

Advancing Systems of Services Network Café Notes

School Re-Opening

August 14,2020

Key Discussion Questions

1. Who have you partnered with to address school reopening for CYSHCN?
2. What have you done to help get Title V to the table?
3. What are the key challenges you are experiencing?
 - a. Any successes in addressing them?
4. How are you helping to address family concerns and perspectives?
5. What potential role could Title V play in supporting families in whatever decision they make regarding school re-opening?

Poll Question Responses

- Are public schools open in your state? (as of August 14, 2020)
 - Yes=20%
 - No=80%

Parent Perspectives

- Cara Coleman, Project Manager at Family Voices, shared the perspective of families on school re-openings. In a word, “chaos.” This is the result of:
 - constant changes taking place in school re-opening plans;
 - lack of communication between schools and families;
 - limited choices available to families whose children have special needs;
 - heightened concerns for their children and family’s safety, physical and mental health, and reduced service access.
- Families feel isolated and need the support of other families and providers to help with decision-making about school re-opening. In addition, children whose parents speak English as a second language face the added barrier of helping their children complete school assignments.
- Cara suggested several strategies for Title V agencies, including:
 - Finding creative ways to connect families, such as Zoom happy hours, and other platforms to reach families without internet.
 - Ensuring translation of school assignments and help with homework if the parent is unable to assist.
 - Partnering with schools and community-based organizations to ensure that students with IEPs have access to needed services, including assistive devices, and other basic services (eg, food).
 - Working with Family Voices, F2Fs, PTIs, and other support groups to share tools/resources (eg, FL’s tool described under Resources Shared below) to help

families determine the most critical things that youth and families need to consider with school re-opening virtually, in-person, or some hybrid.

Florida Title V CYSHCN Efforts

- Dr. Jeff Brosco, Florida's Title V CYSHCN program director, and Joni Hollis, Bureau Chief of Florida's Office of Children's Medical Services Managed Care Plan and Specialty Programs, spoke about Florida's Title V CYSHCN efforts related to school re-opening and their new checklist to help families communicate with their providers about factors they are considering as they weigh school options (see Resources Shared below).
 - Title V worked with the Florida Network on Disabilities to obtain input from over 1,000 families on their perspectives about the most important issues related to school re-opening. The FL AAP Chapter and the University of Miami's Mailman Center for Child Development were also authors on this checklist.
 - Title V is currently working with federal agencies and the Stanford Center for Health Literacy to make the new checklist available as an online, interactive tool/App. The tool will include a function that uses the family's zip code to provide local resources for families, such as a local Parent-to-Parent program or other family resource center. Information on this new tool will be shared with this group soon to gain feedback on usability. Jeff noted that families' biggest unmet need during COVID-19 is for mental health services and supports.
 - Additional advice, reflections, and strategies were offered by the FL Title V team. When considering if it is safe to go back to school, keep in mind social factors (e.g., if the family member needs to go to work in order to get food, pay for rent or a grandparent is living with the family) and consider the range of issues that are important for families to decide what is best for them. A shared decision-making approach is important. While COVID-19 may not be a direct threat to most children, it is to their family.

State Title V Strategies

- Attend to families at greater risk during COVID-19 – for example, children in foster care and kinship care. One state expressed concern about an expected influx into the state's foster care program as a result of COVID-19 (i.e., when a child's caregiver dies). A challenge with kinship care is that it is not state supported like foster care, so the families do not have the same level of resources and supports available to them.
- Use Title V care coordination services to work with families around school re-opening to alleviate anxieties for families by providing a trusted source for the family. Partnering with Medicaid managed care organizations can also be helpful because of the care coordination services they offer.
- Emergency planning (see Resources Shared section for examples)
 - Encourage advanced care planning among families and providers, including deciding about what will happen to a child if their caregiver dies from COVID-19 infection.
 - Consider meeting with your state Children's Hospital Association to formalize back up plans for CYSHCN when caregivers become ill or pass away.

- West Virginia state has funded a Healthy Families grant project that supports creating records of children's medical information that is transferrable between providers.
- Partner with your state AAP chapter around sharing information about the availability of clear masks, especially when providing care for children and families who are deaf or hard of hearing.
- Reach out to speech therapists, physical therapists, and occupational therapists to learn how they are providing their services during this time.
- Utilize a coaching model with the caregivers to provide therapy services and behavioral interventions.
- Partner with family networks that can share information with other families through social media.
- Consider different ways to accomplish the IEP process, including small groups. It is important to support creative and mutually supportive work-arounds, especially in the context of possible adversarial relationships between families and schools.
- Encourage Medicaid to reimburse for internet access, especially in rural communities where the cost of internet is a huge barrier for families.
- Focus on the individual. Deciding whether or not to send a child back to school is an incredibly difficult and individualized decision for families. It is different for every family, with a lot of competing factors to consider.

Resources Shared

- Alaska Department of Health and Social Services Circle of Support, which has been translated into 8 languages: <http://www.dhss.alaska.gov/dph/Epi/id/Pages/COVID-19/circleofsupport.aspx>
 - Circle of Support is a planning tool and has been translated into eight languages. This plan for families helps to identify their circle of support, plan ahead, know when to activate your plan, and find help outside of your circle of support. It also includes a worksheet for families to complete and a child's COVID-19 Go-Bag
- Back-to-School Checklist: <https://emscimprovement.center/domains/preparedness/COVID-19-coronavirus/family-preparedness/>
- Reopening Washington Schools 2020: Special Education Guidance (developed with CYSHCN advocates and families/caregivers): <https://www.k12.wa.us/about-opsi/workgroups-committees/currently-meeting-workgroups/reopening-washington-schools-2020-21-workgroup>
- Website Delaware has to connect with families -www.FamilyShade.org
- Website for the Florida Family Network on Disabilities that Title V partners with <https://fndusa.org>

Related Resources

- Journal of the American Medical Association article: Plans of US parents regarding school attendance for their children in the Fall of 2020. https://jamanetwork.com/journals/jamapediatrics/fullarticle/2769634?guestAccessKey=1406f45e-8ba8-4153-a701-f1da59cb3f4c&utm_source=silverchair&utm_medium=email&utm_campaign=article_alert-jamapediatrics&utm_content=olf&utm_term=081420
- Journal of the American Medical Association Editorial: Returning to school in the era of COVID-19. https://jamanetwork.com/journals/jamapediatrics/fullarticle/2769633?guestAccessKey=169912a7-1a63-431e-9571-80e9719732a4&utm_source=silverchair&utm_medium=email&utm_campaign=article_alert-jamapediatrics&utm_content=olf&utm_term=081420
- Urban Institute post: Students with disabilities can't just be an afterthought this Fall. <https://www.urban.org/urban-wire/students-disabilities-cant-just-be-afterthought-fall>
The post linked to the following state guidance:
 - Illinois Board of Education guidance for students with specialized education needs: <https://www.isbe.net/Pages/Special-Education-Programs.aspx>
 - North Carolina Department of Public Instruction: <https://sites.google.com/view/COVIDspedconsiderations/home-supplemental-optional>