

# Children and Youth with Special Healthcare Needs Family Forum

*Einstein and WIHD Regional Support Centers*

July 12, 2021

Montefiore



Westchester Institute  
for Human Development

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## Agenda

- Overview of Regional Support Centers
- Lessons Learned from Families
- Small Group Discussion
- Resource Spotlight

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## Overview of Regional Support Centers

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### Who are CYSHCN?



Children, birth to 21 years old, who:

- have or at increased risk for chronic physical, developmental, behavioral or emotional conditions and
- require health and related services of a type or amount beyond that required by children generally.

*Examples: Asthma, ADHD, anxiety, autism, diabetes, Down syndrome, epilepsy, food allergies, hearing impairment, muscular dystrophy, traumatic brain injury, visual impairment...*

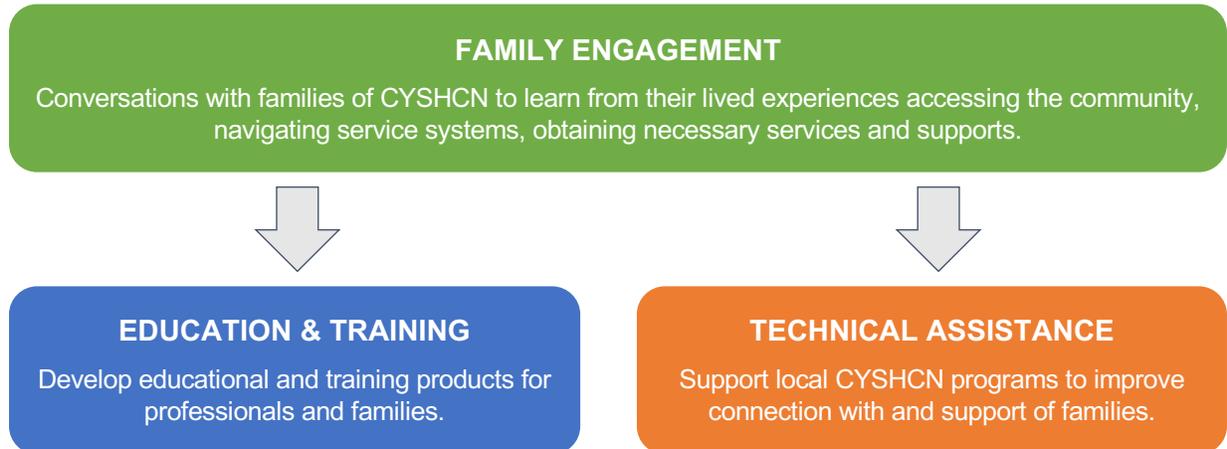
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## What are CYSHCN Programs?

- Located at participating local health departments
- Provide information and referrals to families of CYSHCN to assist with medical and non-medical needs
  - Direct families to local, state and national resources
  - Share information about available services and supports
  - Promote opportunities for families to connect with each other
  - Direct families to organizations to assist with issues and concerns related to education/special education
  - Assist families in locating providers
  - Provide information about navigating various service systems

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## What do RSCs do?



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## Challenges & Supports For the Family

Economic and Psychological costs associated with caring for a child with a disability. Parents often feel overwhelmed.

***I cannot work. I do not have any respite care. I don't have any caregivers, and she's in and out of the hospital where I'm expected to sit with her. When they're this young, you're expected to have a caregiver with them all the time when they're in ICU. So, it makes working really challenging (Kings)***

Support from other parents, extended family/friends, social media and internet sources.

***I think the ones who helped me the most were the parents.... There was very little professional help, and when there was... it was all very confusing. So, I think the biggest help I got was the discussions with parents, their experiences and introductions. ... I always think that the most practical and useful help for us is for parents to communicate and help each other. (Queens-MAN)***

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## Advocacy and Balance are Keys to Success

***It never stops.... like from the minute I finish work, I am constantly emailing, talking to teachers, therapists, you have to always show them that, you know, you are proactive. You know.... as a parent with a kid with special needs, .... you have to show them that you don't back down. That's what I have learned, you have to be prepared when you come to meetings... like when I wanted my son to get ABA services in the school... I had videos, I had pictures... I came prepared and that's what you have to do too... I would recommend to other parents that you have to come always prepared to these meetings. (Westchester)***

***Someone had recently reached out to me again saying he got approved for the services, which I was told he wasn't approved. And now I have to resubmit stuff all over again. And it's exhausting and I haven't reached back out to her yet.... I was doing so much for him and it was so exhausting and I was getting absolutely nowhere that I just said—I can't do this anymore. You know, I just had no space for my other kids. (Dutchess)***

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## Accessing Supports and Services



"we **didn't have to wait that long** before she got her Medicaid waiver. And then we got started getting EI services at home as well." (Bronx/Queens)

...home nursing care and respite services ... It allows me to kind of, you know, **take some of the pressure off of me, so I can kind of reset and get things done that I need to do.** And know that he's going to be taken care of at home kind of gives you a little bit of a breather to kind of reenergize and handle everything else. (Bronx/New York)

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## Barriers to Services and Supports

- Personnel Shortages
- Rigid Rules
- Providers not familiar with range of supports available (AT)
- Financial
- Geographical
- Language

*I have Respite and community habilitation hours that ... somebody can make a good living if ... I had the availability of the person, ... **the hours are there, the funding is there, it's just there's, there's not, you get put on a waiting list.*** (Otsego/Schoharie)

***I have experienced financial difficulties with paying** for the overnight sleep EEG. However, her Medicaid wouldn't pay for it in full. So, I will have to come out of pocket like \$400- \$500.* (Richmond/Nassau)

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## Overly Complex Support Systems

*It might be available, but it's not accessible. (Otsego/Schoharie)*

### Educational System

- Not meeting needs of diverse learners

### Transition to Adulthood

- Worried for future

### OPWDD

- Good supports/Long Process

### Medicaid

- Confusing Process/Approvals

*all I want is my son to learn. ...But I find that it is unnecessary work because as a parent I'm already having to deal with the disability, **why is it that you're making it harder for the parent to get the child to be as independent as possible.** (Bronx)*

*The whole process of getting involved with OPWDD and getting him approved for a self-directed budget it, I have a four-year degree from Geneseo. I'm not, I'm not a high school dropout. And **I found the whole process extremely confusing, vague and sometimes I felt like it was confusing and vague and awful** on purpose to deter people from going through with it. (Geneseo)*

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## Benefits of Inclusion in the Community



Successful Inclusion leads to Growth and Socialization

*“Um, he got much better especially since he's been in Anderson because they make that part of their teaching as well. They go into the community and roller skate and different things” (Putnam).*

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## Common Barriers to Community Inclusion

- Attitudes and understanding
- Sensory issues
- Distance
- Financial
- Cultural
- Lack of accommodations

*He made the team and wanted to try so we, you know, we're going to try to support you however we **can, but he was tired of being yelled at and I think a lot of it is when a lot of directions are given to him, he can't process them quickly.***  
(Broome/Chenango)

*I had to take him to the women's room. He's grown up now. I don't even take him with me these days. Until he was 19, I took him to the ladies' room. In this way, some people will understand you, and some people will scold you. **That's the biggest problem in the community. In some places, there is no family room and I can't get into the men's room.** He is so big that he will frighten others. If some people are too rude, I will quarrel with them. People who understand are OK. People who don't understand will discriminate against us. It happens all the time. (Queens-MAN)*

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## Successful Inclusion addresses Isolation and provides Socialization

***My community's amazing.** First of all, the school my daughter is in, I can call in any time of day and I talk to the principal to discuss my concerns. They'll try to help. They'll try to do anything to help me. There's also so many programs that my daughter is in. There's a Sunday program for her, with girls who are just like her. Not exactly her age. Well, teenagers, little girls who can do things together. They have twice a weekend night. They do baking, they do art. There're so many programs that she's in. There's even a camp that she goes to over the summer. So, something like an inclusion type of camp and they try to just get all the kids to do the same thing, include everybody and she really, her social skills built over there. **She made tons of friends and I feel like I get a lot of support.*** (Kings/Queens)

*Our church has a separate room for children, which works out great because we, and we go to a Christian church now. We used to go to a Catholic church, and he wouldn't sit in the pews either I have to recall this and that and then let him play games on the phone muted. **But now that we go to this other church that takes the kids and puts them in a separate room and does their own activities with them, he loves it. He loves going to church*** (Dutchess/Putnam)

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## Disability Awareness and Education

- Good education and awareness are key to making our society more accessible for all.



*You know, I think it's helpful if a lot of people that either teach classes or different activities or even places like [...] libraries understand what autism is and not just autism. I know there's other things out there even ADHD is really tough. Even if they have a little [...] information on it. Here's -- here's what might happen, here's what you might see in a child in the community that might act this way.... I think people just don't know what it is or don't know what to look for if they [don't] have a family member [...] or a friend [with it...]. So when your child's doing a temper tantrum on the floor at 10 years old, maybe they'll understand, oh, you know, maybe this kid has autism or maybe they have this going on or they have something else going on [...] I am so tired of explaining my kids away every time we sign up for an activity or anything. (Monroe)*

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## Supports for Entire Family

*And sometimes you're like oh, if I would have known about that a year ago or and really, **I should have added other parents because honestly 95% of what I've learned has been from other parents.** Even going to the whole SSI process and that whole nightmare and, you know, it's – yeah, the other parents are the ones and really, I mean going back to the school, somehow the schools just don't have that information or resource. (Suffolk)*

- Making connections with parents who have similar experiences
- Support for siblings of CYSHCN
- Online support groups and social media groups

*Maybe something for siblings. I don't know. I think because my son has an older sibling and a younger sibling. **A support system for them on how to cope with having a sibling who has, disabilities because it's not always easy.** You're never able to enjoy the same things outside of your family unit. (Bronx/Queens)*

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## Supports for Transition Points & Care Coordination

*I'm not always sure people understand how challenging it is for the families to coordinate between all the different providers and so, you know, service coordinators and everything and yet it doesn't seem to be like one kind of clearing house where we could,... get the information that we need to get to... providers and community helpers programs that might be able to assist our families like it's really especially families with medical needs **I feel like this is like more than a part time job, just managing components of his care ... what I'm asking for just more coordination or at least appreciation of the fact that this is not-this is not an easy thing.** (Monroe)*

*... I really wish that there was kind of almost like a standard program. If you have a child that is, say, when they **turn 17**, you know, or say okay, like, this is a transition year, like, these are the things you should know if you have a child, ...do you have sort of like a-a power of attorney, do you have, you know, medical, you know, abilities, all those sort of things and so it's like I wish that they had more of that kind of stuff, have you put his in place where your child is if they're willing or able to give you permission, you know. (Onondaga)*

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## Small Group Discussions

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## Small Group Topics

- Community Education
- Family Education
- Outreach and Social Media
- Parent Support Groups
- Transition

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## Small Group Discussions

- Each group will include one CYSHCN RSC staff facilitator who will inform you of your group's topic and guide the conversation
- You will have 40 minutes to discuss with your small group
- Be prepared to share 1 to 2 main ideas from your discussions with the large group

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## Large Group Shareback

**Community Education, Family Education, Outreach + Social Media,  
Parent Support Groups, Transition**

*What was your group's topic?*

*What was the focus of your discussion?*

*Were there any key takeaways from your discussion?*

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## Resource Spotlight

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## CYSHCN Websites

- **Children and Youth with Special Health Care Needs** - this website gives a description of the role of local CYSHCN programs and RSCs, and also has links to educational materials and newsletters containing resources  
[https://www.health.ny.gov/community/special\\_needs/rsc/](https://www.health.ny.gov/community/special_needs/rsc/)
- **Local CYSHCN Programs** - this website provides information on all the local CYSHCN programs in the state, as well as the contact person to reach out to with questions  
[https://www.health.ny.gov/community/special\\_needs/county\\_programs.htm](https://www.health.ny.gov/community/special_needs/county_programs.htm)

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## Educational Materials

### Healthcare Transition Video

Overview of guidelines and issues to be aware of while children transition from pediatric to adult health care services

(<https://www.youtube.com/watch?v=pqt5sG6raiE>)



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## Educational Materials

### Parent Advocacy Webinar

Two experienced parent advocates highlight types of advocacy, tips for advocacy and systems surrounding advocacy

(<https://www.wihd.org/research/cyshcn/>)



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## Other Resources

A screenshot of the "Regional Resource Guides" website. It features a grid of seven regional guides: Mid-Hudson, Mohawk Valley, North Country, Southern Tier, Capital, Long Island, and New York City. Each guide lists the counties it covers. Below the grid is an "Educational Video Library" section with two video thumbnails: "Navigating Multiple Systems" and "Support your EXPENSES in a complex world".

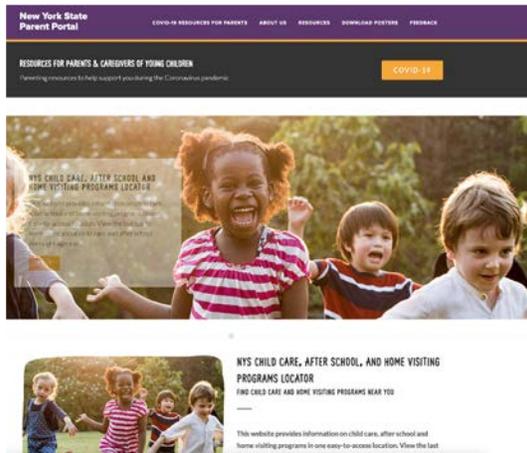
### Regional Resource guides

Compilation of local, state, and national resources categorized by counties served, CYSHCN condition and issues addressed (e.g., Community living & Recreation; Financial, Legal, & Advocacy; Accessibility & Assistive Technology; Early Childhood & School Age)

(<https://www.wihd.org/research/cyshcn/>)

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## Other Resources



**New York State Parenting Portal**  
Caregiving tips; Child care, afterschool, and home visiting program locator; Parent Guide; Multiple Systems Navigator; and Helping your child succeed at school (<https://www.nysparenting.org/>)

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