

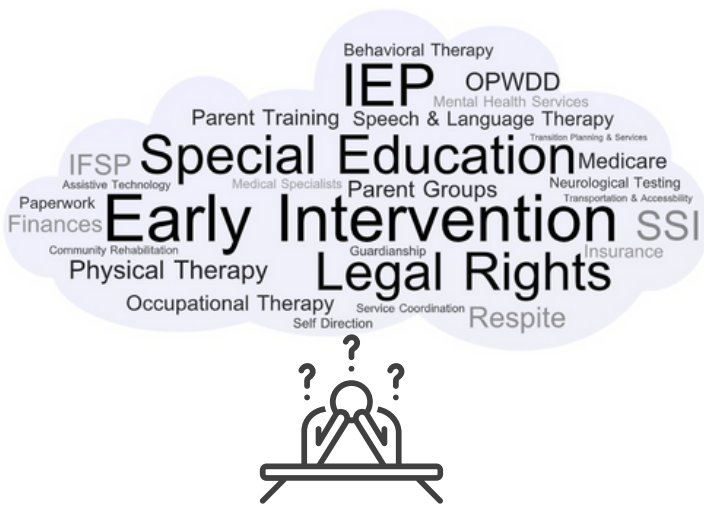


# ACCESSING SERVICES & SUPPORTS

## CHILDREN & YOUTH WITH SPECIAL HEALTH CARE NEEDS

Raising a child is exciting and challenging at the same time. When a child has a special health care need, challenges can be more complex. Parents and caregivers are often unfamiliar with the health care system and supports they need. Getting services set up as early as possible leads to better outcomes. Here are challenges families face and areas where the Children and Youth with Special Health Care Needs Program can help.

### COMMON CHALLENGES FACED BY FAMILIES



- Not enough guidance to navigate resources
- Shortages and long wait times for providers
- Accessibility issues for children/youth with mobility impairment
- Financial hardship to cover all needs
- Difficulty navigating the special education system and finding the right services
- Language barriers increase challenges

### CHILDREN & YOUTH WITH SPECIAL HEALTH CARE NEEDS PROGRAM

The Children and Youth with Special Health Care Needs Program is a statewide, no-cost public health program that provides information and referrals for children/youth (birth-21 years) and their families. Your local program coordinator can assess your family's needs and direct you to the appropriate agencies, services, and supports.

#### HELPFUL RESOURCES

[NYS Children & Youth with Special Health Care Needs Program](http://health.ny.gov/community/special_needs/)  
[health.ny.gov/community/special\\_needs/](http://health.ny.gov/community/special_needs/)

[Early Intervention](http://health.ny.gov/community/infants_children/early_intervention/)  
[health.ny.gov/community/infants\\_children/early\\_intervention/](http://health.ny.gov/community/infants_children/early_intervention/)

[Office for People With Developmental Disabilities \(OPWDD\)](http://opwdd.ny.gov)  
[opwdd.ny.gov](http://opwdd.ny.gov)

[NY Connects](http://nyconnects.ny.gov)  
[nyconnects.ny.gov](http://nyconnects.ny.gov)

[NYS Parent Portal](http://nysparenting.org)  
[nysparenting.org](http://nysparenting.org)

[Center for Parent Information & Resources](http://parentcenterhub.org)  
[parentcenterhub.org](http://parentcenterhub.org)

[HEARS \(Help, Empower, Advocate, Reassure, Support\) Family Line](http://ocfs.ny.gov/programs/cwcs/hears.php)  
[ocfs.ny.gov/programs/cwcs/hears.php](http://ocfs.ny.gov/programs/cwcs/hears.php)

[Family & Community Engagement \(FACE\) Centers](http://osepartnership.org/about)  
[osepartnership.org/about](http://osepartnership.org/about)

[Parent to Parent of NYS](http://ptopnys.org)  
[ptopnys.org](http://ptopnys.org)





# NAVIGATING THE EDUCATIONAL SYSTEM

## CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Navigating the educational system for a child with a special health care need can be challenging. It is important that parents/caregivers understand the process and elements they need to be the best advocates for their children. The Children and Youth with Special Health Care Needs Program can help.

### CHALLENGES

Difficulty obtaining an evaluation

Schools not prepared to meet needs of diverse learners

Can be hard for families to understand rights, supports, services

Lack of communication with school

### IMPORTANT TO KNOW

- The Individuals with Disabilities Education Act (IDEA) entitles children with disabilities to a Free Appropriate Public Education (FAPE)
- Parents have the right to have their child evaluated by the school district
- Individualized Education Programs (IEPs) and 504 Plans are legal documents that must be followed
- A child may qualify for services under Section 504, even if they do not have a learning or developmental problem
- Parents are the experts on their children
- Parents should attend all Committee on Special Education IEP/504 meetings

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### HELPFUL EDUCATIONAL RESOURCES

[NYS Children & Youth with Special Health Care Needs Program](https://health.ny.gov/community/special_needs/)

[Disability Rights NY](https://drny.org)

[NY Connects](https://nyconnects.ny.gov)

[IDEA, US Dept. of Education](https://sites.ed.gov/idea/)

[Difference between IEPs & 504 Plans](https://understood.org/en/articles/the-difference-between-ieps-and-504-plans)

[Family & Community Engagement \(FACE\) Centers](https://osepartnership.org/about)

[Parent Center Hub](https://parentcenterhub.org)

[Parent to Parent of NYS](https://ptopnys.org)

[A Parents Guide to Special Education NY](https://nysed.gov/special-education/parents-guide-special-education)





# ACCESSING THE COMMUNITY

## CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Community is important for everyone, especially for children and youth with special health care needs and their families. It provides a sense of belonging, a place to learn new skills, and the opportunity to grow independence. Yet feedback from families shows there are still challenges accessing the community and participating in activities. The Children and Youth with Special Health Care Needs Program can help.

### FAMILY FEEDBACK ABOUT COMMUNITY ACCESS

Many families have anxiety and face stigma about behavioral and sensory challenges

Behavioral issues can make it hard to engage socially, specifically with peers

Lack of accommodations and limited public awareness can make it hard to participate

There are limited opportunities to participate in community activities

Disability-specific events are accommodating and tend to be less stigmatizing

When kids are welcomed into community activities, it can be a very positive experience

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The Children and Youth with Special Health Care Needs Program is a statewide, no-cost public health program that provides information and referrals for children/youth (birth–21 years) and their families. Your local program coordinator can assess your family’s needs and direct you to the appropriate agencies, services, resources and events.

### HELPFUL COMMUNITY RESOURCES

[NYS Children & Youth with Special Health Care Needs Program](http://health.ny.gov/community/special_needs/)  
[health.ny.gov/community/special\\_needs/](http://health.ny.gov/community/special_needs/)

[Fitness Inclusion Network \(Fit-IN\)](http://bbi.syr.edu/projects/fit-in-network/)  
[bbi.syr.edu/projects/fit-in-network/](http://bbi.syr.edu/projects/fit-in-network/)

[Parent to Parent of NYS](http://ptopnys.org)  
[ptopnys.org](http://ptopnys.org)

[Accessibility with Disabilities](http://dec.ny.gov/about/accessibility-for-persons-with-disabilities)  
[dec.ny.gov/about/accessibility-for-persons-with-disabilities](http://dec.ny.gov/about/accessibility-for-persons-with-disabilities)

[NY Connects](http://nyconnects.ny.gov)  
[nyconnects.ny.gov](http://nyconnects.ny.gov)

[Adaptive Winter Sports Program](http://hnyconnects.ny.gov/services/adaptive-winter-sports-program-422)  
[hnyconnects.ny.gov/services/adaptive-winter-sports-program-422](http://hnyconnects.ny.gov/services/adaptive-winter-sports-program-422)

[Adaptive Skiing](http://iloveny.com/things-to-do/winter/adaptive-skiing/)  
[iloveny.com/things-to-do/winter/adaptive-skiing/](http://iloveny.com/things-to-do/winter/adaptive-skiing/)

[NYS Recreation Resources for Children/Teens with Physical Disabilities](http://aptany.org/general/custom.asp?page=93)  
[aptany.org/general/custom.asp?page=93](http://aptany.org/general/custom.asp?page=93)

[Justice Center](http://justicecenter.ny.gov/recreation)  
[justicecenter.ny.gov/recreation](http://justicecenter.ny.gov/recreation)





# IMPACT ON THE FAMILY UNIT

## CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Raising a child with special health needs impacts the family in profound ways – emotionally, functionally, financially, and socially. Family feedback shows a range of helpful supports, but also many challenges. The Children and Youth with Special Health Care Needs Program can help.

### FAMILIES FOUND STRENGTH IN THESE SUPPORTS...



### BUT STILL FACE CHALLENGES



- Navigating multiple organizations and systems
- Financial stress and career disruption
- Lack of specialists in rural and suburban areas
- Accessing consistent care coordination
- Dismissiveness from some providers
- Limited early childhood placement options
- Limited options for community participation
- Socio-economic and language barriers impact access to supports

### CHILDREN & YOUTH WITH SPECIAL HEALTH CARE NEEDS PROGRAM

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### HELPFUL FAMILY RESOURCES

[NYS Children & Youth with Special Health Care Needs Program](http://health.ny.gov/community/special_needs/)

[NYS Parent Portal](http://nysparenting.org)

[Early Intervention](http://health.ny.gov/community/infants_children/early_intervention/)

[Sibling Support Project](http://siblingsupport.org/)

[Office for People With Developmental Disabilities \(OPWDD\)](http://opwdd.ny.gov)

[Center for Parent Information & Resources](http://parentcenterhub.org)

[NY Connects](http://nyconnects.ny.gov)

[Parent to Parent of NYS](http://ptopnys.org)

[Families Together in NYS](http://fnys.org/resources/ny-state-agencies-programs/)





# COVID-19 AND THE IMPACT ON FAMILIES

## CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

The COVID-19 pandemic impacted everyone, particularly families with children/youth with special health needs, who rely on more medical and educational support than others. Family feedback shows the range of challenges and areas where the Children and Youth with Special Health Care Needs Program can help.

### FAMILY EXPERIENCES DURING THE PANDEMIC

#### Disruptions to Services

- Decreased availability of support services, especially mental health providers
- Fewer services led to loss of skills and regression
- Difficulties in adapting to telehealth due to technical and accessibility problems

#### Disruptions to Education

- Difficulty engaging in remote learning
- Development was affected by loss of socialization and breaks in routines & activities
- Mixed experiences with school communications and remote learning support

#### Mental Health Concerns

- Families faced stress, isolation, behavioral challenges, regression
- Families struggled to balance 24/7 care, work, and remote schooling
- Financial strain added to mental health concerns

### HELPFUL SUPPORTS AND POSITIVE EXPERIENCES

Some schools had strong outreach, tech hardware, teacher help, food support

Parent support groups were lifelines

Success with remote learning for some

Teletherapy and telemedicine were helpful for many

### CHILDREN & YOUTH WITH SPECIAL HEALTH CARE NEEDS PROGRAM

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### HELPFUL EMERGENCY PREPAREDNESS RESOURCES

[NYS Children & Youth with Special Health Care Needs Program](https://health.ny.gov/community/special_needs/)  
[health.ny.gov/community/special\\_needs/](https://health.ny.gov/community/special_needs/)

[HEARS \(Help, Empower, Advocate, Reassure, Support\) Family Line](https://ocfs.ny.gov/programs/cwcs/hears.php)  
[ocfs.ny.gov/programs/cwcs/hears.php](https://ocfs.ny.gov/programs/cwcs/hears.php)

[American Academy of Pediatrics](https://aap.org/en/patient-care/disasters-and-children/)  
[aap.org/en/patient-care/disasters-and-children/](https://aap.org/en/patient-care/disasters-and-children/)

[HHS Health Emergency Toolkit](https://aspr.hhs.gov/at-risk/Pages/CYSHCN-planning-toolkit.aspx)  
[aspr.hhs.gov/at-risk/Pages/CYSHCN-planning-toolkit.aspx](https://aspr.hhs.gov/at-risk/Pages/CYSHCN-planning-toolkit.aspx)

[CDC-Caring for Children in a Disaster](https://cdc.gov/childrenindisasters/checklists/special-healthcare-needs.html)  
[cdc.gov/childrenindisasters/checklists/special-healthcare-needs.html](https://cdc.gov/childrenindisasters/checklists/special-healthcare-needs.html)

[NYS Office of Mental Health](https://omh.ny.gov)  
[omh.ny.gov](https://omh.ny.gov)

[NY Connects](https://nyconnects.ny.gov)  
[nyconnects.ny.gov](https://nyconnects.ny.gov)

