



## Children & Youth with Special Health Care Needs

### Program Executive Summary

The American Academy of Pediatrics (AAP) provides technical assistance and support to promote effective systems of services for children and youth with special health care needs (CYSHCN).

#### Why is this program important?

- In the United States, approximately 1 in 5 children have a special health care need, and approximately 1 in 6 children have a developmental disability. CYSHCN oftentimes require increased care coordination, health care technology and other services within a system of care. Yet, CYSHCN and their families frequently experience fragmented, uncoordinated, systems of care, with only 14% of families with CYSHCN reporting receiving care in a well-functioning system.
- The AAP has extensive experience in providing technical assistance and support to build effective systems of care for CYSHCN and their families.

#### Who can benefit?

- Pediatricians, pediatric medical subspecialists, pediatric surgical specialist
- Other pediatric clinicians, such as nurses, nurse practitioners, physician assistants
- Families/caregivers of CYSHCN
- Public health professionals
- Other stakeholders that work with families and CYSHCN, including schools, therapists, early childhood professionals, etc.

#### Program details

The AAP CYSHCN team is available to provide technical assistance and support to build effective systems of care for CYSHCN through many unique and innovative modalities. Support is available on any topic related to six core components of effective systems for CYSHCN:

- Early and continuous screening for special health care needs
- Partnership with families of CYSHCN to engage in shared decision-making
- Community-based services are organized and families can easily use them
- CYSHCN receive care in a medical home
- Adequate insurance and funding to pay for services
- CYSHCN receive services needed to transition to adult health care systems

We have created many resources that are designed to be adapted to the needs of specific communities. Some of these technical assistance services include:

- Online virtual education modules on a variety of topics (developmental surveillance/screening, autism spectrum disorder, telehealth implementation)
- Online curricula
- Webinars
- Training-of-trainers
- Toolkits (online/virtual)
- Telementoring programs (Project ECHO)
- Virtual learning communities
- Podcasts

#### How is the program implemented?

Technical assistance and support can be delivered virtually using WebEx, Zoom, or any other platform that can be used with a reliable internet connection.

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## **Delivering value and impact**

Building effective systems of care for CYSHCN helps improve health, wellbeing, and quality of life for CYSHCN and their families. Technical assistance efforts of the SSCYSHCN team have a wide reach, with current online modules reaching over 2,000 individuals through PediaLink, AAP's online learning center.

## **Program partnerships**

System building efforts cannot occur without authentic and meaningful partnership with community members directly impacted by these systems or engagement of family members with lived experience. Therefore, in order to successfully improve and build effective systems of care for CYSHCN, partnership with families, caregivers, youth/young adults, and other individuals with lived experiences, as equal team members, is critical. These partners should be from the communities that are the target audiences of any technical assistance initiative.



If you have questions about AAP's suite of global programs, products and services, please contact Albert Jones, Director of Global Business Development, at [ajones@aap.org](mailto:ajones@aap.org) or [aapglobal@aap.org](mailto:aapglobal@aap.org).