TRANSFORMING CHILDREN'S HEALTH CARE TO IMPROVE LIFELONG BEHAVIORAL HEALTH FOR ALL

CHILDREN'S MENTAL HEALTH AND THE LIFE COURSE MODEL: A VIRTUAL WEBINAR SERIES

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WELCOME

INTRODUCTION TO THIS PRESENTATION AND

THE CHILDREN'S MENTAL HEALTH AND THE LIFE COURSE PERSPECTIVE WEBINAR SERIES

LIFE COURSE APPROACH TO THE MENTAL HEALTH OF KIDS

- 8 Webinars co-developed & sponsored
  - MCH Life Course Intervention Research Network (LCIRN)
  - National Academy of Science's (NAS) Forum for Child Well-Being
- Goals
  - Describe how mental health and mental health disorders develop over the lifespan
  - Identify gaps in knowledge, explore new strategies, consider new approaches to prevention and optimization
  - Catalyze transdisciplinary and transformational approaches
  - LCIRN research nodes (families, schools, early childhood mental health)
- Summary "workshop" publication created by NAS

DISCLOSURES

- We are both pediatricians

OBJECTIVES FOR THIS WEBINAR

- Discuss why a focus on transforming children's health care to improve behavioral health for all
- Identify potential changes in pediatric primary care and subspecialty settings
- Challenge us to embrace transformational change

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WHY FOCUS ON IMPROVING BEHAVIORAL HEALTH, PARTICULARLY FOR CHILDREN?

- From previous webinars, massive shift in epidemiology of behavioral/mental health disorders
  - Increasing "deaths of despair" in adults
  - Increasing symptoms of disorders in children, adolescents, and young adults ("children")

- It's URGENT that we as a society respond NOW

WHY A FOCUS ON IMPROVING BEHAVIORAL HEALTH, PARTICULARLY FOR CHILDREN?

- Previous webinars have discussed how neuroscience supports
  - A life course approach
  - A two-/multi-generational approach
  - Consideration of adverse childhood experiences (ACES) and societal health on the health of children and adults
  - Focus on promotion of emotional well-being and resilience not just the medical model of risk identification and treatment

WHY A FOCUS ON CHILD HEALTH CARE SETTINGS?

A child health care setting provides comprehensive care, including

- Preventive care (well-child visits)
- Acute care (treatment of sudden onset illnesses and injuries)
- Chronic illness care (treatment of long-term conditions)
- Continuity

WHO CARES FOR CHILDREN IN THESE SETTINGS?

- Providers may include
  - Traditional health care professionals (e.g., pediatricians (general and subspecialty), family physicians, physician assistants, nurse practitioners, nurses, clinical nurse specialists)
  - Increasingly include
    - Mental health professionals (e.g., psychologists, social workers, therapists)
    - Child development specialists
    - Community health workers
    - Parents/patients as peers/peer navigators

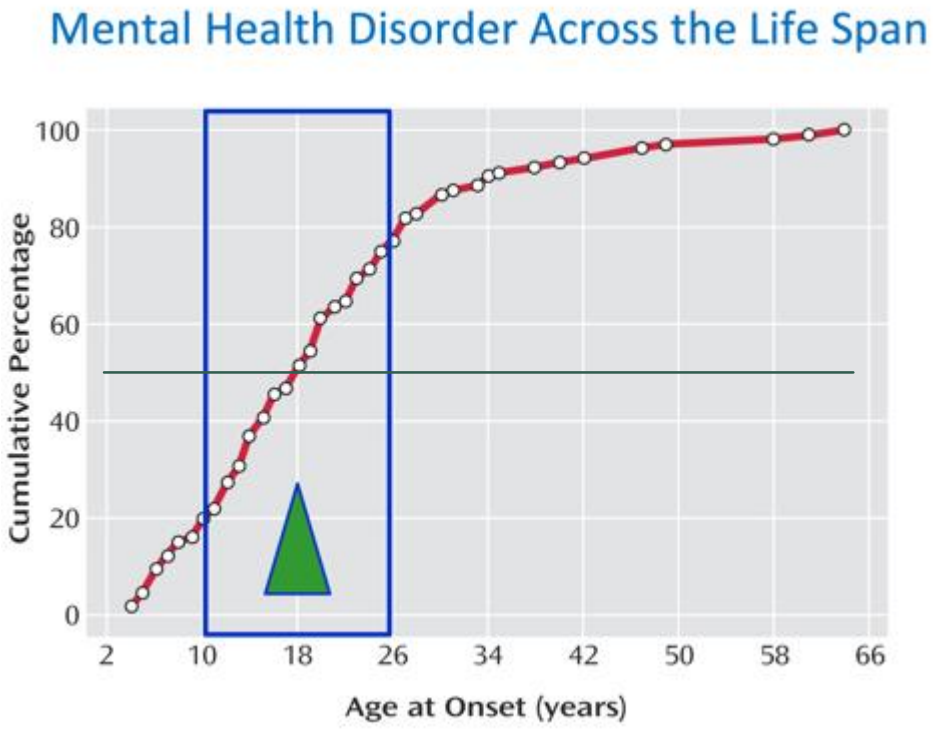
WHAT SHOWS UP IN HEALTH CARE SETTINGS

- 10-14% of children <5 years have social-emotional problems
- 45% of children experience at least one adverse childhood event (ACES)
- 20% of children and adolescents in the U.S. meet diagnostic criteria for a mental health disorder
- Suicide is the 2nd leading cause of death among 15-24 year olds and among 10-14 year olds

- Murphey D, et al: Robert Wood Johnson Foundation 2014.
- Bitsko, et al: Morb Mortal Wkly Rep. 2016;65(9):221–226.
- Houtrow AJ, et al: Pediatrics. 2014;134(3):530.
- National Vital Statistics System, National Center for Health Statistics, CDC.
- https://www.childtrends.org/publications/prevalence-adverse-childhood-experiences-nationally-state-race-ethnicity

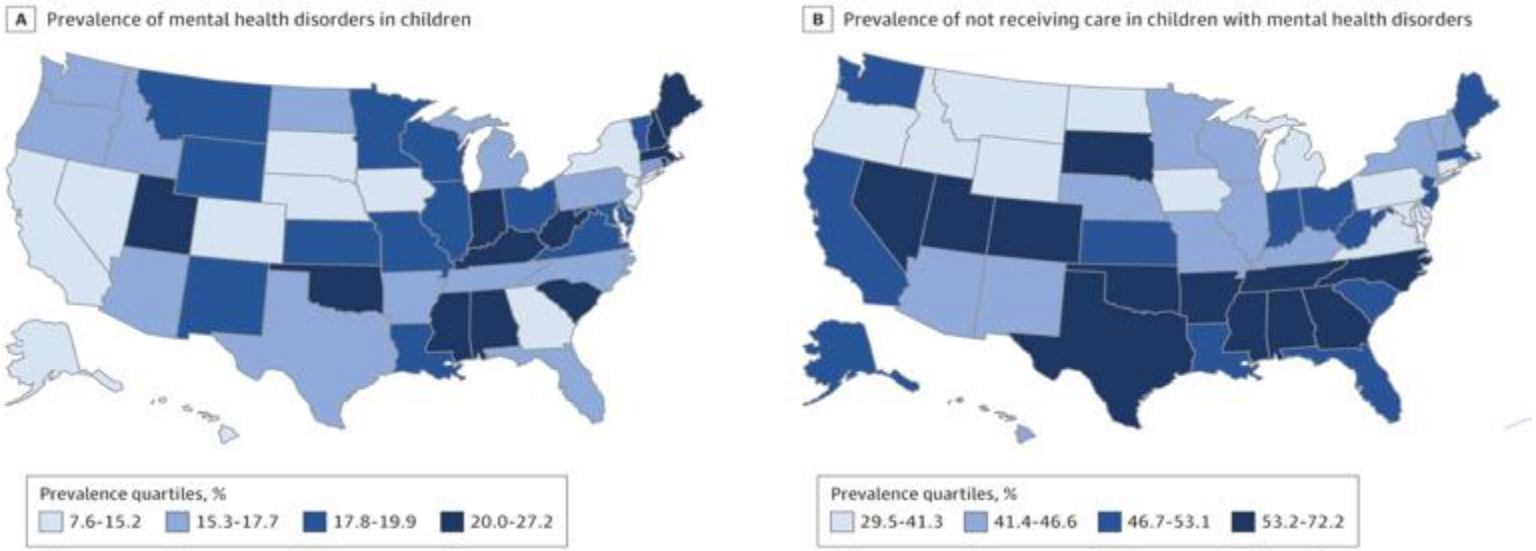
MENTAL HEALTH DISORDERS LINK BACK TO CHILDHOOD

- The age of onset for most mental health disorders is <26 years
- 50% of US adults with mental health disorders had symptoms by 14-18 years of age



LACK OF EQUITY

Prevalence and Treatment of Mental Health Disorders in the U.S. (age <18)



- **Half (50%)** of the estimated 7.7 million U.S. children with a treatable mental health disorder did not receive needed treatment from a mental health professional.
- **Alabama, Mississippi, Oklahoma, and Utah** in top quartile for **both prevalence** and those who **did not receive needed treatment** for mental health disorders

NYU Langone Health

Source: Whitney and Peterson, 2019.

MENTAL HEALTH SYSTEM NOT ENOUGH

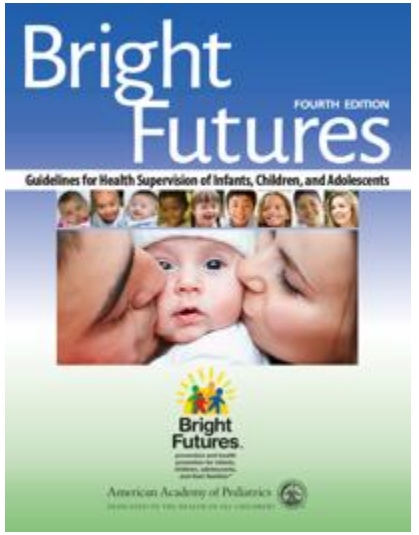
- Average delay of 8-10 years from onset of symptoms to intervention
- Insufficient providers
- Silos in care lead to inefficiencies, increased costs, confusion for families, and less effective care
- <50% of referrals to mental health occur
- 40-50% terminate services prematurely due to lack of access, transportation, finances, or stigma
-

U.S. Department of Health and Human Services. (1999). Mental Health: A Report of the Surgeon General. Rockville, Md: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration,

INCORPORATING A PROMOTION, LIFECOURSE, AND SYSTEMS INTEGRATION PERSPECTIVE

ADVANTAGES OF PEDIATRIC PRIMARY CARE

- Patient Protection and Affordable Care Act (ACA) requires health plans to cover, at no out-of-pocket cost to families, preventive care services outlined in *Bright Futures*
  - 30 well-child visits recommended between 0-21 yrs of age
- Where we prevent, identify, and treat most childhood onset health conditions
- Long-term relationships with families
- Strong and growing evidence base for
  - Promotion
  - Screening and behavioral interventions
  - Psychotropic medications
- Potential to link across child-serving programs and systems



ADVANTAGES OF PEDIATRIC SUBSPECIALTY CARE

- Where we identify and treat most childhood chronic health conditions
- Long-term relationships with families
- Growing interest in
  - Promotion
  - Screening and behavioral interventions
  - Psychotropic medications
- Potential to link across child-serving programs and systems

WHY NOT PEDIATRIC CARE SETTINGS?

- Social norms about mental health
- Medical model focuses on identification and treatment and not promotion
- Not the expectation for healthcare training or care (yet)
- Inadequate and underfunded training
- Inadequate supply and distribution of non-physician providers in primary care settings
- Inadequate linkages to community program
- Health systems do not support promotion, identification, and treatment
  - Time, reimbursement, personnel

OBJECTIVES

- Discuss why a focus on children's health care for transformative change to improve behavioral health for all
- Identify potential changes in pediatric primary care and subspecialty settings
- Challenge us to embrace transformational change

PRIMARY CHILD HEALTH CARE

HEALTH CARE CAN BE PART OF THE SOLUTION

SYSTEM DESIGN	Health service providers, operating separately	Team-based care within health	Community integrated services, health care as one component
CARE MODEL	Little coordination betwe in/out patient care, e treatment	Chronic condition m patient-centered coordinatio	Health, psychosoci ness care integrated e life course
DOMINANT PAYMENT APPROACH	F vice	V ased health payments	n-based global budgets, lin to multi-sector financial impact
APPROACH TO QUALITY	Variable, low transparency	Consistent, standardize processes and outcomes	Continuous learning and quality improvement
BENEFICIARY LENS	Individual	Patient and family	Subpopulations and communities, equity- oriented

Medical Model

Health Care Model

Health System Model

Halfon et al., 2014. Adapted from Figure 2.

MOVING FROM MEDICAL CARE MODEL (1.0) TO HEALTH SYSTEM MODEL (3.0)

The 2004 Institute of Medicine report *Children's Health, the Nation's Wealth* defined health as the extent to which individual children or groups of children are able or enabled to

- Develop and realize their potential,
- Satisfy their needs, and
- Develop the capacities that allow them to interact successfully with their biological, physical, and social environments.[p33]

EXAMPLES OF INTERVENTIONS

- Health care
  - Standardized screening and personalized treatment using evidence-based approaches
  - Reach out and read and other programs in primary care
  - Linkages to other programs and systems
    - Home visitation
    - Early intervention/school-based services
    - Mental health
- Health system
  - Integrated training
  - Integrated care in health care settings
  - Universal access to parenting programs

TRANSFORMATIONWILL REQUIRE MOVING TOWARDS INTEGRATION AND IMPLEMENTATION

INTEGRATED TRAINING

- Psychologists, child developmental specialists, community health workers, and peer navigators embedded in training settings
- Cross-training across different disciplines/professions so can truly integrate care
- Shared competencies and curriculum across disciplines/professions and evaluation metrics
- Child and family emotional health and resilience attended to no matter what health care setting a trainee finds him/her/their self
- Patients and families integrated into care team

INTEGRATED CARE

- Inclusion of non-medical professionals, parent/young adult patient peers and community health workers, and office staff in the team
- Supervision models
- Cross-disciplinary records with evidence-based decision support
- Cross-disciplinary mechanisms for payment
- Cross-walk of different risk identification and treatment protocols, including the family
- Network of medical and non-medical resources to link ~~to~~ with

OUTCOMES INTEGRATED CARE

- From A Family Guide: Integrating Mental Health and Pediatric Primary Care, the National Alliance on Mental Illness.
- Based on data from the Massachusetts Child Psychiatry Access Project and a demonstration project for behavioral health integration into primary care practices in North Carolina.

- Health care
  - Improved access
  - Lack of duplication
  - Shorter wait times
  - Decreased use of emergency services
  - Reduced errors
  - Clear lines of responsibility

- Families
  - Regular contact
  - Reduced stigma
  - Improved adherence
  - Better incorporation of family preferences into treatment plan
  - Greater convenience and satisfaction

MULTI-LEVEL FAMILY-FOCUSED PROGRAMS

- Growing evidence base for family-focused programs
  - Annie E. Casey Foundation https://www.blueprintsprograms.org/
  - Washington State Institute for Public Policy https://www.wsipp.wa.gov/
- Three levels of promotion/prevention
  - Universal: expectant parents, parents of adolescents
  - Selective: families identified with special needs or vulnerabilities (e.g., pregnant teenagers, children of divorced parents, children diagnosed with a chronic condition, children in foster care)
  - Indicated: already showing symptoms (e.g., autism, anxiety)

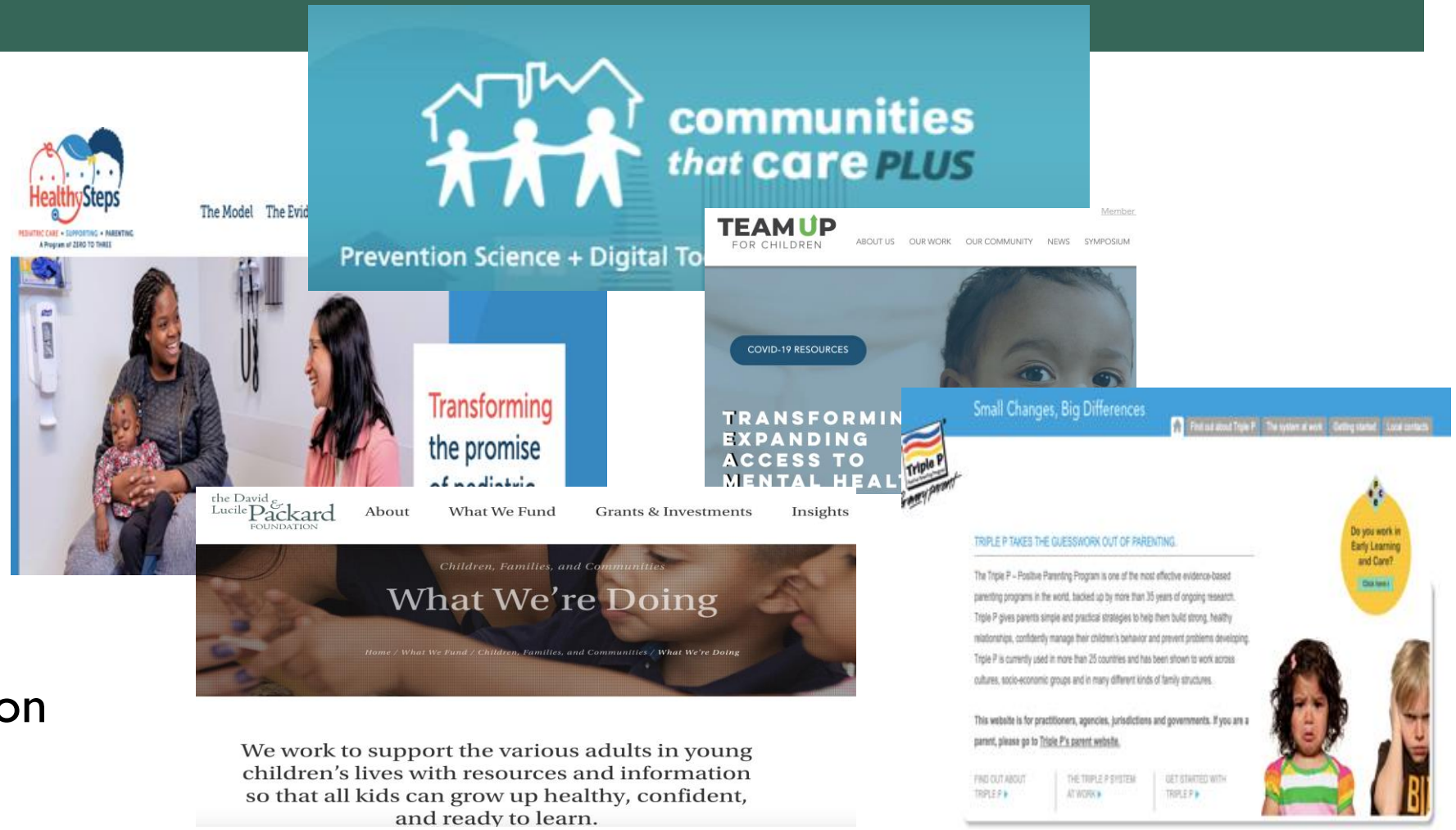
Leslie et al. Primary health care: Potential home for family-focused prevention interventions. AJPM 2016, 41 (4S2): S106-118.

BUILD OFF OF A PROMOTION, LIFECOURSE, AND SYSTEMS INTEGRATION PERSPECTIVE

EXAMPLES

Components include:

- Community-based
- Culturally sensitive
- Accessible
- Developmentally appropriate
- Supportive relationships
- Peers/Navigators
- Education/information
- Practice/homework
- Measure outcomes



SUBSPECIALTY CHILD HEALTH CARE

FOSTERING MEB HEALTH OF YOUTH: ROLE OF PEDIATRIC SUBSPECIALTY CARE

- >30% of children have a chronic health condition
- A growing number (est: 5%) of all children have a disabling, life-threatening condition (CMC)
  - Rare diseases
  - Congenital anomalies
  - Prematurity-related disorders
  - Mental health disorders
- For many CMCs, subspecialty care functions as primary care setting

CONSEQUENCES OF CHILDHOOD CHRONIC DISEASE

- Increased prevalence of behavioral disorders for the child, parents, siblings
- Family economic and social adversities
  - Recurring and chronic stress
  - Disruption of family structure and function
- Lifetime risks for parental health and longevity (Cohn L., Pediatrics, Acad Pediatr, 2020)
- Increased costs of health care with behavioral co-morbidities (Perrin J., Acad Pediatr, 2019)

PEDIATRIC CHRONIC CARE MODELS INCREASINGLY RESPOND TO BEHAVIORAL HEALTH NEEDS

- Social work and behavioral professionals on chronic care teams
- Screening, diagnosis and treatment for behavioral conditions
  - Children and adolescents
  - Parents

UNMET NEEDS

- Integration of behavioral health into the care model
- Promotion of child and family behavioral health
- Identifying and mitigating risks for behavioral health

AS THE FAMILY GOES, SO GOES THE CHILD

CF WELL

A Family-Focused Approach to Prospectively Supporting Behavioral Health and Wellness

- Attention to lifestyle factors
- Managing stress
- Encouraging moments of joy and satisfaction
- Addressing adverse social and economic determinants
- Surveillance for family behavioral disorders

LIFESTYLE FACTORS

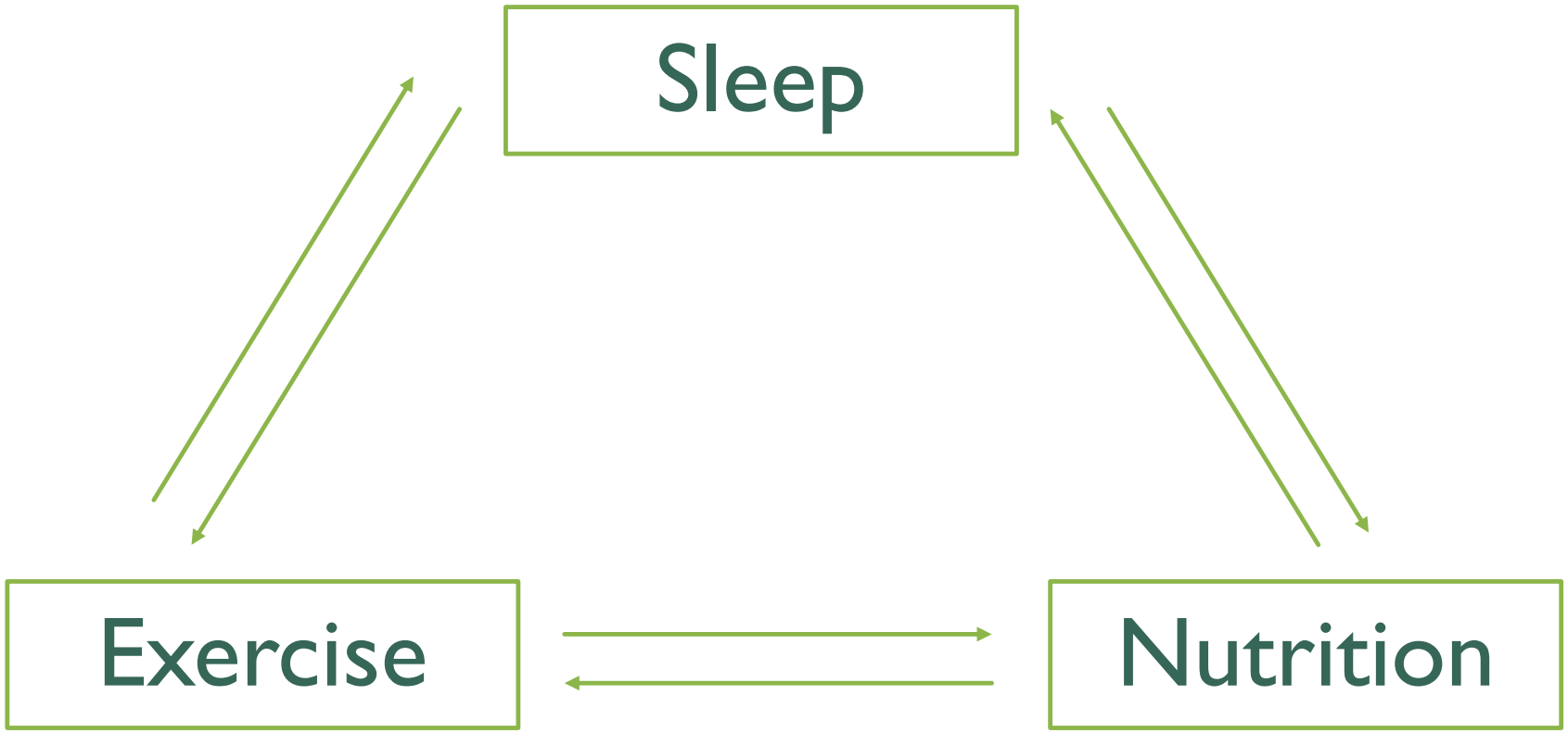
- Sleep
- Exercise
- Nutrition
- Normalizing treatment regimens
- Finding joy

SLEEP DISRUPTION AND INSUFFICIENCY FOR CF FAMILIES BYARS K. ET AL, IN PRESS

- One third of families experience disordered sleep
- A strong correlation of sleep for parents and sleep of the child with CF
- Not related to severity of lung disease or socioeconomic status of the family
- 40% of parents report daytime sleepiness
- Most parents do not see sleep as a priority consideration

NUTRITION AND EXERCISE

- Treatment regimens and other demands encroach on time for food preparation and exercise
- High carbohydrate, prepared foods are prioritized
- Frequent outcomes: excess body fat and limited skeletal muscle development



INTERACTIONS AMONG LIFESTYLE FACTORS

ADDRESSING LIFESTYLE FACTORS

- Introduce the importance of lifestyle factors for family resilience and wellness at the time of diagnosis
- Reinforce wellness considerations at each clinic visit
- Consultation with sleep, exercise, and nutrition specialists as needed and accepted by families

STRESS: A UNIVERSAL EXPERIENCE FOR FAMILIES OF CHILDREN WITH CMC

- General stress
- Situational stress
- Chronicity defines this stress as an adverse experience

STRESS: A UNIVERSAL EXPERIENCE FOR FAMILIES OF CHILDREN WITH CMC

General Stress

- Worries about the child's health and mortality
- Worries about siblings
- Worries about money
- Food and housing insecurity

Situational Stress

- Clinic visits and health status testing
- Hospitalization
- School engagement

SCHOOL ENGAGEMENT FOR YOUNG PEOPLE WITH CF

- Average annual days absent: 25+
- 15-20% concerned about failure
- More than 75% of parents stressed by inability to advocate for school accommodations
- Many schools, teachers at a loss for how to support a CF student's academic and social needs
- School success is critical for independent living as an adult

AN INTERVENTION TO REDUCE SCHOOL-RELATED STRESS

- Hired a school intervention specialist who bridges family needs and school responses
  - Survey of family school-related needs
  - Assist families with advocating for school response to their child's needs
  - Assist teachers, school nurses, administrators with understanding needs
- Uniform appreciation from patients, families, schools, and care team personnel
- Less school-related stress and improvement of advocacy on the part of parents?

ATTENDING TO THE EMOTIONAL HEALTH OF THE CF CARE TEAM

HENTE E., J PEDIATR, IN PRESS

- Stress and burnout symptoms are prevalent for health professionals in chronic care teams
- Tested six sessions of group mindfulness-based CBT for all interested team staff
- Documented improved perspective taking, perceived stress and anxiety, depersonalization, empathy, and resilience at one month
- Sustained, but blunted improvement demonstrated at 15 months

BARRIERS TO WELLNESS PROMOTION AND RISK PREVENTION

- Cost and reimbursement
- Health system structure
- Care model rigidity
- Recognition of need, or willingness to communicate need, by stressed and overwhelmed families
- Lack of training of health professionals

RECOMMENDATIONS FOR SUBSPECIALTY PROGRAMS

- Address demands, stresses, and their behavioral consequences from the time of diagnosis
- Build attention to lifestyle factors and stress reduction into the care model
- Recognize that family adherence to recommend therapies is dependent on family wellness and resilience
- Partner with other providers to promote family wellness (primary care, child care, preschools, schools, social services)

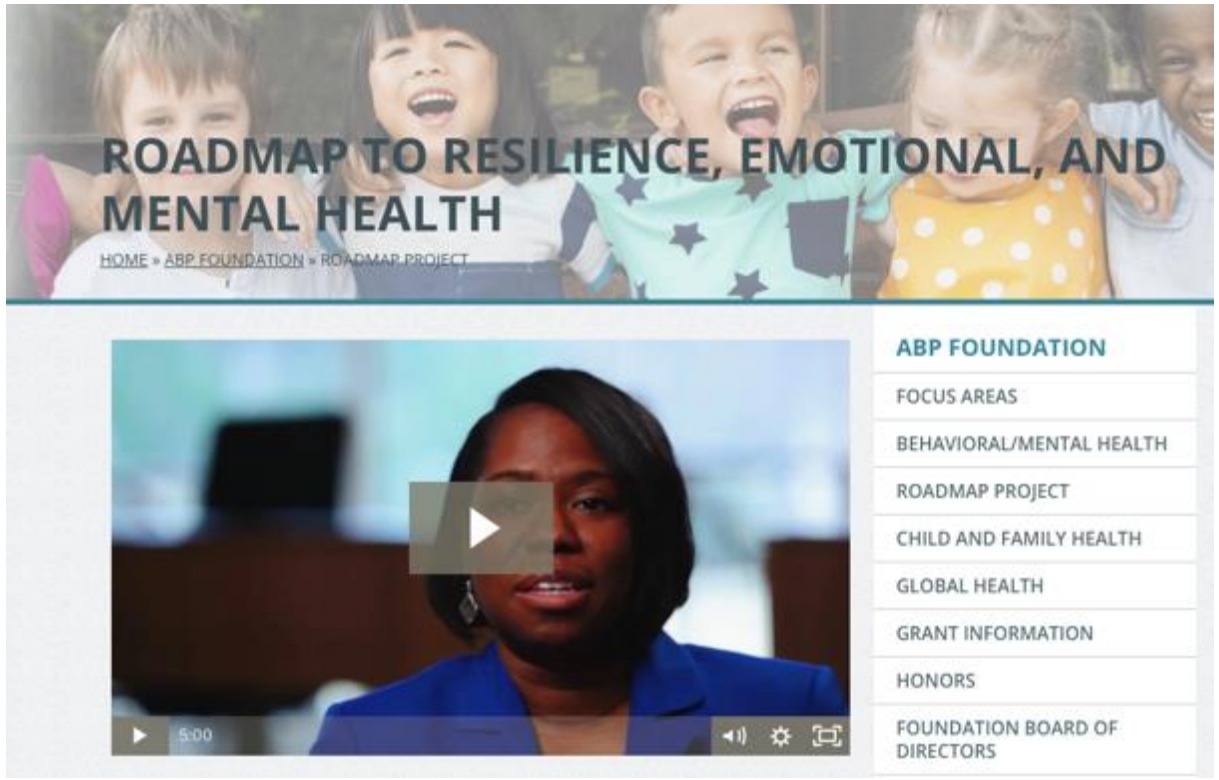
A ROADMAP TO EMOTIONAL HEALTH FOR CHILDREN AND FAMILIES WITH PEDIATRIC CONDITIONS

PICKLES, D.M., LIHN S.L., BOAT, T.F., AND LANNON, C. (2020). *PEDIATRICS, 145*(2), 7-10.

An outcome of conversations among patients, families, subspecialty clinicians, clinical and training leadership, stakeholder organizations, and quality improvement specialists, sponsored by the American Board of Pediatrics.

- All health professionals must support promotion of emotional health from the time of diagnosis
- Scripts for conversation openers
- Realize that families may be reluctant to share vulnerabilities
- All stakeholders are needed to transform care and training

ABP.ORG/FOUNDATION/ROADMAP



OBJECTIVES FOR THIS WEBINAR

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MOVING TO 3.0

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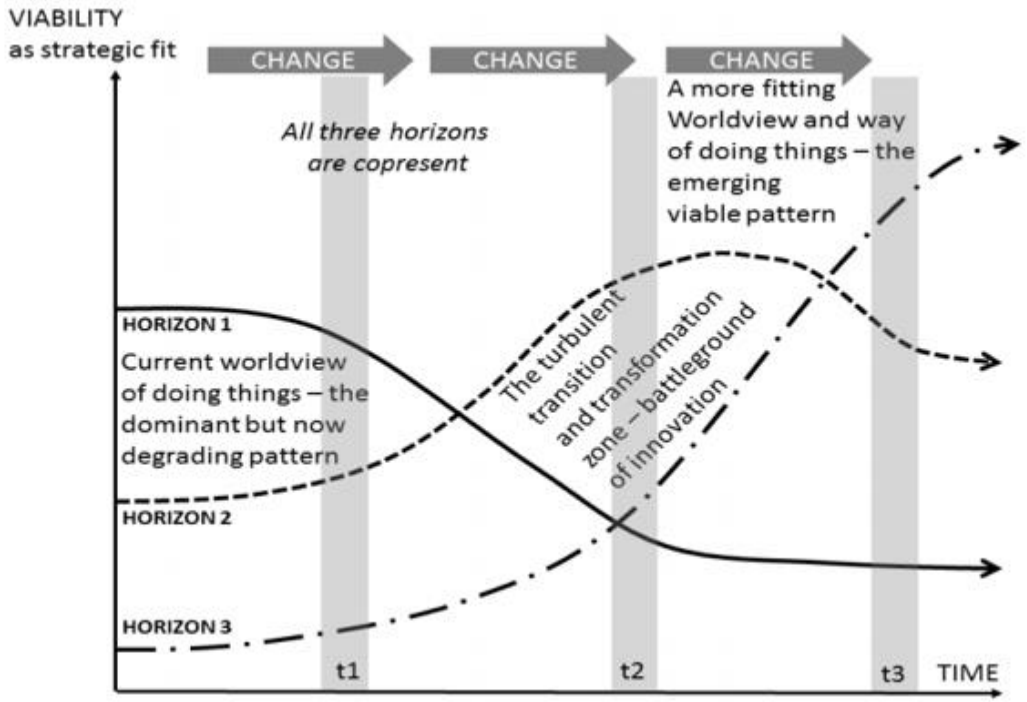
CARE MODEL	Little coordination between in/out patient care, episodic treatment	Chronic condition management, patient-centered care coordination	Health, psychosocial, and wellness care integrated across the life course
DOMINANT PAYMENT APPROACH	Fee-for-service	Value-based health payments	Population-based global budgets, linked to multi-sector financial impact
APPROACH TO QUALITY	Variable, low transparency	Consistent, standardize processes and outcomes	Continuous learning and quality improvement
BENEFICIARY LENS	Individual	Patient and family	Subpopulations and communities, equity- oriented

Halfon et al., 2014. Adapted from Figure 2.

ADDRESSING BARRIERS

- Incremental change (Horizon 1): identification and treatment
  - Changing epidemiology
  - Public/health care providers' recognition
  - ER demand/hospital beds
- Disruptive/transformative change: promotion and life span approach (Horizon 2/3)
  - New science
  - Visioning by foundations/states
  - ????



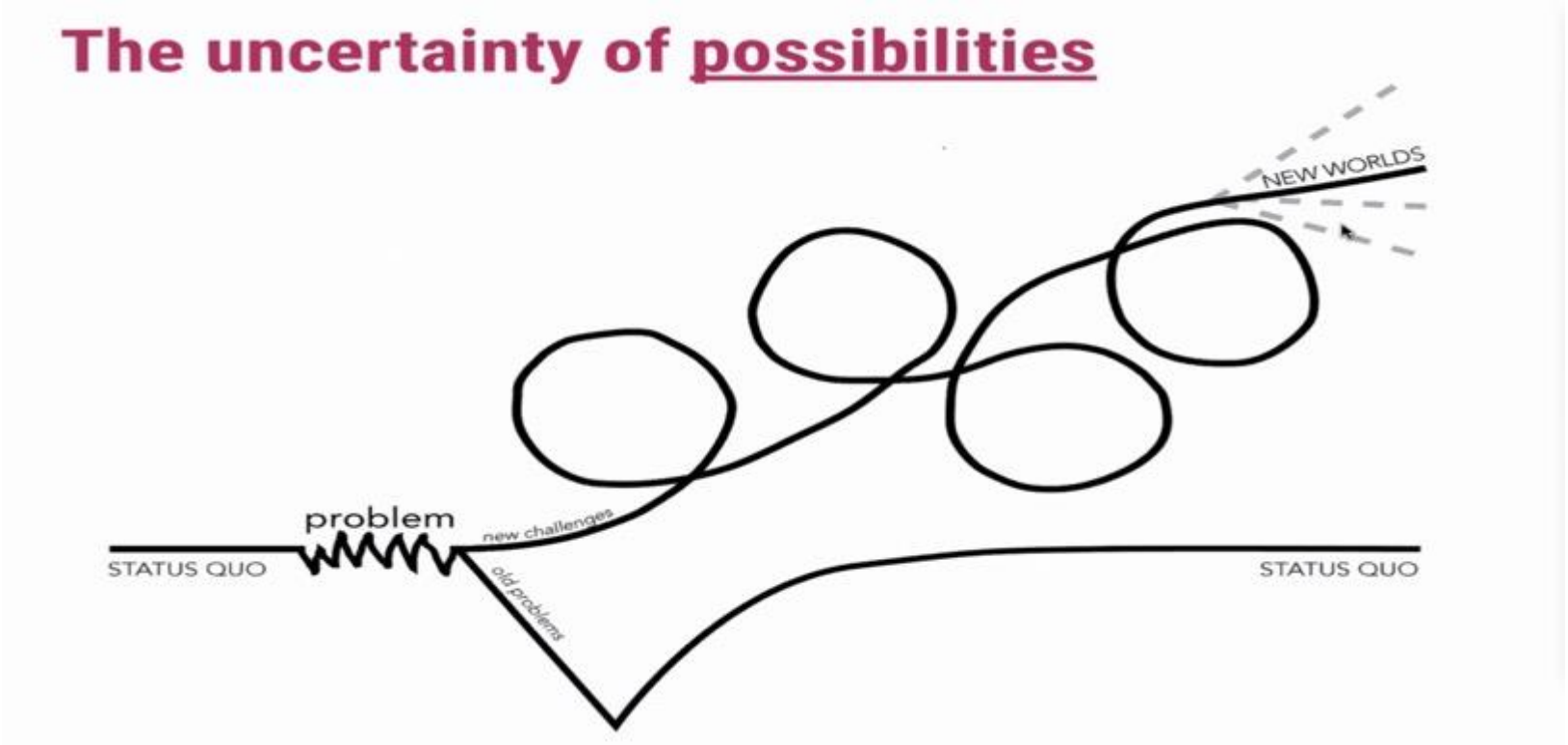
OPPORTUNITY TO WORK WITH OTHERS

- Other professionals involved with children
- Public service sectors
- Families
- Business leaders
- Policy-makers

OPPORTUNITY WITH A DISRUPTION LIKE COVID-19?

- Already embracing
  - Rapid changes in HIPAA around privacy
  - Telehealth
  - Public health prevention, screening, and treatment
  - Impact of COVID-19
    - Need to focus on children's emotional health and resilience and that parental well-being impacts the child
    - Home schooling and recognition of what teachers do
    - Social distancing on mental well-being
    - Economics and interplay with disease on families, community, and society
    - Health care financing on care settings and on families

THIS IS NOT THE TIME TO BE SILENT ON CHILDREN'S NEEDS



You can't go back and change the beginning,
but you can start where you are
and change the ending.

Attributed to C.S. Lewis

QUESTIONS AND COMMENTS?