Background

There are 498,486 children with disabilities receiving special education services in New York (NYSED, 2019). Despite the emphasis on school partnerships with families and shared decision making, the journey for parents to navigate this partnership has been challenging (Zagona et al., 2019).

- Most parents believed schools were doing little or nothing to address their child’s most pressing needs (Spann et al. 2003)
- Parents were overwhelmed with learning their role in the special education process (Rossetti et al., 2021)

Objectives

The aim was to advance educational equity in New York. The present study chronicles the experiences of parents of children with disabilities and/or special health care needs navigating the educational system in New York, and identifies patterns of strengths and areas in need of improvement.

Participant Demographics

Parent Participants (n=44): 4 male, 34 female
- 5 Spanish-speaking and 36 English-speaking parents were recruited through community outreach in New York
- 83% respondents report at least some college education

Children of Reference: 55 children ages 0-21
- Children were confirmed with a range of diagnoses or at risk of disability related diagnoses

Methods

Data Collection
- 90 minute semi-structured individual and group sessions completed via Zoom from June 2020 to June 2021.
- This study focused primarily on topics related to navigating the public education school system.

Data Analysis
- Data analysis was performed via Dedoose software by coding for common themes.
- Thematic analysis was conducted to identify common trends among parental experiences.

Results

Inadequate school-family partnerships

“I [parent] think I gave up on them um in elementary school, um when all I felt was um no help at all, working against us every step of the way.”

-Westchester County Resident

Schools struggle to meet the needs of diverse learners

“She [school counselor] had offered to come talk to us in high school because she, she was in a resource room, and she looked at him and she goes, “You don’t fit in anywhere.”

-Westchester County Resident

Reliance on other parents for emotional support and system guidance

“…for families to try their best in the CSE meetings, know your rights, know what you are entitled to and what you’re there to do.”

-Putnam County Resident

Therapists provide consistent, valuable support

“She would come every year and provide an in-service to whoever is working with (child) to go over things they might see and things they may have to do in the classroom.”

-Westchester County Resident

Lack of parental awareness of their rights and/or role

“One thing I can recommend, …for families to try their best in the CSE meetings, know your rights, know what you are entitled to and what you’re there to do.”

-Putnam County Resident

Discussion

Parents of children with disabilities and/or special health care needs in New York State continue to encounter challenges navigating the educational system.

Based on the results of this study, we have compiled the following recommendations:

- **Acknowledgement**: the parent community as an essential resource for guidance, knowledge and support.
- **Create**: resources for parents as a guide for navigating the special education process.
- **Expand**: training that promotes inclusiveness and effective teaching methods for diverse learners.

Future study may include: Exploring differences of parent experience based on demographics.

References

