COMPLEX MEDICAL CONDITIONS IN CHILDREN: UTILIZING PERSONALIZED TREATMENTS AND ADDRESSING HEALTH DISPARITIES

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Part I

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Learning objectives

- Describe the impact social determinants of health (SDoH) have on the diagnosis, treatment and outcomes of children with complex medical conditions (CMC)
- Address the importance of access to personalized care that children with rare and CMC require to live their healthiest lives
- Identify practices and strategies that the interprofessional health care team may employ to address negative SDoH
- State resources available to champion equitable change for children with CMC

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Children's health

"The extent to which individual children or groups of children are able or enabled to

a) develop and realize their potential,

b) satisfy their needs, and

c) develop the capacities that allow them to interact successfully with their biological, physical and social environment."

Hagan JF et al. (2017) Bright Futures 4th edition

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Social Determinants of Health

"Health starts in our homes, schools, workplaces, neighborhoods, and communities…Our health is also determined in part by access to social and economic opportunities; the resources and supports available in our homes, neighborhoods, and communities; the quality of our schooling; the safety of our workplaces; the cleanliness of our water, food, and air; and the nature of our social interactions and relationships."

Hagan JF et al. (2017) Bright Futures 4th edition

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Health equity

"Attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally, with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities."

Hagan JF et al. (2017) Bright Futures 4th edition

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Equitable change

- Children with medical complexity children just like any other child
  - They need the same kind of consideration and planning
  - Their accommodations may just be a little different

Image from: https://educationpost.org/guess-what-equity-and-equality-are-not-the-same-thing/

Life course

- Children and families are affected by biological and ecological exposures
- These exposures promote healthy development or increase risk of impairment or disease
- Health and development are intertwined and inseparable
- Drivers of life course health include:
  - Biological (nature): genetics, uterine environment (epigenetics, exposures)
  - Ecological (nurture):
    - Protective factors – e.g., stimulation, attentiveness, resiliency, emotional competence, social competence
    - Risk factors – e.g., abuse, neglect, poverty, disabilities / chronic disease, natural disasters

Considerations

Personalized treatment

- The best clinical care is "personalized"
- Personalized medicine:
  - Individualized approach
  - Used by NIH as **genetics**
  - However, much of health is NOT determined by genetics
- Every child and family has an individual journey and lived experience

Health disparities

- Every child deserves the same potential
- Every child needs resources and services, delivered in a predictable and designed manner
- Some children need more resources and service than others
  - Biological illness
  - Consider systemic factors, e.g., racism, poverty, ableism
- *Addressing health disparities requires identifying children more at-risk, developing relationships and partnerships, and connecting to resources*

https://www.nih.gov/about-nih/what-we-do/nih-turning-discovery-into-health/personalized-medicine

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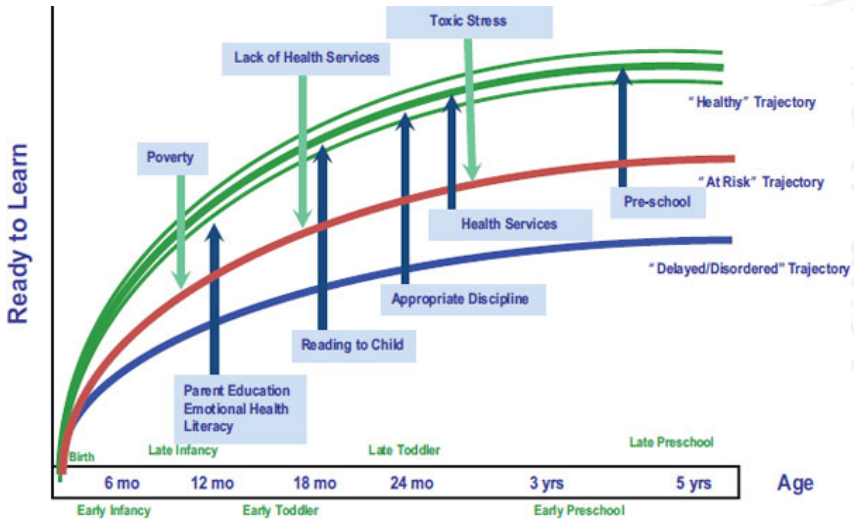
May 2018

Opportunity for Long-term Impact



Source: NYS DOH First 1000 Days Initiative

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Part II

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Medical complexity

- Multiple chronic conditions
- Technology dependence
- High resource use
- High level of family need

- Examples may include:
  - Down syndrome
  - Spina bifida
  - Cerebral palsy, feeding difficulty, non ambulatory
- Higher incidence of
  - Developmental delay
  - Inpatient and ER use

Cohen, Kuo et al *Pediatrics* 2011

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Medical complexity: Impact on families

- High stress levels
- Missed workdays
- Out of pocket costs
- Impact on family members

- Driven by:
  - High service need
  - Fragmented care system
- Families often feel like they have to drive the system

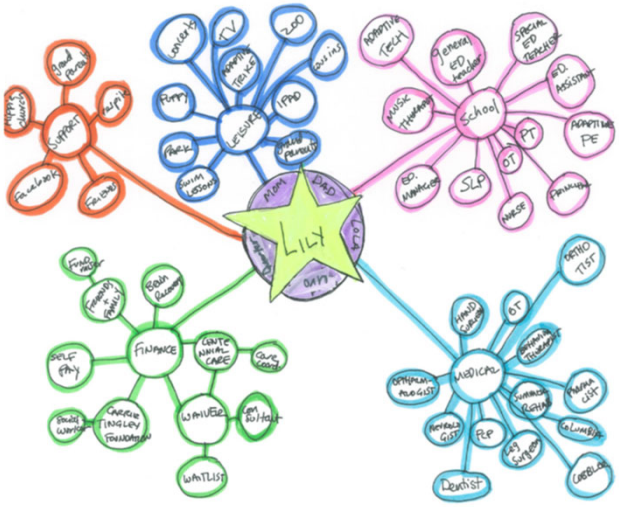
Allshouse et al *Pediatrics* 2018

Access to care for medical complexity

- Enhanced primary care
- Tertiary care center-based services
- Designated care coordinator to navigate
- Community-based resources

- However, think of the model of care as a lived experience, instead of a series of components
- ***Access to care components:***
  - Coverage
  - Service
  - Timeliness
  - Capability
- *Then we have to make it all work*

Care map: why we perform care coordination
(and what needs coordinating)



Kuo, D. Z., et al. (2018). "Care Coordination for Children With Medical Complexity: Whose Care Is It, Anyway?" Pediatrics **141**(Suppl 3): S224-S232.

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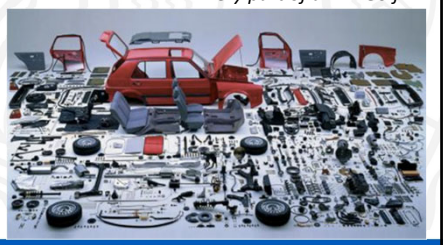
The life course isn't consistently designed

- Variation in how coordination of services is **operationalized**
  - Training, staffing levels, and location of staffing
  - Scope of duties, ranging from case management of a specific condition to collaboration with community-based services
  - Evidence thus far is limited - intensive care management services may have some impact on preventable hospitalizations for specific children
- How do you make all of this work properly?
- **"Whose care is it anyway?"**

"Every part of a VW Golf"



Kuo, D. Z., et al. (2018). "Care Coordination for Children With Medical Complexity: Whose Care Is It, Anyway?" Pediatrics **141**(Suppl 3): S224-S232.
https://katrinadstevens.com/2012/12/19/sandy-hook-lets-respond-thoughtfully-and-compassionately-not-simply-react/car-parts/ but unattributed

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Part III

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"Personalized medicine" = an individualized approach

- Grounded in the life course model of care
- High performing practice
  - Identify service needs
  - Identify risk factors
  - Identify protective factors
- Standardize approach
  - Screener tools
  - Care teams with roles and assignments
- EXAMPLE: 4 year with Rett's Syndrome
- Service need
  - Coverage
  - Service: specialists, therapies, school
  - Timeliness: hours of practice, phone coverage, distance to care
  - Capability: is the right care being given?
- Coordinate service delivery and experience (care manager)

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At the practice level

- Timely and accessible care
  - Population based registry – identify children at risk
  - Accessibility audit of your practice
- Staff training for disability care
- Office protocols
  - Screenings – development, psychosocial
    - Keep in mind that programs are not necessarily standardized for CMC
  - Team-based care, including care coordination services
  - Linkages to resources, including educational, therapies, family support

(https://nwadacenter.org/sites/adanw/files/files/IdahoClinics%20Checklist_November2015.pdf)

Life course: considerations for CMC

- Definition of health and wellness are the same; the implications may be greater
  - Consider the influence of complex adaptive systems that can be nonlinear, occur in multiple levels, and are sensitive to timing
  - Mechanisms include adversity and allostatic load; epigenetics; and buffers including parenting, health promotion, and social supports
- More research can be done on developmental trajectories, i.e., what skills early on are important to later independence and transition
- Address the intersectionality of racism, ableism, poverty

Msall ME et al. In Halfon N et al Handbook of Life Course Health Development.

Ableism

- Ableism is the notion that attainment of a function connotes superiority
- Iezzoni (2021) – adult physicians
  - 82% of physician respondents reported that people with significant disability have worse QOL
  - 41% of physicians confident about ability to provide same level of care
  - 57% agreed welcoming patients with disabilities in their practices

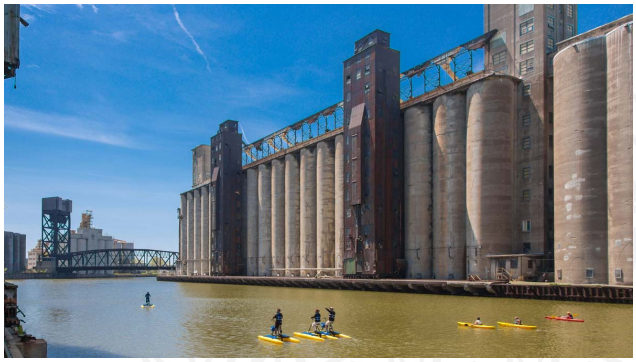
Reynolds JM. AMA J Ethics (2018):20(12):E1181-1187.
Iezzoni LI et al. Health Aff (Millwood) 2021 Vol. 40 Issue 2 Pages 297-306

The role of social determinants of health

- Social determinants of health impact and drive overall health and wellness
- Even higher impact for CMC given how much of health is determined by communities
- Life course is particularly susceptible to the impact of SDoH
- Impacts include home, schools, environment, distance, available resources to child
- Impact also include systemic forces to recognize including systemic racism, ableism, classism

Silos are not just a tourist attraction in Buffalo

- Health care, educational services, and social services are, and remain, highly siloed
- Lack of universal and equitable services and coverage for all children
- Need to navigate services as a lived experience



Fry-Bowers, E. K., et al. (2014) e JAMA Pediatr **168**(6): 505-506.
Edwards, S. T., et al. (2014). J Gen Intern Med.

Part IV

Getting started

- Consider a single, designated central care coordination staff member acting as the "single point of contact"
- Standardize the training on the range of services that CMC utilize
  - Medical
  - Psychosocial (don't forget behavioral)
- Centralized electronic communication tools, assessment tools, and a "care coordination dashboard" can be helpful to care coordinators

Experience from the Children's Hospital Association *Coordinating All Resources Effectively* award

Practices and strategies to address SDoH

- Know the system of public and private partnerships
- Schools are an exceptionally important partner in addressing SDoH. The COVID-19 pandemic highlighted what happens when schools are hamstrung by closure and remote.
- Consider care navigators, family support systems, and partnerships
- Shared decision-making

Resources available to champion equitable change for children with CMC

Coverage
- Primary insurance
- Secondary insurance
- State resources, including Title V

Timeliness
- Hours
- Phones
- Care planning to anticipate emergencies

Services
- Direct (primary, specialty)
- Therapies, school, support
- Telehealth

Capability
- Interdisciplinary care team
- Care manager/navigators
- Family partners

Shared Decision Making

- Essential to care of CMC
- Elements
  - information is exchanged in both directions
  - all parties are aware of treatment options and what they are, and
  - all bring their knowledge and values-related priorities equally into the decision-making process
- Implementation
  - Demonstrate and model SDM
  - Utilize SDM tools in EMR/templates

Adams, R. C., et al. (2017). "Shared Decision-Making and Children With Disabilities: Pathways to Consensus." Pediatrics **139**(6).

Advocacy

- Link to anti-poverty resources
  - Insurance coverage including Medicaid waivers
  - WIC
  - SNAP
  - SSI
- Understand the laws that protect and ensure equity for children with medical complexity, particularly those with disabilities
- Educational resources, therapies, rights to "free and appropriate public education"

Laws and advocacy

- Americans with Disabilities Act requires nondiscrimination against disabled people
- Individuals with Disabilities Education Act entitles students to a free and appropriate public education in the least restrictive environment
- Advocate for children and adolescents to receive the accommodations and services to which they are entitled
- Refer to legal advocates (medico-legal partnership), state protection and advocacy organizations, and the U.S. Department of Justice Civil Rights Division

Cyr P, Agrawal R. https://www.aappublications.org/news/2021/09/01/anti-ableism090121

Life course questions: preconception/prenatal

- Did the mother (and father) get appropriate health care?
  - Did the parents get optimal health care when younger?
  - Did the mother get appropriate sexual health education, particularly if the mother has a disability?
- Did the mother get appropriate social supports?
- Did the mother get appropriate prenatal health care?
- Did the mother get appropriate medical care when delivering?

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Life course: the perinatal/infancy period

- Consider coverage, service, timeliness, capability
- Does the family have sufficient social support?
- Does the family have access to appropriate health care?
- How well can the family self-manage them the services, and what kind of support does the family need to navigate?

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Life course: the child gets older

- Did the child have appropriate developmental screening and access to Early Intervention and Special Education?
- Did the child get appropriate psychosocial screening?
- Did the youth get appropriate sexual education?
  - Timing of puberty may differ; menstrual manipulation/suppression; counseling on sexual activity / safe sex practices; appropriate/inappropriate sexual behaviors; HPV vaccine
- Did the child and family have access to appropriate resources?
- Does the PCP office have policies to address health care transition?

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How well do you and your team address disabilities across the life course?

- Does your team understand ableism, discrimination, implicit bias?
- Does the practice setting accommodate children with disabilities?
- Does the team prepare for culturally competent care? Particularly with parent who may have a disability?
- Does the team understand the protections parents have for equal access under the ADA?
  - Interpreter use
  - Hearing impaired

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Conclusion

- Personalized care for CMC includes identifying service needs, linkage to resources, and assistance with navigation
- Social determinants of health can be navigated through
  - Registry, team-based care, assigned roles
  - Standardized practices including screenings, cultural awareness, linkages to resources
- Resources include community partnerships, care navigators, and family advocacy groups

Resources/References

- American Academy of Pediatrics. Bright Futures. https://brightfutures.aap.org/Pages/default.aspx
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- Milbank Q. 2002 Sep; 80(3): 433–479. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2690118/

Q & A

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Thank You!

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