Models for Reducing Health Disparities:

The Case of “Children with Complex Health Needs”

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One Family: Aliyah, Ariel and Ana

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Aliyah: 7 year-old girl with severe intellectual disability, congenital heart disease, chronic lung disease, and gastrostomy-tube feeding

12 subspecialists
5 community agencies
3 hospitals

Ariel: 5 year-old girl with obesity

Ana: A single mother with limited literacy and LEP.

What kind of care system is required to support this family's health?

- Definitions
- Epidemiology of Child Health Needs
- Care System Models

Definitions

Special Health Care Need

"has or are at increased risk for chronic **physical, developmental, behavioral or emotional** conditions, AND requires health and related services of a type or amount **beyond that required by children generally**." (MCHB 1998)

Chronic Illness

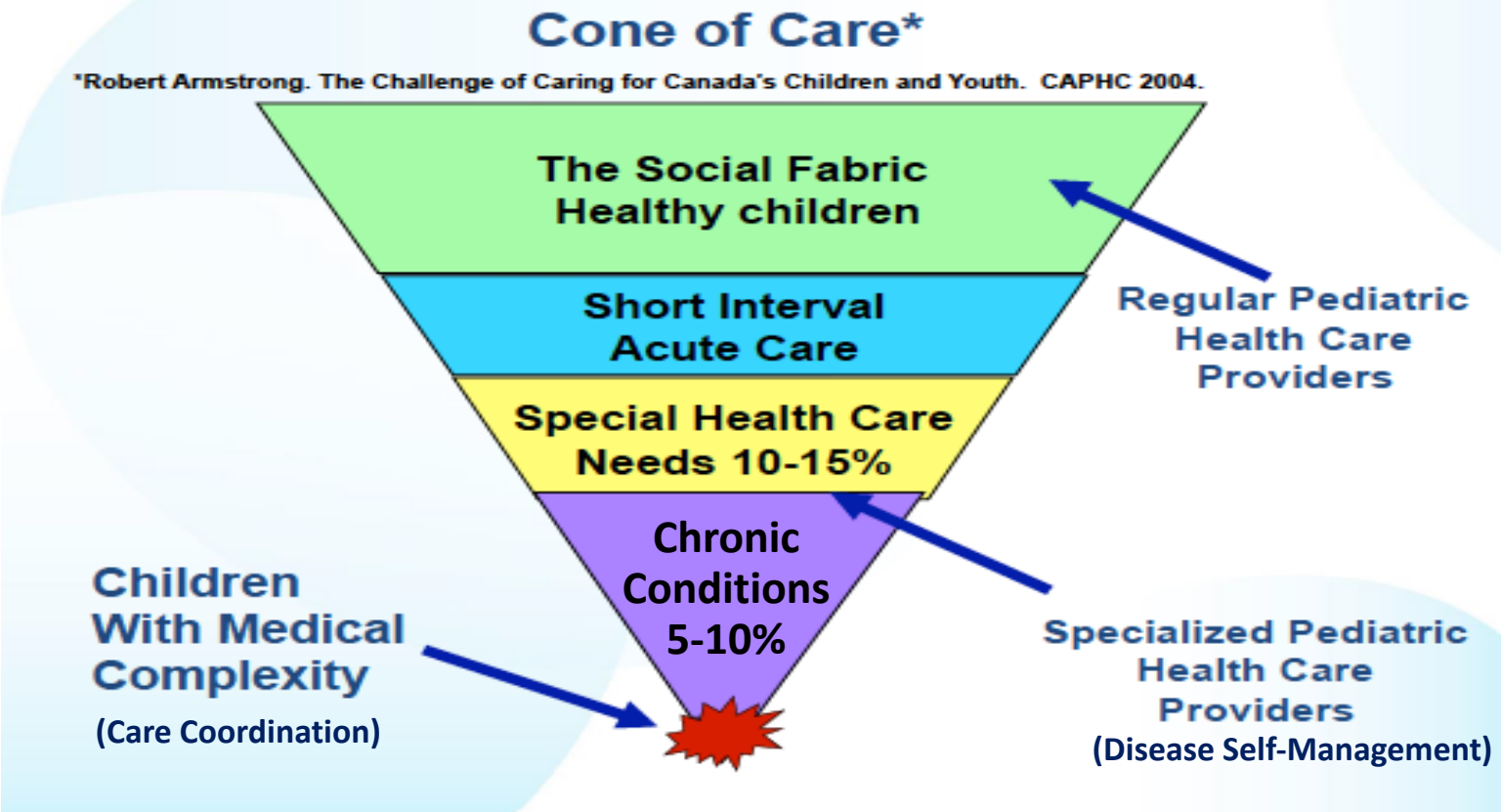
"lasts **a year or more** AND requires **ongoing medical attention** and/or limit activities of daily living" (DHHS, Health Affairs 2001)

Medical Complexity

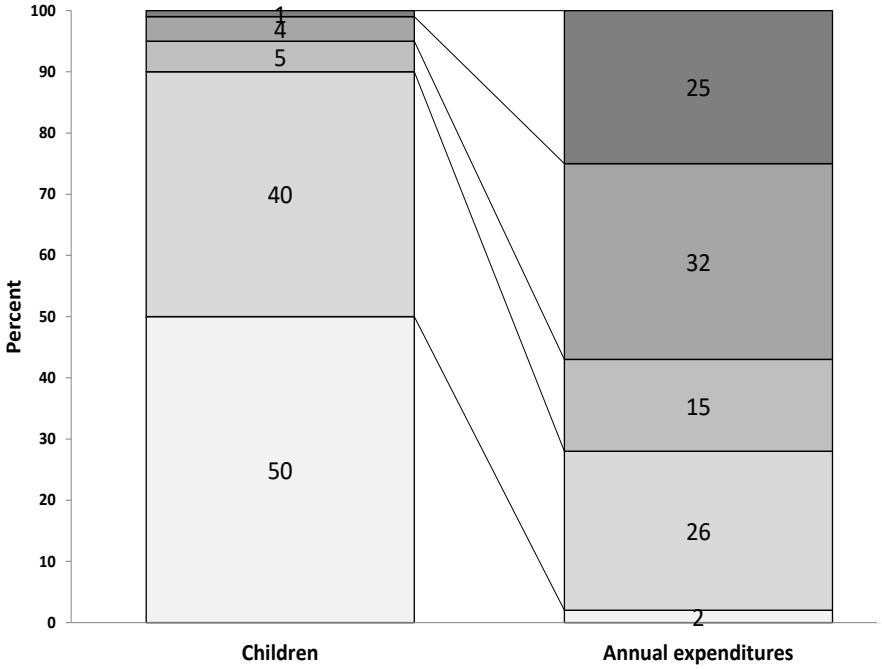
"(1) intensive hospital- and/or community-based service need, (2) reliance on technology, polypharmacy, and/or home care … (3) risk of frequent and prolonged hospitalizations, … and (4) an elevated need for care coordination." (Cohen 2011)

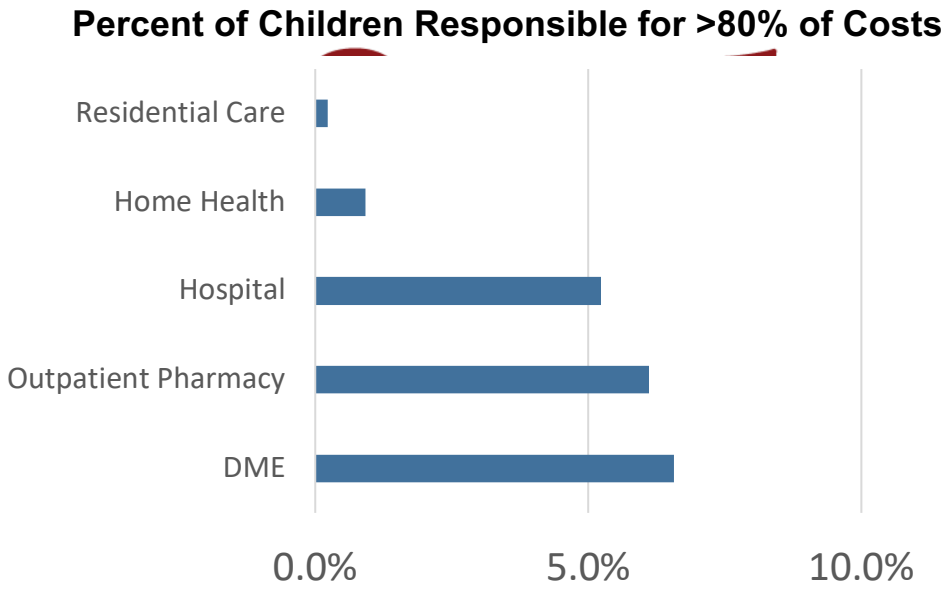
- Definitions
- **Epidemiology of Child Health Needs**
- Care System Models

Epidemiology:
Extreme Skewing of Child Health Needs



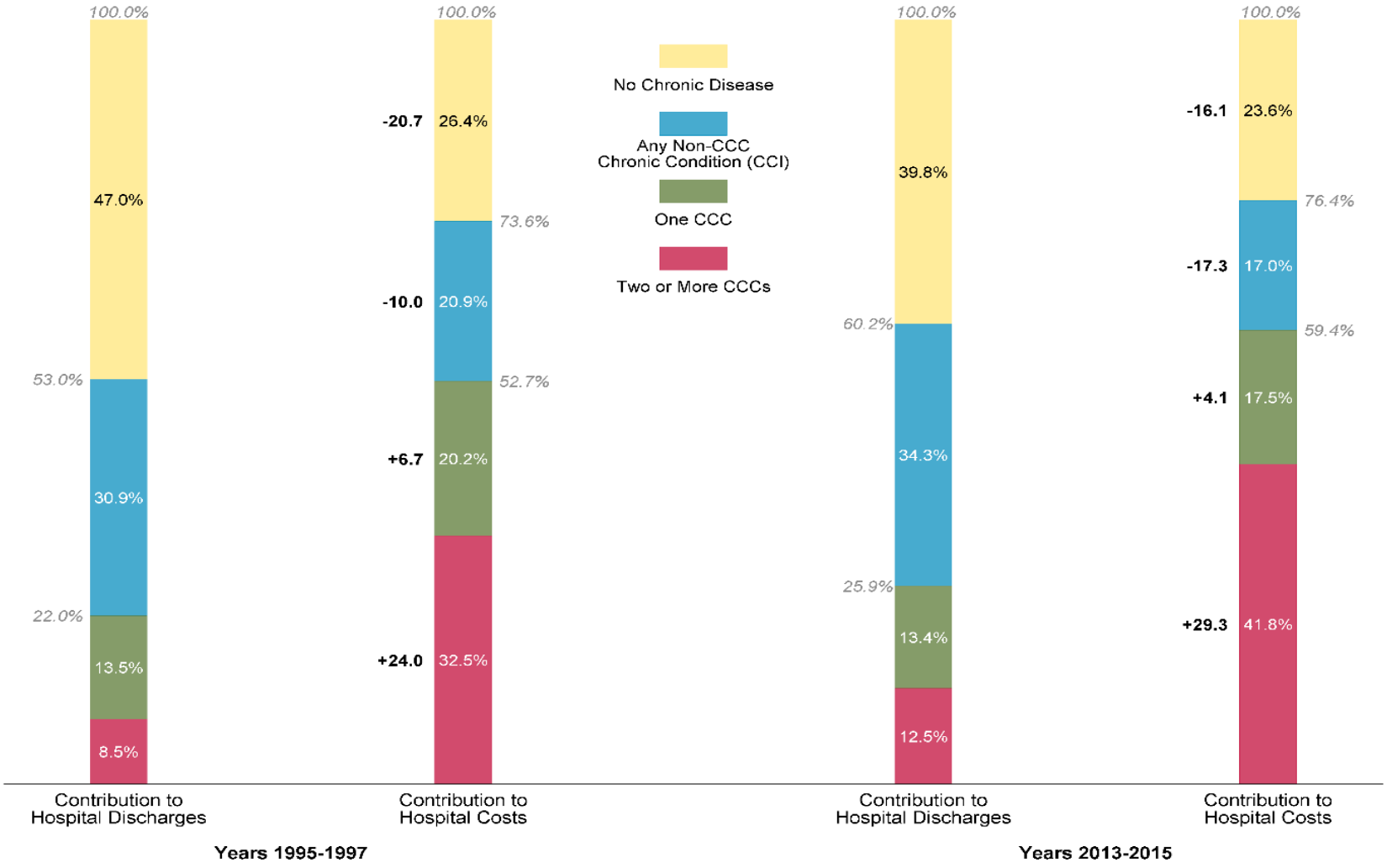
Epidemiology:
Extreme Skewing of Use and Costs



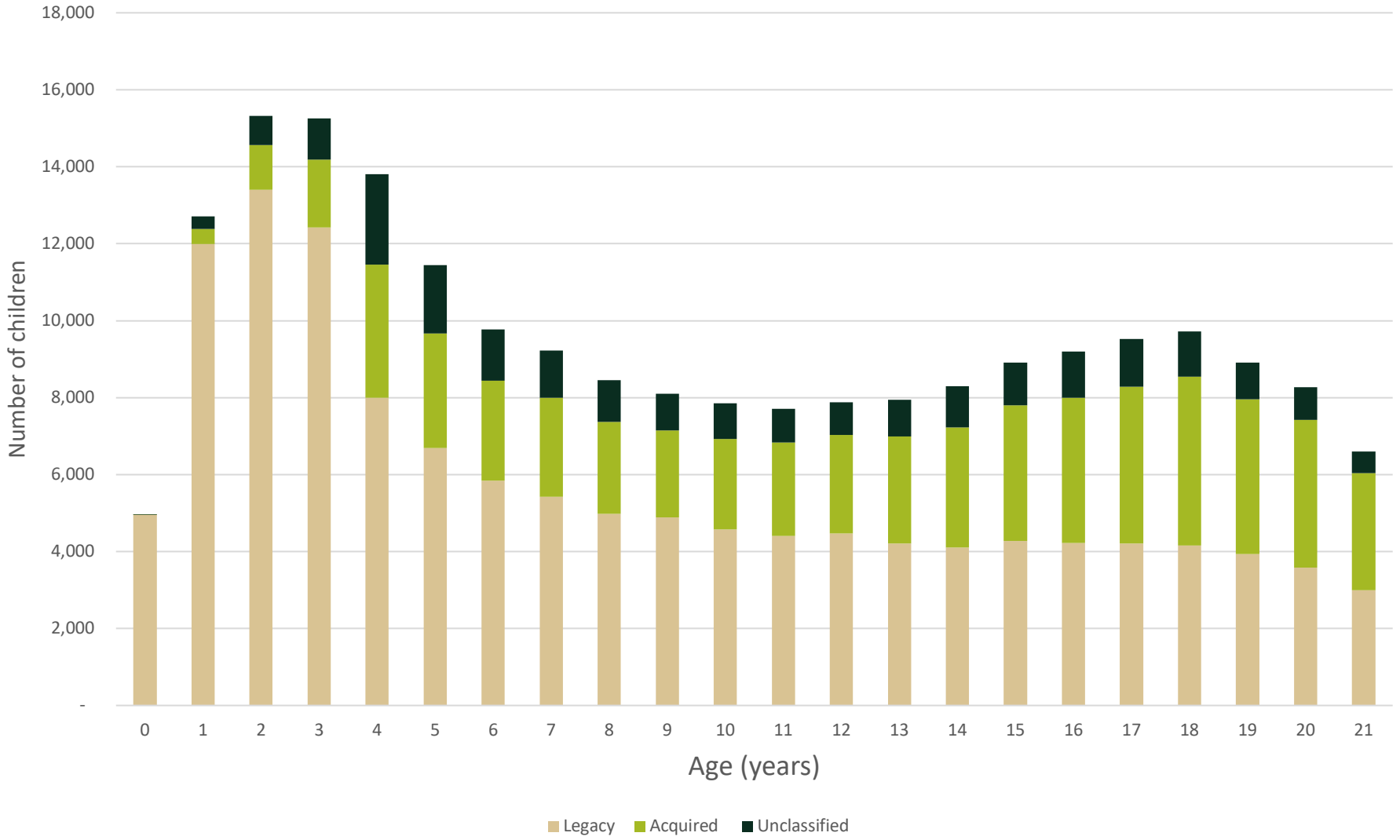


Sanders 2017

Increasing share of hospital costs is for multi-morbid conditions (medical complexity)

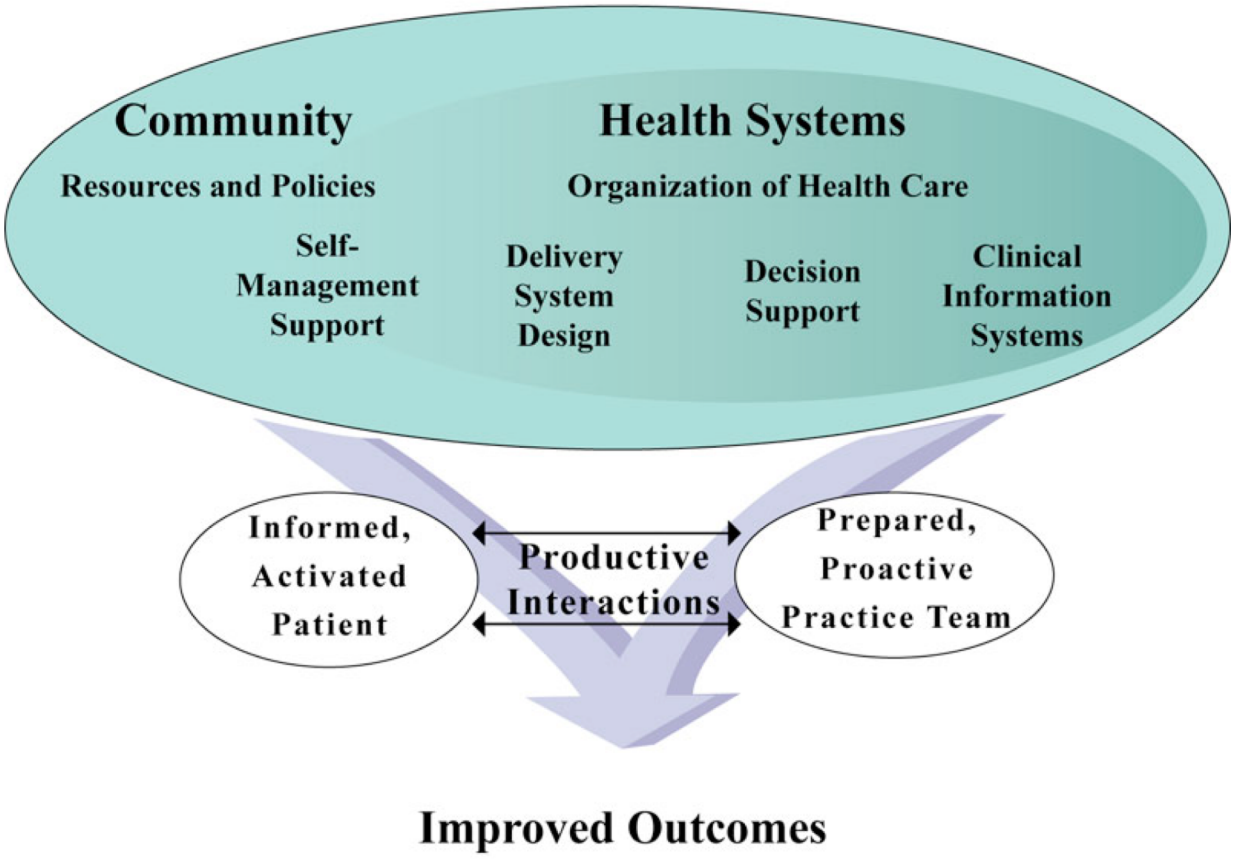


Nearly half of teens with chronic illness have neonatal-onset conditions



- Definitions
- Epidemiology of Child Health Needs
- **Care System Models**

Chronic Care Model



Ed Wagner 2004

Family-Centered Medical Home

MEDICAL HOME COMPONENTS INCLUDE...

ACCESSIBLE
Care is physically and geographically accessible, practice hours are accessible, and the clinic accepts all insurance types

COMPASSIONATE CARE
Well-being of the child and family is explicitly expressed and demonstrated

COMPREHENSIVE CARE
All health care needs of the child/youth are met, including well-care, sick-care, and behavioral health needs

CONTINUOUS CARE
Children and families develop relationships and are cared for by the same care team from infancy through young adulthood

COORDINATED CARE
Care is coordinated among multiple providers and community services, including adult providers to assist with transition from pediatric to adult care

CULTURALLY COMPETENT CARE
Child and family culture, beliefs, rituals, and traditions are valued, respected, and incorporated into care

FAMILY-CENTERED CARE
Care is centered on the goals, needs, and preferences of the child and their principal caregivers

Sia C, 1978
AAP 2002

Effective Medical Homes:
Evidence Base for Adults

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Review of 75 systematic reviews of Care Coordination for Adults

McDonald K, et al. 2007

Care Coordination Component	Outcome	Condition
Multidisciplinary teams	Improved symptoms Improved continuity of care Reduced mortality	Cancer Mental illness Heart Dz, Stroke
Disease management	Improved symptoms Improved adherence Reduced mortality	Mental illness Diabetes Heart disease
Case management	Reduced readmission rates Improved adherence	Mental illness Diabetes

Systematic Review of 30 studies of Patient-Centered Medical Home (Nielsen M, et al 2014)

- Increased patient engagement
- Reduced unnecessary utilization (ambulatory sensitive conditions, readmissions)
- Reduced health care costs

Effective Medical Homes:
Evidence Base for Children

Stanford MEDICINE

Systematic Review of the "Child Medical Home"
(Kuhlthau, et al 2011)

- More efficient use of services (lower ED use, lower rates of hospitalization)
- Improved child health status
- Improved access to care
- Improved family functioning

Study of 43 pediatric primary care sites, across 5 states
(Cooley WC, et al 2009)
Improved Medical Home (MHI) scores were associated with better chronic care

- Reduced ED visits
- Reduced hospitalizations

Medical Home:
Indicators of Unmet Needs

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Indicator	N	%
Routine Primary Care: >= 2 Primary Care Visits (age <24 months)*	6,823	63
Routine Primary Care: >=1 Primary Care Visit (age >= 24 months)*	44,706	38
Routine Specialty Care: >=1 Subspecialty Care Visit	100,226	69
Usual Source of Care: >= 2 Visits with same MD	84,409	78
Care Coordination: >= 1 care coordination claim	64,269	44

Paid claims for all children enrolled > 6 months in California Children's Services (2011-2012)

“American Medical Home Runs”

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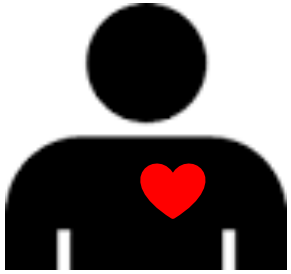


Heart
Patient-Centered

(Literacy-Appropriate; Activated Patients)

Head
Tiered Care

(Wide Scope of Practice, Stratified to Need)

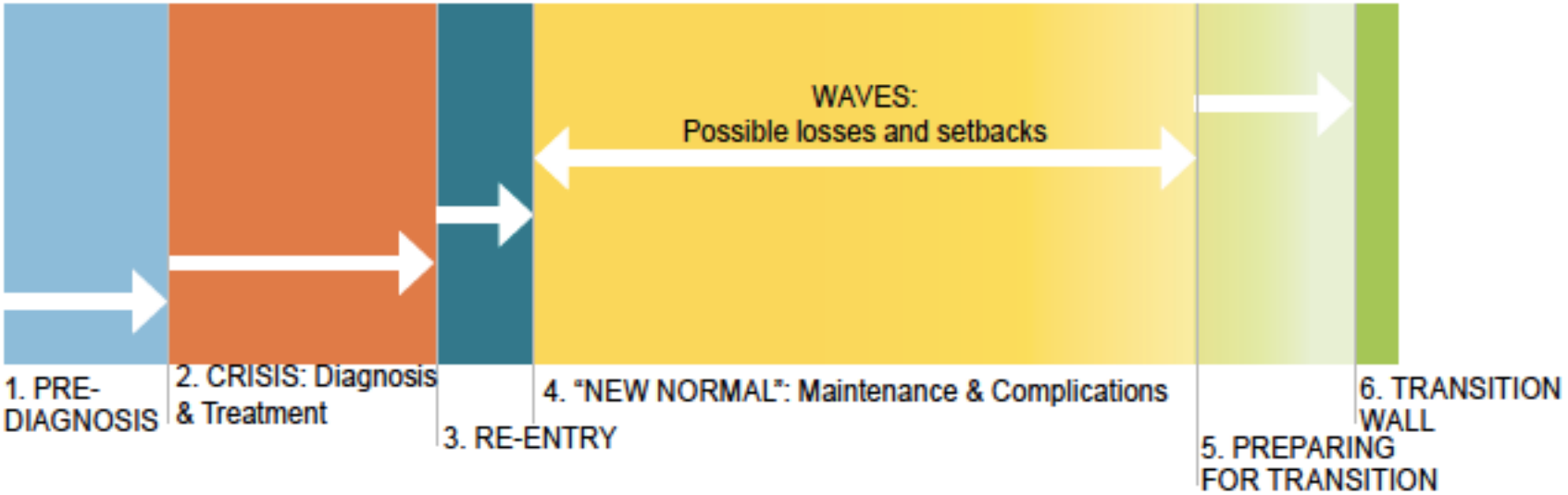
Heft
Coordinated Teams

(Upshifted tasks)

Better quality and Lower cost

Milstein A 2009. Casey PH 2011

Medical Home:
Family-Centered Models

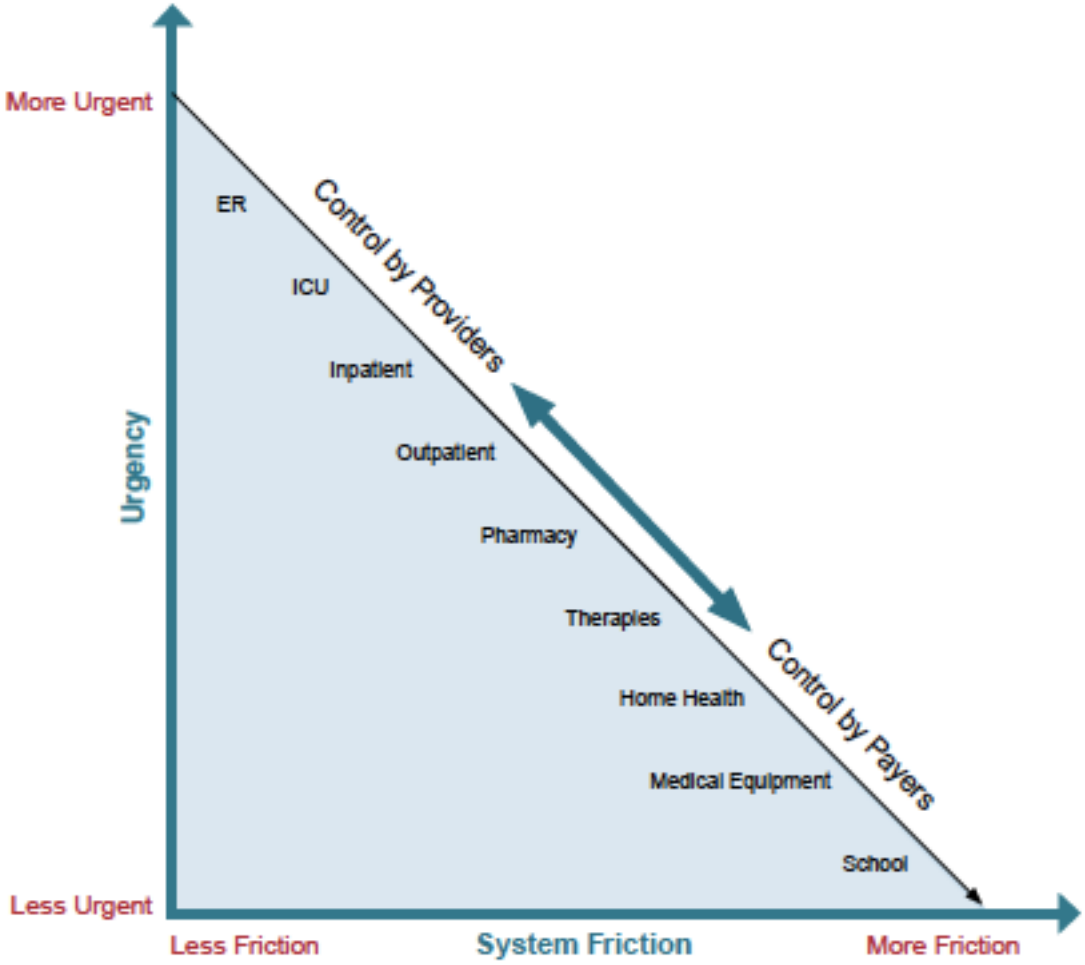


Dana Hughes 2014

Medical Home:
Family-Centered Models

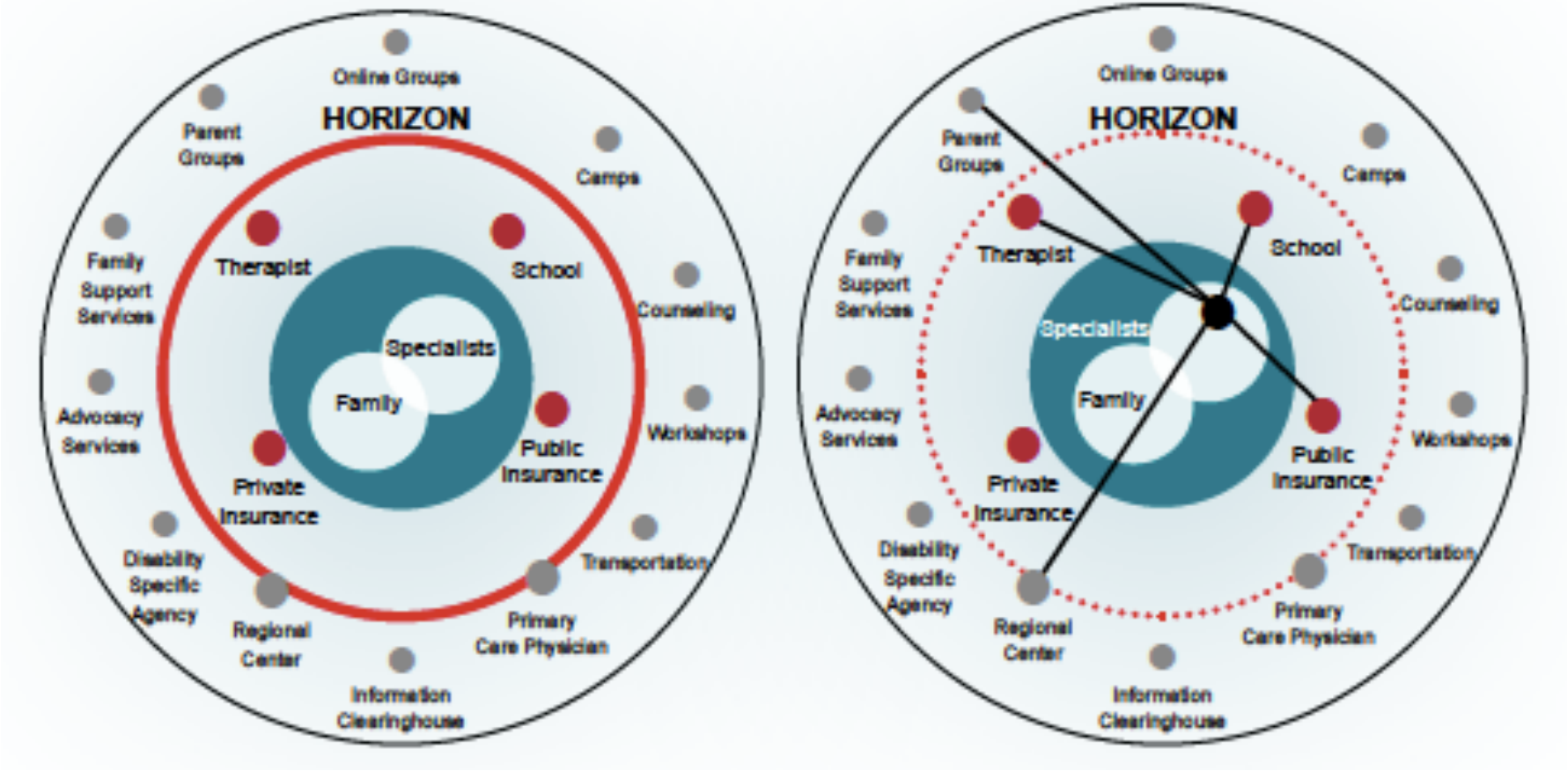
Dana Hughes 2014

Medical Home:
Family-Centered Models



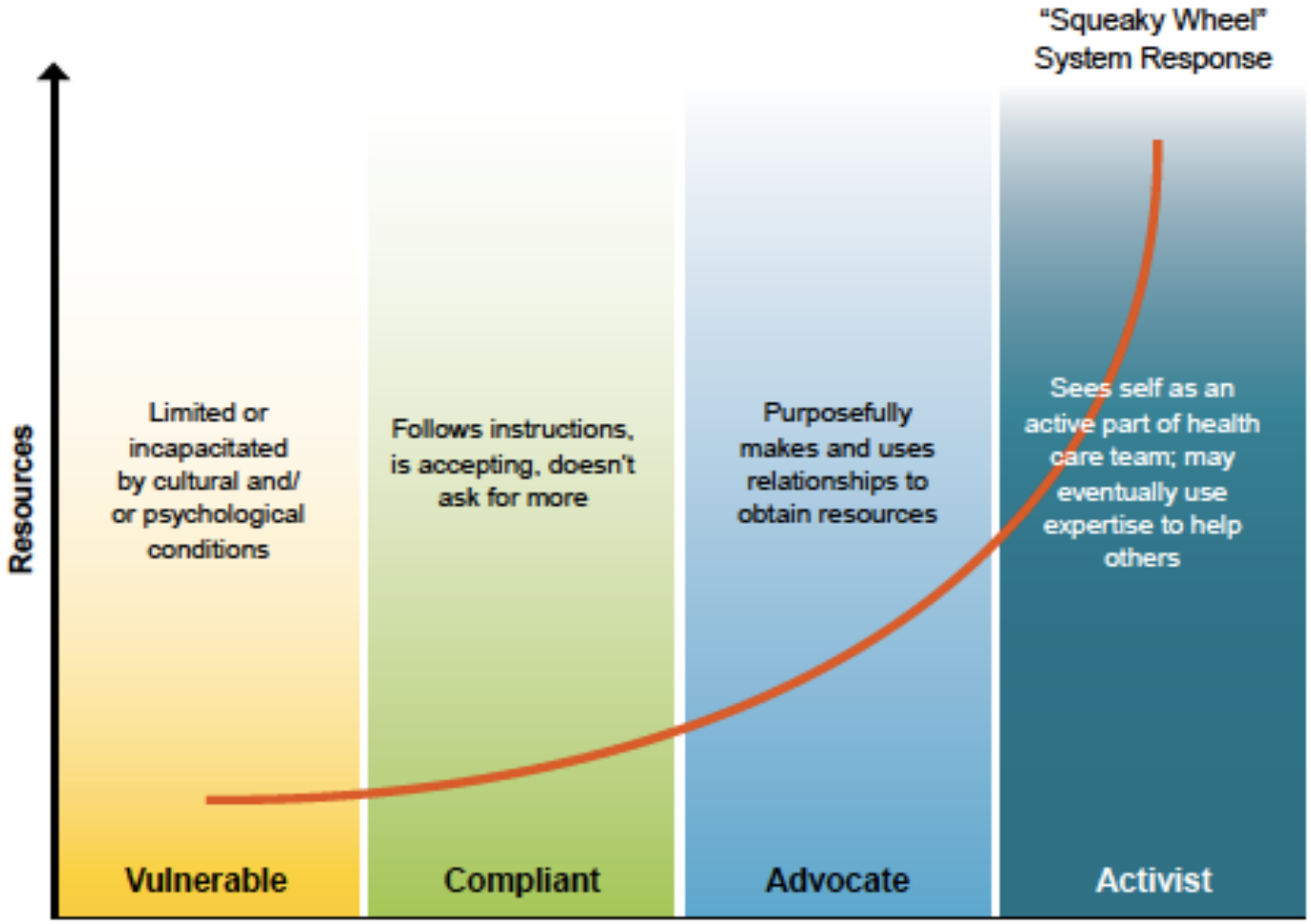
Dana Hughes 2014

Medical Home:
Family-Centered Models



Dana Hughes 2014

Medical Home:
Family-Centered Models



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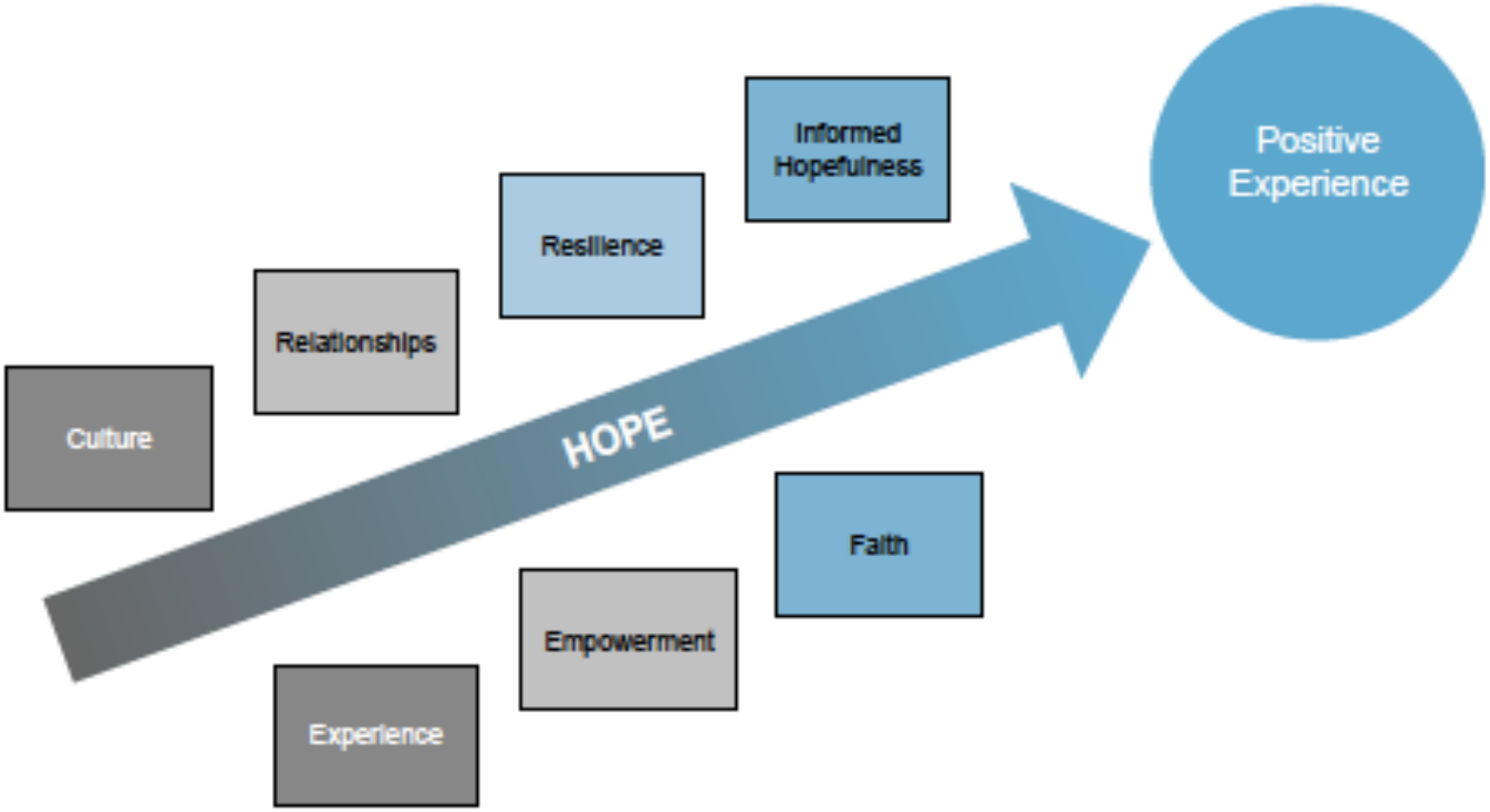
Medical Home:
Family-Centered Models



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Advanced Medical Home
for Children with Medical Complexity

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Dynamic Care Team

- Multi-disciplinary Clinic
  - MSW, Pharmacist, Educator
  - MA as "Health Coach"
- Integrated Care Plans

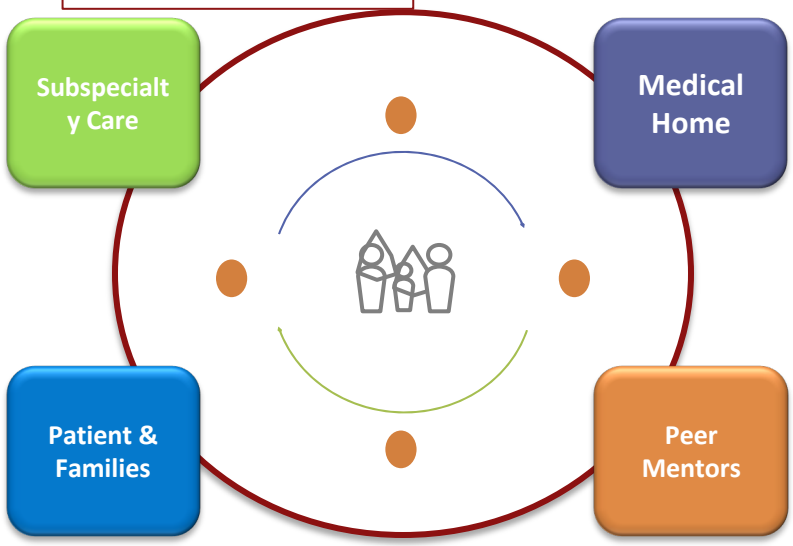
Primary Care & Community Integration

- Tiered Care
  - Medical Complexity
  - Social Complexity
- Community Outreach

Family Self-Management

- Parent mentors
- 24/7 Access Plans

CMMI "CARE" Award
$23 million
9 Children's Hospitals



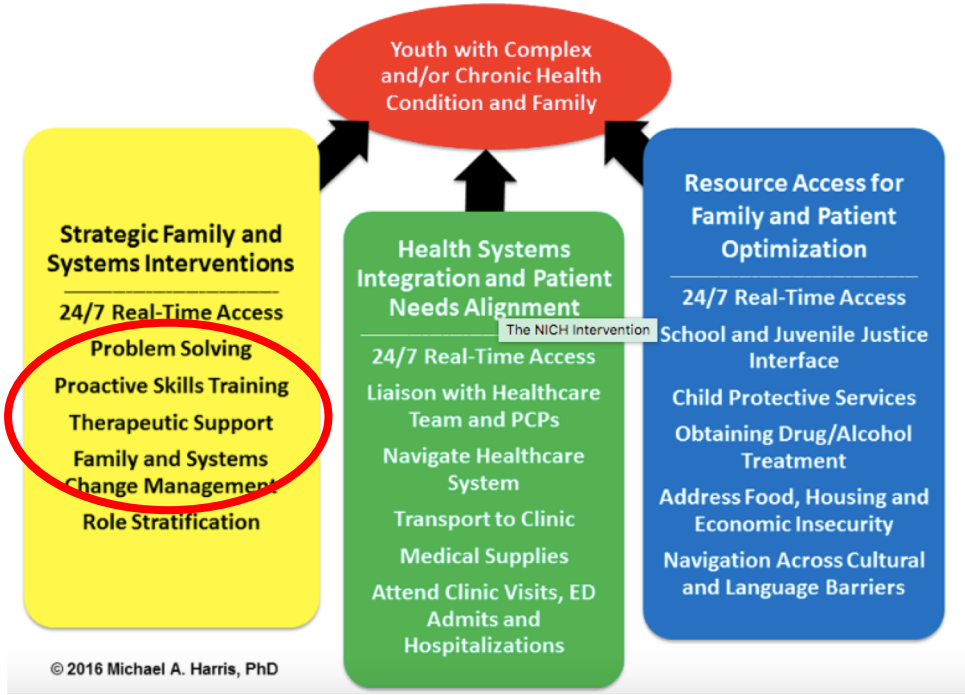
Stein REGK 1984. Bodenheimer T 2002. Palfrey J 2004.

Advanced Medical Home:
Integrating Behavioral Health

- Uptrain non-health professionals
- “Case finding” for children with behavioral/developmental needs
- Access to community-based mental-health services

Results from Trials

- Fewer missed school days and fewer parent missed days of work
- Fewer hospitalizations
- Cost Savings



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Advanced Medical Home:
Role for Information Technology?

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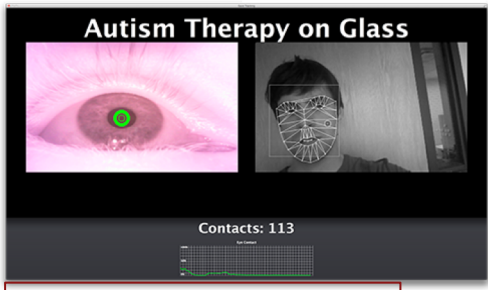
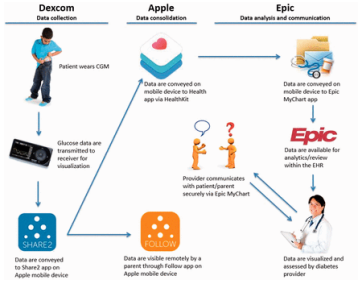
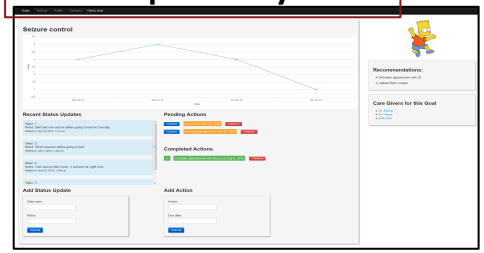
Tools
- Communication across teams
- Continuous monitoring (“wearables”)
- Self-management plans (“bots”)

Results
- Better screening ?
- Improved self management ?
- Improved health outcomes ?



GoalKeeper Study





Funded by NCI

Amir O 2015. Zulman DM 2015; Miner AS 2016

ImproveCareNow.org; NightScout.info

Aliyah, Ariel and Ana:
How can we improve their care system?

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Medical Home

Tailored to Health Needs
Culturally Appropriate
Coordinated

Advanced Medical Home

- “High Touch”
  - 24/7 access
  - Up-trained non-health professionals
  - Integrated with behavioral health
- “High Tech”
  - Continuous monitoring
  - AI Supported Coordination

Summary

- ✓ Child health faces systemic challenges from epidemiology, policy and social pressures.
- ✓ These challenges may be addressed through a culturally informed approach to coordinating care delivery.
- ✓ Effective care coordination includes accessible, multi-disciplinary teams -- supported by emerging IT.

Thank You

Clinical Advisory Board

David Bergman, MD

Sherri Spunt, MD

Keith van Haren, MD

MyMy Buu, MD

Community PT, OT

Greg Makoul, PhD

Jay Berry, MD

Others

Family Advisory Board

Teresa Jurado

Select CPCC families

Questions?

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