National Resource Center
FOR PATIENT/FAMILY-CENTERED MEDICAL HOME

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)
Episode 2

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Questions and Answers

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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 for Jeff, Gerri, and Marcus	Answers
How are your state Title V/CYSHCN programs preparing to respond to, what will most likely be, huge spikes of SDOH needs, especially for families of CYSHCN?	**Gerri Mattson:** We have expedited the roll out of NCCARE 360 to occur statewide 6 months early. Currently, NCCARE 360 system is operating in all 100 counties. Our state continues to enroll additional agencies including agencies that would be serving CYSHCN. **Marcus Allen:** In Virginia, we rely on our partners to help us with this. Most of our work is done in partnership with major health care systems who employ social workers. They help our clients figure out how to meet certain needs and to overcome barriers to care. Our CYSHCN program has a large budget but the partnerships make a big impact (in my opinion). I admit though that this does not cover all CYSHCN in the state. I am not sure that I have an answer for that completely but two of our programs do make an attempt to help families (information and referral) even if the person who calls is not a client.

What role are your state Title V/CYSHCN programs taking to address well documented racial inequities in SDOH for CYSHCN and their families of color?	**Gerri Mattson:** NC has been involved in a CoIIN about SDOH to address racial inequities in MCH for our Title V programs. This has not just focused on CYSHCN but the whole MCH population. Through this COIIN we have worked with partners such as our Kids Count state program, NC Child. NC Child has highlight racial disparities in our mutual Child Health report card which includes many measures including SDOH. **Marcus Allen:** In Virginia, we have worked on this for sickle cell disease some. When the CDC released their opioid guidelines one of our physician partners and Community Based Organizations (CBO) reached out to our agency to share information about unintended consequences. Historically, people with sickle cell disease have been treated as "drug seekers" when the actual data does not support that. This issue was brought to the attention of our Commissioner at the time (at the request of the CBO) and she signed a letter of support for our CBO to use for advocacy. To make a long story short, the partnership actually led to some changes in our state regarding how people living with sickle cell disease are treated (when it comes to prescribing opioids for the severe pain they live with).
Rural areas are more likely to have single providers who would consider transformation to a patient-centered medical home (PCMH) if it were more affordable. That sentiment is more pronounced during the pandemic. Do you know of any efforts (in your states or otherwise) to make it more affordable for these type practices?	**Marcus Allen:** One thing that may be helpful regarding this is for providers to consider making incremental changes to their practices that build over time. This is what Virginia recommends in our medical home training modules.
What remediation network (if any) has been put in place so that families who are NEGATIVELY impacted by the switch from fee-for-service Medicaid to managed care can have their issues addressed?	**Gerri Mattson:** NC has planned to have ombudsmen and care coordinators work with families who are negatively impacted have issues addressed. NC Medicaid also had email and phone numbers for Medicaid patients and providers to communicate concerns during the months we had started rolling out enrollment. However, we have not yet implemented managed care in NC. Stay tuned. **Marcus Allen:** In Virginia, we encourage our partners to work with families to reach out to their MCOs regarding issues that they face. It also helps that they

	learn the process to work through the system when their issues are not being addressed. The MCOs must have some type of process for members to notify them of problems. **Marcus Allen:** On a system level, Virginia's CYSHCN director worked with our state Medicaid agency directly regarding certain widespread issues with reimbursement. There is no quick fix to deal with Medicaid issues. It requires persistence and time to learn/understand the rules/processes. Experienced and appropriate advocates can be very helpful to families when it comes to this. Virginia programs/partners have staff who are knowledgeable, and they support families in dealing with reimbursement issues.
How are families with CYSHCN responding to telemedicine services?	**Gerri Mattson:** We are seeing that some families and youth are responding well. However, there are also families who are not getting their needs met and benefit better from face to face services. For chronic condition management this has been a way to check in and address some needs so they are not neglected. However, especially for patients with intellectual or developmental disabilities, the telemedicine platform does not work and is distracting and difficult. In addition, some families are having issues with broad band and the technology and it does not always work. **Marcus Allen:** Virginia has not done a survey on this yet.
What strategies, if any, are your states using for expanding access to broadband (to support telemedicine services)?	**Gerri Mattson:** Our state in partnership with Medicaid has mapped where there are broadband gaps and also mapped the uptake of telemedicine by providers across our state. We are trying to map broadband deserts and also providers who are not adopting telemedicine. NC has been working on expanding access to broad band for years and we continue to explore funding opportunities. This also overlaps with our state's interest in broadband access for education since we have issue with keeping students engaged in their studies. We have had some companies, such as Duke Energy and another business donate buses that have broad band access across the state for students to improve broad band access. These buses serve as mobile hot spots. We have also had pediatric and other practices have patients come to their parking lots to use broad band for part of the visit and limit the in-person visits.

	Marcus Allen: This is an issue for Virginia. One approach that we use in a very rural part of our state is to hold telemedicine clinics. In this situation, families come to a local health department building and have remote appointments with specialty physicians who are several hours away. We have care coordination staff on the ground who attend appointments with the families to help them. Health department secure equipment is used for this. At times, there can be network issues. However, Virginia Title V provided some infrastructure funding to improve connectivity at the health department location.
Questions for Gerri Mattson	**Answers**
Questions about resources: Can Dr Mattson share the survey or questions you ask families to evaluate the quality of life measures? Can Dr Mattson share the life skills progression tool? Can Dr Mattson share all other SDOH resources from North Carolina that were discussed?	The Life Skills Progression (LSP) Tool is copyrighted and for purchase. We only have a license to use with our state and we do not own the tool or rights to the tool. The best place to find out information about North Carolina's efforts through NCCARE360 is at our website. You can find out more information about the Healthy Opportunities Pilots, the Interactive GIS Map, Screening Questions and much more at this webpage.
How is the NC CARE360 survey marketed to clients/patients? Traditionally a doctor's office would not be the place to discuss a parent's employment challenges. Are clients suspicious about why this data is being gathered and how it is used?	The SDOH questionnaire will be rolled out when patients/clients are enrolled into Medicaid. It is not being required that doctor's office screen. This is part of how Medicaid managed care with transformation will be rolled out. We are promoting that physician offices screen if they wish but they are not required at this time. Some have chosen to use the tool which has not started to be used yet across the state since Medicaid transformation has been put on hold since February. The data is being kept confidential and patients/clients are told it is only used for care management use and not shared with any identifiers.
Can you discuss how the NC program to build the capacity of family leaders, specifically the curriculum she mentioned based on the Virginia model Parents as Collaborative Leaders.	Parents as Collaborative Leaders is based on a curriculum from Vermont or New Hampshire, I believe. The contact person in the brochure is out of date. To learn more, contact is Holly Shoun who can be at holly.shoun@dhhs.nc.gov. Ms. Shoun is also leading the Branch Family Partners programs of parents across the state. More information online about Branch Family Partners can be found at their website.

Is NC CARE360 only being used in Health Departments or is it also used in other settings? If so, which settings is it being used?	NCCARE360 is being used all across the state with all types of public and private providers. It is available to any provider or professional who knows about it. More information about NCCARE360 can be found on their website.
How many "care coordinators" are involved in NC CARE 360? Which agency or where are they located?	Care coordinators are with different agencies including with NCCARE360. Care coordinators will be in the Prepaid Health Plans (when they go live but right now Medicaid transformation is on hold), medical homes have care coordinators of their own or with Community Care of North Carolina (NC Medicaid primary care case management which has existed in NC for decades), with health departments who do care management for Medicaid and non-Medicaid clients from birth to five with special health care needs. So, care coordinators are located in many different agencies including through NCCARE360 in partnership with NC 211 and UniteUs. There is a spectrum of care coordination depending on where the care coordinator is employed. With a care coordinator employed by the medical home or employed by the health department but working closely with the medical home, there is more one and one with patient and more than just related to SDOH. With other care coordination such as with NC211 and Unite Us, there is more coordination with needs identified related to the NCCARE360 platform. This is from the slide from the webinar about NCCARE360: *A **robust statewide resource directory** powered by NC 2-1-1 that will include a call center with dedicated navigators, a data team verifying resources, and text and chat capabilities.* ○ *A **community repository** powered by Expound to integrate multiple resource directories across the state and allow data sharing.* ○ *A **shared technology platform** powered by Unite Us to send and receive electronic referrals, seamlessly communicate in real-time, securely share client information, and track outcomes.* ○ *A **community engagement team** powered by Unite Us to guide change management, workflows and training, and provide ongoing network partner support.*