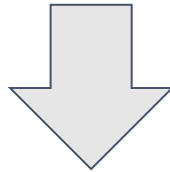


What do RSCs do?

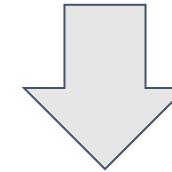
FAMILY ENGAGEMENT

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 Sessions

Table 1. Family sessions and participants by RSC.

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

51 NYS counties represented

- Albany, Allegany, Bronx, Broome, Cattaraugus, Cayuga, Chautauqua, Chemung, Chenango, Clinton, Cortland, Delaware, Dutchess, Erie, Essex, Genesee, Herkimer, Jefferson, Kings, Lewis, Livingston, Madison, Monroe, Nassau, Niagara, New York, Niagara, Oneida, Onondaga, Ontario, Orange, Orleans, Oswego, Otsego, Putnam, Queens, Rensselaer, Richmond, Rockland, Schenectady, Schoharie, Seneca, St. Lawrence, Suffolk, Tioga, Tompkins, Ulster, Warren, Wayne, Westchester, Wyoming

63 group sessions, 104 interviews

- 4 participants in group sessions on average (range, 2 to 10)
- 149 English, 7 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)

Community type

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

33% indicated COVID-19 impacted their employment



CYSHCN

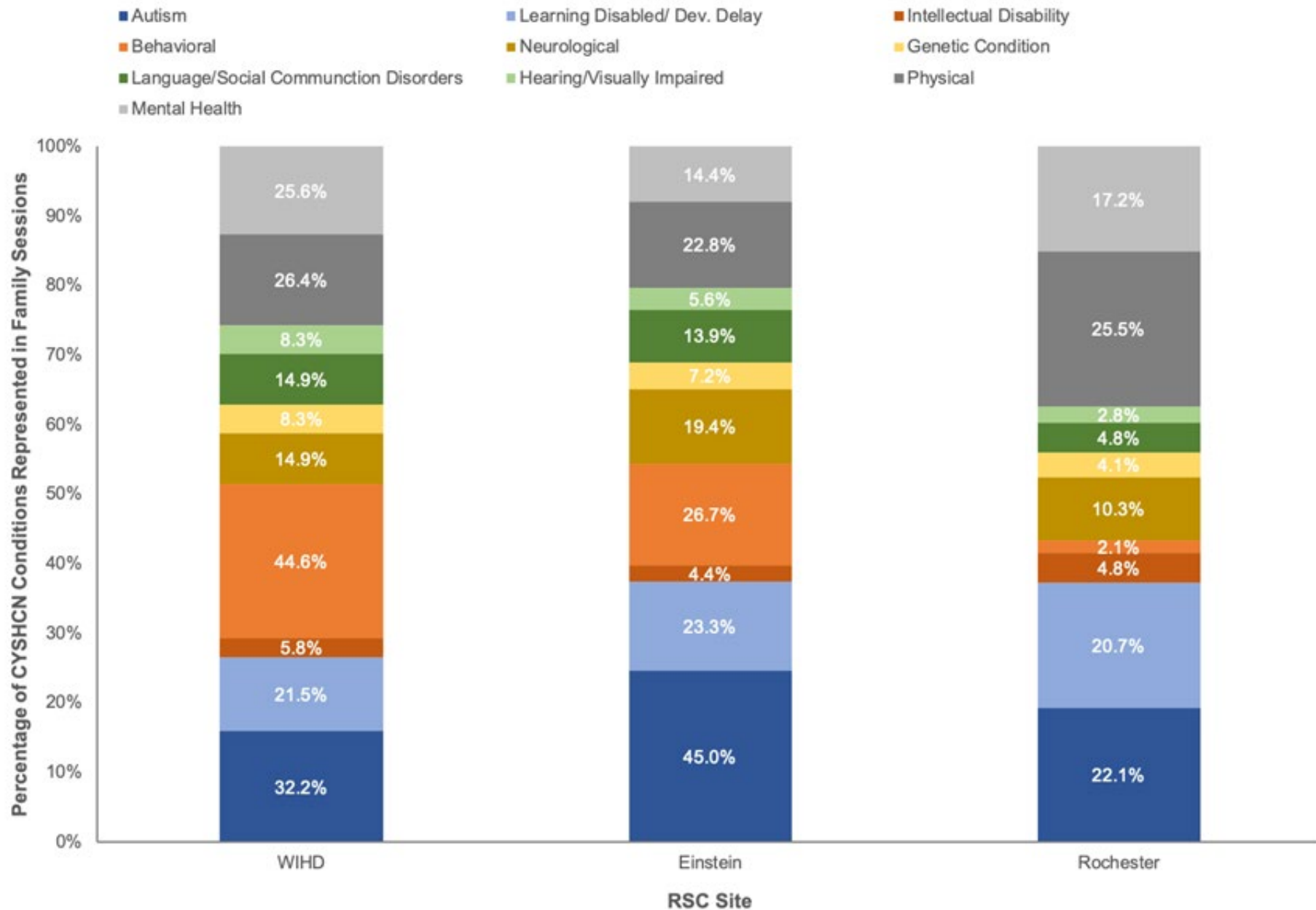
447 CYSHCN represented

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



Placeholder for CYSHCN age breakdown

CYSHCN Conditions by RSC



Main Findings



- Impact on the Family Unit
- Accessing Services & Supports
- Accessing the Community
- Impact of COVID-19

Impact on the Family Unit

- Challenges to obtain diagnosis
- Diagnosis affects all aspects of family functioning (e.g., finances, employment, mental health,
- Parents become strong advocates, utilizing formal and informal supports
- Struggle to balance unique needs of the child with a SHCN and other members of the family

It never stops...from the minute I finish work, I am constantly emailing, talking to teachers, therapists, you have to always show them that, you are proactive. ...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... 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)

Accessing Services & Supports

- Positive impact of high-quality services and supports
- Barriers to accessing services and supports
 - Personnel shortages, rigid regulations, lack of provider knowledge, financial, location, language
- Overly complex support systems
 - Education system – not meeting needs of diverse learners
 - Transition to adulthood – parents worried about the future
 - OPWDD – good supports, lengthy process
 - Medicaid – confusing processes and approvals

...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)

...he's going to be going to a BOCES program. ...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)

Accessing the Community

- Positive community access provides needed socialization opportunities
- Barriers to community inclusion
 - Attitudes and understanding, Sensory issues, Location, Financial, Cultural, Lack of accommodations
- Negative experiences and efforts required may hinder community access

*He made the team and wanted to try so we...try to support [him] 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 have to be mentally prepared ...and ... watch as other children distance from my son, because many times **they do not want to play with him**, they take him as if he were going to do something to them. But I have always tried to mentally prepare him for that, to teach him that he can count on me, that **everything is alright and that there are other children who are different.** In other words, I teach him so he won't be affected emotionally because that **isolation is something you live on a daily basis.** (New York)*

Impact of COVID-19

- Exacerbate existing issues; additional burden placed on parents
- Concerns about regression
- Parent and child anxieties
- 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 COVID I found it was challenging with the remote learning, just because **it's a lot on the parent, you have to become, you know, the teacher, the ABA therapist, the speech, the OT,** and it's a lot because I find, because there is **environmental triggers, such as the iPad, the TV that's what makes it very difficult,** because you try to sustain your son's attention, and it's really hard, it's just different when they are in school, there is less distraction. (Westchester)*

Parent Recommendations



1. Establish supports for the entire family
2. Increase information on and coordination between systems
3. Provide care coordinators
4. Disability Awareness training for medical, educational, and community organization staff
5. Increased opportunities for community inclusion