

New York State

Children and Youth with Special Health Care Needs (CYSHCN)

Resource Guide



Westchester Institute
for Human Development

**Southern Tier Region
2024**

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 \(WIHD\).](#)

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/

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
FIND A LOCAL HEALTH DEPARTMENT	ALL	Local Health Departments https://www.health.ny.gov/community/special_needs/county_programs.htm 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.
	Albany	Albany County Department for Children, Youth & Families https://www.albanycounty.com/departments/children-youth-and-families/children-with-special-needs 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.
	Allegany	Allegany County Department of Health https://www.alleganyco.com/departments/health/childrens-programs 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.
	Broome	Broome County Department of Health http://gobroomecounty.com/hd/cshcn 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Cattaraugus	Cattaraugus County Department of Health https://www.cattco.org/health/services/children-families/special-needs 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.
	Cayuga	Cayuga County Department of Health https://www.cayugacounty.us/379/Children-with-Special-Health-Care-Needs 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.
	Chautauqua	Chautauqua County Department of Health http://www.co.chautauqua.ny.us/226/Early-Intervention-Program 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.
	Chemung	Chemung County Health Department http://www.chemungcountyhealth.org/cshcn 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Chenango	Chenango County Department of Health http://www.co.chenango.ny.us/public-health/children-with-special-needs 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.
	Clinton	Clinton County Department of Health http://www.clintonhealth.org/specialneeds 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.
	Columbia	Columbia County Department of Health https://www.columbiacountynyhealth.com/programs-and-services/nursing-and-clinical-services 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.
	Cortland	Cortland County Department of Health https://www.cortland-co.org/474/Children-With-Special-Health-Care-Needs 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.
	Delaware	Delaware County Department of Health http://delawarecountypublichealth.com/programs/childrens-programs/special-healthcare-needs 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Dutchess	Dutchess County Department of Health https://www.dutchessny.gov/Departments/DBCH/Nursing-Services.htm 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.
	Erie	Erie County Department of Health https://www2.erie.gov/health/index.php?q=node/50 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.
	Essex	Essex County Department of Health https://www.co.essex.ny.us/Health/childrens-services 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.
	Franklin	Franklin County Department of Health https://www.franklincountyny.gov/departments/human_services/public_health/services.php 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Fulton	Fulton County Department of Health https://www.fultoncountyny.gov/children-special-health-care-needs 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.
	Genesee	Genesee County Department of Health http://co.genesee.ny.us/departments/health/children_with_special_health_care_needs.php 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.
	Greene	Greene County Public Health https://www.greenegovernment.com/departments/public-health/childrens-programs/special-health-care-needs-program 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Hamilton	Hamilton County Department of Health https://www.hamiltoncounty.com/health-human-services/public-health-home/family-health-services 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.
	Herkimer	Herkimer County Public Health https://www.herkimercounty.org/services-and-departments/public-health.php 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.
	Jefferson	Jefferson County Department of Health https://co.jefferson.ny.us/departments/PublicHealth/cshcn-phcp 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.
	Lewis	Lewis County Public Health https://www.lewiscounty.org/departments/public-health/children-with-special-needs 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Livingston	Livingston County Department of Health https://www.livingstoncounty.us/1157/Children-with-Special-Healthcare-Needs-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.
	Madison	Madison County Department of Health https://www.madisoncounty.ny.gov/445/Children-With-Special-Healthcare-Needs 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.
	Monroe	Monroe County Department of Health https://www2.monroecounty.gov/health-maternal-children-health-needs 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.
	Montgomery	Montgomery County Department of Health https://www.co.montgomery.ny.us/web/sites/departments/publichealth 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Nassau	Nassau County Department of Health https://nassaucountyny.gov/3666/Children-Youth The Children with Special Health Care Needs Program (CSHCN) in Nassau County can be contacted by calling 516-227-8665.
	New York City (Bronx/Kings/New York/Richmond/Queens)	New York City Department of Health and Mental Hygiene https://www1.nyc.gov/site/doh/health/health-topics/children-with-special-healthcare-needs.page 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.
	Niagara	Niagara County Department of Health https://www.niagaracounty.com/health/Services/Children-With-Special-Needs/Children-With-Special-Health-Care-Needs 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.
	Oneida	Oneida County Department of Health https://www.ocgov.net/oneida/health/programservices 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Onondaga	Onondaga County Health Department http://www.ongov.net/health/SCS.html 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.
	Ontario	Ontario County Department of Health https://www.co.ontario.ny.us/632/Children-with-Special-Needs-Program 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.
	Orange	Orange County Department of Health https://www.orangecountygov.com/774/Children-with-Special-Health-Care-Needs 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.
	Orleans	Orleans County Department of Health https://gohealthny.org/children-with-special-needs/ 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 & referrals, public programs, speakers, in-service trainings, social media, etc.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Oswego	Oswego County Department of Health https://health.oswegocounty.com/programs/1_children_with_special_needs/index.php 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.
	Otsego	Otsego County Health Department https://www.otsegocounty.com/departments/children_with_special_needs/index.php The Otsego County Health Department offers the following programs for children with special needs: Early Intervention, Preschool Special Education, and Evaluation and Education Services.
	Putnam	Putnam County Department of Health https://www.putnamcountyny.com/health/child 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.
	Rensselaer	Rensselaer County Department of Health https://www.rensco.com/departments/public-health/children-with-special-needs 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Rockland	Rockland County Department of Health http://rocklandgov.com/departments/health/programs-and-services/children-with-special-needs-programs 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.
	Saratoga	Saratoga County Public Health Services https://www.saratogacountyny.gov/departments/publichealth/children-with-special-health-care-needs-cshcn 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.
	Schenectady	Schenectady County Department of Health https://www.schenectadycounty.com/CWSN 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Schoharie	Schoharie County Public Health https://www4.schohariecounty-ny.gov/departments/public-health/preschool 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.
	Schuyler	Schuyler County Public Health http://www.schuylercounty.us/622/Children-with-Special-Health-Care-Needs 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.
	Seneca	Seneca County Department of Health https://senecacountyhealthdepartment.com/public-health/programs-services/children-with-special-health-care-needs/ 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.
	St. Lawrence	St. Lawrence County Department of Health https://www.stlawco.org/Departments/PublicHealth/ChildrenSpecialHealthCareNeeds 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Steuben	Steuben County Department of Health https://www.steubencony.org/pages.asp?PID=178 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.
	Suffolk	Suffolk County Department of Health https://www.suffolkcountyny.gov/Departments/Health-Services/Children-With-Special-Needs 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.
	Sullivan	Sullivan County Public Health Services http://sullivanny.us/Departments/Publichealth/Childrenwithspecialhealthcareneeds 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).
	Tioga	Tioga County Department of Health https://www.tiogacountyny.com/departments/public-health 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Tompkins	Tompkins County Health Department http://tompkinscountyny.gov/health/cscn#CSCN 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.
	Ulster	Ulster County Department of Health http://ulstercountyny.gov/health/divisions/patient-services-division The Children with Special Health Care Needs Program ensures access to quality health care for children who are chronically ill and/or have disabilities.
	Warren	Warren County Department of Health https://warrencountyny.gov/healthservices/children 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.
	Washington	Washington County Health Department https://washingtoncountyny.gov/299/Public-Health-Services 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.

	COUNTIES SERVED	RESOURCE
FIND A LOCAL HEALTH DEPARTMENT	Wayne	Wayne County Department of Health https://www.wcphny.com/children-with-special-health-care-needs/ 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.
	Westchester	Westchester County Department of Health https://health.westchestergov.com/children-with-special-health-care-needs-program-cshcn 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.
	Wyoming	Wyoming County Youth Bureau http://www.wyomingco.net/263/Children-with-Special-Health-Care-Needs 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.
	Yates	Yates County Department of Health https://www.yatescounty.org/213/Children-Services 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.

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
- WIOA Overview - <https://www.dol.gov/agencies/eta/wioa>
- Local Workforce Development Area Director Contacts- <https://dol.ny.gov/lwdbbs>
- 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

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

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

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 & SupportsFinancial Legal & AdvocacyGovernment AgencyInformation & Referral
Conditions Covered:	AllergiesArthritisAnxietyAsthmaAttention-Deficit/Hyperactivity Disorder (ADHD)Autism Spectrum Disorder (ASD)Behavioral / Conduct ProblemBlindness or Problems with SeeingBlood DisordersBrain Injury, Concussion, or Head InjuryCerebral Palsy (CP)Cystic Fibrosis (CF)Deafness or Problems with HearingDepressionDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionHeart ConditionIntellectual DisabilityLearning DifficultyMigrainesOtherOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette 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

Agency	American Academy of Pediatrics (AAP) Disasters and Children resources
Agency Description:	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.
Phone Number:	(800) 433-9016
Email Address:	https://www.aap.org/en/community/aap-councils/council-on-
Website:	https://www.aap.org/en/patient-care/disasters-and-children/
Counties Served:	State-Wide
Content Categories:	Family & Supports Information & Referral Early Childhood & School Aged Disaster/Emergency Preparedness Crisis Resources
Conditions Covered:	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
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

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

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

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
Website:	https://www.clmhd.org/
Counties Served:	State-Wide
Content Categories:	Early Childhood & School AgedGovernment AgencyMedical Dental & Behavioral HealthFinancial Legal & Advocacy
Conditions Covered:	DepressionAnxietyOther Mental Health ConditionIntellectual DisabilityDown SyndromeDevelopmental DelayLearning 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

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

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

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

Website: 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/

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 1. 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

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

Website: 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

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

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)

Regional Resource Guide
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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
Phone Number:	(617) 287-4300
Email Address:	thinkcollege@umb.edu
Website:	http://thinkcollege.net/
Counties Served:	State-Wide
Content Categories:	Information & ReferralTransitioning to Adulthood (Youth)
Conditions Covered:	Down SyndromeIntellectual DisabilityLearning DifficultyAutism 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

Agency	National Center on Health, Physical Activity and Disability (NCHPAD)
Agency Description:	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.
Phone Number:	(866) 866-8896
Email Address:	nchpad@uab.edu
Website:	http://www.nchpad.org/Directories/Youth/USA/New~York
Counties Served:	State-Wide
Content Categories:	Community Living & Recreation Transitioning to Adulthood (Youth) Family & Supports Information & Referral Accessibility & Assistive Technology
Conditions Covered:	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

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
Counties Served:	State-Wide
Content Categories:	Government AgencyInformation & ReferralMedical Dental & Behavioral HealthFinancial Legal & Advocacy
Conditions Covered:	Developmental DelayOther Mental Health ConditionLearning DifficultySpeech or Language DisorderAttention-Deficit/Hyperactivity Disorder (ADHD)AllergiesAnxietyArthritisAsthmaAutism Spectrum Disorder (ASD)Behavioral / Conduct ProblemBlood DisordersCerebral Palsy (CP)Cystic Fibrosis (CF)DepressionDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionBrain Injury, Concussion, or Head InjuryDeafness or Problems with HearingHeart ConditionIntellectual DisabilityMigrainesSpina BifidaOtherSubstance Use DisorderTourette 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
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

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

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

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
Website:	http://researchautism.org/
Counties Served:	State-Wide
Content Categories:	Information & ReferralFamily & SupportsFinancial 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

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
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Health Care Needs (CYSHCN) Project

Agency	American Association of People with Disabilities (AAPD)
Agency Description:	The American Association of People with Disabilities is a convener, connector, and catalyst for change, increasing people's political and economic power with disabilities.
Phone Number:	(800) 840-8844
Email Address:	communications@aapd.com
Website:	http://www.aapd.com/
Counties Served:	State-Wide
Content Categories:	Financial Legal & Advocacy
Conditions Covered:	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

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

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

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

Broome County Department of Health



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

Agency Broome 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: (607) 778- 3930

Email Address: BCHealth@broomecountyny.gov

Website: <https://gobroomecounty.com/hd/youth-and-family-services>

Counties Served: Broome 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)

Chenango County

Department of Health



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

Agency Chenango 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: (607) 337-1729

Email Address:

Website: <https://www.chenangocountyny.gov/209/Children-with-Special-Needs>

Counties Served: Chenango 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)

Delaware County Department of Health



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

Agency Delaware 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: (607) 832-5200

Email Address:

Website: <https://www.delcony.us/ph/child-family-services/cyshcn/>

Counties Served: Delaware 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)

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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 TechnologyEarly Childhood & School AgedTransitioning to Adulthood (Youth)Family & Supports
Conditions Covered:	Attention-Deficit/Hyperactivity Disorder (ADHD)AnxietyBehavioral / Conduct ProblemBlindness or Problems with SeeingBlood DisordersAutism Spectrum Disorder (ASD)Cystic Fibrosis (CF)Brain Injury, Concussion, or Head InjuryCerebral Palsy (CP)Deafness or Problems with HearingDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderHeart ConditionIntellectual DisabilityGenetic or Inherited ConditionLearning DifficultyOther Mental Health ConditionOtherSpeech or Language DisorderSpina BifidaTourette 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

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

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

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

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.nylpi.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 & ReferralFamily & SupportsCare CoordinationFinancial Legal & Advocacy
Conditions Covered:	Genetic or Inherited Condition

Regional Resource Guide
of the Children and Youth with Special
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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 & SupportsInformation & ReferralEarly Childhood & School AgedMedical Dental & Behavioral Health
Conditions Covered:	Developmental DelayOther

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

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

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
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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.aaid.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

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

Counties Served: State-Wide

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

Conditions Covered: Other

New York State Department of Health: Physician Profile



Regional Resource Guide
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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

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
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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



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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
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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

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
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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

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

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

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
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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
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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 .
Phone Number:	(877) 846- 7369
Email Address:	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
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

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
Website:	http://ddpc.ny.gov/
Counties Served:	State-Wide
Content Categories:	Accessibility & Assistive TechnologyFamily & SupportsFinancial Legal & AdvocacyInformation & ReferralGovernment Agency
Conditions Covered:	Developmental DelayLearning DifficultyIntellectual DisabilityCerebral Palsy (CP)Down SyndromeAutism Spectrum Disorder (ASD)Genetic or Inherited ConditionEpilepsy / Seizure DisorderAttention-Deficit/Hyperactivity Disorder (ADHD)Blindness or Problems with SeeingSpeech or Language DisorderTourette 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

Agency	National Institute of Mental Health (NIMH)
Agency Description:	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.
Phone Number:	(866) 615-6464
Email Address:	nimhinfo@nih.gov
Website:	http://www.nimh.nih.gov/index.shtml
Counties Served:	State-Wide
Content Categories:	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
Conditions Covered:	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 TechnologyCommunity Living & RecreationCare CoordinationFamily & SupportsInformation & ReferralTransitioning to Adulthood (Youth)Financial Legal & Advocacy
Conditions Covered:	Attention-Deficit/Hyperactivity Disorder (ADHD)Developmental DelayLearning DifficultyIntellectual DisabilityAllergiesAnxietyArthritisAsthmaAutism Spectrum Disorder (ASD)Behavioral / Conduct ProblemBlood DisordersBrain Injury, Concussion, or Head InjuryCerebral Palsy (CP)Cystic Fibrosis (CF)DepressionDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionDeafness or Problems with HearingHeart ConditionMigrainesOtherOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette 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
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
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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
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

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
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
Website:	http://www.lpaonline.org/district-2-nj-ny-pa
Counties Served:	State-Wide
Content Categories:	Community Living & RecreationFamily & SupportsFinancial Legal & AdvocacyInformation & ReferralTransitioning to Adulthood (Youth)
Conditions Covered:	Genetic or Inherited ConditionOther

American Academy of Developmental Medicine & Dentistry (AADMD)



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

Agency American Academy of Developmental Medicine & Dentistry (AADMD)

Agency Description: 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.

Phone Number: (845) 204- 8004

Email Address:

Website: <http://www.aadmd.org/>

Counties Served: State-Wide

Content Categories: Medical Dental & Behavioral Health Information & Referral

Conditions Covered: 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

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

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

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 no charges for membership or any of DCMP's services.

Phone Number: (800) 237-6213

Email Address: 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
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

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

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

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
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

Phone Number: (518) 473-7016

Email Address: beipub@health.ny.gov

Website: 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

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

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
Website:	http://www.ldaamerica.org
Counties Served:	State-Wide
Content Categories:	Early Childhood & School AgedFamily & SupportsInformation & ReferralFinancial Legal & AdvocacyDisaster/Emergency PreparednessTransitioning to Adulthood (Youth)
Conditions Covered:	Learning DifficultyAttention-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@ncld.org
Website:	http://www.ncld.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

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

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 & AdvocacyLGBTQIA+ Resources
Conditions Covered:	Attention-Deficit/Hyperactivity Disorder (ADHD)AllergiesAnxietyArthritisAutism Spectrum Disorder (ASD)AsthmaBehavioral / Conduct ProblemBlood DisordersCerebral Palsy (CP)Cystic Fibrosis (CF)DepressionDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionBrain Injury, Concussion, or Head InjuryDeafness or Problems with HearingHeart ConditionIntellectual DisabilityMigrainesOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette Syndrome (TS)Blindness or Problems with SeeingOtherLearning 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/default.aspx
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)



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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

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)



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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

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)



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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

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



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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

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



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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)



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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
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



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Agency	New York State Department of Health, Wadsworth Center: Specialty Care Centers
Agency Description:	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.
Phone Number:	(518) 473-7552
Email Address:	nbsinfo@health.ny.gov
Website:	http://www.wadsworth.org/programs/newborn/screening/specialty-care-
Counties Served:	State-Wide
Content Categories:	Medical Dental & Behavioral Health Information & Referral
Conditions Covered:	Genetic or Inherited Condition Allergies Cystic Fibrosis (CF) Diabetes Blood Disorders Other

American Diabetes Association: Upstate New York



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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

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



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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

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



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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

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)



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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

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

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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
Website:	http://www.wrightslaw.com/
Counties Served:	State-Wide
Content Categories:	Financial Legal & AdvocacyInformation & Referral
Conditions Covered:	Attention-Deficit/Hyperactivity Disorder (ADHD)AllergiesAnxietyArthritisAsthmaAutism Spectrum Disorder (ASD)Behavioral / Conduct ProblemBlood DisordersCerebral Palsy (CP)Cystic Fibrosis (CF)DepressionDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionBrain Injury, Concussion, or Head InjuryDeafness or Problems with HearingHeart ConditionIntellectual DisabilityLearning DifficultyMigrainesOtherOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette Syndrome (TS)Blindness or Problems with Seeing

endABUSE of People with Disabilities



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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)



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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

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
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Living Resources



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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)



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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
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



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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 & ReferralGovernment Agency
Conditions Covered:	Attention-Deficit/Hyperactivity Disorder (ADHD)AllergiesAnxietyArthritisAutism Spectrum Disorder (ASD)AsthmaBehavioral / Conduct ProblemBlood DisordersCerebral Palsy (CP)Cystic Fibrosis (CF)DepressionDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionBrain Injury, Concussion, or Head InjuryDeafness or Problems with HearingHeart ConditionIntellectual DisabilityMigrainesOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette Syndrome (TS)Blindness or Problems with SeeingOther

New York State Independent Living Council (NYSILC)



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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



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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 TechnologyCommunity Living & RecreationFinancial Legal & AdvocacyInformation & ReferralTransitioning to Adulthood (Youth)Family & Supports
Conditions Covered:	Attention-Deficit/Hyperactivity Disorder (ADHD)AllergiesAnxietyArthritisAutism Spectrum Disorder (ASD)AsthmaBehavioral / Conduct ProblemBlood DisordersCerebral Palsy (CP)Cystic Fibrosis (CF)DepressionDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionBrain Injury, Concussion, or Head InjuryDeafness or Problems with HearingHeart ConditionIntellectual DisabilityMigrainesOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette Syndrome (TS)Blindness or Problems with SeeingOtherLearning Difficulty

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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
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

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Agency Elmcrest

Agency Description: Elmcrest is a community of caring professionals providing service to children with a variety of emotional, behavioral, and developmental limitations in order to help them overcome barriers to success in their home, school and community. Our services for children and families range from early education programs to services for children with medical and developmental disabilities. While our early education programs are open to all children in Onondaga County, our services for children with developmental disabilities require a referral from the county. We provide respite, residential, supported employment and community-based service options throughout Central New York.

Phone Number: (315) 446-6250

Email Address:

Website: <http://www.elmcrest.org/>

Counties Served: Cortland County Onondaga County Oswego County Broome County

Content Categories: Early Childhood & School Aged Family & Supports Community Living & Recreation Transitioning to Adulthood (Youth) Medical Dental & Behavioral Health Care Coordination

Conditions Covered: Autism Spectrum Disorder (ASD) Cerebral Palsy (CP) Asthma Developmental Delay Down Syndrome Intellectual Disability Spina Bifida Behavioral / Conduct Problem Depression Epilepsy / Seizure Disorder Learning Difficulty Speech or Language Disorder Other Mental Health Condition Tourette Syndrome (TS) Cystic Fibrosis (CF) Genetic or Inherited Condition

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

Association for Vision Rehabilitation and Employment, Inc. (AVRE)



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

Agency Association for Vision Rehabilitation and Employment, Inc. (AVRE)

Agency Description: AVRE is a private, non-profit organization that serves people who are blind or visually impaired. People of all ages, from school-age children to seniors, can and do benefit from our services. We offer a range of learning, living, and working options for people experiencing vision loss. AVRE works with individuals who live in the New York counties of Broome, Chemung, Chenango, Cortland, Delaware, Otsego, Schuyler, Tioga, and Tompkins.

Phone Number: (607) 724-2428

Email Address: avreinfo@avreus.org

Website: <http://www.avreus.org/>

Counties Served: Broome County Chemung County Chenango County Cortland County Delaware County Otsego County Schuyler County Tioga County Tompkins County

Content Categories: Accessibility & Assistive Technology Community Living & Recreation Early Childhood & School Aged Transitioning to Adulthood (Youth) Care Coordination

Conditions Covered: Blindness or Problems with Seeing

Rural Health Network of South Central New York (RHNSCNY)



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

Agency Rural Health Network of South Central New York (RHNSCNY)

Agency Description: The Rural Health Network works toward optimal individual and community health and wellness. We aim for a reduction in health disparities for the most vulnerable population and strong community norms for healthy lifestyle choices and optimal physical and mental health. Services include case management, health coaching, Living Healthy chronic disease education workshops. case management, and referrals to appropriate health-related services.

Phone Number: (607) 692-7669

Email Address:

Website: <http://rhnscny.org/>

Counties Served: Broome County Delaware County Tioga County Chemung County Chenango County Cortland County Otsego County Schuyler County Tompkins County Steuben County

Content Categories: Family & Supports Financial Legal & Advocacy Care Coordination Information & Referral Medical Dental & Behavioral Health Community Living & Recreation

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

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

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

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)

BroomeINCLUDES



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

Agency BroomeINCLUDES

Agency Description: BroomeINCLUDES is a county-wide initiative aimed at making sure everyone of every ability gets the assistance and help they need. The goal is to promote inclusion of community members who experience behavioral health challenges such as developmental disabilities, mental health, addiction and co-occurring disorders with a focus on serving community members with intellectual, developmental, physical, mental health, or substance use challenges.

Phone Number: (607) 778-1109

Email Address: Megan.Wise@BroomeCounty.US

Website: <http://broomeincludes.org/>

Counties Served: Broome County

Content Categories: Information & Referral

Conditions Covered: Anxiety Cerebral Palsy (CP) Cystic Fibrosis (CF) Depression Developmental Delay Down Syndrome Intellectual Disability Other Mental Health Condition Substance Use Disorder Blindness or Problems with Seeing Other Autism Spectrum Disorder (ASD)

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)

Family Enrichment Network



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

Agency Family Enrichment Network

Agency Description: The mission of Family Enrichment Network is to provide supportive services for the optimal development of children and families. We believe in coordinating children and family services using a comprehensive and collaborative approach to improve their quality of life while ensuring the greatest value for our investment in child, adult, and parent development.

Phone Number: (800) 281-8741

Email Address:

Website: <http://www.familyenrichment.org/~familyen/index.php>

Counties Served: Chenango County Broome County Schoharie County Tioga County

Content Categories: 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: Allergies 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

Broome-Tioga Workforce New York



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

Agency Broome-Tioga Workforce New York

Agency Description: The Disability Resource Coordinator (DRC) from the Broome-Tioga Workforce New York can assist individuals with disabilities with finding job and training opportunities, accessing community resources, and understanding the impact of work earnings on their benefits. The DRC is certified to provide SSD/SSI benefits advisement, including use of the Student Earned Income Exclusion and ABLE accounts.

Phone Number: (607) 778-6478

Email Address: randall.cook@broomecounty.us

Website: <http://www.broometiogaworks.com/disabilityresource>

Counties Served: Broome County Tioga County

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

Conditions Covered: Allergies 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

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

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

Epilepsy Foundation



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

Agency Epilepsy Foundation

Agency Description: The Epilepsy Foundation increases awareness and changes the conversation around epilepsy, improves and saves lives through care, advocacy, research and new therapies, and education, and mobilizes everyone to take action. There are multiple local Epilepsy Foundations in New York.

Phone Number: (301) 459-3700

Email Address: ContactUs@efa.org

Website: <http://www.epilepsy.com/affiliates?>

Counties Served: Bronx County Kings County New York County Queens County Richmond County Clinton County Westchester County Albany County Columbia County Delaware County Nassau County Essex County Dutchess County Fulton County Franklin County

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

Conditions Covered: Epilepsy / Seizure Disorder

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

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

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

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

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

Agency	New York State Association of Independent Schools (NYSAIS): Special Education
Agency Description:	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.
Phone Number:	(518) 694-5500
Email Address:	
Website:	http://www.nysais.org/page.cfm?p=923&max=1000&filter_data7=Yes
Counties Served:	State-Wide
Content Categories:	Information & Referral Early Childhood & School Aged
Conditions Covered:	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

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

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
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

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
Website:	http://chailifeline.org
Counties Served:	State-Wide
Content Categories:	Community Living & RecreationMedical Dental & Behavioral HealthFamily & SupportsAccessibility & Assistive Technology
Conditions Covered:	Genetic or Inherited ConditionBlood DisordersOtherBrain Injury, Concussion, or Head InjuryCystic Fibrosis (CF)Spina BifidaArthritisDiabetesCerebral Palsy (CP)Epilepsy / Seizure DisorderDeafness or Problems with HearingHeart ConditionAsthmaAllergiesAttention-Deficit/Hyperactivity Disorder (ADHD)Blindness or Problems with SeeingTourette Syndrome (TS)Behavioral / Conduct ProblemAnxietyAutism Spectrum Disorder (ASD)DepressionDevelopmental DelayDown SyndromeIntellectual DisabilityLearning DifficultyOther Mental Health ConditionMigrainesSpeech or Language DisorderSubstance 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
Website:	http://www.nylag.org/
Counties Served:	State-Wide
Content Categories:	Financial Legal & AdvocacyInformation & Referral
Conditions Covered:	Developmental DelayOtherAttention-Deficit/Hyperactivity Disorder (ADHD)AllergiesAnxietyArthritisAsthmaAutism Spectrum Disorder (ASD)Behavioral / Conduct ProblemBlood DisordersCerebral Palsy (CP)Cystic Fibrosis (CF)DepressionDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionBrain Injury, Concussion, or Head InjuryDeafness or Problems with HearingHeart ConditionIntellectual DisabilityLearning DifficultyMigrainesOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette 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

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

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

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

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

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

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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)



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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

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)



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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)



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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 TechnologyCommunity Living & RecreationFinancial Legal & AdvocacyInformation & ReferralTransitioning to Adulthood (Youth)Family & SupportsEarly Childhood & School Aged
Conditions Covered:	Attention-Deficit/Hyperactivity Disorder (ADHD)AllergiesAnxietyArthritisAutism Spectrum Disorder (ASD)AsthmaBehavioral / Conduct ProblemBlood DisordersCerebral Palsy (CP)Cystic Fibrosis (CF)DepressionDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionBrain Injury, Concussion, or Head InjuryDeafness or Problems with HearingHeart ConditionIntellectual DisabilityMigrainesOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette Syndrome (TS)Blindness or Problems with SeeingOtherLearning Difficulty

Family Resource Network



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Agency Family Resource Network

Agency Description: The Family Resource Network is dedicated to supporting families through provision of information and support. We accomplish this through trainings, our library and sample letters that may be used to request a particular service or evaluation.

Phone Number: (607) 432-0001

Email Address:

Website: <http://www.familyrn.org/>

Counties Served: Chenango County Broome County Delaware County Otsego County Tioga County Tompkins County

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

Conditions Covered: Allergies 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

Cerebral Palsy Association of New York State



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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

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



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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
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



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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

Website: 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

Lincoln Center Passport to the Arts



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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

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



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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

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
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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

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)



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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
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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
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

Disability Rights New York (DRNY)



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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

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)



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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)



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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
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

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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
Website:	http://www.additudemag.com/
Counties Served:	State-Wide
Content Categories:	Early Childhood & School AgedAccessibility & Assistive TechnologyFamily & SupportsInformation & ReferralCommunity Living & RecreationFinancial Legal & AdvocacyTransitioning to Adulthood (Youth)
Conditions Covered:	Attention-Deficit/Hyperactivity Disorder (ADHD)

Healthy Transitions NY



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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)



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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

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



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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
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
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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/
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



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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 AgedCommunity Living & RecreationAccessibility & Assistive TechnologyTransitioning to Adulthood (Youth)Information & Referral
Conditions Covered:	ArthritisBrain Injury, Concussion, or Head InjuryCerebral Palsy (CP)Cystic Fibrosis (CF)Epilepsy / Seizure DisorderGenetic or Inherited ConditionHeart ConditionOtherSpina Bifida

Fitness Inclusion Network (Fit-IN)



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

Agency Fitness Inclusion Network (Fit-IN)

Agency Description: The Fitness Inclusion Network (Fit IN) is a cross-institutional collaboration in Central New York and beyond committed to expanding access and furthering conversations on inclusion in outdoor recreation, team sports, mindful movement, and personal fitness for people of all ability levels. Our Mission is to develop innovative ways to promote and support inclusive fitness for children, adolescents, and adults with disabilities in Central New York.

Phone Number: (315) 443-2863

Email Address: sefickj@upstate.edu

Website: <http://bbi.syr.edu/projects/fit-in-network/>

Counties Served: Madison County Oneida County Herkimer County Montgomery County Schoharie County Chenango County Otsego County Broome County

Content Categories: Community Living & Recreation

Conditions Covered: Allergies Anxiety Arthritis Attention-Deficit/Hyperactivity Disorder (ADHD) 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 Mental Health Condition Other Speech or Language Disorder Spina Bifida Substance Use Disorder Tourette Syndrome (TS) Blindness or Problems with Seeing

National Eating Disorders Association (NEDA)



Regional Resource Guide
of the Children and Youth with Special
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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

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.

Phone Number: (518) 439-8311

Email Address: 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

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)



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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
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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
Website:	http://www.bestbuddies.org/newyork/
Counties Served:	State-Wide
Content Categories:	Community Living & RecreationFamily & SupportsTransitioning to Adulthood (Youth)
Conditions Covered:	Autism Spectrum Disorder (ASD)Cerebral Palsy (CP)Down SyndromeIntellectual DisabilityDevelopmental DelayCystic Fibrosis (CF)Genetic or Inherited ConditionSpina BifidaTourette Syndrome (TS)Brain Injury, Concussion, or Head Injury

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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
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

New York State Office for People With Developmental Disabilities (OPWDD): Statewide Family Support Services Committee (FSS)



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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

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

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 & RecreationFamily & SupportsInformation & ReferralFinancial Legal & AdvocacyTransitioning to Adulthood (Youth)
Conditions Covered:	AllergiesAnxietyArthritisAsthmaAttention-Deficit/Hyperactivity Disorder (ADHD)Autism Spectrum Disorder (ASD)Behavioral / Conduct ProblemBlood DisordersBrain Injury, Concussion, or Head InjuryCerebral Palsy (CP)Cystic Fibrosis (CF)DepressionDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionDeafness or Problems with HearingHeart ConditionIntellectual DisabilityLearning DifficultyMigrainesOtherOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette Syndrome (TS)Blindness or Problems with Seeing

Adoptive and Foster Family Coalition of New York (AFFCNY)



Regional Resource Guide
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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

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

New York State Justice Center for the Protection of People with Special Needs



Regional Resource Guide
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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

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)



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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
Website:	http://www.ndss.org/
Counties Served:	State-Wide
Content Categories:	Family & SupportsCommunity Living & RecreationFinancial Legal & AdvocacyInformation & ReferralTransitioning to Adulthood (Youth)
Conditions Covered:	Down Syndrome

InterAgency Council (IAC) of Developmental Disabilities Agencies, Inc.



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Agency	InterAgency Council (IAC) of Developmental Disabilities Agencies, Inc.
Agency Description:	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.
Phone Number:	(212) 645-6360
Email Address:	info@iacny.org
Website:	http://www.iacny.org/
Counties Served:	State-Wide
Content Categories:	Family & Supports Early Childhood & School Aged Care Coordination Accessibility & Assistive Technology Financial Legal & Advocacy Medical Dental & Behavioral Health Transitioning to Adulthood (Youth) Information & Referral
Conditions Covered:	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)

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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)



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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
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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

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
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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
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

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
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
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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

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
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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



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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
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Agency American Academy of Pediatrics Family Readiness Kit to Handle Disasters

Agency Description: AAP Family Readiness Kit to Handle Disasters

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

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

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

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 Greater Hudson Region



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

Agency Autism Society Greater Hudson Region

Agency Description: The Autism Society Greater Hudson Region, New York is a not-for-profit organization that serves people living with autism in the Greater Capital District and their families. Our vision is a society where all individuals on the autism spectrum are fully participating members of our community.

Phone Number: (518) 355-2191

Email Address: support@asghr.org

Website: <https://asghr.org/>

Counties Served: Albany County, Chenango County, Columbia County, Delaware County, Dutchess County, Fulton County, Greene County, Montgomery County, Orange County, Otsego County, Putnam County, Rensselaer County, Rockland County, Saratoga County, Schenectady County, Schoharie County, Sullivan County, Ulster County, Warren County, Washington County, Westchester County

Content Categories: Family & Supports, Financial Legal & Advocacy, Information & Referral, Community Living & Recreation, Early Childhood & School Aged, Transitioning to Adulthood (Youth), Care Coordination

Conditions Covered: Autism Spectrum Disorder (ASD)

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

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

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)

Transitions USA



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

Agency	Transitions USA
Agency Description:	The Transitions program focuses on building academic skills, life skills and general independence for high school graduates and young adults with autism and learning differences. Its specialty isn't just in teaching students how to study or learn a trade – it's in showing its students that they can live a life that even they never dreamed of. Through partnership with local colleges, internships in community businesses and supported living opportunities, Transitions helps young people on the autism spectrum or with learning differences make successful transitions from adolescence to young adulthood. Students have access to state-of-the-art facilities, an experienced staff and an evidence-based curriculum that provides individualized attention and training in skills students will use for the rest of their lives. Transitions gives students the tools and supports they need to learn, thrive, and live happy and productive lives that they and their
Phone Number:	(518) 775-5384
Email Address:	info@transitionsusa.org
Website:	https://www.transitionsusa.org/?
Counties Served:	Albany County Schoharie County Fulton County Schenectady County Montgomery County Saratoga County Otsego County Delaware County Rensselaer County
Content Categories:	Community Living & Recreation Transitioning to Adulthood (Youth) Information & Referral Family & Supports
Conditions Covered:	Autism Spectrum Disorder (ASD) Brain Injury, Concussion, or Head Injury Cerebral Palsy (CP) Down Syndrome Developmental Delay Intellectual Disability Other Mental Health Condition Speech or Language Disorder Learning Difficulty Genetic or Inherited Condition Other

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
Website:	https://www.specialtomato.com/
Counties Served:	State-Wide
Content Categories:	Accessibility & Assistive TechnologyEarly Childhood & School Aged
Conditions Covered:	Autism Spectrum Disorder (ASD)Brain Injury, Concussion, or Head InjuryCerebral Palsy (CP)Developmental DelayDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionIntellectual DisabilitySpina BifidaOtherOther 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

Website: 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

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



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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
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.

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

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

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
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Health Care Needs (CYSHCN) Project

Agency	New York State Children's Asthma Initiative		
Agency Description:	APNY fosters collaboration across partners working to expand based asthma control services in NYS and disseminates educational for asthma-related trainings and resources.	comprehensive, evidence-information and opportunities	
Phone Number:			
Email Address:	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

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

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

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

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

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
Website:	https://www.campwhitman.org/pine-camp
Counties Served:	State-Wide
Content Categories:	Community Living & Recreation
Conditions Covered:	

Low Sensory Nights at Animal Adventure Park



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

Agency Low Sensory Nights at Animal Adventure Park

Agency Description: Famed for its viral sensation giraffes, Animal Adventure Park is home to cuddly creatures from a variety of species. While you can book animal encounters with adorable penguins, majestic African lions, and exotic capybaras any time, the park hosts two low sensory night events throughout the year as well as a low sensory morning. During these events, visitors with sensory sensitivities and other needs can visit the park before or after closing without all the crowds. Animal feedings, concessions, attractions, and other activities will all be on offer!

Phone Number: (607) 760-4429

Email Address:

Website: <https://theanimaladventurepark.com/Event/low-sensory-evening>

Counties Served: Broome County

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

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:

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)

Otsego Northern Catskills BOCES: Regional Partnership FACE Center- Southeast



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

Agency	Otsego Northern Catskills BOCES: Regional Partnership FACE Center- Southeast
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:	(607) 335-1352
Email Address:	ccrisell@oncboces.org
Website:	https://osepartnership.org/center/southeast-rpc
Counties Served:	Delaware County Chenango County Madison County Otsego County Schoharie County Greene 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

Southern Tier Independence Center: Early Childhood FACE Center- Southeast



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

Agency	Southern Tier Independence Center: Early Childhood FACE Center- Southeast
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:	(607) 724-2111 ext. 393
Email Address:	karen1@stic-cil.org
Website:	https://osepartnership.org/center/south-ec-face-center
Counties Served:	Delaware County Chenango County Madison County Otsego County Schoharie County Greene County Broome County Tioga County Schuyler County Steuben County Chemung County Allegany 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

Southern Tier Independence Center: School-Age FACE Center- South



Regional Resource Guide
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Health Care Needs (CYSHCN) Project

Agency	Southern Tier Independence Center: School-Age FACE Center- South
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:	(607) 724-2111 ext. 336
Email Address:	taraa@stic-cil.org
Website:	https://osepartnership.org/center/south-sa-face-center
Counties Served:	Delaware County Chenango County Madison County Otsego County Schoharie County Greene County Broome County Tioga County Schuyler County Steuben County Chemung County Allegany 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

Greater Southern Tier BOCES: Regional Partnership Center FACE Center- Southwest



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

Agency Greater Southern Tier BOCES: Regional Partnership Center FACE Center- Southwest

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: (607) 873-3788

Email Address: tmishook@gstboces.org

Website: <https://osepartnership.org/center/southwest-rpc>

Counties Served: Broome County Tioga County Schuyler County Steuben County Chemung County Allegany 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

NYSARC Statewide Voucher Program



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

Agency	NYSARC Statewide Voucher Program
Agency Description:	After a pause, NYSARC 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
Website:	https://www.nysarc.org/respite-voucher-program
Counties Served:	State-Wide
Content Categories:	Care CoordinationFamily & Supports
Conditions Covered:	ArthritisAutism Spectrum Disorder (ASD)Blindness or Problems with SeeingBlood DisordersBrain Injury, Concussion, or Head InjuryCerebral Palsy (CP)Cystic Fibrosis (CF)Tourette Syndrome (TS)Intellectual DisabilityEpilepsy / Seizure DisorderDeafness or Problems with HearingDevelopmental DelayDown SyndromeDiabetesGenetic or Inherited ConditionSpeech or Language DisorderLearning Difficulty

NYSARC Family Mediation and Conflict Coaching



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

Agency NYSARC 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

Website: <https://www.nysarc.org/mediaton>

Counties Served: State-Wide

Content Categories: Care Coordination Family & Supports

Conditions Covered:

NYSARC Emergency Respite Program



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

Agency NYSARC 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

Website: <https://www.nysarc.org/emergency-respite>

Counties Served: State-Wide

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

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-

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
Website:	https://www.foodallergy.org/living-food-allergies/food-allergy-essentials/food-
Counties Served:	State-Wide
Content Categories:	Disaster/Emergency PreparednessCrisis Resources
Conditions Covered:	Allergies

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

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



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Agency The Center: The Lesbian, Gay, Bisexual & Transgender Community Center: LGBTQIA+ & Disability Pride Social Support Group

Agency Center Support: LGBTQIA+ & Disability Pride
Description: 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



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Agency ASAN: Autistic Self-Advocacy Network

Agency Description: **Our Mission**
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

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
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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



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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

Delaware Opportunities, Inc.



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Agency	Delaware Opportunities, Inc.
Agency Description:	Helping people achieve self-sufficiency and a better quality of life since 1965. Delaware Opportunities offers a host of programs and services that respond to the needs of the citizens of Delaware County, New York. Our programs and services are annually assessed and considered in light of the following: Remove obstacles and solve problems that block the achievement of self-sufficiency Secure and retain meaningful employment Attain an adequate education Make better use of available income Obtain emergency and other assistance
Phone Number:	(607) 746-1600
Email Address:	info@delop.org
Website:	https://delawareopportunities.org/
Counties Served:	Delaware County
Content Categories:	Care CoordinationCommunity Living & RecreationDisaster/Emergency PreparednessFinancial Legal & AdvocacyFamily & SupportsInformation & ReferralTransitioning to Adulthood (Youth)Early Childhood & School Aged
Conditions Covered:	AsthmaAttention-Deficit/Hyperactivity Disorder (ADHD)Autism Spectrum Disorder (ASD)Behavioral / Conduct ProblemBlindness or Problems with SeeingBlood DisordersBrain Injury, Concussion, or Head InjuryCerebral Palsy (CP)Cystic Fibrosis (CF)Deafness or Problems with HearingDepressionDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionHeart ConditionIntellectual DisabilityLearning DifficultyMigrainesOtherOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette Syndrome (TS)AnxietyAllergiesArthritis

Family of Woodstock, Inc.



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Agency	Family of Woodstock, Inc.
Agency Description:	PRIMARY FUNCTION: Case management for children, adolescents and young adults; independent living skills for older adolescents and youth in foster care; Family Peer Support for families with youth ages 0-21, at risk of hospitalization or other placement outside the home; vocational training and employment assistance; anger management classes; counseling; mediation with family members; substance abuse prevention and early intervention; detention diversion; and advocacy with systems as needed. ANCILLARY SERVICES: Crisis intervention; individual and family case management and mediation; educational advocacy; life skills training; job preparedness instruction; mentorships and work experiences; assistance in locating permanent housing; outreach and community education; information and referrals; and community service supervision.
Phone Number:	(845) 331-7080
Email Address:	ycms@familyofwoodstockinc.org
Website:	https://www.familyofwoodstockinc.org/
Counties Served:	Ulster County Delaware County Greene County Sullivan County Orange County Columbia County Dutchess County Putnam County
Content Categories:	Care Coordination Community Living & Recreation Early Childhood & School Aged Family & Supports 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 Arthritis Anxiety Allergies Tourette Syndrome (TS)

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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+ ResourcesFamily & SupportsCommunity Living & Recreation
Conditions Covered:	AllergiesAnxietyArthritisAsthmaAttention-Deficit/Hyperactivity Disorder (ADHD)Autism Spectrum Disorder (ASD)Behavioral / Conduct ProblemBlindness or Problems with SeeingBlood DisordersBrain Injury, Concussion, or Head InjuryCerebral Palsy (CP)Cystic Fibrosis (CF)Deafness or Problems with HearingDepressionDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionHeart ConditionIntellectual DisabilityLearning DifficultyMigrainesOtherOther Mental Health ConditionSpeech or Language DisorderTourette Syndrome (TS)Substance Use DisorderSpina Bifida

OPWDD LGBTQIA+ Training Curriculum



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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+ ResourcesTransitioning to Adulthood (Youth)Government Agency
Conditions Covered:	AsthmaAttention-Deficit/Hyperactivity Disorder (ADHD)Autism Spectrum Disorder (ASD)Behavioral / Conduct ProblemBlindness or Problems with SeeingBlood DisordersBrain Injury, Concussion, or Head InjuryCerebral Palsy (CP)Cystic Fibrosis (CF)Deafness or Problems with HearingDepressionDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionHeart ConditionIntellectual DisabilityLearning DifficultyMigrainesOtherOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette Syndrome (TS)ArthritisAnxietyAllergies

MAP: Movement Advancement Project- LGBT People with Disabilities Fact Sheet



Regional Resource Guide
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Agency	MAP: Movement Advancement Project- LGBT People with Disabilities Fact Sheet
Agency Description:	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. 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. Research shows that LGBT people are more likely than the general population to have a disability and
Phone Number:	(303) 578-4600
Email Address:	info@mapresearch.org
Website:	https://www.lgbtmap.org/lgbt-people-disabilities
Counties Served:	State-Wide
Content Categories:	LGBTQIA+ Resources Financial Legal & Advocacy 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) Anxiety Allergies Arthritis Asthma

RespectAbility: LGBTQ+ People with Disabilities



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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

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



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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.

Phone Number:

Email Address: 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



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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

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

Children's Cardiomyopathy foundation



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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

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



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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

American College of Allergy, Asthma, and Immunology



Regional Resource Guide
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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



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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



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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
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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

Website: <https://fragilex.org>

Counties Served: State-Wide

Content Categories: Financial Legal & Advocacy Information & Referral

Conditions Covered: Genetic or Inherited Condition

The Marfan Foundation



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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
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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
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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

Regional Resource Guide
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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
Website:	https://www.npkua.org
Counties Served:	State-Wide
Content Categories:	Financial Legal & AdvocacyInformation & 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



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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 forum (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
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Agency Center on the Social and Emotional Foundations for Early Learning

Agency Description: 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.

Phone Number:

Email Address:

Website: <http://csefel.vanderbilt.edu/resources/family.html>

Counties Served: State-Wide

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

Conditions Covered: 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
Website:	https://www.spinabifidaassociation.org/
Counties Served:	State-Wide
Content Categories:	Family & SupportsFinancial Legal & AdvocacyInformation & 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 McClaflin 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.McClaflin@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

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

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

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 & RecreationAccessibility & Assistive Technology
Conditions Covered:	AsthmaAttention-Deficit/Hyperactivity Disorder (ADHD)Autism Spectrum Disorder (ASD)Behavioral / Conduct ProblemBlindness or Problems with SeeingBlood DisordersBrain Injury, Concussion, or Head InjuryCerebral Palsy (CP)Cystic Fibrosis (CF)Deafness or Problems with HearingDepressionDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionHeart ConditionIntellectual DisabilityLearning DifficultyMigrainesOtherOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette Syndrome (TS)AllergiesAnxietyArthritis

Getthere Connection to Care



Regional Resource Guide
of the Children and Youth with Special
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Agency Getthere Connection to Care

Agency Description: Connection to Care, or CTC, provides financial assistance to qualifying residents of Broome, Chenango, Delaware, Otsego, and Tioga counties for transportation to health-related services. A caring Getthere Call Center staff member conducts an intake to identify the transportation need and determine all possible transportation options. The call center staff member then works with the individual to develop and help finance a customized, cost-effective, and appropriate transportation solution. The individual in need helps to determine if and how much he or she can contribute to the cost of the transportation. Transportation services eligible for support from Connection to Care include: pre-paid fuel cards that can be used by the individual in need, or by a family member or friend who is providing the ride; public transportation fares; volunteer driver programs; and private transportation services, including cabs, medivans, or coach buses.

Phone Number: 18553734040

Email Address: getthere@rhnscny.org

Website: <https://gettherescny.org/getthere-programs/connection-to-care>

Counties Served: Chenango County Broome County Delaware County Otsego County Tioga County

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

A&D Transport Services, Inc.



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

Agency A&D Transport Services, Inc.

Agency Description: A&D Transport Services, Inc. now provides medical transport in Broome, Cayuga, Chenango, Cortland, Delaware, Fulton, Greene, Herkimer, Madison, Montgomery, Oneida, Oswego, Otsego, Schoharie, Tioga and Tompkins Counties. We have been a reliable source for many patients, as well as providers. We have developed a business model that provides specialized service catering specifically to medical transport passenger eligible for this service. We do not simply provide the transport, we build relationships with all involved and will not let you down.

We also now have wheelchair accessible van and can provide service in the following counties: Broome, Chenango, Cortland, Delaware, Herkimer, Madison, Oneida, Otsego, Schoharie and Tioga.

Phone Number: 18663331030

Email Address:

Website: <https://www.adtransportservices.com/services/patient-medicaid>

Counties Served:

Broome County

Cayuga County

Chenango County

Cortland County

Delaware County

Fulton County

Greene County

Herkimer County

Madison County

Montgomery County

Oneida County

Oswego County

Otsego County

Schoharie County

Tioga County

Tompkins County

Content Categories:

Accessibility & Assistive Technology

Family & Supports

Community Living & Recreation

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

Healthy Families Broome-PACT



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

Agency Healthy Families Broome- PACT

Agency Description: Through an agreement with Ascension-Lourdes we offer free home-based services to support families! You can enroll anytime from before your child is born up to three months of age. Services are available until your child turns six years old. Healthy Families Broome provides information on prenatal care, parenting guidance, bonding, attachment, child brain development, child growth, and so much more! We can also provide connections to community resources.

You may be eligible for this free program! Click here to fill out the form and to learn more:
https://forms.office.com/pages/responsepage.aspx?id=1FpKda7RDkq1OkZFRKINsihiNZ_4adNDIQr18lpxBV9UOVdFQ1NCMjiHOUVSRIhDTUxNQUTU5QU41TS4u&fbclid=IwZXh0bgNhZW0CMTAAAR3XhijyXHhjaT2FjqnColmg-Fyo4H_1PYpwq4YhxxfQp61-2WpMKyFCPc0_aem_AVOMJTX-

Phone Number: (607) 778-2851

Email Address: healthyfamilies@broomecounty.us

Website: <https://www.facebook.com/HealthyFamiliesBroome>

Counties Served: Broome County

Content Categories: Community Living & Recreation Early Childhood & School Aged 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) Allergies Arthritis Anxiety Asthma

Mothers & Babies Perinatal Network



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

Agency Mothers & Babies Perinatal Network

Agency Description: We educate our communities, connect individuals and families to health and other services, advocate for system improvements, and partner with other agencies, government, and providers to strengthen families. We focus on every element of care, from the individual to the health care system to policymakers. For over 25 years, we have been at the forefront of innovative strategies, serving as a trusted resource and authority in maternal and child health care.

Phone Number: (607) 772-0468

Email Address:

Website: <https://mothersandbabies.org/>

Counties Served: Broome County, Chenango County, Chemung County, Cortland County, Delaware County, Otsego County, Tioga County, Tompkins County

Content Categories: 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

Parents as Leaders (PAL) Center



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

Agency Parents as Leaders (PAL) Center

Agency Description: Mothers and Babies Perinatal Network runs drop-in centers for low income families. Provides areas for socialization between kids and among parents. Offers educational sessions and informational resources. Free childrens closet for clothing and a lending library on-site.

Phone Number: (607) 771-6334

Email Address:

Website: <https://www.nyconnects.ny.gov/services/pal-parents-as-leaders-center->

Counties Served: Broome County, Chenango County, Tioga County, Tompkins County

Content Categories: Community Living & Recreation, 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

Southern Tier Independence Center (STIC)



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

Agency	Southern Tier Independence Center (STIC)
Agency Description:	Imagine a world that is accessible to everyone -where no barriers to independence exist; where you're allowed to be yourself and free to let your disability be just one more part of you. Together we can shape this world. Join the Independent Living (R)evolution! Our unity can be a potent force for change. In addition to providing services, the Southern Tier Independence Center is a gathering place for people and information. Our joint efforts in understanding the issues and concerns of people with disabilities can pave the way to this more accessible world. The Center believes that people have the right to be responsible for making their own choices. By
Phone Number:	(607) 724-2111
Email Address:	stic@stic-cil.org
Website:	https://stic-cil.org/
Counties Served:	Allegany County Broome County Cattaraugus County Chautauqua County Chemung County Chenango County Cortland County Delaware County Otsego County Schoharie County Schuyler County Steuben County Tioga County Tompkins County
Content Categories:	Accessibility & Assistive Technology Community Living & Recreation Family & Supports Financial Legal & Advocacy Information & Referral Transitioning to Adulthood (Youth) Medical Dental & Behavioral Health Care Coordination
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

Helping Celebrate Abilities



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

Agency	Helping Celebrate Abilities
Agency Description:	HCA, Helping Celebrate Abilities, has been providing services in our community since 1947. What began as a small preschool for children with special needs has since grown into a much larger organization serving people with intellectual and developmental disabilities of all ages. These programs include 15 residential group homes, 9 integrated preschool classrooms, one UPK classroom, as well as respite, habilitation, counseling, employment, and self-directed services. HCA is a CP State Affiliate.
Phone Number:	(607) 798-7117
Email Address:	contact@hcaserves.com
Website:	https://www.hcaserves.com/
Counties Served:	Broome County
Content Categories:	Community Living & Recreation 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 Brain Injury, Concussion, or Head Injury Developmental Delay Intellectual Disability Learning Difficulty Other Other Mental Health Condition Spina Bifida Down Syndrome Genetic or Inherited Condition Speech or Language Disorder

Institute for Child Development at Binghamton University



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

Agency Institute for Child Development at Binghamton University

Agency Description: The Institute for Child Development (ICD) provides an array of exemplary programs, resources, outreach and training to Binghamton University and the greater community related to Autism. Our Mission: To improve quality of life for autistic and neurodivergent individuals, their families, and communities through excellence in the provision of high-quality, person-centered, evidence-based and innovative practice, education and research.

Phone Number: (607) 777-2829

Email Address: icd@binghamton.edu

Website: <https://www.binghamton.edu/institutes/child-development/>

Counties Served: Broome County

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

Conditions Covered: Autism Spectrum Disorder (ASD)

Health MCs



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

Agency Health MCs

Agency Description: The 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:

Building Brighter Futures for Broome



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

Agency Building Brighter Futures for Broome

Agency Description: Through the Broome County Health Department, Building Brighter Futures for Broome provides education to parents on proper child care for healthy development and education. Also provides means for economic stability.

Phone Number: (607) 778-2802

Email Address: jperney@familyenrichment.org

Website: <https://www.facebook.com/BuildingBrighterFuturesforBroome/>

Counties Served: Broome County

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

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

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

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

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

Agency	Young Center for Anabaptist and Pietist (Amish) Studies
Agency Description:	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.
Phone Number:	
Email Address:	
Website:	https://groups.etown.edu/amishstudies/
Counties Served:	State-Wide
Content Categories:	Community Living & RecreationFamily & SupportsInformation & Referral
Conditions Covered:	Genetic or Inherited ConditionOther

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

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
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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

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/

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 Description: **Mission**
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

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 & RecreationDisaster/Emergency PreparednessFamily & SupportsGovernment AgencyInformation & Referral
Conditions Covered:	Attention-Deficit/Hyperactivity Disorder (ADHD)Autism Spectrum Disorder (ASD)Behavioral / Conduct ProblemBlindness or Problems with SeeingBlood DisordersBrain Injury, Concussion, or Head InjuryCerebral Palsy (CP)Cystic Fibrosis (CF)Deafness or Problems with HearingDepressionDevelopmental DelayDiabetesDown SyndromeEpilepsy / Seizure DisorderGenetic or Inherited ConditionHeart ConditionIntellectual DisabilityLearning DifficultyMigrainesOtherOther Mental Health ConditionSpeech or Language DisorderSpina BifidaSubstance Use DisorderTourette Syndrome (TS)AnxietyAllergiesArthritisAsthma

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

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

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