. with adult and paediatric specialists
- Develop a crisis plan of youth's daily routine
- Make a list of technology, equipment, supplies
- Submit Ontario Disability Support Program (ODSP) application at age 17.5*
- Transfer of home care services
- Determine future respite needs
- Request prescription refill for medications & enteral formula for 6 months
- Caregiver to have copies of care plan/key reports

AGE 18
- Last check-in with paediatric team/family
- Adult care providers to have care plan/last consultation note/relevant medical records
- Confirm 1st or 2nd appts. with PCP and all adult care specialists
- Receiving DSO and Passport funding, and ODSP after age 18

*** = Time-sensitive tasks**
This timeline presents some key tasks. Please see the full checklists and *Transition Resource Guide* for further details. Each age lists new tasks to do *in addition* to the items in the previous age as some tasks build on tasks listed in the preceding age.

HCP Checklist



Healthcare Provider Resource

Complex Care for Kids Ontario
Youth Transition to Adult Care Toolkit
Healthcare Provider Checklist

February 2022

Provincial Council for Maternal and Child Health
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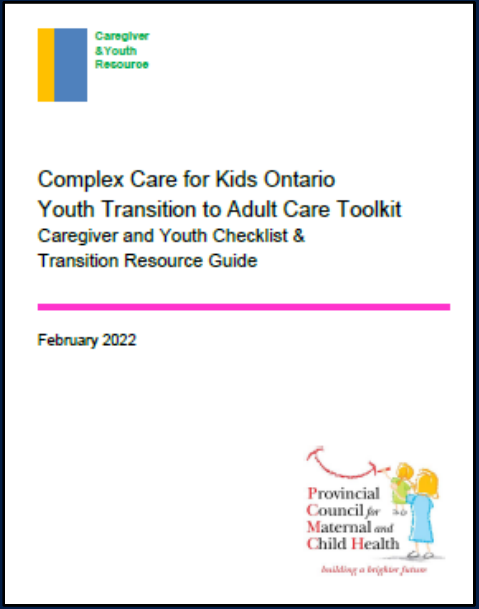
Youth & Caregiver Checklist



Caregiver & Youth Resource

Complex Care for Kids Ontario
Youth Transition to Adult Care Toolkit
Caregiver and Youth Checklist &
Transition Resource Guide

February 2022

Provincial Council for Maternal and Child Health
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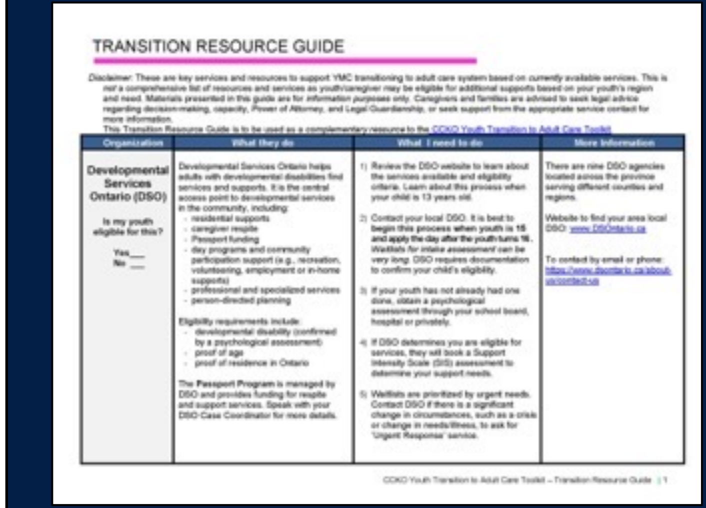
Transition Resource Guide



TRANSITION RESOURCE GUIDE

Disclaimer: These are key services and resources to support YMC transitioning to adult care system based on currently available services. This is *not* a comprehensive list of resources and services as youth/caregiver may be eligible for additional supports based on your youth's region and need. Materials presented in this guide are for *information purposes* only. Caregivers and families are advised to seek legal advice regarding decision-making, capacity, Power of Attorney, and Legal Guardianship, or seek support from the appropriate service contact for more information.
This Transition Resource Guide is to be used as a complementary resource to the CCKO Youth Transition to Adult Care Toolkit.

Organization	What they do	What I need to do	More Information
Developmental Services Ontario (DSO) Is my youth eligible for this? Yes___ No ___	Developmental Services Ontario helps adults with developmental disabilities find services and supports. It is the central access point to developmental services in the community, including: - residential supports - caregiver respite - Passport funding - day programs and community participation support (e.g., recreation, volunteering, employment or in-home supports) - professional and specialized services - person-directed planning Eligibility requirements include: - developmental disability (confirmed by a psychological assessment) - proof of age - proof of residence in Ontario The **Passport Program** is managed by DSO and provides funding for respite and support services. Speak with your DSO Case Coordinator for more details.	1) Review the DSO website to learn about the services available and eligibility criteria. Learn about this process when your child is 13 years old. 2) Contact your local DSO. It is best to **begin this process when youth is 15 and apply the day after the youth turns 16.** *Waitlists for intake assessment can be very long.* DSO requires documentation to confirm your child's eligibility. 3) If your youth has not already had one done, obtain a psychological assessment through your school board, hospital or privately. 4) If DSO determines you are eligible for services, they will book a Support Intensity Scale (SIS) assessment to determine your support needs. 5) Waitlists are prioritized by urgent needs. Contact DSO if there is a significant change in circumstances, such as a crisis or change in needs/illness, to ask for "Urgent Response" service.	There are nine DSO agencies located across the province serving different counties and regions. Website to find your area local DSO: www.DSOntario.ca To contact by email or phone: https://www.dsontario.ca/about-us/contact-us

CCKO Youth Transition to Adult Care Toolkit – Transition Resource Guide | 1

COMPLEX CARE FOR KIDS ONTARIO

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*** = Time-sensitive tasks**
This timeline presents some key tasks. Please see the full checklists and *Transition Resource Guide* for further details. Each age lists new tasks to do *in addition* to the items in the previous age as some tasks build on tasks listed in the preceding age.

Practical Tips: How can I use this Toolkit?

- The two Transition checklists are ***fillable*** – can be downloaded, saved and/or printed
- ***Inform*** families of the checklist as soon as you can and ***work in parallel*** with HCPs/ Complex Care team based on age
- ***Use the checklist as a guidance*** and consider youth and family's goals and expectations in the transition process
- ***Keep track of adult providers*** (PCP and adult specialists) as they are identified
- The ***bolded tasks*** are to be ***prioritized*** in the transition journey, putting ***deadlines is helpful*** to ensure tasks are not missed (prompting to set appt dates on caregiver's phone)

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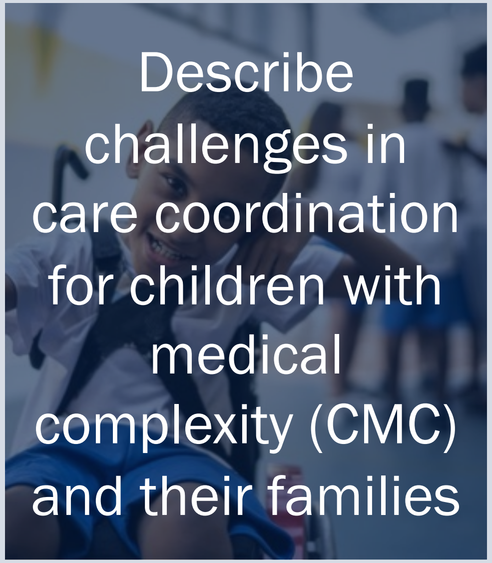
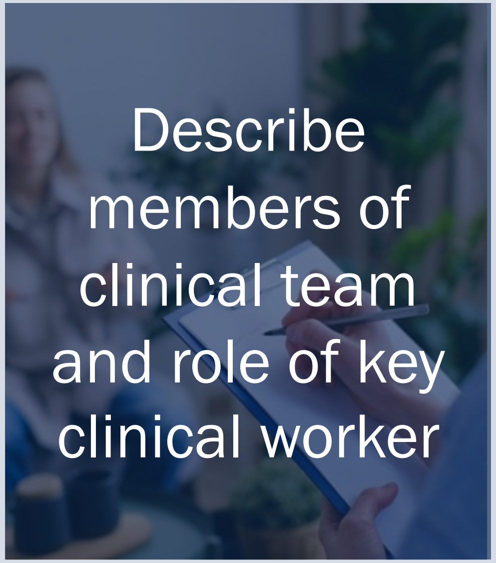
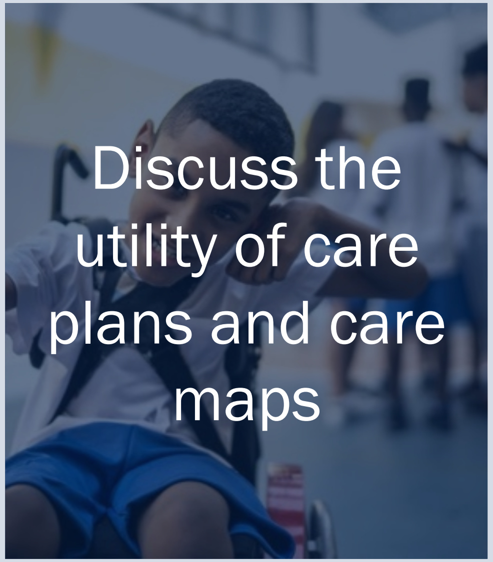
Learning Objectives



Describe challenges in care coordination for children with medical complexity (CMC) and their families



Describe members of clinical team and role of key clinical worker



Discuss the utility of care plans and care maps

Review an approach to transition to adult care for CMC

THANK YOU