



Department  
of Health

# Children and Youth with Special Health Care Needs

NYSACHO Conference May 2-3, 2023

# Agenda

- Introductions
- Background
- Children and Youth with Special Health Care Needs (CYSHCN)  
Program Overview
- CYSHCN Support Services (CYSHCN SS)
- Regional Support Centers (RSC)
- Questions and Answers

# NYSDOH CYSHCN staff

Director, Bureau of Child Health	Suzanne Swan
Assistant Director, Bureau of Child Health	Claire Rudolph
Unit Manager, Community Based Health unit	Carolyn Perry
CYSHCN Program Manager	Mari Sepowski
CYSHCN Program Manager	Avani Pathak
Assistant Director, Bureau of Data Analytics, Research, and Evaluation	Jo-Yu Chin
Computer Support Specialist	Vicki Zafke
Public Health Program Nurse, Central Regional Office	Cheryl Geiler
Public Health Program Nurse, Western Regional Office	Jill Kaczor

# Purpose

The [Children and Youth with Special Health Care Needs \(CYSHCN\) Program](#) seeks to provide support for CYSHCN and their families and to improve the system of care for children and youth with special health care needs from birth to 21 years of age and their families.

CYSHCN are defined as children who have or are at increased risk for a chronic physical condition, intellectual or developmental disability, behavioral or emotional condition. CYSHCN and their families may require health and support services of a type or amount beyond what is required by children generally.

# NYSDOH CYSHCN Program

- Administered by the Bureau of Child Health in the Division of Family Health with funding from the Title V Maternal and Child Health Services Block Grant.
- \$5.2M in grant funding supports contracts with 52 local health departments (LHDs) to implement local community CYSHCN projects.
- \$1M in grant funding supports contracts with three Regional Support Centers that are designated University Centers for Excellence in Developmental Disabilities to provide support, technical assistance, and training.

# National Survey of Children's Health

## New York State

The 2020-2021 data estimates that **743,518** (18.6%) youth, age 0-17 years, have a special health care need.

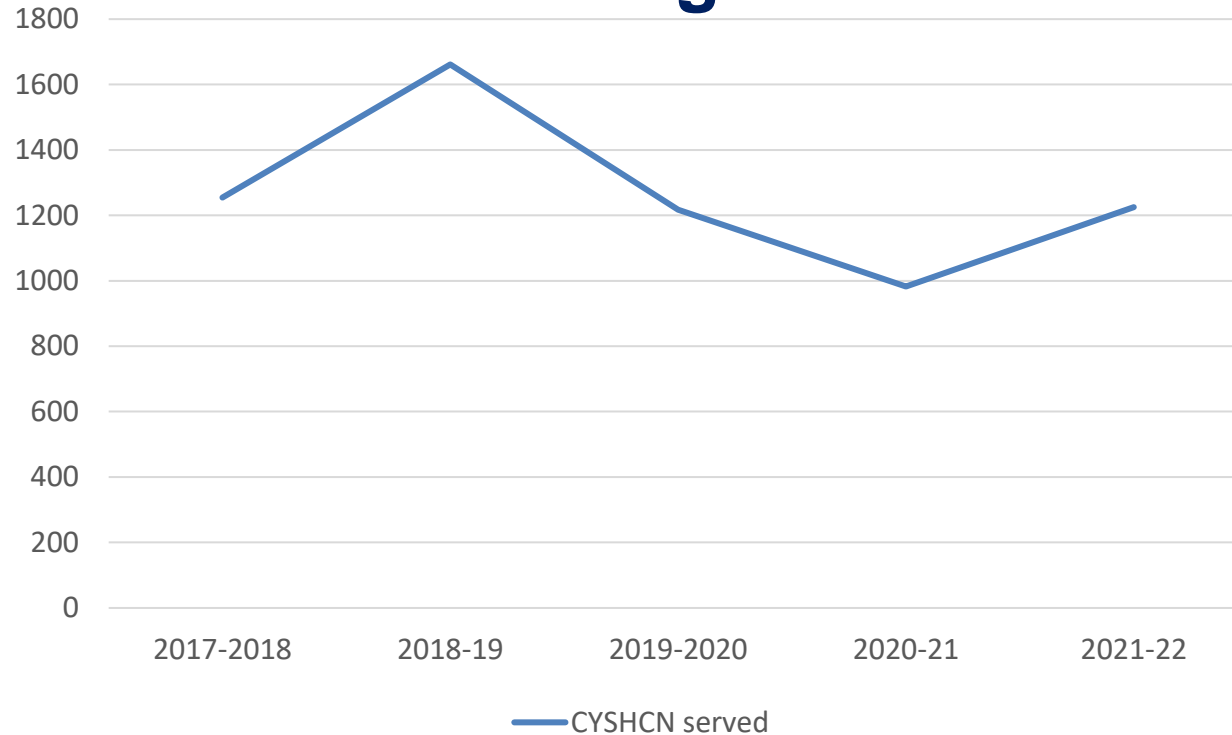
<u>CYSHCN</u>
0-5 years old
147,650
6-11 years old
254,632
12-17 years old
341,236

# New York State Data

- Approx. **876,872** CYSHCN from 0-20 years of age (2020 NSCH)
- October 2022 enhanced funding and full time equivalent requirement
- The CYSHCN program served:

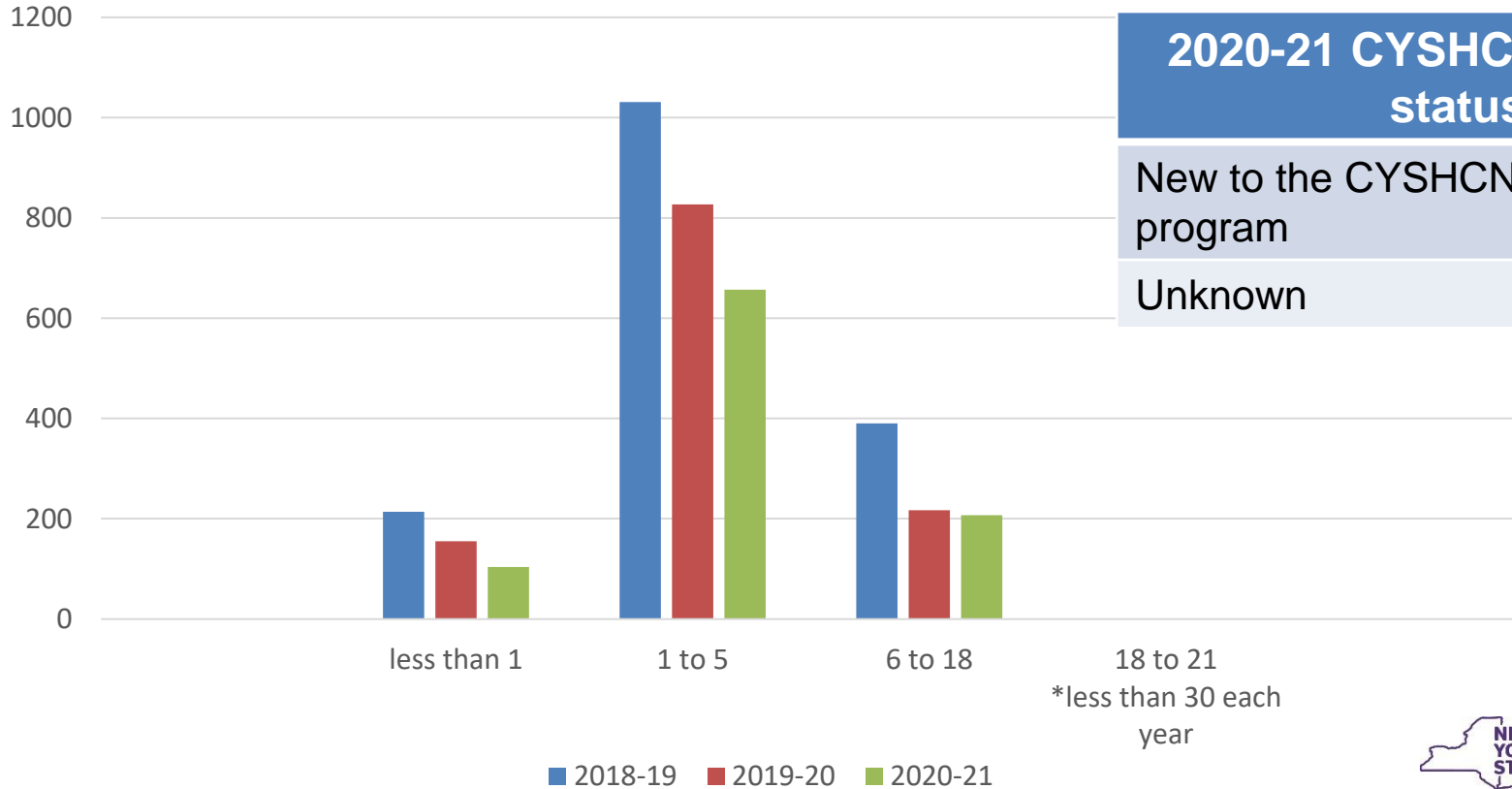
Contract Year	CYSHCN Served
2017- 2018	1,254
2018 - 2019	1,661
2019 - 2020	1,217
2020 - 2021	982
2021 - 2022	preliminary 1,225

# CYSHCN Program Served



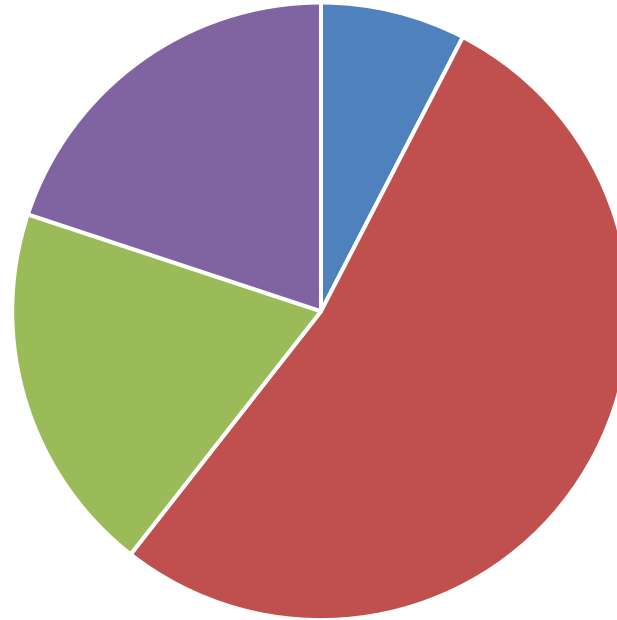


# Age Category



2020-21 CYSHCN program status	
New to the CYSHCN program	45%
Unknown	47%

## 2020-21 Insurance Type

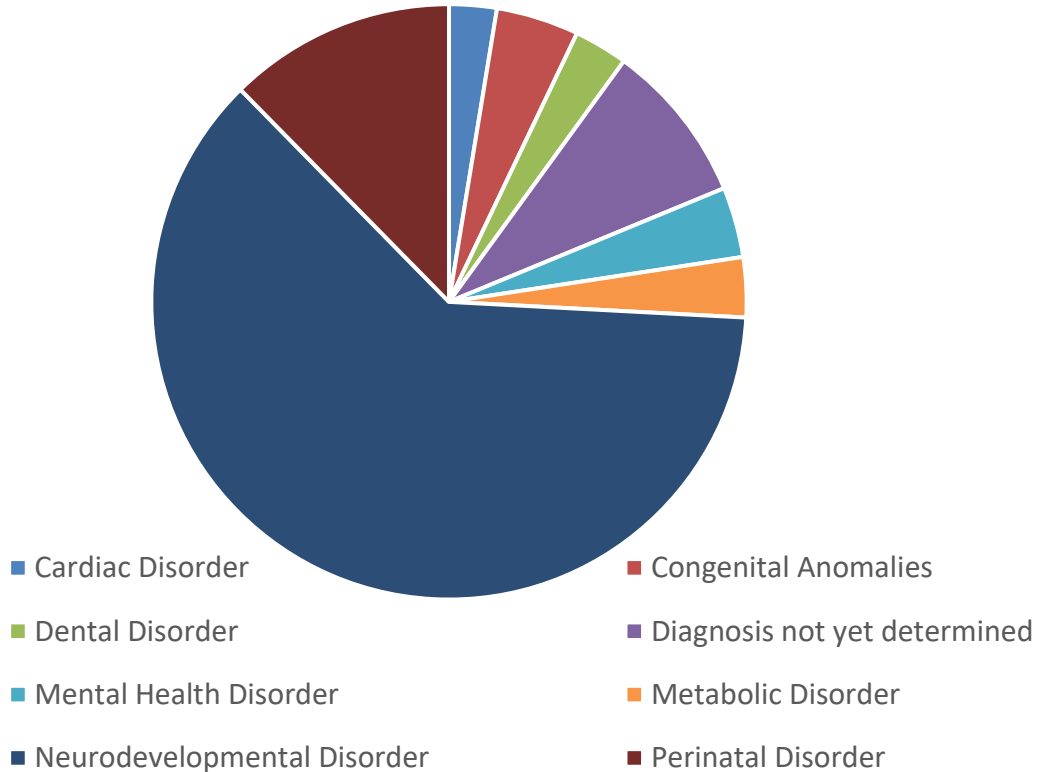


Supplemental  
Security Income

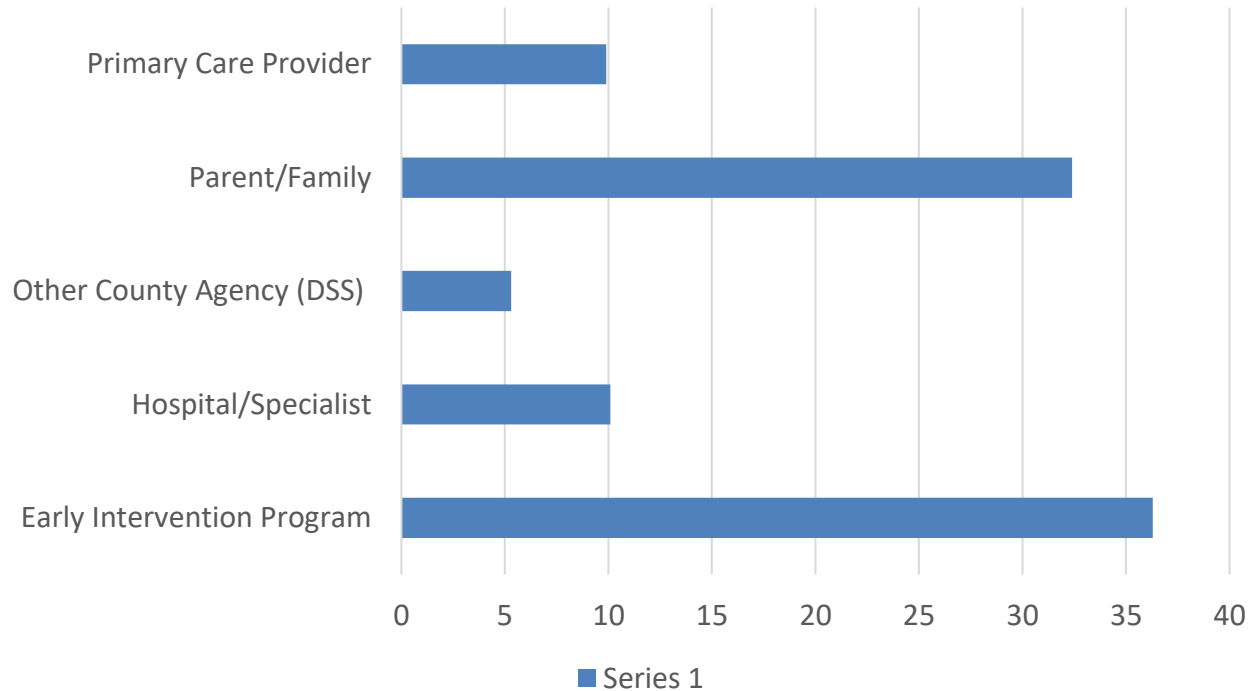
7.7%

■ Child Health Plus ■ Medicaid ■ Private ■ Other

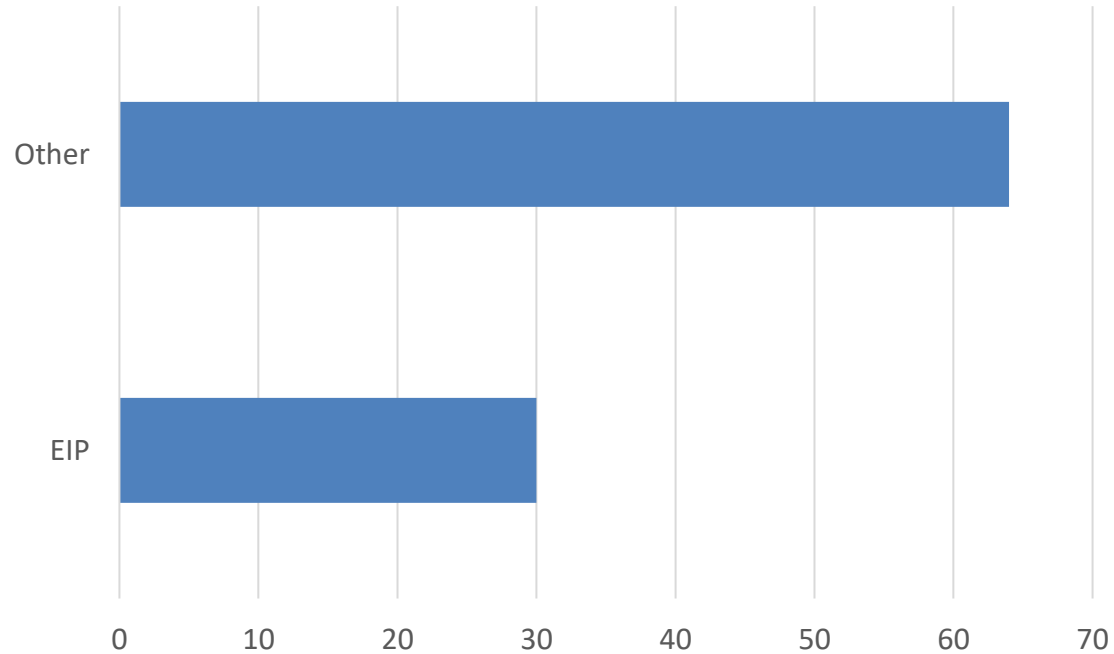
# 2020-21 General Medical Conditions



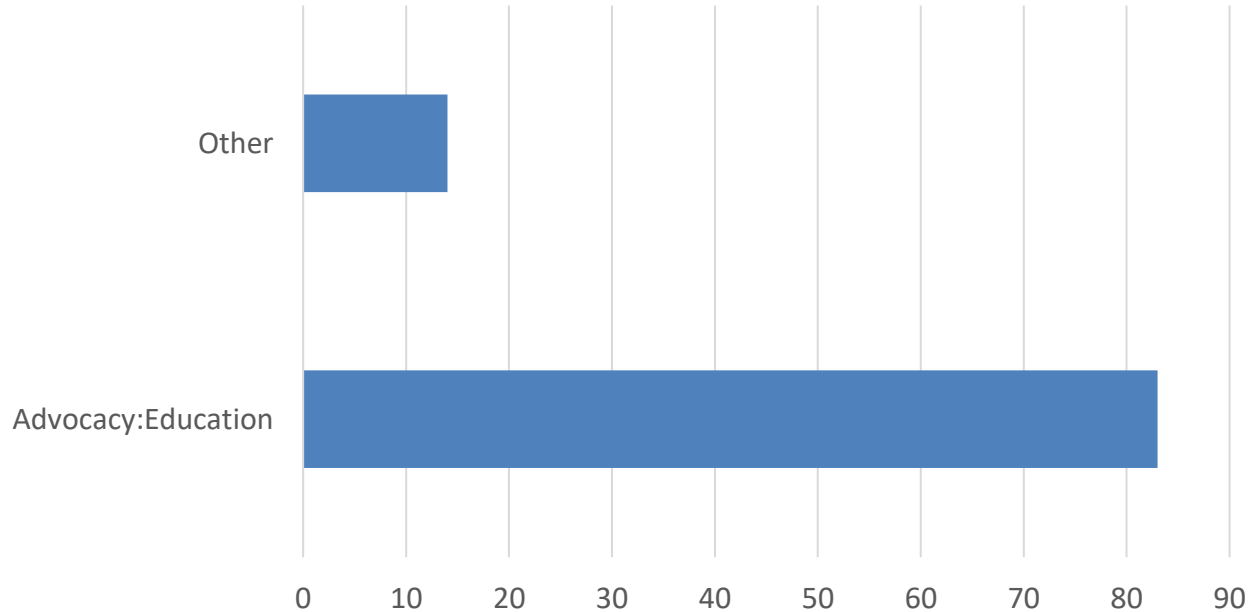
## 2020-21 Referral Source %



## 2020-21 Referral Provided %



# 2020-21 Enabling Services Provided %



# CYSHCN Program

[Children and Youth with Special Health Care Needs \(CYSHCN\) in New York State – Statewide Family and Provider Care Mapping](#) findings to support the health and developmental needs of CYSHCN and their families.

- Build capacity
- Resource development
- Training opportunities
- Identify social and emotional supports

# LHD CYSHCN Workplan Activities

- Collaboration and Resource Development
- Outreach, Engagement and Community Promotion
- Coordination of Community Resources
- Transition Services
- Family Satisfaction
- Health Equity
- Database
- Program Administration
- Policies and Procedures







# Partnerships

- Schools
- Child care providers
- Medical providers
- Other, e.g. community-based organizations, coalitions



# Coordination of Community Resources

- Provide CYSHCN and their families referrals to services and connections to community resources.
- Inform families about support meetings and training workshops on CYSHCN-related topics offered by community organizations and the Regional Support Centers.
- Ensure that outreach and engagement strategies reflect the diversity of the community.



# CYSHCN Support Services (CYSHCN SS)

# CYSHCN SS

- The [CYSHCN SS](#) program assists families in paying medical bills for CYSHCN in NYS with severe chronic illnesses and/or physical disabilities, between birth and 21 years of age.
- The program is located at local health departments.
- Prior authorization from the local CYSHCN SS must be obtained for all services.
- CYSHCN SS has two components:
  - Diagnosis and Evaluation Program (D&E) will reimburse specialty providers for the diagnosis and development of a treatment plan for eligible children.
  - The Treatment Program will reimburse specialty providers for the ongoing health and related services for children who are medically and financially eligible in their county of residence.

# Regional Support Centers (RSC)

# Regional Support Centers (RSC)

NYSDOH contracts with three federally-designated University Centers for Excellence in Developmental Disabilities (UCEDDs).

The RSC staff support the program and LHD staff to:

- Increase knowledge of CYSHCN resources.
- Develop and maintain online Resource Directory.
- Enhance families' skills and confidence to navigate systems of care.
- Engage communities and provide social support.
- Provide a family feedback loop.

# Collaboration and Resource Development

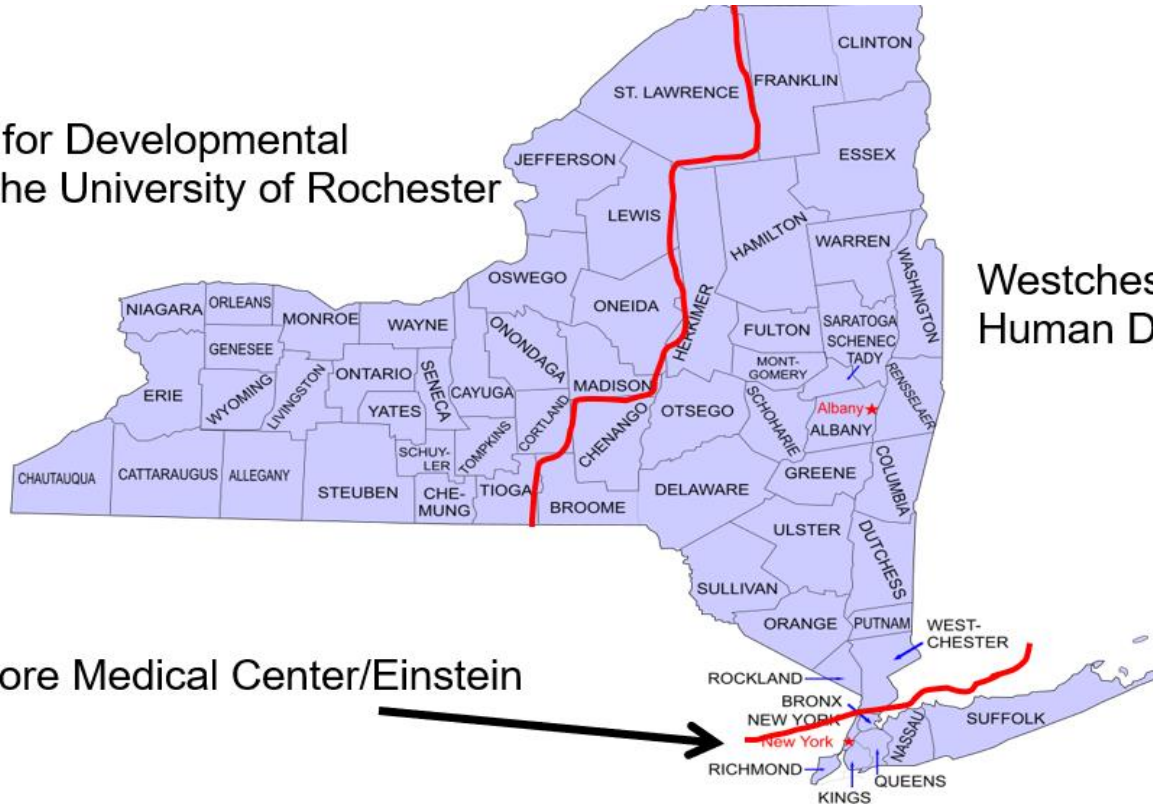
CYSHCN LHD staff can collaborate with the RSCs to:

- Identify resources and develop a comprehensive state-wide resource list.
- Access technical assistance.
- Develop Family Engagement Plans.
- Participate in webinars and professional development.
- Identify unmet needs of CYSHCN and their families.



# Regional Support Centers

Strong Center for Developmental Disabilities at the University of Rochester



Westchester Institute for Human Development (WIHD)

Montefiore Medical Center/Einstein

# Next Steps

- NYS DOH quarterly meetings
  - Thursday, June 1, 2023 from 10:00 am to 11:00 am
  - Tuesday, September 12, 2023 from 10:00 am to 11:00
  - Thursday, December 7, 2023 from 10:00 am to 11:00 am
- PERDS Data Dashboard
- RSC tools and resources in development

# Questions and Answers



# **NYSDOH Contact Information**

## **Bureau of Child Health**

**Email: [CYSHCN@health.ny.gov](mailto:CYSHCN@health.ny.gov)**

**Phone: 518-474-1961**



We appreciate you and all the work that you do on behalf of CYSHCN and their families in your community!