



Defining Features of Inclusive Communities: Perceptions of Parents of CYSHCN

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Background

New York State has **791,909** Children & Youth with Special Health Care Needs (CYSHCN; NYS DOH, 2020).

- There are often limited resources for community inclusion available.
- Many parents of CYSHCN struggle to achieve this social inclusion for the family.
- Full inclusion and participation in the community is a fundamental equal right for everyone (United Nations, 2022).

Objectives

Explore parent experiences to identify factors promoting community inclusion.

Methods

- Semi-structured focus groups conducted with 86 parents (2020-2021).
- Transcripts of interviews were coded into categories.
- Thematic analysis was conducted.

Demographics

Figure 1. Parent race.

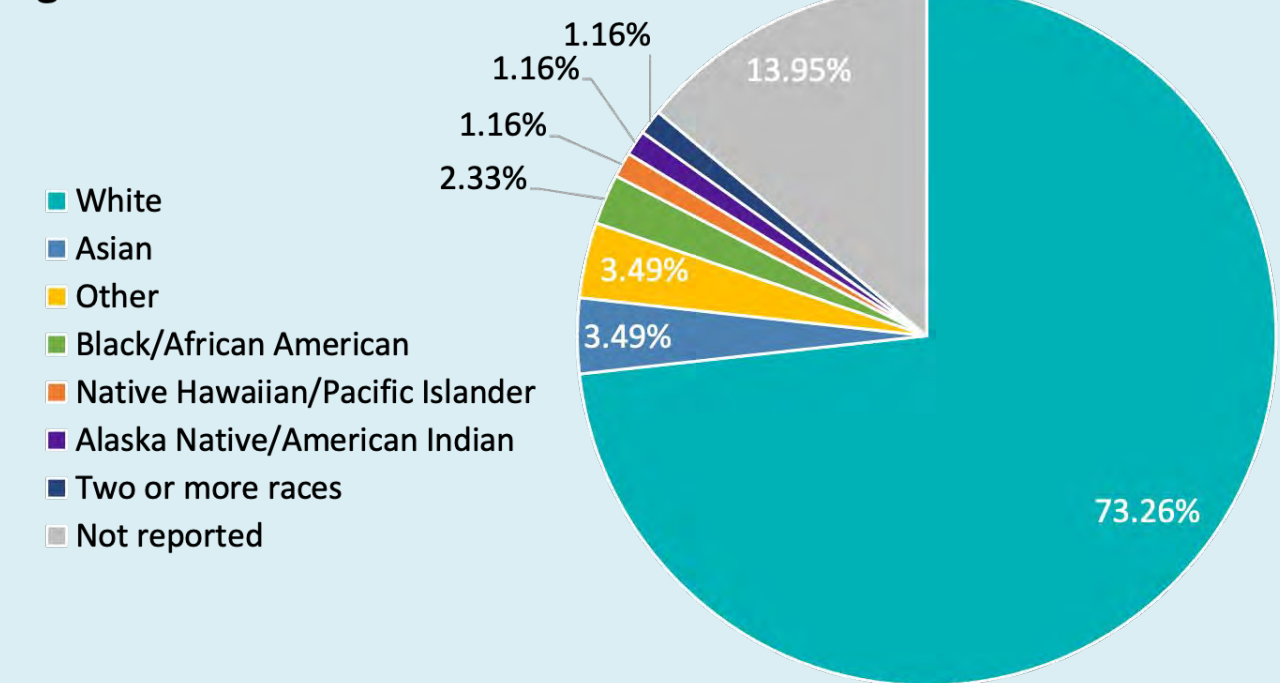


Figure 2. Child age.

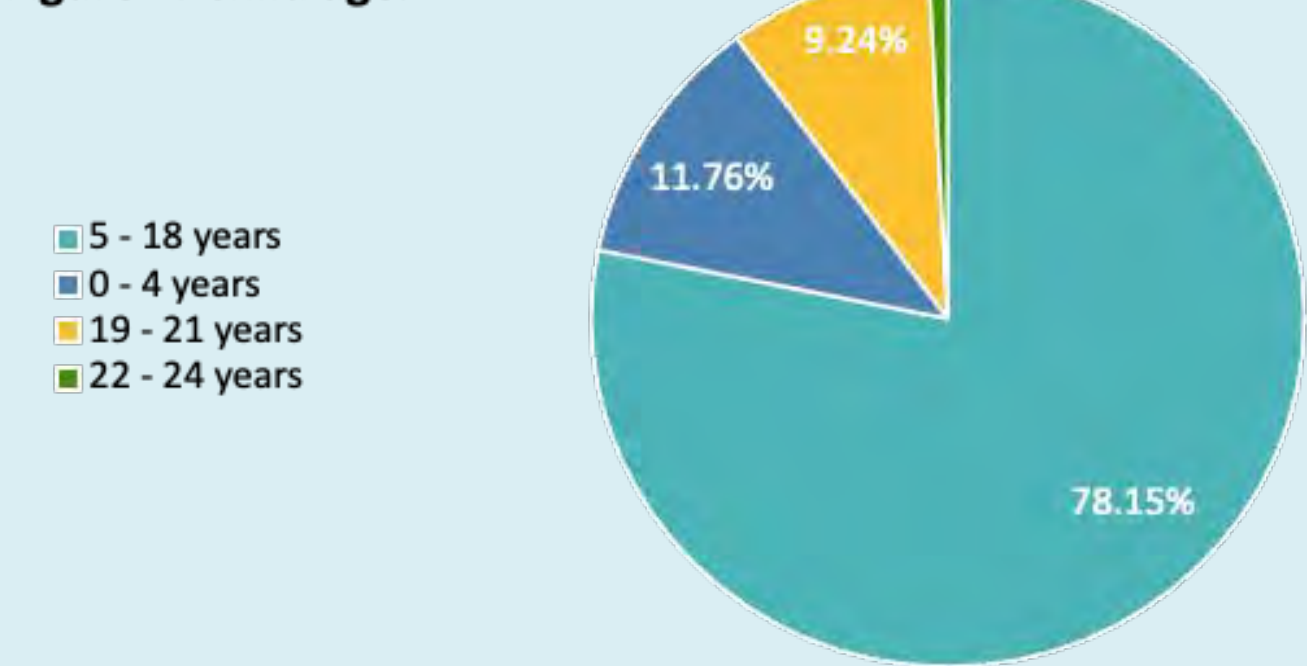
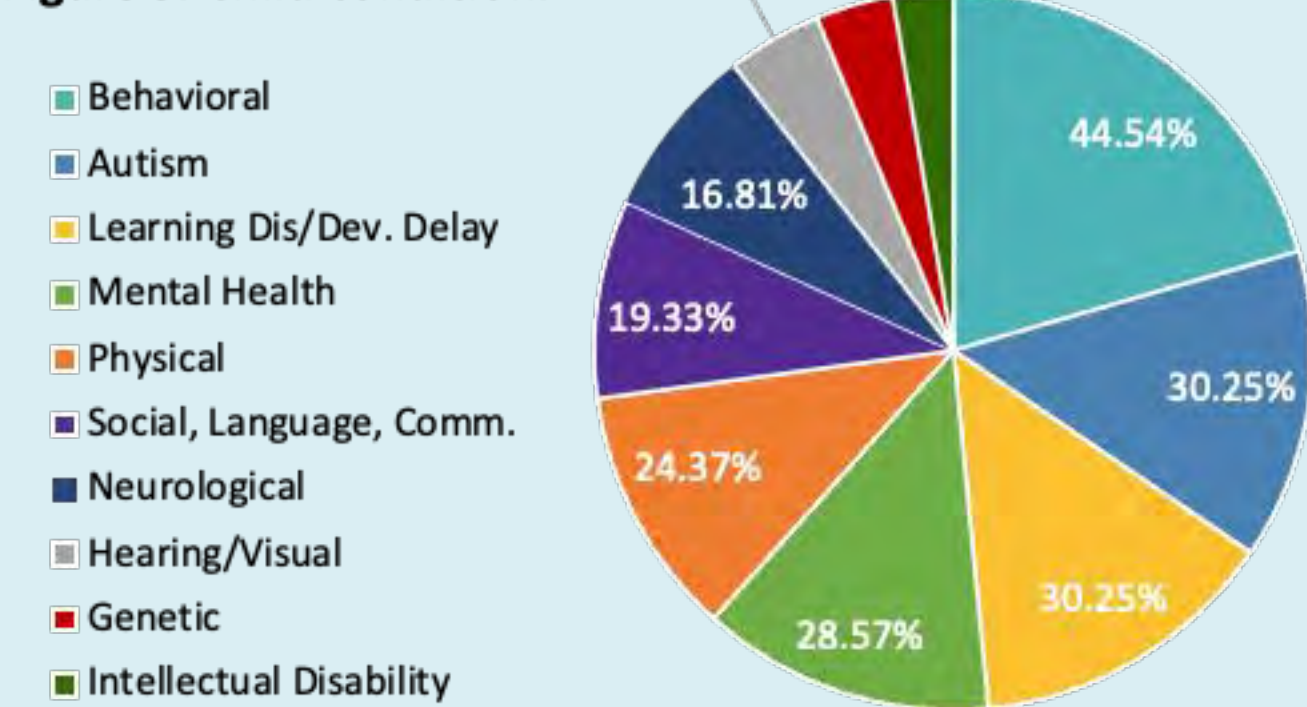


Figure 3. Child condition.



*Respondents could select multiple conditions

Results

Flexible, safe, supportive and welcoming environments

“So what I would like in terms of the support...[the providers] have a more open mind in terms of if they do not have an experience to be able to have the ability to say, **we're ready to learn, we're ready to listen** [...] that's happened from camps [...] they just put the kids with somebody who is a high schooler or, just say we're going to have somebody shadow and **the person does not have experience.**”

Prepare child to navigate different community contexts

“Learning how to use the buses, learning how to ask these questions and **getting that confidence to not be afraid and timid.** Then also too, the bus drivers are wonderfully receptive. They will sit there and they'll actually yell back to him or they'll tell him, ‘Hey, when we're doing this, I want you to be here.’”

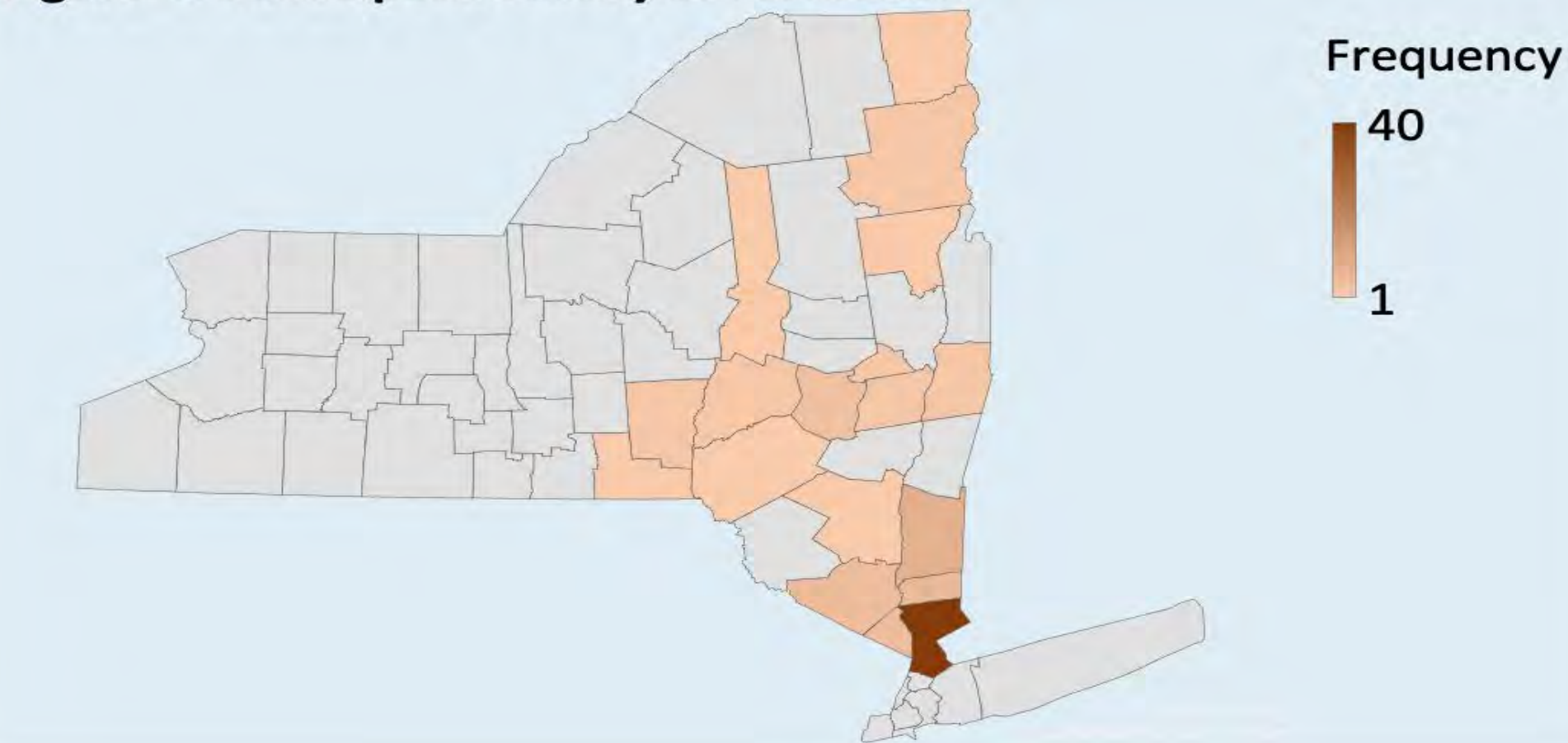
Boost parent confidence to access their community

“I think if they were exposed to like a mini service public announcement or a mini commercial, saying, “Your child -- **my child is not like yours.**” One of those like touchy, feely kind of thing that, gives you a tear in your eye at the end. And if more people are exposed to this type of things,[...] we spend so much money on marketing, **maybe people would have a better understanding and feel what we feel.**”

Disability awareness / sensitivity training for community

“I took my son[...]to get his haircut [...] and I remember a parent [who] didn't have a child with special needs, called me an awful mom [...] because I let my son scream in the chair [...] And she cursed at me after [...] it was horrible and saying **I am an awful mom, just because I let my son scream.**”

Figure 4. Participant county of residence.



Recommendations

- Expand community trainings and encourage local town representatives to increase knowledge of strategies, foster attitudes of acceptance, and create accessible environments
- Teach individuals with disabilities how to access settings in the community and target life skills
- Increase parent awareness of their rights and laws related to accessibility, educational training and access to family advocates