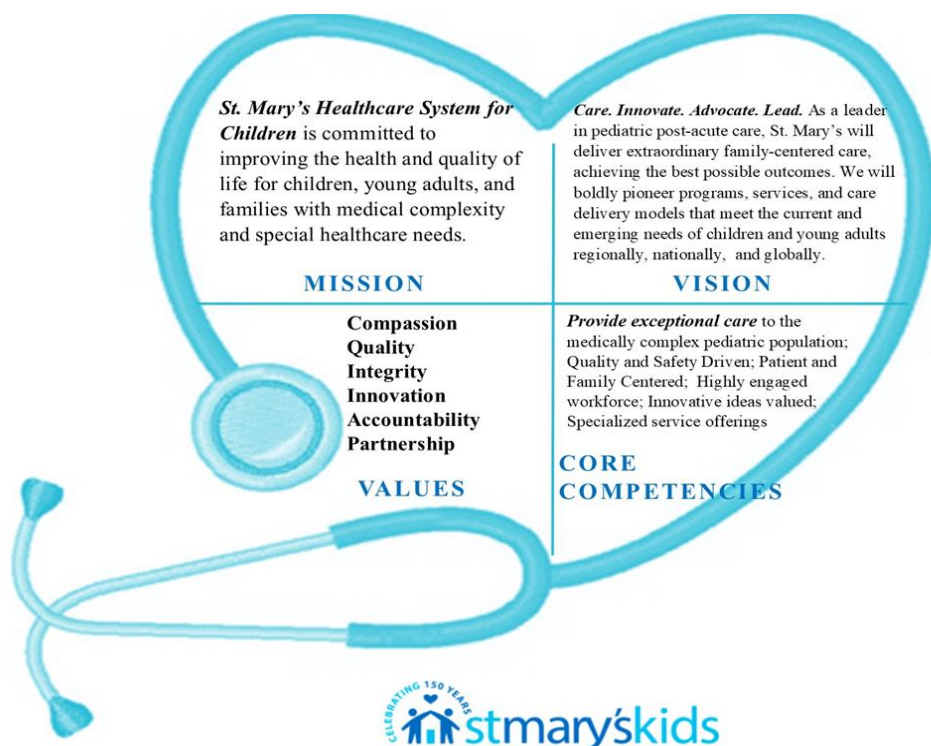




Navigating Your Child's Care

A Practical Guide and Resource Directory for Children and Young Adults with Medical Complexity and Special Healthcare Needs



Learning your child is ill is extremely difficult and brings with it many emotions. These emotions can include: shock, anger, sadness, confusion, hopelessness and feeling overwhelmed. It is important to know that all of these feelings are normal. Learning to live with a child with medical complexity and special health care needs brings many new challenges for every member of the family. It will take time to adapt to these changes. Take one day at a time and know you are not alone.

Finding Help for Your Child

The path to finding ways to help your child may be very challenging. Don't ever be afraid to ask questions. Although there will be many people involved in your child's care, you are your child's best advocate. The following are some tips from other parents who have children with medical complexity and special needs to try to assist you along the way.

1. **Educate yourself-** get information from doctors, hospital libraries, support groups, reliable internet websites, advocacy organizations and other parents. Learning about your child's condition and available resources will help to prepare you to care for your child and face any challenges that might be ahead.
2. **Reach out to other parents-** you are not alone in this journey and it can be very helpful to speak to other parents who have gone through similar circumstances. Speaking to other parents can help you with emotional support, and finding resources that can help you along the way. Speak to your social worker or patient navigator about this possible option.
3. **Develop a strong family-professional team-** although there are times when you might be frustrated, overwhelmed, and angry at the circumstances it is important to try to partner with health professionals as they are important in the care of your child. Try to find ways to communicate in a positive way and remain focused on what is best for your child. St Mary's knows you are the expert when it relates to your child and is committed to providing "family centered care".
4. **Keep trying-** if you do not get the answers or information that you are seeking it is important to continue to try to find them. There is so much going on at this time, don't be afraid to ask others to help.



ST. MARY'S HEALTHCARE SYSTEM FOR CHILDREN - PROGRAMS & SERVICES

St. Mary's Healthcare System for Children is committed to improving the health and quality of life for children, young adults, and families with medical complexity and special healthcare needs.

St. Mary's provides a continuum of services and specialized in-patient care, day healthcare, rehabilitation, home care, and education services to children and young adults that are medically complex and/or have special healthcare needs, following an acute care hospitalization. Our family-centered philosophy, combined with advances in medicine and technology, help children survive illness and injury once thought impossible to overcome. We welcome and thoroughly support children and their families every step of the way.

Below is a detailed list of the programs and services that are provided within the St. Mary's care continuum along with our website for additional information and resources. <https://www.stmaryskids.org/>

St. Mary's Aquatic Therapy Out-Patient Program

Program provides skilled intervention in our state-of-the-art aquatic center. The highly trained physical and occupational therapists utilize the properties of the water combined with specified room/water temperature to achieve therapeutic outcomes of patients with a variety of diagnosis included but not limited to musculoskeletal, neurological and sensory issues.

- 29-01 216th Street Bayside, NY 11360
- (718) 281-8987

Center for Pediatric Feeding Disorders

The Cindy and Todd Johnson Center for Pediatric Feeding Disorders offers an interdisciplinary evaluation service & the only intensive day patient program in NYS to help diagnose and treat feeding disorders as well as outpatient speech-feeding services.

- 29-01 216th Street Bayside, NY 11360
- (718) 281-8541

St. Mary's Certified Home Care Agency (CHHA)

Special needs CHHA that provides home care services to medically fragile individuals (birth – 44 years old). Services include skilled nursing visits, physical therapy, occupational therapy, speech-feeding therapy, nutrition, social work, and home-health aide services.

- 5 Dakota Dr. #200 New Hyde Park, NY 11042
- Central Intake #: 800-270-2478 or (516) 471-9300

St. Mary's Early Education & Preschool Programs

St. Mary's is a New York State approved provider of Evaluations, Preschool, & Special Education Itinerant Teacher (SEIT) Services NYC residents only. In person preschool for those children who qualify. Special Education services bedside or in onsite day care setting.

- 29-01 216th Street Bayside, NY 11360
- (718) 281-8857

Extraordinary Pediatrics, PC

Extraordinary Pediatrics provides Committee for Special Education (CSE), School Age IEP home-based and School Based Related Services through school district contracts. In addition, Home and Community based ABA services for children that have a diagnosis of Autism in the home and or community private or insurance, as well as, in-home Early Intervention Services and Multidisciplinary Evaluations for children 0-3years of age

- 5 Dakota Dr. #200 New Hyde Park, NY 11042
- (516) 621-2681



ST. MARY'S HEALTHCARE SYSTEM FOR CHILDREN - PROGRAMS & SERVICES

St. Mary's Health Home Care Coordination

NYS Medicaid Pediatric Health Home Care Coordination program that provides case management and intensive care coordination services. Enables child's caregivers and healthcare providers to communicate with one another to meet child's needs. Assists families navigate the complex medical system while providing optimal care.

- 5 Dakota Dr. #200 New Hyde Park, NY 11042
- (631) 844-4834

St. Mary's Hospital for Children (inpatient program)

NYC's only pediatric post-acute facility, caring for children with special healthcare needs and medically complex conditions. Services include Pediatric/Adolescent Medical Care, Rehabilitation (PT/OT/ST/ Aquatic Therapy) Intensive Feeding Therapy, Locomotor Spinal Cord Rehab, Specialized Skilled Nursing, Neuro-Rehab and TBI, Respiratory and Vent Care/Wean, Social Work/Family Services, Art/Music Therapy, Pastoral/Palliative/End of life care, Neuromuscular Electrical Stimulation (NMES), Caregiver Education Program.

- 29-01 216th Street Bayside, NY 11360
- (718) 281-8800

St. Mary's Medical Day Healthcare (MDHC)

Therapeutic & Medical after school and weekend program. Services include nursing, rehabilitation, recreational activities, homework assistance, outdoor/indoor play and field trips. Round trip transportation included.

- 29-01 216th Street Bayside, NY 11360
- (718) 281-8729

St. Mary's Rehab – Locomotor Program

Locomotor Training (LT) is an intensive, individualized, outpatient/day, therapy program that improves function in persons with spinal cord injury and other neurological diagnoses.

- 29-01 216th Street Bayside, NY 11360
- (718) 281-8987

St. Mary's Rehab-Seating & Mobility Program

A program focused on evaluating a patient's functional need for assistive technology/durable medical equipment (DME). The focus is to find an alternate means of mobility to maximize independence within the community with ease and safety.

- 29-01 216th Street Bayside, NY 11360
- (718) 281-8987



ADDITIONAL RESOURCES

After a family learns that their child is ill parents/caregivers typically begin to think about how they can best care for their child. The information in this directory is provided to help you find resources to assist you with finding help for your child. The range of care/disability/health issues varies amongst children with special health care needs so the information may or may not pertain to your child. Although we attempt to keep the directory current, resources constantly change. The directory is intended to be a starting point to help you be the best advocate for your child.

ADVOCACY

COMMUNITY AGENCIES

EDUCATION THERAPEUTIC SERVICES

GOVERNMENT AGENCIES - NEW YORK STATE

HOUSING/ LEGAL SERVICES

MEDICAL/NURSING ORGANIZATIONS

MISCELLANEOUS/ OTHER

MODIFICATIONS/ EQUIPMENT

NYC ACCESSIBLE PLAYGROUNDS

SOCIAL SERVICE ORGANIZATIONS

SUPPORT GROUPS



Administration for Community Living (ACL)

ACL advocates across the federal government for people with disabilities, older adults, families and caregivers; funds services and supports provided primarily by states and networks of community-based programs; and invests in training, education, research, and innovation. We manage a variety of programs, providing assistance on health and wellness, protecting rights and preventing abuse, supporting consumer control, strengthening the networks of community-based organizations, funding research, and much more. People of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities. By funding services and supports, ACL helps make this principle a reality for millions of Americans.

- 330 C St SW Washington, DC 20201 (Federal)
- 26 Federal Plaza New York NY 10278 (Regional)
- (202) 401-4634
- <https://acl.gov/>

Family Voices

Family Voices is a national family-led organization of family and friends of children and youth with special health care needs (CYSHCN) and disabilities. Family Voices connects a network of family organizations across the United States that provide support to families of CYSHCN. The organization promotes a 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.

- 561 Virginia Rd., Bldg. 4, Suite 300, Concord, MA 01742
- (781) 674-7224, Toll-free: (888) 835-5669
- www.familyvoices.org

INCLUDEnyc

INCLUDEnyc's mission is to promote positive futures and enhance the quality of life for New York City children and youth with disabilities, ages birth through 26, and their families. INCLUDEnyc empowers families of children and youth with disabilities with the knowledge, confidence, and skills to make informed decisions, effectively access and navigate systems and services, and advocate for themselves and other young people with disabilities and their families.

- 520 Eighth Avenue 25th floor, suite 2503 New York, NY 10018
- (212) 677-4660
- www.includeNYC.org

New York State Commission on Quality of Care and Advocacy for Persons with Disabilities - CQCAPD

Provides legal and other protection and advocacy services for people with disabilities.

- 401 State Street Schenectady, NY 123051
- NYCONNECTS 1(800) 342-9871
- www.NY.gov/services

New York State Department of Health -Resource Directory For Children and Young Adults with Special Health Care Needs - CYSHCN

Provides resources for families of children and young adults who have serious illness or long lasting conditions for which they need extra health care and support services. Available in English, Spanish, French, Russian and Chinese.

- 1(800) 522-5006
- <https://www.health.ny.gov>



Parent Center of New York- United We Stand of New York

Resource center serving culturally diverse families who have children with disabilities throughout Brooklyn, Queens, Bronx and Harlem. The organization is staffed by parents of children with disabilities.

- 91 Harrison Avenue Brooklyn New York 11206
- (718) 302-4313
- www.uwsofny.org

Parent to Parent Support of NYS

A New York State non-for-profit, Parent to Parent is an organization established to provide support to parents/caregivers of those with special needs and medical complexities. Has a link to resources. The organization connects parents to other parents who are facing similar challenges. Parent to Parent serves all ages.

NYC:

- 25 Beaver Street New York, NY 10004
- (646) 766-3461 Statewide: (518) 381-4350

Long Island:

- 415-A Oster Avenue, Hauppauge NY 11788
- (631) 434-6196
- <https://www.ptopnys.org>



COMMUNITY AGENCIES

A&T Healthcare

Has a pediatric nursing division which provides skilled nursing services specific to the care of neonates, infants, children and adolescents at home. Covers 5 boroughs accepts NYS Medicaid.

- 274 Madison Avenue Suite # 1301 New York, NY 10016
- NYC: (212) 683-2250. Main (845) 638-4342
- www.At-healthcare.com

Access –VESID

ACCES-VR (formerly VESID) assists individuals with disabilities to achieve and maintain employment and to support independent living through training, education, rehabilitation, and career development.

- 11-15 47th Avenue Long Island City, NY 11101
- (347) 510-3100
- www.acces.nysed.gov

Adapt Community Network (formerly United Cerebral Palsy of NYC)

Provides a wide range of services to individuals with disabilities and their families including: education, employment and family support.

- 80 Maiden Lane New York, NY 10038
- (212) 683-6700. **Programs and Services Inquiries** (877) 827-2666
- www.adaptcommunitynetwork.org

AHRC New York City

AHRC provides a range of services to individuals with special needs and their families. , including: respite, family education, educational advocacy, guardianship services, supports for siblings, clinical services, in-home services.

- 83 Maiden Lane New York, NY 10038
- (212) 780-2500 or (212) 780-4491
- <https://www.ahrcnyc.org>

Angela's House

Angela's House is a 501 C3 non-profit organization that assists families caring for children with special health care needs that are medically fragile, chronically ill or living with a life threatening illness.

- P.O. Box 5052 Hauppauge New York 11788
- (631) 979-2620
- www.angelashouse.org

Association for Neurologically Impaired Brain Injured Children

This organization offers a wide range of services to individuals ages 5 through adulthood including: service coordination, day programs, recreational services, residential services and family services.

- 61-35 220th Street Oakland Gardens NY 11364
- (718) 423-9550
- www.anibic.org

Catholic Charities of Brooklyn and Queens

Large multi service agency serving the needs of the poor, sick, aged, developmentally disabled.

Offers preventative services such as parenting classes. Languages spoken English, Creole, French, and Spanish.

- 23-40 Astoria Blvd. Astoria NY 11102. (718) 726-9790
- 191 Joralemon Street Brooklyn NY 11201 (718) 722 -6001
- www.ccbq.org



COMMUNITY AGENCIES

Contractor for Kids (A Children's Charity)

Contractors For Kids (CFK) is a not-for-profit corporation founded for the purpose of providing assistance to families in our communities. Our goal is to assist children and their families overcome obstacles that have unfortunately changed or have impacted their lives through the sickness, injury or death of a child. We are committed to this cause and want to give hope and reassurance for their futures. CFK is passionate about their vision: "Whether it is to pay a phone bill or mortgage payment, we will be there. Whether it be aiding in paying for medical bills deemed "experimental" or due to lack of insurance, we will be there. Whether it be arranging transportation or paying for a room to allow families to remain close during these tough times, we will be there. In heartbreaking cases when a child does not survive their illness and a family needs financial help with burying a child, we will be there. We will do as many of these things to the best of ability, we will always be there."

- 20 Peachtree Court Suite 103-L Holbrook, New York 11741
- 888-208-5437 or 631-617-5152
- <https://contractorsforkids.org/>

Heart Share Human Services

Provides supports and services (educational, respite, residential) for people (all ages) with developmental disabilities.

- 12 Metro Tech Center, 29th Floor Brooklyn NY 1120.
- (718) 422-4200
- www.heartshare.org

Heaven's Hands Community Services

Provides supports and services for people of all ages, with developmental disabilities. Their services include: day habilitation, community habilitation, respite, recreation.

- 67-10 Myrtle Ave, Glendale, NY 11385
- (718) 788-5252
- www.hhcsny.org

Queens Center for Progress

Serves individuals with developmental disabilities. QCP has a preschool program. QCP has day and residential programs for adults and adult vocational support services.

- 249-16 Grand Central Pkwy Bellerose, NY 11426
- (718) 279-94
- www.queenscp.org

Queens Chinese American Planning Council

Provides services for Asian persons with developmental disabilities (ages 0-up)

- 133-14 41st Avenue Flushing NY 11354
- (718) 358-8899
- www.cpc-nyc.org

Sick Kids Need Involved People (SKIP of NY)

Provides assistance to help very sick and/or developmentally disabled children in the state of New York to get home from hospitals and institutions to live with their families and participate in their schools and communities to the fullest extent possible.

- 601 W. 26th Street Suite 500, New York, New York 10001
- (212) 268-5999
- www.skipofny.org



COMMUNITY AGENCIES

Sinergia NYC

Provides advocacy for people in low-income, underserved communities. A member of the household must have OPWDD eligibility to qualify for services.

- 2082 Lexington Avenue (125th Street), 4th floor New York, NY 10035
- (212) 643-2840. 1(866) 867-9665
- www.sinergiany.org

South Asian Council for Social Services

Assists underserved south Asian community. Provides counseling, health care assess, medical insurance assistance, parent education, preventive services. Populations served: Indian, Pakistani, Bangladeshi, Nepali, Sri Lankan, Afghan. Do not have to be documented immigrant to receive services. Languages spoken: Bengali, Gujarati, Hindi, Kannada, Punjabi, Urdu.

143-02 45th Avenue, Flushing, NY 11355

- (718) 321-7929
- www.sacssny.org

The Compassionate Friends (Supporting Families After a Child Dies)

The mission of The Compassionate Friends: When a child dies, at any age, the family suffers intense pain and may feel hopeless and isolated. The Compassionate Friends provides highly personal comfort, hope, and support to every family experiencing the death of a son or a daughter, a brother or a sister, or a grandchild, and helps others better assist the grieving family. The Compassionate Friends was founded 50 years ago. Each chapter, along with the supporting National Office, is committed to helping every bereaved parent, sibling, or grandparent who may walk through our doors or contact us. Services include: local chapters to offer support/connection/guidance, crisis hotline information, online magazine, multiple resources and Private online support groups. Go to their website to find your local chapter.

- 877.969.0010
- <https://www.compassionatefriends.org/>

The Family Center

Works with families who are affected by crisis, illness or loss. Provides free social and legal services, including health-care coordination. English, Spanish, Korean, French Creole, French, Hindi, Urdu, and American Sign Language, confidential, offered in the home when needed. Provides services to residents of all five boroughs of New York City.

- 493 Nostrand Avenue Brooklyn, NY 11216
- (718) 230-1379
- www.thefamilycenter.org

United Cerebral Palsy (UCP)

National organization that provides support services (educational, rehabilitation, respite, residential) to children and adults with physical and developmental disabilities.

- 8401 Old Courthouse Rd, Vienna, VA 22182
- 1(866) 827-1692
- www.ucp.org



COMMUNITY AGENCIES

YAI/ National Institute for People with Disabilities

National organization that provides support services (educational, rehabilitation, respite, residential) to children and adults with physical and developmental disabilities.

- 220 East 42nd Street, 8th floor 10017
- (212) 273-610
- www.yai.org

Zero to Three

Zero to Three's mission is to ensure that all babies and toddlers have a strong start in life. We envision a society that has the knowledge and will to support all infants and toddlers in reaching their full potential. During the first three years of life, emotionally nourishing relationships lay the foundation for lifelong health and well-being. By supporting the caring adults who touch the lives of infants and toddlers, we hope to maximize our long-term impact in ensuring all infants and toddlers have a bright future. We provide information, resources, practical tools, and responsive policies for parents.

- 2445 M Street NW, Suite 600 Washington, DC 20037
- (202) 638-1144
- www.zerotothree.org



EDUCATION/THERAPEUTIC SERVICES

Advocates for Children of New York

Works on protecting education rights for children who are at greatest risk for school-based discrimination and/or academic failure due to poverty, disability, race, ethnicity, immigration status, homelessness, or involvement in the foster care or juvenile justice systems.

- 151 W. 30th Street, 5th Floor New York, NY 10001
- (212) 947-9779
- www.advocatesforchildren.org

The Viscardi Center

Services for young adults and school aged children (pre-school—high school) with physical disabilities and medical complexities. Assist with job training and a variety of community supports.

- 201 I.U. Willets Road Albertson, NY 11507
- (516) 465-1400
- <https://www.viscardicenter.org/services/abilities-inc>

Vocational and Educational Services for Individuals with Disabilities (VESID) (is now ACCESS-VR)

For high school students provides counselors who work with student within 2 years of expected graduation to help with the transition planning process VESID NY City regional office Brooklyn NY

- (718) 722-4544
- www.vesid.nysed.gov



GOVERNMENT AGENCIES - NEW YORK STATE (EDUCATIONAL SERVICES)

Early Intervention Program (EIP)

The New York State Early Intervention Program (EIP) is for infants and toddlers with disabilities and their families. The EIP is administered by the New York State Department of Health through the Bureau of Early Intervention. To be eligible for services, children must be under 3 years of age and have a confirmed disability or established developmental delay in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and/or adaptive. The Early Intervention Program offers a variety of therapeutic and support services to eligible infants and toddlers with disabilities and their families, including: assistive technology devices and services, audiology, family education and counseling, home visits, and parent support groups, nursing services, nutrition services, occupational therapy, physical therapy, psychological services, service coordination, social work services, special instruction, speech pathology, vision services. For more info <https://youtu.be/rkE6OoX4W2M> OR to make a referral <https://www.health.ny.gov/forms/doh-5775.pdf>

- (518) 473-7016 or e-mail beipub@health.ny.gov.
- Nassau County 60 Charles Lindberg Blvd., # 100 Uniondale, New York 11553 – Phone: 516-227-8661
- Suffolk County - 50 Laser Court Hauppauge, New York 11788 - Phone: 631-853-3100
- Bronx - 1309 Fulton Avenue, 5th Floor Bronx, NY 10456 - Phone: 718-838-6887
- Brooklyn - 16 Court Street, 2nd & 6th Floor Brooklyn, NY 11241 - Phone: 718-694-6000
- Manhattan - 42 Broadway, Suite 1611 New York, NY 10004 - Phone: 212-436-0900
- Queens - 90-27 Parson Blvd. Jamaica, New York 11432 - Phone: 718-553-3954
- Staten Island - 135 Canal Street, 2nd Floor Staten Island, NY 10304 - Phone: 718-568-2300
- https://www.health.ny.gov/community/infants_children/early_intervention/

Committee Pre-School Education (CPSE)

Preschool special education services are available for children ages 3 to 5 with disabilities or delays in development that affect learning. These services are provided free of charge to eligible children. The parent can contact the Committee on Preschool Special Education (CPSE) to request an evaluation to determine if child is eligible for special education services. The CPSE is responsible for coordinating the special education process for children ages 3 to 5.

NYC Contacts

- 718-935-2007 or 311
- <https://www.schools.nyc.gov/learning/special-education/help/committees-on-special-education>

Nassau County Contacts

- 200 County Seat Drive North Entrance Mineola, NY, 11501
- 516-227-9697
- <https://www.nassaucountyny.gov/4270/Preschool-Special-Education-Program>

Suffolk County Contacts

- 3500 Sunrise Highway Great River New York 11739
- (631) 853-3100
- <https://suffolkcountyny.gov/Departments/Health-Services/Children-With-Special-Needs>

Committee for Special Education (CSE)

The CSE is a multidisciplinary team established by law and regulations for students ages 5 to 21m and is responsible for conducting evaluations to assess your child and to determine if your child is eligible for special education services or support. They, evaluate the data presented about students with respect to eligibility for special education services; design and recommends an Individualized Educational Program (IEP) for each student determined to have a disability and reviews annually the placement of all students with disabilities.

- <https://www.nysed.gov/special-education>
- <https://www.schools.nyc.gov/learning/special-education/help/committees-on-special-education>



GOVERNMENT AGENCIES - NEW YORK STATE (PUBLIC HEALTH INSURANCE)

NYS Marketplace

A way for people to shop for, compare and enroll in health coverage. It is also the only place to get financial assistance provided by the federal government to lower the cost of your health coverage. To shop in the Marketplace, you: must live in New York, be a U.S. citizen, national or lawfully present immigrant, and cannot be applying for coverage of nursing home care or care provided in a Residential Treatment Facility for Children and Youth, Developmental Center or Intermediate Care Facility for the Developmentally Disabled. The Marketplace gives you an easy way to compare health insurance plans so you can choose the one that's right for your health needs and your budget. Health insurance offered through the Marketplace will include a comprehensive set of benefits and coverage. In the Marketplace, you can apply for help to lower the cost of your health coverage. The Marketplace will also see if you qualify and are determined eligible for free or low-cost coverage from Medicaid, the Essential Plan or Child Health Plus.

- 1.855.355.5777
- <https://nystateofhealth.ny.gov/individual/>

New York State Medicaid

NYS 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. Medicaid Managed Care offers many New Yorkers a chance to choose a Medicaid health plan. Managed Care plans focus on preventive health care and provide enrollees with a medical home for themselves and their families. Local Department of Social Services Your Local Department of Social Services (LDSS) may be able to assist you in obtaining your health insurance coverage and/or provide you with information about other programs and benefits you may qualify.

- NYS Medicaid Hotline (800) 541-2831
- https://www.health.ny.gov/health_care/medicaid/
- Local LDSS contact based on location - https://www.health.ny.gov/health_care/medicaid/ldss.htm

Child Health Plus

Child Health Plus provides free or low-cost health insurance to children under the age of 19 who do not qualify for Medicaid and do not have other health insurance coverage. All children under 19 years of age are potentially eligible Child Health Plus regardless of income or immigration status. They must also reside in New York State, meet certain income eligibility requirements tied to household size. View income chart to see income levels for children and have no other health insurance coverage

- 1-800-698-4KIDS (1-800-698-4543)
- https://www.health.ny.gov/health_care/child_health_plus/

Medicaid Health Homes - Comprehensive Care Management

In New York State, many people get their health benefits through the Medicaid Program. Most people are generally healthy, however, others may have chronic health problems. Many are unable to find providers and services, which makes it hard for people to get well and stay healthy. The goal of the Health Home program is to make sure its members get the care and services they need. This may mean fewer trips to the emergency room or less time spent in the hospitals, getting regular care and services from doctors and providers, finding a safe place to live, and finding a way to get to medical appointments. The Health Home Serving Children's (HHSC) program was launched in December 2016, with 16 Health Homes designated to serve children. Visit our Find a Health Home page to locate a Health Home by county and to access contact information.

- (518) 649-4335
- https://www.health.ny.gov/health_care/medicaid/program/medicaid_health_homes/index.htm



GOVERNMENT AGENCIES - NEW YORK STATE (PUBLIC HEALTH INSURANCE)

Medicaid Home and Community Based Waiver Services (HCBS)

HCBS are Medicaid services that give children and youth with complex care needs the choice to stay in their homes and communities. HCBS are for children/youth who, without these supportive services, would need care in a more restrictive setting, such as a residential care facility, nursing home or inpatient care. *If qualify, these programs and services “waive” or remove some of the usual financial requirements for getting Medicaid.* If you know a medically complex or developmentally disabled child or youth who needs help to be able to live in their community, they may qualify for HCBS. Some examples include, Community and Day Habilitation, Respite Services, Caregiver Support, Palliative Care and Home/Vehicle Modification.

- https://www.health.ny.gov/health_care/medicaid/redesign/behavioral_health/children/overview.htm

Children and Youth Evaluation Service (C-YES)

This agency will assist with connecting children to Home and Community Based Services (HCBS). The Children and Youth Evaluation Service (C-YES) is a statewide program that determines whether a child/youth (under age 21) is eligible for Home and Community Based Services (HCBS) through the Children’s Waiver. C-YES evaluates Medicaid eligibility and serves children/youth or who opt-out of the Health Home Serving Children’s program.

- PO Box 5008 New York, NY 10275
- 1-833-333-CYES (1-833-333-2937)
- <https://www.nymedicaidchoice.com/connecting-children-home-and-community-based-services>
- https://www.health.ny.gov/health_care/medicaid/redesign/behavioral_health/children/c-yes.htm?language=en



GOVERNMENT AGENCIES - NEW YORK STATE (PUBLIC, TEMPORARY AND DISABILITY ASSISTANCE)

Supplemental Security Income (SSI)

SSI provides monthly payments to children under 18 with a disability that causes marked and severe functional limitations and can be expected to last for a continuous period of at least 12 months. You can begin your SSI application online and they will review every detail you submit. If documents or more information is needed they will let you know by mail or phone within 14 days. To avoid delays, don't mail any documents unless asked to. You can also schedule an appointment to apply in person.

- 1(800) 772-1213
- <https://www.ssa.gov/ssi>

Supplemental Nutrition Assistant Program (SNAP)

SNAP benefits can help you put healthy food on the table. SNAP monthly benefits can be used to purchase food at authorized retail food stores. This food stamp Program is for qualified low income families. Benefits are provided through an electronic benefit card, similar to a debit or credit card. Eligibility for food stamps is based on household size, income, expenses and other factors. You can apply for SNAP benefits online at www.myBenefits.ny.gov or in person by visiting your local department of social services or in New York City at a SNAP Center. Check website for your local center or to connect with a SNAP outreach provider.

- 1(800) 342-3009 (718) 557-1399
- <https://otda.ny.gov/programs/snap/>

Women, Infants and Children (WIC) program

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) provides federal grants to states for supplemental foods, health care referrals, and nutrition education for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, and to infants and children up to age 5 who are found to be at nutritional risk. You must meet certain income and health criteria to qualify. All NYS WIC offices are available to provide services in person and by phone for appointments. Check the website or call the hotline number to apply for WIC or to locate your local agency that provides WIC services.

- 1(800) 522-5006
- <https://www.health.ny.gov/prevention/nutrition/wic/>
- www.wicprograms.org/state/new_york

The Home Energy Assistance Program (HEAP)

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. Questions regarding the HEAP program should be directed to your HEAP Local District Contact. Eligibility and benefits are based on income, household size, the primary heating source, and the presence of a household member who is under age 6 or permanently disabled.

- <https://otda.ny.gov/programs/heap/>

Temporary Assistance (TA)/ Family Assistance (FA)/Emergency Assistance (EA)

Public Assistance (PA) is temporary help for needy adults, and children. If you are unable to work or can't find a job, **Temporary Assistance TA** may be able to help. **Family Assistance (FA)** provides cash assistance to eligible needy families that have a minor child living with the parent/relative. **Emergency Assistance (EA)** is a category of Temporary Assistance that helps resolve an urgent need or situation. Some examples include homelessness, little or no food, received eviction papers, no fuel for heating in the cold weather period, utilities are shut-off or you or someone in your family has been physically harmed, or threatened with violence by a partner or other household member. You can apply online or in person. Check website or call hotline number for more information.

- <https://otda.ny.gov/programs/temporary-assistance/>
- 1-800-342-3009



GOVERNMENT AGENCIES— NEW YORK STATE (CHILDREN AND FAMILY SERVICES)

Child Care Services

The New York State Office of Children and Family Services (OCFS) provides a range of resources to help parents with their child care needs, people who want to start or are currently running child care programs, and anyone with a concern about the health or safety of a child in a day care program. Choosing child care is an important decision. Learn what child care resources are available to you in New York State. OCFS can both help you with finding child care services and with finding financial assistance in paying for it.

- <https://ocfs.ny.gov/programs/childcare/>
- 1-800-732-5207

Child Welfare and Preventive Services

Child abuse/neglect is an issue that exists in communities throughout New York State and across the country. Visit the website for information about several programs available in NYS to help keep children safe and prevent from abuse and maltreatment. **If you think a child may be at risk of abuse or neglect, please contact the New York State Child Abuse Hotline (State Central Register for Child Abuse and Maltreatment) at 1-800-342-3720. If you believe that a child may be in immediate danger, call 911 or contact your local law enforcement.**

- <https://ocfs.ny.gov/programs/prevention/>
- Abuse Hotline # 1-800-342-3720

Child Safety Services

Learn about child safety recourses that are available to you regarding a variety of different topics such as recent recalls, lead protection, CPR/First Aid Training, household safety, summer safety and transportation safety

- <https://ocfs.ny.gov/programs/cwcs/child-safety.php>

Domestic Violence Services

Domestic violence may involve physical, psychological, sexual, financial or emotional abuse and can affect anyone. If you or someone you know is a victim of domestic violence, help is available. **Contact the New York State Domestic and Sexual Violence Hotline for confidential support, 24/7 at 800-942-6906, text 844-997-2121, or chat at [opdv.ny.gov](https://ocfs.ny.gov).** The Hotline can connect you with a program near you for help with advocacy, housing, counseling, and legal assistance. The state Office of Victim Services assists individuals with expenses resulting from being the victim of domestic violence such as, medical and counseling expenses, moving expenses, and lost wages, in addition to other forms of assistance.

- <https://ocfs.ny.gov/programs/domestic-violence/>
- DV Hotline # 1-800-942-6906

Child Community Services

Offers important information on adoption, foster care and kinship (program for relatives and family friends caring for a child).

- <https://ocfs.ny.gov/programs/cwcs/>



HOUSING/LEGAL SERVICES

Catholic Migration Services, Inc.

Provides services to all immigrants living in Brooklyn and Queens that assist with health care access, housing advocacy, legal rights. Nominal fees. Do not have to be documented immigrant to receive services. Languages include: Albanian, Creole, French, Spanish, and Urdu.

- 191 Joralemon Street, Brooklyn, NY 11219
- (718) 236-3000
- 47-01 Queens Blvd., Suite 203B Sunnyside, NY 11104
- (347) 472-3500
- www.catholicmigration.org

Centers for Independence of the Disabled, New York

Provides a variety of services for people with disabilities. Benefit counselors can help with housing, health benefits, transportation, youth services, SSDI, SSI, food stamps.

- Intake (212) 674-2300 or (646) 442-1520

Brooklyn Center for Independence of the Disabled (BCID) and Brooklyn Parent Center

- 27 Smith St, Suite 200 Brooklyn, NY 11201
- (718) 998-3000

Queens Center for Independence of the Disabled

- 80-02 Kew Gardens Road #107 Kew Gardens, NY 11415
- (646) 442-1520
- www.cidny.org

Bronx Independent Living Services Inc.

- 4419 Third Avenue, Suite 2C Bronx, NY 10457
- (718) 515-2800
- www.bils.org

CHHAY Community Development Corporation (CHHAYA CDC)

Wide range of free services (i.e. housing, legal) for immigrants from India, Bangladesh, Pakistan, and Caribbean nations such as Guyana and Trinidad. All services are offered in Bangla/Bengali, English, Hindi, and Urdu. Do not have to be documented immigrant to receive services.

- 37-43 77th Street, 2nd floor, Jackson Heights, NY 11372
- 121-18 Liberty Ave, 2nd floor Richmond Hill, NY 11419
- (718) 478-3848
- www.chhayacdc.org

Housing Connect

NYC Housing Connect is a portal to help individuals and families find and apply for affordable housing opportunities in New York City. This often takes time To qualify, the household must meet the income and size requirements. For more information, go to the Housing Connect Website: or

- Call 311
- <https://housingconnect.nyc.gov>

Immigration Advocacy Services, Inc.

Provides legal counseling and immigration services to NYC residents. Client does not have to be documented immigrant, English, Arabic, Greek Hindi, Italian, and Spanish.

- 36-16 Astoria Blvd South, Astoria NY 11103
- (718) 956- 8218 or (718) 956-6800
- www.immigrationadvocacy.com



HOUSING/LEGAL SERVICES

Legal Services NYC

Provides free legal help on cases involving housing, family, domestic violence, public benefits, income tax, employment, education, immigration, and consumer rights. Staff fluent in Chinese, Croatian, French, Italian, Korean and Spanish.

- 349 E.149th Street 10th floor Bronx, NY
- (718) 928- 3700
- 105 Court Street, Brooklyn NY
- (718) 237-5500
- 89-00 Sutphin Boulevard 5th Floor, Jamaica, NY
- (347) 592 2200
- www.legalservicesnyc.org

New York City Bar Association

Provides legal referral services and advocacy.

- 42 West 44th Street New York, NY 10038
- (212) 382-6663 Customer Relations
- (212) 626-7383 The Legal Hotline
- <https://www.nycbar.org>

New York City Housing Prevention Assistance and Temporary Housing (PATH)

All families with children must apply for shelter at DHS' Prevention Assistance and Temporary Housing (PATH) intake center. PATH, located in the Bronx, is a state-of-the-art and eco-friendly facility that has been specifically sized, staffed, and laid out to meet the demand for homeless services.

- 51 East 151st Street Bronx, NY
- (718) 503-6400
- www.nyc.gov/dhs

New York Lawyers for the Public Interest

Serves the legal needs of underserved, underrepresented New Yorkers and their communities. Links low income clients and organizations with attorneys willing to volunteer pro bono legal services. Disability Law Center works towards protecting rights of people with disabilities: children with disabilities trying to secure appropriate, integrated special education, fights for equal access for transportation, housing medical care and equipment. Health Justice Program works with communities to ensure access to quality health care including those who face barriers due to limited English or racial, ethnic discrimination.

- 151 West 30th street, 11th floor, New NY 10001
- (212) 244-4664
- www.NYLPI.org

New York Legal Assistance Group (NYLAG)

NYLAG Fights For Fair & Equal Access to Justice and they protect the rights of individuals and families. Founded in 1990, NYLAG is a leading civil legal services organization combatting economic, racial, and social injustice by advocating for people experiencing poverty or in crisis. NYLAG believes that poverty is a systemic issue shaped by laws, institutional policies, cultural representations, racism, and widespread beliefs—not the result of individual behaviors. We know that without a lawyer, justice may be out of reach. Services include: comprehensive and free civil legal services, financial empowerment, impact litigation, policy advocacy, and community partnership.

- 100 Pearl St., 19th Floor New York, NY 10004
- 212-613-5000
- <https://nylag.org/>
- EFLRP@nylag.org (email)



HOUSING/LEGAL SERVICES

Partnership for Children's Rights

Fights for the rights of disadvantaged and disabled children throughout New York City. Lawyers and social workers can assist with special education, social security disability benefits. Mobilization for Justice

- 100 Williams Street, 6th floor New York, NY 10038
- (212) 683-7999 or (212) 417-3732
- <https://mobilizationforjustice.org>

Public Housing Information and Resource Center (PIH)

U.S. Department of Housing Urban Development

Provides decent and safe rental housing for eligible low-income families, and persons with disabilities. PIH Information/Resource Center is staffed to answer questions/inquiries regarding public housing and housing choice voucher programs and regulations. PIH Service Center

- 1(800) 955-2232 or (212) 306-3000
- www.hud.gov

The Legal Aid Society

Provides free legal services for clients who cannot afford to pay for counsel. Represents low-income families and individuals in legal matters involving housing, benefits, disability, domestic violence, family issues, health, employment, immigration, HIV/AIDS, prisoners' rights and elder law.

- Main # (212) 577-3300
- 120-46 Queens Blvd, Kew Gardens, NY 11415
(718) 286-2450
- 111 Livingston Street, 7th Floor Brooklyn, NY 11201
(718) 645-3111
- 260 E. 161st Street Bronx, NY 10451 (718) 579-3000
- www.legal-aid.org

The Queens Community House

Provides programs and services which help all people improve their lives. Provides housing assistance, financial literacy workshops, and citizenship classes. Bengali, Chinese, French, Pashto, Russian, Spanish. Do not have to be documented immigrant to receive services.

- 108-25 62nd Drive, Forest Hills, NY 11375
- (347)965-1213 (718) 592-5757
- www.queenscommunityhouse.org



MEDICAL/NURSING ORGANIZATIONS

Brain Injury Association of NYS (BIANYS)

Advocates on behalf of individuals with brain injuries and their families, and promotes prevention. Provides education, advocacy, and community support services that lead to improved outcomes for children and adults with brain injuries and their families. Offers a toll free Family Help Line, chapters and support groups.

- 5 Pine West Plaza, Suite 506 Albany, NY 12205
- (518) 459-7911
- Family Help Line 1(800) 444-6443
- www.bianys.org

Certified Home Health Agency (CHHA)

Services provided by a CHHA may be available, which can include skilled nursing, physical therapy, occupational therapy, speech/feeding/language therapy, nutrition, social work services, telehealth and home health aides. Recommended services are determined by your medical providers and ask your insurance/Medicaid Case Manager about in-network agencies. St. Mary's Healthcare System for Children has a CHHA that is highly recommended for services. However, if they are not available, below is another CHHA option for your child.

- Extended Homecare 212-356-4200

Epilepsy Foundation of Metropolitan New York

Provides a wide variety of services and supports to persons with epilepsy, their families and the community. Respite services, service coordination, information and referral services, socialization programs and educational presentations.

- 40 Exchange Place, Suite 1700 New York, NY 10005
- (212) 677-8550
- www.efmny.org

Genetic Alliance, Inc.

An organization devoted to promoting optimum health care for people suffering from genetic disorders. Network of 1000 disease specific advocacy organizations. Resources include online genetic disease database, provides information about support groups, clinical descriptions, treatments, research, insurance issues.

- 26400 Woodfield Rd. #189 Damascus, MD. 20872
- (202) 966-5557
- www.geneticalliance.org
- www.diseaseinfosearch.org

Healthy Children.Org

Provides information/resources for parents from the American Academy of Pediatrics. Includes information on chronic illnesses and how to help your child.

- 345 Park Blvd Itasca, IL 60143
- (630) 626-6000
- www.healthychildren.org



MEDICAL/NURSING ORGANIZATIONS

Licensed Complete Homecare Service Agency (LCHS)

LCHS provides Private Duty Nursing (PDN). This is shift nursing and is provided based on your child's skilled nursing and clinical needs. Approved skilled needs may include trach, ventilator and/or GTube care. Hours are based on your child's medical provider's recommendation. Below is a list of local LCHS agencies that provide Private Duty Nursing. Be sure to ask your insurance/Medicaid Case Manager about agencies that are in-network

- Bayada Nurses 718-224-0262
- Caring Hands Homecare 631-419-6737
- Christian Nursing Homecare 631-265-5300
- Family Pediatric Homecare 516-933-0485
- Greater New York 212-687-7464
- Homecare At Its Best 718-468-6923
- Human Care 718-435-1100
- JSP Life Agency 718-944-4705
- Milestones 516-293-0051
- Pioneer Homecare 718-671-2100

March of Dimes Birth Defects Foundation

Works on behalf of the prevention of birth defects and provides support to families affected by birth defects (prematurity, heart defects, genetic diseases) New York Chapter

- 515 Madison Avenue, 20th Floor, New York, NY 10022
- (212) 353-8353. 1(888) 663-4637
- www.marchofdimes.com

Medline Plus National Library of Medicine

National Institutes of Health's Web site for patients and their families and friends. Provides information about diseases, conditions, in language you can understand. You can also get links to the latest medical research on your topic or find out about clinical trials on a disease or condition.

- 8600 Rockville Pike Bethesda, MD 20894
- 1(888) 346-3656
- www.nlm.nih.gov/medlineplus

National Institute of Health (NIH)

Nation's leading medical research agency has different institutes for specific disease areas.

- 9000 Rockville Pike Bethesda MD 20892
- (301) 496-4000
- www.nih.gov

Clinical Trials- database of research studies for new therapies, to test new ways of using known treatments, or to find out more about a disorder. To learn about clinical trials or to find a clinical that your child might be able to participate in visit www.ClinicalTrials.gov

National Institute of Neurological Disease (NINDS) - leading supporter of biomedical research on disorders of the brain and nervous system.

- 1-800-352-9424
- www.ninds.nih.gov

Office of Rare Diseases (ORDR) - provides information on specific rare diseases, patient advocacy groups, research studies.

- 1-888-205-2311
- www.raredisease.info.nih.gov



MEDICAL/NURSING ORGANIZATIONS

National Organization for Rare Diseases (NORD)

Helps people (all ages) with rare orphan diseases through information, programs of education, advocacy, research, and service.

- 55 Kenosia Avenue Danbury, CT 06810
- (203) 744-0100 (800) 999-6673
- www.rarediseases.org

New York State Genetic Services Program

Program that ensures that individuals with genetic disorders have access to genetic services (i.e. diagnostic, counseling and preventive services). All services are available whether or not the patient is able to pay for them. V

- 120 New Scotland Ave Albany, NY 12208.
- (518) 473-7552
- www.wadsworth.org/newborn



MISCELLANEOUS/ OTHER

Courageous Parents Network

Courageous Parents Network is a non-profit organization and educational platform that orients, empowers and accompanies families and providers caring for children with serious illness.

- <https://courageousparentsnetwork.org>

Find a Friend

Support group for parents or caregivers of children with any chronic disease or special needs.

The Children's Hospital at Montefiore

- 3415 Bainbridge Avenue Bronx, NY 10467
- (718) 741-2223
- Family Learning Place, 2nd floor Bronx, NY 10467
- (718) 741-2357
- www.cham.org

Friends of Karen

Provides emotional, financial and advocacy support for children with a life-threatening illness and their families, New York City Office:

- 205 East 42nd Street, 20th floor New York, NY 10017
- (212) 308-1378 or (914) 277-4547
- www.friendsofkaren.org

Make a Wish Foundation of America

Organization that fulfills wishes of children with life threatening medical conditions. National:

- 1702 E. Highland Ave Suite 400 Phoenix AZ 85016
- (602) 279-WISH (9474) Toll-free: (800) 722-WISH (9474) Metro New York and Western New York
- 500 Fifth Avenue, Suite 2900 New York, NY 10110
- www.wish.org

National Respite Locator Service

Helps parents, and caregivers find respite services in their state and local area to match their specific needs. The database is provided for informational purposes only and is not all-inclusive. The fact that an organization is or is not listed in the database does not represent an endorsement or lack of endorsement for any purpose.

- 4220 NC-55 Suite 330 Durham, NC 27713
- (703) 256-2084
- www.Archrespite.org

Southampton Fresh Air Camp

The Southampton Fresh Air Home is a not-for-profit camp offering summer sessions and year-round programs and opportunities for children and youth with physical disabilities.

- 36 Barkers Island Rd, Southampton, NY 11968
- Camp Office Tel: 631-283-1594 Business Office: (631) 283-5847
- www.sfah.org



MODIFICATIONS/EQUIPMENT

Bussani Mobility Team

Bussani Mobility assists with the vehicle modifications for individuals with disabilities. They have offices in Long Island and Westchester.

- 1(888) 379-4709
- <https://www.bussanimobility.com>

NYS Justice Center (TRAID) Program

The Technology Related Assistance for Individuals with Disabilities TRAIID Program supports individuals of all ages with disabilities and special needs who are in need of assistive technology. To locate the nearest Regional TRAIID center, contact the Justice Center for the Protection of People with Special Needs at

- 1(800) 624-4143
- <https://www.justicecenter.ny.gov>



NYC ACCESSIBLE PLAYGROUNDS

LET KIDS PLAY!

Home of accessible and inclusive playgrounds. Here you will find great resources on how to develop an accessible playground from A to Z. You will also find hundreds of examples of what other people have done. In addition, if you are heading out on vacation and want to ensure you have an accessible place to play, the site can point you in the right direction.

- 1463 Greystone Dr. Pittsburgh, PA 15206
- (412) 334-2652
- <https://www.accessibleplayground.net>

New York City Parks

Queens: Flushing Meadows Corona Park

The Playground for All Children was one of the first inclusive playgrounds constructed in the United States, and has been the model for many more after it. The playgrounds are designed to accommodate children with wheelchairs, crutches, walkers, and more. It also has play structures that stimulate social, cognitive, sensory and motor activity for every kid.

- 11101 Corona Ave Corona NY 11368
- Call 311 (in New York City)
- <https://www.nycgovparks.org/facility/playgrounds/accessible-playground>

New York Family

17 Inclusive Playgrounds for Kids with Special Needs in New York

One thing New York has is playgrounds. There are also inclusive playgrounds throughout the city with sensory and adaptable features that allow kids extra support, such as adaptable swings, cushioned flooring, and parks with wheelchair-accessible features.

- One Metrotech Center North, 3rd floor, Brooklyn New York 11201
- (718) 260-4501
- <https://www.newyorkfamily.com/inclusive-playgrounds-kids-adaptable-nyc>



SOCIAL SERVICE ORGANIZATIONS

Arab American Family Support Center

Provides a range of supports to families including: preventative services, mental health services, educational support, and legal services with offices in Brooklyn, Bronx, and Queens.

- 37-10 30th Street, 2nd floor Long Island City, NY 11101
- (718) 643-8000
- www.aafscny.org

Community League of the Heights (CLOTH)

CLOTH is a multi-service community development organization dedicated to supporting and empowering the economically disadvantaged residents of Washington Heights, Inwood and Hamilton Heights. CLOTH provides a comprehensive framework of social and neighborhood services to stabilize and strengthen family life. Among the services provided, CLOTH offers adult education and affordable housing.

- 511 West 157th Street, NY, NY 10032
- (212) 795-4779
- <https://www.cloth159.org>

Jewish Board of Family and Children Services (JBFCFS)

A health and human services agency providing mental health, housing and social services to individuals and families across the five boroughs.

- 463 7th Ave, 18th Floor, NY, NY 10018
- (212) 582-9100 • 1(888)523-2769 • Intake: 1(844) 663-2255
- <https://jewishboard.org>

The Puerto Rican Family Institute

PRFI offers a comprehensive array of social and behavioral health care services. Core services includes Mental Health Treatment, Crisis Intervention, Child Placement Prevention, Adult Residential Care facilities, Head Start programs, and Care Coordination/Case Management. PRFI serves all ages.

- 145 W 15th Street New York, NY 10011
- (212) 924-6320
- www.prfiorg.com



SUPPORT GROUPS

SIBS Place

SIBS Place is a program that focuses on providing support to the siblings of individuals with medical complexities and illnesses.

- 510 Merrick Road Rockville Centre, NY 11570
- (516) 374-3000
- <https://sibsplace.org>

St. Mary's Healthcare System for Children – Support Groups

St. Mary's offers a variety of support group options for parents and family members, which are led by the licensed Social Workers as part of our Patient and Family Service (PFS) Division. **If interested in any of the below groups, please contact the PFS Division at 718-281-8826**

- **Sibling Group (currently only available to inpatient siblings)** - A support group for siblings of patients currently at St. Mary's Hospital for Children. Occurs monthly and each group covers a different topic. Siblings are encouraged to attend and activities are varied.
- **Caregivers Connect- (currently available to both inpatient AND community parents/caregivers)** - A group created to provide information, mostly to families of patients admitted for short-term care, of resources, agencies and organizations available to provide support and assistance to them once discharged home and in the community. The group is held monthly via Zoom.
- **Grandparent Group- (currently only available to inpatient grandparents)** - A group that meets monthly to provide support to grandparents of patients currently at St. Mary's. Provides a safe space for participants to share their experience and meet individuals who have a grandchild that is medically complex.

