

New York State

**Children and Youth with Special Health Care Needs  
(CYSHCN)**

**Resource Guide**



# Welcome to the New York State Children and Youth with Special Health Care Needs (CYSHCN) Resource Directory!

This directory lists resources for children and youth with special health care needs (CYSHCN), as well as their advocates, caregivers, families, and providers. The New York State Department of Health (NYS DOH) defines CYSHCN as people from birth to 21 years old who require extra health care and support services because of developmental, emotional, intellectual, learning, medical and/or physical conditions. Resources in this directory are specific to the state of New York. The NYS DOH is committed to the well-being of CYSHCN and their support networks. If you have up-to-date information on a resource or if you would like to add a resource to this directory, please visit our Resource Referral Portal (<https://airtable.com/shrkMnVBdLJTryIVP>).

This directory is funded by the NYS DOH and the resources are maintained (through September 2024) by the three NYS University Centers for Excellence on Developmental Disabilities (UCEDDs). The three UCEDDs are as follows:



[The Rose F. Kennedy \(RFK\) Center at Einstein/Montefiore](#)



[The Strong Center at the University of Rochester](#)



[The Westchester Institute for Human Development \(WIHD\).](#)

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For more information on the New York State Department of Health Children and Youth with Special Health Care Needs (CYSHCN) Program, please visit: [https://www.health.ny.gov/community/special\\_needs/](https://www.health.ny.gov/community/special_needs/)

### **DISCLAIMER**

*The New York State Department of Health (NYSDOH)'s Children and Youth with Special Health Care Needs (CYSHCN) Program assembled this resource guide to enhance public access to information about human service resources available to New York residents. The inclusion of any organization, agency or service in this guide does not imply or constitute an endorsement or recommendation, nor does exclusion imply disapproval. The NYS DOH neither guarantees nor makes any representations as to the accuracy or completeness of the information contained in this resource guide. Furthermore, the NYSDOH does not claim responsibility for any actions taken by any of the organizations or agencies included in this resource guide. Under no circumstances shall the NYSDOH or its employees be liable for any direct, indirect, incidental, special, punitive or consequential damages which may result in any way from the use of the information included in the printed or online versions of this resource guide.*

**Children and Youth with Special Health Care Needs (CYSHCN)  
LOCAL HEALTH DEPARTMENTS**

	COUNTIES SERVED	RESOURCE
<b>FIND A LOCAL HEALTH DEPARTMENT</b>	ALL	<p><b>Local Health Departments</b>  <a href="https://www.health.ny.gov/community/special_needs/county_programs.htm">https://www.health.ny.gov/community/special_needs/county_programs.htm</a></p> <p>Local health departments (LHDs) help families of CYSHCN by giving them information on health insurance and connecting them with health care providers. These programs will also work with families to help them meet the medical and non-medical needs of their children.</p>
	Albany	<p><b>Albany County Department for Children, Youth &amp; Families</b>  <a href="https://www.albanycounty.com/departments/children-youth-and-families/children-with-special-needs">https://www.albanycounty.com/departments/children-youth-and-families/children-with-special-needs</a></p> <p>Programs for children with special health care needs perform various functions to assure that children up to the age of 21 with certain disabilities and/or chronic health conditions receive quality care while limiting the financial impact on families.</p>
	Allegany	<p><b>Allegany County Department of Health</b>  <a href="https://www.alleganyco.com/departments/health/childrens-programs">https://www.alleganyco.com/departments/health/childrens-programs</a></p> <p>The Children with Special Health Care Needs Program (CSHCN) program is an informational, referral and advocacy program for children from birth to 21 years of age who have, or are suspected of having a serious or chronic physical, developmental, behavioral, and/or emotional condition, and who require health or related services of a type of amount beyond that typically required of children.</p>
	Broome	<p><b>Broome County Department of Health</b>  <a href="http://gobroomecounty.com/hd/cshcn">http://gobroomecounty.com/hd/cshcn</a></p> <p>Through the Children with Special Health Care Needs program, assistance is given to families in finding appropriate community resources. Families are referred to community or state agencies to help them access health insurance and/or services for their children with special needs. Follow-up is offered to check on the need for further assistance. Outreach is provided within the community, including various community agencies, medical offices, daycare centers, preschools, and health fairs regarding services for children with special needs.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Cattaraugus	<p><b>Cattaraugus County Department of Health</b>  <a href="https://www.cattco.org/health/services/children-families/special-needs">https://www.cattco.org/health/services/children-families/special-needs</a></p> <p>Families with physically disabled, cognitively challenged, or chronically ill children often need a wide range of services to meet their child's special needs. The CSHCN Program can help: link you with affordable health care; connect you with community programs; and, can answer questions about how to meet your child's needs.</p>
	Cayuga	<p><b>Cayuga County Department of Health</b>  <a href="https://www.cayugacounty.us/379/Children-with-Special-Health-Care-Needs">https://www.cayugacounty.us/379/Children-with-Special-Health-Care-Needs</a></p> <p>The Children with Special Health Care Needs program is a resource and referral program for children birth through age 21. The CSHCN program provides assistance to families who may need help accessing various health care professionals and other community resources.</p>
	Chautauqua	<p><b>Chautauqua County Department of Health</b>  <a href="http://www.co.chautauqua.ny.us/226/Early-Intervention-Program">http://www.co.chautauqua.ny.us/226/Early-Intervention-Program</a></p> <p>Children with Special Health Care Needs (CSHCN) is a referral linkage system to provide information to families of children, birth to 21 years of age, who have, or are suspected of having, a serious or chronic physical condition and require health-related services beyond those that are generally required by children. The goal of this program is to assist families who have children with special health care needs to obtain necessary health and community services.</p>
	Chemung	<p><b>Chemung County Health Department</b>  <a href="http://www.chemungcountyhealth.org/cshcn">http://www.chemungcountyhealth.org/cshcn</a></p> <p>Families with physically disabled, cognitively challenged or chronically ill children often need a wide range of services to meet their child's special needs: financial, medical, legal, educational, and emotional. Any child, ages birth to 21, who resides in New York State county who has or is suspected of having a serious or chronic physical, developmental, behavioral, or emotional condition that will require health and related services of a type or amount beyond that required by a typical child, is eligible to participate. CSHCN staff can assist families by providing useful information and making referrals to community and government resources that will help them provide for the needs of their child. Some counties also offer short-term case management and advocacy services on the child's behalf if needed.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Chenango	<p><b>Chenango County Department of Health</b>  <a href="http://www.co.chenango.ny.us/public-health/children-with-special-needs">http://www.co.chenango.ny.us/public-health/children-with-special-needs</a></p> <p>This program provides services for children who have a developmental delay, disability, or condition. The division offers several programs designed to help families receive evaluation and treatment services.</p>
	Clinton	<p><b>Clinton County Department of Health</b>  <a href="http://www.clintonhealth.org/specialneeds">http://www.clintonhealth.org/specialneeds</a></p> <p>Children with Special Health Care Needs (CSHCN) are children 0-21 years of age that have, or are suspected of having a serious or chronic physical, developmental or emotional condition. This program is designed to improve the health and care needs of children who meet the eligibility criteria.</p>
	Columbia	<p><b>Columbia County Department of Health</b>  <a href="https://www.columbiacountynyhealth.com/programs-and-services/nursing-and-clinical-services">https://www.columbiacountynyhealth.com/programs-and-services/nursing-and-clinical-services</a></p> <p>The Columbia County Department of Health’s Children with Special Health Care Needs – CSHCN – is a program designed to provide information and guidance to families with a special needs child. A registered nurse is on staff to offer assistance with access to appropriate specialty care. Resource information and group support for a child’s particular condition is provided. The nurse may also assist with organizing your child’s medical history and records, help find transportation for medical appointments, and obtain translation services in Spanish or other languages.</p>
	Cortland	<p><b>Cortland County Department of Health</b>  <a href="https://www.cortland-co.org/474/Children-With-Special-Health-Care-Needs">https://www.cortland-co.org/474/Children-With-Special-Health-Care-Needs</a></p> <p>CSHCN is a referral program for children birth to 21 years of age who have or are suspected of having a serious or chronic physical, developmental behavioral, or emotional condition that requires health and related services beyond that required by children generally. Anyone can call for information and referral through CSHCN.</p>
	Delaware	<p><b>Delaware County Department of Health</b>  <a href="http://delawarecountypublichealth.com/programs/childrens-programs/special-healthcare-needs">http://delawarecountypublichealth.com/programs/childrens-programs/special-healthcare-needs</a></p> <p>The Children with Special Health Care Needs Program provides assistance to families of children with special health care needs birth through age 21 who need help in accessing various health care professionals and other community resources. We will also help you to access appropriate health care coverage such as Child Health Plus, Family Health Plus and Medicaid.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Dutchess	<p><b>Dutchess County Department of Health</b>  <a href="https://www.dutchessny.gov/Departments/DBCH/Nursing-Services.htm">https://www.dutchessny.gov/Departments/DBCH/Nursing-Services.htm</a></p> <p>The Children With Special Health Care Needs Program is a referral service for families with health and related concerns. The Program refers children ages birth to 21 who are diagnosed or at risk for a developmental delay or disability that affects a child physically, behaviorally or intellectually; Is ongoing or chronic; and, requires health or health-related interventions beyond what a typical developing child would need.</p>
	Erie	<p><b>Erie County Department of Health</b>  <a href="https://www2.erie.gov/health/index.php?q=node/50">https://www2.erie.gov/health/index.php?q=node/50</a></p> <p>Early Intervention (EI) is a voluntary developmental evaluation and services program offered by New York State and administered locally by the Erie County Department of Health. The County EI Program is subject to NYS regulations. EI serves children from birth through 2 years of age and their families where there is a high risk of delay, a suspected delay in development, or a confirmed diagnosis of developmental disability. Evaluations are conducted to determine eligibility. A variety of therapeutic and support services are offered to eligible infants and toddlers with disabilities and their families. If a child is found not eligible, parents can request developmental monitoring.</p>
	Essex	<p><b>Essex County Department of Health</b>  <a href="https://www.co.essex.ny.us/Health/childrens-services">https://www.co.essex.ny.us/Health/childrens-services</a></p> <p>This program is for families of children ages birth to 21 who have or may have a serious health condition. The program gives information and referral services for families of children who need health or related services beyond those normally needed by children.</p>
	Franklin	<p><b>Franklin County Department of Health</b>  <a href="https://www.franklincountyny.gov/departments/human_services/public_health/services.php">https://www.franklincountyny.gov/departments/human_services/public_health/services.php</a></p> <p>The Children and Youth with Special Health Care Needs Program seeks to improve the system of care for children with special health care needs from birth to 21 years of age and their families. The Program helps to shape public policy so families can get the best health care for their children.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Fulton	<p><b>Fulton County Department of Health</b>  <a href="https://www.fultoncountyny.gov/children-special-health-care-needs">https://www.fultoncountyny.gov/children-special-health-care-needs</a></p> <p>The Children with Special Health Care Needs Program seeks to improve the system of care for children with special health care needs from birth to 21 years of age and their families. Children served by the CSHCN Program have an illness or condition for which they need extra health care and support services. These children might have a serious or long-lasting physical condition, intellectual or developmental disability; and/or behavioral or emotional condition. This program is strictly a referral program. Services include information about health insurance, community resources, specialists and accessing health care providers. We also work with families to help them meet the medical and non-medical needs of their children.</p>
	Genesee	<p><b>Genesee County Department of Health</b>  <a href="http://co.genesee.ny.us/departments/health/children_with_special_health_care_needs.php">http://co.genesee.ny.us/departments/health/children_with_special_health_care_needs.php</a></p> <p>This program is an informational, referral and advocacy program for children from birth to 21 years of age who may require health or related services, of a type or amount, beyond that typically required by children. Program assistance does not require eligibility or fees in order to obtain services. Case Management services, funded by the Children with Special Health Care Needs Grant, offer outreach and referral to connect families with appropriate services. We want to help you help your child reach his or her full potential.</p>
	Greene	<p><b>Greene County Public Health</b>  <a href="https://www.greenegovernment.com/departments/public-health/childrens-programs/special-health-care-needs-program">https://www.greenegovernment.com/departments/public-health/childrens-programs/special-health-care-needs-program</a></p> <p>The Children with Special Health Care Needs Program is an information and referral service. We provide assistance to families of children with special health care needs from birth to age 21. Raising a child with special health care needs can be challenging. It can be difficult to identify what services are available to you and to your child. Please contact us with any questions you may have about the Children with Special Health Care Needs Program so we can provide assistance at no cost to your family.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Hamilton	<p><b>Hamilton County Department of Health</b>  <a href="https://www.hamiltoncounty.com/health-human-services/public-health-home/family-health-services">https://www.hamiltoncounty.com/health-human-services/public-health-home/family-health-services</a></p> <p>Children served by the CSHCN Program have an illness or condition for which they need extra health care and support services. These children might have a serious or long-lasting physical condition, intellectual or developmental delay, and/or behavioral or emotional condition. HCPHNS supports families of children with special health care needs by giving them information on health insurance and connecting them with health care providers and programs.</p>
	Herkimer	<p><b>Herkimer County Public Health</b>  <a href="https://www.herkimercounty.org/services-and-departments/public-health.php">https://www.herkimercounty.org/services-and-departments/public-health.php</a></p> <p>The Herkimer County Public Health team is dedicated to the protection and promotion of our resident's health through the provision of high quality, comprehensive, individualized services, in all phases of the life cycle. Available programs for children with special needs include Early Intervention, Child Find, and Pre-School Special Education.</p>
	Jefferson	<p><b>Jefferson County Department of Health</b>  <a href="https://co.jefferson.ny.us/departments/PublicHealth/cshcn-phcp">https://co.jefferson.ny.us/departments/PublicHealth/cshcn-phcp</a></p> <p>CSHCN serves children from birth to 21 years of age who have (or may have) a serious or chronic physical, developmental, behavioral, or emotional condition. The Program provides: assistance in locating a physician or other health care provider; assistance in obtaining insurance and other programs that cover health care costs; assistance in finding other help and support such as home care, parents support groups, and information about medical conditions; and, care coordination services that assist families to access the various services available.</p>
	Lewis	<p><b>Lewis County Public Health</b>  <a href="https://www.lewiscounty.org/departments/public-health/children-with-special-needs">https://www.lewiscounty.org/departments/public-health/children-with-special-needs</a></p> <p>Children with Special Care Needs (CSCN) Programs assist children from birth to age 21 to reach toward and achieve developmental and educational goals. We can assist with accessing health and non-health care services. We can help with obtaining insurance, educational resources, social program assistance (public health services, social services, WIC, food stamps, SSI, transportation, respite services), and medical equipment.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Livingston	<p><b>Livingston County Department of Health</b>  <a href="https://www.livingstoncounty.us/1157/Children-with-Special-Healthcare-Needs-P">https://www.livingstoncounty.us/1157/Children-with-Special-Healthcare-Needs-P</a></p> <p>The Children with Special Healthcare Needs Program administered by the Livingston County Department of Health focuses on children ages 0-21 who have, or are suspected of having a serious or chronic condition that also requires services of a type or amount beyond what is required generally. Key activities of the program include disseminating Child Health Plus information and facilitating access to health care coverage for children who are uninsured or under-insured.</p>
	Madison	<p><b>Madison County Department of Health</b>  <a href="https://www.madisoncounty.ny.gov/445/Children-With-Special-Healthcare-Needs">https://www.madisoncounty.ny.gov/445/Children-With-Special-Healthcare-Needs</a></p> <p>The Children with Special Health Care Needs Program assists families of children birth to 21 years who have or are suspected of having a serious or chronic physical, developmental, or emotional condition. Information and referral services are provided to help the family access community resources as well as appropriate health care. The Program helps families of children under 21 years to access available community resources and services; assists families with health insurance needs; and, provides information and referrals regarding disability and health topics. Services are free of charge to families.</p>
	Monroe	<p><b>Monroe County Department of Health</b>  <a href="https://www2.monroecounty.gov/health-maternal-children-health-needs">https://www2.monroecounty.gov/health-maternal-children-health-needs</a></p> <p>The Children with Special Health Care Needs Program (CSHCN) is a statewide public health program that provides information and referral services for health and related areas for families of CSHCN. The CSHCN Program provides families with information and referrals to fit their child’s growing needs. Children who are enrolled in the Early Intervention Program can continue to receive help through CSHCN when they “age out” of Early Intervention.</p>
	Montgomery	<p><b>Montgomery County Department of Health</b>  <a href="https://www.co.montgomery.ny.us/web/sites/departments/publichealth">https://www.co.montgomery.ny.us/web/sites/departments/publichealth</a></p> <p>The Children with Special Health Care Needs Program (CSHCN) is a statewide referral system of care for children and their families, linking them to appropriate health and related services to identify and resolve gaps and barriers, and to assure access to quality health care. For all children from birth to 21 years of age who have an identified disability, the following services are available: connect families with community resources and programs; provide support and guidance Information about children with special needs, illness, and disability; research additional resources not available to the family; address concerns and required health or related services beyond what children generally need; employ state tracking system to identify gaps in services for children with special health care needs.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Nassau	<p><b>Nassau County Department of Health</b>  <a href="https://nassaucountyny.gov/3666/Children-Youth">https://nassaucountyny.gov/3666/Children-Youth</a></p> <p>The Children with Special Health Care Needs Program (CSHCN) in Nassau County can be contacted by calling 516-227-8665.</p>
	New York City (Bronx/Kings/New York/Richmond/Queens)	<p><b>New York City Department of Health and Mental Hygiene</b>  <a href="https://www1.nyc.gov/site/doh/health/health-topics/children-with-special-healthcare-needs.page">https://www1.nyc.gov/site/doh/health/health-topics/children-with-special-healthcare-needs.page</a></p> <p>Children with Special Health Care Needs is a program that provides information as well as referrals to health services and community resources for children with special needs. This program also helps families apply for low or no-cost health insurance. The program can help families with: applying for low- or no-cost health insurance; finding free medical evaluations and low-cost health services in your community; locating medical providers who can examine your child and develop an individual care plan; and, finding referrals to medical specialists who can care for children with complex needs.</p>
	Niagara	<p><b>Niagara County Department of Health</b>  <a href="https://www.niagaracounty.com/health/Services/Children-With-Special-Needs/Children-With-Special-Health-Care-Needs">https://www.niagaracounty.com/health/Services/Children-With-Special-Needs/Children-With-Special-Health-Care-Needs</a></p> <p>The Children with Special Health Care Needs Program assists families who have children that have a chronic physical, developmental, behavioral or emotional condition, and require health and related services of a type or amount beyond that required by children generally. The Program assists the family through information and referral to various community resources that are child and family specific.</p>
	Oneida	<p><b>Oneida County Department of Health</b>  <a href="https://www.ocgov.net//oneida/health/programservices">https://www.ocgov.net//oneida/health/programservices</a></p> <p>Children and Youth with Special Health Care Needs is a referral program for children birth to 21 years of age who have or are suspected of having a serious or chronic physical, developmental, behavioral or emotional condition that requires health and related services beyond that required by children generally. Services include: helping coordinate referrals to specialty care providers; providing limited case management; facilitating access to health insurance, such as Child Health Plus and Medicaid; and, providing information and referrals to appropriate programs.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Onondaga	<p><b>Onondaga County Health Department</b>  <a href="http://www.ongov.net/health/SCS.html">http://www.ongov.net/health/SCS.html</a></p> <p>The Onondaga County Health Department’s Special Children Services provides evaluations, education, and therapy for children up to age five who have a developmental delay or disability. Programs include Early Intervention and Preschool Special Education.</p>
	Ontario	<p><b>Ontario County Department of Health</b>  <a href="https://www.co.ontario.ny.us/632/Children-with-Special-Needs-Program">https://www.co.ontario.ny.us/632/Children-with-Special-Needs-Program</a></p> <p>The Children With Special Health Care Needs (CSHCN) Program focuses on children ages 0-21 who have, or are suspected of having, a serious or chronic physical, developmental, behavioral, or emotional condition and who also require services of a type or amount beyond that required by children generally. The Bureau of Child and Adolescent Health hopes that by creating this program it will better define the issues and priorities of this population. Key activities for this program include: disseminating Child Health Plus information and facilitating access to health care coverage for CSHCN's who are uninsured or under-insured; reporting on contacts made to the program.</p>
	Orange	<p><b>Orange County Department of Health</b>  <a href="https://www.orangecountygov.com/774/Children-with-Special-Health-Care-Needs">https://www.orangecountygov.com/774/Children-with-Special-Health-Care-Needs</a></p> <p>The Children with Special Health Care Needs Program is an information and referral service designed to assist the families of physically challenged or chronically ill children from birth through age 21 years. Our staff will help to coordinate specialty care, provide information about programs and resources appropriate for your child with special needs. We will assist families to locate community based services such as Health Navigators/NYS of Health Marketplace at 800-453-4666 and Medicaid, Early Intervention, Women, Infants and Children (WIC), Developmental Disabilities Service Office (DDSO) and other parent supports.</p>
	Orleans	<p><b>Orleans County Department of Health</b>  <a href="https://gohealthny.org/children-with-special-needs/">https://gohealthny.org/children-with-special-needs/</a></p> <p>The Orleans County Public Health Department conducts programs that are shown to effectively make communities healthier, including the Children with Special Needs Program. Services are provided through free resources &amp; referrals, public programs, speakers, in-service trainings, social media, etc.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Oswego	<p><b>Oswego County Department of Health</b>  <a href="https://health.oswegocounty.com/programs/1_children_with_special_needs/index.php">https://health.oswegocounty.com/programs/1_children_with_special_needs/index.php</a></p> <p>As your child with special needs travels through the many phases of his or her life, the Oswego County Health Department-Children with Special Needs Division hopes you will find comfort in knowing there is a whole team of professionals who are here to help. We can guide you through the sometimes confusing educational and health care systems, and help you find the services that best suit your family's needs. Our service coordinators provide one-on-one services to determine the best course of action for you and your family.</p>
	Otsego	<p><b>Otsego County Health Department</b>  <a href="https://www.otsegocounty.com/departments/children_with_special_needs/index.php">https://www.otsegocounty.com/departments/children_with_special_needs/index.php</a></p> <p>The Otsego County Health Department offers the following programs for children with special needs: Early Intervention, Preschool Special Education, and Evaluation and Education Services.</p>
	Putnam	<p><b>Putnam County Department of Health</b>  <a href="https://www.putnamcountyny.com/health/child">https://www.putnamcountyny.com/health/child</a></p> <p>The Putnam County Department of Health offers the following programs for children with special needs: Early Intervention, Preschool Special Education, and Child Find, which seeks to improve the identification of infants and children ages 0-3 at risk for developmental delays and disabilities and to ensure their referral to care, follow-up and monitoring.</p>
	Rensselaer	<p><b>Rensselaer County Department of Health</b>  <a href="https://www.rensco.com/departments/public-health/children-with-special-needs">https://www.rensco.com/departments/public-health/children-with-special-needs</a></p> <p>Children with special health care needs are children birth to 21 years of age who have or are suspected of having a serious or chronic physical, developmental, behavioral or emotional condition. Also, under this are children who require special health or related services beyond that is required by children generally. Our Child Services Specialists can assist families with providing support and resources to access services to improve the quality of life for their Children with Special Health Care Needs and their families.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Rockland	<p><b>Rockland County Department of Health</b>  <a href="http://rocklandgov.com/departments/health/programs-and-services/children-with-special-needs-programs">http://rocklandgov.com/departments/health/programs-and-services/children-with-special-needs-programs</a></p> <p>The Children with Special Health Care Needs Program (CYSHCN) is an effort to positively impact the lives of children and youth with special health care needs and their families by providing resources needed to access appropriate services. Through the coordination and delivery of medical, educational, and related services identified needs of the child and family are met, thus enhancing the child's quality of life. CYSHCN assists families with children from birth to twenty-one (21) years of age that have a chronic physical, developmental, behavioral, or emotional condition and require health and related services beyond that generally required by children. The program assists the family through information and referral to various community resources that are child and family specific. Rockland County Department of Health staff can connect your family to support networks that understand the challenges of caring for children and youth with special needs.</p>
	Saratoga	<p><b>Saratoga County Public Health Services</b>  <a href="https://www.saratogacountyny.gov/departments/publichealth/children-with-special-health-care-needs-cshcn">https://www.saratogacountyny.gov/departments/publichealth/children-with-special-health-care-needs-cshcn</a></p> <p>Children and Youth with Special Health Care Needs (CYSHCN) are those from birth to age 21 who require health care or related services beyond regular well care and preventive measures to keep children healthy. CYSHCN is a New York State Department of Health initiative designed to provide information, guidance and referrals to families with a special needs child.</p>
	Schenectady	<p><b>Schenectady County Department of Health</b>  <a href="https://www.schenectadycounty.com/CWSN">https://www.schenectadycounty.com/CWSN</a></p> <p>The Children with Special Health Care Needs Program (CSHCN) is a statewide public health program that provides information and referral services for health and related areas for families of CSHCN. This program is a referral linkage system to provide for those children ages birth to 21 who have, or are suspected of having, a serious or chronic physical, developmental, behavioral, or emotional condition and who require a health or related service of a type or amount beyond what is required by children generally.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Schoharie	<p><b>Schoharie County Public Health</b>  <a href="https://www4.schohariecounty-ny.gov/departments/public-health/preschool">https://www4.schohariecounty-ny.gov/departments/public-health/preschool</a></p> <p>Schoharie County Public Health has programs for children with special needs that include preschool and early intervention referrals as well as Child Find, a component of the Early Intervention Program that assures that children at-risk (birth-3 years) will receive the help needed for the best growth and development in the early years. Child Find ensures tracking and screening of children at-risk of developmental delay through ongoing contact with families and the primary care provider. This program can provide direct developmental screenings when no other resource is available.</p>
	Schuyler	<p><b>Schuyler County Public Health</b>  <a href="http://www.schuylercounty.us/622/Children-with-Special-Health-Care-Needs">http://www.schuylercounty.us/622/Children-with-Special-Health-Care-Needs</a></p> <p>Schuyler County Public Health seeks to improve the system of care for all children and their families. Our goal is to help shape public policy so families can get the best health care for their children including those who have health concerns or delays which require extra support and services. The Children with Special Health Care Needs Program serves children and their families from birth to 21 years of age who have long term conditions that require support.</p>
	Seneca	<p><b>Seneca County Department of Health</b>  <a href="https://senecacountyhealthdepartment.com/public-health/programs-services/children-with-special-health-care-needs/">https://senecacountyhealthdepartment.com/public-health/programs-services/children-with-special-health-care-needs/</a></p> <p>The program for children with special health care needs performs various functions to assure that children up to the age of 21 with certain disabilities and/or chronic health conditions receive quality care while limiting the financial impact on families. Seneca County Health Department houses this program that connects families with much needed resources. Community outreach at events and through programs helps to ensure that families are aware of the assistance that is there for them.</p>
	St. Lawrence	<p><b>St. Lawrence County Department of Health</b>  <a href="https://www.stlawco.org/Departments/PublicHealth/ChildrenSpecialHealthCareNeeds">https://www.stlawco.org/Departments/PublicHealth/ChildrenSpecialHealthCareNeeds</a></p> <p>The Children With Special Health Care Needs Program provides assistance in locating a physician or other health care provider to ensure each child has a medical home. The program may also provide assistance in obtaining insurance and/or other programs that help to cover health care costs – i.e. Medicaid, Child Health Plus. Supportive measures as well as medical information may be provided.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Steuben	<p><b>Steuben County Department of Health</b>  <a href="https://www.steubencony.org/pages.asp?PID=178">https://www.steubencony.org/pages.asp?PID=178</a></p> <p>The Children with Special Health Care Needs Program provides information and referral services for health and related topics to families of children, from birth to 21 years of age. Any family that has children who have, or are suspected of having, a serious or chronic healthcare condition is eligible for information and referral services at no cost.</p>
	Suffolk	<p><b>Suffolk County Department of Health</b>  <a href="https://www.suffolkcountyny.gov/Departments/Health-Services/Children-With-Special-Needs">https://www.suffolkcountyny.gov/Departments/Health-Services/Children-With-Special-Needs</a></p> <p>The Children with Special Health Care Needs Program performs various functions to assure that children up to the age of 21 with certain disabilities and/or chronic health conditions receive quality care while limiting the financial impact on families. Service coordinators provide case management to empower families to meet challenges of caring for a child with special health care needs and assist families in accessing educational services, as well as community resources.</p>
	Sullivan	<p><b>Sullivan County Public Health Services</b>  <a href="http://sullivanny.us/Departments/Publichealth/Childrenwithspecialhealthcareneeds">http://sullivanny.us/Departments/Publichealth/Childrenwithspecialhealthcareneeds</a></p> <p>The Children with Special Health Care Needs Program (CSHCN) includes three programs: the Early Intervention Program (ages 0-3), the Preschool Special Education Program (ages 3-5), and the Children and Youth with Special Health Care Needs Supportive Services (CYSHCN-SS up to age 21).</p>
	Tioga	<p><b>Tioga County Department of Health</b>  <a href="https://www.tiogacountyny.com/departments/public-health">https://www.tiogacountyny.com/departments/public-health</a></p> <p>The Children with Special Health Care Needs (CSHCN) program is an informational referral and advocacy program for children birth to 21 years who have, or are suspected of having, a serious or chronic physical, developmental, behavioral, and/or emotional condition, and require health or related services of a type or amount beyond that typically required of children. This program can help families: make referrals for special health care or related services; obtain information on programs and services available in the community; increase knowledge regarding available resources; navigate through Preschool Special Education process (for children ages 3-5); and, obtain family support services.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Tompkins	<p><b>Tompkins County Health Department</b>  <a href="http://tompkincountyny.gov/health/cscn#CSCN">http://tompkincountyny.gov/health/cscn#CSCN</a></p> <p>The Children with Special Health Care Needs Program provides assistance to families of children with special health care needs birth through age 21 who need help in accessing various health care professionals and other community resources. We will also help you to access appropriate health care coverage such as Child Health Plus, Family Health Plus and Medicaid. Our Family Outreach Worker is a Certified Social Worker who will work one-on-one with you to help you meet your family's needs.</p>
	Ulster	<p><b>Ulster County Department of Health</b>  <a href="http://ulstercountyny.gov/health/divisions/patient-services-division">http://ulstercountyny.gov/health/divisions/patient-services-division</a></p> <p>The Children with Special Health Care Needs Program ensures access to quality health care for children who are chronically ill and/or have disabilities.</p>
	Warren	<p><b>Warren County Department of Health</b>  <a href="https://warrencountyny.gov/healthservices/children">https://warrencountyny.gov/healthservices/children</a></p> <p>The Children and Youth with Special Healthcare Needs Program (CYSHCN) is a state wide public health program that provides information and referral services for health and related areas for families of CYSHCN. Warren County's CYSHCN program provides case management services as needed. The CYSHCN assists families in paying medical bills for children with severe chronic illnesses and/or disabilities, between birth and 21 years of age, who live in New York State and meet medical and financial eligibility requirements.</p>
	Washington	<p><b>Washington County Health Department</b>  <a href="https://washingtoncountyny.gov/299/Public-Health-Services">https://washingtoncountyny.gov/299/Public-Health-Services</a></p> <p>Washington County Public Health Services offers the following programs for children with special needs: Child Find, Early Intervention, and Preschool Program for Children with Disabilities.</p>

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Wayne	<p><b>Wayne County Department of Health</b>  <a href="https://www.wcphny.com/children-with-special-health-care-needs/">https://www.wcphny.com/children-with-special-health-care-needs/</a></p> <p>Children with Special Health Care Needs is an informational and referral program for children from birth to 21 who have or are suspected of having a serious chronic physical, developmental and/or emotional condition that requires health or related services. This program can help families by: Acting as advocate with health care providers; Obtaining information about various programs; Acting as advocate with school districts; and Making referrals as needed.</p>
	Westchester	<p><b>Westchester County Department of Health</b>  <a href="https://health.westchestergov.com/children-with-special-health-care-needs-program-cshcn">https://health.westchestergov.com/children-with-special-health-care-needs-program-cshcn</a></p> <p>Children with Special Health Care Needs (CSHCN) is an information and referral service for families with children with special needs from birth through 21 years of age. CSHCN staff work with families to ensure that children in need of special services are able to receive them without undue financial hardship. Staff members in the Children with Special Needs division of the Health Department can provide guidance on access to care, and refer families to the department's Facilitated Enrollment Program for access to programs including Child Health Plus A and Child Health Plus B enrollment outreach.</p>
	Wyoming	<p><b>Wyoming County Youth Bureau</b>  <a href="http://www.wyomingco.net/263/Children-with-Special-Health-Care-Needs">http://www.wyomingco.net/263/Children-with-Special-Health-Care-Needs</a></p> <p>The Children with Special Health Care Needs (CSHCN) Program is a public health program that provides information and referral services in health and related areas for families of CSHCN are those children from birth to 21 years of age who have or are suspected of having a serious or chronic developmental, physical, behavioral or emotional condition and who also require health and related services of a type or amount beyond that typically required by children. The CSHCN can help: link families to community resources and programs to assist them in caring or their child; provide support and guidance with issues such as equipment, education, respite care, insurance and health care financing; and, connect families to appropriate support groups and networks.</p>
	Yates	<p><b>Yates County Department of Health</b>  <a href="https://www.yatescounty.org/213/Children-Services">https://www.yatescounty.org/213/Children-Services</a></p> <p>The Children with Special Health Care Needs (CSHCN) Program focuses on children birth to age 21. Information, referrals and advocacy for children who may require health or related services of a type or amount beyond that typically required by children. Case management is a free service under this program, offering outreach and referral to connect families with appropriate services.</p>

**Children and Youth with Special Health Care Needs (CYSHCN)  
INDIVIDUAL RESOURCE PROFILES**

# New York State Department of Labor



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Labor

**Agency Description:** The New York State Department of Labor (NYSDOL) provides seamless and accessible services to all individuals in our Career Centers, including people with disabilities. It is the policy of NYSDOL and the State of New York to provide universal access and full participation in all of its programs, services, and activities. The NYSDOL website can connect you with Career Centers, Disability Resource Coordinators (DRCs) and more.

- New York State Career Centers- <https://dol.ny.gov/career-centers>
- Overview of Career Center services video [https://youtu.be/Umr\\_SrR9dbo](https://youtu.be/Umr_SrR9dbo)
- WIOA Overview - <https://www.dol.gov/agencies/eta/wioa>
- Local Workforce Development Area Director Contacts- <https://dol.ny.gov/lwdb>
- Youth Program- <https://dol.ny.gov/youth>

**Phone Number:** (518) 457-9000 | (888) 4-

**Email Address:** n/a

**Website:** <https://dol.ny.gov/career-services/career-services-for-persons-with-disabilities>

**Counties Served:** State-Wide Albany County Allegany County Bronx County Broome County Cattaraugus County Cayuga County Chautauqua County Chemung County Chenango County Clinton County Columbia County Cortland County Delaware County Dutchess County Erie County Essex County Franklin County Fulton County Genesee County Greene County Hamilton County Herkimer County Jefferson County Kings County Lewis County Livingston County

**Content Categories:** Transitioning to Adulthood (Youth) Government Agency Information & Referral Community Living & Recreation

**Conditions Covered:** Autism Spectrum Disorder (ASD) Blindness or Problems with Seeing Allergies Arthritis Anxiety Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Behavioral / Conduct Problem Brain Injury, Concussion, or Head Injury Blood Disorders Cerebral Palsy (CP) Deafness or Problems with Hearing Cystic Fibrosis (CF) Depression Developmental Delay Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Intellectual Disability Migraines Other Mental Health Condition Spina Bifida Speech or Language Disorder Substance Use Disorder Tourette Syndrome (TS) Learning Difficulty Heart Condition Diabetes Other

# Project SEARCH



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Project SEARCH

**Agency Description:** The Project SEARCH Transition-to-Work Program is a unique, business-led, one-year employment preparation program that takes place entirely at the workplace. Total workplace immersion facilitates a seamless combination of classroom instruction, career exploration, and hands-on training through worksite rotations. The program culminates in individualized job development.

**Phone Number:** n/a

**Email Address:** <https://www.projectsearch.us/contact/>

**Website:** <https://www.projectsearch.us/>

**Counties Served:** State-Wide

**Content Categories:** Transitioning to Adulthood (Youth) Community Living & Recreation

**Conditions Covered:** Intellectual Disability Learning Difficulty Developmental Delay Down Syndrome

# Advance 2 Apprenticeship



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Advance 2 Apprenticeship

**Agency Description:** Advance 2 Apprenticeship is an employment initiative through the Strong Center for Developmental Disabilities to improve access to apprenticeship programs for people with intellectual and developmental disabilities (I/DD) within the manufacturing industry. The project is a collaboration with Mohawk Valley Community College (MVCC), Manufacturers Association of Central New York (MACNY), Center for Workforce Development at Monroe 2–Orleans BOCES (CWD) and Rochester Technology & Manufacturing Association (RTMA). Courses at MVCC start in Fall 2023. Courses at CWD start in Spring 2024

**Phone Number:** (585) 276-5915

**Email Address:** brandy\_solomon@urmc.rochester.edu

**Website:** <https://www.urmc.rochester.edu/strong-center-developmental->

**Counties Served:** Monroe County

**Content Categories:** Transitioning to Adulthood (Youth) Community Living & Recreation

**Conditions Covered:** Intellectual Disability Developmental Delay Down Syndrome Learning Difficulty

# ZERO TO THREE: HealthySteps Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** ZERO TO THREE: HealthySteps Program

**Agency Description:** The HealthySteps model is based on the most recent scientific understandings and helps to ensure individual, family, community, and societal well-being. The HealthySteps Specialist, a child development and behavioral health promotion and prevention expert, joins the team to promote nurturing parenting, which improves babies' and toddlers' healthy development and well-being where they are most likely to be – the pediatric primary care office. Together with cutting-edge pediatric primary care practices, we prepare young children for school and life.

**Phone Number:**

**Email Address:** <https://www.healthysteps.org/contact-us/>

**Website:** <https://www.healthysteps.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Family & Supports Early Childhood & School Aged Medical Dental & Behavioral Health

**Conditions Covered:** Other

# New York State Department of Health Children and Families Parent Portal



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health Children and Families Parent Portal

**Agency Description:** The Council on Children and Families (the Council) coordinates New York's health, education and human services systems to provide more effective systems of care for children and families. This NYS Parenting website is funded by the Preschool Development Grant Birth through Five Initiative, Grant Number 90TP0019-01-01, from the Department of Health and Human Services, as a one-stop, digital parent portal for information on parenting, child care options, concerns about child development and how to talk and work together with your child's teachers.

The Council worked closely with its member agencies to develop each of these main resources:

Every Student Present  
Multiple Systems Navigator

**Phone Number:** (518) 473-3652

**Email Address:** nysb5@ccf.ny.gov

**Website:** <https://www.nysparenting.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Government Agency Early Childhood & School Aged  
Transitioning to Adulthood (Youth)

**Conditions Covered:** Other

# New York State Department of Health Childhood Lead Poisoning Prevention Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health Childhood Lead Poisoning Prevention Program

**Agency Description:** Studies show that no amount of lead exposure is safe for children. Lead is a metal that can harm children when it gets into their bodies. Lead can harm a young child's growth, behavior, and ability to learn. It can also cause anemia, kidney damage, and hearing loss. There are many sources of lead. Lead can be found in dust, air, water, soil, and in some products used in and around our homes.

Children younger than six years old are more likely to get lead poisoning than any other age group. Most often, children get lead poisoning from breathing in or swallowing dust from old lead paint. It can be found on floors and windowsills, hands, and toys. Lead can also be passed from pregnant person to baby during pregnancy.

Although lead poisoning is preventable, lead continues to be a major cause of poisoning among

**Phone Number:** (518) 402-7500

**Email Address:** [ceheduc@health.ny.gov](mailto:ceheduc@health.ny.gov)

**Website:** <https://www.health.ny.gov/environmental/lead/>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Government Agency Family & Supports Information & Referral Medical Dental & Behavioral Health Disaster/Emergency Preparedness

**Conditions Covered:** Other

# FEMA and Red Cross

## "Preparing for Disaster with People with Disabilities and other Special Needs" online document

Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** FEMA and Red Cross "Preparing for Disaster with People with Disabilities and other Special Needs" online document

**Agency Description:** Where will you, your family, your friends or personal care attendants be when an emergency or disaster strikes? You, and those you care about, could be anywhere – at home, work, school or in transit. How will you find each other? Will you know your loved ones will be safe? Emergencies and disasters can strike quickly and without warning and can force you to evacuate your neighborhood or confine you to your home. What would you do if basic services – water, gas, electricity or telephones – were cut off? Local officials and relief workers will be on the scene after a disaster, but they cannot reach everyone right away.

**Phone Number:** (800) 480-2520

**Email Address:** askia@fema.dhs.gov

**Website:** [https://www.fema.gov/pdf/library/pfd\\_all.pdf](https://www.fema.gov/pdf/library/pfd_all.pdf)

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Early Childhood & School Aged Transitioning to Adulthood (Youth) Community Living & Recreation  
Accessibility & Assistive Technology Medical Dental & Behavioral Health Information & Referral  
Disaster/Emergency Preparedness Crisis Resources

**Conditions Covered:** Allergies Arthritis Attention-Deficit/Hyperactivity Disorder (ADHD) Anxiety Asthma Behavioral / Conduct Problem  
Blindness or Problems with Seeing Autism Spectrum Disorder (ASD) Blood Disorders  
Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing  
Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition  
Heart Condition Learning Difficulty Intellectual Disability Migraines Other Other Mental Health Condition  
Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Family Voices National Center for Family Professional Partnerships (FVNCFPP)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Family Voices National Center for Family Professional Partnerships (FVNCFPP)

**Agency Description:** The NCFPP provides assistance and support to the HRSA-funded Family-to-Family Health Information Centers (F2F HICs) and other MCHB programs related to family engagement and cultural and linguistic competence. The Center also implements family and youth leadership development and training activities, specifically for racially and ethnically diverse families of children with special health care needs (CYSHCN) and youth with special health care needs (YSHCN).

**Phone Number:** (781) 674-7224

**Email Address:** <https://familyvoices.org/contact/>

**Website:** <http://www.fv-ncfpp.org/helping-families-of-children-with-special-needs-to->

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial Legal & Advocacy Government Agency Information & Referral

**Conditions Covered:** Allergies Arthritis Anxiety Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# American Academy of Pediatrics (AAP) Disasters and Children resources



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

<b>Agency</b>	American Academy of Pediatrics (AAP) Disasters and Children resources
<b>Agency Description:</b>	Infants, children and adolescents have unique needs that must be considered in disaster management efforts. Pediatricians and others who may care for children have key roles to play in disaster preparedness, response and recovery to ensure these unique needs are met. The AAP provides resources for pediatricians and others to take strategic actions (personally and professionally) to support planning, provide services and play a leadership role in disasters and public health emergencies.
<b>Phone Number:</b>	(800) 433-9016
<b>Email Address:</b>	<a href="https://www.aap.org/en/community/aap-councils/council-on-">https://www.aap.org/en/community/aap-councils/council-on-</a>
<b>Website:</b>	<a href="https://www.aap.org/en/patient-care/disasters-and-children/">https://www.aap.org/en/patient-care/disasters-and-children/</a>
<b>Counties Served:</b>	State-Wide
<b>Content Categories:</b>	Family & Supports   Information & Referral   Early Childhood & School Aged   Disaster/Emergency Preparedness Crisis Resources
<b>Conditions Covered:</b>	Other

# New York State Local Departments of Social Services (LDSS) Tool



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Local Departments of Social Services (LDSS) Tool

**Agency Description:** Provides an interactive map and corresponding list of all social services departments across the state of New York by county. This tool provides easy access for caregivers and other adults to identify which county they are in and who they can contact and where

**Phone Number:**

**Email Address:**

**Website:** [https://www.health.ny.gov/health\\_care/medicaid/ldss.htm](https://www.health.ny.gov/health_care/medicaid/ldss.htm)

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Financial Legal & Advocacy Government Agency Information & Referral Family & Supports

**Conditions Covered:** Other

# Catholic Charities New York State Kinship Navigator



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Catholic Charities New York State Kinship Navigator

**Agency Description:** The Navigator seeks to assist these caregivers by providing information on financial assistance, legal information and referrals, and other types of issues that caregivers face when raising children in order to provide stability and permanency in the home. Call us today for more information!

Our County Resources allow kinship caregivers to find resources specific to the county they reside in. Each county displays kinship, legal, aging, youth, and any other services that are available in that county, along with program descriptions and contact information.

**Phone Number:** (877) 454-6463

**Email Address:** [Navigator@nysnavigator.org](mailto:Navigator@nysnavigator.org)

**Website:** <https://www.nysnavigator.org/>

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Family & Supports Financial Legal & Advocacy Early Childhood & School Aged Crisis Resources Information & Referral

**Conditions Covered:** Other

# New York Department of Health Women, Infant, and Children (WIC) Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York Department of Health Women, Infant, and Children (WIC) Program

**Agency Description:** WIC's goal is to improve the health and nutrition of moms and kids. It is well known that pregnancy and early childhood are among the most important times for growth and development.

**Phone Number:** (844) 540-3013

**Email Address:** NYSWIC@health.ny.gov

**Website:** <https://www.health.ny.gov/prevention/nutrition/wic/>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Government Agency Family & Supports Information & Referral

**Conditions Covered:** Other

# New York State Office for People With Developmental Disabilities (OPWDD) Front Door Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Office for People With Developmental Disabilities (OPWDD) Front Door Program

**Agency Description:** The Front Door is the way OPWDD connects you to the services you want and need. Once you enter, a person-centered planning process begins, which helps you learn about and access service options that take your needs and desires into consideration. It will also give you the chance to direct your own service plan or help your family member or loved one as they direct theirs.

The Front Door is based on the understanding that, as a person with developmental disabilities you have the right to:

Enjoy meaningful relationships,  
Experience personal growth,  
Participate in your community and,

**Phone Number:** (866) 946-9733

**Email Address:** [info@opwdd.ny.gov](mailto:info@opwdd.ny.gov)

**Website:** <https://opwdd.ny.gov/get-started/front-door>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Government Agency Early Childhood & School Aged  
Transitioning to Adulthood (Youth)

**Conditions Covered:** Developmental Delay Learning Difficulty Intellectual Disability Allergies Anxiety Arthritis Asthma  
Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem  
Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP)  
Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Diabetes Down Syndrome  
Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Migraines Other  
Other Mental Health Condition Speech or Language Disorder Spina Bifida Tourette Syndrome (TS)  
Substance Use Disorder

# New York State Office of Children and Family Services



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Office of Children and Family Services

**Agency Description:** The Office of Children and Family Services serves New York's public by promoting the safety, permanency and well-being of our children, families and communities. We will achieve results by setting and enforcing policies, building partnerships, and funding and providing quality services.

**Phone Number:** (518) 473-7793

**Email Address:** [info@ocfs.ny.gov](mailto:info@ocfs.ny.gov)

**Website:** <https://ocfs.ny.gov/main/>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Government Agency Family & Supports Care Coordination Information & Referral Financial Legal & Advocacy

**Conditions Covered:** Other

# New York State Conference of Local Mental Hygiene Directors, Inc.



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Conference of Local Mental Hygiene Directors, Inc.

**Agency Description:** The New York State Conference of Local Mental Hygiene Directors is a statewide membership organization that was statutorily incorporated under Article 41 of the Mental Hygiene Law in 1976.

The Conference is comprised of the Directors of Community Services (DCS)/Mental Health Commissioners for 57 counties and the City of New York. Also known as the Local Governmental Unit (LGU), the DCS has a statutory authority and responsibility for oversight and cross-system management of the local mental hygiene system to meet the needs of individuals and families affected by mental illness, substance use disorder and/or intellectual/developmental disability in their communities. [CLICK HERE](#) to learn how the DCS connects the dots in the community!

The LGUs develop and oversee comprehensive, integrated and cost-effective systems of care locally

**Phone Number:** (518) 462-9422

**Email Address:** [fs@clmhd.org](mailto:fs@clmhd.org)

**Website:** <https://www.clmhd.org/>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Government Agency Medical Dental & Behavioral Health Financial Legal & Advocacy

**Conditions Covered:** Depression Anxiety Other Mental Health Condition Intellectual Disability Down Syndrome Developmental Delay Learning Difficulty

# New York State Office of Temporary and Disability Assistance SSI/Social Security Disability Benefits



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Office of Temporary and Disability Assistance SSI/Social Security Disability Benefits

**Agency Description:** Social Security Disability Insurance pays benefits to you and certain members of your family if you are "insured," meaning that you worked long enough and paid Social Security taxes.

The amount of your monthly benefit is based on your lifetime average earnings covered by Social Security.

Social Security Disability Insurance benefits are paid starting six months from the onset date of the disability, but no more than 12 months prior to application.

A claimant receives monthly benefits deposited directly into their bank account or on a SSA Direct Express Card.

Supplemental Security Income pays benefits based on financial need.

**Phone Number:** (800) 772-1213

**Email Address:** NY.DD.PC3.CORRES@ssa.gov

**Website:** <https://otda.ny.gov/programs/disability-determinations/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Government Agency Early Childhood & School Aged Transitioning to Adulthood (Youth) Family & Supports Information & Referral

**Conditions Covered:** Anxiety Allergies Attention-Deficit/Hyperactivity Disorder (ADHD) Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Deafness or Problems with Hearing Diabetes Epilepsy / Seizure Disorder Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Heart Condition Other Down Syndrome Developmental Delay Speech or Language Disorder Genetic or Inherited Condition Spina Bifida Tourette Syndrome (TS) Substance Use Disorder

# New York State Office of Children and Family Services (OCFS) Child Welfare and Community Services



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Office of Children and Family Services (OCFS) Child Welfare and Community Services

**Agency Description:** The HEARS family line assists parents and families by providing resources and referrals to a variety of services. Caring representatives guide families to services including food, clothing, housing, medical and behavioral health care services, parenting education and child care.

Representatives are available to help Monday through Friday from 8:30 a.m.-4:30 p.m. The line offers messages in 12 languages.

**Phone Number:** (888) 554-3277

**Email Address:** [info@ocfs.ny.gov](mailto:info@ocfs.ny.gov)

**Website:** <https://ocfs.ny.gov/programs/cwcs/hears.php>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Medical Dental & Behavioral Health Government Agency Information & Referral  
Early Childhood & School Aged

**Conditions Covered:** Other

# United Healthcare Children's Foundation Grant



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** United Healthcare Children's Foundation Grant

**Agency Description:** The UnitedHealthcare Children's Foundation (UHCCF) offers timely financial support to families, so they can focus on what is most important – improving the quality of life of their child. UHCCF grants help with medical expenses not covered, or not fully covered, by a family's commercial health insurance.

**Phone Number:** (855) 698-4223

**Email Address:** [uhccfcustomerservice@uhc.com](mailto:uhccfcustomerservice@uhc.com)

**Website:** <https://www.uhccf.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial Legal & Advocacy Early Childhood & School Aged

**Conditions Covered:** Other

# New York State Office of Temporary and Disability Assistance Home Energy Assistance Program (HEAP)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Office of Temporary and Disability Assistance Home Energy Assistance Program (HEAP)

**Agency Description:** The Home Energy Assistance Program (HEAP) can help eligible New Yorkers heat and cool their homes. If you are eligible, you may receive one regular HEAP benefit per program year and could also be eligible for emergency HEAP benefits if you are in danger of running out of fuel or having your utility service shut off.

**Phone Number:** (800) 342-3009

**Email Address:** [nyspio@otda.ny.gov](mailto:nyspio@otda.ny.gov)

**Website:** <https://otda.ny.gov/programs/heap/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Government Agency Financial Legal & Advocacy Disaster/Emergency Preparedness

**Conditions Covered:** Other

# New York State Medicaid Disability Review Unit and Manual



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Medicaid Disability Review Unit and Manual

**Agency Description:** The Medicaid Disability Manual is the official policy guide for disability determinations for the Medicaid program in New York State. It includes six sections: Table of Contents, Introduction, Official Policy, Listing of Impairments, Adult and Children (Appendix I), Medical Vocational Guidelines (Appendix II), and Disability Review Forms.

The Manual is updated whenever changes in disability policy, procedures, or Listing of Impairments take effect. These updates are listed below.

The Medicaid Disability Manual is available online at the DOH website. Forms referred to in the Manual may be obtained online through the Health Commerce System (Access Required).

**Phone Number:** (800) 541-2831

**Email Address:** [medicaid@health.ny.gov](mailto:medicaid@health.ny.gov)

**Website:** [https://www.health.ny.gov/health\\_care/medicaid/reference/mdm/](https://www.health.ny.gov/health_care/medicaid/reference/mdm/)

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Government Agency Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Deafness or Problems with Hearing Cystic Fibrosis (CF) Depression Developmental Delay Down Syndrome Diabetes Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Other Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# New York State Provider & Health Plan Look-Up Tool



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Provider & Health Plan Look-Up Tool

**Agency Description:** The NYS Provider & Health Plan Look-Up, launched in May 2017, is an on-line tool that can be used by consumers to research provider networks and health plans. By using this tool, consumers can search for their preferred providers, including doctors and hospitals to see which health plans have those providers in their network.

The NYS Provider & Health Plan Look-Up includes information about the health care providers that participate with health plans offered through the NY State of Health Marketplace, including Qualified Health Plans, the Essential Plan, Child Health Plus and Medicaid Managed Care. The Look-Up Tool also includes provider information for other NYS Medicaid programs including Managed Long Term Care Plans, Health and Recovery Plans, Fully Integrated Dual Advantage Plans, as well as, Commercial, Commercial Non-MCO Medical plans, Commercial Non-MCO Dental plans and Commercial Non-MCO

**Phone Number:** (518) 473-0180

**Email Address:** dohweb@health.ny.gov

**Website:** [https://www.health.ny.gov/health\\_care/pnds/](https://www.health.ny.gov/health_care/pnds/)

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Medical Dental & Behavioral Health Care Coordination Family & Supports

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Brain Injury, Concussion, or Head Injury Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# New York State Department of Health Asthma Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health Asthma Program

**Agency Description:** Asthma is a chronic disease of the lungs. In New York State (NYS), more than 1.4 million adults have asthma. Asthma occurs at any age but is more common in children than adults. Nationally, nearly one in 13 school-age children have asthma, and that rate is rising more rapidly in preschool-aged children and those living in urban inner cities than in any other group. Although there is no cure for asthma, asthma attacks can be prevented and controlled with proper care. New York is actively working with health care providers, community coalitions, schools, families and many others to fight asthma so people with asthma can live a full and active life.

This web site is designed to provide accurate, current and useful information for people with asthma and for the people who care for them. New resources will be added often. Please check back frequently.

**Phone Number:**

**Email Address:** [asthma@health.ny.gov](mailto:asthma@health.ny.gov)

**Website:** <https://www.health.ny.gov/diseases/asthma/>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Government Agency Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Asthma

# New York State Department of Health Early Intervention Program (EIP)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health Early Intervention Program (EIP)

**Agency Description:** The New York State Early Intervention Program (EIP) is part of the national Early Intervention Program for infants and toddlers with disabilities and their families. First created by Congress in 1986 under the Individuals with Disabilities Education Act (IDEA), the EIP is administered by the New York State Department of Health through the Bureau of Early Intervention. In New York State, the Early Intervention Program is established in Article 25 of the Public Health Law and has been in effect since July 1, 1993.

To be eligible for services, children must be under 3 years of age and have a confirmed disability or established developmental delay, as defined by the State, in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and/or adaptive.

**Phone Number:**

**Email Address:** [beipub@health.ny.gov](mailto:beipub@health.ny.gov)

**Website:** [https://www.health.ny.gov/community/infants\\_children/early\\_intervention/](https://www.health.ny.gov/community/infants_children/early_intervention/)

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Early Childhood & School Aged Government Agency Accessibility & Assistive Technology Family & Supports Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Allergies Anxiety Asthma Arthritis Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Healthy Families New York



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Healthy Families New York

**Agency Description:** Healthy Families New York (HFNY), a Healthy Families America (HFA) accredited home visiting program, seeks to improve the health and well-being of infants and children through home-based services delivered by non-profit organizations in local communities. HFNY was established in 1995 by the New York State Office of Children and Family Services (OCFS).

HFNY is an evidence-based voluntary home visiting model designed to provide services to families that begin prenatally, or at birth, through age five. HFNY uses an infant mental health/relational development approach that promotes parent-child attachment to achieve its mission of preventing child abuse, neglect, and other adverse childhood outcomes.

HFNY strategies are relationship-based, culturally sensitive, family centered, strength-based (building

**Phone Number:** (518) 591- 8610

**Email Address:** support@chsr1.zohosupport.com

**Website:** <https://www.healthyfamiliesnewyork.org/default.htm>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Medical Dental & Behavioral Health Care Coordination Early Childhood & School Aged Information & Referral

**Conditions Covered:** Other

# New York State Department of Health Health Homes Serving Children (HHSC) Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health Health Homes Serving Children (HHSC) Program

**Agency Description:** The New York State Health Home Program was launched in 2012. While children who meet the Health Home eligibility requirements have been eligible for Health Home enrollment since that time, it has been the intent of the State to work with existing Health Homes and other providers to tailor New York State's Health Home Model to better serve children and to recognize the important differences in the approach to care management and planning for children and adults. The links below provide important information, guidance and presentation/webinars that has been developed by the State (e.g. The New York State Department of Health, the Office of Mental Health, the Office of Alcoholism and Substance Abuse Services, and the Office of Children and Family Services) in consultation with Health Homes, Managed Care Plans, children's advocates and other stakeholders to tailor the Health Home model to better serve children. The Health Home Serving Children's (HHSC) program was launched in December 2016, with 16 Health Homes designated to serve children. Of the 16 designated Health Homes, 13 of

**Phone Number:**

**Email Address:** <https://apps.health.ny.gov/pubpal/builder/email-health-homes>

**Website:** [https://www.health.ny.gov/health\\_care/medicaid/program/medicaid\\_health\\_home](https://www.health.ny.gov/health_care/medicaid/program/medicaid_health_home)

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Care Coordination Family & Supports Government Agency Financial Legal & Advocacy Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Other Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# The Disability Information and Access Line (DIAL)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** The Disability Information and Access Line (DIAL)

**Agency Description:** The Disability Information and Access Line (DIAL) helps people with disabilities get connected to information about local community resources that support independent living. Launched in 2021 to help people with disabilities access COVID-19 vaccinations, DIAL also provides information about essential services such as transportation, housing support, disability rights, and more.

**Phone Number:** (888) 677-1199

**Email Address:** [DIAL@usaginganddisability.org](mailto:DIAL@usaginganddisability.org)

**Website:** <https://dial.acl.gov/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Information & Referral Medical Dental & Behavioral Health Government Agency Family & Supports Care Coordination

**Conditions Covered:** Other Allergies Anxiety Asthma Arthritis Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cystic Fibrosis (CF) Cerebral Palsy (CP) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Migraines Learning Difficulty Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Think College



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Think College

**Agency Description:** Think College is a national organization dedicated to developing, expanding, and improving inclusive higher education options for people with intellectual disability. The Think College directory includes information on college programs in New York for students with intellectual disability:  
[https://thinkcollege.net/college-search?f%5B0%5D=tc\\_state\\_province%3ANew%20York](https://thinkcollege.net/college-search?f%5B0%5D=tc_state_province%3ANew%20York)

**Phone Number:** (617) 287-4300

**Email Address:** [thinkcollege@umb.edu](mailto:thinkcollege@umb.edu)

**Website:** <http://thinkcollege.net/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Transitioning to Adulthood (Youth)

**Conditions Covered:** Down Syndrome Intellectual Disability Learning Difficulty Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Genetic or Inherited Condition

# National Center on Health, Physical Activity and Disability (NCHPAD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

<b>Agency</b>	National Center on Health, Physical Activity and Disability (NCHPAD)
<b>Agency Description:</b>	NCHPAD is the premier resource for information on physical activity, health promotion, and disability, serving persons with physical, sensory and cognitive disabilities across the lifespan. NCHPAD features a variety of resources and services which can benefit all ages and populations in New York.
<b>Phone Number:</b>	(866) 866-8896
<b>Email Address:</b>	nchpad@uab.edu
<b>Website:</b>	<a href="http://www.nchpad.org/Directories/Youth/USA/New~York">http://www.nchpad.org/Directories/Youth/USA/New~York</a>
<b>Counties Served:</b>	State-Wide
<b>Content Categories:</b>	Community Living & Recreation   Transitioning to Adulthood (Youth)   Family & Supports   Information & Referral Accessibility & Assistive Technology
<b>Conditions Covered:</b>	Cerebral Palsy (CP)   Autism Spectrum Disorder (ASD)   Developmental Delay   Down Syndrome   Epilepsy / Seizure Disorder Intellectual Disability   Learning Difficulty   Other   Attention-Deficit/Hyperactivity Disorder (ADHD)   Allergies   Anxiety Arthritis   Asthma   Behavioral / Conduct Problem   Blood Disorders   Brain Injury, Concussion, or Head Injury Cystic Fibrosis (CF)   Depression   Diabetes   Genetic or Inherited Condition   Deafness or Problems with Hearing Heart Condition   Other Mental Health Condition   Speech or Language Disorder   Spina Bifida   Tourette Syndrome (TS) Blindness or Problems with Seeing

# National Association of the Deaf (NAD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** National Association of the Deaf (NAD)

**Agency Description:** The mission of the National Association of the Deaf is to preserve, protect and promote the civil, human and linguistic rights of deaf and hard of hearing people in the United States of America. Provides contact information for the Empire State Association of the Deaf (ESAD) in New York and the following directories: (1) State Agencies of Deaf and Hard of Hearing (2) ASL at Universities (3) Senior Resources and (4) Statewide Vocational Rehabilitation Services.

**Phone Number:** (301) 587-1788

**Email Address:** [nad.info@nad.org](mailto:nad.info@nad.org)

**Website:** <http://www.nad.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral, Transitioning to Adulthood (Youth), Financial Legal & Advocacy, Accessibility & Assistive Technology, Community Living & Recreation, Family & Supports, LGBTQIA+ Resources

**Conditions Covered:** Deafness or Problems with Hearing

# New York State Department of Health: Growing Up Healthy Hotline (GUHH)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health: Growing Up Healthy Hotline (GUHH)

**Agency Description:** The Growing Up Healthy Hotline helps pregnant and parenting people in New York State find the help they need. Help is available in many areas, including health care and children's special needs. Call the Hotline anytime: 1-800-522-5006  
TTY (TeleTYpe): 1-800-655-1789

**Phone Number:** (800) 522-5006

**Email Address:** bwh@health.ny.gov

**Website:** [http://www.health.ny.gov/community/pregnancy/health\\_care/prenatal/guh.htm](http://www.health.ny.gov/community/pregnancy/health_care/prenatal/guh.htm)

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Medical Dental & Behavioral Health Financial Legal & Advocacy

**Conditions Covered:** Developmental Delay Other Mental Health Condition Learning Difficulty Speech or Language Disorder Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Spina Bifida Other Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Wonder Baby



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Wonder Baby

**Agency Description:** Wonder Baby is dedicated to helping parents of young children with visual impairments and children with multiple disabilities. We have a database of articles written by parents who want to share with others what they've learned about playing with and teaching a blind child, as well as links to meaningful resources and ways to connect with other families.

**Phone Number:**

**Email Address:** [help@wonderbaby.org](mailto:help@wonderbaby.org)

**Website:** <http://www.wonderbaby.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Care Coordination Accessibility & Assistive Technology

**Conditions Covered:** Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Developmental Delay Epilepsy / Seizure Disorder Genetic or Inherited Condition Intellectual Disability Speech or Language Disorder

# Live Accessible



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Live Accessible

**Agency Description:** We are a resource for individuals and families with blindness or low vision who want to live a more accessible life, created by a family who are all visually impaired and blind themselves.

This website is an ongoing list of resources for those with sight loss. We have a YouTube channel called Live Accessible with videos on tips, how-tos, and advice with new videos every week.

**Phone Number:** (303) 893-0552

**Email Address:** [carrie@liveaccessible.com](mailto:carrie@liveaccessible.com)

**Website:** <https://www.facebook.com/LiveAccessible/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Accessibility & Assistive Technology

**Conditions Covered:** Blindness or Problems with Seeing

# National Organization for Albinism and Hypopigmentation (NOAH)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** National Organization for Albinism and Hypopigmentation (NOAH)

**Agency Description:** NOAH serves the albinism community by providing information and support. NOAH's mission is to act as a conduit for accurate and authoritative information about all aspects of living with albinism and to provide a place where people with albinism and their families in the U.S. and Canada can find acceptance, support and fellowship.

**Phone Number:** (800) 473-2310

**Email Address:** [info@albinism.org](mailto:info@albinism.org)

**Website:** <http://www.albinism.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Financial Legal & Advocacy Family & Supports Community Living & Recreation  
Transitioning to Adulthood (Youth)

**Conditions Covered:** Other Genetic or Inherited Condition

# CHARGE Syndrome Foundation



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** CHARGE Syndrome Foundation

**Agency Description:** The CHARGE Syndrome Foundation leads and partners to improve the lives of people with CHARGE syndrome locally, nationally, and internationally through outreach, education, and research. The primary goals of the Foundation include: growing our outreach and support programs; increasing our knowledge base; promoting awareness; building networks and partnerships; and investing in leading-edge research.

**Phone Number:** (800) 442-7604

**Email Address:** [info@chargesyndrome.org](mailto:info@chargesyndrome.org)

**Website:** <http://www.chargesyndrome.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Financial Legal & Advocacy Early Childhood & School Aged

**Conditions Covered:** Genetic or Inherited Condition

# Organization for Autism Research (OAR)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Organization for Autism Research (OAR)

**Agency Description:** OAR uses science to address the social, educational, and treatment concerns of self-advocates, parents, autism professionals, and caregivers. We disseminate new and useful information to as many members of the autism community as possible, and direct all research and program initiatives toward enhancing the quality of life for individuals with autism.

**Phone Number:** (866) 366-9710

**Email Address:** [info@researchautism.org](mailto:info@researchautism.org)

**Website:** <http://researchautism.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Family & Supports Financial Legal & Advocacy

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# New York State Department of Health: Special Education Services



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health: Special Education Services

**Agency Description:** Children ages 3-21 with disabilities who live in New York State are eligible. Students thought to have a disability are referred to a multidisciplinary team (e.g., teachers, psychologists, and therapists) called the Committee on Preschool Special Education or the Committee on Special Education. The Committee arranges for an evaluation of the student's abilities and needs. Based on evaluation results, the committee decides if the student is eligible to receive special education services and programs.

**Phone Number:** (518) 473-2878

**Email Address:**

**Website:** [http://www.health.ny.gov/publications/0548/special\\_education\\_services.htm](http://www.health.ny.gov/publications/0548/special_education_services.htm)

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Early Childhood & School Aged Transitioning to Adulthood (Youth)

**Conditions Covered:** Developmental Delay Other Mental Health Condition Learning Difficulty Speech or Language Disorder Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Spina Bifida Other Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# American Association of People with Disabilities (AAPD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

<b>Agency</b>	American Association of People with Disabilities (AAPD)
<b>Agency Description:</b>	The American Association of People with Disabilities is a convener, connector, and catalyst for change, increasing people's political and economic power with disabilities.
<b>Phone Number:</b>	(800) 840-8844
<b>Email Address:</b>	communications@aapd.com
<b>Website:</b>	<a href="http://www.aapd.com/">http://www.aapd.com/</a>
<b>Counties Served:</b>	State-Wide
<b>Content Categories:</b>	Financial Legal & Advocacy
<b>Conditions Covered:</b>	Anxiety Arthritis Allergies Asthma Autism Spectrum Disorder (ASD) Attention-Deficit/Hyperactivity Disorder (ADHD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Other Mental Health Condition Speech or Language Disorder Spina Bifida Tourette Syndrome (TS)

# American Council of the Blind (ACB)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** American Council of the Blind (ACB)

**Agency Description:** American Council of the Blind (ACB) advocates for equality of people who are blind and visually impaired, inspires community, and connects you with education, resources, and each other to support your independence. Find the ACB of New York here: <https://www.acb.org/affiliate-new-york>.

**Phone Number:** (800) 424-8666

**Email Address:** [info@acb.org](mailto:info@acb.org)

**Website:** <http://www.acb.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral Transitioning to Adulthood (Youth) Community Living & Recreation

**Conditions Covered:** Blindness or Problems with Seeing

# Job Accommodation Network (JAN)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Job Accommodation Network (JAN)

**Agency Description:** The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on job accommodations and disability employment issues. Serving customers across the United States and around the world for more than 35 years, JAN provides free one-on-one practical guidance and technical assistance on job accommodation solutions, Title I of the Americans with Disabilities Act (ADA) and related legislation, and self-employment and entrepreneurship options for people with disabilities

**Phone Number:** (800) 526-7234

**Email Address:** [jan@askjan.org](mailto:jan@askjan.org)

**Website:** <https://askjan.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Transitioning to Adulthood (Youth) Financial Legal & Advocacy LGBTQIA+ Resources

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# The Color of Autism Foundation



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** The Color of Autism Foundation

**Agency Description:** The Color of Autism Foundation is committed to serving people of color who are affected by Autism Spectrum Disorders. We are devoted to empowering families and lessening their isolation. Our goal is to build efficacy and end the stigma of Autism Spectrum Disorders in communities of color.

**Phone Number:** (313) 444-9035

**Email Address:** [info@thecolorofautism.org](mailto:info@thecolorofautism.org)

**Website:** <https://thecolorofautism.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Financial Legal & Advocacy Transitioning to Adulthood (Youth)

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# Neighborhood Legal Services Inc.



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Neighborhood Legal Services Inc.

**Agency Description:** NYS Assistive Technology Project  
We represent children and adults statewide when funding for AT/specialized equipment is denied. We handle cases involving Medicaid, Medicare, special education, private insurance, and a range of other issues. In some cases, we may refer you to an attorney or advocate in your part of the state who can assist you for no charge.

**Phone Number:** (716) 847-0655

**Email Address:** mgustas@nls.org

**Website:** <http://nls.org/disability/nys-assistive-technology-project/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Financial Legal & Advocacy

**Conditions Covered:** Autism Spectrum Disorder (ASD) Blindness or Problems with Seeing Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Developmental Delay Down Syndrome Epilepsy / Seizure Disorder Intellectual Disability Learning Difficulty Genetic or Inherited Condition Speech or Language Disorder

# Genesee County Department of Health



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Genesee County Department of Health

**Agency Description:** New York State (NYS) Local Health Departments (LHDs) help CYSHCN and their families by providing information and referrals including but not limited to community resources, health insurance and connecting them with health care providers. They also work with families to help them meet the medical and non-medical needs of their children.

**Phone Number:** (585) 344-6110

**Email Address:**

**Website:** <https://www.co.genesee.ny.us/departments/health/specialhealthcare.php>

**Counties Served:** Genesee County

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Early Childhood & School Aged, Family & Supports, Financial Legal & Advocacy, Government Agency, Information & Referral, Medical Dental & Behavioral Health, Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# Livingston County

## Department of Health



### Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Livingston County Department of Health

**Agency Description:** New York State (NYS) Local Health Departments (LHDs) help CYSHCN and their families by providing information and referrals including but not limited to community resources, health insurance and connecting them with health care providers. They also work with families to help them meet the medical and non-medical needs of their children.

**Phone Number:** (585) 243-7000

**Email Address:**

**Website:** <http://www.livingstoncounty.us/1157/Children-with-Special-Healthcare-Needs>

**Counties Served:** Livingston County

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Early Childhood & School Aged, Family & Supports, Financial Legal & Advocacy, Government Agency, Information & Referral, Medical Dental & Behavioral Health, Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# Monroe County Department of Health



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Monroe County Department of Health

**Agency Description:** New York State (NYS) Local Health Departments (LHDs) help CYSHCN and their families by providing information and referrals including but not limited to community resources, health insurance and connecting them with health care providers. They also work with families to help them meet the medical and non-medical needs of their children.

**Phone Number:** (585) 753-5223

**Email Address:** LaurenReed@monroecounty.gov

**Website:** <http://www2.monroecounty.gov/health-maternal-children-health-needs>

**Counties Served:** Monroe County

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Early Childhood & School Aged, Family & Supports, Financial Legal & Advocacy, Government Agency, Information & Referral, Medical Dental & Behavioral Health, Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# Orleans County Department of Health



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Orleans County Department of Health

**Agency Description:** New York State (NYS) Local Health Departments (LHDs) help CYSHCN and their families by providing information and referrals including but not limited to community resources, health insurance and connecting them with health care providers. They also work with families to help them meet the medical and non-medical needs of their children.

**Phone Number:** (585) 344-2580

**Email Address:** OCPublicHealth@orleanscountyny.gov

**Website:** [http://www.orleansny.com/departments/public\\_health/index.php](http://www.orleansny.com/departments/public_health/index.php)

**Counties Served:** Orleans County

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Early Childhood & School Aged, Family & Supports, Financial Legal & Advocacy, Government Agency, Information & Referral, Medical Dental & Behavioral Health, Transitioning to Adulthood (Youth), Disaster/Emergency Preparedness

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# Seneca County Department of Health



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Seneca County Department of Health

**Agency Description:** New York State (NYS) Local Health Departments (LHDs) help CYSHCN and their families by providing information and referrals including but not limited to community resources, health insurance and connecting them with health care providers. They also work with families to help them meet the medical and non-medical needs of their children.

**Phone Number:** (315) 539-1938

**Email Address:**

**Website:** <https://senecacountyhealthdepartment.com/public-health/programs->

**Counties Served:** Seneca County

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Early Childhood & School Aged, Family & Supports, Financial Legal & Advocacy, Government Agency, Information & Referral, Medical Dental & Behavioral Health, Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# Wyoming County Youth Bureau



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Wyoming County Youth Bureau

**Agency Description:** New York State (NYS) Local Health Departments (LHDs) help CYSHCN and their families by providing information and referrals including but not limited to community resources, health insurance and connecting them with health care providers. They also work with families to help them meet the medical and non-medical needs of their children.

**Phone Number:** (585) 786-8850

**Email Address:**

**Website:** <http://www.wyomingco.net/226/Youth-Bureau>

**Counties Served:** Wyoming County

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Early Childhood & School Aged, Family & Supports, Financial Legal & Advocacy, Government Agency, Information & Referral, Medical Dental & Behavioral Health, Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# Yates County Department of Health



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Yates County Department of Health

**Agency Description:** New York State (NYS) Local Health Departments (LHDs) help CYSHCN and their families by providing information and referrals including but not limited to community resources, health insurance and connecting them with health care providers. They also work with families to help them meet the medical and non-medical needs of their children.

**Phone Number:** (315) 536-5160

**Email Address:**

**Website:** <http://www.yatescounty.org/213/Children-Services>

**Counties Served:** Yates County

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Early Childhood & School Aged, Family & Supports, Financial Legal & Advocacy, Government Agency, Information & Referral, Medical Dental & Behavioral Health, Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# MaxMods

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** MaxMods

**Agency Description:** MaxMods is a Colorado-based nonprofit corporation founded to assist people with physical limitations with modifications and adaptations of toys and devices. We conduct an event called Santa's Little Hackers that provides adapted toys for disabled individuals.

**Phone Number:**

**Email Address:**

**Website:** <http://www.maxmods.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Early Childhood & School Aged Transitioning to Adulthood (Youth) Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Anxiety Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Autism Spectrum Disorder (ASD) Cystic Fibrosis (CF) Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Deafness or Problems with Hearing Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Heart Condition Intellectual Disability Genetic or Inherited Condition Learning Difficulty Other Mental Health Condition Other Speech or Language Disorder Spina Bifida Tourette Syndrome (TS)

# Wayne County Public Health



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Wayne County Public Health

**Agency Description:** New York State (NYS) Local Health Departments (LHDs) help CYSHCN and their families by providing information and referrals including but not limited to community resources, health insurance and connecting them with health care providers. They also work with families to help them meet the medical and non-medical needs of their children.

**Phone Number:** (315) 946-5749

**Email Address:** [wcph@co.wayne.ny.us](mailto:wcph@co.wayne.ny.us)

**Website:** <http://www.wcphny.com/children-with-special-needs/>

**Counties Served:** Wayne County

**Content Categories:** Accessibility & Assistive Technology Care Coordination Community Living & Recreation Early Childhood & School Aged Family & Supports Financial Legal & Advocacy Government Agency Information & Referral Medical Dental & Behavioral Health Transitioning to Adulthood (Youth) Disaster/Emergency Preparedness

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Hands & Voices



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Hands & Voices

**Agency Description:** As a national presence, Hands & Voices has built a strong network of families, professionals in all related fields, state/federal tech support resources, modality-based groups, institutions of higher education, service providers, and consumers who are deaf or hard of hearing. We help each other by sharing ideas and advice, collaborating on projects, and passing on information of interest to each other. Our goal is to improve educational and social outcomes for children who are deaf or hard of hearing. There is a NY Chapter.

**Phone Number:** (860) 508- 8996

**Email Address:** handsandvoicesny@gmail.com

**Website:** <http://handsandvoices.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Family & Supports, Financial Legal & Advocacy, Early Childhood & School Aged, Information & Referral

**Conditions Covered:** Deafness or Problems with Hearing

# Chromosome Disorder Outreach Inc,



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Chromosome Disorder Outreach Inc,

**Agency Description:** Our mission is to provide support and information to anyone diagnosed with a rare chromosome change, rearrangement, or disorder. Additionally, Chromosome Disorder Outreach (CDO) actively promotes research and a positive community understanding of all chromosome disorders.

**Phone Number:** (561) 395-4252

**Email Address:** [info@chromodisorder.org](mailto:info@chromodisorder.org)

**Website:** <https://chromodisorder.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral

**Conditions Covered:** Genetic or Inherited Condition Other

# Five P Minus Society



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Five P Minus Society

**Agency Description:** Our Society is a support organization that works diligently to spread awareness and provide valuable information, education, and support for families, educators, and medical professionals. The society sponsors programs such as Family Support Services, Annual National Meetings, Newsletters, Grandparent Support Services, and a reference library to encourage and facilitate open communication for people and families dealing with 5P-/Cri du Chat Syndrome.

**Phone Number:** (888) 970-0777

**Email Address:** [director@fivepminus.org](mailto:director@fivepminus.org)

**Website:** <https://fivepminus.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Medical Dental & Behavioral Health Family & Supports

**Conditions Covered:** Genetic or Inherited Condition Other

# National Stuttering Association



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** National Stuttering Association

**Agency Description:** The National Stuttering Association (NSA) provides education and support to children and adults who stutter, family members, professionals, and the public, in an ongoing effort to increase understanding of stuttering.

**Phone Number:** (800) 937-8888

**Email Address:** Info@WeStutter.org

**Website:** <https://westutter.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral

**Conditions Covered:** Speech or Language Disorder Other

# The Stuttering Foundation



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** The Stuttering Foundation

**Agency Description:** The Stuttering Foundation provides free online resources, services, and support to those who stutter and their families and support for research into the causes of stuttering.

**Phone Number:** (800) 992- 9392

**Email Address:** [info@stutteringhelp.org](mailto:info@stutteringhelp.org)

**Website:** <https://www.stutteringhelp.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Early Childhood & School Aged Transitioning to Adulthood (Youth)

**Conditions Covered:** Speech or Language Disorder

# Progeria Research Foundation



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Progeria Research Foundation

**Agency Description:** Our mission is to discover treatments and the cure for Progeria and its aging-related conditions, including heart disease. Today, PRF continues to be the only organization in the world solely dedicated to this mission. We have filled a void, taking these children out of the background where they had been for over 100 years and putting them and Progeria at the forefront of scientific efforts.

**Phone Number:** (978) 535-2594

**Email Address:** [info@progeriaresearch.org](mailto:info@progeriaresearch.org)

**Website:** <http://www.progeriaresearch.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Financial Legal & Advocacy

**Conditions Covered:** Genetic or Inherited Condition

# New York Lawyers for the Public Interest (NYPLI)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York Lawyers for the Public Interest (NYPLI)

**Agency Description:** Our committed staff of lawyers, community organizers, policy experts, and other advocates combine forces with 80 member firms, 900 pro bono attorneys, and thousands of community members. We marshal these resources to protect civil rights and improve the lives of millions of New Yorkers.

**Phone Number:** (212) 244-4664

**Email Address:**

**Website:** <http://www.nympi.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Be My Eyes

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Be My Eyes

**Agency Description:** Be My Eyes is a free mobile app with one main goal: to make the world more accessible for blind and low-vision people. The app connects blind and low-vision individuals with sighted volunteers and companies from all over the world through a live video call.

**Phone Number:**

**Email Address:** sales@bemyeyes.com

**Website:** <http://www.bemyeyes.com/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology

**Conditions Covered:** Blindness or Problems with Seeing

# Global Genes



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Global Genes

**Agency Description:** Global Genes provides hope for the more than 400 million people affected by rare disease around the globe. We fulfill our mission by helping patients find and build communities, gain access to information and resources, connect to researchers, clinicians, industry, government, and other stakeholders, share data and experiences, stand up, stand out, and become effective advocates on their own behalf.

**Phone Number:** (949) 248-7273

**Email Address:** careaboutrare@globalgenes.org

**Website:** <http://globalgenes.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral, Family & Supports, Care Coordination, Financial Legal & Advocacy

**Conditions Covered:** Genetic or Inherited Condition

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Pathways.org

**Agency Description:** Free resources to help understand, track, and encourage your baby's milestones for the best possible outcomes.

**Phone Number:** (800) 955-2445

**Email Address:** friends@pathways.org

**Website:** <http://pathways.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Early Childhood & School Aged Medical Dental & Behavioral Health

**Conditions Covered:** Developmental Delay Other

# The Asian Americans with Disabilities Initiative



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** The Asian Americans with Disabilities Initiative

**Agency Description:** The Asian Americans with Disabilities Initiative is a youth-led nonprofit organization aiming to uplift disabled Asian American voices. Welcome to the movement.

**Phone Number:**

**Email Address:** [hello@aaddinitiative.org](mailto:hello@aaddinitiative.org)

**Website:** <http://www.aadinitiative.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Feeding Matters



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Feeding Matters

**Agency** PFD ICD-10 TOOLKIT

**Description:**

Feeding Matters is the first organization in the world to unite the concerns of families with the field's leading advocates, experts, and allied healthcare professionals to improve the system of care for pediatric feeding disorder through advocacy, education, support, and research.

The Pediatric Feeding Disorder (PFD) ICD-10 Toolkit is a collection of free resources designed to promote awareness, identification, and comprehensive assessment and management of PFD. The Toolkit can be downloaded in its entirety or as individual resources. The Toolkit will be periodically updated and expanded as additional resource needs are identified.

**Phone Number:** (800) 233-4658

**Email Address:** [info@feedingmatters.org](mailto:info@feedingmatters.org)

**Website:** <https://www.feedingmatters.org/toolkit/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Family & Supports Financial Legal & Advocacy

**Conditions Covered:** Developmental Delay

# American Association on Intellectual and Developmental Disabilities (AAIDD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** American Association on Intellectual and Developmental Disabilities (AAIDD)

**Agency Description:** AAIDD promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities.

AAIDD's goals are to

1. Enhance the capacity of professionals who work with individuals with intellectual and developmental disabilities.
2. Promote the development of a society that fully includes individuals with intellectual and developmental disabilities.

**Phone Number:** (202) 387-1968

**Email Address:**

**Website:** <https://www.aidd.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Family & Supports Financial Legal & Advocacy

**Conditions Covered:** Intellectual Disability

# Families Together in New York State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Families Together in New York State

**Agency Description:** Families Together in New York State is a family-run organization that represents families of children with social, emotional, behavioral and cross-systems challenges. Our goal is to ensure that ALL children and youth have the support they need in order to succeed. We represent thousands of families from across the state whose children have been involved in many systems including mental health, substance abuse, special education, juvenile justice, and foster care. Our board and staff are made up primarily of family members and youth who have been involved in these systems

**Phone Number:** (518) 432-0333

**Email Address:** [info@ftnys.org](mailto:info@ftnys.org)

**Website:** <https://www.ftnys.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Other

# Help me Grow Finger Lakes



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Help me Grow Finger Lakes

**Agency Description:** Help Me Grow ensures that all children have the best possible start in life by connecting them to resources that help them reach their full potential.

We offer families, caregivers, and community providers tools they need to give children the best chances for health, happiness, and success. We listen. We answer your questions. We help you connect with information, programs, and services. And we provide ongoing, confidential support as a child grows and develops.

Help Me Grow offers a proven model that creates a strong, interconnected network of local partners to help communities flourish.

**Phone Number:** (585) 295- 1008

**Email Address:** support@getreadytogrow.org

**Website:** <https://helpmegrowny.org/>

**Counties Served:** Chemung County Livingston County Monroe County Steuben County Wayne County Yates County

**Content Categories:** Early Childhood & School Aged Information & Referral Family & Supports

**Conditions Covered:** Developmental Delay

# Help Me Grow Western New York



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Help Me Grow Western New York

**Agency Description:** Help Me Grow ensures that all children have the best possible start in life by connecting them to resources that help them reach their full potential.

We offer families, caregivers, and community providers tools they need to give children the best chances for health, happiness, and success. We listen. We answer your questions. We help you connect with information, programs, and services. And we provide ongoing, confidential support as a child grows and develops.

Help Me Grow offers a proven model that creates a strong, interconnected network of local partners to help communities flourish.

**Phone Number:** (716) 760-4769

**Email Address:** [info@hmgwny.org](mailto:info@hmgwny.org)

**Website:** <https://helpmegrowny.org/>

**Counties Served:** Allegany County Cattaraugus County Chautauqua County Erie County Genesee County Niagara County Orleans County Wyoming County

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:** Developmental Delay

# New York State Department of Health: Physician Profile



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health: Physician Profile

**Agency Description:** This web site was created after former Governor George Pataki signed the New York Patient Health Information and Quality Improvement Act of 2000 to make it possible for all citizens of New York to get information about physicians (doctors).

**Phone Number:** (888) 338-6999

**Email Address:**

**Website:** [http://www.nydoctorprofile.com/dispatch?action=display\\_search\\_parameters](http://www.nydoctorprofile.com/dispatch?action=display_search_parameters)

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Developmental Delay Other Mental Health Condition Learning Difficulty Speech or Language Disorder Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Spina Bifida Other Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# American Medical Association: DoctorFinder



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** American Medical Association: DoctorFinder

**Agency Description:** This online physician locator helps you find a perfect match for your medical needs. DoctorFinder provides you with basic professional information on virtually every licensed physician in the United States. This includes more than 814,000 doctors.

**Phone Number:** (800) 262-3211

**Email Address:**

**Website:** <http://doctorfinder.ama-assn.org/doctorfinder/recaptcha.do>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# New York State 2-1-1



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** New York State 2-1-1

**Agency Description:** 2-1-1 helps people assess their needs and links them directly to the resources that will help. The DD Info Link is an online, searchable database that provides detailed information specifically for people with intellectual and developmental disabilities, their families and service providers.

**Phone Number:** 2-1-1

**Email Address:**

**Website:** <http://211nys.org/disability-services>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Disaster/Emergency Preparedness

**Conditions Covered:** Developmental Delay Other Mental Health Condition Learning Difficulty Speech or Language Disorder Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Spina Bifida Other Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Nurturing Dyslexics

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Nurturing Dyslexics

**Agency Description:** Nurturing Dyslexics supports dyslexic children and their families through the shared journey of dyslexia. Nurturing Dyslexics has two initiatives: (1) Nurturing Dyslexia resources and (2) Dystinct Magazine. Nurturing Dyslexics resources are specifically designed to help struggling readers. Dystinct Magazine is a resource of inspiration and expertise for the families and educators of children with learning difficulties.

**Phone Number:**

**Email Address:** [hello@nurturingdyslexics.com](mailto:hello@nurturingdyslexics.com)

**Website:** <http://nurturingdyslexics.com/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Early Childhood & School Aged

**Conditions Covered:** Learning Difficulty Other Intellectual Disability

# New York Housing Resource Center (HRC) for People with Intellectual / Developmental Disabilities (I/DD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York Housing Resource Center (HRC) for People with Intellectual / Developmental Disabilities (I/DD)

**Agency Description:** The New York Housing Resource Center (HRC) for People with Intellectual / Developmental Disabilities (I/DD) was developed by New York Alliance for Inclusion & Innovation. The HRC acts as a clearinghouse for information and resources to foster collaboration between and among the housing industry and people with I/DD, and provides community training for people with I/DD and their families.

**Phone Number:** (929) 260-3877

**Email Address:** [info@nyhrc.org](mailto:info@nyhrc.org)

**Website:** <http://nyhrc.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Financial Legal & Advocacy Transitioning to Adulthood (Youth) Community Living & Recreation

**Conditions Covered:** Developmental Delay Intellectual Disability Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Blindness or Problems with Seeing Cerebral Palsy (CP) Deafness or Problems with Hearing Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Learning Difficulty Speech or Language Disorder Tourette Syndrome (TS)

# Sesame Street in Communities



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Sesame Street in Communities

**Agency Description:** Sesame Street in Communities unites communities, foster families' and kids' resilience, nurture their physical and mental health, and provide critical early learning opportunities. Here, you'll find hundreds of bilingual multi-media tools to help kids and families enrich and expand their knowledge during the early years of birth through six, a critical window for brain development.

**Phone Number:**

**Email Address:** [Communities@sesame.org](mailto:Communities@sesame.org)

**Website:** <http://sesamestreetincommunities.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial Legal & Advocacy Information & Referral Early Childhood & School Aged  
Community Living & Recreation

**Conditions Covered:** Autism Spectrum Disorder (ASD) Asthma Speech or Language Disorder Substance Use Disorder Anxiety Depression  
Learning Difficulty Other Mental Health Condition Developmental Delay Behavioral / Conduct Problem  
Attention-Deficit/Hyperactivity Disorder (ADHD) Intellectual Disability

# Juvenile Diabetes Research Foundation (JDRF)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Juvenile Diabetes Research Foundation (JDRF)

**Agency Description:** JDRF is the leading global organization funding type 1 diabetes (T1D) research. From funding innovative research to advocating for government action to providing a support structure for our community, no other organization does more to fight T1D than JDRF.

**Phone Number:** (800) 533-2873

**Email Address:** [info@jdrf.org](mailto:info@jdrf.org)

**Website:** <http://www.jdrf.org/chapter-finder/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Community Living & Recreation, Early Childhood & School Aged, Information & Referral, Financial Legal & Advocacy, Family & Supports, Disaster/Emergency Preparedness, Crisis Resources, Medical Dental & Behavioral Health

**Conditions Covered:** Diabetes

# American Academy of Pediatric Dentistry (AAPD): Pediatric Dentist Search



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** American Academy of Pediatric Dentistry (AAPD): Pediatric Dentist Search

**Agency Description:** The American Academy of Pediatric Dentistry (AAPD) is the recognized authority on children's oral health. As advocates for children's oral health, the AAPD promotes evidence-based policies and clinical guidelines; educates and informs policymakers, parents and guardians, and other health care professionals; fosters research; and provides continuing professional education for pediatric dentists and general dentists who treat children. Its members provide primary care and comprehensive dental specialty treatments for infants, children, adolescents and individuals with special health care needs

**Phone Number:** (312) 337-2169

**Email Address:**

**Website:** <http://www.mychildrensteeth.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Medical Dental & Behavioral Health Financial Legal & Advocacy Early Childhood & School Aged  
Transitioning to Adulthood (Youth) Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma  
Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression  
Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition  
Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability  
Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder  
Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# New York State Office of Addiction Services and Supports (NYS OASAS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Office of Addiction Services and Supports (NYS OASAS)

**Agency Description:** OASAS is the single designated state agency responsible for the coordination of state-federal relations in the area of addiction services. Our mission is to improve the lives of New Yorkers by leading a comprehensive system of addiction services for prevention, treatment, and recovery. Available addiction treatment can be found using the NYS OASAS Treatment Availability Dashboard at [www.FindAddictionTreatment.ny.gov](http://www.FindAddictionTreatment.ny.gov).

**Phone Number:** (877) 846- 7369

**Email Address:** [communications@oasas.ny.gov](mailto:communications@oasas.ny.gov)

**Website:** <http://oasas.ny.gov/>

**Counties Served:** State-Wide

**Content Categories:** Medical Dental & Behavioral Health Government Agency Information & Referral Transitioning to Adulthood (Youth) LGBTQIA+ Resources Early Childhood & School Aged Family & Supports Financial Legal & Advocacy Care Coordination

**Conditions Covered:** Substance Use Disorder

# Exceptional Parent Magazine



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Exceptional Parent Magazine

**Agency Description:** Exceptional Parent magazine provides practical advice, emotional support, and the most up-to-date educational information for families of children and adults with disabilities and special healthcare needs. It has the endorsement of a professional medical society, the American Academy of Developmental Medicine and Dentistry (ADMD).

**Phone Number:**

**Email Address:**

**Website:** <http://www.epmagazine.com/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Family & Supports, Information & Referral, Financial Legal & Advocacy, Early Childhood & School Aged, Transitioning to Adulthood (Youth), Community Living & Recreation, Care Coordination, Medical Dental & Behavioral Health

**Conditions Covered:** Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), Behavioral / Conduct Problem, Cerebral Palsy (CP), Brain Injury, Concussion, or Head Injury, Down Syndrome, Allergies, Anxiety, Arthritis, Asthma, Blood Disorders, Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Blindness or Problems with Seeing, Tourette Syndrome (TS)

# Complex Child

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Complex Child

**Agency Description:** Complex Child is a free, monthly online magazine written by parents of children with special healthcare needs and disabilities. It is intended to provide medical information, along with personal experiences, in simple language that other parents can understand.

**Phone Number:**

**Email Address:** [info@complexchild.org](mailto:info@complexchild.org)

**Website:** <http://complexchild.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Accessibility & Assistive Technology Information & Referral Care Coordination  
Financial Legal & Advocacy Medical Dental & Behavioral Health Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem  
Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Developmental Delay  
Epilepsy / Seizure Disorder Allergies Anxiety Arthritis Asthma Depression Diabetes Down Syndrome  
Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability  
Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida  
Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# American Cleft Palate- Craniofacial Association (ACPA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** American Cleft Palate-Craniofacial Association (ACPA)

**Agency Description:** The American Cleft Palate-Craniofacial Association (ACPA) is a non-profit association of interested individuals and healthcare professionals who are interested in clinical care and research advancements for those affected by cleft and craniofacial conditions.

ACPA works to support the care of individuals affected by cleft and craniofacial conditions. These patients require care from a variety of specialists over time, and ACPA optimizes outcomes for individuals with oral cleft and craniofacial conditions through education, support, research and interdisciplinary team care.

**Phone Number:** (919) 933-9044

**Email Address:** [info@acpa-cpf.org](mailto:info@acpa-cpf.org)

**Website:** <http://acpa-cpf.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Accessibility & Assistive Technology Information & Referral Financial Legal & Advocacy Medical Dental & Behavioral Health Community Living & Recreation

**Conditions Covered:** Other

# National Organization Rare Diseases (NORD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** National Organization Rare Diseases (NORD)

**Agency Description:** NORD is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

**Phone Number:** (617) 249-7300

**Email Address:**

**Website:** <http://rarediseases.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Financial Legal & Advocacy Medical Dental & Behavioral Health

**Conditions Covered:** Epilepsy / Seizure Disorder Cerebral Palsy (CP) Spina Bifida Cystic Fibrosis (CF) Genetic or Inherited Condition Blood Disorders Down Syndrome Tourette Syndrome (TS) Blindness or Problems with Seeing Heart Condition Diabetes Behavioral / Conduct Problem Speech or Language Disorder Arthritis Deafness or Problems with Hearing Intellectual Disability Developmental Delay Learning Difficulty Migraines Other

# New York State Developmental Disabilities Planning Council (DDPC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Developmental Disabilities Planning Council (DDPC)

**Agency Description:** The DDPC works to improve the lives of people with intellectual and developmental disabilities by funding projects related to health and wellness, education, transportation, housing, life skills and more.

**Phone Number:** (518) 486-7505

**Email Address:** [Information@ddpc.ny.gov](mailto:Information@ddpc.ny.gov)

**Website:** <http://ddpc.ny.gov/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Family & Supports Financial Legal & Advocacy Information & Referral Government Agency

**Conditions Covered:** Developmental Delay Learning Difficulty Intellectual Disability Cerebral Palsy (CP) Down Syndrome Autism Spectrum Disorder (ASD) Genetic or Inherited Condition Epilepsy / Seizure Disorder Attention-Deficit/Hyperactivity Disorder (ADHD) Blindness or Problems with Seeing Speech or Language Disorder Tourette Syndrome (TS) Deafness or Problems with Hearing

# National Institute of Mental Health (NIMH)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

<b>Agency</b>	National Institute of Mental Health (NIMH)
<b>Agency Description:</b>	The NIMH is the lead federal agency for research on mental behaviors and disorders. Its mission is to reduce the burden of these conditions through research on mind, brain and behavior which will lead to better prevention and recovery from mental disorders. It provides information on mental disorders and lists clinical trials in progress.
<b>Phone Number:</b>	(866) 615-6464
<b>Email Address:</b>	nimhinfo@nih.gov
<b>Website:</b>	<a href="http://www.nimh.nih.gov/index.shtml">http://www.nimh.nih.gov/index.shtml</a>
<b>Counties Served:</b>	State-Wide
<b>Content Categories:</b>	Government Agency Information & Referral Financial Legal & Advocacy Medical Dental & Behavioral Health Crisis Resources Community Living & Recreation Early Childhood & School Aged Transitioning to Adulthood (Youth) Disaster/Emergency Preparedness Family & Supports
<b>Conditions Covered:</b>	Other Mental Health Condition Anxiety Depression Substance Use Disorder Other Genetic or Inherited Condition Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD)

# National Collaborative on Workforce and Disability for Youth (NCWD/Youth)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** National Collaborative on Workforce and Disability for Youth (NCWD/Youth)

**Agency Description:** NCWD/Youth works to ensure that transition age youth are provided full access to high quality services in integrated settings to gain education, employment and independent living. NCWD/Youth offers a variety of publications and tip sheets to help youth, make informed choices about their futures.

**Phone Number:** (877) 871-0744

**Email Address:**

**Website:** <http://www.ncwd-youth.info/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Community Living & Recreation, Care Coordination, Family & Supports, Information & Referral, Transitioning to Adulthood (Youth), Financial Legal & Advocacy

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Developmental Delay, Learning Difficulty, Intellectual Disability, Allergies, Anxiety, Arthritis, Asthma, Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Deafness or Problems with Hearing, Heart Condition, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing

# Parent Advocacy Coalition for Educational Rights (PACER) Center



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Parent Advocacy Coalition for Educational Rights (PACER) Center

**Agency Description:** PACER is dedicated to improving the lives of children and youth with special health care needs. Services include: support, assistive technology, education and helpful information, and links towards independent living. The website has a variety of helpful videos and guides and useful information on laws and people's rights. All services are provided free of charge.

**Phone Number:** (952) 838-9000

**Email Address:** [pacer@pacer.org](mailto:pacer@pacer.org)

**Website:** <http://www.pacer.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Early Childhood & School Aged Family & Supports Information & Referral  
Community Living & Recreation Care Coordination Financial Legal & Advocacy Transitioning to Adulthood (Youth)  
Medical Dental & Behavioral Health Disaster/Emergency Preparedness LGBTQIA+ Resources

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD)  
Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP)  
Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder  
Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability  
Learning Difficulty Migraines Other Other Mental Health Condition Spina Bifida Speech or Language Disorder  
Tourette Syndrome (TS) Blindness or Problems with Seeing Substance Use Disorder

# Youthhood

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Youthhood

**Agency Description:** Youthhood is an informational site which helps youth plan for life after high school. It is a youth-designed site for youth with special health care needs. Youthhood provides easily accessible information on postsecondary education, independent living, and opportunities to achieve a successful future.

**Phone Number:** (612) 624-2097

**Email Address:** youthhood@umn.edu

**Website:** <http://www.youthhood.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Accessibility & Assistive Technology Information & Referral Transitioning to Adulthood (Youth) Community Living & Recreation Financial Legal & Advocacy Early Childhood & School Aged

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** TransCen, Inc.

**Agency Description:** TransCen, Inc., is a non-profit organization dedicated to improving education and employment success of youth and young adults with disabilities. TransCen's webinar trainings translate research and effective practices into useable, practical information. Our webinars assist vocational rehabilitation staff, policymakers, researchers, individuals with disabilities and their families, educators, practitioners, service providers, and employers.

**Phone Number:** (301) 424-2002

**Email Address:** [inquiries@transcen.org](mailto:inquiries@transcen.org)

**Website:** <http://www.transcen.org/>

**Counties Served:** State-Wide

**Content Categories:** Transitioning to Adulthood (Youth) Accessibility & Assistive Technology Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Spina Bifida Speech or Language Disorder Blindness or Problems with Seeing Tourette Syndrome (TS) Substance Use Disorder

# National Suicide Prevention Lifeline



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** National Suicide Prevention Lifeline

**Agency Description:** The Lifeline provides 24/7, free and confidential support for people in distress, prevention and crisis resources for you or your loved ones, and best practices for professionals. The National Suicide Prevention Lifeline has a Spanish Language line at 1-888-628-9454. We also provide the Tele-Interpreters service to our crisis centers, which supports over 150 languages.

**Phone Number:** 988

**Email Address:**

**Website:** <http://suicidepreventionlifeline.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Family & Supports Information & Referral Transitioning to Adulthood (Youth) Medical Dental & Behavioral Health Early Childhood & School Aged LGBTQIA+ Resources Government Agency Disaster/Emergency Preparedness

**Conditions Covered:** Anxiety Behavioral / Conduct Problem Depression Other Mental Health Condition Substance Use Disorder

# Active Minds



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Active Minds

**Agency Description:** We are dedicated to saving lives and to building stronger families and communities. Through education, research, advocacy, and a focus on young adults ages 14–25, Active Minds is opening up the conversation about mental health and creating lasting change in the way mental health is talked about, cared for, and valued in the United States.

**Phone Number:** (202) 332-9595

**Email Address:** info@activeminds.org

**Website:** <http://www.activeminds.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Information & Referral, Transitioning to Adulthood (Youth), Community Living & Recreation, Financial Legal & Advocacy, Medical Dental & Behavioral Health, LGBTQIA+ Resources, Early Childhood & School Aged

**Conditions Covered:** Anxiety, Behavioral / Conduct Problem, Depression, Other Mental Health Condition, Brain Injury, Concussion, or Head Injury, Substance Use Disorder

# The Trevor Project



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** The Trevor Project

**Agency Description:** The Trevor Project provides crisis intervention and suicide prevention services to lesbian, gay, bisexual, transgender, queer & questioning youth. If you are thinking about suicide or are feeling alone and need someone to talk to, please call the Trevor Lifeline at 1-866-488-7386 for immediate help. It's free, confidential, and available 24/7.

**Phone Number:** (212) 695-8650

**Email Address:** [info@thetrevorproject.org](mailto:info@thetrevorproject.org)

**Website:** <http://www.thetrevorproject.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Family & Supports Information & Referral Financial Legal & Advocacy  
Community Living & Recreation Medical Dental & Behavioral Health LGBTQIA+ Resources Crisis Resources

**Conditions Covered:** Anxiety Behavioral / Conduct Problem Depression Other Mental Health Condition Substance Use Disorder

# Ditch the Label



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Ditch the Label

**Agency Description:** Ditch the Label is a leading global youth charity helping young people aged 12-25 through some of the issues affecting them the most. Bullying, mental health, relationships, identity – whatever the issue, were there.

**Phone Number:** (323) 922-3741

**Email Address:** Hello@DitchtheLabel.org

**Website:** <http://www.ditchthelabel.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Community Living & Recreation Medical Dental & Behavioral Health  
Transitioning to Adulthood (Youth) Financial Legal & Advocacy LGBTQIA+ Resources

**Conditions Covered:** Anxiety Depression Other Mental Health Condition Substance Use Disorder

# Inclusive Recreation Resource Center (IRRC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Inclusive Recreation Resource Center (IRRC)

**Agency Description:** The mission of the Inclusive Recreation Resource Center (IRRC) is to promote and sustain participation by people of all abilities in inclusive recreation activities and resources. We have a searchable database on how inclusive and accessible recreation resources are, to help people with disabilities better plan their recreation.

**Phone Number:**

**Email Address:**

**Website:** <http://inclusiverec.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Accessibility & Assistive Technology Transitioning to Adulthood (Youth) Family & Supports

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Disability and Sexuality Access Network (DASANetwork)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Disability and Sexuality Access Network (DASANetwork)

**Agency Description:** The Disability and Sexuality Access Network (DASANetwork) is a community of disabled peers, researchers, practitioners, activists, allies, students, artists, and others who believe that access to sexuality, pleasure, and intimacy is a fundamental human right.

**Phone Number:**

**Email Address:** [info@dasanetwork..org](mailto:info@dasanetwork..org)

**Website:** <http://dasanetwork.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Little People of America (LPA)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Little People of America (LPA)

**Agency Description:** LPA is dedicated to improving the quality of life for people with dwarfism throughout their lives while celebrating with great pride Little People's contribution to social diversity. District 2 includes New York.

**Phone Number:** (714) 368-3689

**Email Address:** [director@lpadistrict2.org](mailto:director@lpadistrict2.org)

**Website:** <http://www.lpaonline.org/district-2-nj-ny-pa>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Family & Supports Financial Legal & Advocacy Information & Referral  
Transitioning to Adulthood (Youth)

**Conditions Covered:** Genetic or Inherited Condition Other

# American Academy of Developmental Medicine & Dentistry (AADMD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

<b>Agency</b>	American Academy of Developmental Medicine & Dentistry (AADMD)
<b>Agency Description:</b>	To provide a forum for healthcare professionals who provide clinical care to people with intellectual & developmental disabilities (IDD) and improve the quality of healthcare for individuals with IDD.
<b>Phone Number:</b>	(845) 204- 8004
<b>Email Address:</b>	
<b>Website:</b>	<a href="http://www.aadmd.org/">http://www.aadmd.org/</a>
<b>Counties Served:</b>	State-Wide
<b>Content Categories:</b>	Medical Dental & Behavioral Health Information & Referral
<b>Conditions Covered:</b>	Developmental Delay Intellectual Disability

# Global Healthy Living Foundation (GHLF)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Global Healthy Living Foundation (GHLF)

**Agency Description:** The Global Healthy Living Foundation (GHLF) is a non-profit organization with the mission to improve the quality of life for people living with chronic illness. GHLF advocates for improved access to care at the community level, amplifying education and awareness efforts within its social media framework.

**Phone Number:** (845) 348-0400

**Email Address:** [info@ghlf.org](mailto:info@ghlf.org)

**Website:** <http://www.ghlf.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Financial Legal & Advocacy Family & Supports

**Conditions Covered:** Arthritis Asthma Blood Disorders Cystic Fibrosis (CF) Diabetes Migraines Genetic or Inherited Condition Other

# Help Me Grow New York



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Help Me Grow New York

**Agency Description:** Help Me Grow New York ensures that all children have the best possible start in life by connecting them to resources that help them reach their full potential. We offer families, caregivers, and community providers tools and connect them with information, programs, and services. "Help Me Grow exists in Western New York, Rochester, Onondaga County, and Long Island. For contact information for each respective program, visit [www.helpmegrowny.org](http://www.helpmegrowny.org)

**Phone Number:** 2-1-1

**Email Address:** [support@childrensinstitute.com](mailto:support@childrensinstitute.com)

**Website:** <http://helpmegrowny.org/about-us/contact-us/>

**Counties Served:** Allegany County, Cattaraugus County, Chautauqua County, Erie County, Genesee County, Niagara County, Orleans County, Wyoming County, Nassau County, Suffolk County, Onondaga County, Monroe County, Livingston County, Ontario County, Seneca County, Wayne County, Yates County, Chemung County, Steuben County, Cayuga County

**Content Categories:** Information & Referral, Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Developmental Delay, Genetic or Inherited Condition, Deafness or Problems with Hearing, Intellectual Disability, Learning Difficulty, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Tourette Syndrome (TS), Blindness or Problems with Seeing

# Kessler Foundation



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Kessler Foundation

**Agency Description:** The mission of Kessler Foundation is to improve quality of life for people with disabilities through discovery, innovation, demonstration, application, and dissemination. Kessler Foundation leads the way in linking science and grantsmanship so that people living with disabilities can lead more productive, independent, and fulfilling lives.

**Phone Number:** (973) 324-8362

**Email Address:** [info@kesslerfoundation.org](mailto:info@kesslerfoundation.org)

**Website:** <http://kesslerfoundation.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral Transitioning to Adulthood (Youth)

**Conditions Covered:** Cerebral Palsy (CP) Brain Injury, Concussion, or Head Injury Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Other

# Described and Captioned Media Program (DCMP)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Described and Captioned Media Program (DCMP)

**Agency Description:** We're here to educate students with sensory disabilities, along with their parents and teachers. Our educational content is carefully customized to serve the needs of K-12 students, as well as adult students studying to meet the needs of blind and deaf students. DCMP has thousands of videos that are accessible and there are no charges for membership or any of DCMP's services.

**Phone Number:** (800) 237-6213

**Email Address:** [info@dcmp.org](mailto:info@dcmp.org)

**Website:** <http://dcmp.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral, Early Childhood & School Aged, Accessibility & Assistive Technology, Transitioning to Adulthood (Youth), Family & Supports, Community Living & Recreation

**Conditions Covered:** Blindness or Problems with Seeing, Deafness or Problems with Hearing

# Sickle Cell Disease Association of America, Inc. (SCDAA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Sickle Cell Disease Association of America, Inc. (SCDAA)

**Agency Description:** The mission of SCDAA is: To advocate for people affected by sickle cell conditions and empower community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure. The Queens Sickle Cell Advocacy Network, Inc. (QSCAN) and Sickle Cell/Thalassemia Patients Network (SCTPN) are member organizations in New York.

**Phone Number:**

**Email Address:** [info@sicklecelldisease.org](mailto:info@sicklecelldisease.org)

**Website:** <http://sicklecelldisease.net/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Family & Supports Care Coordination Information & Referral  
Community Living & Recreation

**Conditions Covered:** Blood Disorders

# Catholic Charities USA



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Catholic Charities USA

**Agency Description:** The mission of Catholic Charities is to provide service to people in need, to advocate for justice in social structures, and to call the entire church and other people of good will to do the same.

**Phone Number:** (703) 549-1390

**Email Address:** info@catholiccharitiesusa.org

**Website:** <http://www.catholiccharitiesusa.org/find-help/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation, Family & Supports, Financial Legal & Advocacy, Information & Referral, Disaster/Emergency Preparedness, Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing

# National Multiple Sclerosis (MS) Society



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** National Multiple Sclerosis (MS) Society

**Agency Description:** The National Multiple Sclerosis (MS) Society is a gathering place for people with MS, their family and loved ones, healthcare providers, volunteers, donors, fundraisers, advocates, community leaders and all those that seek a world free of MS. In order to change the world, we mobilize all possible human and financial resources to achieve results.

**Phone Number:** (800) 344-4867

**Email Address:**

**Website:** <https://www.nationalmssociety.org/resources/get-connected/in-your-area>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Family & Supports Financial Legal & Advocacy Community Living & Recreation

**Conditions Covered:** Other

# Big Brothers Big Sisters of America



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Big Brothers Big Sisters of America

**Agency Description:** Big Brothers Big Sisters operates under the belief that inherent in every child is incredible potential. As the nation's largest donor- and volunteer-supported mentoring network, Big Brothers Big Sisters makes meaningful, monitored matches between adult volunteers ("Bigs") and children ("Littles"), ages 5 through young adulthood in communities across the country. We develop positive relationships that have a direct and lasting effect on the lives of young people.

**Phone Number:** (813) 720-8778

**Email Address:** BBBS.Safety@praesidiuminc.com

**Website:** <http://www.bbbs.org/about-us/local-offices/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Community Living & Recreation Early Childhood & School Aged Transitioning to Adulthood (Youth)

**Conditions Covered:** Other Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Disability Horizons



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Disability Horizons

**Agency Description:** Disability Horizons magazine is an online, disability lifestyle publication that aims to give disabled people a voice. Disability Horizons publishes articles on a wide variety of topics, all to support the aim of a world where disabled people live exactly as they choose to. You can sign up for our newsletter to get all our articles directly to your inbox, along with our Ultimate Disability Survival guide.

**Phone Number:**

**Email Address:** [martyn@disabilityhorizons.com](mailto:martyn@disabilityhorizons.com)

**Website:** <http://disabilityhorizons.com>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Community Living & Recreation, Financial Legal & Advocacy, Information & Referral, Transitioning to Adulthood (Youth), Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# Assistance Dogs International, Inc. (ADI)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Assistance Dogs International, Inc. (ADI)

**Agency Description:** Assistance Dogs International, Inc. (ADI) is a worldwide coalition of not-for-profit programs that train and place Assistance Dogs.

**Phone Number:**

**Email Address:** [info@assistedogsinternational.org](mailto:info@assistedogsinternational.org)

**Website:** <http://assistedogsinternational.org>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Community Living & Recreation Transitioning to Adulthood (Youth) Family & Supports Information & Referral

**Conditions Covered:** Anxiety Attention-Deficit/Hyperactivity Disorder (ADHD) Arthritis Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Other Mental Health Condition Speech or Language Disorder Spina Bifida Tourette Syndrome (TS) Blindness or Problems with Seeing

# Caregiver Action Network (CAN)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Caregiver Action Network (CAN)

**Agency Description:** Caregiver Action Network (CAN) is the nation's leading family caregiver organization working to improve the quality of life for Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN serves a broad spectrum of family caregivers ranging from the parents of children with significant health needs to the families and friends of wounded soldiers, from a young couple dealing with a diagnosis of MS to adult children caring for parents with Alzheimer's disease.

**Phone Number:** (202) 454-3970

**Email Address:** [info@caregiveraction.org](mailto:info@caregiveraction.org)

**Website:** <http://caregiveraction.org>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Financial Legal & Advocacy, Information & Referral, Medical Dental & Behavioral Health, Transitioning to Adulthood (Youth), Family & Supports, Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# Center for Parent Information and Resources (CPIR)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Center for Parent Information and Resources (CPIR)

**Agency Description:** The Center for Parent Information and Resources (CPIR) serves as a central resource of information for parents, individuals, caregivers and other people involved in the lives of people with special needs. You can find Parents Centers in New York here: <https://www.parentcenterhub.org/find-your-center/>.

**Phone Number:** (973) 642-8100

**Email Address:**

**Website:** <http://www.parentcenterhub.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral, Transitioning to Adulthood (Youth), Family & Supports, Early Childhood & School Aged, Accessibility & Assistive Technology

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# New York State Department of Health: Children and Youth with Special Health Care Needs (CYSHCN) Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health: Children and Youth with Special Health Care Needs (CYSHCN) Program

**Agency Description:** The New York State Children and Youth with Special Health Care Needs (CYSHCN) Program seeks to improve the system of care for children with special health care needs from birth to 21 years of age and their families. The Program helps to shape public policy so families can get the best health care for their children.

**Phone Number:** (518) 474-1961

**Email Address:**

**Website:** [http://www.health.ny.gov/community/special\\_needs](http://www.health.ny.gov/community/special_needs)

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Care Coordination Community Living & Recreation Financial Legal & Advocacy Information & Referral Medical Dental & Behavioral Health Transitioning to Adulthood (Youth) Government Agency Early Childhood & School Aged Family & Supports LGBTQIA+ Resources

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# U.S. Department of Labor, Office of Disability Employment Policy



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** U.S. Department of Labor, Office of Disability Employment Policy

**Agency Description:** The federal government website for comprehensive information about disability-related programs, services, policies, laws and regulations. The site links to thousands of resources from many different federal government agencies, as well as state and local governments and nonprofit organizations across the country.

**Phone Number:** (866) 487-2365

**Email Address:**

**Website:** <https://www.dol.gov/agencies/odep>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Early Childhood & School Aged Family & Supports Disaster/Emergency Preparedness Accessibility & Assistive Technology Medical Dental & Behavioral Health Transitioning to Adulthood (Youth)

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# New York State Early Intervention Program (EIP)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** New York State Early Intervention Program (EIP)

**Agency Description:** The New York State Early Intervention Program offers a variety of therapeutic and support services to eligible infants and toddlers with disabilities and their families. To be eligible for services, children must be under 3 years of age and have a confirmed disability or established developmental delay, as defined by the State, in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and/or adaptive. Municipal/County Contacts for the Early Intervention Program can be found here:  
[https://www.health.ny.gov/community/infants\\_children/early\\_intervention/county\\_eip.htm](https://www.health.ny.gov/community/infants_children/early_intervention/county_eip.htm)

**Phone Number:** (518) 473-7016

**Email Address:** [beipub@health.ny.gov](mailto:beipub@health.ny.gov)

**Website:** [http://www.health.ny.gov/community/infants\\_children/early\\_intervention/](http://www.health.ny.gov/community/infants_children/early_intervention/)

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Care Coordination Community Living & Recreation Financial Legal & Advocacy Information & Referral Medical Dental & Behavioral Health Government Agency Early Childhood & School Aged Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Other Mental Health Condition Speech or Language Disorder Spina Bifida Blindness or Problems with Seeing Other Learning Difficulty Depression Migraines Substance Use Disorder Tourette Syndrome (TS)

# Family Caregiver Alliance (FCA)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Family Caregiver Alliance (FCA)

**Agency Description:** The Family Caregiver Alliance (FCA) has supports families and friends nationwide who care for young adult loved ones with chronic, disabling health conditions. Our Family Care Navigator helps family caregivers locate public, nonprofit, and private programs and services nearest their loved one—living at home or in a residential facility. Resources include government health and disability programs, legal resources, disease-specific organizations and more.

**Phone Number:** (800) 445-8106

**Email Address:**

**Website:** [http://www.caregiver.org/state-list-views?field\\_state\\_tid=91](http://www.caregiver.org/state-list-views?field_state_tid=91)

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Care Coordination Community Living & Recreation Financial Legal & Advocacy Information & Referral Medical Dental & Behavioral Health Transitioning to Adulthood (Youth) Family & Supports Early Childhood & School Aged LGBTQIA+ Resources

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Family Voices



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Family Voices

**Agency Description:** Family Voices is a national family-led organization of families and friends of children and youth with special health care needs (CYSHCN) and disabilities. We connect a network of family organizations across the United States that provide support to families of CYSHCN. We promote partnership with families at all levels of health care—individual and policy decision-making levels—in order to improve health care services and policies for children.

**Phone Number:** (888) 835-5669

**Email Address:** [mcyr@familyvoices.org](mailto:mcyr@familyvoices.org)

**Website:** <http://familyvoices.org>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Care Coordination Community Living & Recreation Financial Legal & Advocacy Information & Referral Medical Dental & Behavioral Health Transitioning to Adulthood (Youth) Early Childhood & School Aged Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Got Transition



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Got Transition

**Agency Description:** Got Transition aims to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

**Phone Number:** (202) 769-0486

**Email Address:** info@GotTransition.org

**Website:** http://www.gottransition.org

**Counties Served:** State-Wide

**Content Categories:** Transitioning to Adulthood (Youth) Care Coordination

- Conditions Covered:**
- Attention-Deficit/Hyperactivity Disorder (ADHD)
  - Allergies
  - Anxiety
  - Arthritis
  - Autism Spectrum Disorder (ASD)
  - Asthma
  - Behavioral / Conduct Problem
  - Blood Disorders
  - Cerebral Palsy (CP)
  - Cystic Fibrosis (CF)
  - Depression
  - Developmental Delay
  - Diabetes
  - Down Syndrome
  - Epilepsy / Seizure Disorder
  - Genetic or Inherited Condition
  - Brain Injury, Concussion, or Head Injury
  - Deafness or Problems with Hearing
  - Heart Condition
  - Intellectual Disability
  - Migraines
  - Other Mental Health Condition
  - Speech or Language Disorder
  - Spina Bifida
  - Substance Use Disorder
  - Tourette Syndrome (TS)
  - Blindness or Problems with Seeing
  - Other
  - Learning Difficulty

# Learning Disabilities Association of America (LDA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Learning Disabilities Association of America (LDA)

**Agency Description:** LDA's mission is to create opportunities for success for all individuals affected by learning disabilities through support, education, and advocacy. We provide support to people with learning disabilities, their parents, teachers and other professionals with cutting edge information on learning disabilities, practical solutions, and a comprehensive network of resources.

**Phone Number:** (412) 341-1515

**Email Address:** [info@LDAAmerica.org](mailto:info@LDAAmerica.org)

**Website:** <http://www.ldaamerica.org>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged, Family & Supports, Information & Referral, Financial Legal & Advocacy, Disaster/Emergency Preparedness, Transitioning to Adulthood (Youth)

**Conditions Covered:** Learning Difficulty, Attention-Deficit/Hyperactivity Disorder (ADHD), Other

# National Center for Learning Disabilities (NCLD)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** National Center for Learning Disabilities (NCLD)

**Agency Description:** NCLD works every day to make meaningful change for individuals with learning and attention issues. Our work includes advocacy, research, scholarship and awards, and young adult initiatives.

**Phone Number:** (301) 966-2234

**Email Address:** [info@nclد.org](mailto:info@nclد.org)

**Website:** <http://www.nclد.org>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Transitioning to Adulthood (Youth) Early Childhood & School Aged  
Community Living & Recreation Family & Supports Information & Referral Accessibility & Assistive Technology

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Learning Difficulty

# NYS Multiple Systems Navigator



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** NYS Multiple Systems Navigator

**Agency Description:** The primary goal of the Navigating Multiple Systems initiative is to provide easily accessible resources, service information and tools to assist youth, parents, family members/caregivers, and front-line staff currently struggling to effectively and efficiently navigate multiple human service systems – creating a web-based, 'one-stop-shop' for user-friendly, accurate and up-to-date disability information and tools.

**Phone Number:**

**Email Address:** [msnavigator@ccf.ny.gov](mailto:msnavigator@ccf.ny.gov)

**Website:** <http://www.msnavigator.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# New York State Office of Children and Family Services (OCFS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Office of Children and Family Services (OCFS)

**Agency Description:** The Office of Children and Family Services (OCFS) serves New York's public by promoting the safety, permanency and well-being of our children, families and communities. OCFS offers numerous services in a wide variety of programs, including child care and child welfare, prevention, residential programs for youth, and services for adolescents, older adults, and New Yorkers who are legally blind. OCFS has regional offices and Local Departments of Social Services.

**Phone Number:** (518) 473-7793

**Email Address:** [info@ocfs.ny.gov](mailto:info@ocfs.ny.gov)

**Website:** <http://ocfs.ny.gov/main/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Care Coordination Community Living & Recreation Financial Legal & Advocacy Information & Referral Medical Dental & Behavioral Health Transitioning to Adulthood (Youth) Government Agency Family & Supports LGBTQIA+ Resources Disaster/Emergency Preparedness

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# New York State Office of Mental Health (OMH): Program Directory



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Office of Mental Health (OMH): Program Directory

**Agency Description:** The New York State Office of Mental Health (OMH) program directory allows you to search for mental health programs by county, program category or subcategory; view program details including program name, address and phone number; and, click on any county on the map to view all of the programs in that county.

**Phone Number:** 988

**Email Address:**

**Website:** <http://my.omh.ny.gov/bi/pd/saw.dll?PortalPages>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Crisis Resources Family & Supports Medical Dental & Behavioral Health

**Conditions Covered:** Anxiety Depression Other Mental Health Condition Substance Use Disorder

# RespectAbility



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency**      RespectAbility

**Agency Description:**      RespectAbility works collaboratively with employers, entertainment leaders, governors, policy makers, educators, self-advocates, non-profits, faith-based organizations, philanthropists and the media to fight stigmas and advance opportunities.

**Phone Number:**      (202) 517-6272

**Email Address:**      info@respectability.org

**Website:**      <http://www.respectability.org>

**Counties Served:**      State-Wide

**Content Categories:**      Financial Legal & Advocacy      LGBTQIA+ Resources

**Conditions Covered:**

- Attention-Deficit/Hyperactivity Disorder (ADHD)
- Allergies
- Anxiety
- Arthritis
- Autism Spectrum Disorder (ASD)
- Asthma
- Behavioral / Conduct Problem
- Blood Disorders
- Cerebral Palsy (CP)
- Cystic Fibrosis (CF)
- Depression
- Developmental Delay
- Diabetes
- Down Syndrome
- Epilepsy / Seizure Disorder
- Genetic or Inherited Condition
- Brain Injury, Concussion, or Head Injury
- Deafness or Problems with Hearing
- Heart Condition
- Intellectual Disability
- Migraines
- Other Mental Health Condition
- Speech or Language Disorder
- Spina Bifida
- Substance Use Disorder
- Tourette Syndrome (TS)
- Blindness or Problems with Seeing
- Other
- Learning Difficulty

# Association of Maternal & Child Health Programs (AMCHP)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Association of Maternal & Child Health Programs (AMCHP)

**Agency Description:** SPHARC is a comprehensive, national web-based resource center intended to provide ongoing technical assistance and facilitate cross-state learning to increase the capacity of states, particularly Title V programs, in developing and implementing systems of care for children and youth with autism spectrum disorders and other developmental disabilities (ASD/DD). SPHARC can support families in locating resources and making connections at the state or national level. SPHARC Resource Search: <http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc/resources/Pages/default.aspx>

**Phone Number:** (202) 775-0436

**Email Address:**

**Website:** <http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc/Pages/defa>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral Family & Supports Transitioning to Adulthood (Youth) Early Childhood & School Aged LGBTQIA+ Resources Medical Dental & Behavioral Health

**Conditions Covered:** Autism Spectrum Disorder (ASD) Developmental Delay Intellectual Disability Learning Difficulty Speech or Language Disorder

# Council for Exceptional Children (CEC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Council for Exceptional Children (CEC)

**Agency Description:** The Council for Exceptional Children (CEC) advocates for appropriate governmental policies and is known as THE source for information, resources, and professional development for special educators. CEC has local Units in all 50 states and Canada, as well as 18 optional Special Interest Divisions focused on a specific topic, specialty area, role, or exceptionality. We also have CEC Student Chapters at hundreds of colleges and universities.

**Phone Number:** (888) 232-7733

**Email Address:** [service@exceptionalchildren.org](mailto:service@exceptionalchildren.org)

**Website:** <http://www.cec.sped.org>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral Transitioning to Adulthood (Youth)

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Federation for Children with Special Needs (FCSN)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Federation for Children with Special Needs (FCSN)

**Agency Description:** The Federation for Children with Special Needs (FCSN) provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities.

**Phone Number:** (617) 236-7210

**Email Address:** [info@fcsn.org](mailto:info@fcsn.org)

**Website:** <http://fcsn.org>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Community Living & Recreation Family & Supports Financial Legal & Advocacy  
LGBTQIA+ Resources

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma  
Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression  
Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition  
Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability  
Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder  
Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Through the Looking Glass (TLG)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Through the Looking Glass (TLG)

**Agency Description:** Through the Looking Glass (TLG) is a nationally recognized center that has pioneered research, training, and services for families in which a child, parent or grandparent has a disability or medical issue.

**Phone Number:** (510) 848-1112

**Email Address:** [tlg@lookingglass.org](mailto:tlg@lookingglass.org)

**Website:** <http://www.lookingglass.org>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Financial Legal & Advocacy, Information & Referral, Medical Dental & Behavioral Health, Transitioning to Adulthood (Youth), Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# The M.O.R.G.A.N. Project



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** The M.O.R.G.A.N. Project

**Agency Description:** The M.O.R.G.A.N. Project is a national, community-based organization of volunteers dedicated to promoting awareness and facilitating support of parents caring for their children/young adults with special health care needs, thereby enhancing the Quality-of-Life for these special families.

**Phone Number:** (321) 506-2707

**Email Address:** [info@themorganproject.org](mailto:info@themorganproject.org)

**Website:** <http://themorganproject.org>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# New York State Justice Center for the Protection of People With Special Needs: Technology Related Assistance for Individuals



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Justice Center for the Protection of People With Special Needs: Technology Related Assistance for Individuals with Disabilities (TRAID) Program

**Agency Description:** The TRAID Program supports a system that responds to the individual needs of people with disabilities who need assistive technology. The TRAID Program helps people learn about, obtain, and be able to use assistive technology services and devices which meet their needs.

**Phone Number:** (800) 624-4143

**Email Address:**

**Website:** <http://www.justicecenter.ny.gov/traid-program>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Information & Referral Financial Legal & Advocacy Family & Supports Government Agency

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Understanding Our Differences (UOD)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Understanding Our Differences (UOD)

**Agency Description:** Understanding Our Differences (UOD) uses a hands-on, participatory curriculum to foster respect, acceptance, and inclusion for people of all abilities in elementary schools and communities at large.

**Phone Number:** (617) 795-0374

**Email Address:** [info@UnderstandingOurDifferences.org](mailto:info@UnderstandingOurDifferences.org)

**Website:** <http://understandingourdifferences.org>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Financial Legal & Advocacy Information & Referral Transitioning to Adulthood (Youth) Family & Supports Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# New York State Department of Health, Wadsworth Center: Specialty Care Centers



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

<b>Agency</b>	New York State Department of Health, Wadsworth Center: Specialty Care Centers
<b>Agency Description:</b>	Lists specialty care centers for Inherited Metabolic Disorder, Severe Combined Immunodeficiency, Cystic Fibrosis, Endocrine Disorder, Hemoglobinopathy, Neuromuscular issues. Health care providers at these specialized care centers are experienced in treating infants with one or a group of the disorders detected by NYS newborn screening.
<b>Phone Number:</b>	(518) 473-7552
<b>Email Address:</b>	nbsinfo@health.ny.gov
<b>Website:</b>	<a href="http://www.wadsworth.org/programs/newborn/screening/specialty-care-">http://www.wadsworth.org/programs/newborn/screening/specialty-care-</a>
<b>Counties Served:</b>	State-Wide
<b>Content Categories:</b>	Medical Dental & Behavioral Health Information & Referral
<b>Conditions Covered:</b>	Genetic or Inherited Condition Allergies Cystic Fibrosis (CF) Diabetes Blood Disorders Other

# GiGi's Playhouse



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** GiGi's Playhouse

**Agency Description:** We change lives through consistent delivery of free educational, therapeutic-based and career development programs for individuals with Down syndrome, their families and the community, through a replicable playhouse model. GiGi's Playhouse is the ONLY network of Down Syndrome Achievement Centers.

**Phone Number:** (847) 885-6149

**Email Address:** info@gigisplayhouse.org

**Website:** <http://www.gigisplayhouse.org>

**Counties Served:** Cayuga County, Cortland County, Jefferson County, Lewis County, Madison County, Oneida County, Onondaga County, Oswego County, Erie County, Yates County, Monroe County, Westchester County, Suffolk County, Bronx County, Nassau County, New York County

**Content Categories:** Community Living & Recreation, Family & Supports, Early Childhood & School Aged, Medical Dental & Behavioral Health

**Conditions Covered:** Down Syndrome

# American Diabetes Association: Upstate New York



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** American Diabetes Association: Upstate New York

**Agency Description:** We fund research to prevent, cure and manage diabetes. We deliver services to hundreds of communities. We provide objective and credible information. We give a voice to those denied their rights because of diabetes.  
Offers literature for patient and professional education. Provides on-line and call enter support for newly diagnosed diabetes patients. Residential camp program for children living with Type 1 diabetes - camp scholarships available based on need. Eligibility: Individuals with diabetes and their families.

**Phone Number:** (800) 676-4065

**Email Address:** [adaupstateny@diabetes.org](mailto:adaupstateny@diabetes.org)

**Website:** <http://www.diabetes.org/community/local-offices>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral, Community Living & Recreation, Financial Legal & Advocacy, Medical Dental & Behavioral Health, Family & Supports, Disaster/Emergency Preparedness

**Conditions Covered:** Diabetes

# Feeding Tube Awareness Foundation



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Feeding Tube Awareness Foundation

**Agency Description:** Feeding Tube Awareness was founded in 2010 to support parents of children who are tube-fed, while raising positive awareness of tube feeding as a lifesaving medical intervention. Our mission is twofold. First, we would like to help other parents by sharing practical experience tube-feeding infants and children. Second, we would like to raise positive awareness of tube feeding so that families have the support they need.

**Phone Number:**

**Email Address:** [info@feedingtubeawareness.org](mailto:info@feedingtubeawareness.org)

**Website:** <http://www.feedingtubeawareness.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Family & Supports Financial Legal & Advocacy Information & Referral  
Community Living & Recreation Early Childhood & School Aged

**Conditions Covered:** Autism Spectrum Disorder (ASD) Genetic or Inherited Condition Cerebral Palsy (CP) Other Cystic Fibrosis (CF)  
Heart Condition Diabetes Brain Injury, Concussion, or Head Injury Spina Bifida Blood Disorders

# Okayso: Expert Advice



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Okayso: Expert Advice

**Agency Description:** When you're having a personal problem, you need advice from real people you can trust. okayso is an app that gives you access to experts you can't reach any other way to get support and information whenever you need it. From sex and dating to identity and more, we're here for you. The app is free and you can communicate anonymously.

**Phone Number:**

**Email Address:**

**Website:** <http://okayso.co/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Information & Referral Transitioning to Adulthood (Youth) Community Living & Recreation Family & Supports

**Conditions Covered:** Anxiety Other Mental Health Condition Depression

# Board of Cooperative Educational Services (BOCES) of New York State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Board of Cooperative Educational Services (BOCES) of New York State

**Agency Description:** The New York State legislature created Boards of Cooperative Educational Services (BOCES) to provide shared educational programs and services to school districts within the state. Today there are 37 BOCES that are partnering with nearly all of the state's school districts to help meet students' evolving educational needs through cost-effective and relevant programs. Many BOCES programs are instructional and include, but are not limited to, services for students with disabilities.

**Phone Number:** (518) 464-3963

**Email Address:** [bocesofnys@neric.org](mailto:bocesofnys@neric.org)

**Website:** <http://www.boces.org/contact-a-boces/>

**Counties Served:** Albany County Allegany County Broome County Cattaraugus County Cayuga County Chautauqua County Chemung County Chenango County Clinton County Columbia County Cortland County Delaware County Dutchess County Erie County Essex County Franklin County Fulton County Genesee County Greene County Hamilton County Herkimer County Jefferson County Lewis County Livingston County Madison County

**Content Categories:** Care Coordination Family & Supports Early Childhood & School Aged Financial Legal & Advocacy Information & Referral Transitioning to Adulthood (Youth)

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Council of Parent Attorneys and Advocates, Inc. (COPAA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Council of Parent Attorneys and Advocates, Inc. (COPAA)

**Agency Description:** The Council of Parent Attorneys and Advocates, Inc. (COPAA) is an independent, nonprofit, organization of attorneys, advocates, parents and related professionals. COPAA focuses on the rights of children who receive special education services and supports, and who are eligible to be served under the Individuals with Disabilities Education Act (IDEA) and other statutes. Parents who are looking to find a special education attorney, a special education advocate, or a related professional may look up referrals in the COPAA Member Directory.

**Phone Number:** (844) 426-7224

**Email Address:** [exec@copaa.org](mailto:exec@copaa.org)

**Website:** <http://www.copaa.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Wrightslaw

**Agency Description:** Parents, educators, advocates, and attorneys use Wrightslaw for reliable information about special education law and advocacy for children with disabilities.

**Phone Number:**

**Email Address:** [webmaster@wrightslaw.com](mailto:webmaster@wrightslaw.com)

**Website:** <http://www.wrightslaw.com/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# endABUSE of People with Disabilities



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** endABUSE of People with Disabilities

**Agency Description:** endAbuse of People with Disabilities is a website that provides a repository of accurate and reliable resources about the abuse of people with disabilities. Users can access multi-media content that offers information about the forms of abuse, targets of abuse, peer-to-peer support, and advocacy. Additionally, those in need have the ability to get immediate assistance from the "Get Help Now" section which includes a "quick escape" browsing option.

**Phone Number:** (855) 274-8222

**Email Address:** endabusepwd@activatingchange.org

**Website:** <http://www.endabusepwd.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Care Coordination Community Living & Recreation Financial Legal & Advocacy Information & Referral Medical Dental & Behavioral Health Transitioning to Adulthood (Youth) Family & Supports Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Families Together in New York State (FTNYS)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Families Together in New York State (FTNYS)

**Agency Description:** Families Together in New York State is a family-run organization that represents families of children with social, emotional, behavioral and cross-systems challenges. We represent thousands of families from across the state whose children have been involved in many systems including mental health, substance abuse, special education, juvenile justice, and foster care.

**Phone Number:** (518) 432-0333

**Email Address:** [info@ftnys.org](mailto:info@ftnys.org)

**Website:** <http://www.ftnys.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Financial Legal & Advocacy Information & Referral Medical Dental & Behavioral Health  
Transitioning to Adulthood (Youth) Early Childhood & School Aged Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma  
Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression  
Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition  
Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability  
Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder  
Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Living Resources

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Living Resources

**Agency Description:** Living Resources is dedicated to providing life enhancing services to individuals challenged by intellectual and developmental disabilities, as well as those who are brain injury survivors. We offer a safe and nurturing environment that allows individuals to meet and exceed their personal goals.

**Phone Number:** (518) 218-0000

**Email Address:**

**Website:** <http://www.livingresources.org>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Medical Dental & Behavioral Health

**Conditions Covered:** Brain Injury, Concussion, or Head Injury Intellectual Disability Developmental Delay Learning Difficulty Cerebral Palsy (CP) Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Down Syndrome Tourette Syndrome (TS) Genetic or Inherited Condition

# Mental Health Association of New York State (MHANYS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Mental Health Association of New York State (MHANYS)

**Agency Description:** MHANYS is a not-for-profit organization that works to end the stigma against mental illness and promotes mental health wellness in New York State. MHANYS achieves this through training, education, advocacy and policy, community-based partnership programming, and by connecting individuals and families to help.

**Phone Number:** (518) 434-0439

**Email Address:** [info@mhany.org](mailto:info@mhany.org)

**Website:** <http://mhany.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Financial Legal & Advocacy, Information & Referral, Medical Dental & Behavioral Health, Transitioning to Adulthood (Youth), Early Childhood & School Aged, Family & Supports

**Conditions Covered:** Depression, Anxiety, Other Mental Health Condition

# NY Connects



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** NY Connects

**Agency Description:** NY Connects provides information and assistance related to long-term services and supports in New York State for people of all ages or with any type of disability. NY Connects uses a searchable directory for programs, providers, and services in your area. NY Connects staff can help link you to long-term services and supports, such as home care, transportation and meals.

**Phone Number:** (800) 342-9871

**Email Address:**

**Website:** <http://www.nyconnects.ny.gov/contact-us>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Government Agency

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other

# New York State Independent Living Council (NYSILC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Independent Living Council (NYSILC)

**Agency Description:** The mission of the New York State Independent Living Council, Inc. (NYSILC) is to promote independent living for people with disabilities across New York State, in partnership with the network of community-based Centers for Independent Living (CILs). Independent Living is a peer-based model run and supported by people with disabilities, with the goal of ensuring access to the services needed to improve quality of life in the community. A CIL directory can be found on the website.

**Phone Number:** (518) 427-1060

**Email Address:**

**Website:** <http://nysilc.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Financial Legal & Advocacy Information & Referral Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Understood



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Understood

**Agency Description:** Understood has programs for families, educators, and young adults that focus on empowering people who learn and think differently and those who support them. We offer customized, accessible resources and a compassionate community. Our Workplace program helps organizations across industries create inclusive workplaces..

**Phone Number:** (646) 757-3100

**Email Address:** support@understood.org

**Website:** <http://www.understood.org/about>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Community Living & Recreation, Financial Legal & Advocacy, Information & Referral, Transitioning to Adulthood (Youth), Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Anxiety, Arthritis, Autism Spectrum Disorder (ASD), Asthma, Behavioral / Conduct Problem, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other, Learning Difficulty

# Ride Livingston

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Ride Livingston

**Agency Description:** Our goal is to match the transportation needs of Livingston County residents with rides that work for them.

**Phone Number:**

**Email Address:**

**Website:** <http://www.ridelivingston.com/>

**Counties Served:** Livingston County

**Content Categories:** Accessibility & Assistive Technology Family & Supports

**Conditions Covered:** Cerebral Palsy (CP) Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Blood Disorders Behavioral / Conduct Problem Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Clarity Wellness Community



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Clarity Wellness Community

**Agency Description:** Clarity Wellness Community empowers people with care, connections and support for a lifetime of choice. Our vision is a supportive community where all people lead the lives they choose. We provide clinic services, community-based services, and recovery-oriented services for children, adolescents, and adults.

**Phone Number:** (585) 593-6300

**Email Address:** [info@goclarity.org](mailto:info@goclarity.org)

**Website:** <http://www.claritywellnesscommunity.org/>

**Counties Served:** [Allegany County](#) [Wyoming County](#)

**Content Categories:** [Family & Supports](#) [Medical Dental & Behavioral Health](#) [Community Living & Recreation](#)  
[Transitioning to Adulthood \(Youth\)](#)

**Conditions Covered:** [Behavioral / Conduct Problem](#) [Substance Use Disorder](#) [Depression](#) [Other Mental Health Condition](#)

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Pathways, Inc.

**Agency Description:** Pathways, Inc. serves individuals and families across the Finger Lakes, Southern Tier, and Rochester areas of New York by providing an array of services through our core programs. Core programs include: Children and Family Services, Community and Habilitation Services, Educational and Contracted Services and Residential Services.

**Phone Number:** (607) 937-3200

**Email Address:** [info@pathwaysforyou.org](mailto:info@pathwaysforyou.org)

**Website:** <http://www.pathwaysforyou.org/>

**Counties Served:** Allegany County Livingston County Monroe County Ontario County Schuyler County Seneca County Steuben County Tioga County Tompkins County Wayne County Wyoming County Yates County Chemung County Erie County Broome County

**Content Categories:** Care Coordination Early Childhood & School Aged Family & Supports Information & Referral Transitioning to Adulthood (Youth) Medical Dental & Behavioral Health

**Conditions Covered:** Developmental Delay Intellectual Disability Autism Spectrum Disorder (ASD) Down Syndrome Cerebral Palsy (CP) Spina Bifida Brain Injury, Concussion, or Head Injury Substance Use Disorder Anxiety Depression Other Mental Health Condition

# Brian Bisgrove Home of Courage



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Brian Bisgrove Home of Courage

**Agency Description:** Offers a three-day respite home for families with children who have life-threatening or severely debilitating medical conditions. Eligibility: Children from birth through 18 years who have a medical diagnosis of cancer or life-altering illness.

**Phone Number:** (315) 252-9305

**Email Address:** Brianshome453@championsforlife.org

**Website:** <http://www.homeofcourage.com/about-us/>

**Counties Served:** Cayuga County, Erie County, Herkimer County, Jefferson County, Lewis County, Monroe County

**Content Categories:** Family & Supports

**Conditions Covered:** Cerebral Palsy (CP), Down Syndrome, Behavioral / Conduct Problem, Intellectual Disability, Other

# Family Counseling Service of the Finger Lakes (FCSFL)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Family Counseling Service of the Finger Lakes (FCSFL)

**Agency Description:** Provides professional counseling and support services to individuals, children and families to improve the quality of their life at home and in the community. Today, FCSFL has multiple programs including Domestic Violence, Child Sexual Abuse Assessment and Treatment, Trauma Therapy and General Counseling, LGBTQ (lesbian, gay, transgender, queer/questioning) Support and Advocacy, Employee Assistance, Hispanic Bilingual Family Services and Domestic Violence Accountability.

**Phone Number:** (315) 789-2613

**Email Address:** [familycounseling@fcsfl.org](mailto:familycounseling@fcsfl.org)

**Website:** <http://www.fcsfl.org>

**Counties Served:** [Ontario County](#) [Yates County](#) [Wayne County](#) [Seneca County](#)

**Content Categories:** [Family & Supports](#) [Care Coordination](#) [Information & Referral](#) [Medical Dental & Behavioral Health](#)

**Conditions Covered:** [Behavioral / Conduct Problem](#) [Other Mental Health Condition](#) [Depression](#) [Anxiety](#)

# Unity House of Cayuga County, Inc.



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Unity House of Cayuga County, Inc.

**Agency Description:** Unity House of Cayuga County, Inc. provides transitional and permanent housing, respite care, and rehabilitative and employment services for adults with mental illness, developmental disabilities, and/or chemical dependencies from which they are recovering. Unity House is committed to freeing our communities of misconceptions associated with disabilities through innovation, education, and advocacy.

**Phone Number:** (315) 253-6227

**Email Address:**

**Website:** <http://www.unityhouse.com>

**Counties Served:** Cayuga County, Ontario County, Onondaga County, Seneca County, Tompkins County, Wayne County

**Content Categories:** Community Living & Recreation, Family & Supports, Information & Referral

**Conditions Covered:** Developmental Delay, Other Mental Health Condition, Autism Spectrum Disorder (ASD), Cerebral Palsy (CP), Down Syndrome, Intellectual Disability, Spina Bifida, Anxiety, Attention-Deficit/Hyperactivity Disorder (ADHD), Blindness or Problems with Seeing, Depression, Deafness or Problems with Hearing, Substance Use Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury

# Spina Bifida Association of Northeastern New York (SBANENY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Spina Bifida Association of Northeastern New York (SBANENY)

**Agency Description:** Spina Bifida Association of Northeastern New York (SBANENY) focuses on building a better and brighter future for all those impacted by Spina Bifida. SBANENY provides information and education, referrals, support, advocacy, systems navigation, and programming for individuals and families living with Spina Bifida.

**Phone Number:** (518) 399-9151

**Email Address:** admin@sbaneny.org

**Website:** <http://www.sbaneny.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Transitioning to Adulthood (Youth) Financial Legal & Advocacy

**Conditions Covered:** Spina Bifida

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** People Inc.

**Agency Description:** People Inc. serves Western New York and the Greater Rochester region. Through a variety of services including residential, employment, community outreach, health care and recreation programs, we help older adults, families and people with disabilities live more healthy, independent and productive lives.

**Phone Number:** (716) 817-7400

**Email Address:** [admissions@people-inc.org](mailto:admissions@people-inc.org)

**Website:** <http://www.people-inc.org>

**Counties Served:** Monroe County Livingston County Genesee County Ontario County Wayne County Orleans County Erie County

**Content Categories:** Family & Supports Community Living & Recreation Care Coordination Transitioning to Adulthood (Youth) Medical Dental & Behavioral Health

**Conditions Covered:** Other Mental Health Condition Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Down Syndrome Speech or Language Disorder Developmental Delay Intellectual Disability Deafness or Problems with Hearing Attention-Deficit/Hyperactivity Disorder (ADHD) Anxiety Arthritis Blindness or Problems with Seeing Brain Injury, Concussion, or Head Injury Depression Genetic or Inherited Condition Learning Difficulty Tourette Syndrome (TS)

# Spotted Rabbit Creative Arts Therapy



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Spotted Rabbit Creative Arts Therapy

**Agency Description:** Offers individual and small-group art and music psychotherapy services by Licensed Creative Arts Therapists. As Licensed Creative Arts Therapists we work with individuals of all abilities, including those who may be non-verbal and/or have significant physical limitations. Depending on client needs, services are offered at our studio or in the client's home.

**Phone Number:** (585) 430-9877

**Email Address:** sarah@spottedrabbitstudio.com

**Website:** <http://www.spottedrabbitstudio.com>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation Medical Dental & Behavioral Health

**Conditions Covered:** Developmental Delay Behavioral / Conduct Problem Other Mental Health Condition Intellectual Disability Depression Anxiety Autism Spectrum Disorder (ASD) Tourette Syndrome (TS) Cerebral Palsy (CP) Substance Use Disorder Cystic Fibrosis (CF) Down Syndrome Epilepsy / Seizure Disorder Attention-Deficit/Hyperactivity Disorder (ADHD) Genetic or Inherited Condition Speech or Language Disorder Spina Bifida

# Heritage Christian Services



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Heritage Christian Services

**Agency Description:** Heritage Christian Services offers residential and day programs for people with intellectual and developmental disabilities; respite; self-direction; community services; supported employment; brokers and fiscal intermediaries; Consumer Directed Personal Assistance Program (CDPAP); therapeutic riding and a health and wellness center.

**Phone Number:** (585) 340-2000

**Email Address:** [info@heritagechristianservices.org](mailto:info@heritagechristianservices.org)

**Website:** <http://www.heritagechristianservices.org>

**Counties Served:** Erie County, Monroe County, Ontario County, Wayne County, Hamilton County, Jefferson County, Yates County, Allegany County, Cattaraugus County, Chautauqua County, Wyoming County, Genesee County, Orleans County, Niagara County

**Content Categories:** Community Living & Recreation, Family & Supports, Transitioning to Adulthood (Youth), Medical Dental & Behavioral Health

**Conditions Covered:** Autism Spectrum Disorder (ASD), Cerebral Palsy (CP), Developmental Delay, Down Syndrome, Intellectual Disability, Spina Bifida, Tourette Syndrome (TS), Genetic or Inherited Condition, Epilepsy / Seizure Disorder, Cystic Fibrosis (CF)

# Holy Childhood



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Holy Childhood

**Agency Description:** Holy Childhood provides state-of-the-art programs and services setting the standard for the education, habilitation and treatment of individuals with intellectual and developmental disabilities. We prepare children and adults with intellectual and developmental disabilities for maximum independence and integration in the community through individualized programs and services

**Phone Number:** (585) 359-3710

**Email Address:**

**Website:** <http://www.holychildhood.org>

**Counties Served:** Genesee County Livingston County Monroe County Ontario County Orleans County Seneca County Steuben County Wayne County

**Content Categories:** Accessibility & Assistive Technology Community Living & Recreation Early Childhood & School Aged Family & Supports Transitioning to Adulthood (Youth)

**Conditions Covered:** Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Developmental Delay Down Syndrome Intellectual Disability Spina Bifida

# Hillside Family of Agencies



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Hillside Family of Agencies

**Agency Description:** Hillside provides child welfare, mental and physical health, youth development, juvenile justice, special education and developmental disabilities services across central and western New York.

**Phone Number:** (888) 514-4455

**Email Address:** info@hillside.com

**Website:** http://www.hillside.com/

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Early Childhood & School Aged, Family & Supports, Financial Legal & Advocacy, Information & Referral, Medical Dental & Behavioral Health, Transitioning to Adulthood (Youth)

**Conditions Covered:** Behavioral / Conduct Problem, Anxiety, Other Mental Health Condition, Substance Use Disorder, Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), Allergies, Arthritis, Asthma, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Speech or Language Disorder, Spina Bifida, Tourette Syndrome (TS), Blindness or Problems with Seeing

# Camp Good Days & Special Times



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Camp Good Days & Special Times

**Agency Description:** Camp Good Days & Special Times offers weeklong summer camping sessions, weekend adult retreats, and year round programs for families who have been touched by cancer and other life challenges. All programs are provided free of charge.

**Phone Number:** (800) 785-2135

**Email Address:** Info@CampGoodDays.org

**Website:** <http://www.campgooddays.org>

**Counties Served:** Cayuga County Chemung County Cortland County Herkimer County Jefferson County Lewis County

Madison County Oneida County Onondaga County Oswego County Schuyler County St. Lawrence County

Tioga County Tompkins County Monroe County

**Content Categories:** Family & Supports Community Living & Recreation

**Conditions Covered:** Blood Disorders Other

# Epilepsy-Pralid (EPI)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Epilepsy-Pralid (EPI)

**Agency Description:** EPI provides a comprehensive range of services funded through the New York State Office of People With Developmental Disabilities. From residential services to community and day habilitation to the growing Self-Direction Services, EPI is an expert in creating compassionate, tailored supports that help each person live the life of their choice.

**Phone Number:** (585) 442-6420

**Email Address:** [info@epiny.org](mailto:info@epiny.org)

**Website:** <http://www.epiny.org>

**Counties Served:** Cayuga County Chemung County Chenango County Cortland County Livingston County Madison County Monroe County Oneida County Onondaga County Ontario County Oswego County Schuyler County Steuben County Seneca County Tioga County Tompkins County Wayne County Wyoming County Yates County

**Content Categories:** Early Childhood & School Aged Care Coordination Family & Supports Information & Referral Community Living & Recreation Transitioning to Adulthood (Youth)

**Conditions Covered:** Developmental Delay Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Down Syndrome Intellectual Disability Epilepsy / Seizure Disorder Genetic or Inherited Condition Speech or Language Disorder Spina Bifida Tourette Syndrome (TS)

# Prime Care Coordination



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Prime Care Coordination

**Agency Description:** Provides Care Coordination serves children and adults with intellectual and developmental disabilities. Care coordination combines developmental disability services and supports with health, wellness, behavioral health and family services.

**Phone Number:** (844) 347-3168

**Email Address:** [info@primecareny.org](mailto:info@primecareny.org)

**Website:** <http://www.primecareny.org>

**Counties Served:** Cayuga County Livingston County Monroe County Ontario County Seneca County Wayne County

**Content Categories:** Care Coordination

**Conditions Covered:** Developmental Delay Autism Spectrum Disorder (ASD) Down Syndrome Intellectual Disability

# Anderson Center for Autism



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Anderson Center for Autism

**Agency Description:** Anderson Center provides education, support and outreach services, and information aimed at delivering assistance and increasing overall autism awareness. Based on the principles of Applied Behavior Analysis (ABA), our treatment approach focuses on techniques and interventions that use reinforcement to teach our individuals the skills they need to strive for independence and reach their full potential. Family Support Services offers short-term, in-home, or community services and training to families of children and adults with autism or related developmental disabilities.

**Phone Number:** (845) 889-4034

**Email Address:** admissions@andersoncares.org.

**Website:** <http://www.andersoncenterforautism.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology, Care Coordination, Community Living & Recreation, Early Childhood & School Aged, Family & Supports, Financial Legal & Advocacy, Information & Referral, Medical Dental & Behavioral Health, Transitioning to Adulthood (Youth)

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# New York State Children's Alliance, Inc. (NYSCA)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** New York State Children's Alliance, Inc. (NYSCA)

**Agency Description:** The Mission of New York State Children's Alliance, Inc. (NYSCA) is to promote the development, growth, and continuation of Child Advocacy Centers (CACs) and Multidisciplinary Teams (MDTs) throughout New York State in order to provide healing and justice to abused and neglected children, and their families. CACs are child-focused facilities that help abused children heal by coordinating the investigation and treatment of child sexual abuse and providing children and families access to long-term advocacy and healthcare.

**Phone Number:** (585) 402-8086

**Email Address:**

**Website:** <http://www.nyschildrensalliance.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral Care Coordination Family & Supports

**Conditions Covered:** Anxiety Asthma Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Attention-Deficit/Hyperactivity Disorder (ADHD) Arthritis Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Epilepsy / Seizure Disorder

# National Organization on Fetal Alcohol Syndrome (NOFAS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** National Organization on Fetal Alcohol Syndrome (NOFAS)

**Agency Description:** The National Organization on Fetal Alcohol Syndrome (NOFAS) is the leading voice and resource of the Fetal Alcohol Spectrum Disorders (FASD) community. NOFAS effectively increases public awareness and mobilizes grassroots action in diverse communities and represents the interests of persons with FASD and their caregivers as the liaison to researchers and policymakers. NOFAS strives to reduce the stigma and improve the quality of life for affected individuals and families.

**Phone Number:** (202) 785-4585

**Email Address:** [information@nofas.org](mailto:information@nofas.org)

**Website:** <http://www.nofas.org/state-resources-for-new-york>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Financial Legal & Advocacy Community Living & Recreation

**Conditions Covered:** Other Mental Health Condition Substance Use Disorder

# Arthritis Foundation



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Arthritis Foundation

**Agency Description:** The Arthritis Foundation provides resources, science, advocacy and community connections for children and youth with Juvenile idiopathic arthritis and other pediatric rheumatic diseases. Whether it's online or in person, we are all working together to promote life-changing resources and research, to push for change and to create community connections that welcome, inform and uplift.

**Phone Number:** (800) 283-7800

**Email Address:** NYC@arthritis.org

**Website:** <http://www.arthritis.org/local-offices/ny>

**Counties Served:** State-Wide

**Content Categories:** Medical Dental & Behavioral Health Early Childhood & School Aged Community Living & Recreation  
Transitioning to Adulthood (Youth) Financial Legal & Advocacy Family & Supports Information & Referral

**Conditions Covered:** Arthritis

# Cystic Fibrosis (CF) Foundation



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Cystic Fibrosis (CF) Foundation

**Agency Description:** The mission of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with CF the opportunity to lead long, fulfilling lives by funding research and drug development, partnering with the CF community, and advancing high-quality specialized care. There are multiple local CF chapters across New York State.

**Phone Number:** (800) 344-4823

**Email Address:** [info@cff.org](mailto:info@cff.org)

**Website:** <http://www.cff.org/Locations/Find-a-Local-Chapter/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Community Living & Recreation Financial Legal & Advocacy  
Medical Dental & Behavioral Health Care Coordination

**Conditions Covered:** Cystic Fibrosis (CF)

# American Lung Association



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** American Lung Association

**Agency Description:** The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through education, advocacy and research. The American Lung Association is also a medical Helpline, with medical professionals who help people with questions and information related to the lungs and lung disease. Our Lung HelpLine: 1-800-586-4872.

**Phone Number:** (800) 586-4872

**Email Address:** info@lung.org

**Website:** <http://www.lung.org/lung-health-diseases/lung-disease-lookup/asthma>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Financial Legal & Advocacy, Medical Dental & Behavioral Health, Care Coordination, Information & Referral

**Conditions Covered:** Asthma

# Asthma and Allergy Foundation of America (AAFA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Asthma and Allergy Foundation of America (AAFA)

**Agency Description:** The Asthma and Allergy Foundation of America (AAFA), a not-for-profit organization founded in 1953, is the leading patient organization for people with asthma and allergies, and the oldest asthma and allergy patient group in the world. AAFA offers many educational programs and tools, works with the government to create laws that improve and protect quality of life and, awards research grants for the study of asthma and allergies.

**Phone Number:** (800) 727-8462

**Email Address:** [info@aafa.org](mailto:info@aafa.org)

**Website:** <http://www.aafa.org/aafa-affiliated-asthma-allergy-support-groups/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Financial Legal & Advocacy Early Childhood & School Aged  
Community Living & Recreation

**Conditions Covered:** Asthma Allergies

# Autism Speaks New York State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Autism Speaks New York State

**Agency Description:** Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support, increasing understanding and acceptance of people with autism.

**Phone Number:** (888) 288-4762

**Email Address:** [help@autismspeaks.org](mailto:help@autismspeaks.org)

**Website:** <http://www.autismspeaks.org/new-york-state>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Community Living & Recreation Financial Legal & Advocacy

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# Hydrocephalus Association (HA)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Hydrocephalus Association (HA)

**Agency Description:** The Hydrocephalus Association (HA) serves as the primary nexus for research on hydrocephalus. HA works to educate national and state policymakers, the medical community, and the general population about the nature and extent of hydrocephalus, and to focus attention on the condition and the legislation/attention needed for individuals to overcome challenges.

**Phone Number:** (301) 202-3811

**Email Address:** [Info@hydroassoc.org](mailto:Info@hydroassoc.org)

**Website:** <http://www.hydroassoc.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Financial Legal & Advocacy Information & Referral Family & Supports  
Community Living & Recreation

**Conditions Covered:** Other Brain Injury, Concussion, or Head Injury

# New York State Association of Independent Schools (NYSAIS): Special Education



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

<b>Agency</b>	New York State Association of Independent Schools (NYSAIS): Special Education
<b>Agency Description:</b>	The New York State Association of Independent Schools (NYSAIS) promotes the independence, well-being and public understanding of, and respect for, New York independent schools and serves as an accrediting body chartered by the New York State Board of Regents. NYSAIS has a searchable, online directory of special education schools.
<b>Phone Number:</b>	(518) 694-5500
<b>Email Address:</b>	
<b>Website:</b>	<a href="http://www.nysais.org/page.cfm?p=923&amp;max=1000&amp;filter_data7=Yes">http://www.nysais.org/page.cfm?p=923&amp;max=1000&amp;filter_data7=Yes</a>
<b>Counties Served:</b>	State-Wide
<b>Content Categories:</b>	Information & Referral   Early Childhood & School Aged
<b>Conditions Covered:</b>	Attention-Deficit/Hyperactivity Disorder (ADHD)   Learning Difficulty   Allergies   Anxiety   Arthritis   Asthma Autism Spectrum Disorder (ASD)   Behavioral / Conduct Problem   Blood Disorders   Cerebral Palsy (CP)   Cystic Fibrosis (CF) Depression   Developmental Delay   Diabetes   Down Syndrome   Epilepsy / Seizure Disorder   Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury   Deafness or Problems with Hearing   Heart Condition   Intellectual Disability Migraines   Other   Other Mental Health Condition   Speech or Language Disorder   Spina Bifida   Substance Use Disorder Tourette Syndrome (TS)   Blindness or Problems with Seeing

# American Foundation for the Blind (AFB)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** American Foundation for the Blind (AFB)

**Agency Description:** AFB provides the following services to the blind and visually-impaired, and to organizations/individuals working with this audience Information and referral, Publications on blindness, Data collection and information dissemination, Production of recorded materials for the blind through the Talking Books Program. We conduct a wide variety of programs to support independent living, literacy, employment and access to technology. We operate a web site which offers access to an online book store, Career Connect (employment planning tool), and Braille Bug (children's web channel for literacy).

**Phone Number:** (212) 502-7600

**Email Address:** [info@aph.org](mailto:info@aph.org)

**Website:** <http://afb.org>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Blindness or Problems with Seeing

# New York Deaf-Blind Collaborative (NYDBC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York Deaf-Blind Collaborative (NYDBC)

**Agency Description:** NYDBC is a statewide project that provides technical assistance to professionals and families on behalf of children and young adults who are deaf-blind between the ages of 0–21. The project is funded by the Office of Special Education Programs (OSEP) through the CUNY Research Foundation and is housed at Queens College in Flushing, NY. Any and all interested parties in New York State can access NYDBC, free of charge, as a resource on deaf-blindness.

**Phone Number:** (718) 997-4856

**Email Address:** nydeafblind@gmail.com

**Website:** <http://nydeafblind.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Information & Referral Family & Supports Early Childhood & School Aged  
Transitioning to Adulthood (Youth)

**Conditions Covered:** Deafness or Problems with Hearing Blindness or Problems with Seeing

# Guide Dog Foundation for the Blind, Inc.



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Guide Dog Foundation for the Blind, Inc.

**Agency Description:** The Guide Dog Foundation's mission is to provide guide dogs and training – free of charge – to people who are blind or visually impaired. The Guide Dog Foundation pairs each student with the dog that's right for them – and the power of their bond makes ordinary moments extraordinary.

**Phone Number:** (631) 930-9000

**Email Address:** [info@guidedog.org](mailto:info@guidedog.org)

**Website:** <http://www.guidedog.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Accessibility & Assistive Technology Community Living & Recreation Financial Legal & Advocacy

**Conditions Covered:** Blindness or Problems with Seeing

# New York State Commission for the Blind (NYSCB)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Commission for the Blind (NYSCB)

**Agency Description:** The New York State Commission for the Blind (NYSCB) provides vocational rehabilitation and other direct services to legally blind New York State residents, including children, adults, and elderly persons.

Vocational Rehabilitation Services <https://ocfs.ny.gov/programs/nyscb/programs/transition.php>

**Phone Number:** (866) 871-3000

**Email Address:** [lauren.corp@ocfs.ny.gov](mailto:lauren.corp@ocfs.ny.gov)

**Website:** <https://ocfs.ny.gov/programs/nyscb/programs/children.php>

**Counties Served:** State-Wide Albany County Allegany County Bronx County Broome County Cattaraugus County Cayuga County Chautauqua County Chemung County Chenango County Clinton County Columbia County Cortland County Delaware County Dutchess County Erie County Essex County Franklin County Fulton County Genesee County Greene County Hamilton County Herkimer County Jefferson County Kings County Lewis County Livingston County

**Content Categories:** Family & Supports Accessibility & Assistive Technology Early Childhood & School Aged Transitioning to Adulthood (Youth) Medical Dental & Behavioral Health

**Conditions Covered:** Blindness or Problems with Seeing Deafness or Problems with Hearing

# Chai Lifeline



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Chai Lifeline

**Agency Description:** Chai Lifeline's programs and services meet the unique emotional, social and financial needs of families living with serious illness or loss. From the moment of diagnosis or trauma, Chai Lifeline's professionals and trained, compassionate volunteers step in to help restore equilibrium and bring joy and hope back into lives devastated by illness and crises. Offers respite, tutoring, camps, and transportation.

**Phone Number:** (212) 465-1300

**Email Address:** [info@chailifeline.org](mailto:info@chailifeline.org)

**Website:** <http://chailifeline.org>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Medical Dental & Behavioral Health Family & Supports  
Accessibility & Assistive Technology

**Conditions Covered:** Genetic or Inherited Condition Blood Disorders Other Brain Injury, Concussion, or Head Injury Cystic Fibrosis (CF)  
Spina Bifida Arthritis Diabetes Cerebral Palsy (CP) Epilepsy / Seizure Disorder Deafness or Problems with Hearing  
Heart Condition Asthma Allergies Attention-Deficit/Hyperactivity Disorder (ADHD) Blindness or Problems with Seeing  
Tourette Syndrome (TS) Behavioral / Conduct Problem Anxiety Autism Spectrum Disorder (ASD) Depression  
Developmental Delay Down Syndrome Intellectual Disability Learning Difficulty Other Mental Health Condition  
Migraines Speech or Language Disorder Substance Use Disorder

# New York Legal Assistance Group (NYLAG)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** New York Legal Assistance Group (NYLAG)

**Agency Description:** The New York Legal Assistance Group (NYLAG) uses the power of the law to help New Yorkers in need combat social and economic injustice. We address emerging and urgent legal needs with comprehensive, free civil legal services, impact litigation, policy advocacy, and community education.

**Phone Number:** (212) 613-5000

**Email Address:** [info@nylag.org](mailto:info@nylag.org)

**Website:** <http://www.nylag.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Developmental Delay Other Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Office for People With Developmental Disabilities (OPWDD): Front Door



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Office for People With Developmental Disabilities (OPWDD): Front Door

**Agency Description:** The Front Door is the way OPWDD connects you to the services you want and need. Once you enter, a person-centered planning process begins, which helps you learn about and access service options that take your needs and desires into consideration. There are multiple Front Door offices across New York State.

**Phone Number:** (866) 946-9733

**Email Address:** [info@opwdd.ny.gov](mailto:info@opwdd.ny.gov)

**Website:** <http://opwdd.ny.gov/contact-us#access-services-through-front-door>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Care Coordination

**Conditions Covered:** Developmental Delay Autism Spectrum Disorder (ASD) Down Syndrome Behavioral / Conduct Problem Cerebral Palsy (CP) Epilepsy / Seizure Disorder Brain Injury, Concussion, or Head Injury Attention-Deficit/Hyperactivity Disorder (ADHD) Other Mental Health Condition Genetic or Inherited Condition Learning Difficulty Intellectual Disability Blindness or Problems with Seeing Other Anxiety Cystic Fibrosis (CF) Depression Deafness or Problems with Hearing Speech or Language Disorder Spina Bifida Arthritis Asthma Allergies

# National Autism Association (NAA)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** National Autism Association (NAA)

**Agency Description:** The mission of the National Autism Association is (NAA) to respond to the most urgent needs of the autism community, providing real help and hope so that all affected can reach their full potential. NAA has New York Metro chapter, proudly serve the five boroughs of New York City, Long Island, Westchester County, and Rockland County.

**Phone Number:** (877) 622-2884

**Email Address:** [naa@nationalautism.org](mailto:naa@nationalautism.org)

**Website:** <http://nationalautismassociation.org/resources/naa-local-chapters/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Family & Supports Community Living & Recreation Early Childhood & School Aged  
Transitioning to Adulthood (Youth) Information & Referral

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# Kids Enjoy Exercise Now (KEEN)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Kids Enjoy Exercise Now (KEEN)

**Agency Description:** KEEN provides free recreational opportunities to children and young adults with disabilities by pairing them with trained volunteers for fun, non competitive activities. KEEN seeks to develop each athlete's self-esteem and confidence, as well as recreational skills and talents, and to increase each athlete's ability to participate in a broader range of recreational activities and environments.

**Phone Number:** (212) 768-6785

**Email Address:** [info@keennewyork.org](mailto:info@keennewyork.org)

**Website:** <http://www.keennewyork.org>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation

**Conditions Covered:** Developmental Delay, Autism Spectrum Disorder (ASD), Intellectual Disability, Other, Learning Difficulty, Blood Disorders, Cerebral Palsy (CP), Cystic Fibrosis (CF), Arthritis, Anxiety, Allergies, Attention-Deficit/Hyperactivity Disorder (ADHD), Asthma, Behavioral / Conduct Problem, Depression, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Brain Injury, Concussion, or Head Injury, Deafness or Problems with Hearing, Heart Condition, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing

# Creative Adaptations For Learning (CAL)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Creative Adaptations For Learning (CAL)

**Agency Description:** Creative Adaptations for Learning (CAL) creates and publishes innovative educational braille flashcards, embossed pictures, and tactile illustrations that bring raised line drawings to life. CAL creates tactile graphics for children and adults who are blind, visually impaired, or have dyslexia, autism, cognitive learning disability, or other special needs.

**Phone Number:** (516) 466-9143

**Email Address:** [calinfo@cal-s.org](mailto:calinfo@cal-s.org)

**Website:** <http://www.cal-s.org>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Accessibility & Assistive Technology Early Childhood & School Aged

**Conditions Covered:** Autism Spectrum Disorder (ASD) Intellectual Disability Learning Difficulty Attention-Deficit/Hyperactivity Disorder (ADHD) Blindness or Problems with Seeing Down Syndrome Speech or Language Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Developmental Delay

# Making Authentic Friendships (MAF)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Making Authentic Friendships (MAF)

**Agency Description:** Making Authentic Friendships' responsive web-based application helps individuals with special needs (age 13 and older) find friends at home or on the go, based off of their geolocation, diagnosis, age, and interests. It works like a game, is interactive, fun, and user friendly.

**Phone Number:** (631) 374-0518

**Email Address:**

**Website:** <http://makingauthenticfriendships.com/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Accessibility & Assistive Technology Transitioning to Adulthood (Youth)

**Conditions Covered:** Blindness or Problems with Seeing Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Depression Cerebral Palsy (CP) Developmental Delay Genetic or Inherited Condition Epilepsy / Seizure Disorder Intellectual Disability Down Syndrome Other Mental Health Condition Speech or Language Disorder Other Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Blood Disorders Cystic Fibrosis (CF) Diabetes Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Learning Difficulty Migraines Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Emotions Anonymous International (EAI)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Emotions Anonymous International (EAI)

**Agency Description:** Emotions Anonymous International (EAI) is a nonprofit organization that facilitates the ongoing efforts of an international fellowship of men and women who desire to improve their emotional well-being. EA members come together in weekly meetings for the purpose of working toward recovery from any sort of emotional difficulties.

**Phone Number:** (651) 647-9712

**Email Address:** [info@emotionsanonymous.org](mailto:info@emotionsanonymous.org)

**Website:** <http://emotionsanonymous.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Transitioning to Adulthood (Youth) Community Living & Recreation Information & Referral  
Medical Dental & Behavioral Health

**Conditions Covered:** Depression Anxiety Other Mental Health Condition Substance Use Disorder

# Child Mind Institute



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Child Mind Institute

**Agency Description:** The Child Mind Institute is an independent, national nonprofit dedicated to transforming the lives of children and families struggling with mental health and learning disorders. Our teams work every day to deliver the highest standards of care, advance the science of the developing brain and empower parents, professionals and policymakers to support children when and where they need it most.

**Phone Number:** (212) 308-3118

**Email Address:** developmentInfo@childmind.org

**Website:** <http://childmind.org/>

**Counties Served:** State-Wide

- Content Categories:**
- Accessibility & Assistive Technology
  - Care Coordination
  - Family & Supports
  - Early Childhood & School Aged
  - Financial Legal & Advocacy
  - Medical Dental & Behavioral Health
  - Transitioning to Adulthood (Youth)
  - Information & Referral

- Conditions Covered:**
- Developmental Delay
  - Learning Difficulty
  - Intellectual Disability
  - Anxiety
  - Depression
  - Other Mental Health Condition
  - Down Syndrome
  - Genetic or Inherited Condition
  - Brain Injury, Concussion, or Head Injury
  - Speech or Language Disorder
  - Substance Use Disorder

# Brain Injury Association of New York State (BIANYS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Brain Injury Association of New York State (BIANYS)

**Agency Description:** Brain Injury Association of New York State (BIANYS) is a statewide non-profit membership organization that advocates on behalf of individuals with brain injuries and their families. BIANYS provides education, advocacy, and community support services that lead to improved outcomes for children and adults with brain injuries and their families. The Association also offers a toll free family helpline, chapters and support groups throughout the state, prevention programs, professional development programs, and a video and publications library. BIANYS plays a central role in the development of public policy on the federal, state and local level.

**Phone Number:** (518) 459-7911

**Email Address:** [info@bianys.org](mailto:info@bianys.org)

**Website:** <http://bianys.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Financial Legal & Advocacy, Community Living & Recreation, Early Childhood & School Aged, Transitioning to Adulthood (Youth)

**Conditions Covered:** Brain Injury, Concussion, or Head Injury

# Adult Career and Continuing Education Services: Vocational Rehabilitation (ACCES-VR)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Adult Career and Continuing Education Services: Vocational Rehabilitation (ACCES-VR)

**Agency Description:** Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR) assists individuals with disabilities to achieve and maintain employment and to support independent living through training, education, rehabilitation, and career development. Vocational Rehabilitation Counselors guide individuals through service programs they need to reach their employment goal.

**Phone Number:** (518) 474-3852

**Email Address:**

**Website:** <http://www.acces.nysed.gov/vr>

**Counties Served:** State-Wide Albany County Allegany County Bronx County Broome County Cattaraugus County Cayuga County Chautauqua County Chemung County Chenango County Clinton County Columbia County Cortland County Delaware County Dutchess County Erie County Essex County Franklin County Fulton County Genesee County Greene County Hamilton County Herkimer County Jefferson County Kings County Lewis County Livingston County

**Content Categories:** Transitioning to Adulthood (Youth) Government Agency

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Intellectual Disability Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# New York State Parenting Education Partnership (NYSPEP)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Parenting Education Partnership (NYSPEP)

**Agency Description:** NYSPEP's mission is to promote and improve parenting education, in order to enhance parenting skills, knowledge and behavior. Community Cafes is one of our tools to advance family engagement and community-level, cross-systems communications with the hope of increasing reciprocity within these relationships; infusing cross-systems learning with parent and caregiver perspective; and building communities' capacity for action that strengthens families.

**Phone Number:** (800) 244-5373

**Email Address:**

**Website:** <http://nyspep.org/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Community Living & Recreation Financial Legal & Advocacy Information & Referral  
Transitioning to Adulthood (Youth) Family & Supports Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma  
Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression  
Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition  
Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability  
Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder  
Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Rayim

**Agency Description:** Rayim is an organization that helps people with developmental disabilities enjoy more meaningful lives by delivering high-quality supports and services to them and their families. Our services range from Medicaid service coordination to home-based care and respite to providing financial assistance to alleviate the tremendous costs that can be incurred with an exceptional child.

**Phone Number:** (718) 946-7700

**Email Address:** [info@rayim.org](mailto:info@rayim.org)

**Website:** <http://www.rayim.org/>

**Counties Served:** Westchester County Orange County Rockland County Sullivan County Kings County Monroe County

**Content Categories:** Care Coordination Family & Supports Financial Legal & Advocacy Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Anxiety Cerebral Palsy (CP) Developmental Delay Down Syndrome Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Intellectual Disability Learning Difficulty Speech or Language Disorder Spina Bifida Tourette Syndrome (TS) Blindness or Problems with Seeing Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD)

# Cerebral Palsy Association of New York State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Cerebral Palsy Association of New York State

**Agency Description:** The mission of Cerebral Palsy Associations of New York State is to provide for the exchange of ideas, education and communication between groups and people interested in advocacy for people with cerebral palsy and other developmental disabilities, as well as people with significant other disabilities for which the Corporation's local Affiliates provide support.

**Phone Number:** (518) 235-1880

**Email Address:** [info@cpstate.org](mailto:info@cpstate.org)

**Website:** <http://www.cpstate.org/affiliates/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Family & Supports Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Cerebral Palsy (CP) Developmental Delay

# Office for People With Developmental Disabilities (OPWDD): Provider Directory



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Office for People With Developmental Disabilities (OPWDD): Provider Directory

**Agency Description:** OPWDD offers individualized, person-centered supports to children and young adults aged birth to 21 who are OPWDD-eligible with a qualifying diagnosis. OPWDD services can be provided in addition to supports received through Early Intervention (EI), the education system, and the Office for Children and Family Services (OCFS), which are the primary systems serving children with disabilities in New York State.

**Phone Number:** (866) 946-9733

**Email Address:** [info@opwdd.ny.gov](mailto:info@opwdd.ny.gov)

**Website:** <http://providerdirectory.opwdd.ny.gov/>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral

**Conditions Covered:** Developmental Delay Autism Spectrum Disorder (ASD) Down Syndrome Behavioral / Conduct Problem Cerebral Palsy (CP) Epilepsy / Seizure Disorder Brain Injury, Concussion, or Head Injury Attention-Deficit/Hyperactivity Disorder (ADHD) Other Mental Health Condition Genetic or Inherited Condition Learning Difficulty Intellectual Disability Blindness or Problems with Seeing Other Anxiety Cystic Fibrosis (CF) Depression Deafness or Problems with Hearing Speech or Language Disorder Spina Bifida Arthritis Asthma Allergies

# Medical Directory of New York State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Medical Directory of New York State

**Agency Description:** The information listed is extracted from the Medical Society of the State of New York physician database used in production of the Medical Directory of New York State. The MSSNY Physician Lookup service includes only current members of the Medical Society of the State of New York (MSSNY).

**Phone Number:** (516) 488-6100

**Email Address:** [mssny@mssny.org](mailto:mssny@mssny.org)

**Website:** [http://www.mssny.org/MSSNY/Doc\\_Lookup/Default.aspx](http://www.mssny.org/MSSNY/Doc_Lookup/Default.aspx)

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Autism Spectrum Disorder (ASD) Asthma Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing Other Learning Difficulty

# Camp Abilities Brockport



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency**            Camp Abilities Brockport

**Agency Description:**    The mission of Camp Abilities Brockport is to empower children and teens with visual impairments to be physically active and productive members of their schools, towns, cities, and communities, as well as to improve the health and well-being of people with sensory impairments. They camp experience also provide training and respite.

**Phone Number:**    (585) 395-2629

**Email Address:**    campabilitiesbrockport01@gmail.com

**Website:**            <http://www.campabilities.org/>

**Counties Served:**    Monroe County

**Content Categories:**    Community Living & Recreation    Family & Supports    Transitioning to Adulthood (Youth)

**Conditions Covered:**    Blindness or Problems with Seeing    Deafness or Problems with Hearing

# Lincoln Center Passport to the Arts



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Lincoln Center Passport to the Arts

**Agency Description:** Designed for children, teens, and adults with disabilities and their families, Passport to the Arts provides a welcoming, accessible, and affordable introduction to the performing arts at Lincoln Center at no cost. Families will receive pre-visit materials, including social narratives, photos, and links, before each program. All programs currently take place via Zoom.

**Phone Number:** (212) 875-5456

**Email Address:** [guestexperience@lincolncenter.org](mailto:guestexperience@lincolncenter.org)

**Website:** <http://lincolncenter.org/lincoln-center-at-home/series/passport-to-the-arts>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Accessibility & Assistive Technology Family & Supports

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Primary Ciliary Dyskinesia (PCD) Foundation



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Primary Ciliary Dyskinesia (PCD) Foundation

**Agency Description:** The PCD Foundation envisions a world free from illness and early death due to primary ciliary dyskinesia (PCD), and in order to carry out that vision, we strive to do the following by 1) improving diagnosis, quality of life, and prognosis through research, 2) educating & supporting patient, scientific, and medical communities and 3) raising awareness of PCD.

**Phone Number:** (844) 287-3723

**Email Address:** [info@pcdfoundation.org](mailto:info@pcdfoundation.org)

**Website:** <http://pcdfoundation.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Financial Legal & Advocacy

**Conditions Covered:** Genetic or Inherited Condition

# Supportive Housing Network of New York (SHNNY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Supportive Housing Network of New York (SHNNY)

**Agency Description:** The Supportive Housing Network of New York (SHNNY) is focused on supportive housing. Supportive housing hopes to end homelessness for vulnerable people: individuals and families dealing with mental illness, trauma/abuse, addiction, and chronic illness including HIV/AIDS. Our work includes advocacy, policy analysis, training, technical assistance, and public education.

**Phone Number:** (646) 619-9640

**Email Address:** [info@shnny.org](mailto:info@shnny.org)

**Website:** <http://shnny.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Family & Supports Information & Referral Community Living & Recreation  
Transitioning to Adulthood (Youth)

**Conditions Covered:** Behavioral / Conduct Problem Depression Developmental Delay Genetic or Inherited Condition  
Other Mental Health Condition Substance Use Disorder Other Anxiety Cystic Fibrosis (CF) Blood Disorders Diabetes

# New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)

**Agency Description:** The New York-Mid-Atlantic-Caribbean (NYMAC) Regional Genetics Network is one of seven Regional Genetics Networks in the country. Individuals from our region with genetic disease and their families, advocates, healthcare professionals and public health professionals collaborate to ensure that individuals with heritable disorders and their families have access to quality care and appropriate genetic expertise.

**Phone Number:**

**Email Address:** NYMAC@ferre.org

**Website:** <http://nymacgenetics.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Community Living & Recreation

**Conditions Covered:** Genetic or Inherited Condition

# New York State Talking Book and Braille Library (TBBL)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Talking Book and Braille Library (TBBL)

**Agency Description:** The Talking Book and Braille Library (TBBL) lends braille and audiobooks and magazines, and special playback equipment to residents of the 55 upstate counties of New York State who are unable to read printed materials because of a visual or physical disability.

**Phone Number:** (800) 342-3688

**Email Address:** [tbbl@nysed.gov](mailto:tbbl@nysed.gov)

**Website:** <http://www.nysl.nysed.gov/tbbl/>

**Counties Served:** Albany County Allegany County Broome County Cattaraugus County Cayuga County Chautauqua County Chemung County Chenango County Clinton County Columbia County Cortland County Delaware County Dutchess County Erie County Essex County Franklin County Fulton County Genesee County Greene County Hamilton County Herkimer County Jefferson County Lewis County Livingston County Madison County

**Content Categories:** Early Childhood & School Aged Family & Supports Accessibility & Assistive Technology Government Agency

**Conditions Covered:** Blindness or Problems with Seeing Learning Difficulty Developmental Delay Arthritis Cerebral Palsy (CP) Brain Injury, Concussion, or Head Injury Genetic or Inherited Condition Intellectual Disability Other Spina Bifida

# Person Centered Services



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Person Centered Services

**Agency Description:** Person Centered Services provides care coordination for people with intellectual and developmental disabilities in 18 counties throughout the Western New York, Finger Lakes, and Southern Tier regions. At the heart of Care Coordination are connections and referrals. Care Coordinators work with individuals, families, community providers, and organizations to make sure the dots are connected between all aspects of a person's care.

**Phone Number:** (888) 977-7030

**Email Address:** [customerservice@personcenteredservices.com](mailto:customerservice@personcenteredservices.com)

**Website:** <http://personcenteredservices.com/>

**Counties Served:** Allegany County, Cattaraugus County, Cayuga County, Chemung County, Chautauqua County, Erie County, Genesee County, Livingston County, Monroe County, Niagara County, Ontario County, Orleans County, Schuyler County, Seneca County, Steuben County, Wayne County, Wyoming County, Yates County

**Content Categories:** Care Coordination, Family & Supports, Information & Referral, Transitioning to Adulthood (Youth), Community Living & Recreation

**Conditions Covered:** Arthritis, Allergies, Anxiety, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Deafness or Problems with Hearing, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing, Other

# Disability Rights New York (DRNY)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Disability Rights New York (DRNY)

**Agency Description:** DRNY advocates for the civil and legal rights for New Yorkers with disabilities. DRNY provides free legal and advocacy services to individuals with disabilities. Working tirelessly to protect and advance the rights of children and adults with disabilities, DRNY is committed to enabling those we serve to exercise their own life choices and fully participate in community life.

**Phone Number:** (518) 432-7861

**Email Address:** [intake@drny.org](mailto:intake@drny.org)

**Website:** <http://www.drny.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial Legal & Advocacy Information & Referral Community Living & Recreation

**Conditions Covered:** Brain Injury, Concussion, or Head Injury Developmental Delay Down Syndrome Intellectual Disability Learning Difficulty Other Mental Health Condition Cerebral Palsy (CP) Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cystic Fibrosis (CF) Depression Diabetes Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Migraines Other Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Parents of Blind Children of New York (POBCNY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Parents of Blind Children of New York (POBCNY)

**Agency Description:** The POBCNY is a parent advocacy group working to improve the lives of blind children within the state of New York. It is our mission to elevate the quality of education for blind children, to affect our children's access to services, to create opportunities in theatre and the arts, in sports and recreation, and to raise the level of expectation that those around us have of our children.

**Phone Number:** (917) 475-6642

**Email Address:** pobcny@gmail.com

**Website:** <http://www.nypobc.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Transitioning to Adulthood (Youth) Early Childhood & School Aged  
Community Living & Recreation Financial Legal & Advocacy Accessibility & Assistive Technology

**Conditions Covered:** Blindness or Problems with Seeing

# National Federation of the Blind of New York State (NFB of NYS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** National Federation of the Blind of New York State (NFB of NYS)

**Agency Description:** The National Federation of the Blind is the only organization that believes in the full capacity of blind people and has the power, influence, diversity, and determination to help transform dreams into reality. We offer many programs, services, and resources for parents of blind children. NFB has NYS-specific chapters, divisions, and groups.

**Phone Number:** (716) 222-3632

**Email Address:** [president@nfbny.org](mailto:president@nfbny.org)

**Website:** <http://nfbny.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Financial Legal & Advocacy Community Living & Recreation

**Conditions Covered:** Blindness or Problems with Seeing

# ADDitude Magazine



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** ADDitude Magazine

**Agency Description:** ADDitude is required reading for anyone touched by ADHD — plain & simple. The nation’s leading source of important news, expert advice, and judgment-free understanding for families and adults living with attention deficit disorder. ADDitude is your voice and your advocate. Subscriptions vary in price but you also can read free online on their website.

**Phone Number:** (888) 762-8475

**Email Address:** [customerservice@additudemag.com](mailto:customerservice@additudemag.com)

**Website:** <http://www.additudemag.com/>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged, Accessibility & Assistive Technology, Family & Supports, Information & Referral, Community Living & Recreation, Financial Legal & Advocacy, Transitioning to Adulthood (Youth)

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD)

# Healthy Transitions NY



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Healthy Transitions NY

**Agency Description:** This website is for youth with developmental disabilities ages 14-25 years, family caregivers, service coordinators, and health care providers. Use this site to develop skills for transitioning from pediatric to adult healthcare. Our curriculum and tools raise awareness about developmental disabilities, improve communication, and build effective partnerships during the transition process.

**Phone Number:** (315) 464-7561

**Email Address:** dosan@upstate.edu

**Website:** <http://healthytransitionsny.org/>

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Accessibility & Assistive Technology Information & Referral Family & Supports  
Financial Legal & Advocacy Medical Dental & Behavioral Health

**Conditions Covered:** Developmental Delay Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Cerebral Palsy (CP)  
Intellectual Disability Tourette Syndrome (TS) Deafness or Problems with Hearing Blindness or Problems with Seeing  
Speech or Language Disorder Learning Difficulty

# New York State Office for People With Developmental Disabilities (OPWDD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Office for People With Developmental Disabilities (OPWDD)

**Agency Description:** The New York State Office for People With Developmental Disabilities (OPWDD) is responsible for coordinating services for New Yorkers with developmental disabilities and neurological impairments. We provide services directly and through a network of approximately 600 nonprofit service providing agencies, with about 80 percent of services provided by the private nonprofits and 20 percent provided by state-run services.

**Phone Number:** (866) 946-9733

**Email Address:** [info@opwdd.ny.gov](mailto:info@opwdd.ny.gov)

**Website:** <http://opwdd.ny.gov/>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Government Agency Financial Legal & Advocacy Family & Supports  
Accessibility & Assistive Technology Care Coordination Medical Dental & Behavioral Health Information & Referral  
Community Living & Recreation Transitioning to Adulthood (Youth)

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem  
Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Brain Injury, Concussion, or Head Injury Developmental Delay  
Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing  
Heart Condition Intellectual Disability Learning Difficulty Migraines Other

# Easterseals New York



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Easterseals New York

**Agency Description:** Easterseals provides exceptional services, education, outreach, and advocacy so that people living with autism and other disabilities can live, learn, work and play in our communities. From child development centers to physical rehabilitation and job training for people with disabilities, Easterseals offers a variety of services to help people with disabilities.

**Phone Number:** (212) 943-4364

**Email Address:** [mamoran@fedcap.org](mailto:mamoran@fedcap.org)

**Website:** <http://www.easterseals.com/newyork/connect-locally/new-york.html>

**Counties Served:** Westchester County, Suffolk County, Sullivan County, Delaware County, Ulster County, Greene County, Orange County, Albany County, Monroe County, New York County, Bronx County, Queens County, Kings County

**Content Categories:** Family & Supports, Community Living & Recreation, Information & Referral, Early Childhood & School Aged, Financial Legal & Advocacy, Transitioning to Adulthood (Youth), Medical Dental & Behavioral Health

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Developmental Delay, Intellectual Disability, Learning Difficulty, Allergies, Anxiety, Arthritis, Asthma, Behavioral / Conduct Problem, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Depression, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Deafness or Problems with Hearing, Heart Condition, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Blindness or Problems with Seeing

# New York State Conference of Local Mental Hygiene Directors



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Conference of Local Mental Hygiene Directors

**Agency Description:** The Conference has the responsibility of meeting the needs of individuals and families affected by mental illness, substance use disorder and/or developmental disability in their communities. The 'Contact local mental hygiene departments' page allows you to find the specific information about the local governmental unit in your county.

**Phone Number:** (518) 462-9422

**Email Address:**

**Website:** [http://www.clmhd.org/contact\\_local\\_mental\\_hygiene\\_departments/](http://www.clmhd.org/contact_local_mental_hygiene_departments/)

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Care Coordination Government Agency

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Brain Injury, Concussion, or Head Injury Depression Developmental Delay Intellectual Disability Genetic or Inherited Condition Learning Difficulty Anxiety Substance Use Disorder Down Syndrome Deafness or Problems with Hearing Other Mental Health Condition Tourette Syndrome (TS) Speech or Language Disorder Blindness or Problems with Seeing

# Rising New York Road Runners (NYRR): Wheelchair Training Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Rising New York Road Runners (NYRR): Wheelchair Training Program

**Agency Description:** Rising New York Road Runners Wheelchair Training Program is a free, year-round program for youth with physical disabilities ages 6 to 21. The program offers weekly training sessions, in-school resources, and competitive events on the road and track, regardless of experience or prior NYRR affiliation. This program is for children who are dependent on a wheelchair to run. This includes kids with hypertonia, ataxia and/or athetosis, impaired muscle power, impaired passive muscle range of motion, and/or limb deficiency and those who do not wish to run with prosthetics.

**Phone Number:** (855) 569-6977

**Email Address:** risingnyrr@nyrr.org

**Website:** <http://www.nyrr.org/Youth/Youth-Initiatives/Rising-New-York-Road-Runners->

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Community Living & Recreation Accessibility & Assistive Technology  
Transitioning to Adulthood (Youth) Information & Referral

**Conditions Covered:** Arthritis Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Epilepsy / Seizure Disorder  
Genetic or Inherited Condition Heart Condition Other Spina Bifida

# National Eating Disorders Association (NEDA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** National Eating Disorders Association (NEDA)

**Agency Description:** The National Eating Disorders Association (NEDA) is the largest nonprofit organization dedicated to supporting individuals and families affected by eating disorders. NEDA supports individuals and families affected by eating disorders, and serves as a catalyst for prevention, cures and access to quality care.

**Phone Number:** (212) 575-6200

**Email Address:** [info@NationalEatingDisorders.org](mailto:info@NationalEatingDisorders.org)

**Website:** <http://www.nationaleatingdisorders.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Family & Supports Community Living & Recreation Medical Dental & Behavioral Health

**Conditions Covered:** Other Mental Health Condition

# The Arc New York



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** The Arc New York

**Agency Description:** The Arc New York's mission is to advocate and provide support and services to people with intellectual, developmental, and other disabilities, emphasizing choice and community engagement. You can find additional local chapters in New York here: <https://thearc.org/chapter/the-arc-new-york/>. A second email for The Arc New York is: [info@nysarc.org](mailto:info@nysarc.org).

**Phone Number:** (518) 439-8311

**Email Address:** [Info@TheArcNY.org](mailto:Info@TheArcNY.org)

**Website:** <http://www.thearcny.org/find-your-chapter>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial Legal & Advocacy Information & Referral Transitioning to Adulthood (Youth) Early Childhood & School Aged Community Living & Recreation

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Spectrum Creative Arts



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Spectrum Creative Arts

**Agency Description:** Spectrum Creative Arts is an inclusive arts education and therapy center, specializing in person-centered opportunities for learners with special needs. Spectrum offers individual sessions, group classes, and ensembles both on-site at our clinic, and throughout the Greater Rochester community. Our mission to inspire and empower our students through active participation in the creative arts.

**Phone Number:** (585) 383-1999

**Email Address:** [office@spectrumcreativearts.org](mailto:office@spectrumcreativearts.org)

**Website:** <http://spectrumcreativearts.org/>

**Counties Served:** [Monroe County](#)

**Content Categories:** [Community Living & Recreation](#) [Early Childhood & School Aged](#) [Transitioning to Adulthood \(Youth\)](#)  
[Medical Dental & Behavioral Health](#)

**Conditions Covered:** [Developmental Delay](#) [Autism Spectrum Disorder \(ASD\)](#) [Down Syndrome](#) [Intellectual Disability](#)

# Golisano Autism Center



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Golisano Autism Center

**Agency Description:** The Golisano Autism Center has experts in ASD knowledge and follows a one-stop approach to accessing a wide variety of supports. Family Navigators are available on-site to help connect families with on-site providers, services and supports within the Center.

**Phone Number:** (585) 685-8300

**Email Address:** info@golisanoautismcenter.org

**Website:** <http://www.golisanoautismcenter.org/>

**Counties Served:** Monroe County

**Content Categories:** Family & Supports, Early Childhood & School Aged, Community Living & Recreation, Care Coordination, Transitioning to Adulthood (Youth), Medical Dental & Behavioral Health, Information & Referral, Financial Legal & Advocacy

**Conditions Covered:** Autism Spectrum Disorder (ASD)

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** AutismUp

**Agency Description:** AutismUp aspires to provide the very best in autism support programs and services in the Greater Rochester and surrounding areas, and aims to support peak performance at every age and ability.

**Phone Number:** (585) 248-9011

**Email Address:** [contact@autismup.org](mailto:contact@autismup.org)

**Website:** <http://autismup.org/>

**Counties Served:** [Monroe County](#) [Wayne County](#) [Livingston County](#) [Ontario County](#)

**Content Categories:** [Community Living & Recreation](#) [Family & Supports](#) [Information & Referral](#) [Care Coordination](#)  
[Financial Legal & Advocacy](#)

**Conditions Covered:** [Autism Spectrum Disorder \(ASD\)](#)

# Rochester Rotary Sunshine Campus



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Rochester Rotary Sunshine Campus

**Agency Description:** Rochester Rotary Sunshine Campus provides a summer camp where children with disabilities can simply have fun, without any barriers. Today, this 157-acre camp in Rush, N.Y. meets the needs of thousands of children with disabilities and their families.

**Phone Number:** (585) 533-2080

**Email Address:**

**Website:** <http://www.sunshinecamp.org/>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation Early Childhood & School Aged Transitioning to Adulthood (Youth) Family & Supports

**Conditions Covered:** Developmental Delay Autism Spectrum Disorder (ASD) Down Syndrome Intellectual Disability Attention-Deficit/Hyperactivity Disorder (ADHD) Cerebral Palsy (CP) Speech or Language Disorder Tourette Syndrome (TS) Spina Bifida Blindness or Problems with Seeing Learning Difficulty Deafness or Problems with Hearing Diabetes Brain Injury, Concussion, or Head Injury Heart Condition

# Endless Highway

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Endless Highway

**Agency Description:** Endless Highway is a not-for-profit organization dedicated to ensuring children and young adults with physical disabilities have opportunities to participate in adaptive and inclusive sports, recreation, and arts.

**Phone Number:** (585) 739-2659

**Email Address:** [info@endless-highway.org](mailto:info@endless-highway.org)

**Website:** <http://endless-highway.org/>

**Counties Served:** [Monroe County](#)

**Content Categories:** [Community Living & Recreation](#)

**Conditions Covered:** [Diabetes](#) [Down Syndrome](#) [Spina Bifida](#) [Cerebral Palsy \(CP\)](#) [Other](#) [Arthritis](#) [Brain Injury, Concussion, or Head Injury](#)  
[Genetic or Inherited Condition](#)

# Rochester Accessible Adventures (RAA)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Rochester Accessible Adventures (RAA)

**Agency Description:** Rochester Accessible Adventures ensures individuals with disabilities are able to access inclusive active recreation and sports opportunities. Rochester Accessible Adventures helps people with disabilities and their families have access to active, healthy lifestyle opportunities.

**Phone Number:** (585) 491-6011

**Email Address:** [RAA@rochesteraccessibleadventures.org](mailto:RAA@rochesteraccessibleadventures.org)

**Website:** <http://rochesteraccessibleadventures.org/>

**Counties Served:** Monroe County

**Content Categories:** Accessibility & Assistive Technology Family & Supports Community Living & Recreation

**Conditions Covered:** Cerebral Palsy (CP) Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Blood Disorders Behavioral / Conduct Problem Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Tourette Association of America (TAA)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency**            Tourette Association of America (TAA)

**Agency Description:**    The Tourette Association of America (TAA) serves the community, and works to raise awareness, advance research, and provide ongoing support to patients and families impacted by Tourette Syndrome and Tic Disorders. TAA has multiple chapters in New York.

**Phone Number:**    (888) 486-8738

**Email Address:**    support@tourette.org

**Website:**            <http://tourette.org/resources/local-support/>

**Counties Served:**    State-Wide

**Content Categories:**    Family & Supports    Financial Legal & Advocacy    Information & Referral    Community Living & Recreation

**Conditions Covered:**    Tourette Syndrome (TS)

# Special Olympics New York (SONY)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Special Olympics New York (SONY)

**Agency Description:** Our mission is to provide year-round sports training and athletic competition in a variety of Olympic-style sports for all children and adults with intellectual disabilities giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy, and participate in a sharing of skills and friendship with their families, Special Olympics athletes and the community. We cover many areas across New York.

**Phone Number:** (518) 388-0790

**Email Address:**

**Website:** <http://www.specialolympics.org/programs/united-states/new-york?locale=en>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Family & Supports

**Conditions Covered:** Arthritis Attention-Deficit/Hyperactivity Disorder (ADHD) Cerebral Palsy (CP) Cystic Fibrosis (CF) Autism Spectrum Disorder (ASD) Brain Injury, Concussion, or Head Injury Blood Disorders Developmental Delay Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Deafness or Problems with Hearing Intellectual Disability Learning Difficulty Other Other Mental Health Condition Spina Bifida Blindness or Problems with Seeing Tourette Syndrome (TS)

# Best Buddies



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Best Buddies

**Agency Description:** Best Buddies International is a nonprofit organization dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment, leadership development, and inclusive living for individuals with intellectual and developmental disabilities (IDD). The IDD community that Best Buddies serves includes, but is not limited to, people with Down syndrome, autism, Fragile X, Williams syndrome, cerebral palsy, traumatic brain injury and other undiagnosed disabilities.

**Phone Number:** (800) 892-8339

**Email Address:** [newyork@bestbuddies.org](mailto:newyork@bestbuddies.org)

**Website:** <http://www.bestbuddies.org/newyork/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Family & Supports Transitioning to Adulthood (Youth)

**Conditions Covered:** Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Down Syndrome Intellectual Disability Developmental Delay Cystic Fibrosis (CF) Genetic or Inherited Condition Spina Bifida Tourette Syndrome (TS) Brain Injury, Concussion, or Head Injury

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Starbridge, Inc.

**Agency Description:** We partner with people who have disabilities, their families, and others who support them, to achieve success in education, employment, and healthy living. Services include: education, transition planning, employment, family supports, self-direction, home and living.

**Phone Number:** (585) 546-1700

**Email Address:** [info@starbridgeinc.org](mailto:info@starbridgeinc.org)

**Website:** <http://www.starbridgeinc.org/>

**Counties Served:** Monroe County Yates County Wayne County Ontario County Livingston County Albany County Allegany County

Broome County Cattaraugus County Cayuga County Chautauqua County Chemung County Chenango County

Clinton County Columbia County Cortland County Delaware County Dutchess County Erie County Essex County

Franklin County Fulton County Genesee County Greene County Hamilton County Herkimer County

**Content Categories:** Care Coordination Family & Supports Financial Legal & Advocacy Transitioning to Adulthood (Youth)

Early Childhood & School Aged

**Conditions Covered:** Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Cerebral Palsy (CP) Developmental Delay

Epilepsy / Seizure Disorder Intellectual Disability Speech or Language Disorder Tourette Syndrome (TS)

Blindness or Problems with Seeing Learning Difficulty Spina Bifida Attention-Deficit/Hyperactivity Disorder (ADHD)

Cystic Fibrosis (CF) Down Syndrome Brain Injury, Concussion, or Head Injury Genetic or Inherited Condition

Deafness or Problems with Hearing

# Homesteads for Hope



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Homesteads for Hope

**Agency Description:** Homesteads for Hope is a non-profit Community Farm. The Community Farm experience promotes skills training, socialization, self-awareness and career exploration on an organically practiced farm; offering effortless inclusion with its many collaborative partnerships within the greater community. As the demand for self-directed and inclusive community services continues to rise, particularly for young adults, Homesteads for Hope will provide high-quality services to people of all abilities.

**Phone Number:** (585) 352-4673

**Email Address:** [Info@HomesteadsforHope.org](mailto:Info@HomesteadsforHope.org)

**Website:** <http://www.homesteadsforhope.org/>

**Counties Served:** [Monroe County](#) [Ontario County](#) [Livingston County](#)

**Content Categories:** [Family & Supports](#) [Community Living & Recreation](#) [Transitioning to Adulthood \(Youth\)](#)

**Conditions Covered:** [Autism Spectrum Disorder \(ASD\)](#) [Behavioral / Conduct Problem](#) [Cerebral Palsy \(CP\)](#) [Developmental Delay](#) [Epilepsy / Seizure Disorder](#) [Intellectual Disability](#) [Speech or Language Disorder](#) [Tourette Syndrome \(TS\)](#) [Blindness or Problems with Seeing](#) [Learning Difficulty](#) [Spina Bifida](#)

# New York State Office for People With Developmental Disabilities (OPWDD): Statewide Family Support Services Committee (FSS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Office for People With Developmental Disabilities (OPWDD): Statewide Family Support Services Committee (FSS)

**Agency Description:** The Statewide Family Support Services Committee is made up of one representative from each of the nineteen local Family Support Services Advisory Councils and advises OPWDD regarding families' support needs and the design, implementation and monitoring of Family Support Services.

**Phone Number:** (866) 946-9733

**Email Address:** [info@opwdd.ny.gov](mailto:info@opwdd.ny.gov)

**Website:** <http://opwdd.ny.gov/statewide-family-support-services-committee-fss>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Government Agency

**Conditions Covered:** Autism Spectrum Disorder (ASD) Developmental Delay Cerebral Palsy (CP) Down Syndrome Epilepsy / Seizure Disorder Intellectual Disability Attention-Deficit/Hyperactivity Disorder (ADHD) Tourette Syndrome (TS) Speech or Language Disorder Behavioral / Conduct Problem Brain Injury, Concussion, or Head Injury Genetic or Inherited Condition Cystic Fibrosis (CF) Diabetes Deafness or Problems with Hearing Other Mental Health Condition Learning Difficulty Blindness or Problems with Seeing Depression Other Spina Bifida

# University of Rochester, Warner School of Education: Center for Disability and Education



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** University of Rochester, Warner School of Education: Center for Disability and Education

**Agency Description:** The Center for Disability and Education provides high quality information to people navigating the world of disability. The Center provides expertise, guidance, and linkage to community members, students, families, school districts, non-profit agencies, and higher education institutions.

**Phone Number:** (585) 276-7079

**Email Address:** CDE@warner.rochester.edu

**Website:** <http://www.rochester.edu/warner/cde/>

**Counties Served:** Monroe County

**Content Categories:** Transitioning to Adulthood (Youth) Family & Supports Information & Referral

**Conditions Covered:** Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Down Syndrome Intellectual Disability Tourette Syndrome (TS) Attention-Deficit/Hyperactivity Disorder (ADHD) Cystic Fibrosis (CF) Epilepsy / Seizure Disorder Genetic or Inherited Condition Learning Difficulty Spina Bifida Blindness or Problems with Seeing Speech or Language Disorder

# University of Rochester Medical Center (URMC): Strong Center for Developmental Disabilities (SCDD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** University of Rochester Medical Center (URMC): Strong Center for Developmental Disabilities (SCDD)

**Agency Description:** The Strong Center for Developmental Disabilities (SCDD) develops partnerships, fosters accessibility, translates research to best practice, and promotes diversity and inclusion with and for people with intellectual and developmental disabilities in our community.

**Phone Number:** (585) 275-0355

**Email Address:**

**Website:** <http://www.urmc.rochester.edu/strong-center-developmental-disabilities.aspx>

**Counties Served:** Monroe County

**Content Categories:** Family & Supports Information & Referral Accessibility & Assistive Technology Care Coordination  
Community Living & Recreation Early Childhood & School Aged Financial Legal & Advocacy  
Medical Dental & Behavioral Health Transitioning to Adulthood (Youth)

**Conditions Covered:** Developmental Delay Other Mental Health Condition Autism Spectrum Disorder (ASD) Cerebral Palsy (CP)  
Down Syndrome Intellectual Disability Spina Bifida Attention-Deficit/Hyperactivity Disorder (ADHD)  
Epilepsy / Seizure Disorder Genetic or Inherited Condition Speech or Language Disorder Tourette Syndrome (TS) Allergies  
Anxiety Arthritis Asthma Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury  
Cystic Fibrosis (CF) Depression Diabetes Deafness or Problems with Hearing Heart Condition Learning Difficulty  
Migraines Other Substance Use Disorder Blindness or Problems with Seeing

# Children's Dyslexia Centers



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Children's Dyslexia Centers

**Agency Description:** The Children's Dyslexia Centers are equipping students with the skills and confidence they need to approach learning with eagerness and without fear. Our more than 40 Dyslexia Centers in 13 states provide intervention at reduced or no charge to children from early elementary through high school who have a profile suggesting dyslexia.

**Phone Number:** (877) 861-0528

**Email Address:**

**Website:** <http://www.childrensdyslexiacenters.org/>

**Counties Served:** Monroe County Oneida County

**Content Categories:** Early Childhood & School Aged Medical Dental & Behavioral Health Family & Supports  
Transitioning to Adulthood (Youth) Financial Legal & Advocacy

**Conditions Covered:** Learning Difficulty Speech or Language Disorder

# Open the Lid



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Open the Lid

**Agency Description:** We provide web-based courses, strategies & community for neurodiverse people and allies. Our goal is to empower individuals to move from where they are to where they want to be with simple strategies and supportive people. Created by a Certified Special Education Teacher and coach.

**Phone Number:** (607) 339-8092

**Email Address:** support@openthelid.com

**Website:** <http://www.openthelid.com/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Family & Supports Information & Referral Financial Legal & Advocacy  
Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD)  
Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP)  
Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder  
Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability  
Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida  
Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Adoptive and Foster Family Coalition of New York (AFFCNY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Adoptive and Foster Family Coalition of New York (AFFCNY)

**Agency Description:** The Adoptive and Foster Family Coalition of New York (AFFCNY) unites foster, adoptive and kinship care families, giving them a voice and providing support, information and advocacy. AFFCNY offers resources on health, disabilities and special needs.

**Phone Number:** (888) 354-1342

**Email Address:** [info@affcny.org](mailto:info@affcny.org)

**Website:** <http://affcny.org/family-supports/health-disabilities-and-special-needs/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# Parent Network of Western New York



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Parent Network of Western New York

**Agency Description:** We support families and professionals to empower individuals with disabilities to reach their full potential. We Provide 1-On-1 Support and Education on Disabilities, Special Education, and Services.

**Phone Number:** (716) 332-4170

**Email Address:** [info@parentnetworkwny.org](mailto:info@parentnetworkwny.org)

**Website:** <http://parentnetworkwny.org/>

**Counties Served:** Allegany County Cattaraugus County Chautauqua County Erie County Genesee County Niagara County Orleans County Wyoming County

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# New York State Justice Center for the Protection of People with Special Needs



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Justice Center for the Protection of People with Special Needs

**Agency Description:** The Justice Center for the Protection of People With Special Needs was created to restore public trust in the institutions and individuals charged with caring for vulnerable populations by protecting all people's health, safety, and dignity with special needs. The agency operates a toll-free hotline 24 hours a day, seven days a week, for receiving reports of allegations of abuse and neglect: (855) 373-2122.

**Phone Number:** (518) 549-0200

**Email Address:** [webmaster@justicecenter.ny.gov](mailto:webmaster@justicecenter.ny.gov)

**Website:** <http://www.justicecenter.ny.gov/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Government Agency Information & Referral Accessibility & Assistive Technology Family & Supports

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# New York Alliance for Inclusion and Innovation (NY Alliance)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York Alliance for Inclusion and Innovation (NY Alliance)

**Agency Description:** The New York Alliance for Inclusion and Innovation (NY Alliance) serves as a catalyst for positive change and a leading resource for individuals with disabilities, their families, and their organizations. We do this through: advocacy, education & training, technical assistance & practice improvement, advancing sound public policy.

**Phone Number:** (518) 795-3590

**Email Address:**

**Website:** <http://nyalliance.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Lighthouse Guild



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Lighthouse Guild

**Agency Description:** Lighthouse Guild offers other programs and resources for parents and teens with our tele-support groups. Through our National Tele-Support Network for Parents of Children with Visual Impairment, you can connect with other parents to share resources, experiences, strength, and hope, and our Youth Transition Program helps students prepare for life after high school, including the transition to college.

**Phone Number:** (800) 284-4422

**Email Address:**

**Website:** <http://www.lighthouseguild.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Accessibility & Assistive Technology Information & Referral Transitioning to Adulthood (Youth) Medical Dental & Behavioral Health Financial Legal & Advocacy Community Living & Recreation

**Conditions Covered:** Blindness or Problems with Seeing

# National Down Syndrome Society (NDSS)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** National Down Syndrome Society (NDSS)

**Agency Description:** The National Down Syndrome Society envisions a world in which all people with Down Syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities. NDSS supports and advocates for the Down syndrome community by focusing on three key areas of programming: Resources & Support, Policy & Advocacy, and Community Engagement.

**Phone Number:** (800) 221-4602

**Email Address:** [info@ndss.org](mailto:info@ndss.org)

**Website:** <http://www.ndss.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Community Living & Recreation Financial Legal & Advocacy Information & Referral  
Transitioning to Adulthood (Youth)

**Conditions Covered:** Down Syndrome

# InterAgency Council (IAC) of Developmental Disabilities Agencies, Inc.



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

<b>Agency</b>	InterAgency Council (IAC) of Developmental Disabilities Agencies, Inc.
<b>Agency Description:</b>	The InterAgency Council (IAC) of Developmental Disabilities Agencies, Inc., with over 150 members, is the largest provider association in New York for non-profit agencies that support individuals with intellectual/developmental disabilities. IAC members provide services and supports to individuals with I/DD throughout their lifespan.
<b>Phone Number:</b>	(212) 645-6360
<b>Email Address:</b>	info@iacny.org
<b>Website:</b>	<a href="http://www.iacny.org/">http://www.iacny.org/</a>
<b>Counties Served:</b>	State-Wide
<b>Content Categories:</b>	Family & Supports   Early Childhood & School Aged   Care Coordination   Accessibility & Assistive Technology Financial Legal & Advocacy   Medical Dental & Behavioral Health   Transitioning to Adulthood (Youth) Information & Referral
<b>Conditions Covered:</b>	Developmental Delay   Intellectual Disability   Learning Difficulty   Attention-Deficit/Hyperactivity Disorder (ADHD) Cerebral Palsy (CP)   Blindness or Problems with Seeing   Deafness or Problems with Hearing   Down Syndrome   Other Autism Spectrum Disorder (ASD)

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** myFace

**Agency Description:** myFace is a leading nonprofit organization dedicated to changing the faces - and transforming the lives - of children and adults with facial differences. For 70 years, myFace has focused on providing access to holistic comprehensive care, education, resources, and support that pave the way for better outcomes for those impacted by craniofacial conditions.

**Phone Number:** (917) 720-4701

**Email Address:** info@myface.org

**Website:** <http://www.myface.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Community Living & Recreation Information & Referral Medical Dental & Behavioral Health  
Financial Legal & Advocacy

**Conditions Covered:** Other Genetic or Inherited Condition

# Self-Advocacy Association of New York State, Inc. (SANYS)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Self-Advocacy Association of New York State, Inc. (SANYS)

**Agency Description:** The Self-Advocacy Association of New York State, Inc. (SANYS) is an organization founded and led by people with developmental disabilities, for people with developmental disabilities. We promote the awareness and recognition of our civil rights and responsibilities, which include opportunities and choices of equal citizenship. Our goal is to help self-advocates build the skill and courage needed to speak up for themselves and others.

**Phone Number:** (518) 382-1454

**Email Address:** sandrews@sanys.org

**Website:** <http://sanys.org/regions/>

**Counties Served:** State-Wide

**Content Categories:** Transitioning to Adulthood (Youth) Financial Legal & Advocacy Family & Supports

**Conditions Covered:** Developmental Delay Intellectual Disability Learning Difficulty Attention-Deficit/Hyperactivity Disorder (ADHD) Blindness or Problems with Seeing Cerebral Palsy (CP) Deafness or Problems with Hearing Down Syndrome Epilepsy / Seizure Disorder Autism Spectrum Disorder (ASD) Cystic Fibrosis (CF) Anxiety Speech or Language Disorder Other Mental Health Condition

# Parent to Parent of New York State



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Parent to Parent of New York State

**Agency Description:** Parent to Parent of New York State is a statewide not for profit organization established to support and connect families of individuals with special needs. We have several offices located throughout New York State staffed by Regional Coordinators who are parents or close relatives of individuals with special needs.

**Phone Number:** (800) 305-8817

**Email Address:** [info@ptopnys.org](mailto:info@ptopnys.org)

**Website:** <http://parenttoparentnys.org>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Cerebral Palsy (CP) Other Allergies Anxiety Arthritis Asthma Blood Disorders Cystic Fibrosis (CF) Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# National Alliance on Mental Illness (NAMI)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** National Alliance on Mental Illness (NAMI)

**Agency Description:** NAMI is an association of more than 500 local affiliates. They work to raise awareness and provide support and education to those with mental illness. NAMI has support groups, helplines, and various chapters across New York.

**Phone Number:** (518) 462-2000

**Email Address:** [info@naminys.org](mailto:info@naminys.org)

**Website:** <http://www.naminys.org>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral Financial Legal & Advocacy Transitioning to Adulthood (Youth) Community Living & Recreation

**Conditions Covered:** Anxiety Depression Other Mental Health Condition

# Helen Keller Services (HKS)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Helen Keller Services (HKS)

**Agency Description:** Helen Keller Services enables individuals who are blind, visually impaired, deaf-blind or have combined hearing and vision loss to live, work and thrive in the communities of their choice. Helen Keller Services (HKS) includes two divisions: (1) Helen Keller National Center for Deaf-Blind Youths & Adults (HKNC) and (2) Helen Keller Services for the Blind (HKSB).

**Phone Number:** (718) 522-2122

**Email Address:** [info@helenkeller.org](mailto:info@helenkeller.org)

**Website:** <http://www.helenkeller.org/hks/contact>

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Accessibility & Assistive Technology Family & Supports Transitioning to Adulthood (Youth) Community Living & Recreation

**Conditions Covered:** Blindness or Problems with Seeing Deafness or Problems with Hearing

# Sick Kids [Need] Involved People of New York (SKIP of NY)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Sick Kids [Need] Involved People of New York (SKIP of NY)

**Agency Description:** SKIP of NY helps medically fragile and/or developmentally disabled children in the state of New York get (and stay!) home from hospitals and institutions to live with their families. SKIP acts as a free medical concierge connecting children to the help they need such as nursing care, medical equipment, home modifications, and educational and recreational programs.

**Phone Number:** (212) 268-5999

**Email Address:** [info@skipofny.org](mailto:info@skipofny.org)

**Website:** <http://skipofny.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Accessibility & Assistive Technology Care Coordination Community Living & Recreation Family & Supports Information & Referral

**Conditions Covered:** Developmental Delay Intellectual Disability Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Blood Disorders Brain Injury, Concussion, or Head Injury Heart Condition Spina Bifida Other Cystic Fibrosis (CF)

# New York State Education Department (NYSED): Special Education Approved Schools



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Education Department (NYSED): Special Education Approved Schools

**Agency Description:** NYSED provides lists of approved schools in New York State, which can be filtered by location. Features, approved Preschool Special Education Programs, approved Private, Special Act, State-Operated, and State-Supported Schools in New York State, and information related to the Justice Center for Residential Schools.

**Phone Number:** (518) 474-3862

**Email Address:** [speced@nysed.gov](mailto:speced@nysed.gov)

**Website:** <http://www.p12.nysed.gov//specialed/appschools.html>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Information & Referral

**Conditions Covered:** Developmental Delay Other Mental Health Condition Learning Difficulty Speech or Language Disorder Attention-Deficit/Hyperactivity Disorder (ADHD) Allergies Anxiety Arthritis Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blood Disorders Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Heart Condition Intellectual Disability Migraines Spina Bifida Other Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

# American Academy of Pediatrics - Disasters and Children



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** American Academy of Pediatrics - Disasters and Children

**Agency Description:** This is a useful website to find information about disaster planning and meeting children's needs

**Phone Number:**

**Email Address:**

**Website:** <https://www.aap.org/en/patient-care/disasters-and-children/>

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# American Academy of Pediatrics Emergency Information Form for Children With Special Needs



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** American Academy of Pediatrics Emergency Information Form for Children With Special Needs

**Agency Description:** AAP Emergency Information Form for Children With Special Needs (to be filled out by physicians)

**Phone Number:**

**Email Address:**

**Website:** <https://www.chla.org/sites/default/files/atoms/files/CHLA-AAP-Emergency->

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# American Academy of Pediatrics Family Readiness Kit to Handle Disasters



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** American Academy of Pediatrics Family Readiness Kit to Handle Disasters

**Agency** AAP Family Readiness Kit to Handle Disasters

**Description:**

**Phone Number:**

**Email Address:**

**Website:** <https://www.chla.org/sites/default/files/atoms/files/CHLA-AAP-Family->

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# Emergency Kit Checklist for Families with Children and Youth with Special Healthcare Needs (CYSHCN)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Emergency Kit Checklist for Families with Children and Youth with Special Healthcare Needs (CYSHCN)

**Agency Description:** If a child with special healthcare needs is part of your family it is very important to be prepared for an emergency in which you may have to stay inside for longer than usual or in the event the electricity goes out. An emergency kit is necessary for all families, and especially important for families of children with special healthcare needs.

**Phone Number:**

**Email Address:**

**Website:** <https://www.cdc.gov/childrenindisasters/checklists/special-healthcare->

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# CDC Tip Sheet. Helping Parents Prepare with Disaster



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** CDC Tip Sheet. Helping Parents Prepare with Disaster

**Agency Description:** Anyone who is a parent knows how hard it can be to raise a child. Add a stressful situation, like a natural disaster or other emergencies, and a difficult job gets even harder. When disasters happen, it is important to remember the health and well-being of your children. If you can be prepared for potential disaster situations, your children are likely to handle it better, too

**Phone Number:** 1-800-CDC-INFO

**Email Address:** [cdcinfo@cdc.gov](mailto:cdcinfo@cdc.gov)

**Website:** <https://www.chla.org/sites/default/files/atoms/files//CHLA-CDC-Helping-Parents->

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# CDC Tip Sheet. Helping Parents Cope with Disaster



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** CDC Tip Sheet. Helping Parents Cope with Disaster

**Agency Description:** Anyone who is a parent knows how hard it can be to raise a child. Add a stressful situation, like a natural disaster or other emergencies, and a difficult job gets even harder. When disasters happen, it is important to remember the health and well-being of yourself and your children. If you are prepared for potential disasters, you can be more confident in your ability to keep your family safe, and your children are likely to handle the disaster better as well.

**Phone Number:** 1-800-CDC-INFO

**Email Address:** [cdcinfo@cdc.gov](mailto:cdcinfo@cdc.gov)

**Website:** <https://www.chla.org/sites/default/files/atoms/files//CHLA-CDC-Helping-Parents->

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# FEMA Preparedness Checklist for People with Disabilities and Special Needs



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** FEMA Preparedness Checklist for People with Disabilities and Special Needs

**Agency Description:** Preparing Makes Sense for People with Disabilities and Special Needs. Get Ready Now.

**Phone Number:**

**Email Address:**

**Website:** <https://www.chla.org/sites/default/files/atoms/files//CHLA-FEMA-Preparedness->

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition

# Food and Drug Administration (FDA) Preparing for Power Outages for Medical Devices



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Food and Drug Administration (FDA) Preparing for Power Outages for Medical Devices

**Agency Description:** Home Use Devices: How to Prepare for and Handle Power Outages for Medical Devices that Require Electricity

**Phone Number:**

**Email Address:**

**Website:** <https://www.chla.org/sites/default/files/atoms/files//CHLA-FDA-Preparing-for->

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness

**Conditions Covered:** Allergies, Anxiety, Arthritis, Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS)

# Centers for Disease Control and Prevention: Caring for Children and Youth with Special Healthcare Needs in Emergencies Toolkit



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Centers for Disease Control and Prevention: Caring for Children and Youth with Special Healthcare Needs in Emergencies Toolkit

**Agency Description:** All children have unique needs in emergencies, but care for children with special healthcare needs is often more complex because of their various health conditions and extra care requirements. They may have a hard time moving from one place to another, urgent or constant medical needs, difficulty communicating or have trouble with transitioning to different situations. A disaster can present all these difficulties at once. Knowing what to do can help maintain calm and keep your family safe.

**Phone Number:** (800) 232-4636

**Email Address:**

**Website:** <https://www.cdc.gov/childrenindisasters/children-with-special-healthcare->

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral Disaster/Emergency Preparedness

**Conditions Covered:** Brain Injury, Concussion, or Head Injury Allergies Anxiety Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Blood Disorders Cystic Fibrosis (CF) Down Syndrome Epilepsy / Seizure Disorder Intellectual Disability Spina Bifida Heart Condition

# HHS Child and Adolescent Health Emergency Planning Toolkit



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** HHS Child and Adolescent Health Emergency Planning Toolkit

**Agency Description:** The HHS Child and Adolescent Health Emergency Planning Toolkit addresses the needs of children and youth with special health care needs (CYSHCN) in emergency preparedness, response, recovery, mitigation, and community resilience activities. As a companion to the HHS Maternal-Child Health (MCH) Emergency Planning Toolkit, this toolkit aligns with ongoing HHS objectives to ensure health equity for all children, adolescents, and CYSHCN and their families/caregivers to ensure access to high-quality care, services, and support across the emergency management cycle.

**Phone Number:**

**Email Address:**

**Website:** <https://aspr.hhs.gov/at-risk/Pages/CYSHCN-planning-toolkit.aspx>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Government Agency Disaster/Emergency Preparedness

**Conditions Covered:** Allergies Arthritis Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Blindness or Problems with Seeing Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Developmental Delay Genetic or Inherited Condition Heart Condition Learning Difficulty Other Mental Health Condition Substance Use Disorder Deafness or Problems with Hearing Tourette Syndrome (TS) Spina Bifida Migraines Down Syndrome Other Behavioral / Conduct Problem

# Family Network on Disabilities: Disaster Planning for Children & Youth with Special Health Care Needs



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Family Network on Disabilities: Disaster Planning for Children & Youth with Special Health Care Needs

**Agency Description:** Care for Children and Youth with Special Health Care Needs (CYSHCN) is more complex during emergencies because of their various health conditions and extra care requirements. Families can have trouble moving because of urgent constant medical needs. Knowing what to do ahead of time can help keep your family calm and safe. Planning is extremely important and that is why you need to have an emergency care plan in place already in case of a disaster.

**Phone Number:** (800) 825-5736

**Email Address:**

**Website:** <https://fndusa.org/knowledgebase/disaster-planning-for-children-youth-with->

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Disaster/Emergency Preparedness

**Conditions Covered:** Allergies Arthritis Attention-Deficit/Hyperactivity Disorder (ADHD) Behavioral / Conduct Problem Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Brain Injury, Concussion, or Head Injury Deafness or Problems with Hearing Cystic Fibrosis (CF) Down Syndrome Diabetes Genetic or Inherited Condition Learning Difficulty Speech or Language Disorder Spina Bifida Other Mental Health Condition Substance Use Disorder Epilepsy / Seizure Disorder Developmental Delay Depression

# Emergency Medical Services for Children -Be Ready: Tips for Families of Children and Youth with Special Healthcare Needs



Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Emergency Medical Services for Children -Be Ready: Tips for Families of Children and Youth with Special Healthcare Needs

**Agency Description:** Families with children and youth with disabilities and medical needs are known to be some of the most vulnerable in a disaster. These families have fewer resources, and they require both community and health care provider support to achieve readiness.

When these families are disaster ready, they are less likely to suffer adverse consequences and are more resilient. The following toolkit of videos and accompanying infographics have been designed to meet to the diverse needs of the communities we serve.

**Phone Number:**

**Email Address:**

**Website:** <https://emscimprovement.center/domains/preparedness/asprcoe/region-v-for->

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Disaster/Emergency Preparedness

**Conditions Covered:** Allergies Anxiety Asthma Arthritis Autism Spectrum Disorder (ASD) Attention-Deficit/Hyperactivity Disorder (ADHD) Blood Disorders Blindness or Problems with Seeing Behavioral / Conduct Problem Cerebral Palsy (CP) Brain Injury, Concussion, or Head Injury Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Genetic or Inherited Condition Epilepsy / Seizure Disorder Heart Condition Intellectual Disability Learning Difficulty Migraines Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Other

# Westchester Institute for Human Development: Emergency Preparedness: My Safety, My Responsibility, My Plan



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Westchester Institute for Human Development: Emergency Preparedness: My Safety, My Responsibility, My Plan

**Agency Description:** My Safety, My Responsibility, My Plan is a multi-session program to train adults with intellectual disabilities to understand and to be prepared for emergencies. Information is based on the principles set by FEMA, the Department of Homeland Security, the American Red Cross and the U.S. Fire Administration. Download the Training Program curriculum and the Personal Emergency Plan below and follow along with the videos! Each video matches the section with the same name in the Training Program. You will be guided step-by-step to complete your own Personal Emergency Plan. Families can use the Family Guide to complete a Family Emergency Plan. My Safety, My Responsibility, My Plan was developed through corporate funding from Entergy with the support of the Westchester County Department of Emergency Services and the American Red Cross in Westchester County.

**Phone Number:**

**Email Address:** [sbellantoni@wihd.org](mailto:sbellantoni@wihd.org)

**Website:** <https://www.wihd.org/resources/resource/emergency-preparedness-my-safety->

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Disaster/Emergency Preparedness Medical Dental & Behavioral Health

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# FEMA Youth and Emergency Planning



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** FEMA Youth and Emergency Planning

**Agency Description:** Disaster planning, response and recovery efforts must consider the unique needs and abilities of children, who make up roughly a quarter of the U.S. population.

**Phone Number:**

**Email Address:**

**Website:** <https://www.fema.gov/emergency-managers/individuals-communities/youth>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Disaster/Emergency Preparedness Government Agency

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Autism Society



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Autism Society

**Agency Description:** For 58 years and counting, the Autism Society, including our nationwide network of affiliates, connects people to the resources they need through education, advocacy, support, information and referral, and community programming.

**Phone Number:** 18003288476

**Email Address:** [info@autism-society.org](mailto:info@autism-society.org)

**Website:** <https://autismsociety.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Early Childhood & School Aged, Care Coordination, Community Living & Recreation, Information & Referral, Financial Legal & Advocacy, Transitioning to Adulthood (Youth)

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# Ascent Autism



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Ascent Autism

**Agency Description:** Ascent Autism empowers individuals with autism by nurturing their social skills and fostering meaningful connections with their peers. Our expert-designed program from UCSF and Stanford Medical School has fostered lasting social abilities and friendships for over a thousand participants.

**Phone Number:**

**Email Address:** faraz@ascentautism.com

**Website:** <https://beaminghealth.com/providers/ascent-autism1?service=parent->

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Community Living & Recreation Transitioning to Adulthood (Youth) Early Childhood & School Aged Information & Referral

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# NYS Crisis Text Line



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** NYS Crisis Text Line

**Agency Description:** A crisis can happen at any time. And it isn't always a life-threatening situation.

Maybe you're stressed about school, work, family or your housing situation? Maybe you're a new parent and are overwhelmed?

There's a new way to reach out.

New York State has partnered with Crisis Text Line, an anonymous texting service available 24/7. Starting a conversation is easy. Text GOT5 to 741741 or Got5U to 741741 if you're a college student. We've got time to talk.

**Phone Number:** Text GOT5 to 741741

**Email Address:**

**Website:** [https://omh.ny.gov/omhweb/suicide\\_prevention/cp.html](https://omh.ny.gov/omhweb/suicide_prevention/cp.html)

**Counties Served:** State-Wide

**Content Categories:** Crisis Resources

**Conditions Covered:** Anxiety Behavioral / Conduct Problem Autism Spectrum Disorder (ASD) Blood Disorders Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Brain Injury, Concussion, or Head Injury Allergies Arthritis Blindness or Problems with Seeing Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# 988 Suicide and Crisis Lifeline

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** 988 Suicide and Crisis Lifeline

**Agency Description:** If your life or someone else's is in imminent danger, please call 911. If you are in crisis and need immediate help, please call or text: 988

When people call, text, or chat with the 988 Lifeline, they are connected to trained crisis counselors who are part of the existing 988 Lifeline network, made up of over 200 local crisis centers. These crisis counselors are trained to provide free and confidential emotional support and crisis counseling to people in suicidal crisis or emotional distress and connect them to resources. These services are available 24 hours a day, seven days a week, across the United States.

**Phone Number:** Text 988

**Email Address:**

**Website:** <https://988lifeline.org/current-events/the-lifeline-and-988/>

**Counties Served:** State-Wide

**Content Categories:** Crisis Resources

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Tourette Syndrome (TS) Substance Use Disorder Spina Bifida

# The National Mental Health Hotline



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** The National Mental Health Hotline

**Agency Description:** It's easy to get overwhelmed when you or someone you love is in distress, and talking to friends or relatives may be difficult. Reaching out saves lives, however, and the Mental health hotline provides the ear of a compassionate professional who knows how to deal with a mental health crisis. Sometimes, a brief conversation is all it takes to put things in perspective and move forward.

The Mental Health Hotline at 866-903-3787 can answer your questions confidentially and free of charge.

**Phone Number:** 1-866-903-3787

**Email Address:**

**Website:** <https://mentalhealthhotline.org/>

**Counties Served:** State-Wide

**Content Categories:** Crisis Resources

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Tourette Syndrome (TS) Substance Use Disorder Spina Bifida

# HOPE NY



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** HOPE NY

**Agency Description:** Need help? You are not alone. New York's 24/7 substance use and gambling HOPEline can help.

**Phone Number:** 1-877-846-7369

**Email Address:**

**Website:** <https://oasas.ny.gov/hopeline>

**Counties Served:** State-Wide

**Content Categories:** Crisis Resources

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# NAMI Helpline & More



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** NAMI Helpline & More

**Agency Description:** The National Alliance on Mental Illness provides a wealth of resources, including the NAMI Helpline, which can be reached by calling 1-800-950-6264 or by emailing info@nami.org. Although the helpline is only available Monday through Friday from 10AM until 8PM EST, there is a 24/7 text-line available. Simply text 'NAMI' to 741-741 for assistance.

**Phone Number:** 1-800-950-6264

**Email Address:** info@nami.org

**Website:** <https://nami.org/Home>

**Counties Served:** State-Wide

**Content Categories:** Crisis Resources

- Conditions Covered:**
- Allergies
  - Anxiety
  - Arthritis
  - Asthma
  - Attention-Deficit/Hyperactivity Disorder (ADHD)
  - Autism Spectrum Disorder (ASD)
  - Behavioral / Conduct Problem
  - Blindness or Problems with Seeing
  - Blood Disorders
  - Brain Injury, Concussion, or Head Injury
  - Cerebral Palsy (CP)
  - Cystic Fibrosis (CF)
  - Deafness or Problems with Hearing
  - Depression
  - Developmental Delay
  - Diabetes
  - Down Syndrome
  - Epilepsy / Seizure Disorder
  - Genetic or Inherited Condition
  - Heart Condition
  - Intellectual Disability
  - Learning Difficulty
  - Migraines
  - Other
  - Other Mental Health Condition
  - Speech or Language Disorder
  - Spina Bifida
  - Substance Use Disorder
  - Tourette Syndrome (TS)

# Special Tomato



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Special Tomato

**Agency Description:** Unique innovation is what keeps Special Tomato on the leading edge of pediatric seating & positioning. Our designers and engineers work hand in hand with leading therapists to design versatile, durable products that accommodate a wide range positioning needs.

Thanks for letting us share our Special Tomato product line with you. This unique product line features our proprietary, comfortable cushion technology that provide a proper fit and are very easy to care for. Special Tomato cushions are not only used in our portable bases, but also in our Strollers, Car Seats, Hi-Low Seating Systems, & Potty Seats. Check out all the Special Tomato products today!

**Phone Number:** 1-866-529-8407

**Email Address:** [customerservice@specialtomato.com](mailto:customerservice@specialtomato.com)

**Website:** <https://www.specialtomato.com/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Early Childhood & School Aged

**Conditions Covered:** Autism Spectrum Disorder (ASD) Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Developmental Delay Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Intellectual Disability Spina Bifida Other Other Mental Health Condition

# New York State Parent Portal



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** New York State Parent Portal

**Agency Description:** The NYS Parenting Portal provides caregiving tips and resources to enhance your role as a parent.

**Phone Number:** (518) 473-3652

**Email Address:** nysb5@ccf.ny.gov

**Website:** <https://www.nysparenting.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports, Early Childhood & School Aged, Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Developmental Delay, Other Mental Health Condition, Down Syndrome, Cerebral Palsy (CP)

# New York State Department of Health Resource Directory for Children and Youth with Special Health Care Needs



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health Resource Directory for Children and Youth with Special Health Care Needs

**Agency Description:** This resource directory is for the families of children and youth who have a serious illness or long-lasting condition for which they need extra health care and support services.

**Phone Number:**

**Email Address:** OGS.SM.GDC@OGS.NY.GOV

**Website:** <https://www.health.ny.gov/publications/0548/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Family & Supports Early Childhood & School Aged Transitioning to Adulthood (Youth)

**Conditions Covered:** Allergies Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Blood Disorders Blindness or Problems with Seeing Cerebral Palsy (CP) Cystic Fibrosis (CF) Genetic or Inherited Condition Depression Learning Difficulty Migraines Spina Bifida Brain Injury, Concussion, or Head Injury Developmental Delay Diabetes

# New York State Department of Health Medicaid



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health Medicaid

**Agency Description:** New York's Medicaid program provides comprehensive health coverage to more than 7.3 million lower-income New Yorkers (as of December, 2021.) Medicaid pays for a wide-range of services, depending on your age, financial circumstances, family situation, or living arrangements. These services are provided through a large network of health care providers that you can access directly using your Medicaid card or through your managed care plan if you are enrolled in managed care. Some services may have small co-payments, which can be waived if you cannot afford them.

**Phone Number:** (800) 541-2831

**Email Address:** [medicaid@health.ny.gov](mailto:medicaid@health.ny.gov)

**Website:** [www.health.ny.gov/health\\_care/medicaid/](http://www.health.ny.gov/health_care/medicaid/)

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Medical Dental & Behavioral Health Government Agency

**Conditions Covered:** Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Cerebral Palsy (CP) Cystic Fibrosis (CF) Developmental Delay Spina Bifida Genetic or Inherited Condition Epilepsy / Seizure Disorder Down Syndrome

# Name: New York State Department of Health Medicaid Waiver Program - 1915(c) Children's Waiver and 1115 Waiver Amendments



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Name: New York State Department of Health Medicaid Waiver Program - 1915(c) Children's Waiver and 1115 Waiver Amendments

**Agency Description:** As part of the Children's Medicaid System Redesign, the 1915(c) Children's Waiver and 1115 Demonstration Waiver work together to offer an array of services to provide the right support, in the right amount, at the right time to maintain children/youth in their homes or in their communities in the least restrictive settings. The goals of the Children's Waiver are to keep children/youth on their developmental trajectory, identify needs early and intervene, focus on recovery and building resilience, prevent escalation and need for higher-end services, maintain accountability for improved outcomes and delivery of quality care, and make more services available to children/youth from birth to age 21

**Phone Number:**

**Email Address:** BH.Transition@health.ny.gov

**Website:** [https://www.health.ny.gov/health\\_care/medicaid/redesign/behavioral\\_health/chil](https://www.health.ny.gov/health_care/medicaid/redesign/behavioral_health/chil)

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Medical Dental & Behavioral Health Family & Supports

**Conditions Covered:** Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Developmental Delay Brain Injury, Concussion, or Head Injury Other Mental Health Condition

# New York State Department of Health Home and Community-Based Services Medicaid Waiver for Individuals with Traumatic



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health Home and Community-Based Services Medicaid Waiver for Individuals with Traumatic Brain Injury (HCBS/TBI)

**Agency Description:** The HCBS/TBI waiver is accessed through a network of Regional Resource Development Centers (RRDC) which serve specific counties throughout the state. The Waiver provides a variety of services to support an individual in the community. Each waiver participant selects an approved Service Coordinator to assist them in the development of a Service Plan and to oversee the provision of all services selected by the participant.

**Phone Number:** (518) 474-5271

**Email Address:**

**Website:** [https://www.health.ny.gov/publications/0548/hcbs\\_traumatic\\_brain\\_injury.htm](https://www.health.ny.gov/publications/0548/hcbs_traumatic_brain_injury.htm)

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Medical Dental & Behavioral Health Family & Supports Care Coordination

**Conditions Covered:** Brain Injury, Concussion, or Head Injury

# New York State Department of Health Home and Community-Based Services Waiver/Long-Term Home Health Care Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Department of Health Home and Community-Based Services Waiver/Long-Term Home Health Care Program (HCBS/LTHHCP)

**Agency Description:** State-wide Medicaid based program to prevent premature and/or unwanted institutionalization by providing a coordinated plan of care and services to individuals of any age who would otherwise require nursing facility care

**Phone Number:**

**Email Address:**

**Website:** [https://www.health.ny.gov/publications/0548/hcbs\\_long\\_term\\_home\\_health\\_care](https://www.health.ny.gov/publications/0548/hcbs_long_term_home_health_care).

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Care Coordination Family & Supports Medical Dental & Behavioral Health

**Conditions Covered:** Cerebral Palsy (CP) Cystic Fibrosis (CF) Blood Disorders Epilepsy / Seizure Disorder Spina Bifida

# New York State Office for People With Developmental Disabilities Comprehensive Home and Community Based Services (1915-c HCBS)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Office for People With Developmental Disabilities Comprehensive Home and Community Based Services (1915-c HCBS) Waiver Program

**Agency Description:** The Home and Community-Based Services Waiver is the Medicaid program that provides services for adults and children with developmental disabilities in their own home and community.

**Phone Number:**

**Email Address:** [info@opwdd.ny.gov](mailto:info@opwdd.ny.gov)

**Website:** <https://opwdd.ny.gov/providers/home-and-community-based-services-waiver>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Government Agency Family & Supports Medical Dental & Behavioral Health

**Conditions Covered:** Developmental Delay Autism Spectrum Disorder (ASD) Down Syndrome Intellectual Disability

# New York State Education Department - Special Education



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Education Department - Special Education

**Agency Description:** The Office of Special Education provides assistance related to services and programs for students with disabilities. Staff work to provide the most up to date policy and guidance, technical assistance, professional development, and monitoring to attain equal opportunities and positive results for students with disabilities across New York State.

**Phone Number:** (518) 473-2878

**Email Address:** [speced@nysed.gov](mailto:speced@nysed.gov)

**Website:** <https://www.nysed.gov/special-education>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Early Childhood & School Aged Financial Legal & Advocacy Family & Supports

**Conditions Covered:** Allergies Arthritis Attention-Deficit/Hyperactivity Disorder (ADHD) Anxiety Asthma Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# New York State Children's Asthma Initiative



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** New York State Children's Asthma Initiative

**Agency Description:** APNY fosters collaboration across partners working to expand comprehensive, evidence-based asthma control services in NYS and disseminates educational information and opportunities for asthma-related trainings and resources.

**Phone Number:**

**Email Address:** [asthma@health.ny.gov](mailto:asthma@health.ny.gov)

**Website:** <https://nyschildrensasthmainitiative.com/asthma-partnership-of-new-york/>

**Counties Served:** State-Wide

**Content Categories:**

**Conditions Covered:** Asthma

# Brain Injury Association of New York State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Brain Injury Association of New York State

**Agency Description:** The Brain Injury Association of New York State is a statewide non-profit membership organization that provides advocacy and support to people and families living with brain injuries.

**Phone Number:** (518) 459-7911

**Email Address:** [info@bianys.org](mailto:info@bianys.org)

**Website:** <https://bianys.org/>

**Counties Served:** State-Wide

**Content Categories:**

**Conditions Covered:** Brain Injury, Concussion, or Head Injury

# US Department of Education - Office of Civil Rights



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** US Department of Education - Office of Civil Rights

**Agency Description:** The mission of the Office for Civil Rights is to ensure equal access to education and to promote educational excellence throughout the nation through vigorous enforcement of civil rights.

**Phone Number:** (800) 421-3481

**Email Address:** OCR@ed.gov

**Website:** <https://www2.ed.gov/about/offices/list/ocr/index.html>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Government Agency Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Little Lobbyists

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Little Lobbyists

**Agency Description:** Little Lobbyists seek to protect and expand the rights of children who have complex medical needs and disabilities through advocacy, education, and outreach.

**Phone Number:**

**Email Address:**

**Website:** <http://littlelobbyists.org/>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy

**Conditions Covered:** Tourette Syndrome (TS) Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida

# Abilities Movement



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Abilities Movement

**Agency Description:** Personalized fitness/wellness classes, Power Wheelchair Soccer, and Mighty Dunks basketball. All ages.

**Phone Number:** (585) 690-4408 (call or

**Email Address:**

**Website:** [abilitiesmovement.org](http://abilitiesmovement.org)

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Challenger Miracle Field



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Challenger Miracle Field

**Agency Description:** Challenger Miracle Field is a one-of-a-kind environment for the 150,000 individuals who live with disabilities in and around Rochester, New York.

**Phone Number:**

**Email Address:**

**Website:** <https://rochestermiraclefield.org/>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# The Community Place of Greater Rochester, Inc.



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** The Community Place of Greater Rochester, Inc.

**Agency Description:** The Community Place of Greater Rochester, Inc.(CPGR) is a nonprofit agency founded on the belief that everyone should enjoy the same health, economic, and social opportunities no matter who they are or where they live. Born from the merger of the Lewis Street Center, Genesee Settlement House and Eastside Community Center; The Community Place serves residents of Northeast Rochester. We deliver a wide range of social, developmental, and educational programs delivered through our facilities in the northeast sector of the city of Rochester (NY) and throughout the greater Rochester area. We are a leading neighborhood-based community center, providing a foundation for growth, empowerment and stability for those we serve. The Community Place is proud to continue the legacy built by its former organizations and continue the settlement house movement in Rochester. We invite you to learn more about the programs and services we provide to the people of Rochester—from children and teenagers to families and seniors to individuals with developmentally disabilities.

**Phone Number:** (585) 336-4692

**Email Address:** nseaman@communityplace.org

**Website:** [www.communityplace.org](http://www.communityplace.org)

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# CP Rochester/SportsNet



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** CP Rochester/SportsNet

**Agency Description:** Recreation respite, swimming, fitness, fine arts, cycling, golf, canoeing, hockey, basketball, skiing.  
Ages 5+

**Phone Number:** CP Rochester: (585) 334-

**Email Address:**

**Website:** <http://www.cprochester.org/>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# EquiCenter, Inc.



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** EquiCenter, Inc.

**Agency Description:** Equestrian programs, yoga. Ages 3+

**Phone Number:** (585) 624-7772

**Email Address:** [info@equicenterny.org](mailto:info@equicenterny.org)

**Website:** <https://www.equicenterny.org/>

**Counties Served:** [Monroe County](#)

**Content Categories:** [Community Living & Recreation](#)

**Conditions Covered:**

# Erie Canal Boat Company



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Erie Canal Boat Company

**Agency Description:** Paddling, cycling. All ages.

**Description:**

**Phone Number:** (585) 748-2628

**Email Address:** eriecanalboatcompany@gmail.com

**Website:** <https://eriecanalboatcompany.com/>

**Counties Served:** Monroe County Albany County Oneida County Onondaga County Erie County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Greece Rec Friends and Fun Social

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Greece Rec Friends and Fun Social

**Agency Description:** 1 Vince Tofany Blvd  
Greece, NY 14612

**Phone Number:** (585) 723-2425

**Email Address:**

**Website:** <https://greeceny.gov/>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# R Community Bikes

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** R Community Bikes

**Agency Description:** R Community Bikes (RCB) is a grassroots, 501(c)3 organization, staffed entirely by volunteers, that collects and repairs used bicycles for distribution, free of charge, to the Rochester, NY area's most needy children and adults. We give away over 2,000 bicycles every year and do over 3,000 repairs for our clients, many of whom depend on bicycles as their main source of transportation. Starting in 2014, we began providing tricycles to disabled individuals who wouldn't otherwise be able to ride. In addition, we supply bicycles or repair services to dozens of community organizations, including church groups, youth centers, and neighborhood associations.

**Phone Number:** (585) 234-2008

**Email Address:** [info@rcommunitybikes.net](mailto:info@rcommunitybikes.net)

**Website:** <https://www.rcommunitybikes.net/>

**Counties Served:** [Monroe County](#)

**Content Categories:** [Community Living & Recreation](#)

**Conditions Covered:**

# Rochester Accessible Adventures



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Rochester Accessible Adventures

**Agency Description:** Trains recreation businesses in Greater ROC, Finger Lakes Region, & WNY regions to operate inclusively (follow updated list on website). Also supports adaptive & inclusive sports, eg, wheelchair basketball, sled hockey. All ages.

**Phone Number:** (585) 491-6011

**Email Address:** RAA@rochesteraccessibleadventures.org

**Website:** <https://rochesteraccessibleadventures.org/>

**Counties Served:** Monroe County, Orleans County, Genesee County, Wyoming County, Allegany County, Livingston County, Steuben County, Wayne County, Ontario County, Yates County, Schuyler County, Chemung County, Seneca County, Cayuga County, Tompkins County, Tioga County, Cortland County, Onondaga County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Rochester Rookies



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Rochester Rookies

**Agency Description:** Track, field, road racing, swimming, weight lifting, archery, table tennis. Ages 5+.

**Phone Number:** (585) 301-1144

**Email Address:**

**Website:** <https://therochesterrookies.org/>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# The Pieters Family Life Center



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** The Pieters Family Life Center

**Agency Description:** Fitness room, fitness classes, multi-purpose gymnasium, zumba, yoga, water aerobics, Creative arts studios. Operated by Heritage Christian Services. Ages 12+

**Phone Number:** (585) 487-3500

**Email Address:** [info@pietersfamilylifecenter.org](mailto:info@pietersfamilylifecenter.org)

**Website:** <https://pietersfamilylifecenter.org/>

**Counties Served:** [Monroe County](#)

**Content Categories:** [Community Living & Recreation](#)

**Conditions Covered:**

# Artists Unlimited



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Artists Unlimited

**Agency Description:** To offer a unique expressive experience, in a safe haven, to those individuals who may not otherwise have an opportunity to participate as actors in other venues. Performing quality works with the message of inclusion and respect, Artists Unlimited's theater program and our choral program, Voices, seeks to break down barriers and stereotypes often attributed to those who are disabled. By integrating our cast, individuals with and without disabilities often learn life skills from each other that go beyond the theater venue.

**Phone Number:** (585) 219-5188

**Email Address:** [artistsunlimitedroc@gmail.com](mailto:artistsunlimitedroc@gmail.com)

**Website:** [rocartistsunlimited.com](http://rocartistsunlimited.com)

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Ashford Dance Company



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Ashford Dance Company

**Agency Description:** They offer many styles of dance for dancers ages 1.5 and up, from beginner to advanced, and for dancers with diverse abilities.

**Phone Number:** (585) 417-6580

**Email Address:**

**Website:** <https://www.ashforddanceco.com/>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Hochstein School of Music & Dance



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Hochstein School of Music & Dance

**Agency Description:** The mission of The Hochstein School is to provide people of all ages, backgrounds, and abilities with access to excellent music and dance education in a community that nurtures and encourages personal achievement.

**Phone Number:** (585) 454-4596

**Email Address:**

**Website:** <https://hochstein.org/>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Spectrum Creative Arts



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Spectrum Creative Arts

**Agency Description:** Spectrum Creative Arts is an inclusive arts education and therapy center, specializing in person-centered opportunities for learners with special needs.

**Phone Number:** (585) 383-1999

**Email Address:** [office@spectrumcreativearts.org](mailto:office@spectrumcreativearts.org)

**Website:** <https://spectrumcreativearts.org/>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Spotted Rabbit Studio



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Spotted Rabbit Studio

**Agency Description:** They specialize in quality trauma-informed, strength-based care for neurodivergent individuals and the LGBTQIA+ community. Art, music, creative arts therapy. Ages 5+

**Phone Number:** (585) 430-9877

**Email Address:**

**Website:** <https://spottedrabbitstudio.com/>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# 25 North Dance

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** 25 North Dance

**Agency** Dance. Ages 1-18

**Description:**

**Phone Number:** (585) 737-0680

**Email Address:**

**Website:** 25northdance.com

**Counties** Monroe County

**Served:**

**Content** Community Living & Recreation

**Categories:**

**Conditions**

**Covered:**

# Autism Nature Trail



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Autism Nature Trail

**Agency Description:** An experience in nature, designed specifically for visitors with ASD and their families.

**Phone Number:** 585-237-0270 x2103

**Email Address:**

**Website:** autismnaturetrail.com

**Counties Served:** Livingston County Wyoming County

**Content Categories:**

**Conditions Covered:**

# Kids Out and About in Rochester



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Kids Out and About in Rochester

**Agency Description:** Rochester's online guide to everything for kids, teens, and families

**Phone Number:** (585) 633-8400

**Email Address:** ross@kidsoutandabout.com

**Website:** <https://rochester.kidsoutandabout.com/>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Bleeding Disorders Association of Northeastern New York



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Bleeding Disorders Association of Northeastern New York

**Agency Description:** Established in 1968 as the Upper Hudson Valley Chapter - National Hemophilia Foundation, Inc., the organization provides services and referrals to members of the community (and their families) and encourages them to advocate for their own health care. Furthermore, the organization provides programs that will improve the quality of life for persons afflicted with genetic bleeding disorders and their associated complications. BDANENY currently serves 22 counties of New York State. The territory extends from Ulster and Dutchess counties east to the Green Mountains, west to Oneida County and north to the American/Canadian border. The Association is comprised of dedicated volunteers including patients, family members of patients, and health care professionals.

**Phone Number:** (518) 729-3577

**Email Address:**

**Website:** <https://www.bdaneny.org/about>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral

**Conditions Covered:** Blood Disorders

# Hemophilia Association of New York



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Hemophilia Association of New York

**Agency Description:** Finding healthcare can be confusing and financially challenging. Our direct assistance program helps people with hemophilia gain access to necessary treatment through financial aid and other resources. We work hard to organize information about the ever-changing healthcare landscape and its impact on people with hemophilia. Our quarterly electronic newsletter keeps our community of patients, researchers, and caregivers updated.

**Phone Number:** (212) 682-5510

**Email Address:** admin@hemophiliany.com

**Website:** <https://hemophiliany.com/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Information & Referral

**Conditions Covered:** Blood Disorders

# Mary M. Gooley Hemophilia Center



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Mary M. Gooley Hemophilia Center

**Agency Description:** The Mary M. Gooley Hemophilia Center (the Center) is an independent, federally designated Hemophilia Treatment Center based in Rochester, New York (serving people in the surrounding 14 county region) that cares for people affected by hemophilia, von willebrand disease, other rare bleeding disorders, hemochromatosis and gaucher's disease. The Center is a 501(c)(3) non-profit corporation, licensed and regulated by New York State and governed by a community board of directors.

**Phone Number:** (585) 922-5700

**Email Address:**

**Website:** <https://www.hemocenter.org/>

**Counties Served:** Monroe County

**Content Categories:** Information & Referral

**Conditions Covered:** Blood Disorders

# Bleeding Disorders Advocacy Network



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency**                      Bleeding Disorders Advocacy Network

**Agency Description:**                      We at Bleeding Disorders Advocacy Network believe in the value of fostering independence through knowledge, self-advocacy, and supportive community. Our mission is to provide programs and informational resources to help people affected by bleeding disorders lead healthier, more productive lives.

**Phone Number:**                      (315) 396-2944

**Email Address:**                      bdaninc@gmail.com

**Website:**                      <https://www.bdaninc.org/>

**Counties Served:**                      State-Wide

**Content Categories:**                      Family & Supports    Information & Referral    Financial Legal & Advocacy

**Conditions Covered:**                      Blood Disorders

# Skating Association for the Blind and Handicapped



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Skating Association for the Blind and Handicapped

**Agency Description:** As we celebrate our 47th season of serving those in our community challenged by disability, SABAH continues to be dedicated to the mission of enriching the quality of life for individuals challenged by physical, cognitive, and/or emotional disability by providing education and therapeutic recreation, promoting fitness, and developing social and communication skills. Although the organization began as one which provided adaptive ice skating for those with special needs over the winter, SABAH now offers six year round programs, on ice and on turf, for more than 830 participants. With the support of more than 500 remarkable volunteers from this region, SABAH has expanded programming to increase the physical activity and wellness of those we serve.

**Phone Number:** (716) 362-9600

**Email Address:** SABAH@sabahinc.org

**Website:** <https://sabahinc.org/>

**Counties Served:** Monroe County Erie County

**Content Categories:** Community Living & Recreation

**Conditions Covered:** Blindness or Problems with Seeing

# PATH International North American Riding for the Handicapped



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** PATH International North American Riding for the Handicapped

**Agency Description:** PATH Intl. was founded in 1969 to promote safe and effective therapeutic — also known as adaptive — horseback riding throughout the United States and Canada. Today, PATH Intl. has 794 member centers, nearly 4,000 individual members and more than 4,800 certified professionals in countries all over the world who help and support more than 46,600 children and adults — including 5,200 veterans — with special needs each year through a variety of equine-assisted services.

**Phone Number:** (800) 369-7433

**Email Address:**

**Website:** <https://pathintl.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation

**Conditions Covered:** Cerebral Palsy (CP) Developmental Delay Intellectual Disability

# Very Special Camps



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Very Special Camps

**Agency Description:** Dedicated exclusively to camps that serve individuals with one or more of a wide range of special needs.

**Phone Number:**

**Email Address:**

**Website:** <https://www.veryspecialcamps.com/New-York/Special-Needs-Summer->

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Adaptive Sports Foundation



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Adaptive Sports Foundation

**Agency Description:** Since 1984, the Adaptive Sports Foundation has been providing sports and recreation opportunities to thousands of children and adults with both cognitive and physical disabilities. Considered one of the top adaptive sports programs in the country, the ASF has been on the cutting edge of adaptive sports programming and has provided what participants have often described as "life changing experiences." The Adaptive Sports Foundation is a 501(c)(3) non-profit organization.

**Phone Number:** (518) 734-5070

**Email Address:** [info@adaptivesportsfoundation.org](mailto:info@adaptivesportsfoundation.org)

**Website:** <https://www.adaptivesportsfoundation.org/the-adaptive-sports-foundation/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Camp Whitman on Seneca Lake Pine Camp



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Camp Whitman on Seneca Lake Pine Camp

**Agency Description:** For more than 35 years Camp Whitman has been providing overnight camp or “vacation” weeks for youth and adults with developmental disabilities. Many of our campers have been attending Camp Whitman year after year, and widely share that their week at camp is the highlight of their year. Some campers have been returning for more than 20 years!

All of our popular camp activities are offered to our campers with developmental disabilities, and accommodations are made where needed to provide additional support.

**Phone Number:** (315) 220-0084

**Email Address:** [camp@campwhitman.org](mailto:camp@campwhitman.org)

**Website:** <https://www.campwhitman.org/pine-camp>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Bring on the Spectrum



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Bring on the Spectrum

**Agency Description:** Our community space offers social, recreational and lifestyle activities for neurodiverse and neurotypical children, teens and adults like Art, Yoga, Music, Zumba Life Skills and more. [Click here.](#)

Our Sensory Gym has equipment like swings, slides, fitness and more.

**Phone Number:** (518) 641-1971

**Email Address:** [info@bringonthespectrum.org](mailto:info@bringonthespectrum.org)

**Website:** <https://www.bringonthespectrum.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Rochester Accessible Adventures



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Rochester Accessible Adventures

**Agency Description:** RAA exists to reshape places where inclusion isn't happening, to empower these spaces to operate with full inclusion of people with and without disabilities whenever their doors are open for business.

**Phone Number:** (585) 491-6011

**Email Address:** RAA@RochesterAccessibleAdventures.org

**Website:** <https://rochesteraccessibleadventures.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Genesee Valley Rotary Camp



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Genesee Valley Rotary Camp

**Agency Description:** Genesee Valley Rotary Camp (GVRC), is a one week summer camp for young people (ages 8 – 21) with various disabilities. GVRC is a not-for-profit organization that became incorporated in 1963 and has served children and young adults from four surrounding counties (Livingston, Steuben, Wyoming, and Allegany) ever since.

smrotarywheel

The camp experience is provided free of cost through the efforts and financial support of the Rotary Clubs of the Genesee Valley and through private donations.

**Phone Number:**

**Email Address:**

**Website:** <https://gvrc.org/>

**Counties Served:** Wyoming County, Allegany County, Livingston County, Steuben County

**Content Categories:** Community Living & Recreation

**Conditions Covered:**

# Camp Haccamo



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency**            Camp Haccamo

**Agency Description:**    We are a Rotary Camp designed to provide a FREE, safe and fun summer camping experience for children and adults with a wide range of special needs

**Phone Number:**    (585) 381-5710

**Email Address:**

**Website:**            <https://www.camphaccamo.org/>

**Counties Served:**    Monroe County

**Content Categories:**    Community Living & Recreation

**Conditions Covered:**

# Camp Onseyawa



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency**            Camp Onseyawa

**Agency Description:**    Camp Onseyawa is supported by funds raised by 21 Rotary Clubs covering a four county area in New York State. Clubs from Ontario, Seneca, Yates and Wayne counties conduct annual fund raising events so that these children can attend camp with no cost to their family. Camp Onseyawa gets its name from the first two letters of the name of each county. Legend also has it that by an incredible coincidence it is also an ancient Indian word that translates to "Land of Happiness".

**Phone Number:**    (315) 332-1020

**Email Address:**    onseyawa@gmail.com

**Website:**            <https://www.onseyawa.org/>

**Counties Served:**    [Ontario County](#)   [Seneca County](#)   [Yates County](#)   [Wayne County](#)

**Content Categories:**    [Community Living & Recreation](#)

**Conditions Covered:**

# Rochester Rotary Sunshine Camp



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Rochester Rotary Sunshine Camp

**Agency Description:** Rochester Rotary Sunshine Camp is a fully accessible residential summer camp that has met the needs of children with paralysis and other physical challenges and their families since 1922.

Each summer, more than 2,500 children and adult campers with disabilities and city youth take advantage of this 157-acre campground in Rush, N.Y. It is the only camp facility of its kind in Greater Rochester that gives children with special needs unique overnight camping experiences.

Rochester Rotary Sunshine Camp is owned by Rochester Rotary Charitable Trusts Inc. and operated by the Rochester Rotary Club. The facility hosts summer camps held by Rochester Rotary as well as eight partner agencies.

**Phone Number:** (585) 533-2080

**Email Address:**

**Website:** <https://www.sunshinecamp.org/>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Disability:IN



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Disability:IN

**Agency Description:** Disability:IN share disability related awareness topics for each month and advocates for people with disabilities.

**Phone Number:**

**Email Address:** info@disabilityIN.org

**Website:** <https://disabilityin.org/resource/2024-calendar-of-disability-related-dates/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral

- Conditions Covered:**
- Allergies
  - Arthritis
  - Attention-Deficit/Hyperactivity Disorder (ADHD)
  - Autism Spectrum Disorder (ASD)
  - Blindness or Problems with Seeing
  - Behavioral / Conduct Problem
  - Anxiety
  - Blood Disorders
  - Brain Injury, Concussion, or Head Injury
  - Asthma
  - Cystic Fibrosis (CF)
  - Cerebral Palsy (CP)
  - Depression
  - Deafness or Problems with Hearing
  - Developmental Delay
  - Down Syndrome
  - Diabetes
  - Epilepsy / Seizure Disorder
  - Genetic or Inherited Condition
  - Heart Condition
  - Intellectual Disability
  - Learning Difficulty
  - Migraines
  - Other
  - Other Mental Health Condition
  - Speech or Language Disorder
  - Spina Bifida
  - Substance Use Disorder
  - Tourette Syndrome (TS)

# CDC's Learn the Signs Act Early



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** CDC's Learn the Signs Act Early

**Agency Description:** From birth to 5 years, your child should reach milestones in how he plays, learns, speaks, acts and moves. Track your child's development and act early if you have a concern.

**Phone Number:**

**Email Address:**

**Website:** <https://www.cdc.gov/ncbddd/actearly/index.html?>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Developmental Delay Down Syndrome Cystic Fibrosis (CF) Speech or Language Disorder

# ARCH National Respite Network



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** ARCH National Respite Network

**Agency Description:** We assist and promote the development of quality respite and crisis care programs, help families locate respite and crisis care services, and serve as a strong voice for respite in all forums.

**Phone Number:** (703) 256-2084

**Email Address:**

**Website:** <https://archrespite.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Care Coordination

**Conditions Covered:**

# NEW YORK STATE REGIONAL CENTERS FOR AUTISM SPECTRUM DISORDERS



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** NEW YORK STATE REGIONAL CENTERS FOR AUTISM SPECTRUM DISORDERS

**Agency Description:** The New York State Regional Centers for Autism Spectrum Disorders (NYSRCASD) are a partnership of six university-affiliated programs across New York State. The partnership has an overarching goal of identifying, disseminating, and assisting in the implementation of evidence-based practices to build capacity to improve services and outcomes for children with autism spectrum disorders.

The University at Albany currently serves as headquarters for the statewide network, with partners at the University of Rochester; The Summit Center; SUNY Old Westbury; Binghamton University, SUNY; and the Child Study Center at NYU Langone Medical Center.

**Phone Number:** (518) 442-3300

**Email Address:**

**Website:** <https://www.albany.edu/autism/new-york-state-regional-centers-autism->

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# Syracuse University: Early Childhood FACE Center- Mid-State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Syracuse University: Early Childhood FACE Center- Mid-State

**Agency Description:** Our mission is to support and empower educational organizations, families, and communities to improve equity, access, opportunities, and outcomes for all students with disabilities in New York State.

Our Goal is to:

- provide structure that facilitates systems change efforts and sustainability of those changes
- encourage and promote culturally responsive-sustaining education that includes families and communities as valued partners
- promote greater efficiency and effectiveness in the delivery of high-quality services to families and professionals
- create a comprehensive, multi-disciplinary team approach focused on principles from NYSED's Blueprint for Improved Results for Students with Disabilities that supports our stakeholders

**Phone Number:** (315) 443-4352

**Email Address:** mkgill@syr.edu

**Website:** <https://osepartnership.org/center/mid-state-ec-face-center>

**Counties Served:** Cayuga County Onondaga County Cortland County Madison County Oswego County Tompkins County Seneca County Tioga County

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder

# Monroe 1 BOCES: Early Childhood FACE Center- Mid-West



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Monroe 1 BOCES: Early Childhood FACE Center- Mid-West

**Agency Description:** Our mission is to support and empower educational organizations, families, and communities to improve equity, access, opportunities, and outcomes for all students with disabilities in New York State.

Our Goal is to:

- provide structure that facilitates systems change efforts and sustainability of those changes
- encourage and promote culturally responsive-sustaining education that includes families and communities as valued partners
- promote greater efficiency and effectiveness in the delivery of high-quality services to families and professionals
- create a comprehensive, multi-disciplinary team approach focused on principles from NYSED's Blueprint for Improved Results for Students with Disabilities that supports our stakeholders

**Phone Number:** (585) 249-7818

**Email Address:** beth\_grier-leva@boces.monroe.edu

**Website:** <https://osepartnership.org/center/mid-west-ec-face-center>

**Counties Served:** Genesee County Livingston County Steuben County Wyoming County Orleans County Seneca County

Yates County Wayne County Monroe County Ontario County

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder

# Monroe 1 BOCES: School-Age FACE Center- Mid-West



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Monroe 1 BOCES: School-Age FACE Center- Mid-West

**Agency Description:** Our mission is to support and empower educational organizations, families, and communities to improve equity, access, opportunities, and outcomes for all students with disabilities in New York State.

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- promote greater efficiency and effectiveness in the delivery of high-quality services to families and professionals
- create a comprehensive, multi-disciplinary team approach focused on principles from NYSED's Blueprint for Improved Results for Students with Disabilities that supports our stakeholders

**Phone Number:** (585) 249-7848

**Email Address:** jennifer\_cacioppo@boces.monroe.edu

**Website:** <https://osepartnership.org/center/mid-west-sa-face-center>

**Counties Served:** Genesee County Livingston County Steuben County Wyoming County Orleans County Seneca County

Yates County Wayne County Monroe County Ontario County

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder

# Erie I BOCES: Regional Partnership FACE Center- West



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Erie I BOCES: Regional Partnership FACE Center- West

**Agency Description:** Our mission is to support and empower educational organizations, families, and communities to improve equity, access, opportunities, and outcomes for all students with disabilities in New York State.

Our Goal is to:

- provide structure that facilitates systems change efforts and sustainability of those changes
- encourage and promote culturally responsive-sustaining education that includes families and communities as valued partners
- promote greater efficiency and effectiveness in the delivery of high-quality services to families and professionals
- create a comprehensive, multi-disciplinary team approach focused on principles from NYSED's Blueprint for Improved Results for Students with Disabilities that supports our stakeholders

**Phone Number:** (716) 821-7540

**Email Address:**

**Website:** <https://osepartnership.org/center/west-rpc>

**Counties Served:** Orleans County Niagara County Cattaraugus County Allegany County Erie County Wyoming County

Chautauqua County

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder

# Parent Network of WNY: Early Childhood FACE Center- West



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Parent Network of WNY: Early Childhood FACE Center- West

**Agency Description:** Our mission is to support and empower educational organizations, families, and communities to improve equity, access, opportunities, and outcomes for all students with disabilities in New York State.

Our Goal is to:

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- encourage and promote culturally responsive-sustaining education that includes families and communities as valued partners
- promote greater efficiency and effectiveness in the delivery of high-quality services to families and professionals
- create a comprehensive, multi-disciplinary team approach focused on principles from NYSED's Blueprint for Improved Results for Students with Disabilities that supports our stakeholders

**Phone Number:** (716) 332-4161

**Email Address:** [ktr@parentnetworkwny.org](mailto:ktr@parentnetworkwny.org)

**Website:** <https://osepartnership.org/center/west-ec-face-center>

**Counties Served:** Orleans County Niagara County Cattaraugus County Allegany County Erie County Wyoming County

Chautauqua County

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder

# Parent Network of WNY: School-Age FACE Center- West



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Parent Network of WNY: School-Age FACE Center- West

**Agency Description:** Our mission is to support and empower educational organizations, families, and communities to improve equity, access, opportunities, and outcomes for all students with disabilities in New York State.

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- promote greater efficiency and effectiveness in the delivery of high-quality services to families and professionals
- create a comprehensive, multi-disciplinary team approach focused on principles from NYSED's Blueprint for Improved Results for Students with Disabilities that supports our stakeholders

**Phone Number:** (716) 444-1910

**Email Address:** cac@parentnetworkwny.org

**Website:** <https://osepartnership.org/center/west-sa-face-center>

**Counties Served:** Orleans County Niagara County Cattaraugus County Allegany County Erie County Wyoming County

Chautauqua County

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder

# Syracuse University: Regional Partnership FACE Center-Mid-State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Syracuse University: Regional Partnership FACE Center- Mid-State

**Agency Description:** Our mission is to support and empower educational organizations, families, and communities to improve equity, access, opportunities, and outcomes for all students with disabilities in New York State.

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- provide structure that facilitates systems change efforts and sustainability of those changes
- encourage and promote culturally responsive-sustaining education that includes families and communities as valued partners
- promote greater efficiency and effectiveness in the delivery of high-quality services to families and professionals
- create a comprehensive, multi-disciplinary team approach focused on principles from NYSED's Blueprint for Improved Results for Students with Disabilities that supports our stakeholders

**Phone Number:** (315) 289-5868

**Email Address:** selewis@syr.edu

**Website:** <https://osepartnership.org/center/mid-state-rpc>

**Counties Served:** Cayuga County Onondaga County Cortland County Madison County Oswego County Tompkins County Seneca County Tioga County

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder

# Syracuse University: School-Age FACE Center- Mid-State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Syracuse University: School-Age FACE Center- Mid-State

**Agency Description:** Our mission is to support and empower educational organizations, families, and communities to improve equity, access, opportunities, and outcomes for all students with disabilities in New York State.

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- encourage and promote culturally responsive-sustaining education that includes families and communities as valued partners
- promote greater efficiency and effectiveness in the delivery of high-quality services to families and professionals
- create a comprehensive, multi-disciplinary team approach focused on principles from NYSED's Blueprint for Improved Results for Students with Disabilities that supports our stakeholders

**Phone Number:** (315) 443-4195

**Email Address:** aezogby@syr.edu

**Website:** <https://osepartnership.org/center/mid-state-sa-face-center>

**Counties Served:** Cayuga County Onondaga County Cortland County Madison County Oswego County Tompkins County Seneca County Tioga County

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder

# Monroe 1 BOCES: Regional Partnership FACE Center- Mid-West



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Monroe 1 BOCES: Regional Partnership FACE Center- Mid-West

**Agency Description:** Our mission is to support and empower educational organizations, families, and communities to improve equity, access, opportunities, and outcomes for all students with disabilities in New York State.

Our Goal is to:

- provide structure that facilitates systems change efforts and sustainability of those changes
- encourage and promote culturally responsive-sustaining education that includes families and communities as valued partners
- promote greater efficiency and effectiveness in the delivery of high-quality services to families and professionals
- create a comprehensive, multi-disciplinary team approach focused on principles from NYSED's Blueprint for Improved Results for Students with Disabilities that supports our stakeholders

**Phone Number:** (585) 249-7025

**Email Address:** [kelly\\_endres@boces.monroe.edu](mailto:kelly_endres@boces.monroe.edu)

**Website:** <https://osepartnership.org/center/mid-west-rpc>

**Counties Served:** Genesee County Livingston County Steuben County Wyoming County Orleans County Seneca County

Yates County Wayne County Monroe County Ontario County

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder

# NYSCRC Statewide Voucher Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** NYSCRC Statewide Voucher Program

**Agency Description:** After a pause, NYSCRC is again offering \$600 respite vouchers to informal family caregivers across New York State. The program is open to both Kinship Caregivers caring for a child under 18 years old and caregivers of adults with a long-term chronic condition.

**Phone Number:** (585) 287-6393

**Email Address:** [klawrence@lifespan-roch.org](mailto:klawrence@lifespan-roch.org)

**Website:** <https://www.nyscrc.org/respite-voucher-program>

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Family & Supports

**Conditions Covered:** Arthritis Autism Spectrum Disorder (ASD) Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Tourette Syndrome (TS) Intellectual Disability Epilepsy / Seizure Disorder Deafness or Problems with Hearing Developmental Delay Down Syndrome Diabetes Genetic or Inherited Condition Speech or Language Disorder Learning Difficulty

# NYSCRC Family Mediation and Conflict Coaching



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** NYSCRC Family Mediation and Conflict Coaching

**Agency Description:** Caregivers and their families are rarely prepared for the emotional roller coaster and communication challenges of the caregiving experience. Family mediation and individual conflict coaching can help with planning, conflict resolution, and improved management of the interpersonal issues that arise.

**Phone Number:** (585) 287-6393

**Email Address:** [klawrence@lifespan-roch.org](mailto:klawrence@lifespan-roch.org)

**Website:** <https://www.nyscrc.org/mediaton>

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Family & Supports

**Conditions Covered:**

# NYSCRC Emergency Respite Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** NYSCRC Emergency Respite Program

**Agency Description:** Being a family caregiver can be challenging in of itself, but when the caregiver experiences a health issue, job or family crisis, or another circumstance that prevents them from caring for their loved one, this can often pose a serious dilemma. This is where EMERGENCY RESPITE services can help.

**Phone Number:** (585) 287-6393

**Email Address:** [klawrence@lifespan-roch.org](mailto:klawrence@lifespan-roch.org)

**Website:** <https://www.nyscrc.org/emergency-respite>

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Family & Supports

**Conditions Covered:**

# NYSCRC ROC Respite



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** NYSCRC ROC Respite

**Agency Description:** We are a free neighborhood drop-in respite center for older adults. If you're a family or friend caring for an older adult and could use a little free time to take care of yourself, we provide safe and engaging care weekly with trained staff and volunteers. ROC Respite operates Tuesdays from 11:30 am– 3:30 pm and we are located at the Phillis Wheatley library. We engage caregivers and their care partners in accessing respite services.

**Phone Number:** (585) 287-6393

**Email Address:** [klawrence@lifespan-roch.org](mailto:klawrence@lifespan-roch.org)

**Website:** <https://www.nyscrc.org/roc-respite>

**Counties Served:** Monroe County

**Content Categories:** Care Coordination Family & Supports

**Conditions Covered:**

# NYSCRC Kinship Caregivers Resources



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** NYSCRC Kinship Caregivers Resources

**Agency Description:** The NYS Kinship Navigator is an information, referral and advocacy program for kinship caregivers in New York State. A kinship caregiver is an individual that is caring for a child that is not biologically their own. In New York State, there are an estimated 179,000 caregivers, 131,000 of whom are grandparents. Many others are aunts and uncles. Kinship care refers to grandparents, other relatives, and even family friends who are caring for children. Most kinship caregivers are not foster parents and privately provide full time care for children.

**Phone Number:** (877) 454-6463

**Email Address:** [klawrence@lifespan-roch.org](mailto:klawrence@lifespan-roch.org)

**Website:** <http://www.nysnavigator.org/>

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Family & Supports

**Conditions Covered:**

# ARCH Respite ABCs of Respite Consumer Guide



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** ARCH Respite ABCs of Respite Consumer Guide

**Agency Description:** In this Consumer Guide, you can find insight on how to plan for respite, information about the types of respite available, and answers to the following questions:

- How do I find and pay for Respite?
- How do I choose a respite program or provider?
- How do I choose an Adult Day Services Program?

**Phone Number:** (703) 256-2084

**Email Address:**

**Website:** <https://archrespite.org/library/the-abcs-of-respite/>

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Family & Supports

**Conditions Covered:**

# ARCH Respite or Caregivers of Children with Serious Emotional Disturbance Fact Sheet



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** ARCH Respite or Caregivers of Children with Serious Emotional Disturbance Fact Sheet

**Agency Description:** Finding respite services for a child with challenging behavioral issues can be difficult for families. This fact sheet discusses the definition and characteristics of emotional disturbance, issues for families, program considerations including the referral process, the matching of respite providers and families, training, and evaluation, as well as the need for state involvement in program planning. Written by Susan Dougherty, ARCH Consultant and reviewed by Louise Barnes, Ph.D., Mental Health Program Planner, Office of Children and Youth, Division of Mental Health Services, TN Department of Mental Health and Substance Abuse Services, and Terry Butler, Inclusive Child Care Program, Oregon Council on Developmental Disabilities.

**Phone Number:** (703) 256-2084

**Email Address:**

**Website:** [https://archrespite.org/wp-content/uploads/2022/04/FS\\_34-](https://archrespite.org/wp-content/uploads/2022/04/FS_34-)

**Counties Served:** State-Wide

**Content Categories:** Care Coordination Family & Supports Early Childhood & School Aged Information & Referral

**Conditions Covered:**

# FARE Food Allergy and Anaphylaxis Emergency Care Plan



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** FARE Food Allergy and Anaphylaxis Emergency Care Plan

**Agency Description:** FARE's Food Allergy & Anaphylaxis Emergency Care Plan, formerly the Food Allergy Action 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, and make sure you and others understand what to do in case of an emergency.

This plan was revised by FARE's Education Working Group, a multidisciplinary group of food allergy experts that includes support group leaders, two members of FARE's Medical Advisory Board, experienced parents of children with food allergies, an adult with food allergies, a dietitian, psychologist and a school nurse. The plan was approved by FARE's Medical Advisory Board.

**Phone Number:** (703) 691-3179

**Email Address:**

**Website:** <https://www.foodallergy.org/living-food-allergies/food-allergy-essentials/food->

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness Crisis Resources

**Conditions Covered:** Allergies

# Allergy and Asthma Network

## "How to Prepare for Major Storms or Natural Disasters If you Have Asthma or Allergies"



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Allergy and Asthma Network "How to Prepare for Major Storms or Natural Disasters If you Have Asthma or Allergies"

**Agency Description:** Hurricanes, earthquakes, wildfires, tornadoes, flooding – natural disasters can happen anytime, anywhere. Their suddenness should not catch asthma and allergy patients off guard.

When natural disasters happen and you must evacuate, you may have only precious minutes to grab what you need for a few days, weeks, or longer. Prepare for the unexpected. Take time to put together a disaster preparedness kit and store it in an easily accessible location. Keep it in something easy to transport, such as a backpack or duffel bag.

**Phone Number:** (800) 878-4403

**Email Address:**

**Website:** <https://allergyasthmanetwork.org/news/whats-your-emergency-plan/>

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness Crisis Resources Information & Referral

**Conditions Covered:**

# Allergy Home Resources Page



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Allergy Home Resources Page

**Agency Description:** Video modules, downloadable tools, and web-based content related to allergy preparedness, prevention, and education

**Phone Number:**

**Email Address:**

**Website:** <https://www.allergyhome.org/resources/>

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness Crisis Resources Information & Referral

**Conditions Covered:** Allergies

# Food Allergy and Anaphylaxis Connection Team (FAACT) Emergency Kit Content Guide



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Food Allergy and Anaphylaxis Connection Team (FAACT) Emergency Kit Content Guide

**Agency Description:** There are several medications that can be used to treat anaphylaxis. These include epinephrine, H1 antihistamines, H2 antihistamines, albuterol, and steroids. We recommend your emergency kit include the following

**Phone Number:** (513) 342-1293

**Email Address:** [info@foodallergyawareness.org](mailto:info@foodallergyawareness.org)

**Website:** <https://www.foodallergy.org/living-food-allergies/food-allergy-essentials/food->

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness Crisis Resources

**Conditions Covered:** Allergies

# Dr. Adriana Verwey "A Guide to Recreation and Leisure for All in Greater Rochester" Brochure



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Dr. Adriana Verwey "A Guide to Recreation and Leisure for All in Greater Rochester" Brochure

**Agency Description:** Brochure containing information of inclusive recreational services in the Greater Rochester area for parents of children with various disabilities

**Phone Number:**

**Email Address:**

**Website:** [https://www.urmc.rochester.edu/neuroscience/\\_shared/uploads/8/0082a201-](https://www.urmc.rochester.edu/neuroscience/_shared/uploads/8/0082a201-)

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:**

# Dr. Adriana Verwey

## Interactive Map of Accessible and Inclusive Recreation, Leisure, and Play Locations



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Dr. Adriana Verwey Interactive Map of Accessible and Inclusive Recreation, Leisure, and Play Locations

**Agency Description:** An interactive map containing information of inclusive recreation, leisure, and play areas across the state of New York

**Phone Number:**

**Email Address:**

**Website:** <https://www.urmc.rochester.edu/strong-center-developmental->

**Counties Served:** Monroe County Schuyler County Ontario County Livingston County Wayne County Seneca County

Wyoming County Niagara County Erie County Cattaraugus County Allegany County

**Content Categories:** Community Living & Recreation Family & Supports Information & Referral Early Childhood & School Aged

**Conditions Covered:**

# ROC Artists Unlimited



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** ROC Artists Unlimited

**Agency Description:** To offer a unique expressive experience, in a safe haven, to those individuals who may not otherwise have an opportunity to participate as actors in other venues. Performing quality works with the message of inclusion and respect, Artists Unlimited's theater program and our choral program, Voices, seeks to break down barriers and stereotypes often attributed to those who are disabled. By integrating our cast, individuals with and without disabilities often learn life skills from each other that go beyond the theater venue.

**Phone Number:** (585) 219-5188

**Email Address:** [artistsunlimitedroc@gmail.com](mailto:artistsunlimitedroc@gmail.com)

**Website:** <https://rocartistsunlimited.com/>

**Counties Served:** Monroe County

**Content Categories:** Community Living & Recreation Family & Supports

**Conditions Covered:**

# Caring For Students with Life Threatening Allergies: Toolkit



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Caring For Students with Life Threatening Allergies: Toolkit

**Agency Description:** A guide to caring for children with life threatening allergies.

**Phone Number:**

**Email Address:**

**Website:** [https://www.health.ny.gov/professionals/protocols\\_and\\_guidelines/docs/caring\\_f](https://www.health.ny.gov/professionals/protocols_and_guidelines/docs/caring_f)

**Counties Served:** State-Wide

**Content Categories:** Crisis Resources, Disaster/Emergency Preparedness, Family & Supports, Early Childhood & School Aged, Information & Referral, Government Agency

**Conditions Covered:** Allergies

# The Center: The Lesbian, Gay, Bisexual & Transgender Community Center: LGBTQIA+ & Disability Pride Social Support Group



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** The Center: The Lesbian, Gay, Bisexual & Transgender Community Center: LGBTQIA+ & Disability Pride Social Support Group

**Agency Description:** Center Support: LGBTQIA+ & Disability Pride  
LGBTQIA+ & Disability Pride meets every Monday, from 7-8 p.m. ET (Hybrid) with alternating In-Person & Virtual sessions; \*Every month will start with an In-Person week\*

This hybrid support group is focused on those who identify with both the LGBTQIA+ and disability communities. This space will build pride in disability—destigmatizing, and demystifying disability. Community members will be able to create an uplifting and joyful environment, instill pride and a sense of belonging within disability, celebrate disability, and learn from one another to create lasting networks.

Whether you're looking to find other queer people with shared experiences, combat isolation and

**Phone Number:** (212) 620-7310

**Email Address:**

**Website:** <https://gaycenter.org/event/center-support-lgbtqia-disability-pride-10/>

**Counties Served:** State-Wide

**Content Categories:** LGBTQIA+ Resources Community Living & Recreation Family & Supports

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Tourette Syndrome (TS) Spina Bifida Substance Use Disorder

# ASAN: Autistic Self-Advocacy Network



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** ASAN: Autistic Self-Advocacy Network

**Agency** Our Mission

**Description:** The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!

**Phone Number:**

**Email Address:** [info@autisticadvocacy.org](mailto:info@autisticadvocacy.org)

**Website:** <https://autisticadvocacy.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Family & Supports Financial Legal & Advocacy Information & Referral  
Transitioning to Adulthood (Youth)

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# Proud & Supported: Rights and Respect Toolkit



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Proud & Supported: Rights and Respect Toolkit

**Agency Description:** Proud & Supported is a project to support LGBTQ+ people with intellectual and developmental disabilities. LGBTQ+ stands for lesbian, gay, bisexual, transgender, queer/questioning, and more.

We called the project Proud and Supported. Because we want LGBTQ+ people with intellectual and developmental disabilities to feel proud of who they are. Proud to be a self-advocate, and proud to be part of the LGBTQ+ community. We want everyone to feel supported. Supported as a self-advocate, and supported as a LGBTQ+ person. That is our goal.

The Rights & Respect Toolkit will talk about:

What are my legal rights?

Why is fighting for rights important?

**Phone Number:**

**Email Address:**

**Website:** <https://proudandsupported.org/resources/rights-respect-guide/>

**Counties Served:** State-Wide

**Content Categories:** LGBTQIA+ Resources Community Living & Recreation Family & Supports

**Conditions Covered:** Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Anxiety Allergies

# Proud & Supported: Definitions and Beyond Guide



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Proud & Supported: Definitions and Beyond Guide

**Agency Description:** Proud & Supported is a project to support LGBTQ+ people with intellectual and developmental disabilities. LGBTQ+ stands for lesbian, gay, bisexual, transgender, queer/questioning, and more.

We called the project Proud and Supported. Because we want LGBTQ+ people with intellectual and developmental disabilities to feel proud of who they are. Proud to be a self-advocate, and proud to be part of the LGBTQ+ community. We want everyone to feel supported. Supported as a self-advocate, and supported as a LGBTQ+ person. That is our goal.

There are many ways to identify. Everyone is different and that's good! But sometimes that is confusing. This guide, "Definitions and Beyond," will explain some of the ways people identify. Why is this important? Because many parts of being LGBTQ+ are like being a self-advocate with a disability!

**Phone Number:**

**Email Address:**

**Website:** <https://proudandsupported.org/resources/definitions-and-beyond/>

**Counties Served:** State-Wide

**Content Categories:** LGBTQIA+ Resources Community Living & Recreation Family & Supports Crisis Resources

**Conditions Covered:** Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Anxiety Allergies

## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Equality New York

**Agency Description:** Equality New York works towards advancing equality and justice for all New Yorkers and their families, by using an ecological lens for implementing all policies, programs and projects.

Understanding that real change only works by working on all levels allows us to create programming and priorities that makes the biggest impact.

Through advocacy, community, & coalition building we will make New York a better place for all LGBTQ+ people and their families.

Equality New York's state-wide policy platform focuses on five (5) key domains that affect LGBTQI individuals disproportionately in New York State. In each domain we have identified different statewide

**Phone Number:**

**Email Address:**

**Website:** <https://www.equalityny.org/>

**Counties Served:** State-Wide

**Content Categories:** LGBTQIA+ Resources Family & Supports Community Living & Recreation

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Tourette Syndrome (TS) Substance Use Disorder Spina Bifida

# OPWDD LGBTQIA+ Training Curriculum



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** OPWDD LGBTQIA+ Training Curriculum

**Agency Description:** OPWDD recognizes the importance of each person's rights, including the right to be given respect and dignity, to not be deprived of any civil or legal right solely because of a diagnosis of a developmental disability, and to express sexuality as limited by one's consensual ability to do so, among others (see 14 NYCRR 633.4).

Historically, people with developmental disabilities have been denied the right to express their sexuality or non-conforming gender identity due to societal misconceptions or unaccepting attitudes. To shift to a more supportive and accepting approach, we must acknowledge this historical perspective and work to change it. This includes bringing awareness to people who are part of the LGBTQIA+ community and empowering those supporting them by providing training on this topic.

**Phone Number:**

**Email Address:**

**Website:** <https://opwdd.ny.gov/system/files/documents/2023/06/opwdd-lgbtq-training->

**Counties Served:** State-Wide

**Content Categories:** LGBTQIA+ Resources Transitioning to Adulthood (Youth) Government Agency

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Arthritis Anxiety Allergies

# MAP: Movement Advancement Project- LGBT People with Disabilities Fact Sheet



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

<b>Agency</b>	MAP: Movement Advancement Project- LGBT People with Disabilities Fact Sheet
<b>Agency Description:</b>	<p>MAP is an independent, nonprofit think tank. We work to create a thriving, inclusive, and equitable America where all people have a fair chance to pursue health and happiness, earn a living, take care of the ones they love, be safe in their communities, and participate in civic life.</p> <p>Factsheet: July 26th marks the 29th anniversary of the Americans with Disabilities Act (ADA). The ADA is a civil rights law that protects people with physical or mental impairments that substantially limit major life activities from discrimination in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public. People living with HIV are also protected from discrimination by the ADA.</p> <p>Research shows that LGBT people are more likely than the general population to have a disability and</p>
<b>Phone Number:</b>	(303) 578-4600
<b>Email Address:</b>	info@mapresearch.org
<b>Website:</b>	<a href="https://www.lgbtmap.org/lgbt-people-disabilities">https://www.lgbtmap.org/lgbt-people-disabilities</a>
<b>Counties Served:</b>	State-Wide
<b>Content Categories:</b>	LGBTQIA+ Resources   Financial Legal & Advocacy   Community Living & Recreation   Family & Supports
<b>Conditions Covered:</b>	Attention-Deficit/Hyperactivity Disorder (ADHD)   Autism Spectrum Disorder (ASD)   Behavioral / Conduct Problem Blindness or Problems with Seeing   Blood Disorders   Brain Injury, Concussion, or Head Injury   Cerebral Palsy (CP) Cystic Fibrosis (CF)   Deafness or Problems with Hearing   Depression   Developmental Delay   Diabetes   Down Syndrome Epilepsy / Seizure Disorder   Genetic or Inherited Condition   Heart Condition   Intellectual Disability   Learning Difficulty Migraines   Other   Other Mental Health Condition   Speech or Language Disorder   Spina Bifida   Substance Use Disorder Tourette Syndrome (TS)   Anxiety   Allergies   Arthritis   Asthma

# RespectAbility: LGBTQ+ People with Disabilities



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** RespectAbility: LGBTQ+ People with Disabilities

**Agency Description:** RespectAbility is a diverse, disability-led nonprofit that works to create systemic change in how society views and values people with disabilities, and that advances policies and practices that empower people with disabilities to have a better future. Our mission is to fight stigmas and advance opportunities so people with disabilities can fully participate in all aspects of community.

The LGBTQ+ community and the disability community intersect in significant ways. Here, you can find articles, books, and other resources on the intersection of Disability and LGBTQ+ issues.

**Phone Number:** (202) 517-6272

**Email Address:** [info@respectability.org](mailto:info@respectability.org)

**Website:** <https://www.respectability.org/resources/lgbtq/>

**Counties Served:** State-Wide

**Content Categories:** LGBTQIA+ Resources Family & Supports Community Living & Recreation Financial Legal & Advocacy

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Asthma Arthritis Anxiety Allergies

# Dis-Queer Support Group



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Dis-Queer Support Group

**Agency Description:** LGBTQIA+ individuals with disabilities often feel isolated from two communities at once. Organized in conjunction with accessABILITY, an Indianapolis-based nonprofit, Dis-Queer gives us an opportunity to socialize, educate ourselves on the issues that matter to us, and develop ourselves as self-advocates. Join us on the first Tuesday of every month as we get together and create community!

Everyone who 1) identifies as a member of the LGBTQIA+ community or is questioning their sexual orientation or gender identity, and 2) identifies as having a disability (including neurodivergent folks) is welcome to join! To provide a safe space, we ask that only those who identify with both categories sign up.

If you have any questions or accessibility needs, please email [scampscomms@gmail.com](mailto:scampscomms@gmail.com).

**Phone Number:**

**Email Address:** [scampscomms@gmail.com](mailto:scampscomms@gmail.com)

**Website:** <https://www.eventbrite.com/e/dis-queer-a-disability-lgbtqia-support-group->

**Counties Served:** State-Wide

**Content Categories:** LGBTQIA+ Resources Community Living & Recreation Family & Supports

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Asthma Arthritis Anxiety Allergies

# NIH National Heart, Lung, and Blood Institute



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** NIH National Heart, Lung, and Blood Institute

**Agency Description:** The National Heart, Lung, and Blood Institute (NHLBI) provides global leadership for a research, training, and education program to promote the prevention and treatment of heart, lung, and blood disorders and enhance the health of all individuals so that they can live longer and more fulfilling lives.

**Phone Number:** 1 (877) 645-2448

**Email Address:** [nhlbiinfo@nhlbi.nih.gov](mailto:nhlbiinfo@nhlbi.nih.gov)

**Website:** <https://www.nhlbi.nih.gov>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Information & Referral Government Agency Medical Dental & Behavioral Health

**Conditions Covered:** Blood Disorders Heart Condition

# Mended Little Hearts of Greater Rochester



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Mended Little Hearts of Greater Rochester

**Agency Description:** Mended Little Hearts is a program of the Mended Hearts Inc., a non-profit, volunteer-based organization providing hope, help and healing to heart patients and their families since 1951.

The Mended Little Hearts program works nationally and in communities to support children with congenital heart defects and their families.

Mended Little Hearts of Greater Rochester, NY is a 100% volunteer run, non-profit. We support many families in our community – both near and far. MLH of Greater Rochester supports all families that come to Golisano Children’s Hospital at URMC for heart surgery and care. Families from: Buffalo, Jamestown, Binghamton, Syracuse, Rochester and all the towns in between!

**Phone Number:**

**Email Address:** MendedLittleHeartsROC@gmail.com

**Website:** <https://mlhrochester.com/>

**Counties Served:** Monroe County

**Content Categories:** Information & Referral Medical Dental & Behavioral Health Early Childhood & School Aged

**Conditions Covered:** Heart Condition

# Children's Cardiomyopathy foundation



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Children's Cardiomyopathy foundation

**Agency Description:** The Children's Cardiomyopathy Foundation (CCF) is a non-profit organization focused on pediatric cardiomyopathy, a chronic and potentially life-threatening heart disease. It is a condition that is not well known even though it is a leading cause of heart transplants and sudden cardiac arrest in children.

CCF was established in 2002 as a 501(c)(3) public charity to meet the critical need for more research and education on pediatric cardiomyopathy. Over the years, CCF has grown into a global community of families, physicians, and scientists focused on improving diagnosis, treatment, and quality of life for children with cardiomyopathy. CCF is involved in key areas of the disease and is committed to serving the needs of both the patient and the medical community.

**Phone Number:** (866) 808-2873

**Email Address:** [info@childrenscardiomyopathy.org](mailto:info@childrenscardiomyopathy.org)

**Website:** <https://www.childrenscardiomyopathy.org>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Heart Condition

# American Heart Association



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** American Heart Association

**Agency  
Description:**

**Phone Number:** 1 (800) 242-8721

**Email Address:**

**Website:** <https://www.heart.org/en>

**Counties  
Served:** State-Wide

**Content  
Categories:** Family & Supports Government Agency Medical Dental & Behavioral Health Information & Referral

**Conditions  
Covered:** Heart Condition

# Golisano Division of Pediatric Allergy/Immunology Brochure



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Golisano Division of Pediatric Allergy/Immunology Brochure

**Agency  
Description:**

**Phone Number:** (585) 276-7190

**Email Address:**

**Website:** <https://www.urmc.rochester.edu/MediaLibraries/URMCMedia/childrens->

**Counties  
Served:** Monroe County

**Content  
Categories:** Crisis Resources Early Childhood & School Aged Disaster/Emergency Preparedness Family & Supports  
Information & Referral Medical Dental & Behavioral Health

**Conditions  
Covered:**

# American College of Allergy, Asthma, and Immunology



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** American College of Allergy, Asthma, and Immunology

**Agency Description:** The College fosters a culture of collaboration and congeniality in which its members work together and with others toward the common goals of patient care, education, advocacy and research.

**Phone Number:**

**Email Address:**

**Website:** <https://acaai.org>

**Counties Served:** State-Wide

**Content Categories:** Crisis Resources Disaster/Emergency Preparedness Family & Supports Medical Dental & Behavioral Health Information & Referral

**Conditions Covered:** Allergies Asthma

# Genetic Alliance



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Genetic Alliance

**Agency Description:** Genetic Alliance engages individuals, families and communities to transform health. This requires that we as an organization understand what it means to transform systems, dissolve boundaries, create and sustain open space, and promote the process of openness. We understand that to transform systems, we must start with our own, beginning with our very person. Such work calls us, both personally and professionally, to explore the deepest truths about ourselves and the systems we impact.

**Phone Number:** (202) 966-5557

**Email Address:** info@geneticalliance.org

**Website:** https://geneticalliance.org

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral

**Conditions Covered:**

# NIH Genetic Testing Registry



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** NIH Genetic Testing Registry

**Agency Description:** The Genetic Testing Registry (GTR®) provides a central location for voluntary submission of genetic test information by providers. The scope includes the test's purpose, methodology, validity, evidence of the test's usefulness, and laboratory contacts and credentials. The overarching goal of the GTR is to advance the public health and research into the genetic basis of health and disease

**Phone Number:**

**Email Address:**

**Website:** <https://www.ncbi.nlm.nih.gov/gtr/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Early Childhood & School Aged Information & Referral Government Agency

**Conditions Covered:** Genetic or Inherited Condition

# National Fragile X Foundation



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** National Fragile X Foundation

**Agency Description:** Fragile X syndrome (FXS) is a genetic condition that causes intellectual disability, behavioral and learning challenges, and various physical characteristics. Though FXS occurs in both genders, males are more frequently affected than females, and generally with greater severity. Life expectancy is not affected in people with FXS because there are usually no life-threatening health concerns associated with the condition.

**Phone Number:** (202) 594- 8376

**Email Address:** [contact@fragilex.org](mailto:contact@fragilex.org)

**Website:** <https://fragilex.org>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Genetic or Inherited Condition

# The Marfan Foundation



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** The Marfan Foundation

**Agency Description:** The Marfan Foundation is a nonprofit organization that saves and improves lives while creating a community for all individuals with genetic aortic and vascular conditions, including Marfan, Loeys-Dietz, and Vascular Ehlers-Danlos syndromes.

**Phone Number:** (516) 883- 8712

**Email Address:**

**Website:** <https://marfan.org>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Financial Legal & Advocacy

**Conditions Covered:** Heart Condition Genetic or Inherited Condition

# National Organization for Rare Disorders (NORD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** National Organization for Rare Disorders (NORD)

**Agency Description:** Since 1983, NORD has been a national steward and a steadfast partner helping those who battle and care for rare disease feel seen, heard, supported and connected. We're a full-service, mission-driven nonprofit reimagining a future where every person with a rare disease, and their families live their best lives.

**Phone Number:** (617) 249- 7300

**Email Address:**

**Website:** <https://rarediseases.org>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Family & Supports Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Genetic or Inherited Condition Other

# National PKU Alliance



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** National PKU Alliance

**Agency Description:** The National PKU Alliance (NPKUA) is a vital voice for the PKU community. We work towards expanding PKU research and accelerating the timeline for a cure by investing in peer-reviewed and targeted research. We provide education and support to people living with PKU. We are the national voice for advocacy at the federal level - at the NIH, FDA and in the halls of Congress.

The NPKUA was formed in 2008 by parents, grandparents, and individuals across the country just like you. We are all connected to PKU.

We are the first national non-profit organization to unite adults, families, regional and statewide PKU organizations, the medical community and industry to make a difference in the lives of people with PKU.

**Phone Number:**

**Email Address:**

**Website:** <https://www.npkua.org>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Genetic or Inherited Condition

# FLOK



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** FLOK

**Agency Description:** Founded in 1989 by dietitian Virginia Schuett, National PKU News was the nexus of the PKU community for decades. In July 2023 we became flok, expanding our outreach to all inherited disorders of protein metabolism and focusing on research in addition to support.

**Phone Number:** (973) 619-9160

**Email Address:** [Info@flok.org](mailto:Info@flok.org)

**Website:** <https://www.npkua.org>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Genetic or Inherited Condition

# NIH Online Mendelian Inheritance in Man (OMM)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** NIH Online Mendelian Inheritance in Man (OMM)

**Agency Description:** Sponsored by the National Institutes of Health, this web site provides an online catalog of humane genes and genetic disorders. Primarily for the use of physicians and researchers, patients and the general public can also access basic information.

**Phone Number:**

**Email Address:**

**Website:** <https://www.ncbi.nlm.nih.gov/omim>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Government Agency

**Conditions Covered:** Genetic or Inherited Condition

# Prader-Willi Alliance of New York



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Prader-Willi Alliance of New York

**Agency Description:** Prader-Willi Alliance of New York, Inc. was founded in 1990. The purpose of the organization is ...

To provide information to the general public about Prader-Willi syndrome (PWS): to promote awareness of PWS among the general public and medical and therapeutic professionals; to provide a form (blog, email support) for discussion and professional interchange on the subject of PWS.

To provide assistance, information, referral, and advocacy services to families and friends of persons suffering from PWS.

To encourage and support research into the causes, cure and treatment of PWS.

To assist and support the purposes and activities of the national Prader-Willi Syndrome Association, USA.

To conduct any other appropriate activities that meet the goals of this organization.

**Phone Number:** (800) 442-1655

**Email Address:** Alliance@prader-willi.org

**Website:** <https://www.prader-willi.org>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Financial Legal & Advocacy Medical Dental & Behavioral Health Family & Supports

**Conditions Covered:** Genetic or Inherited Condition

# Prader-Willi Syndrome Association USA

Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Prader-Willi Syndrome Association USA

**Agency Description:** Prader-Willi Syndrome Association | USA was formed in 1975 to unite parents, professionals, and other interested citizens to enhance the quality of life of those affected by Prader-Willi syndrome. PWSA | USA empowers the PWS community through shared experiences, research, education, advocacy, and support. With chapters in most states, ours is the only national PWS support organization whose sole purpose is to assist individuals with the syndrome, and their families, every step of the way.

**Phone Number:** (941) 312-0400

**Email Address:**

**Website:** <https://www.pwsausa.org>

**Counties Served:** State-Wide

**Content Categories:** Financial Legal & Advocacy Family & Supports Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Genetic or Inherited Condition

# Center on the Social and Emotional Foundations for Early Learning



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

<b>Agency</b>	Center on the Social and Emotional Foundations for Early Learning
<b>Agency Description:</b>	Features downloadable/printable free content geared toward parents of younger children. The content focuses on strategies for building social and emotional skills in children along with ways to respond to a child's behavior.
<b>Phone Number:</b>	
<b>Email Address:</b>	
<b>Website:</b>	<a href="http://csefel.vanderbilt.edu/resources/family.html">http://csefel.vanderbilt.edu/resources/family.html</a>
<b>Counties Served:</b>	State-Wide
<b>Content Categories:</b>	Early Childhood & School Aged   Financial Legal & Advocacy   Family & Supports   Information & Referral
<b>Conditions Covered:</b>	Anxiety   Autism Spectrum Disorder (ASD)   Attention-Deficit/Hyperactivity Disorder (ADHD)   Behavioral / Conduct Problem Other Mental Health Condition

# Center for Autism and Related Disabilities (CARD)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Center for Autism and Related Disabilities (CARD)

**Agency Description:** The New York State Regional Centers for Autism Spectrum Disorders (NYSRCASD) are a partnership of six university-affiliated programs across New York State. The partnership has an overarching goal of identifying, disseminating, and assisting in the implementation of evidence-based practices to build capacity to improve services and outcomes for children with autism spectrum disorders.

The University at Albany currently serves as headquarters for the statewide network, with partners at the University of Rochester; The Summit Center; SUNY Old Westbury; Binghamton University, SUNY; and the Child Study Center at NYU Langone Medical Center.

**Phone Number:** (518) 442-3300

**Email Address:** card@albany.edu

**Website:** <https://www.albany.edu/autism/new-york-state-regional-centers-autism->

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Early Childhood & School Aged Information & Referral

**Conditions Covered:** Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Developmental Delay Intellectual Disability Learning Difficulty Genetic or Inherited Condition

# Spina Bifida Association



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Spina Bifida Association

**Agency Description:** The mission of the Spina Bifida Association is to build a better and brighter future for all those impacted by Spina Bifida.

Education- We offer in-person and online education programs featuring medical experts, parents, and adults with Spina Bifida.

Advocacy- We advocate for funding of Spina Bifida Programs at the CDC, disability rights, and affordable accessible health care.

Research- Guidelines for the Care of People with Spina Bifida provide evidence-based guidance on

**Phone Number:** (800) 621-3141

**Email Address:** [sbaa@sbaa.org](mailto:sbaa@sbaa.org)

**Website:** <https://www.spinabifidaassociation.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Financial Legal & Advocacy Information & Referral

**Conditions Covered:** Spina Bifida

# Spina Bifida Association of New York State



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Spina Bifida Association of New York State

**Agency Description:** The Spina Bifida Association of New York State (SBANYS) is a not-for-profit organization whose mission is to build a better and brighter future for all those impacted by Spina Bifida. With that in mind, our goal is to meet that mission through three main areas of service: Support, Education, and Advocacy. Within these areas you will find services that include, but are not limited to: responding to requests for information/referrals, education outreach, advocacy and awareness initiatives, peer support, systems navigation, and programming. These services are available statewide, at no cost, and benefit individuals living with Spina Bifida across the lifespan.

**Phone Number:** (518) 399-9151

**Email Address:** admin@sbanys.org

**Website:** <https://sbanys.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Early Childhood & School Aged Information & Referral Financial Legal & Advocacy

**Conditions Covered:** Spina Bifida

# Individuals with Disabilities Education Act (IDEA) Website



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Individuals with Disabilities Education Act (IDEA) Website

**Agency Description:** The U.S. Department of Education's Individuals with Disabilities Education Act (IDEA) website brings together IDEA information and resources from the Department and our grantees.

Whether you are a student, parent, educator, service provider, or grantee, you are here because you care about children with disabilities and their families and want to find information and explore resources on infants, toddlers, children, and youth with disabilities.

**New York State Contacts**

Customer Service: Jennifer McClafin 202-900-8619

Part B Contact: Justin Arner 202-245-6537

Part C Contact: Susan Kauffman 202-245-6337

**Phone Number:** (202) 900-8619

**Email Address:** Jennifer.McClafin@ed.gov

**Website:** <https://sites.ed.gov/idea/>

**Counties Served:** State-Wide

**Content Categories:** Government Agency Information & Referral

**Conditions Covered:** Allergies Anxiety Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# STRIDE Adaptive Sports



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** STRIDE Adaptive Sports

**Agency Description:** STRIDE Adaptive Sports is a 501(c)(3) nonprofit organization that provided over 14,000 adaptive sport and recreation lessons in 2023-24 to individuals with disabilities, with a focus on youth and Wounded Warriors. STRIDE utilizes over 250 skilled volunteer sport instructors plus over 100 non-skilled volunteers for events, fundraising and maintenance projects; serves over 2000 families; and offers programs in more than 18 different sports at 26 regional locations in the Northeastern US. With a focus on individual lifetime sports, our programs use specialized equipment or teaching aids for successful participation to “level the playing field” for all. STRIDE is a partner member of Move United and Professional Ski Instructors of America (PSIA/AASI); a US Paralympic Sport Club; and a training club for New York Special Olympics. STRIDE Adaptive Sports is recognized as one of the leading adaptive sport programs in the Northeastern United States.

**Phone Number:** (518) 598-1279

**Email Address:** info@stride.org

**Website:** <https://www.stride.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation

**Conditions Covered:** Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Tourette Syndrome (TS), Arthritis, Anxiety, Allergies

# NYS Parks Access Pass



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** NYS Parks Access Pass

**Agency Description:** The Access Pass allows qualified New York State (NY State) residents with disabilities, as defined in the application, free or discounted use of state parks, historic sites, and recreational facilities operated by the NYS Office of Parks, Recreation and Historic Preservation (NY State Parks) and the NY State Department of Environmental Conservation.

**Phone Number:** (518) 474-2324

**Email Address:** [accesspass@parks.ny.gov](mailto:accesspass@parks.ny.gov)

**Website:** <https://parks.ny.gov/admission/access-pass/>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Community Living & Recreation

**Conditions Covered:** Arthritis Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Anxiety Allergies Tourette Syndrome (TS)

# NYS Department of Environmental Conservation: Accessible Recreation Destinations



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** NYS Department of Environmental Conservation: Accessible Recreation Destinations

**Agency Description:** DEC lands and facilities offer many recreational opportunities for people of all ages and abilities including camping, picnicking, fishing, boating, hiking, and nature viewing.

Explore the DEC Accessible Recreation Destinations Map to locate wheelchair accessible features at education centers, campgrounds and day use areas, waterway access sites, and land areas.

You can also navigate to the Accessible Features section on each of the following facility web pages.

For more information, contact:  
Office of Diversity, Inclusion, and Civil Rights  
625 Broadway

**Phone Number:** (518) 402-9295

**Email Address:** [accessibility@dec.ny.gov](mailto:accessibility@dec.ny.gov)

**Website:** <https://dec.ny.gov/places-to-go/accessible-recreation/destinations>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Government Agency Community Living & Recreation

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem  
Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP)  
Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome  
Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty  
Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder  
Allergies Anxiety Arthritis Tourette Syndrome (TS)

# Learning Disabilities Association of New York



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Learning Disabilities Association of New York

**Agency Description:** LDA NYS the nation's oldest learning disability advocacy organization. We are the only voice of advocacy specifically for persons with learning disabilities and neurobiological impairments within all levels of NYS government. We fight every day for the rights of children and adults to education, supports and services. Additionally, our prevention programs protect children from environmental toxins, fetal alcohol exposure and other causes of acquired learning disability.

**Phone Number:**

**Email Address:**

**Website:** <https://ldanys.org/>

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Early Childhood & School Aged Financial Legal & Advocacy

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Intellectual Disability Learning Difficulty

# Adaptive Winter Sports Program



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Adaptive Winter Sports Program

**Agency Description:** The Double H Ranch Adaptive Winter Sports Program, established in 1998, offers children ages 6-16 dealing with chronic and life-threatening illnesses the opportunity to participate in various winter sports in the beautiful Adirondack Mountains FREE of charge with necessary equipment provided. Our Adaptive Winter Sports Program runs from January through March. Activities include Alpine skiing and snowboarding instruction, as well as snowshoeing lessons. This unique program is coordinated by Double H staff, and the magic that takes place on the slopes is made possible through the efforts of our volunteer instructors and National Ski Patrol who provide 1:1 support.

Our winter program is aimed at not only teaching children a life-long skill, but also to provide an experience that can be enjoyed by the entire family. In addition to day programming, we host Family Sleepover Weekends, allowing the entire family to experience the great outdoors, together.

**Phone Number:** (518) 696-5676

**Email Address:**

**Website:** <https://www.nyconnects.ny.gov/services/adaptive-winter-sports-program-422>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Community Living & Recreation Government Agency

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Arthritis Anxiety Allergies

# Food Allergy Research and Education (FARE)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Food Allergy Research and Education (FARE)

**Agency Description:** FARE enhances the lives of individuals with food allergies empowering them to lead safe, productive lives with the respect of others through education and advocacy initiatives and improved awareness around healthcare options and treatment.

**Phone Number:** 18009294040

**Email Address:**

**Website:** <https://www.foodallergy.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Early Childhood & School Aged Family & Supports Information & Referral  
Financial Legal & Advocacy

**Conditions Covered:** Allergies

# Easterseals Camping and Recreation for People with Disabilities

Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Easterseals Camping and Recreation for People with Disabilities

**Agency Description:** Easterseals is proud to be the largest provider of recreation and camping services for children and adults with disabilities in the United States.

Our camping and recreation programs provide safe and accessible spaces where people with disabilities are valued, respected, and accepted. We provide the best environment to try new things and make new friends in an inclusive and fun environment. Programs range from sports and fitness activities to after school play and social activities – all created to elevate community. Children and adults with and without disabilities can experience the joys of a residential or day camp experience while developing independence, confidence, and a sense of self – while their parents and caregivers get much-deserved respite.

**Phone Number:** (800) 221-6827

**Email Address:**

**Website:** <https://www.easterseals.com/programs-and-services/camping-recreation/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Early Childhood & School Aged

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Allergies Anxiety Arthritis Asthma

# Department of Environmental Conservation: Accessibility Services



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Department of Environmental Conservation: Accessibility Services

**Agency Description:** The goal of DEC's accessibility efforts is for people with disabilities to be able to participate in and enjoy the benefits of DEC's services, programs and activities. This may be achieved in a variety of ways, including through physical design, alternative forms of communication, inclusive programs and individual accommodation. Individuals requiring modifications to DEC policies, practices or procedures to participate in a service, program or activity are encouraged to make their needs known to DEC staff.

**Phone Number:** (518) 402-9295

**Email Address:** [accessibility@dec.ny.gov](mailto:accessibility@dec.ny.gov)

**Website:** <https://dec.ny.gov/about/accessibility-for-persons-with-disabilities>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Accessibility & Assistive Technology Government Agency

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Allergies Anxiety Arthritis Asthma

# Adaptive Skiing in New York



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Adaptive Skiing in New York

**Agency Description:** Adaptive snowsport programs at ski areas throughout New York State make winter sports accessible to people of all abilities. Programs offer adaptive skiing instruction, equipment rental or loan, and enthusiastic support.

**Phone Number:**

**Email Address:**

**Website:** <https://www.iloveny.com/things-to-do/winter/adaptive-skiing/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Accessibility & Assistive Technology

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Allergies Anxiety Arthritis

# Health MCs



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Health MCs

**Agency Description:** They have many programs using Hip Hop music to help teach and entertain children from 0-18 years of age. They have many toolkits with songs and videos to up lift kids and open up to many different areas.

**Phone Number:** (929) 335-4474

**Email Address:** info@hhph.org

**Website:** WWW.hhph.org

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Crisis Resources Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:**

# Ferre Genetics



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Ferre Genetics

**Agency Description:** Our community-based genetics service assures access to genetic counseling for patients and their medical providers in the communities where they live and work, and promotes public awareness of genetics in everyday life.

**Phone Number:** (607) 724-4308

**Email Address:**

**Website:** <https://www.ferregenetics.org/>

**Counties Served:** State-Wide

**Content Categories:** Medical Dental & Behavioral Health

**Conditions Covered:** Genetic or Inherited Condition

# Clinic for Special Children



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Clinic for Special Children

**Agency Description:** Our mission is to serve children and adults who suffer from genetic and other complex medical disorders by providing comprehensive medical, laboratory, and consultative services, and by increasing and disseminating knowledge of science and medicine.

Since its founding in 1989, the Clinic for Special Children (CSC) has endeavored to bring compassionate clinical care to children and adults with complex medical disorders. While CSC's focus is the treatment and research of disorders identified in Old Order Amish and Mennonite communities, the impact of CSC's clinical and research work has been felt all over the world.

**Phone Number:** (717) 687-9407

**Email Address:** [queries@clinicforspecialchildren.org](mailto:queries@clinicforspecialchildren.org)

**Website:** <https://clinicforspecialchildren.org/>

**Counties Served:** State-Wide

**Content Categories:** Medical Dental & Behavioral Health

**Conditions Covered:** Genetic or Inherited Condition Other

# Amish, Mennonite, and Hutterite Genetic Disorders Database



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Amish, Mennonite, and Hutterite Genetic Disorders Database

**Agency Description:** Database of rare genetic disorders seen in Amish, Mennonite, and Hutterite populations. Searchable by disorder, mutation, and by clinical features.

**Phone Number:**

**Email Address:** victoria.siu@lhsc.on.ca

**Website:** <https://www.biochemgenetics.ca/plainpeople/index.php>

**Counties Served:** State-Wide

**Content Categories:** Medical Dental & Behavioral Health

**Conditions Covered:** Genetic or Inherited Condition Other

# DDC Clinic: Center for Special Needs Children



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** DDC Clinic: Center for Special Needs Children

**Agency Description:** Our mission is to enhance the quality of life for people with special needs caused by rare genetic disorders. Giving special children the chance to live healthier lives and finding answers for their families is at the heart of what we do.

We're a non-profit primary care, education and research facility. But we're also a gathering place; a place of love, compassion and caring; a place where people take the time to listen and share; a place of faith and hope.

We work with children whose complex medical conditions are difficult to diagnose and treat. Many times, the families of these children have gone to large medical centers, seeking answers. In many cases, these children's diseases are so rare that, after long hospitalizations and expensive testing,

**Phone Number:** (814) 376-1424

**Email Address:** [info@ddcclinic.org](mailto:info@ddcclinic.org)

**Website:** <https://www.ddcclinic.org/>

**Counties Served:** State-Wide

**Content Categories:** Medical Dental & Behavioral Health

**Conditions Covered:** Genetic or Inherited Condition Other

# Young Center for Anabaptist and Pietist (Amish) Studies



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

<b>Agency</b>	Young Center for Anabaptist and Pietist (Amish) Studies
<b>Agency Description:</b>	Amish Studies is an academic website developed by the Young Center for Anabaptist and Pietist Studies at Elizabethtown College to provide reliable information on Amish life and culture. Designed to assist scholars, students and the general public, the site was developed with support from the National Endowment for the Humanities.
<b>Phone Number:</b>	
<b>Email Address:</b>	
<b>Website:</b>	<a href="https://groups.etown.edu/amishstudies/">https://groups.etown.edu/amishstudies/</a>
<b>Counties Served:</b>	State-Wide
<b>Content Categories:</b>	Community Living & Recreation Family & Supports Information & Referral
<b>Conditions Covered:</b>	Genetic or Inherited Condition Other

# OMIM Online Catalog of Human Genes and Genetic Disorders



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** OMIM Online Catalog of Human Genes and Genetic Disorders

**Agency Description:** Welcome to OMIM®, Online Mendelian Inheritance in Man®. OMIM is a comprehensive, authoritative compendium of human genes and genetic phenotypes that is freely available and updated daily. The full-text, referenced overviews in OMIM contain information on all known mendelian disorders and over 16,000 genes. OMIM focuses on the relationship between phenotype and genotype. It is updated daily, and the entries contain copious links to other genetics resources.

**Phone Number:**

**Email Address:**

**Website:** <https://www.omim.org/>

**Counties Served:** State-Wide

**Content Categories:** Medical Dental & Behavioral Health

**Conditions Covered:** Genetic or Inherited Condition Other

# The Difference between IEPs and 504 Plans

Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** The Difference between IEPs and 504 Plans

**Agency Description:** Both IEPs and 504 plans offer formal help for K–12 students who are struggling in school. They're similar in some ways but different in others — from who can get them to what they include. Learn more about the key differences.

**Phone Number:**

**Email Address:**

**Website:** <https://www.understood.org/en/articles/the-difference-between-ieps-and-504->

**Counties Served:** State-Wide

**Content Categories:** Information & Referral Early Childhood & School Aged

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Allergies Anxiety Arthritis

# Autism Care Network



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Autism Care Network

**Agency Description:** The Autism Care Network is the first of its kind learning health network for autism. By adopting innovative research methods built on real-time analysis of embedded clinical data and family priorities, the Network drives rapid and significant effects on quality care, quality of life and reach into underserved communities.

**Phone Number:**

**Email Address:**

**Website:** <https://autismcarenetwork.org/>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Family & Supports Information & Referral

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# A Parent's Guide to Special Education



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** A Parent's Guide to Special Education

**Agency Description:** The Special Education in New York State for Children Ages 3–21: A Parent's Guide is intended to provide parents and persons with parental relationship with:

a broad overview of the special education process in NYS; and  
a resource to help understand some of the rights and protections provided by federal and New York State law and regulations to parents and students throughout the process.

**Phone Number:**

**Email Address:**

**Website:** <https://www.nysed.gov/special-education/parents-guide-special-education>

**Counties Served:** State-Wide

**Content Categories:** Early Childhood & School Aged Family & Supports Government Agency

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem  
Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP)  
Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome  
Arthritis Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability  
Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida  
Substance Use Disorder Tourette Syndrome (TS) Allergies Anxiety

# Sibling Support Project



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Sibling Support Project

**Agency Description:** Founded in 1990, the Sibling Support Project is the first national program dedicated to recognizing, promoting and addressing the life-long and ever-changing concerns of millions of siblings of people with developmental, health, and mental health concerns. We are proud to be a program of Kindering. Our work spans books and publications, online communities for teen and adult siblings, and workshops and training. We are best known for helping local communities start Sibshops—lively peer support groups for school-age brothers and sisters of kids with disabilities and health concerns.

**Phone Number:**

**Email Address:** [info@siblingsupport.org](mailto:info@siblingsupport.org)

**Website:** <https://siblingsupport.org/>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports

- Conditions Covered:**
- Asthma
  - Attention-Deficit/Hyperactivity Disorder (ADHD)
  - Autism Spectrum Disorder (ASD)
  - Behavioral / Conduct Problem
  - Blindness or Problems with Seeing
  - Blood Disorders
  - Brain Injury, Concussion, or Head Injury
  - Cerebral Palsy (CP)
  - Cystic Fibrosis (CF)
  - Deafness or Problems with Hearing
  - Depression
  - Developmental Delay
  - Diabetes
  - Down Syndrome
  - Epilepsy / Seizure Disorder
  - Genetic or Inherited Condition
  - Heart Condition
  - Intellectual Disability
  - Learning Difficulty
  - Migraines
  - Other
  - Other Mental Health Condition
  - Speech or Language Disorder
  - Spina Bifida
  - Substance Use Disorder
  - Tourette Syndrome (TS)
  - Allergies
  - Anxiety
  - Arthritis

# The AAP Parenting Website



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** The AAP Parenting Website

**Agency Description:** HealthyChildren.org is the only parenting website backed by 67,000 pediatricians committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults.

Whether you're looking for general information related to child health or for more specific guidance on parenting issues, you've come to the right place. Here, you'll find information regarding the American Academy of Pediatrics (AAP) many programs and activities, our policies and guidelines, our publications and other child health resources, as well as much, much more. Best of all, you can rest assured that the information comes from the nation's leading child health experts and that we have scientific research supporting our recommendations.

**Phone Number:**

**Email Address:** [info@healthychildren.org](mailto:info@healthychildren.org)

**Website:** <https://www.healthychildren.org/English/Pages/default.aspx>

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Medical Dental & Behavioral Health

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Allergies Anxiety Arthritis Asthma

# NYS Healthy Neighborhoods Program



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** NYS Healthy Neighborhoods Program

**Agency Description:** The New York State Healthy Neighborhoods Program (HNP) seeks to reduce the burden of housing related illness and injury through a holistic, healthy homes approach. The program provides in-home assessments and interventions for asthma, tobacco cessation, indoor air quality, lead, fire safety, and other environmental health hazards in selected communities throughout New York. The program targets housing in high-risk areas that are identified using housing, health, and socioeconomic indicators from census and surveillance data. The HNP uses a combination of door-to-door canvassing (roughly 67 percent of visits) and referrals (32 percent of visits) to reach residents in these high-risk areas. During a visit, the home is assessed for environmental health and safety issues

**Phone Number:**

**Email Address:** bcehfp@health.ny.gov

**Website:** [https://www.health.ny.gov/environmental/indoors/healthy\\_neighborhoods/](https://www.health.ny.gov/environmental/indoors/healthy_neighborhoods/)

**Counties Served:** State-Wide

**Content Categories:** Family & Supports Government Agency

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Arthritis Asthma Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Anxiety Tourette Syndrome (TS) Allergies

# Consumer Directed Choices



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Consumer Directed Choices

**Agency** Mission

**Description:** As the premier provider of consumer self-direction, CDChoices empowers independence and advocates for people with disabilities, seniors, and their families.

**Vision**

CDChoices' vision is an inclusive community without stigma, barriers, or prejudices against people with disabilities. In this community, all people have the choice and necessary supports to live independently in an environment of their choosing.

**Phone Number:** (518) 464-0810

**Email Address:** info@cdchoices.org

**Website:** https://www.cdchoices.org/

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Family & Supports Information & Referral

**Conditions Covered:**

- Attention-Deficit/Hyperactivity Disorder (ADHD)
- Autism Spectrum Disorder (ASD)
- Behavioral / Conduct Problem
- Blindness or Problems with Seeing
- Blood Disorders
- Brain Injury, Concussion, or Head Injury
- Cerebral Palsy (CP)
- Cystic Fibrosis (CF)
- Deafness or Problems with Hearing
- Depression
- Developmental Delay
- Diabetes
- Down Syndrome
- Epilepsy / Seizure Disorder
- Genetic or Inherited Condition
- Heart Condition
- Intellectual Disability
- Learning Difficulty
- Migraines
- Other
- Other Mental Health Condition
- Speech or Language Disorder
- Spina Bifida
- Substance Use Disorder
- Tourette Syndrome (TS)
- Anxiety
- Allergies
- Arthritis
- Asthma

# Mental Health Peer Connection



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Mental Health Peer Connection

**Agency Description:** WNYIL is a family of agencies that provides services and programs which assist individuals with disabilities to remain independently living, working and thriving in the communities of their choice. The below overview will provide information about what an independent living center is, how to obtain services, where each center is located, what independent living skills are, how to obtain transportation and housing information, and how to contact the Independent Living Center.

ADA Compliance, Independent Living Philosophy, Educational Advocacy, Youth Transition Programs, Nursing Home or Hospital Transition, Disability Movement, History and Hiring Individuals with Disabilities, Open Doors, Working with a Disability, Making Your Organization Accessible, Tour of an Independent Living Center, Diabetes Self Management Program/Chronic Disease Self Management Program, Employment, Housing and Intake/Assessments for Individuals with Developmental

**Phone Number:** (716) 836-0822

**Email Address:**

**Website:** <https://wnyil.org/>

**Counties Served:** Allegany County Cattaraugus County Chautauqua County Erie County Genesee County Niagara County Orleans County Wyoming County

**Content Categories:** Transitioning to Adulthood (Youth) Financial Legal & Advocacy Community Living & Recreation Accessibility & Assistive Technology Care Coordination Early Childhood & School Aged Family & Supports Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Allergies Anxiety Arthritis Asthma

# NYS Children's Environmental Health Centers (NYSCHECK)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** NYS Children's Environmental Health Centers (NYSCHECK)

**Agency Description:** The mission of NYSCEHC (or "NYSCHECK") is to prevent, diagnose, and treat environmentally related conditions for families across New York State. As the first state-based model for pediatric environmental health services in the country, New York now has dedicated pediatric champions across the state working together to protect and promote children's health and the environment.

**Phone Number:** 18662656201

**Email Address:**

**Website:** <https://nyscheck.org/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Early Childhood & School Aged Disaster/Emergency Preparedness Medical Dental & Behavioral Health Information & Referral Family & Supports Government Agency

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Anxiety Arthritis Asthma Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Allergies Tourette Syndrome (TS) Substance Use Disorder

# Home Energy Assistance Program (HEAP)



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Home Energy Assistance Program (HEAP)

**Agency Description:** The Home Energy Assistance Program (HEAP) can help eligible New Yorkers heat and cool their homes. If you are eligible, you may receive one regular HEAP benefit per program year and could also be eligible for emergency HEAP benefits if you are in danger of running out of fuel or having your utility service shut off.

**Phone Number:** 18003423009

**Email Address:**

**Website:** <https://otda.ny.gov/programs/heap/>

**Counties Served:** State-Wide

**Content Categories:** Community Living & Recreation Disaster/Emergency Preparedness Family & Supports Government Agency Information & Referral

**Conditions Covered:** Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Anxiety Allergies Arthritis Asthma

# EJScreen: Environmental Justice Screening and Mapping Tool



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** EJScreen: Environmental Justice Screening and Mapping Tool

**Agency Description:** EJScreen is EPA's environmental justice mapping and screening tool that provides EPA with a nationally consistent dataset and approach for combining environmental and socioeconomic indicators. EJScreen users choose a geographic area; the tool then provides socioeconomic and environmental information for that area. All of the EJScreen indicators are publicly-available data. EJScreen simply provides a way to display this information and includes a method for combining environmental and socioeconomic indicators into EJ and supplemental indexes.

**Phone Number:**

**Email Address:**

**Website:** <https://www.epa.gov/ejscreen>

**Counties Served:** State-Wide

**Content Categories:** Disaster/Emergency Preparedness Community Living & Recreation Family & Supports Government Agency Information & Referral

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Arthritis Anxiety Allergies

# Independent Living Centers (ILCs)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Independent Living Centers (ILCs)

**Agency Description:** Independent Living Centers (ILCs) provide an array of services that assist New Yorkers with all disabilities to live fully integrated and self-directed lives. ILCs assist with all aspects of living, learning and earning. They identify and facilitate removal of architectural, communication and attitudinal barriers to full participation in local communities and beyond. ACCES-VR administers base funding for 41 Independent Living Centers (ILCS) throughout the state.

ILCs are private, not-for-profit organizations, governed by a majority of people with disabilities and staffed primarily by people with disabilities. ILCs are service and advocacy centers that do not run residential programs or operate places where people live. The philosophy of independent living is to maximize opportunities for choices and growth through peer driven supports and self-help. ILCs are the voice of people with disabilities and the disability rights movement in local communities across New

**Phone Number:** (518) 473-6829

**Email Address:**

**Website:** <https://www.acces.nysed.gov/vr/independent-living-centers>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Community Living & Recreation Care Coordination Family & Supports  
Transitioning to Adulthood (Youth) Government Agency Information & Referral

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem  
Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP)  
Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome  
Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty  
Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder  
Tourette Syndrome (TS) Arthritis Anxiety Allergies

# Niagara Frontier Radio Reading Service



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Niagara Frontier Radio Reading Service

**Agency Description:** Giving people who are blind or have a print disability a chance to read - every day!  
Your Niagara Frontier Radio Reading Service gives thousands of people throughout Western New York and Southern Ontario who are blind or have another condition that makes reading a challenge 24/7 access to a variety of local and national print publications.

**Phone Number:** (716) 821-5555

**Email Address:** [read@nfradioreading.org](mailto:read@nfradioreading.org)

**Website:** <https://nfradioreading.org/>

**Counties Served:** Allegany County Cattaraugus County Chautauqua County Erie County Genesee County Niagara County  
Orleans County Wyoming County

**Content Categories:** Accessibility & Assistive Technology Community Living & Recreation Information & Referral

**Conditions Covered:** Blindness or Problems with Seeing Brain Injury, Concussion, or Head Injury Learning Difficulty Speech or Language Disorder  
Other

# Spectrum Health and Human Services



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Spectrum Health and Human Services

**Agency Description:** Spectrum Health has been serving the Western New York community since 1973. Our staff of highly trained and experienced professionals are here to help individuals and families through some of the challenges associated with mental health and addiction issues. Spectrum Health offers a larger variety of quality behavioral healthcare services than any other provider in Erie or Wyoming County.

**Phone Number:** (716) 710-5172

**Email Address:** [spectrum@shswny.org](mailto:spectrum@shswny.org)

**Website:** <https://shswny.org/>

**Counties Served:** Allegany County Cattaraugus County Chautauqua County Erie County Genesee County Niagara County Orleans County Wyoming County

**Content Categories:** Crisis Resources Family & Supports Information & Referral Medical Dental & Behavioral Health LGBTQIA+ Resources

**Conditions Covered:** Anxiety Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Brain Injury, Concussion, or Head Injury Depression Developmental Delay Genetic or Inherited Condition Intellectual Disability Learning Difficulty Other Mental Health Condition Substance Use Disorder Tourette Syndrome (TS)

# Every Person Influences Children (EPIC)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Every Person Influences Children (EPIC)

**Agency Description:** OUR VISION: A world where every child has a strong start and a promising future.

OUR MISSION: Strengthening families and building community to raise children who make a positive impact in the world.

OUR VALUES: We value ALL CHILDREN and their potential to shape our future. We value ALL FAMILIES as the core foundation of a child's growth and wellbeing. We value ALL COMMUNITIES and our combined ability to educate, advocate and support children and families.

**Phone Number:** (716) 332-4100

**Email Address:** [hero@epicforchildren.org](mailto:hero@epicforchildren.org)

**Website:** <https://www.epicforchildren.org/>

**Counties Served:** Allegany County Cattaraugus County Chautauqua County Erie County Genesee County Niagara County Orleans County Sullivan County Wyoming County

**Content Categories:** Community Living & Recreation Family & Supports Information & Referral

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Arthritis Anxiety Allergies Tourette Syndrome (TS)

# Independent Living of the Genesee Region



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Independent Living of the Genesee Region

**Agency Description:** **Our Vision**  
Independent Living of the Genesee Region is a catalyst for systems and individual change, enhancing the quality of life for persons with disabilities, while respecting diversity, and promoting choices and alternatives for independent living in our society.

**Our Mission**  
Independent Living of the Genesee Region is a multi-cultural, grassroots, peer directed, civil rights organization that provides a full range of assistance, programs and services to enhance the quality of life for all individuals with disabilities. Independent Living assists persons with disabilities to realize

**Phone Number:** (585) 815-8501

**Email Address:**

**Website:** <https://wnyil.org/ILGR>

**Counties Served:** Genesee County Orleans County Wyoming County

**Content Categories:** Accessibility & Assistive Technology Care Coordination Community Living & Recreation Family & Supports Financial Legal & Advocacy Government Agency Information & Referral Transitioning to Adulthood (Youth)

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Arthritis Anxiety Allergies

# Neighborhood Health Center



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Neighborhood Health Center

**Agency Description:** As an inclusive and welcoming healthcare organization, Neighborhood Health Center cares for the whole you, regardless of insurance status or ability to pay. Neighborhood accepts all patients, participates in most insurance plans, and is proud to provide care to those who are medically underserved.

**Phone Number:** (716) 875-2904

**Email Address:**

**Website:** <https://nhcwny.org/>

- Counties Served:** Allegany County, Cattaraugus County, Chautauqua County, Erie County, Genesee County, Niagara County, Orleans County, Wyoming County

**Content Categories:** Medical Dental & Behavioral Health

- Conditions Covered:** Asthma, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Behavioral / Conduct Problem, Blindness or Problems with Seeing, Blood Disorders, Brain Injury, Concussion, or Head Injury, Cerebral Palsy (CP), Cystic Fibrosis (CF), Deafness or Problems with Hearing, Depression, Developmental Delay, Diabetes, Down Syndrome, Epilepsy / Seizure Disorder, Genetic or Inherited Condition, Heart Condition, Intellectual Disability, Learning Difficulty, Migraines, Other, Other Mental Health Condition, Speech or Language Disorder, Spina Bifida, Substance Use Disorder, Arthritis, Anxiety, Allergies, Tourette Syndrome (TS)

# The Summit Center



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** The Summit Center

**Agency Description:** Simply put, our goal is to make lives better.

**Description:** As Western New York's leading provider of evidence-based services for children and adults with autism and other developmental, social, and behavioral challenges, our team is dedicated to helping everyone we serve achieve the highest level of independence possible.

**Phone Number:** (716) 629-3400

**Email Address:**

**Website:** <https://www.thesummitcenter.org/>

**Counties Served:** Allegany County Cattaraugus County Chautauqua County Erie County Genesee County Niagara County Wyoming County Orleans County

**Content Categories:** Community Living & Recreation Crisis Resources Family & Supports Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Anxiety Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Down Syndrome Genetic or Inherited Condition Intellectual Disability Learning Difficulty Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS)

# Neurodiversity Network of WNY



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Neurodiversity Network of WNY

**Agency Description:** Our mission is to empower and support neurodivergent individuals by advocating for the recognition and acceptance of the neurodiversity paradigm. We aim to shift the narrative around disabilities by promoting the social model of disability and the need for trauma informed care.

**Phone Number:** (716) 992-0402

**Email Address:** wnyneurodiversity@gmail.com

**Website:** <https://www.neurodiversitynetworkofwny.org/>

**Counties Served:** Allegany County Cattaraugus County Chautauqua County Erie County Genesee County Niagara County Orleans County Wyoming County

**Content Categories:** Community Living & Recreation Family & Supports Financial Legal & Advocacy Information & Referral Medical Dental & Behavioral Health

**Conditions Covered:** Autism Spectrum Disorder (ASD)

# Crisis and Re-Stabilization Emergency Services (CARES)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Crisis and Re-Stabilization Emergency Services (CARES)

**Agency Description:** A crisis is defined as a situation in which a youth's behavior gets to the point that the parent, caregiver, or other community person feels that the youth may require help in ways they aren't able to provide and outside assistance is needed. We are available to help, 24/7 by calling 716.882.4357

Our professional team will interview a caregiver and youth to determine what the problems are, and how serious they may be. The goal of the C.A.R.E.S. program is to support families in resolving crisis situations in the home or community and to help prevent future crises. When you call Spectrum C.A.R.E.S. we'll work with you to develop a plan.

**Phone Number:** (716) 882-4357

**Email Address:**

**Website:** <https://shswny.org/services/cares/>

**Counties Served:** Allegany County Cattaraugus County Chautauqua County Erie County Genesee County Niagara County Orleans County Wyoming County

**Content Categories:** Crisis Resources Family & Supports Medical Dental & Behavioral Health

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Arthritis Anxiety Allergies

# Buffalo H.O.P.E.



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Buffalo H.O.P.E.

**Agency Description:** Even in the most challenging times and situations, there is always HOPE. Our team promotes mental wellness and coping strategies in the City of Buffalo to encourage emotional healing and well-being. Look for us at community events, wellness fairs, schools, and other community engagement activities.

Spectrum Health Buffalo H.O.P.E. COMHPS (Community Mental Health Promotion and Support) is supported by the NYS Office of Mental Health.

**Phone Number:** (716) 566-6506

**Email Address:**

**Website:** <https://shswny.org/buffalo-hope/>

- Counties Served:**
- Allegany County
  - Cattaraugus County
  - Chautauqua County
  - Erie County
  - Genesee County
  - Niagara County
  - Orleans County
  - Wyoming County

- Content Categories:**
- Crisis Resources
  - Family & Supports
  - Medical Dental & Behavioral Health

- Conditions Covered:**
- Asthma
  - Attention-Deficit/Hyperactivity Disorder (ADHD)
  - Autism Spectrum Disorder (ASD)
  - Behavioral / Conduct Problem
  - Blindness or Problems with Seeing
  - Blood Disorders
  - Brain Injury, Concussion, or Head Injury
  - Cerebral Palsy (CP)
  - Cystic Fibrosis (CF)
  - Deafness or Problems with Hearing
  - Depression
  - Developmental Delay
  - Diabetes
  - Down Syndrome
  - Epilepsy / Seizure Disorder
  - Genetic or Inherited Condition
  - Heart Condition
  - Intellectual Disability
  - Learning Difficulty
  - Migraines
  - Other
  - Other Mental Health Condition
  - Speech or Language Disorder
  - Spina Bifida
  - Substance Use Disorder
  - Tourette Syndrome (TS)
  - Arthritis
  - Anxiety
  - Allergies

# Buffalo Museum of Science



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Buffalo Museum of Science

**Agency Description:** Since 2010, the BMS has been on an aggressive path to renovate all of the museum's permanent exhibit experiences, transforming its former diorama-based exhibits into eight highly interactive and immersive science studio exhibit spaces. These studios and accompanying workshop spaces leverage collections pieces as a foundation of history and information, and then combine them with immersive exhibits and environments to create modern exhibition spaces. The Museum also added the Buffalo Museum of Science 3D Cinema.

In 2021, the Museum opened Western New York's newest early childhood sensory space with an Erie County twist – SensERIE! This new permanent exhibit gallery on the Museum's first floor offers three distinct Erie County-based environments – forest, city and an underwater scene – that encourage young explorers to learn and understand the world around them by using their senses of touch, sight,

**Phone Number:** (716) 896-5200

**Email Address:**

**Website:** <https://www.sciencebuff.org/>

**Counties Served:** Allegany County Cattaraugus County Chautauqua County Erie County Genesee County Niagara County Orleans County Wyoming County

**Content Categories:** Community Living & Recreation

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Arthritis Anxiety Allergies

# Adult Career and Continuing Education Services (NYSED ACCES)



Regional Resource Guide  
of the Children and Youth with Special  
Health Care Needs (CYSHCN) Project

**Agency** Adult Career and Continuing Education Services (NYSED ACCES)

**Agency Description:** All persons with disabilities can benefit from vocational rehabilitation (VR) services and should have opportunities to work in jobs integrated within their communities

- District Office Locations and Staff Contacts: <https://www.acces.nysed.gov/vr/district-offices>
- Transition and Youth Services (TAYS) : <https://www.acces.nysed.gov/vr/student-and-youth-transition-services>
- Business Relations Team (Integrated Employment Specialists): <https://www.acces.nysed.gov/vr/business-relations-team>

**Phone Number:** 18002225627

**Email Address:**

**Website:** <https://www.acces.nysed.gov/vr>

**Counties Served:** State-Wide

**Content Categories:** Accessibility & Assistive Technology Financial Legal & Advocacy Information & Referral  
Transitioning to Adulthood (Youth)

**Conditions Covered:** Asthma Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem  
Blindness or Problems with Seeing Blood Disorders Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP)  
Cystic Fibrosis (CF) Deafness or Problems with Hearing Depression Developmental Delay Diabetes Down Syndrome  
Epilepsy / Seizure Disorder Genetic or Inherited Condition Heart Condition Intellectual Disability Learning Difficulty  
Migraines Other Other Mental Health Condition Speech or Language Disorder Spina Bifida Substance Use Disorder  
Tourette Syndrome (TS) Arthritis Anxiety Allergies

# Mental Health Advocates of WNY



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Mental Health Advocates of WNY

**Agency Description:** For 60 years, Mental Health Advocates of WNY (formerly Mental Health Association of Erie County) has been deeply committed to providing essential non-clinical services that address the needs of individuals, families and communities living with mental illness.

Through awareness, education, prevention, early intervention programs and supportive services, we advocate for and actively promote mental health and wellness for adults, families and children in homes, schools and workplaces across Western New York.

**Phone Number:** (716) 886-1242

**Email Address:**

**Website:** <https://mhawny.org/>

**Counties Served:** Allegany County Cattaraugus County Chautauqua County Erie County Genesee County Niagara County Orleans County Wyoming County

**Content Categories:** Crisis Resources Family & Supports Medical Dental & Behavioral Health

**Conditions Covered:** Anxiety Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Brain Injury, Concussion, or Head Injury Depression Developmental Delay Intellectual Disability Learning Difficulty Other Mental Health Condition Speech or Language Disorder Substance Use Disorder Tourette Syndrome (TS)

# Just Tell One



## Regional Resource Guide of the Children and Youth with Special Health Care Needs (CYSHCN) Project

**Agency** Just Tell One

**Agency Description:** Just Tell One is a peer-to-peer prevention and early intervention awareness campaign targeted to teens and young adults focusing on depression, suicide, alcohol and drug abuse. Its mission is to give youth the tools, language and confidence to start the conversation about their mental or behavioral health issues.

- Just Tell One PROVIDES:
- Advice for youth seeking help
  - Advice for adults/peers giving help
  - Self-assessment quizzes
  - Peer-to-peer video messages

**Phone Number:** (716) 886-1242

**Email Address:**

**Website:** <https://mhawny.org/programs/just-tell-one/>

**Counties Served:** State-Wide

**Content Categories:** Crisis Resources Medical Dental & Behavioral Health Transitioning to Adulthood (Youth) LGBTQIA+ Resources Information & Referral

**Conditions Covered:** Anxiety Attention-Deficit/Hyperactivity Disorder (ADHD) Autism Spectrum Disorder (ASD) Behavioral / Conduct Problem Brain Injury, Concussion, or Head Injury Depression Developmental Delay Intellectual Disability Learning Difficulty Other Mental Health Condition Substance Use Disorder Tourette Syndrome (TS) Speech or Language Disorder