

Where to Go for Help

FAMILY

Parent Training and Information (PTI) Center

Where: In every state

Funding from: Individuals with Disabilities in Education Act (IDEA)

How they can help you: PTIs support families of children with disabilities, birth to age 22, with free information to maximize your child's education.

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Find your PTI: parentcenterhub.org/find-your-center

Family-to-Family Health Information Center (F2F)

Where: In every state, as well as US territories and tribal nations

Funding from: Health Resources and Services Administration

How they can help you: Each F2F is staffed by highly skilled, knowledgeable family members who have first-hand experience and understanding of the challenges faced by families of Children and Youth with Special Health Care Needs.

Find your F2F: <u>familyvoices.org/affiliates</u>

Parent to Parent (P2P)

Where: Different locations across the US

How they can help you: Parent to Parent USA is a national network of P2P programs that offer emotional support for families of individuals with disabilities and/or special health care needs through a one-to-one "match."

This program was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EASC-IDD-00251).



How they can help you: p2pusa.org/parents

Autism Self Advocacy Network (ASAN)

How they can help you: ASAN has resources about self-advocacy, disability policy, and autistic culture. ASAN also makes reports and policy briefs about social issues that are important to the disability community.

Learn more about Autistic Self Advocacy Network: autisticadvocacy.org

Developmental Disabilities (DD) Council

Where: There are 56 Councils on Developmental Disabilities (DD Councils) across the United States and its territories.

Funding from: Administration on Intellectual and Development Disabilities under the leadership of the Administration for Community Living in the Department of Health and Human Services

How they can help you: DD Councils are made up of volunteer members who are appointed by the state's governor. By law, the majority of members must have a developmental disability or be a family member of a person with developmental disability. The DD Councils focus on creating community programs and advocating for solutions that empower individuals with developmental disabilities.

Find your DD Council: <u>nacdd.org/councils</u>

Partners in Policymaking (PIP)

Where: Currently available in over 30 states, including DC

How they can help you: PIP is a program that prepares people to be effective advocates at the local, state, and federal levels. They work with adults with intellectual/developmental disabilities (I/DD), parents, and family members of children and adults with I/DD.

This program was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EASC-IDD-00251).



Access the online PIP course: partnersonlinecourses.com

University Centers for Excellence in Developmental Disabilities (UCEDDs)

Where: Currently, there are 67 UCEDDs – at least one in every US state and territory.

Funding from: Office of Intellectual and Developmental Disabilities

How they can help you: Centers work with people with disabilities, members of their families, state and local government agencies, and community providers in projects that provide training, technical assistance, service, research, and information sharing.

Learn more about UCEDDS: <u>aucd.org/directory/directory.cfm?program=UCEDD</u>

Leadership Education in Neurodevelopmental and Related Disabilities (LEND)

Where: There are 60 LEND programs in every state, the District of Columbia, the United States Virgin Islands, Puerto Rico, and six Pacific Basin jurisdictions, either as an awardee or in partnership with a LEND program.

How they can help you: LEND programs improve the health of infants, children, and adolescents with disabilities by training professionals. LEND programs operate within a university system, usually as part of a University Center for Excellence (UCEDD). They collaborate with local university hospitals and/or health care centers.

Find a LEND program: mchb.hrsa.gov/training/projects.asp?program=9

This program was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EASC-IDD-00251).



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Where: 22 centers across the US

Funding from: Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD)

How they can help you: IDDRCs work to prevent and treat disabilities through biomedical and behavioral research.

Learn more about IDDRCs: <u>aucd.org/ddrcportal/template/index.cfm</u>

Interagency Autism Coordinating Committee (IACC)

How they can help you: IACC is a Federal advisory committee that gives advice to the Secretary of Health and Human Services on issues related to autism. Its members are officials from federal agencies who work on autism related issues, as well as autistic adults, parents and family members, advocates, community providers, and researchers.

How you can participate: IACC meetings are open to the public, and members of the public can comment during each meeting.

To submit a Public Comment to the IACC, please visit: <u>iacc.hhs.gov/meetings/public-comments/submit/index.jsp</u>.

Information about each meeting, including the minutes, video, and slides, is posted on the <u>meetings page</u>.

Website: <u>iacc.hhs.gov</u>