Reflections on the Emergence of Pediatric Complex Care

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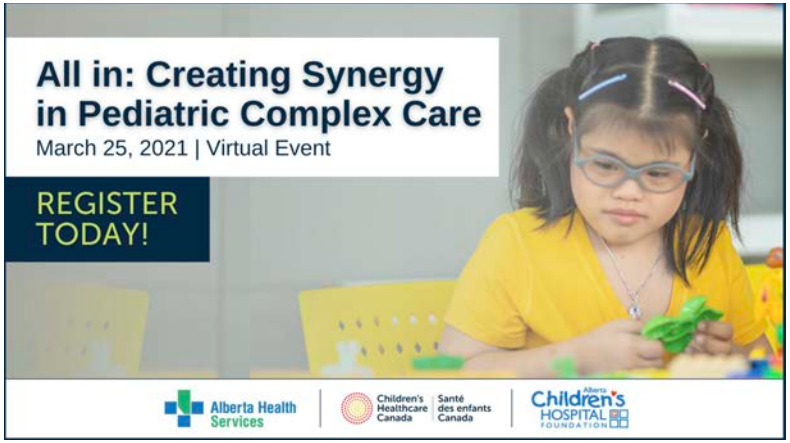
Staff Physician, Division of Pediatric Medicine, Hospital for Sick Children

All in: Creating Synergy in Pediatric Complex Care, March 25, 2021



SickKids® COMPLEX CARE

UNIVERSITY OF TORONTO

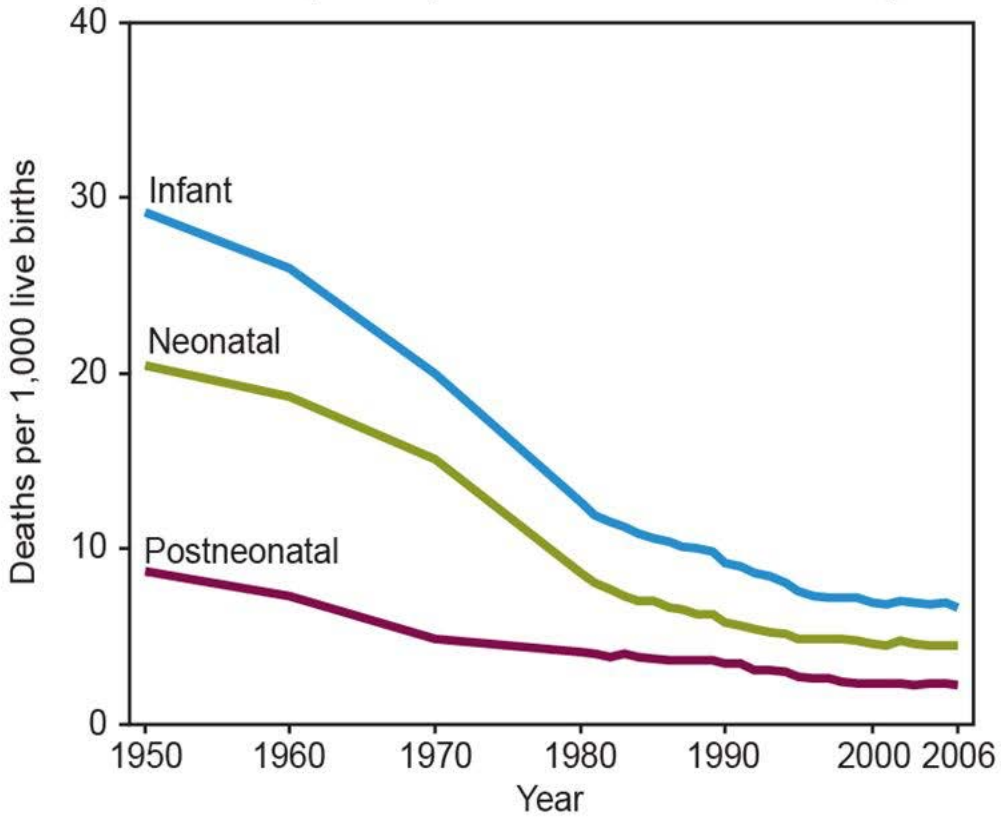
Objectives

1) **WHY**? To describe the growth of populations of children, youth and adults with complex care needs

2) **WHAT**? To explore the challenges of care delivery aimed at this population from the perspectives of patients, their families, their clinicians and the health care system

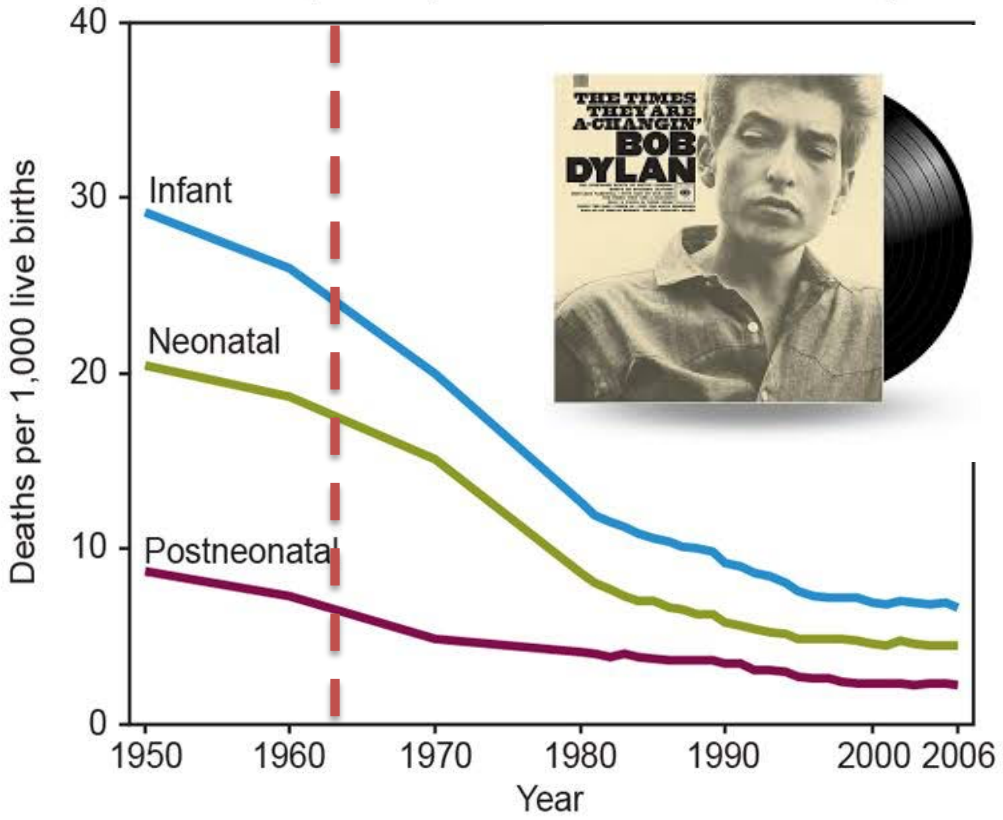
3) **HOW**? To discuss promising tools and programmatic initiatives to better care for this population.

The Times They are A-Changin



SOURCE: CDC/NCHS, *Health, United States, 2009*, Figure 17. Data from the National Vital Statistics System.

The Times They are A-Changin (1963)



SOURCE: CDC/NCHS, *Health, United States, 2009*, Figure 17. Data from the National Vital Statistics System.

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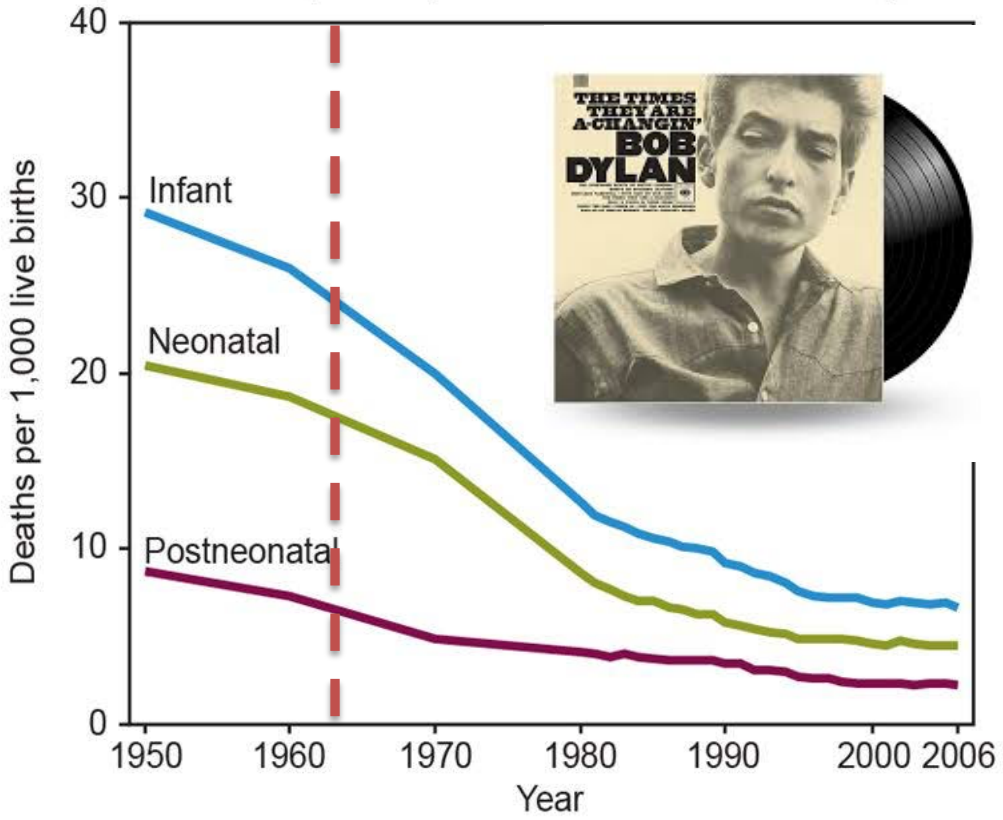


SOURCE: CDC/NCHS, *Health, United States, 2009*, Figure 17. Data from the National Vital Statistics System.

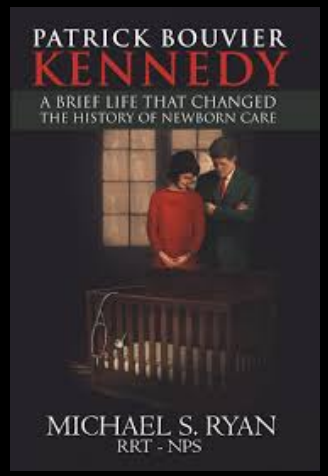
The Rus

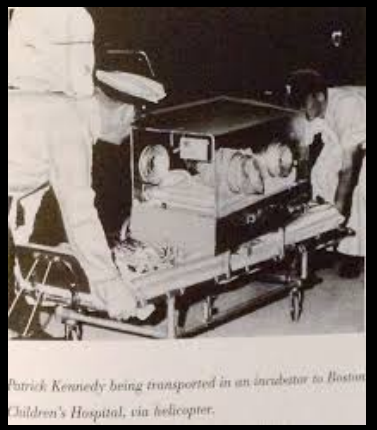
Russell County's Only Daily Paper

VOL. XXXIII — NO. 185

Jackie Gives Birth To Son Prematurely

Wife of President Rushed to Hospital





Patrick Kennedy being transported in an incubator to Boston Children's Hospital, via helicopter.

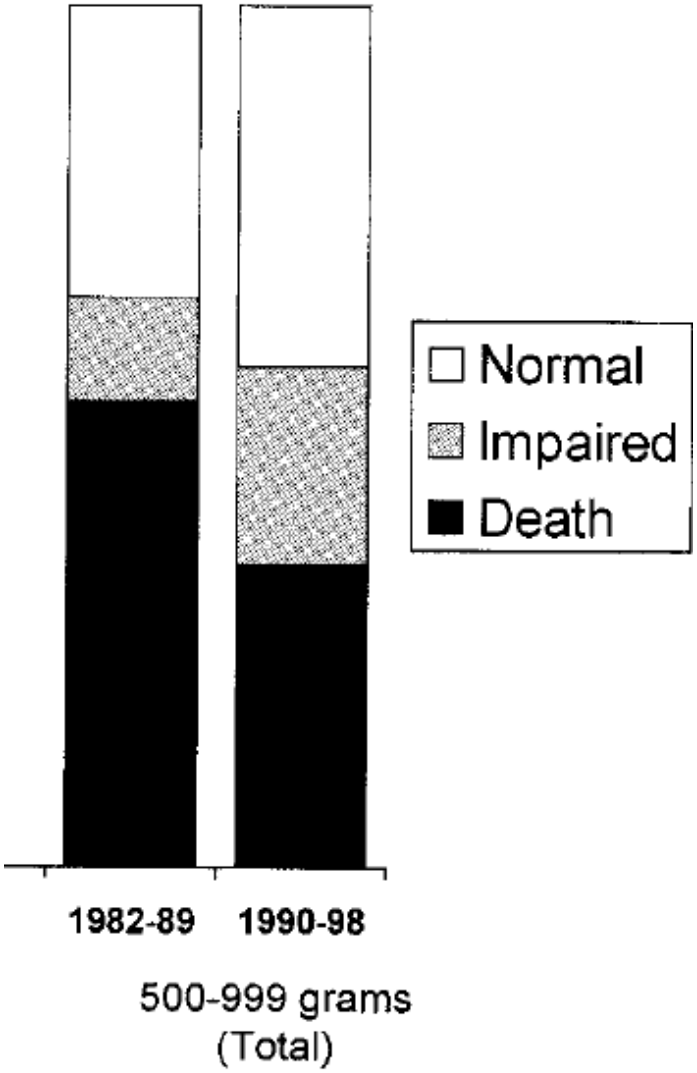
The Detroit Free Press

NEW KENNEDY SON IS HIT BY BREATHING AILMENT

Baby Rushed To Specialists

Officer Clear In Scott Case – Edwards

Auto Plunges Into River; 2 Women Die



Wilson-Costello et al., Pediatrics, 2005

Surgical Innovations (1963)

Surgical Team And New Operation Save Life Of Three-Year-Old Girl

TORONTO (CP)—Debbie is a three-year-old patient in the Hospital for Sick Children who owes her life to a Toronto surgical team and a new operation.

A few months ago she faced almost certain death. Today she is on the road to complete recovery from a heart abnormality which in the past has been fatal for 90 per cent of its tiny victims.

Debbie was at the opening session of the joint annual meeting here of the Canadian Heart Foundation and Canadian Cardiovascular Society. She was presented as an example of what heart funds can do.

When she was born she had what is known as total transposition of the great vessels of the heart. The aortic and pulmonary arteries which carry blood to the lungs and to the body were transposed.

The result was the heart's best merely circulated part of her blood back and forth to the lungs and the rest simply circulated back and forth in the body. No freshly oxygenated blood went to the body to replenish tissue and bone.

Victims of this condition live a few years at most. Even this short period of life is possible only because nature somehow managed to provide a makeshift "shunt" by which blood leaks between the heart chambers, enabling blood from the lungs to get into the circulatory system.

REVERSE HEART

When Debbie was three weeks old Dr. William Mustard and a team of surgeons artificially widened a tiny abnormal hole in her heart wall through which some oxygen-enriched blood could leak to prolong her life. Then, while waiting for her to reach an age when she could undergo an operation, the surgeons practised on animals.

Last May she was put on a heart-lung machine which bypassed her heart. Then the veins which bring blood back to the heart were severed, shifted into reverse positions and sutured into place.

This meant that Debbie had a heart that worked backwards from normal. But it was doing exactly the correct job. Instead of the right side of the heart bringing blood back from the body and into the lungs, it took over the task of the left side.

At the time doctors thought the operation was the first of its kind but several weeks ago they learned a similar operation was performed at almost the same time by a University of Cincinnati team.

So far as is known, these are the first two small children to undergo such operations though a Swedish surgeon a year ago did a successful operation for a comparable condition on an older child.

Presents Mrs. N. Abbey With Nursing Certificate

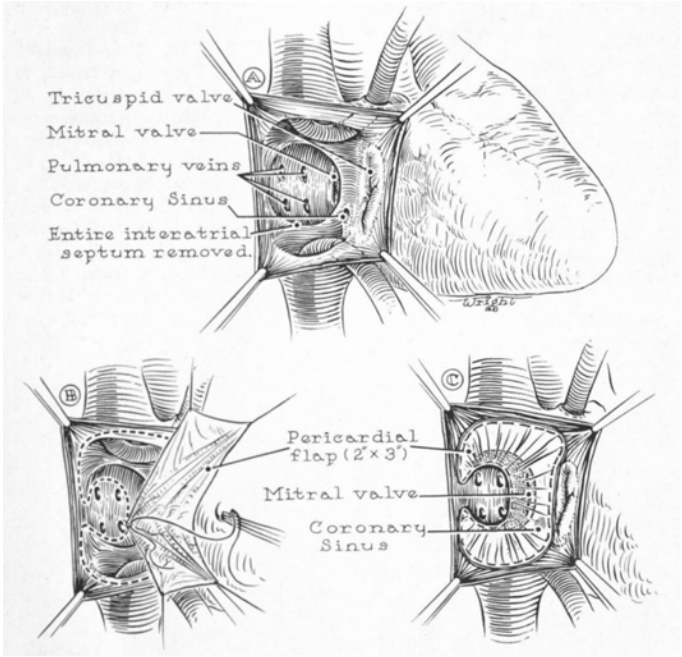
The St. John Ambulance nursing sisters attended a social gathering recently at which L. V. Smith presented a 10-year nursing certificate to Mrs. Nelson Abbey.

Cpl. C. Brown of the Ambulance Brigade gave practical tests at the first aid meeting.

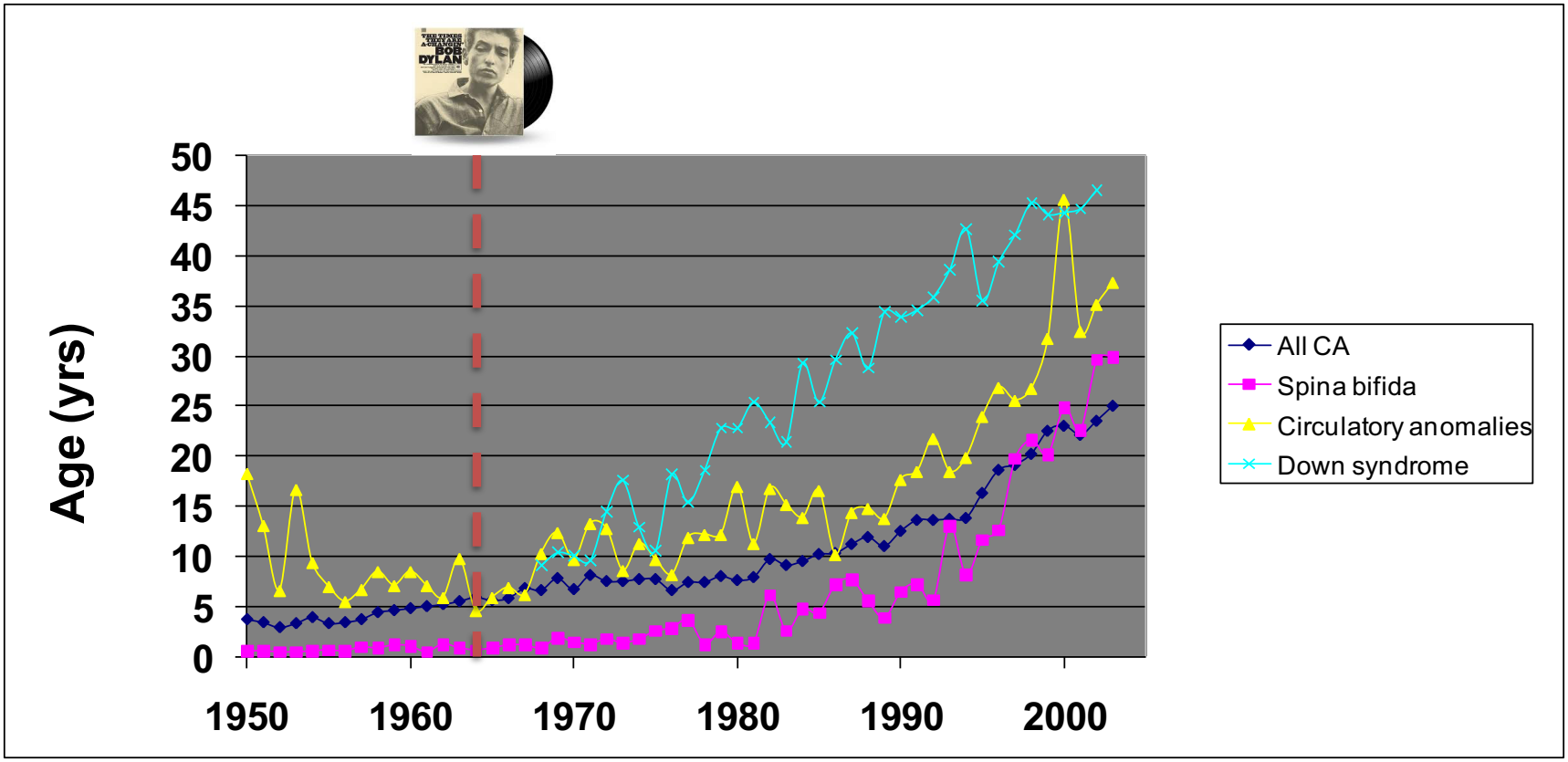
Mrs. P. S. Golding, district superintendent, presented 10-year certificates to Mrs. G. W. Henderson and Mrs. Frank Gauthier at the home nursing meeting. regular meetings will resume Jan. 7, with practical tests being taken.

Celebrates 80th Birthday

ALEXANDER (Special)—Mr. and Mrs. Ralph Speer entertained at a family dinner in honour of Mrs. Speer's grandfather, Mr.



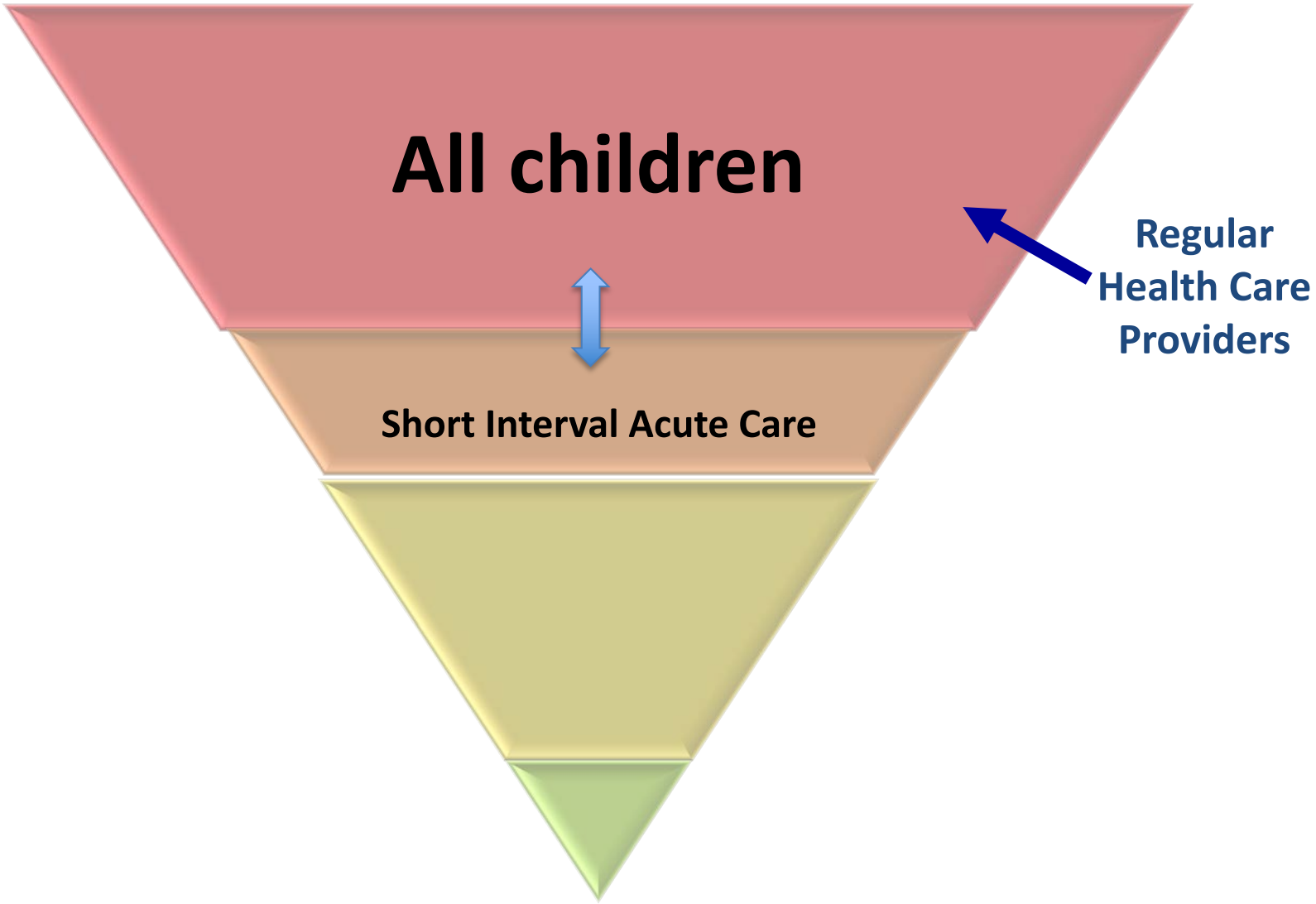
The Times They Are A-Changin



CA = congenital anomalies

Source: Russell Wilkins (Health Information and Research Division, Statistics Canada). *Used with permission*

Children's Health Care Needs



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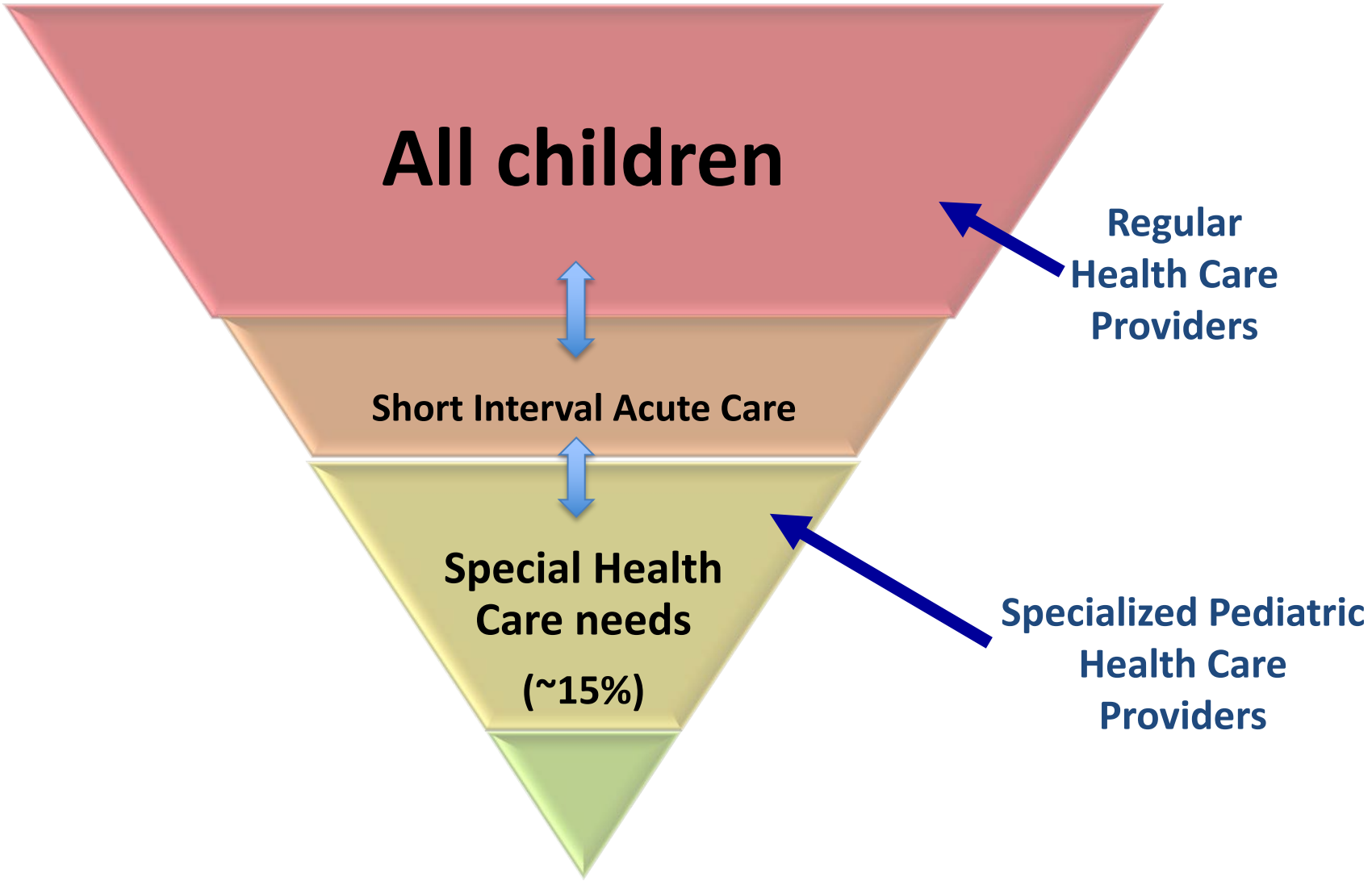

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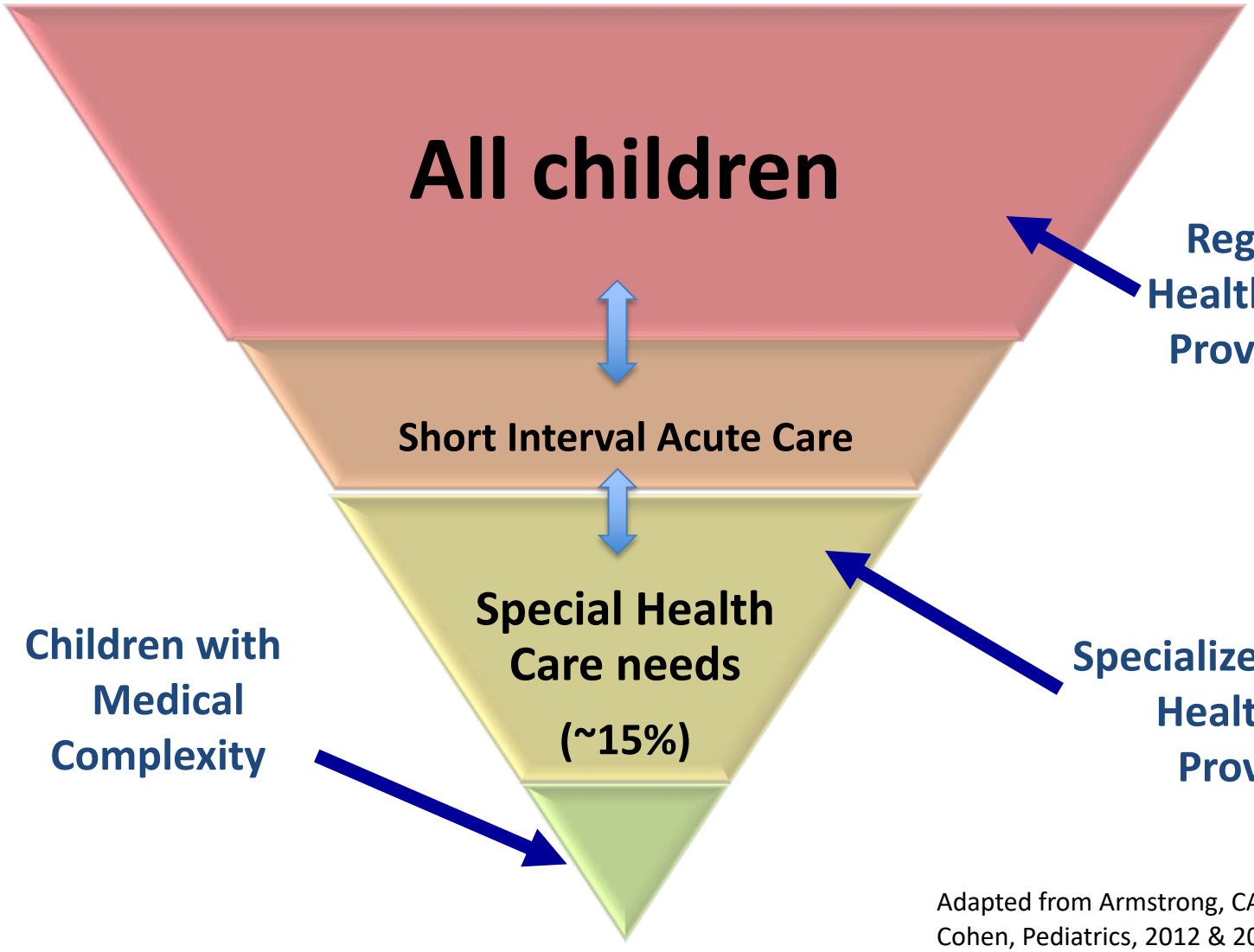
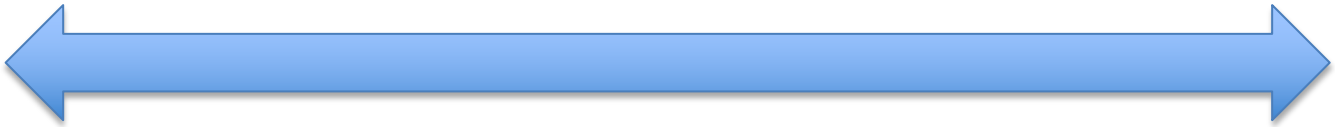


Adapted from Armstrong, CAPHC 2004; and, Cohen, Pediatrics, 2012 & 2018.

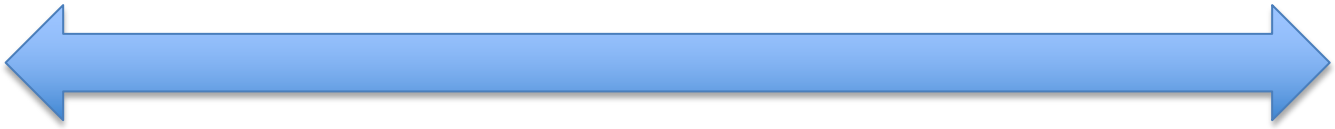
Defining Complexity



Complicated

Complex

Defining Complexity



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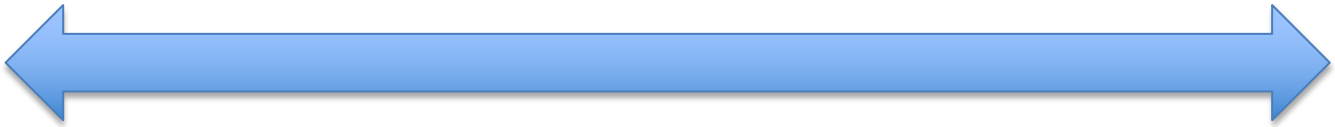

Complicated

Complex

Complexity

- Complexity implies:
  - **Breadth:** The principle of *multiplicity*
    - needs, body systems, specialists, funders, etc.
    - these are inter-related
  - **Depth:** The principle of *intensity*
    - Disability/functional impairment, medical fragility, seriousness of underlying condition

Rankin J & Regan S (2004), *Meeting Complex Needs: The Future of Social Care*, London: Turning Points/ Institute of Public Policy Research

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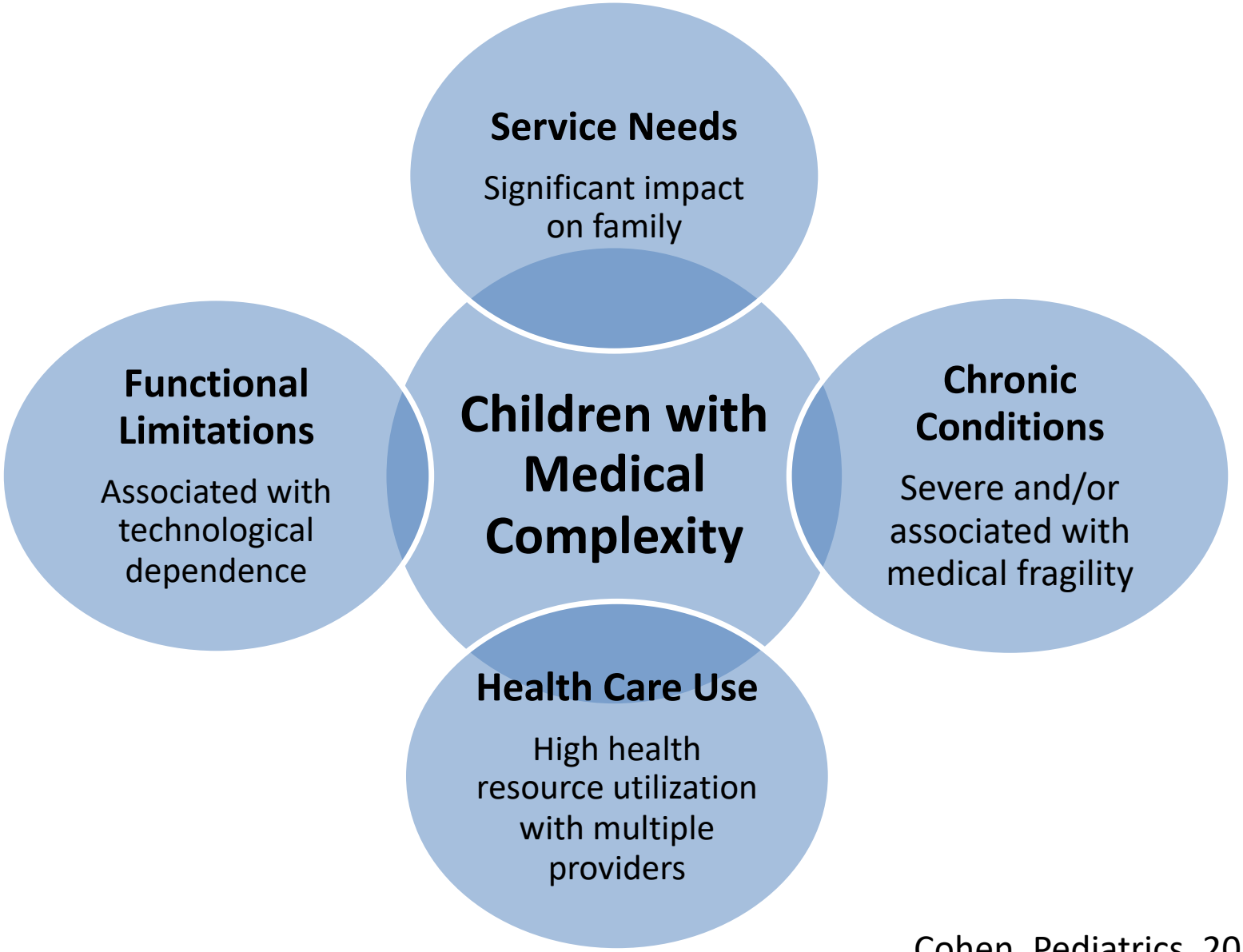
Rankin J & Regan S (2004), *Meeting Complex Needs: The Future of Social Care*, London: Turning Points/ Institute of Public Policy Research

CMC: A Definitional Framework



Cohen, Pediatrics, 2011

Children with Medical Complexity in Ontario

- Total population = **15,771** in Ontario (population 14.5 million)
  - Represented **0.67%** of all children
- Median of:
  - **13** distinct physicians
  - **6** distinct medical specialties
- Accounted for **32.7%** of all child health spending
- Biggest components of care: **hospital care and home care**

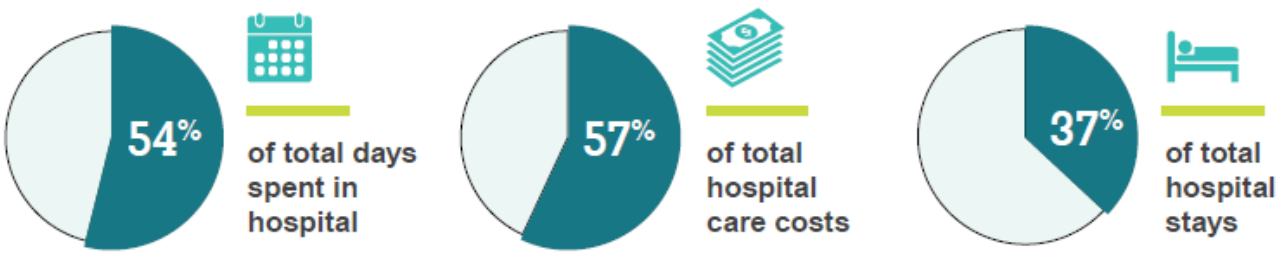
Cohen, Pediatrics, 2012

Children and youth with medical complexity are the highest users of health care services.

This population's unique needs mean

they require more health care compared with other children and youth

2015–2016



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

Other Risks for Children with Medical Complexity

- More likely to need ICU (Srivastava, Ped Clin N Am, 2005)
- More likely to have "preventable" admissions (e.g. inadequate care coordination) (Dosa, Pediatrics, 2001)
- Hospital readmission common (Berry, Jama, 2011)
- Medical error more common (Slonim, Pediatrics, 2003)

NOVEMBER 4, 2014, VOL. 186(16)
WWW.CMAJ.CA

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MEDICAL KNOWLEDGE THAT MATTERS

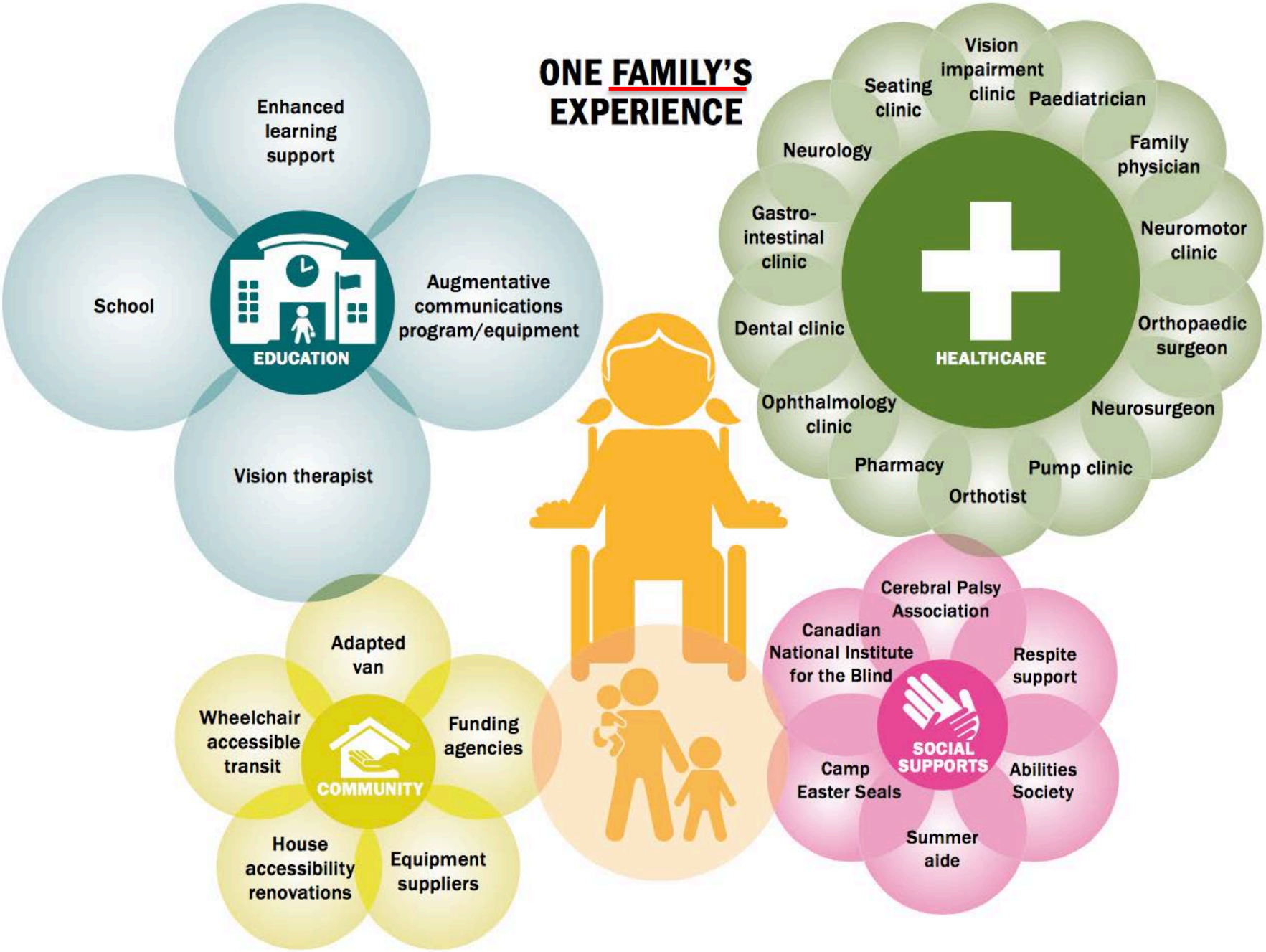
Chronically ill children
The personal and financial strain

RESEARCH
The validity of recommendations from clinical guidelines

GUIDELINES
Recommendations on screening for prostate cancer

PRACTICE
Prednisone and infection risk in an older male patient

Publications Mail Agreement no. 41387051; USPS #0762-530.



Source: Kidshealthalliance.ca

Sleep

Family Caregivers of Children with Medical Technology vs. Controls

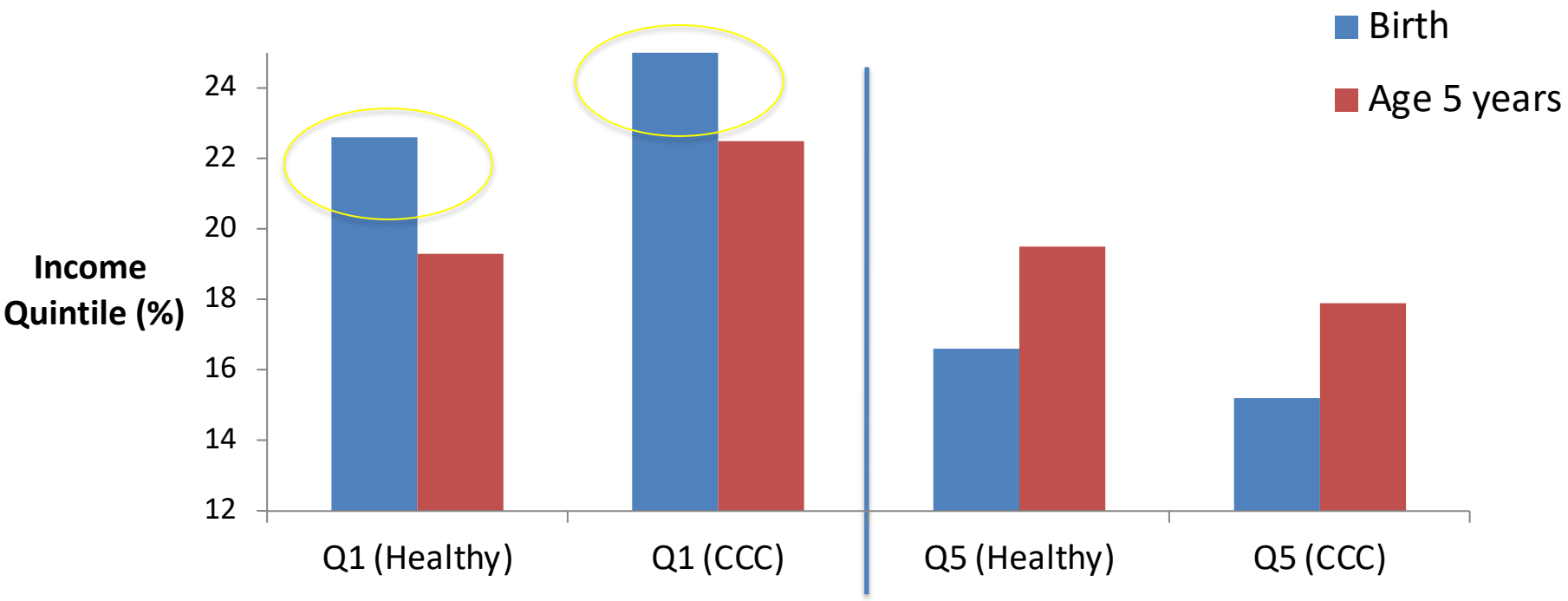
Table 3 Between-group differences on sleep and related outcomes

	FC CMT	FC control	
Sleep outcomes	Mean±SD or count (%)		p Value
Objective measures			
Total sleep time—night (hours)*	6.56±1.4	7.21±0.6	0.019†
Total sleep time—day (hours)*	0.36±0.4	0.15±0.2	0.004†
Longest sleep session—night (hours)*	2.96±1.3	4.21±1.7	0.001
Longest sleep session—day (hours)*	0.24±0.3	0.10±0.1	0.004
Nocturnal awakenings—objective*	8.00±3.9	6.01±3.7	0.014†
Subjective measures			
Sleep quality (PSQI)	7.75±2.9‡	5.45±2.8§	0.001†
Sleep onset latency >30 min¶	68 (23.1)	33 (11.0)	0.001**
Nocturnal awakenings— subjective	2.35±2.0‡	1.42±1.5§	0.005

Keilty, Arch Dis Child, 2018

Family Income

Newborns with Complex Chronic Conditions (CCCs) vs. Healthy Newborns over first 5 years of life



Data from:
Ontario, Canada

Q1 = lowest income
Quintile (poor)

Q5 = highest income
Quintile (rich)

Cohen, Int J Equit Health, 2013

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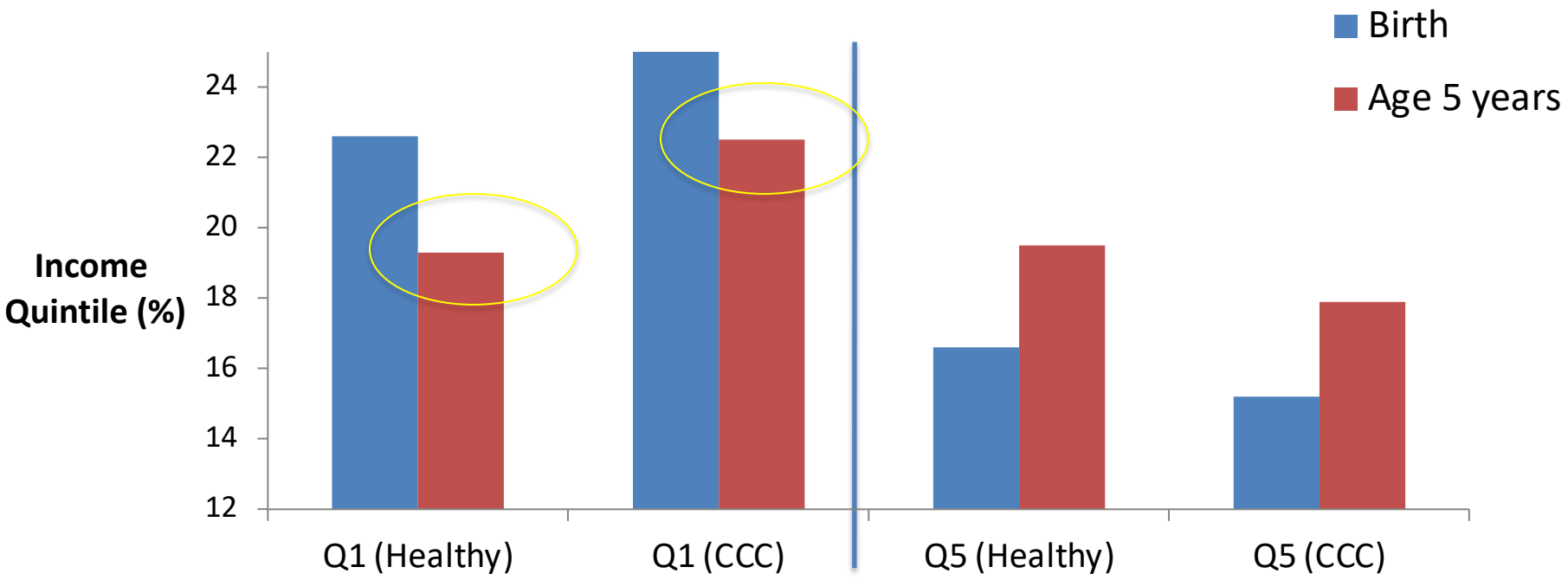

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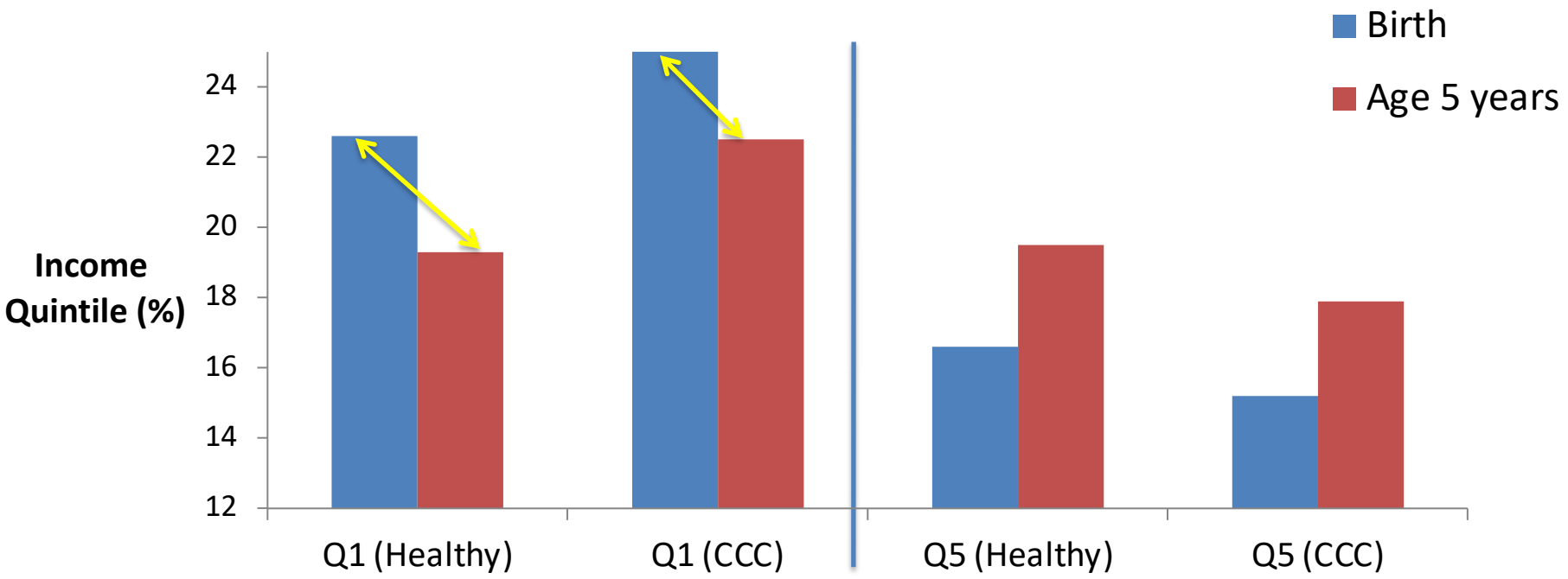

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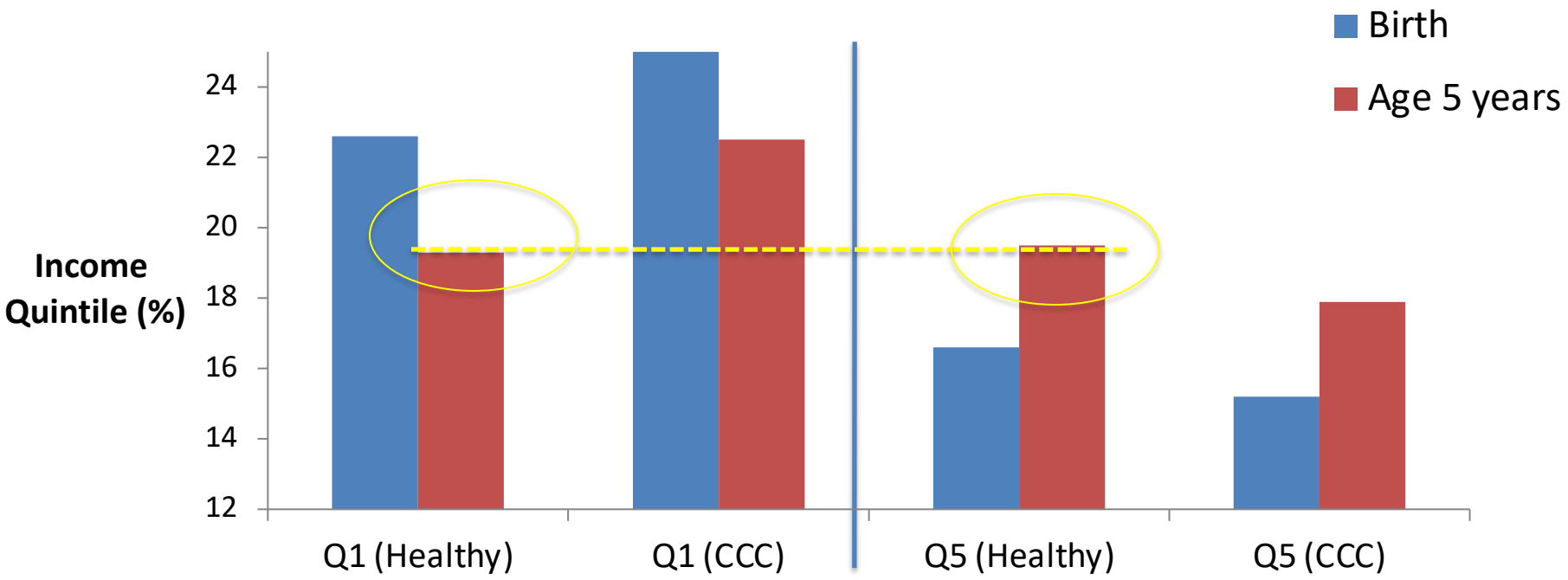

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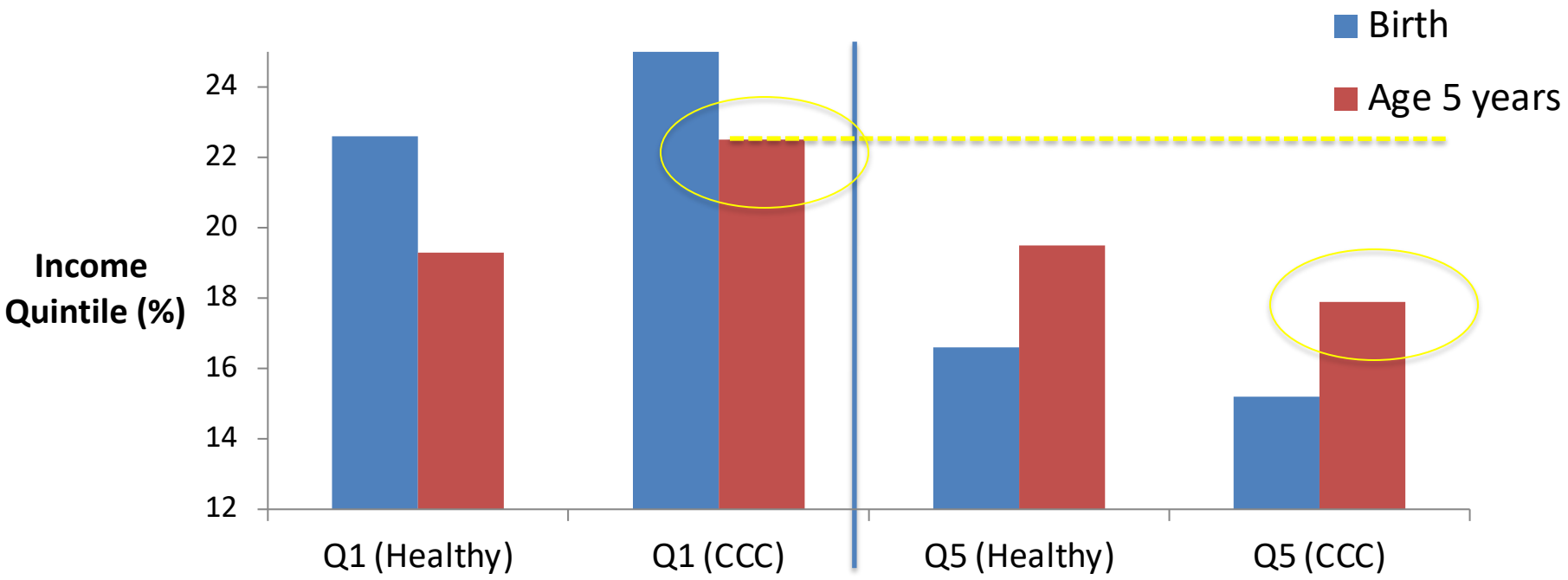

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Ontario, Canada

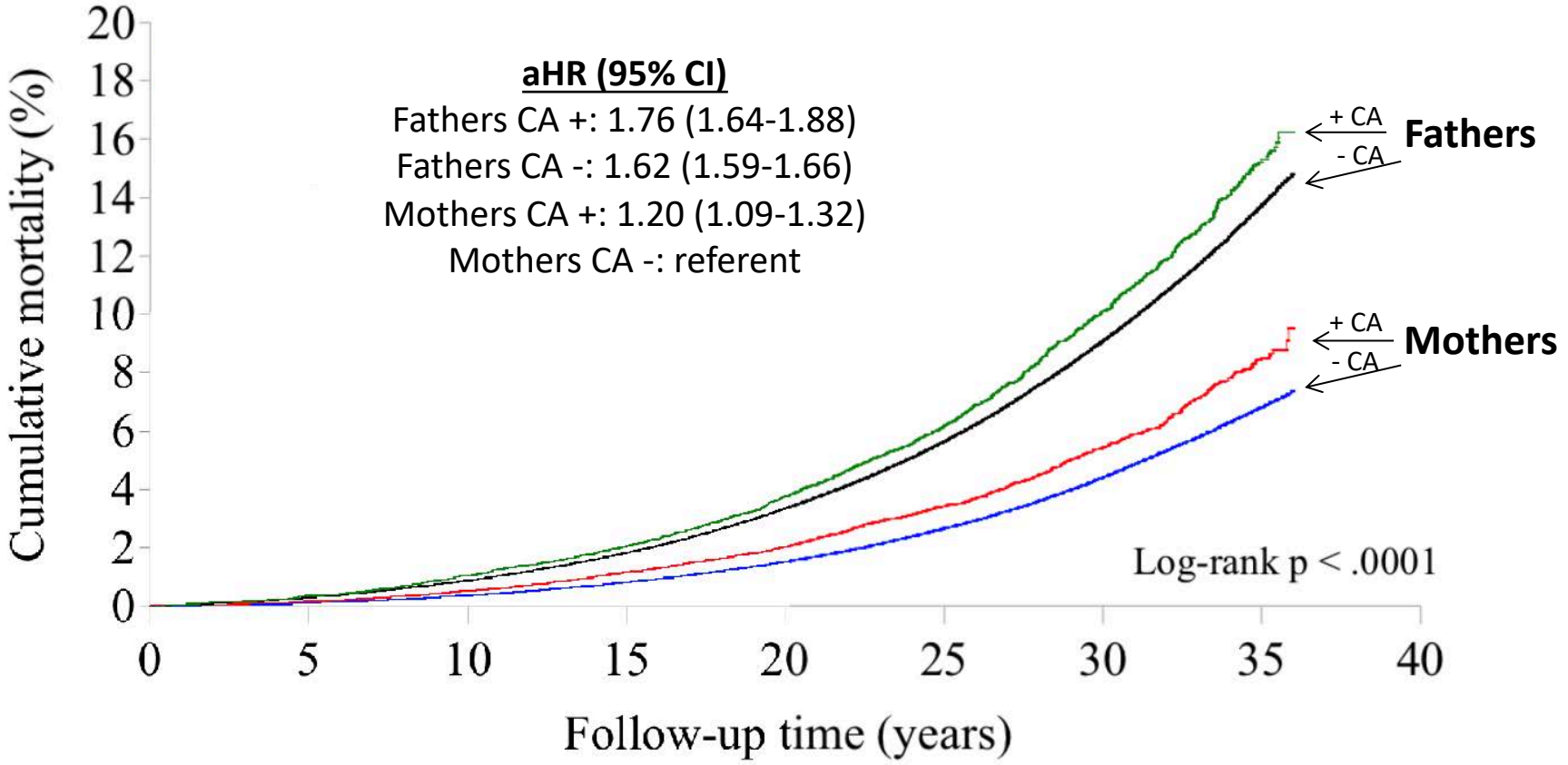
Q1 = lowest income
Quintile (poor)

Q5 = highest income
Quintile (rich)

Cohen, Int J Equit Health, 2013

Mortality (mothers and fathers)

-- + and - child with congenital anomalies (CA)

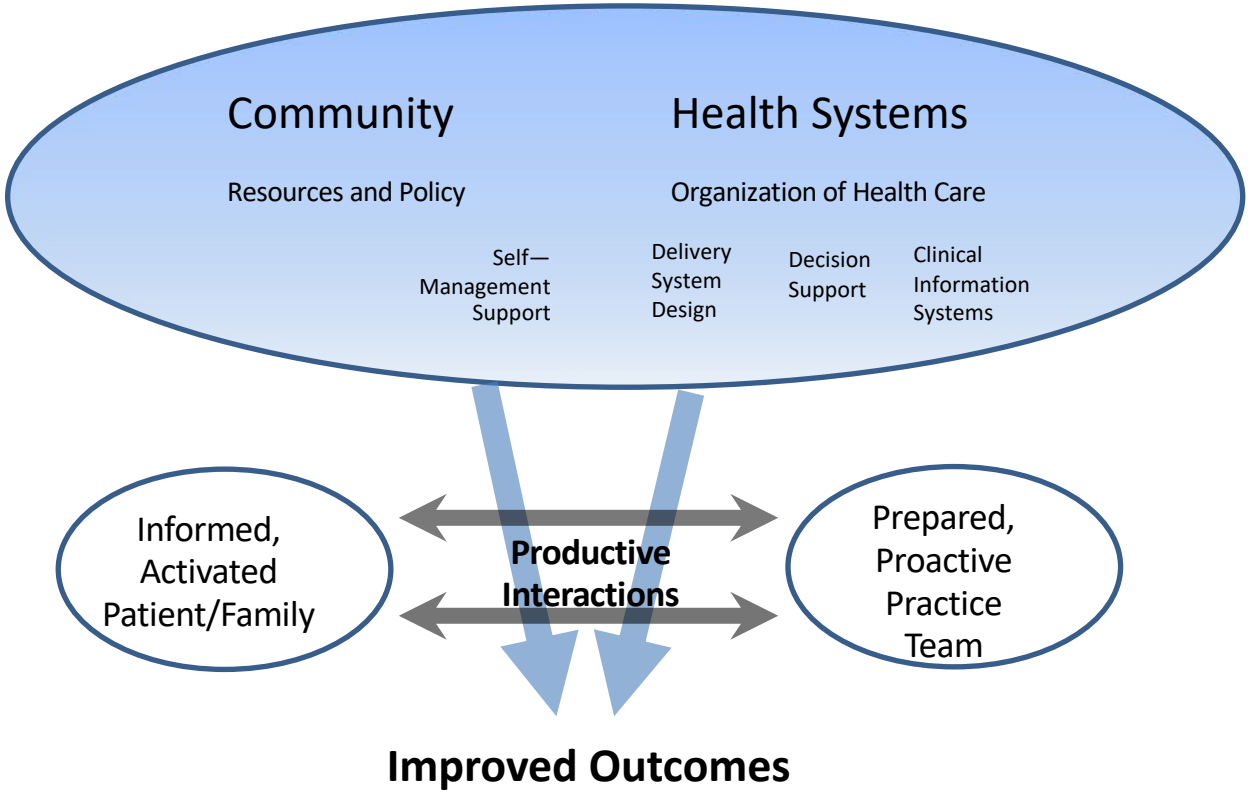


Controlled for matching variables (maternal age, year of delivery, parity) and adjusted for maternal demographics (marital and immigration status), SES (income quartile and education level), previous maternal health, previous spontaneous abortion, pregnancy complications

Fuller, Pediatrics, 2021 (in press)

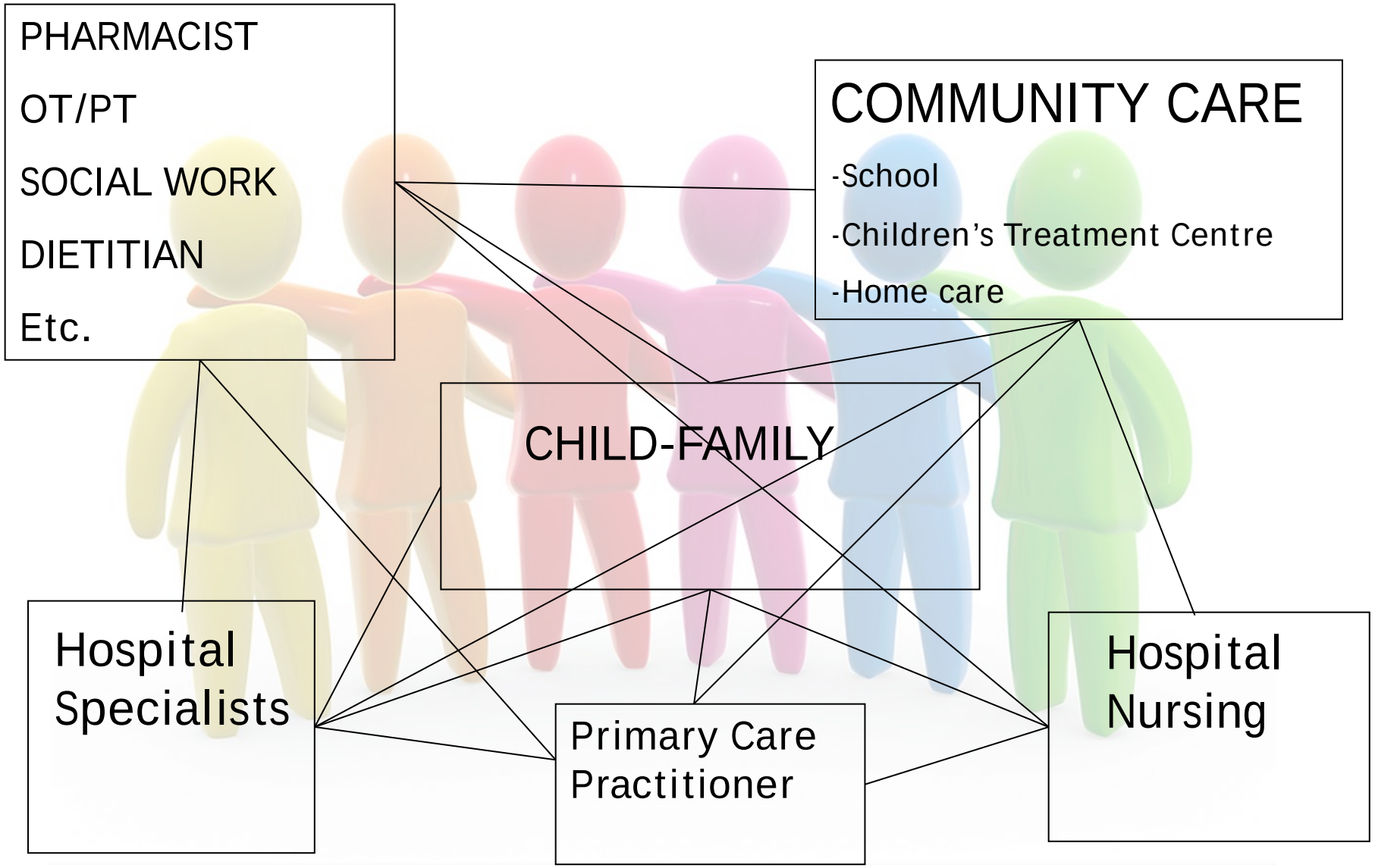
So what works??

The Chronic Care Model

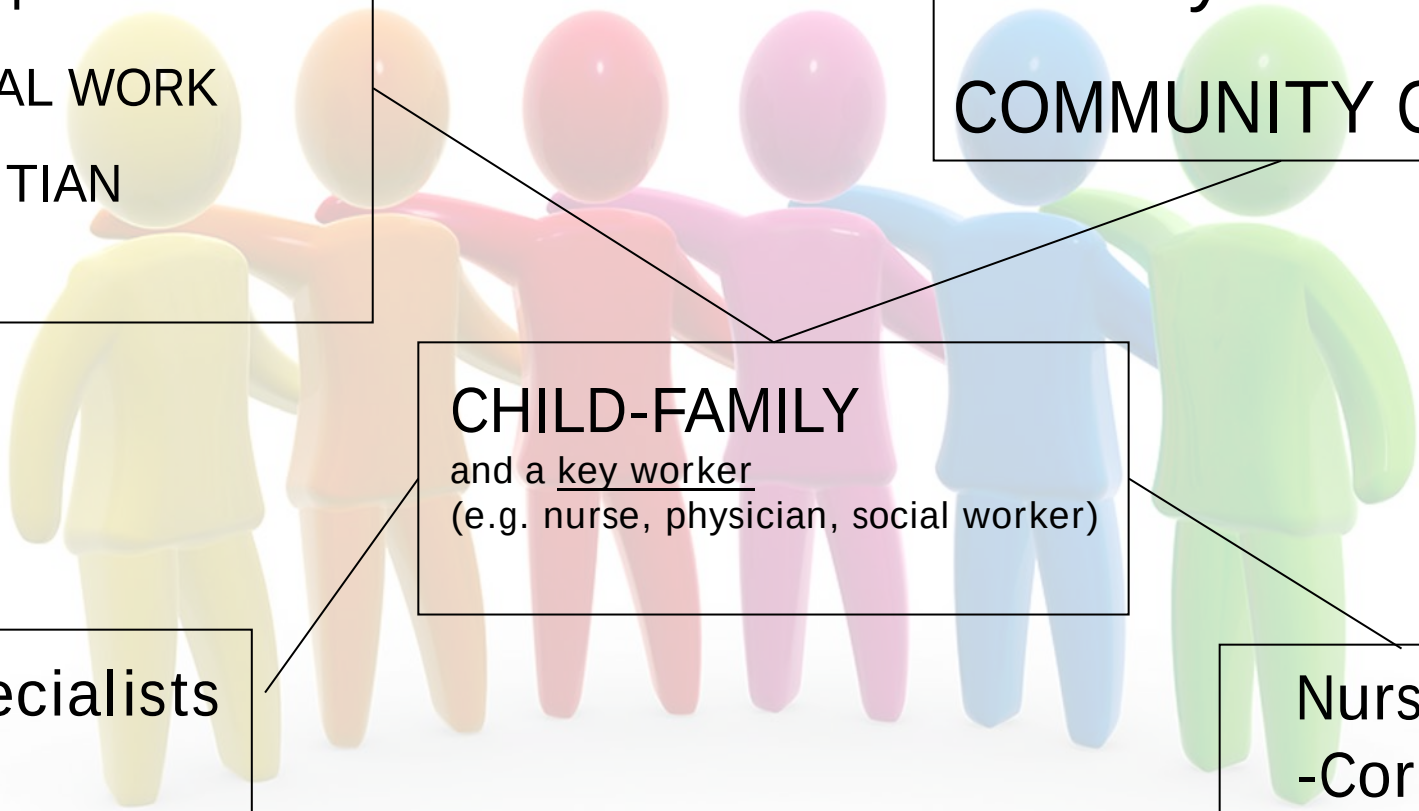


Adapted from
Wagner, Eff Clin Pract., 1998

Complex Care Team



Complex Care Team



PHARMACIST

OT/PT

SOCIAL WORK

DIETITIAN

Etc.

Primary Care

COMMUNITY CARE

CHILD-FAMILY

and a key worker

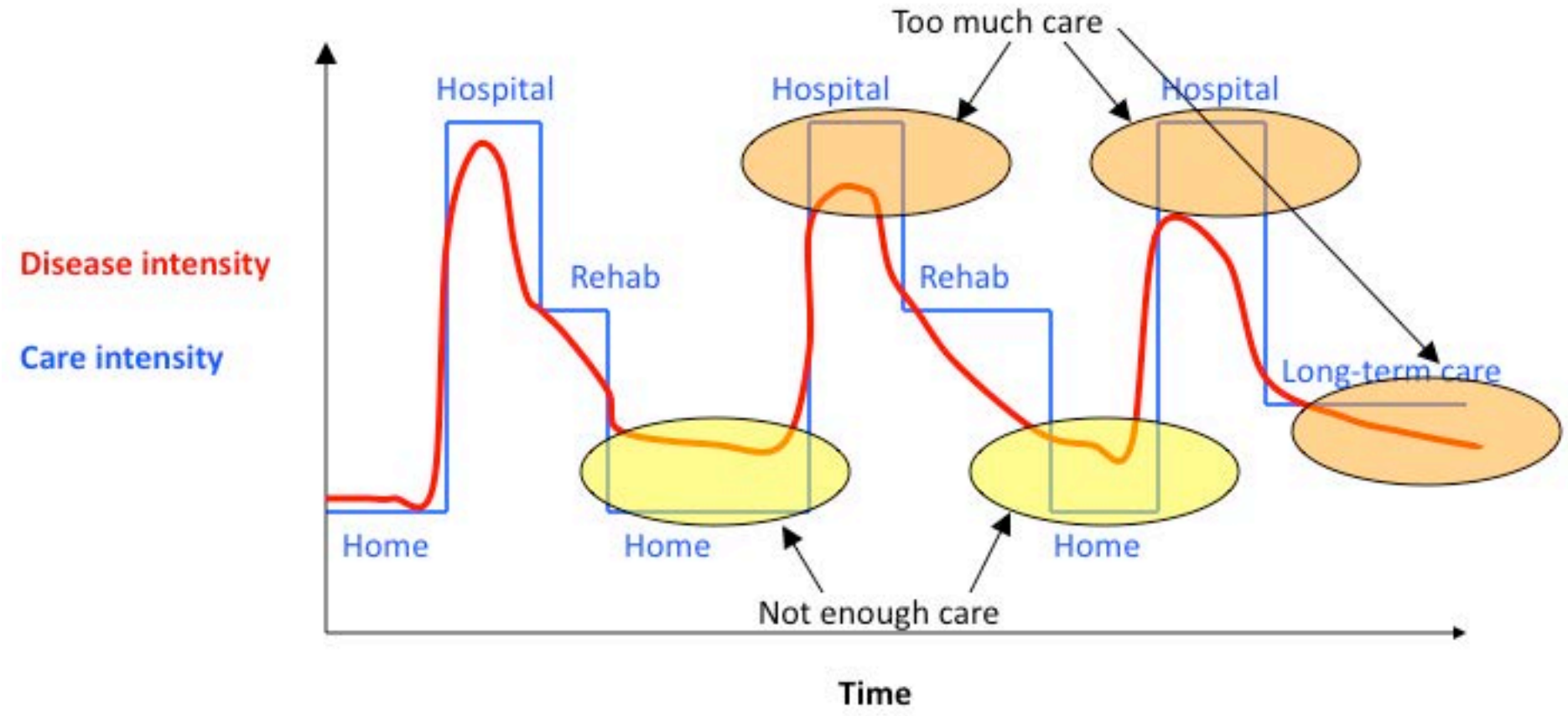
(e.g. nurse, physician, social worker)

Specialists

Nursing

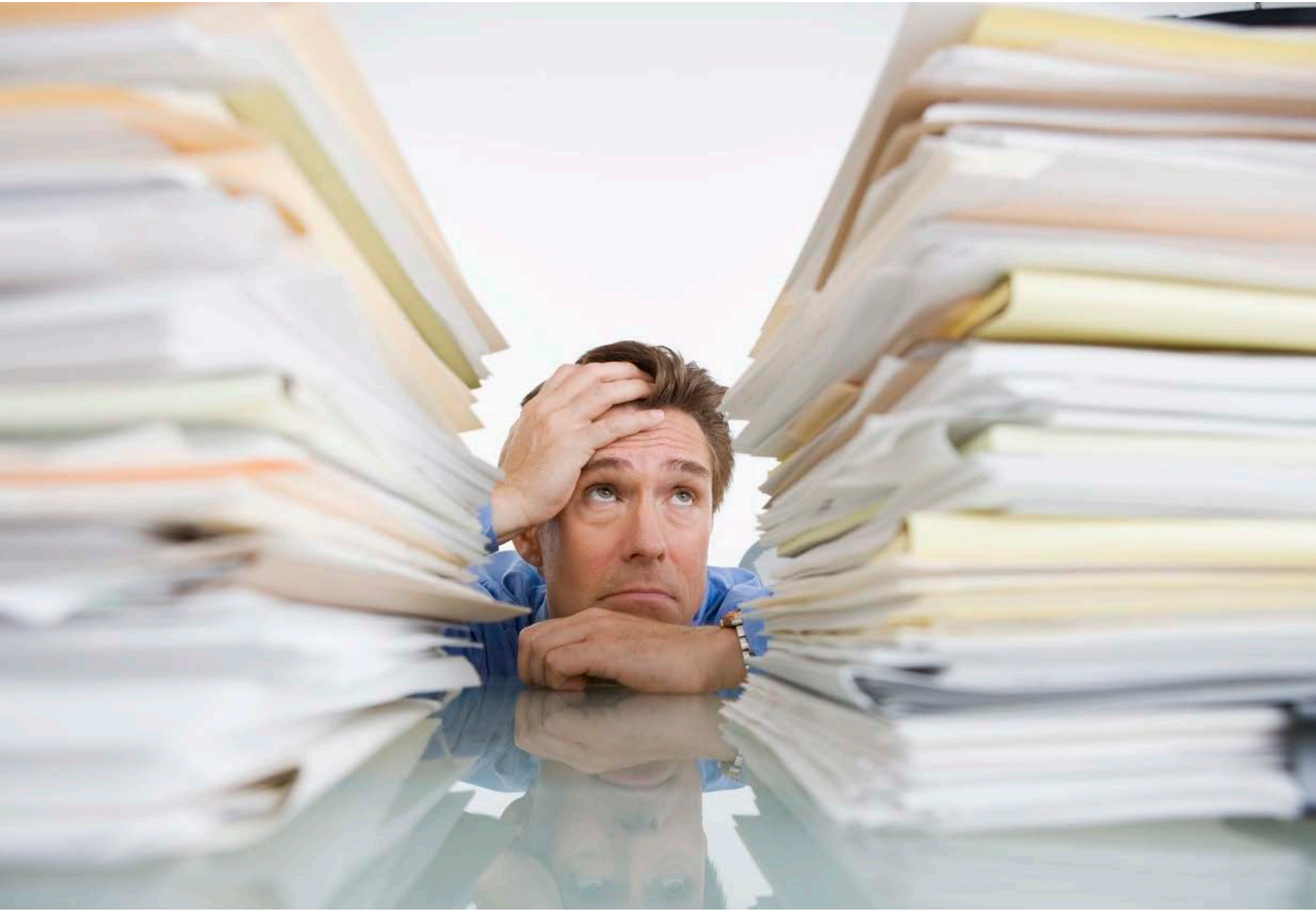
-Core Nursing

Care and Disease Intensity Discordance



Slide Courtesy of: Irfan Dhalla MD

Tools



The 'written' care plan

COMPREHENSIVE CARE PLAN

PATIENT NAME
PARENT/GUARDIAN NAME
Address, Telephone numbers, E-mail address
Medical Record Number
DOB
Allergies
Resuscitation Status
Primary Diagnosis
Secondary Diagnoses

EMERGENCY MANAGEMENT GUIDELINES

Common presenting signs, symptoms, and diagnoses
An approach for work-up
An approach to treatment
Name and contact information for PNP or PH who best knows patient

Procedural Preparation
List any information that is relevant to preparing the child for a procedure
This may include something as straightforward as an IV start

PATIENT DIAGNOSES

Main Diagnosis and relevant information
List common presentations
List relevant test results

Secondary Diagnosis (list all diagnoses)
List common presentations
List relevant tests results

Medications
Scheduled
PRN
Supplements

Nutrition
Formula, route, frequency, duration, calories for enteral or parenteral feeds

Hospitalizations
Date of Admission – Date of Discharge and main issues during hospitalization

Primary Care Provider & contact information

Hospital Contacts and Specialists Involved
List Names and contact phone/e-mail for all involved
Physicians
Nurse Practitioners
Allied Health professionals (e.g. dietitian, social work)
Sub-Specialists

FIGURE 2: Complex Care Comprehensive Care Plan Template

Adams, et al., Hosp Pediatrics, 2009

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)

Adams, *BMC Pediatrics* 2013; Adams, DMCN, 2017


SUCCESS

Examples from Alberta we heard about today!

- **ACH Neurodevelopmental Disorders (NDD) project**
  * Promising outcomes; meaningful to stakeholders!
- **COAST (Community Outreach and Assessment Team)**
  * Cross-ministerial collaboration!
- **First Nations Health Consortium**
  * Substantive equality

Innovations can be hard to spread

CMAJ EDITORIAL

FRANÇAIS À WWW.JAMC.CA

A country of perpetual pilot projects

Hon. Monique Bégin PhD
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University of Ottawa, Ottawa, Ont.
Laura Eggertson BA
Journalist
Noni Macdonald MD MSc
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With the Editorial-Writing Team (Paul C. Hébert MD MHSc,
Matthew B. Stanbrook MD PhD, Ken Flegel MDCM MSc)

Canadian health policy – "narrow but deep" – a barrier to integration

- Federal role (with exceptions) largely advisory
- Canada Health Act: hospitals and doctors
- Mishmash of coverage of:
  - dental care, drugs, developmental services, home care, school-based services, respite, coordination

Provincial Initiatives - Complex Care Kids Ontario (CCKO)

Ontario Ministry of HEALTH AND LONG-TERM CARE

Provincial Council for Maternal and Child Health
building a brighter future

Ontario Ministry of Health & Long-term Care

- **Mission:**

* Province-wide access to integrated care and coordination for children/youth who persistently demonstrate the most complex medical care needs

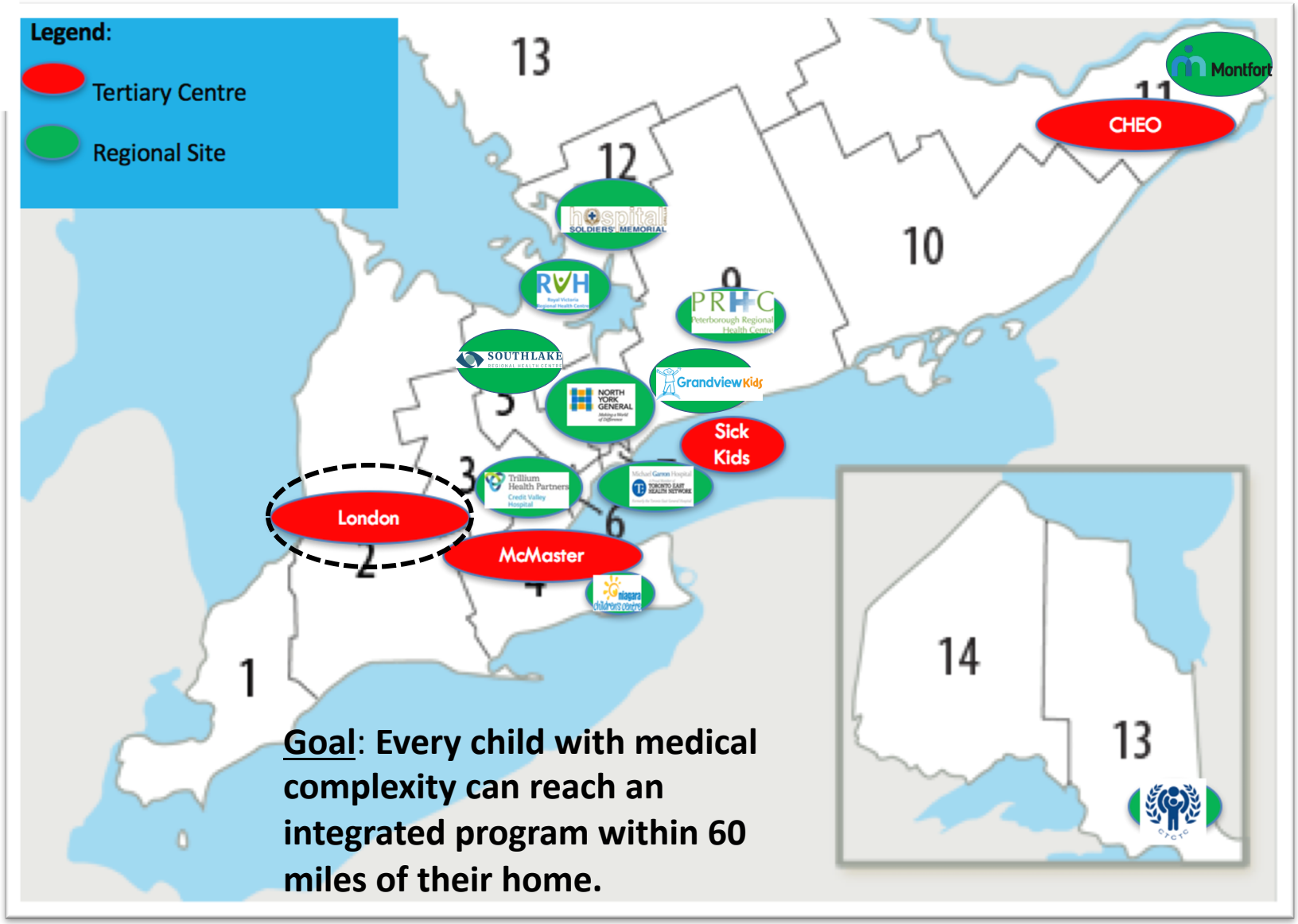
- **Strategic Outcomes:**
  - ✓ Improved child/youth & family experience & outcomes
  - ✓ Improved collaboration and communication between providers
  - ✓ Improved system efficiency, effectiveness and sustainability

Inclusion criteria

At least one criterion from each of the following categories:

Technology-Dependent *and/or* **High Intensity Care** & **Fragility** & **Chronicity** & **Complexity**

Ontario sites



ECHO sessions include:

Didactic Presentations

Quick 10—15 minute presentation on topics selected using comprehensive needs-assessments and feedback from participants.

Q&A Period

An opportunity to ask questions and share additional knowledge.

Case-based Learning

Case discussions among an interprofessional health network garnering multi-modal treatments and recommendations for healthcare providers to consider.

Join **virtual** and **accredited*** community of practice

**Paediatric Project ECHO is a self-approved group learning activity (Section 1) as defined by the Maintenance of Certification program of The Royal College of Physicians and Surgeons of Canada.*

Project ECHO®

sickkids.echoontario.ca

@ECHOPaeds

Parent Well-Being

SickKids CHEO The Ottawa Hospital / L'Hôpital d'Ottawa BC Children's Hospital

Hôpital de Montréal pour enfants Centre universitaire de santé McGill Montreal Children's Hospital McGill University Health Centre Mount Sinai Hospital Sunnybrook Health Sciences Centre

CHILD-BRIGHT Network

IWK Health

CIHR IRSC Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

CHILD-BRIGHT Network

Strongest Families™ NEURODEVELOPMENTAL

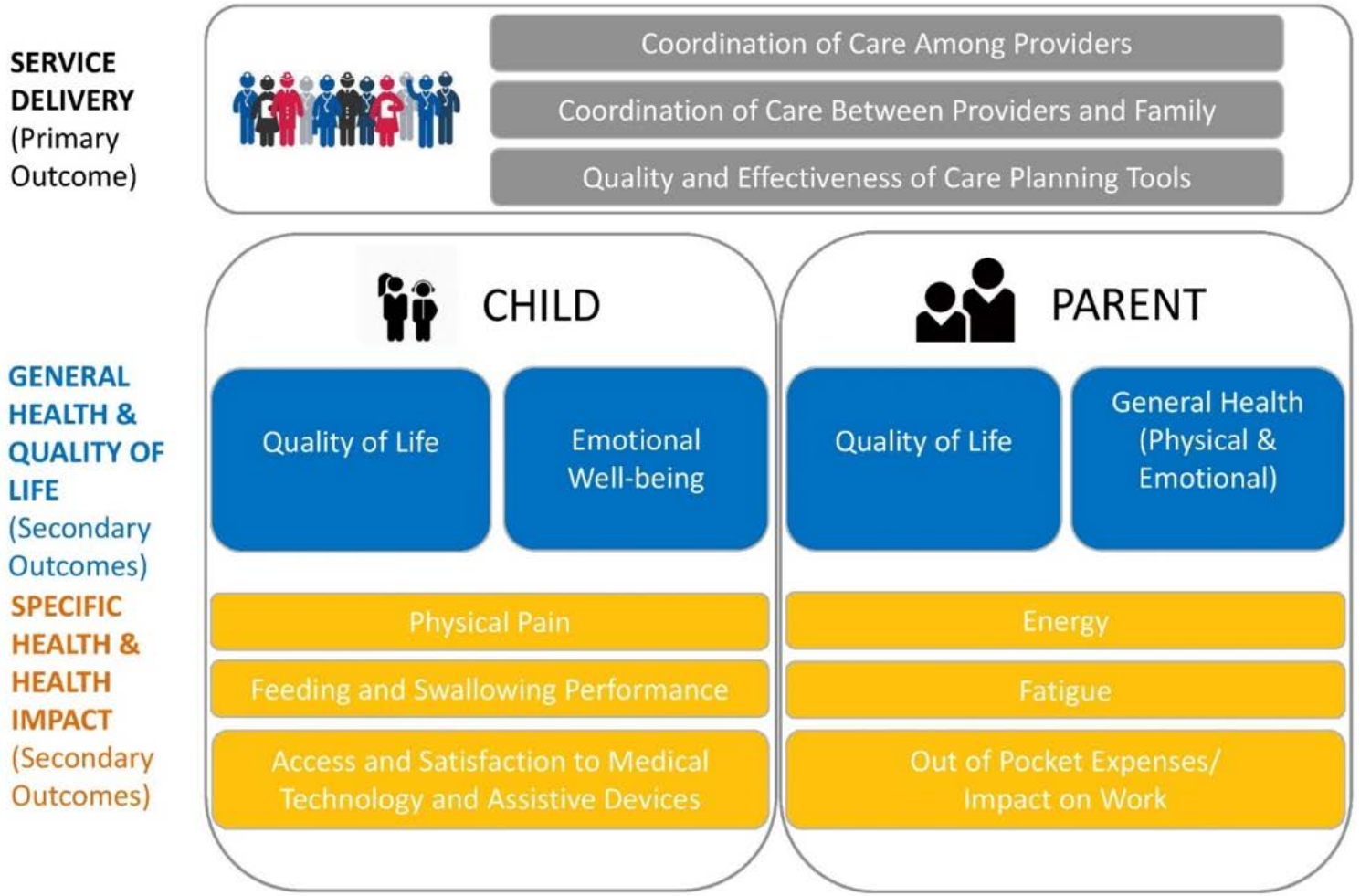
LIFE BEYOND TRAUMA

Elisa Kaltenbach (project coordinator)

Donna Thomson (parent partner)

Patrick McGrath (principal investigator)

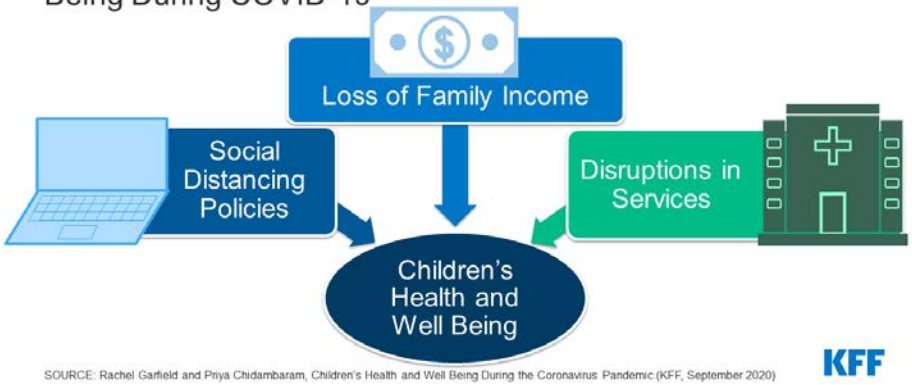
How Do We Measure Success?



Fayed, CMAJ, 2018 & Dev Med Child Neurol, 2019

Figure 1

Factors Negatively Impacting Children's Health and Well-Being During COVID-19



SOURCE: Rachel Garfield and Priya Chidambaram, Children's Health and Well Being During the Coronavirus Pandemic (KFF, September 2020)

KFF

Reflections on caring for children with medical complexity during COVID-19

Posted on {user_locale_blog_date_format} by the **Canadian Paediatric Society** | Permalink

Topic(s): *COVID-19*

By Dr. Catherine Diskin, Dr. Eyal Cohen, and Dr. Julia Orkin

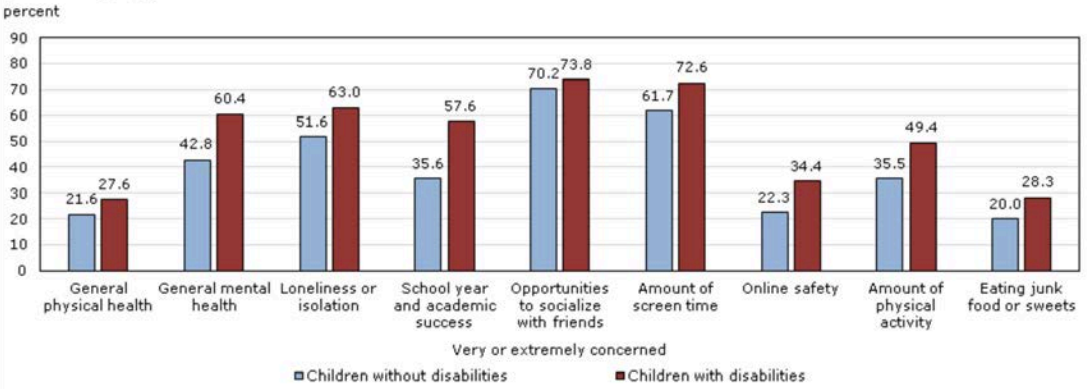
The direct effects of COVID-19 on children have to date been minimal. The indirect consequences for children with medical complexity (CMC) have been significant, including changes to health care delivery to challenges providing care at home, concerns about caregiver illness, home care providers, and limited access to medication and supplies.

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

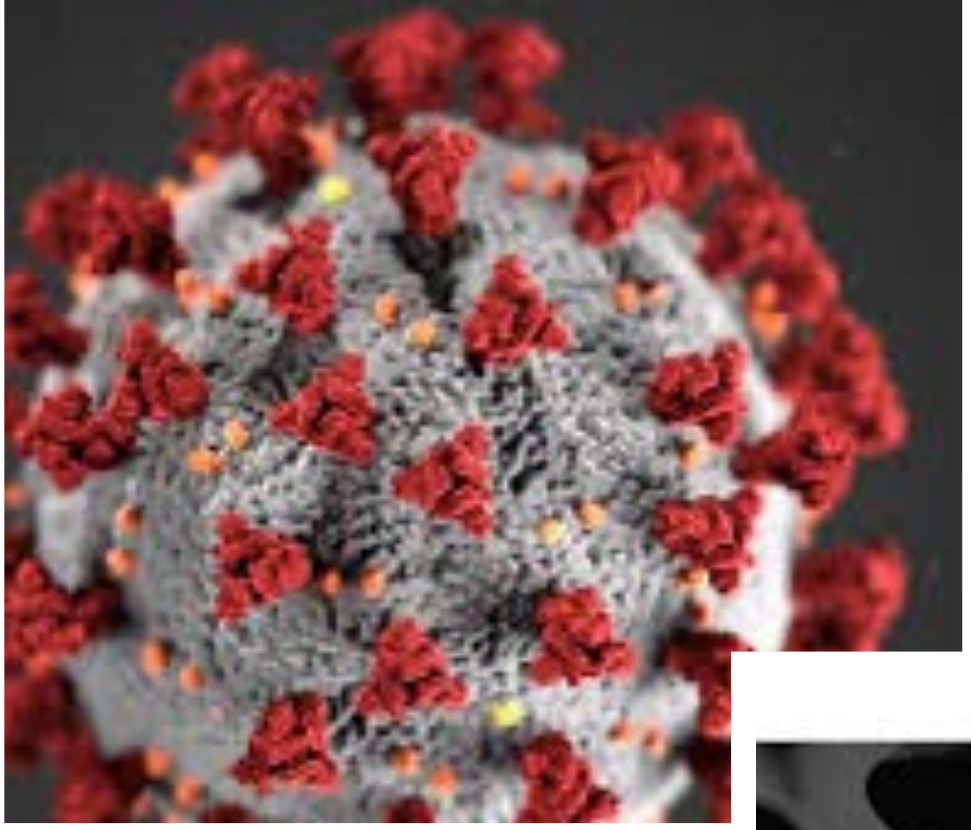
December 2020

REPRESENTATIVE FOR CHILDREN AND YOUTH

Crowdsourcing participants' concerns for their children aged 0 to 14 years due to the COVID-19 pandemic, by presence of children with disabilities at home

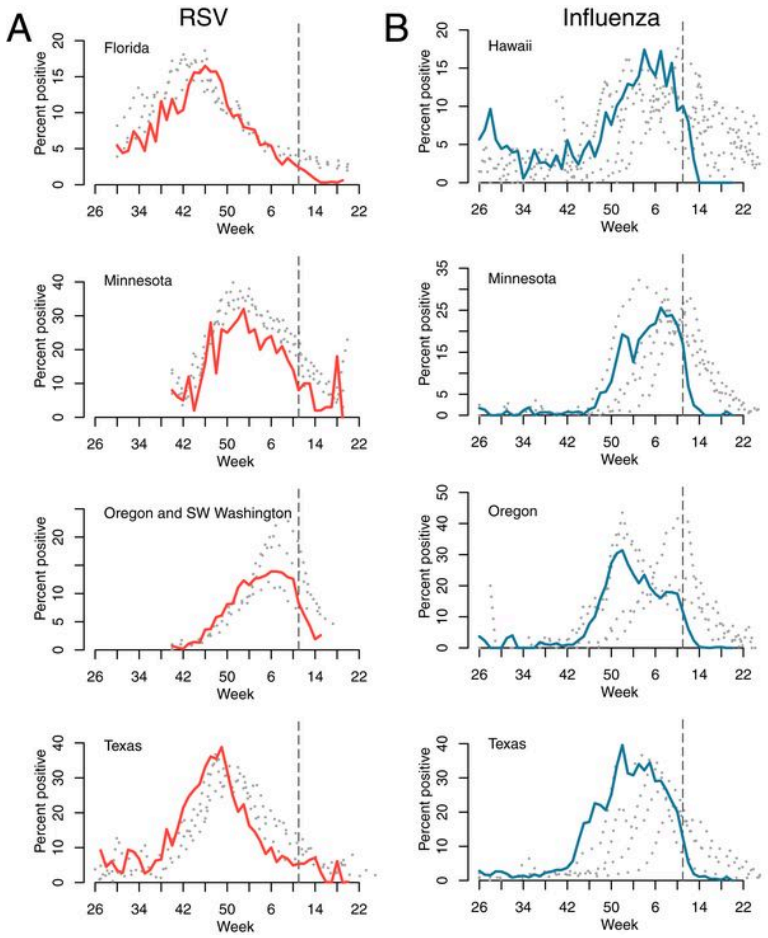


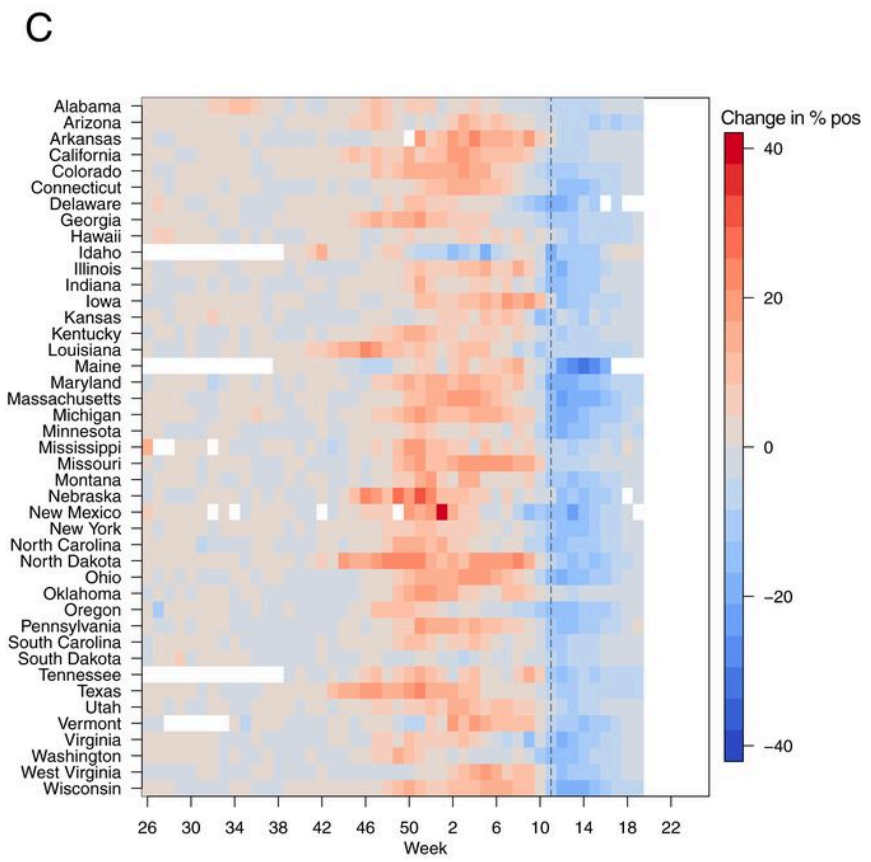
Notes: Percent calculations exclude both "not applicable" and "not stated" responses. The pattern of results was similar when "not applicable" responses were included.
Source: Impacts of COVID-19 on Canadians - Parenting During the Pandemic: Data Collection Series (5323).




“Never let a good crisis
go to waste”

Nonpharmaceutical Interventions and Influenza/RSV





The impact of COVID-19 nonpharmaceutical interventions on the future dynamics of endemic infections

Rachel E. Baker[a,b,1], Sang Woo Park[b], Wenchang Yang[c], Gabriel A. Vecchi[a,c], C. Jessica E. Metcalf[b,d], and Bryan T. Grenfell[b,d,e]

[a]Princeton Environmental Institute, Princeton University, Princeton, NJ 08544; [b]Department of Ecology and Evolutionary Biology, Princeton University, Princeton, NJ 08544; [c]Department of Geosciences, Princeton University, Princeton, NJ 08544; [d]Woodrow Wilson School of Public and International Affairs, Princeton University, Princeton, NJ 08544; and [e]Division of International Epidemiology and Population Studies, Fogarty International Center, National Institutes of Health, Bethesda, MD 20892

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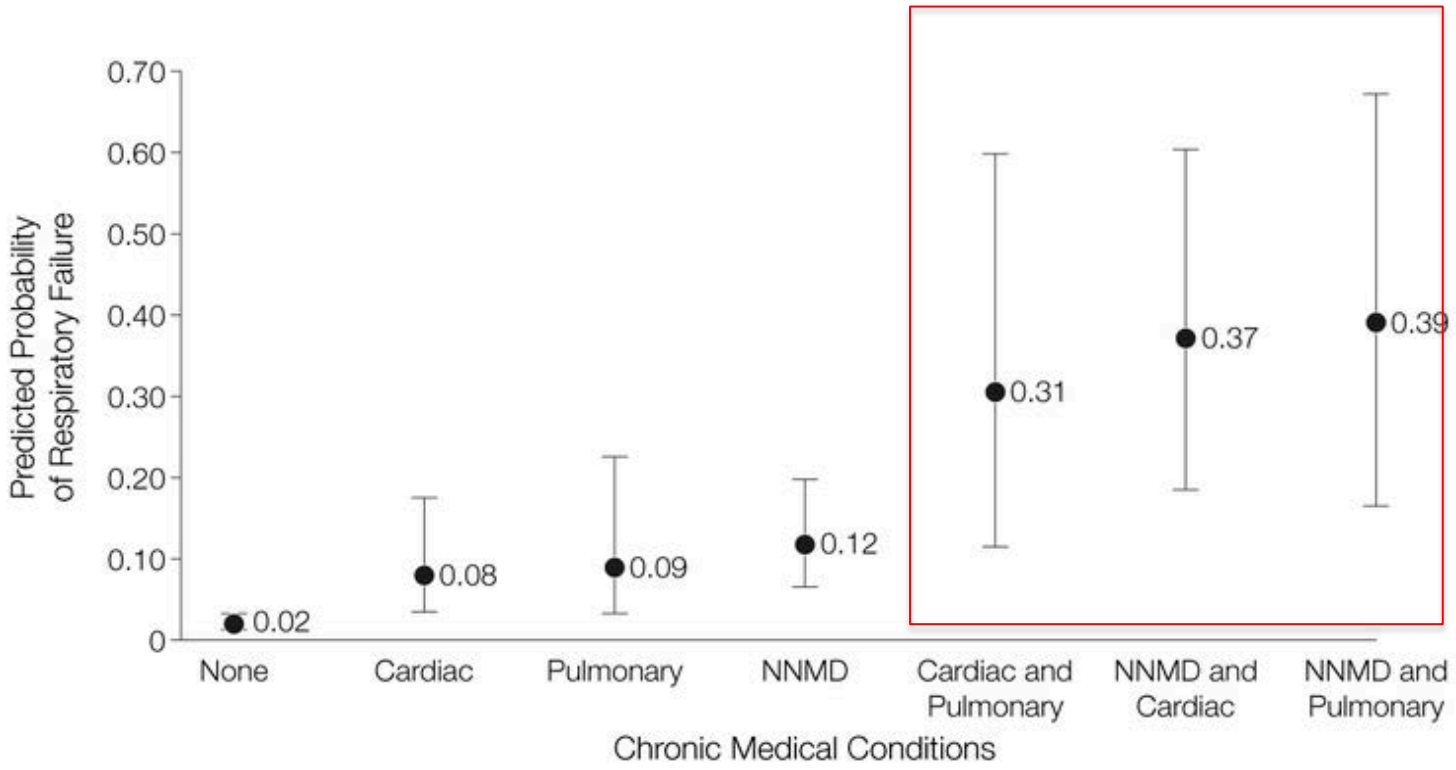
Influenza Risk for Children with Medical Complexity



NNMD indicates neurological and neuromuscular disease. Error bars indicate 95% confidence intervals.

Neurological and Neuromuscular Disease as a Risk Factor for Respiratory Failure in Children Hospitalized With Influenza Infection

Ron Keren, MD, MPH; Theoklis E. Zaoutis, MD, MSCE; Carolyn B. Bridges, MD; et al

> Author Affiliations | Article Information

JAMA. 2005;294(17):2188-2194. doi:10.1001/jama.294.17.2188

Virtual Care

Summary

- There are challenges

  - Our voice is small (but growing!)

  - Solutions will likely fail if they solely focus on silos

- There is much promise
  - Our stories are powerful, our community is strong
  - A growing appetite for reform
  - New emerging opportunities

Summary

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