

# Voices of Families Caring for Children with Special Health Care Needs

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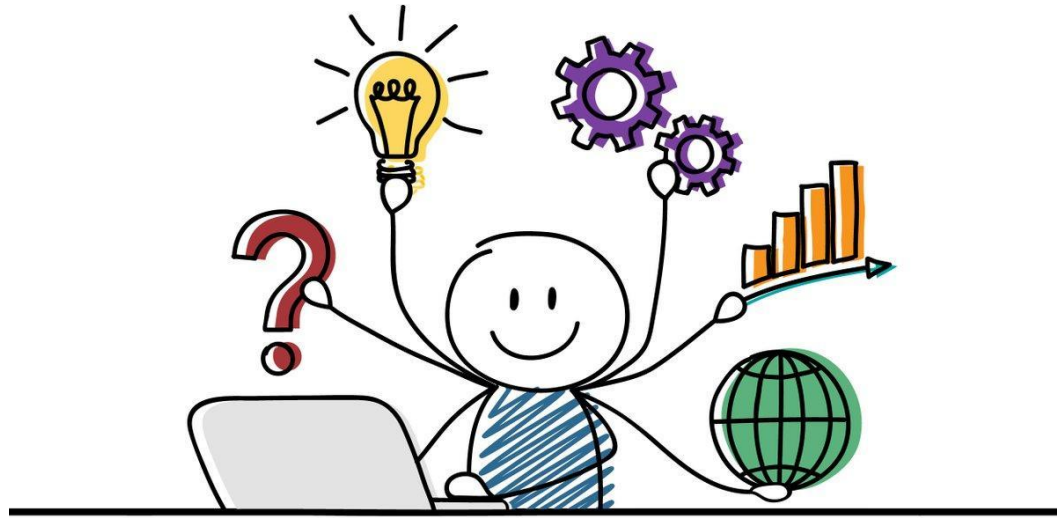
Montefiore



Westchester Institute  
for Human Development

# Agenda

- Background
- Family Engagement Procedures
- Lessons Learned from Families
- Next Steps



**Background**

# Who are Children with Special Health Care Needs?



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...*

# Children & Youth with Special Health Care Needs 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

# New York State Regional Support Centers



## Our Goal

*Increase the capacity of local CYSHCN programs to connect with and support CYSHCN and their families in communities across the state*

# What do NYS Regional Support Centers do?

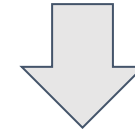
## FAMILY ENGAGEMENT

Conversations with families of CYSHCN to learn from their lived experiences accessing the community, navigating service systems, obtaining necessary services and supports.



## EDUCATION & TRAINING

Develop educational and training products for professionals and families.



## TECHNICAL ASSISTANCE

Support local CYSHCN programs to improve connection with and support of families.



# Family Engagement Procedures

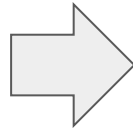


# Family Engagement Procedures



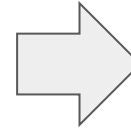
## Recruitment

Materials  
Outreach  
Intake Forms



## Family Sessions

Group & Individual  
Building Rapport  
General Script



## Follow Up

Surveys  
Compensation  
Family Forums

# Family Sessions

**Table 1.** Family sessions and participants by RSC.

<b>RSC Site</b>	<b># Sessions</b>	<b>Total CYSHCN</b>	<b>Total Parents</b>
RFK	42	180	139
SCDD	83	148	114
WIHD	42	119	86
<b>TOTAL</b>	<b>167</b>	<b>447</b>	<b>339</b>

51/58 NYS counties represented

Community type

- 16% Rural
- 35% Urban
- 44% Suburban

63 group sessions, 104 individual interviews

- 4 participants in group sessions on average (range, 2 to 10)
- 144 English, 12 Spanish, 11 Mandarin sessions

# Parents/Caregivers

339 parents/caregivers of CYSHCN participated

- 93% female
- 59% white
- 64% married
- 56% attained Bachelor's degree or greater
- Majority between 30 and 49 years old
- 64% employed either full- or part-time
- Most had one child with a SHCN (range, 1 to 3)

33% indicated COVID-19 impacted their employment



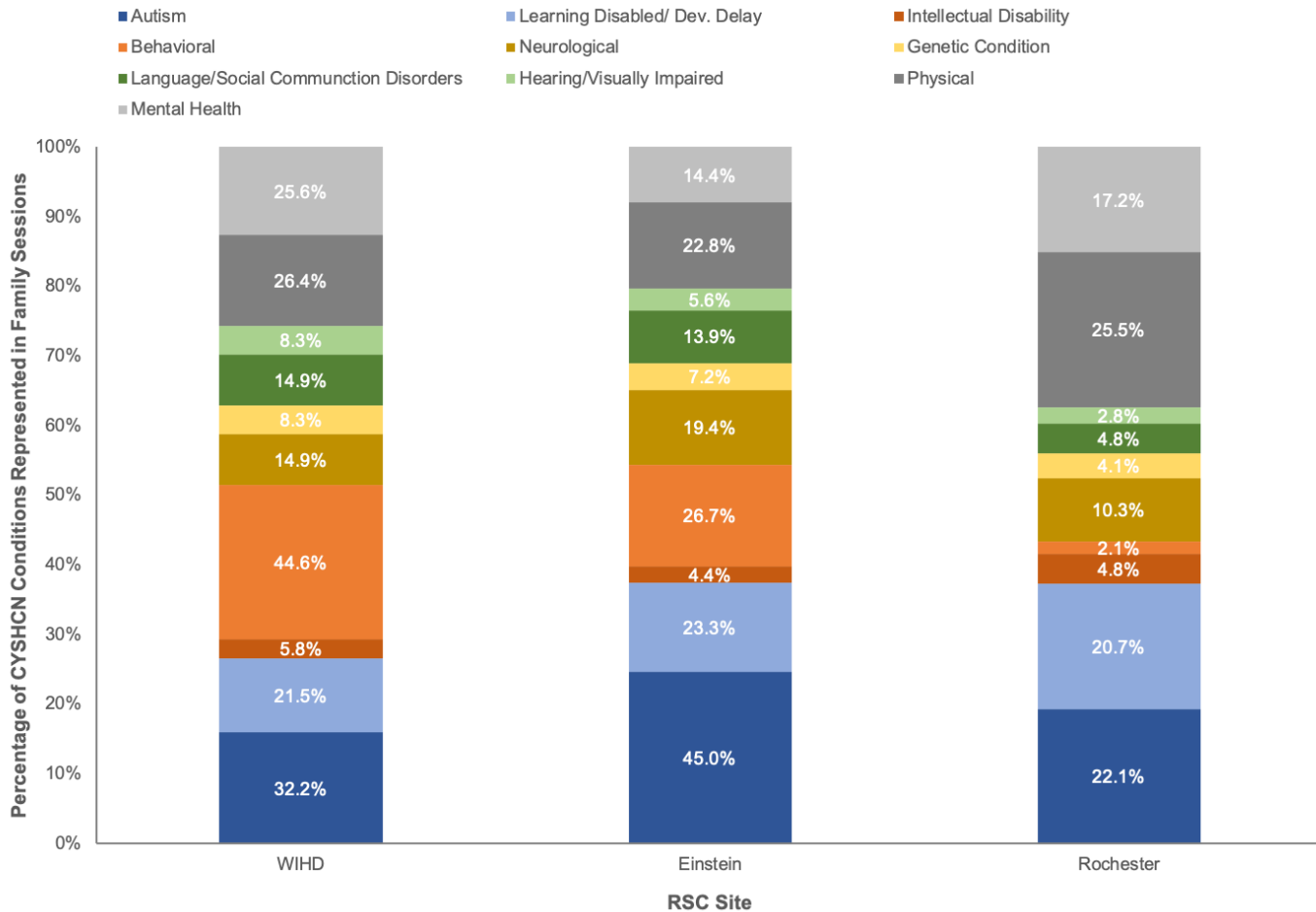
# CYSHCN

447 CYSHCN represented

- 61% male
- 53% white
- 71% between 5 and 17 years
- Variety of conditions

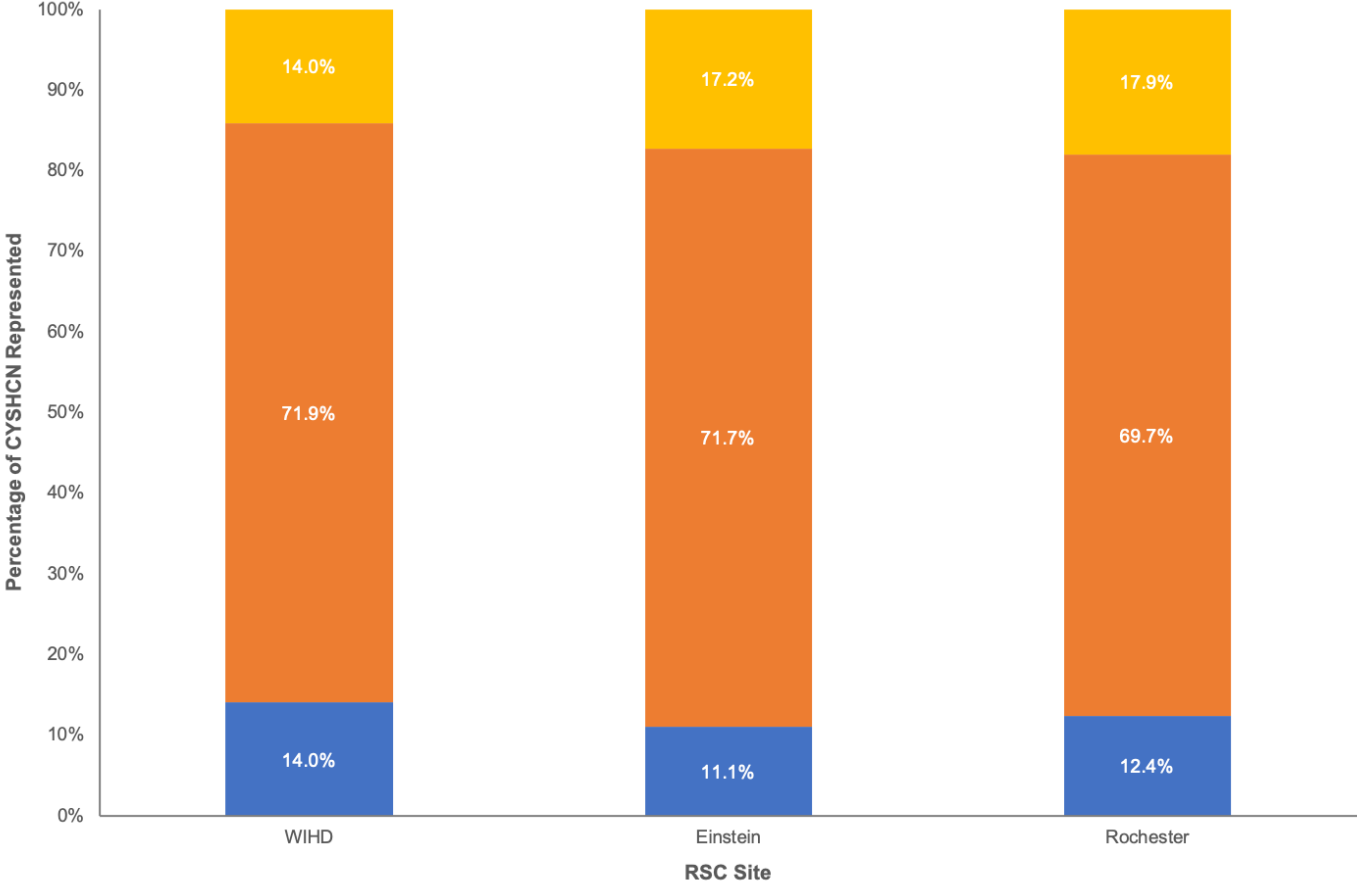


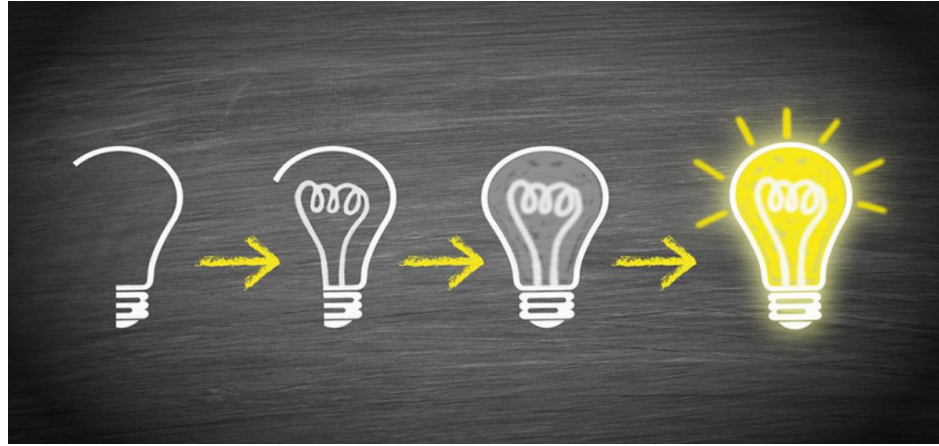
## CYSHCN Conditions by RSC



### CYSHCN Age by RSC

■ Early Childhood (Birth - 4) ■ School Age (5 - 17) ■ Adult (18 - 21)





# Lessons Learned from Families







# Impact on the Family Unit

- Challenges to obtaining diagnosis
- Impact of diagnosis & life balance
- Informal and formal supports
- Parents as advocates

*The dismissiveness, the you're not a good enough parent...  
(Albany/Rensselaer)*

*I realized that what I needed for my son I could not find... So, I created a group,  
(Richmond/Queens)*

*It never stops, like from the day, like from the minute I finished work, I am constantly emailing, talking to teachers, therapists.....(Westchester)*

# Accessing Supports and Services



- Positive impact of services and supports
- Challenging education system
- Barriers to accessing services and supports

# Positive Impact of Services & Supports

High quality services and supports led to:

- Improvements in child skills
- Relieves pressure on primary caregivers

Aspects of helpful services and supports:

- Supportive
- Responsive
- Flexible
- Coordinated

*...home nursing care and respite services...allows me to...**take some of the pressure off of me, so I can kind of reset and get things done that I need to do.** (Bronx/New York)*

*her **teachers brought it to our attention.** ... we live in such a good district...they **walked us through the process...** it was very overwhelming but again, I think they did a lot of handholding and explanation and stuff. ... **it was not as overwhelming as I thought it would have been...** I was grateful for that. (Westchester)*

# Challenging Education System

- Difficult to navigate
- Not meeting needs of diverse learners
- Reliance on out of district placements
- Poor parent-professional partnerships
- Parents resort to litigation
- Concerns about the future

***“She can't go here”...And they wouldn't even consider inclusion and they, they kept saying we don't have a place for her. The experience in school has been a nightmare. (Allegany/Tioga/Wyoming/Cattaraugus)***

***...he spends a lot of time on the bus. ...he actually started preschool...at three but the first week and a half of school, he was still two. So, to take a two-year-old that's never left the house and put them on a bus that he spends about an hour each way on the bus, just because he's the first and last stops. (Niagara)***

# Barriers to Services & Supports

- Personnel shortages
- Lack of provider knowledge
- Systems are too complex
- Financial
- Language
- Geographical

*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)*

*The whole process ... 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. (Genesee)*

# Accessing the Community



- Experiences Accessing Community
- Parent Hesitation, Personality and Effort
- Socialization Opportunities in the Community

# Experiences Accessing Community

Families of CYSHCN are accessing the community with varying levels of success. This may be related to:

- Sensory issues
- Location
  - Rural and suburban families often face a lack of offerings and distance to offerings.
- Financial concerns
- Culture
- Inadequate supports

*...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'm in a very small town... the **school district itself didn't have any activities for special needs kids...**whether or not they don't have enough or they just don't have the funding for it. But I would love for him to play sports. He loves baseball, tee ball, softball, he loves doing all that kind of stuff. But **the closest places to here, we would have to drive 45 minutes.** (Dutchess)*

# Parent Hesitation, Personality and Effort

Parent attitudes and/or concern about reaction of others are changed by:

- Negative experiences with attitudes and lack of understanding
- Time

Parent advocacy and planning is necessary to:

- Obtain quality inclusion and access to community spaces and activities
- Integrate children that need specific accommodations

*For the past few years have **gone to every library in the county in alphabetical order.** So, a lot of times I have to go in there and **tell the librarian in advance**, in case Daniel is being loud or in case he wants to interact with them, just kind of **give them a heads up.** But I find for the most part, **as the years went on**, you know, and people with disabilities are being so **much more integrated into the community...**  
(Westchester)*



# Socialization Opportunities in the Community

Successful community inclusion:

- Addresses isolation
- Can be facilitated by understanding and compassion of others

Established supports and accommodations:

- Can also help to provide families with more access to community spaces

Broad community inclusion:

- Can give CYSHCN opportunities for rich and full lives and provide families with relief

*My church has been very good um, and very supportive. I think it does help because the deacon has a child with special needs himself. But also, the people are compassionate. And so, when, Mary has those public meltdowns, which of course don't elicit sympathy and emotions, because she's 15. I mean the people don't know what to say, but at least, you know, that they'll come over and they'll be like, "Can you hand me a cup of coffee? They'll be like, "Don't worry. So, I'm not judging." So that helps.*

*(Albany/Rensselaer)*

# Impact of COVID-19

- **Exacerbate existing issues; additional burden placed on parents**
- Parent and child anxieties
- Concerns about regression
- Witness child progress

*Wearing a mask is really hard for him, so I'm not really able to take him out much, which makes me kind of sad because...I am so limited just because he can't tolerate wearing it. (Monroe)*

*During the whole COVID outbreak, there – there was **a real gap and problem with special needs children and childcare**. And when the Governor's office I think **mandated that the schools provide childcare for first responders, the special needs children were not taken into consideration**.  
(Suffolk)*

# Impact of COVID-19

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- **Parent and child anxieties**
- Concerns about regression
- Witness child progress

## **PARENT ANXIETY**

*“I'm facing the, “Am I going to lose my job because I can't go to work because I have to be with my child and teach my child and, and do therapy with my child.” (Orange)*

## **CHILD ANXIETY**

*“But where we live, there's less things in walking distance. So, there is a park, we go there. My son since COVID does not want to leave the house. He wants to stay in his room and listen to his music and read his books, getting him to leave the house is really hard. But in the past, you know, we loved the park. We loved the library.” (Queens)*

# Impact of COVID-19

- Exacerbate existing issues; additional burden placed on parents
- Parent and child anxieties
- **Concerns about regression**
- **Witness child progress**

## **REGRESSION**

*I started seeing [my son] do **stimming like I've never have really seen him do that since he was little. So, I knew something was wrong.** So, I've been trying to find, right now, I've been in the process of trying to find counseling for him because **that lack of socialization has really impacted him and learning through a screen... has really impacted him.** (Otsego/Schoharie)*

## **PROGRESSION**

*And recently, during this COVID time (child) has **learned to ride her bike.** So, that was something that was a huge stuff that **I honestly never thought would ever happen.** So, really awesome. (Erie/Genesee/Niagara/Orleans)*

# Variations by Culture and Language



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## Variation by Language

I think there should be a little more humanity in that sense because, in my case, they also gave me the diagnosis for [Child], it was like 'there you go' 'that's it'... I've even remembered that **they've told me that I had to learn English** in order to understand the brochure they were giving me.... **I did not speak English** at that time. **I had to go to a translator** to have everything translated, and I mean **they don't give you enough information in Spanish.** (Westchester-SP)

*Language barriers* were issues for several parents for communicating with doctors for diagnosis and accessing various services and systems of care. In addition, **language barriers** and geographical barriers can stand in the way of a child or family accessing services and supports. Also, given New York's diverse population, **culture** might also affect family's ability to interact in the community.

## Variation by Culture

So, it's a **cultural taboo, being a Bengali mom, having a special need kid, it's a taboo, talking about autism.** So, it's zero. Having some kind of community integration, it's completely zero...And my family doesn't live here. They're back in Bangladesh...So, **no community integration...**(Bronx/New York)

# Parent Recommendations

*I think it would be good if there is more information, more contribution for children with special needs. Not only children but also adults with special needs. (Westchester)*



# Parent Recommendations

- Supports for whole family
- Information and coordination between systems
- Care coordinators
- Disability awareness training
- Inclusive community opportunities

*I think specific areas must be created for our children within the community. (Manhattan) Centers where they can go and feel as a family and talk, communicate with parents and children. (Westchester)*

*Having like a sibling support group or something so that the siblings can try and understand, but the parents need it too. (Orange/Rockland)*

*...more education, speaking generally about the community. Education for schools, teachers, professors, even other children because it's hard for them to understand since they don't have the same experience as we do with our children. (Manhattan)*



# Share your Reaction and/or Experience

- What are your thoughts on the findings shared? Surprising or expected?
  - How do your experiences compare with those described?
  - Are you aware of resources or supports that address the barriers highlighted?
  - Do you have ideas or suggestions for some of the issues mentioned?
- 

## Options for responding

1. Use the chat function to type your response and submit it
2. Select  under reactions and we will unmute you



# Parent Educational Materials

- Healthcare Transition video
- Parent Advocacy Webinar (English)
- Parent Advocacy Webinar (Spanish)
- Navigating Barriers to Community Integration

To access these materials, visit:

[https://www.health.ny.gov/community/special\\_needs/rsc/](https://www.health.ny.gov/community/special_needs/rsc/)



# Additional Resources

## CYSHCN Website

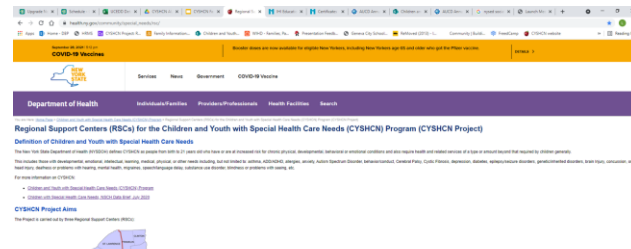
## Local Health Department Webinars

- Transition
- Mental Health
- LGBTQ+

## Family Forums

## Newsletters

## Resource Directory



### Events and Resources for Professionals



Agency 101: Connecting Individuals with Disabilities to Adult Services

September 21th, 10:00 AM - 3:00 PM - By [CNY Regional Interagency Technical Assistance Team](#) - FREE

# Questions



# Contact Us

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