

Children with Special Health Care Needs Resources

Nearly 1 out of every 5 children in the United States has a special healthcare need. Children with special healthcare needs (CSHCN), require more care for their physical, developmental, behavioral, or emotional differences than their typically developing peers. A special healthcare need can include physical, intellectual, and developmental disabilities, as well as long-standing medical conditions, such as asthma, diabetes, or a muscular dystrophy.

Item	Description	Source/ Link
Organizations		
American Diabetes Association	Resources to support those living with diabetes and education for the public about how to stop diabetes. Information includes: risk factors, symptoms, treatment and care, food and fitness, and complications.	Eastern PA and DE: https://diabetes.org/local/eastern-pennsylvania-delaware Pittsburgh: https://diabetes.org/local/western-pennsylvania
Center for the Social and Emotional Foundation for Early Learning (CSEFEL)	Training modules, videos and home of the national pyramid model for states to enhance socio-emotional competent caregiving. Briefs: summaries of effective practices to support children's social-emotional development and prevent challenging behaviors; practical strategies; one-page handouts with major points; English and Spanish	http://csefel.vanderbilt.edu/
Centers for Disease Control and Prevention	Federal agency that conducts and supports health promotion, prevention and preparedness activities in the U.S., with the goal of improving overall public health. Use the Search option to link to specific topics/resources.	https://www.cdc.gov/
Child Care Aware	Helps families and child care providers locate child care resources in their communities across the U.S.	http://www.childcareaware.org/
CONNECT Early Intervention Helpline	Assists families and child care staff in locating resources and providing information regarding child development for children ages birth – 5 years. Makes a direct link to their county Early Intervention program or local preschool Early Intervention program.	https://papromiseforchildren.com/ CONNECT Helpline 877-692-7288
Early Childhood Education Linkage System (ECELS) - Healthy Child Care PA	Statewide program established by the PA Chapter of the American Academy of Pediatrics. Offers professional development, articles, fact sheets and forms for competent and safe care for children.	www.ecels-healthychildcarepa.org
Easter Seals	Services, education, outreach, and advocacy for children and adults living with autism and other disabilities. Support for their families.	http://www.easterseals.com/
Epilepsy Foundation	Goals: insures that people with seizures are able to	https://www.epilepsy.com/

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	participate in all life experiences; improves how people with epilepsy are perceived, accepted and valued; promotes research for a cure.	To find local affiliate: https://www.epilepsy.com/affiliates
Food Allergy Research and Education (FARE)	Dedicated to food allergy awareness, education, research, and advocacy. Provides information, programs, and resources about food allergies and anaphylaxis.	https://www.foodallergy.org/
Head Start Early Childhood Learning and Knowledge Center	Office of Head Start helps young children from low-income families prepare to succeed in school through local programs. Head Start and Early Head Start programs promote children's development through services that support early learning, health, and family well-being. Helpful resources for all types of early education programs.	https://eclkc.ohs.acf.hhs.gov/ Children with Disabilities: https://eclkc.ohs.acf.hhs.gov/children-disabilities
Healthy Children	Information related to child health and specific guidance on parenting issues. Information regarding the American Academy of Pediatrics (AAP) programs and activities, policies and guidelines, publications and other child health resources. Includes special needs information.	https://healthychildren.org/english/our-mission/pages/default.aspx
Kids Together Inc	Website, listserv, email newsletter nationwide. Presents, participates and provides input to state agencies and coalitions. Desires to remove barriers that exclude people with disabilities. Supports the belief that children with disabilities, like all children, have the need to be welcomed, cherished and embraced in their communities.	http://www.kidstogether.org/
My Child Without Limits	Early intervention resource for families of children ages 0-5 yrs. with developmental delays or disabilities, and professionals looking for a single, trusted, aggregate source of information that relates to their needs and interests.	https://mylifewithoutlimits.org/about-my-life-without-limits/
PA Department of Health	Promotes healthy lifestyles, prevents injury and disease, and assures the safe delivery of quality health care for all PA citizens. County-specific resources guides.	http://www.health.pa.gov/Pages/default.aspx#.Wx8uA9UzpUR
Special Kids Network	Partnership with the PA Elks Home Service Program, helps children with special health care needs get services and support required to thrive in their community and develop to full potential. Toll-free helpline; free in-home service coordination (or meet with Elks nurse at ECE program if parent requests); system of community and regional support.	https://www.pa.gov/agencies/health/programs/healthy-living/special-kids-network Helpline (1-800-986-4550)
The Arc	Serves people with intellectual and developmental disabilities. Information about diagnoses, roles (e.g. parent, person with disability, educator) and advocacy.	https://www.thearc.org/
U.S. Department of Health and Human Services (HHS)	Administers more than 100 programs to protect the health of all Americans and provide essential human services, especially for those least able to help themselves. Includes: health insurance options, Health Insurance Portability and Accountability Act	https://www.hhs.gov/

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	(HIPAA) Rule, grants and contracts, and laws and regulations.	
Zero to Three	Information and publications for educators, parents, and health professionals especially pertaining to ages birth – 3 yrs.	www.zerotothree.org
Professional Development		
ECELS/Healthy Child Care PA	See Professional Development/Training tab on ECELS website for Self-Learning Modules, Webinars, and Workshops. Successful completion earns ECELS approval for PA Key credit. (800) 243-2357	https://www.ecels-healthychildcarepa.org/professional-development
Asthma Self-Learning Module (SLM), Webinar and Workshop; Children with Medical and Developmental Special Needs, Inclusive Practices (SLM); Food Allergy SLM and Workshop		
Forms		
Asthma Action Plan Handout	This is one of many options for an Asthma Action Plan for health care providers to share information with child care providers. This plan is meant for children who need medication intermittently in child care.	https://www.ecels-healthychildcarepa.org/files/ugd/750ba9_6f2f0dc43c554251aa9c95ea85f6c223.pdf
Behavioral Data Collection Sheet	Intended for use by ECE staff to document a child's behavior that is of concern. Behavior may warrant evaluation by a health care provider, discussion with parents, and/or consultation with other professionals. Documentation facilitates communication by recording the observations of the child and circumstances in which the observations were made.	https://www.ecels-healthychildcarepa.org/files/ugd/750ba9_935fa4d4ae4d4c1a8a49dc038e267c88.pdf
Care Plan for Children with Special Needs and Process to Enroll	Care Plan gathers key information to provide care for children with special health needs. Process to Enroll is an algorithm or map that describes steps to follow to obtain and use a care plan. The majority of early learning practitioners enroll children with special health needs.	https://www.ecels-healthychildcarepa.org/files/ugd/750ba9_67908a64a15d467585d87748fbaff3b5.pdf
Emergency Information Form for Children with Special Health Care Needs and Instructions	Record of health data for a child with special needs. In an emergency, child care staff can give the form to Emergency Service personnel to inform them about the child's diagnoses, medications and special care needs. Enables Emergency personnel them to make best decisions for the child's care.	https://www.ecels-healthychildcarepa.org/files/ugd/750ba9_e58353d0fda94483844f14d8674d202a.pdf
Food Allergy and Anaphylaxis Emergency Care Plan	Outlines recommended treatment in case of an allergic reaction, is signed by a physician and includes emergency contact information. Keep your plan in a place where others can find it. Know what to do in case of an emergency.	https://www.foodallergy.org/life-with-food-allergies/food-allergy-anaphylaxis-emergency-care-plan

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	<i>References / Publications</i>	
Cara's Kit	Promotes participation of all children in the full early childhood curriculum. Guidance to adapt daily activities and routines so children ages 3-6 with disabilities and other special needs can successfully participate in all activities. Contains booklet and CD with resources about adaptations.	https://www.dec-sped.org/cara-s-kit-base
Cara's Kit for Toddlers	Choose and use effective adaptations for children 18 to 36 months. Learn how to improve toddlers' engagement and participation through adapting the environment, daily schedule, activities for routines, materials, and instructional strategies. Includes booklet and CD.	https://products.brookespublishing.com/CARAs-Kit-for-Toddlers-P619.aspx
<i>Caring for Our Children (CFOC) Standards Online Database</i>	Ten chapters delineate performance expectations for: 1) staffing, 2) program activities, 3) health promotion, 4) nutrition, 5) facilities, 6) play areas, playgrounds and transportation, 7) infectious disease, 8) children with special needs and disabilities, 9) policies, 10) licensing and community action. Available for purchase from: national AAP bookstore and, in the most updated version, online from the NRC.	National Resource Center for Health and Safety in Child Care and Early Education (NRC) http://nrckids.org/ https://nrckids.org/CFOC/ https://nrckids.org/CFOC/Special_Needs
<i>Caring for Children with Special Needs – Special Collection</i>	Compilation of 146 best practices for children with special health care needs in early care and education programs. This collection of standards, when put into practice, is best able to meet the specific needs of this vulnerable population.	**Please note as of October 2025 the CFOC site is down – this sheet will be updated if necessary when the site is back up and running***
<i>Managing Chronic Health Needs in Child Care and Schools, 2nd Ed. (8/2018)</i>	Addresses the challenges of caring for children with chronic health conditions and special health care needs in child care and school settings. More than 50 quick reference sheets. Addresses topics for commonly used, e.g. Care Plan development and implementation, medication administration, and emergency planning. Includes ready-to-use sample forms, letters, and Care Plans.	https://www.aap.org/en/catalog/categories/infectious-diseases/managing-chronic-health-needs-in-child-care-and-schools-a-quick-reference-guide-2nd-edition-paper/
<i>Model Child Care Health Policies, 5th Ed.</i>	Publication of the American Academy of Pediatrics and PA Chapter of the AAP that provides sample policies and forms to be used as fill-in-the-blank document to draft health and safety policies for programs that provide child care.	https://79836e7c-4d98-4cd0-aabf-8be3831cfff9.usrfiles.com/ugd/79836e-eb01e6fd9cd0440da456a384d94d5cf2.pdf