

Children and Youth with Special Health Care Needs (CYSHCN) Family Forum 12/8/2021

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Montefiore

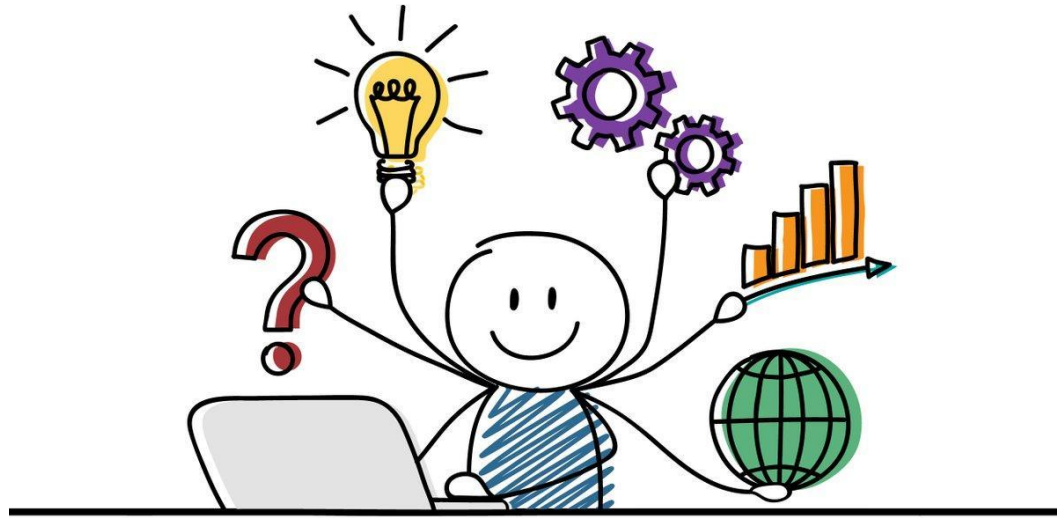


Westchester Institute
for Human Development

Agenda

- Background
- Lessons Learned from Families
- Support for LHDs & CYSHCN
- Your Comments and Suggestions





Background

Who are Children and Youth with Special Health Care Needs?



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 beyond that required by children and youth generally.

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

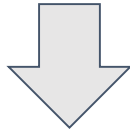
Children & Youth with Special Health Care Needs Programs

- 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

What do NYS Regional Support Centers do?

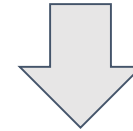
FAMILY ENGAGEMENT

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 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

51/58 NYS counties represented

Community type

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

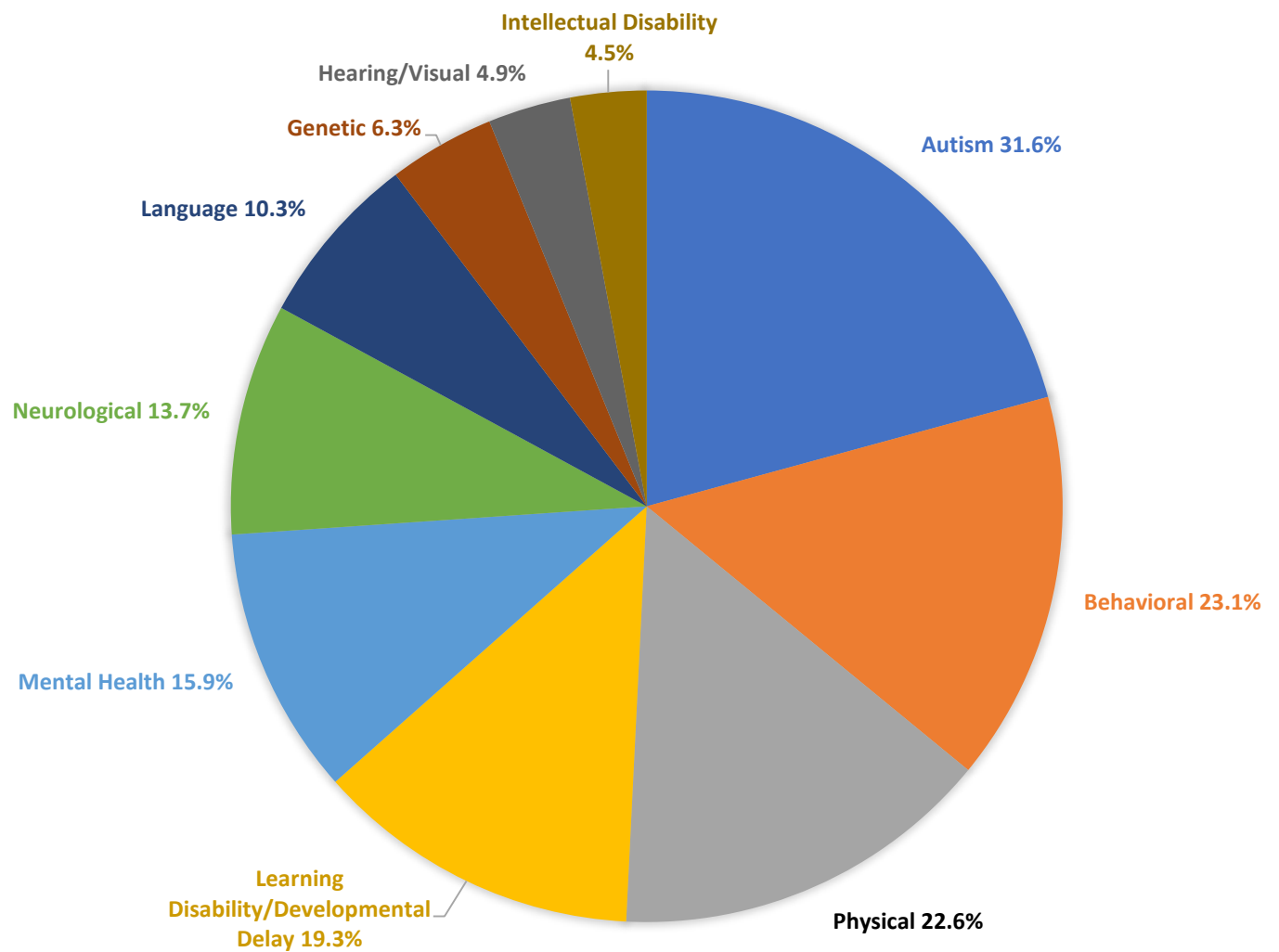
63 group sessions, 104 individual interviews

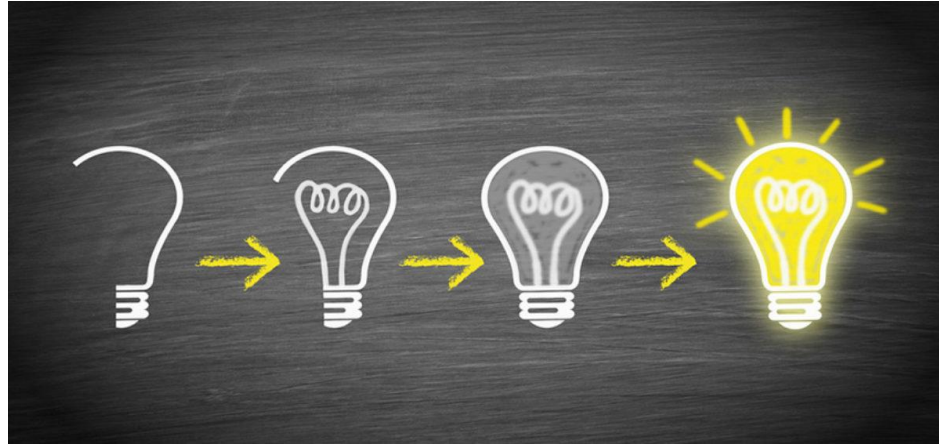
- 4 participants in group sessions on average (range, 2 to 10)
- 144 English, 12 Spanish, 11 Mandarin sessions



CYSHCN

Conditions Represented





Lessons Learned from Families

Impact on the Family Unit

- Challenges to obtaining diagnosis
- Impact of diagnosis
- Parents as advocates
- Complexities adoptive/foster families
- Parents struggle with balance



Accessing Supports and Services



- Barriers to accessing services and supports
- Challenging education system
- Lack of transition services
- Poor Family-Professional Partnerships
- Confusing & Complex systems

Accessing the Community



Families of CYSHCN are accessing the community with varying levels of success.

Common barriers to community inclusion:

- Attitudes and understanding – creates hesitancy
- Inadequate supports or lack of accommodations
- Behavioral/sensory/physical barriers
- Lack of offerings
- Distance/travel and financial

Successful community inclusion addresses isolation and increases socialization and enrichment

Impact of COVID-19

- Exacerbate existing issues
- Disruption to services/evals
- Additional responsibilities placed on parents/caregivers
- Parent and child anxieties
- Increased mental health concerns
- Mixed experience with virtual services
- 33% indicated COVID-19 impacted their employment

The pandemic created some unexpected positive outcomes



Impact of COVID-19

Survey Link



NYS Children and Youth with Special Health Care Needs (CYSHCN): COVID-19

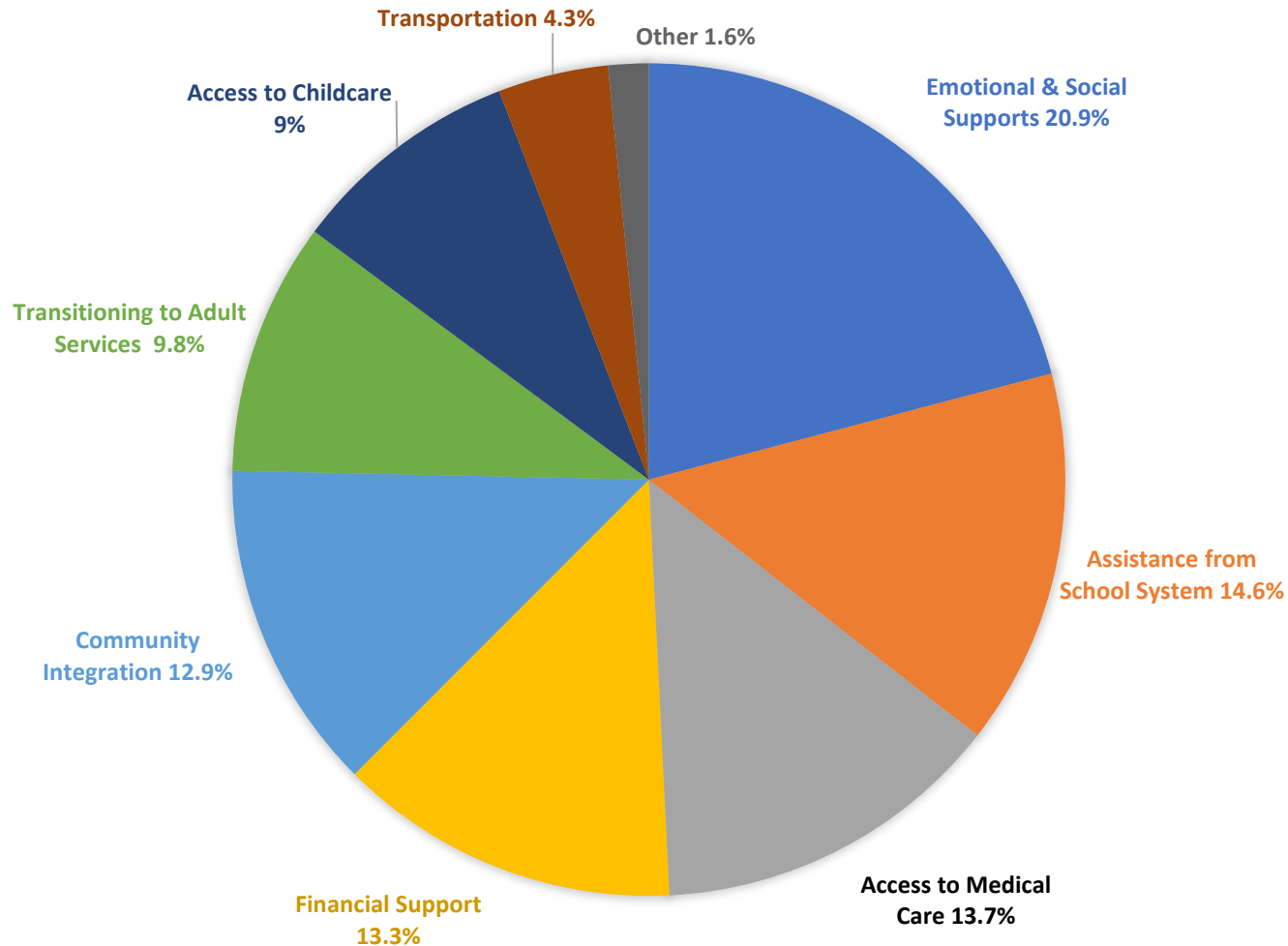
The NYS Department of Health would like to gather information to help prepare and best serve children and youth with special health care needs and their families in future times of crises.

What were your greatest concerns and challenges in meeting your needs/the needs of your children and youth with special health care needs? *

What resources and assistance were available that were most helpful to you and/or your family members? *

What resources and assistance would be most helpful to you and/or your family members? *

Top Support Needs For CYSHCN Families



Parent Recommendations

- Supports for whole family
- Information and coordination between systems
- Accessible care coordinators
- Guides & crisis hotline creation
- Disability awareness & other trainings
- Inclusive community opportunities
- Address staffing shortages
- Increase in mental health and trauma resources



Educational Materials

Healthcare Transition Video

Parent Advocacy Webinar

Navigating Barriers to Community Integration

Mental Health

Effective Communication & more....

[CYSHCN Website](#)



Making Connections

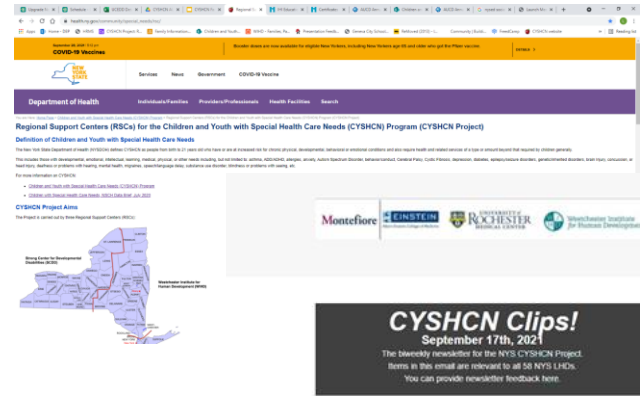
Family Forums

Newsletters

Resource Directory

Networking Meetings

Family Connections



The screenshot shows the NYS Department of Health website. The main heading is "Regional Support Centers (RSCs) for the Children and Youth with Special Health Care Needs (CYSHCN) Program (CYSHCN Project)". Below this, there is a "Definition of Children and Youth with Special Health Care Needs" section, followed by a list of "CYSHCN Project Aims". A map of New York State is visible, showing the locations of the Regional Support Centers. Logos for Montefiore, Einstein, University of Rochester, and Westchester Institute for Human Development are displayed at the bottom of the page.



Children and Youth with Special Healthcare Needs Family Forum

Einstein and WHD Regional Support Centers

July 12, 2021

Montefiore | EINSTEIN | UNIVERSITY OF ROCHESTER | Westchester Institute for Human Development

Events and Resources for Professionals



Connecting Individuals with Disabilities to Adult Services

1:00 AM - 3:00 PM - By CNY Regional Interagency Technical Assistance Team - FREE

Questions and Discussion



- What are your thoughts on the findings? 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/suggestions for some of the issues mentioned?
- Do you have thoughts on how to create more connections for families?
- Do you have ideas/suggestions for future educational topics for LHDs & families?

Contact Us

Feedback and suggestions: [survey link](#)

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[CYSHCN Website](#)

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