

Making Connections: The Critical Role of Family-Centered Care in Addressing Social Determinants of Health for Children and Youth with Special Health Care Needs (CYSHCN)

June 18, 2020, 10-11am Central
Questions and Answers

Faculty:

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Moderator:

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This document includes a summary of major questions presented by participants that were not answered during the live webinar due to time constraints.

Questions	Answers from Dr Amy Houtrow
How would you define “biological environment?”	From the Children’s Health The Nation’s Wealth : “A child’s biology determines how physiological processes unfold and how organ systems adapt to outside influences. Biological response patterns, including responses to stress, novel situations, and primary relationships, can directly and indirectly influence other biological, cognitive (learning), and behavioral processes. The term “biological embedding” has been used to describe how the external environment influences and shapes the biological environment (including the central nervous system), which in turn changes the way the individual interacts with the external environment (Hertzman, 1999). “ page 47.
How do clinics get certified as “a medical home?”	Müge Chavdar: To become certified as a medical home, a pediatric practice needs to demonstrate competence in various criteria. There are 4 main organizations that provide recognition/accreditation for the patient/family-centered medical home and various strategies that clinics can use to transform their practices. Each of the accreditation organizations have their own unique sets of criteria.

	<p>The American Academy of Pediatrics has developed a webpage with resources on the medical home model as well as medical home transformation tools. All relevant information related to accreditation, transformation strategies, and information on financing can be found here.</p> <p>Additionally, developed by the NRC-PFCMH, this medical home transformation website that provides clinicians with direction, resources, and information to support the medical home transformation process.</p>
<p>Natalia Linos, Executive Director of Harvard’s Center for Health and Human Rights refers to SDOH as “political or legal determinant of health since this is not an accident of “society” but a purposefully established to enforce systemic racist and classist desired outcomes. It also establishes the environment in which the solutions to these health problems lie.” What does Dr Houtrow think about this framing?</p>	<p>This is an interesting framing that highlights that these upstream factors are socially constructed. As someone trained in sociology, I see these political and legal constructs as fitting under the umbrella of socially constructed. Certainly, policies were created with intention and some the consequences were unintended. I think stating the political or legal determinants will resonate with people and really emphasizes where we need action. Thank you for bringing up the work of this Harvard group. We as a society need the political will to undo the policies that structure our society in the way that benefits those on the top.</p>
<p>Broadly speaking in pediatrics, transitions to adult care are rocky at best and examples of smooth transition where the young adult has acquired a medical home for adult care that is family centered is rare.</p> <p>Are adult providers receiving this training (webinar) also? Or – are they receiving any training like this?</p>	<p>Amy Houtrow: Transitions are rocky and as a system we underperform doing this successfully. Perhaps in part because adult and pediatric providers are not engaged adequately together. I would be happy to provide a similar talk to adult providers.</p> <p>Tom Scholz: This has been recognized by pediatricians caring for children with medical complexity and has resulted in several specialties using the medical home model to transition children into adulthood. Examples include Pediatric Cardiology and Pediatric Hematology/Oncology divisions (and probably other specialties) where multidisciplinary clinics caring for young adults (including pediatric and adult specialists, psychologists, social workers, dieticians, and others) have been developed.</p>
<p>In reference to the data on the slide titled “Extreme Poverty Trends by Race,” do the data for Native American children only include children living on Native American Reservations? Or is it inclusive of children living in other locations as well?</p>	<p>The data comes from the American Community Survey so does not include institutionalized children but does serve in tribal lands and in all states.</p>

<p>In reference to the data on the slide titled, "Receipt of Family-Centered Care," how was family-centered care measured/defined?</p>	<p>The National Survey of Children's Health defines family-centered care as the following:</p> <p><i>This measure represents the Family-centered care component of the Medical Home composite measure. Family-centered care is comprised of responses to five experience-of-care questions: spends enough time with child (K5Q40), listens carefully to you (K5Q41), sensitive to family values/customs (K5Q42), gives needed information (K5Q43), and family feels like partner (K5Q44). The composite family centered care measure is only considered missing if all components are missing. Therefore, children with a valid, either "Usually" or "Always" response to at least one item and the remainder of the items were missing are categorized as receiving family-centered care. Children who had no health care visits in the past twelve months were not included in this measure.</i></p>
<p>More health insurance plans are moving toward high deductible plans (5K to 10K). What is the research telling us how this is impacting CYSHCN? Is this being monitored? Tracked?</p>	<p>There is research indicating high financial burden for families with CYSHCN. Forgone care is often driven by cost concerns. This article might interest the person who asked the question.</p> <p>Our own research on children with medical complexity indicated that the middle-income group (more likely to have a skinny insurance plan) have more unmet need.</p>
<p>Do you feel that the NCQA and insurance metrics for "medical home" give a false sense of satisfaction to health institutions by giving them a checkmark for PCMH when they may not really be providing a medical home by the clinical/advocacy definition?</p>	<p>The data tells us that when the child has more needs, they are less likely to receive care in a medical home. This suggests that practices have work to do to make sure they can provide care coordination (for example) for a child with more extensive needs. While in general the practice might have a notation for being a qualified medical home, it doesn't mean that all of the children in the practice are receiving it. This is true by income, by race and by health care needs.</p> <p>Regardless of what measure of quality is being used, it is important to remember the purpose of the measure (not just getting a check box and moving on, as noted by the question asker).</p>
<p>In which ways do you think we can best get providers to address their racial discrimination and bias?</p>	<p>I hope we are moving in a direction away from denial about our biases. I encourage my faculty to take the implicit bias tests. Some people get more defensive in the moment and do better after the fact when they can reflect. Some people do best</p>

	<p>when the issue is brought up in real time. A feedback sandwich is a good way to deliver the message. It must be frustrating, it is for me, when families tell me other providers treat them differently. I wish I had a failsafe strategy. For people who are swayed by data, sharing the AAP policy statement on racism might help and showing them the studies that indicate differences in care. I recently tackled the issue in this recorded webinar by highlighting that all of us have biases.</p>
<p>Do you have comments about pediatricians' connections with commercial insurers and their roles in supporting care for CYSHCN?</p>	<p>Some insurers have children with special health care needs (CSHCN) programs that assist with care coordination. This can be very helpful for CSHCN who use home care services or have numerous encounters outside of the primary care office.</p>
<p>What is the best strategy to center conversations about social determinants of health centered on justice for black and brown communities when working at a population level?</p>	<p>As a data driven person, I think presenting the data (which would also include food deserts, housing insecurity, foster care, the criminal justice (injustice) system) would help really show the need for justice for black and brown communities. I also think that highlighting the policy changes that could be made and how they help address these SDOH is helpful.</p>