

Child Care for Children with Disabilities

Experiences of Families & Child Care Providers

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Project Background

Problem: Families continue to face difficulties finding and keeping child care for their children with disabilities or developmental delays.

Project Goals:

- To better understand parent and provider experiences related to child care for children with disabilities
- To inform ways IL can invest in its child care system so children can access care regardless of their abilities

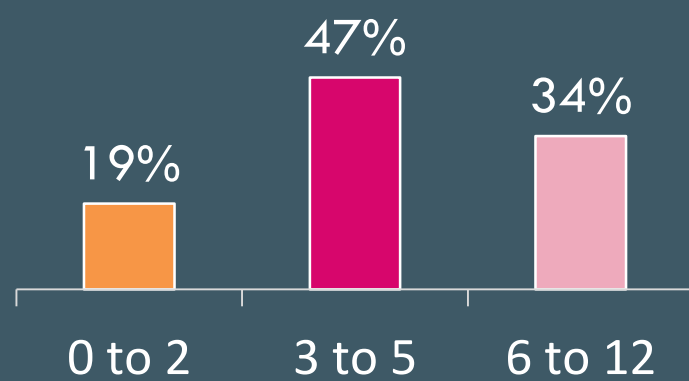
Method: Surveys of parents and child care home and center providers in Chicago or the Chicago area in summer 2023



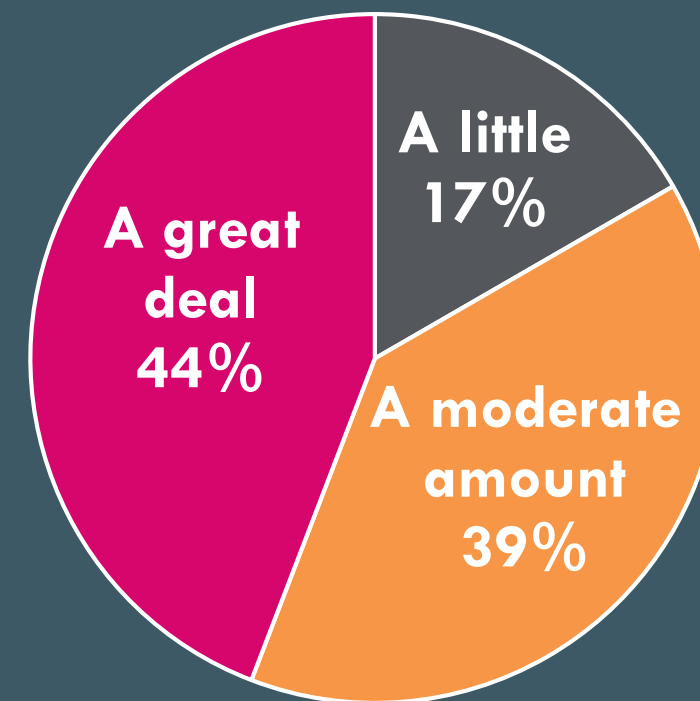
Parents: Who Responded?

121 Parents

- Most recruited through Illinois Action for Children's child care referral program
- 52% Chicago & 48% suburb
- 75% were single parents
- Child age:

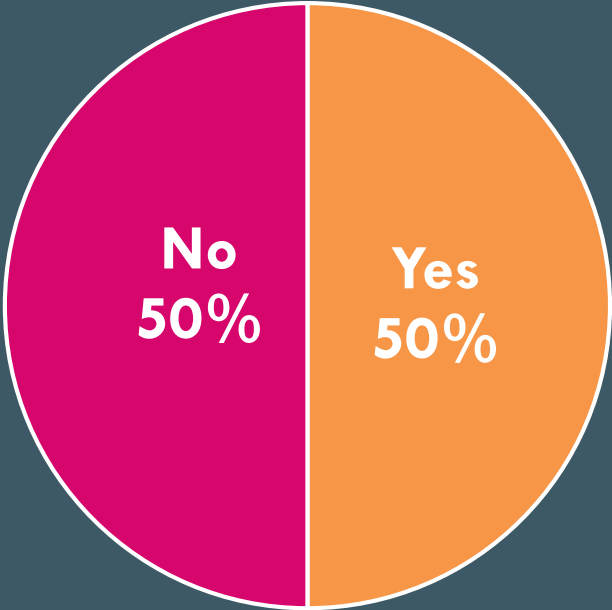


Amount of extra adult support their children need in daily life

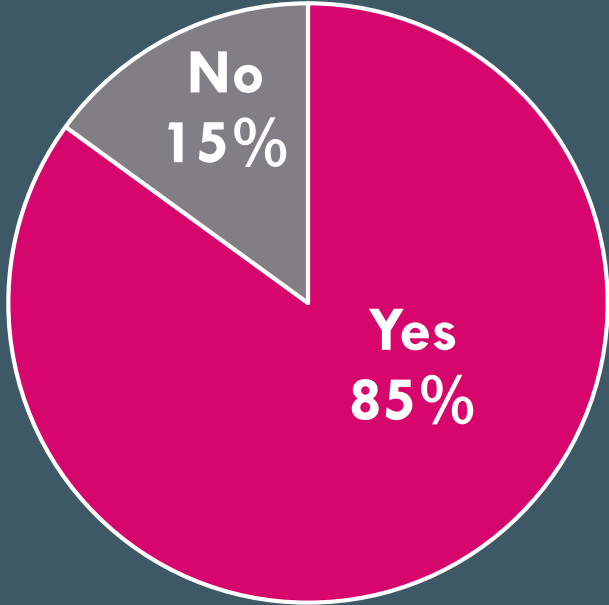


Finding Child Care: Parents' Most Recent Search

Was Parent Able to Find Care?



Did Child's Disability Make Finding Care More Challenging?



“Child care centers ghosted us after learning of my child's disability.”

Top Barriers to Finding Child Care

General unwillingness or inability of providers to enroll a child with a disability

“Once I told them my child has autism they said immediately they can’t take special kids.”
– parent of child with autism spectrum disorder (asd)

Providers do not have enough training

“Most said it had to be certified with a person to care for him.”
– parent of child with Down syndrome

Providers do not have enough staff

“The two that I tried told me they were not staffed to handle my son nor could [they] afford to staff an aid.”
– parent of child not yet diagnosed

Providers couldn’t accommodate specific needs
e.g. G-tube, diapers, seizure medication

“Nobody wanted to take her because of feeding tube and minor incontinence issues.”
– parent of child with short gut syndrome

“At [age] 4 no daycares wanted her with a diaper.”
– parent of child with asd

What Parents Say Would Make Finding Care Easier

More trained and willing providers

“Having more people certified with working with people with disabilities.”

– parent of child with cerebral palsy

Providers with: smaller group sizes/more staff, nurses on site and affordable prices

“Give more licenses to small daycares, they can take [care] of them better than big centers.”

– parent of child with asd

“More centers that have smaller class setting with multiple teachers.”

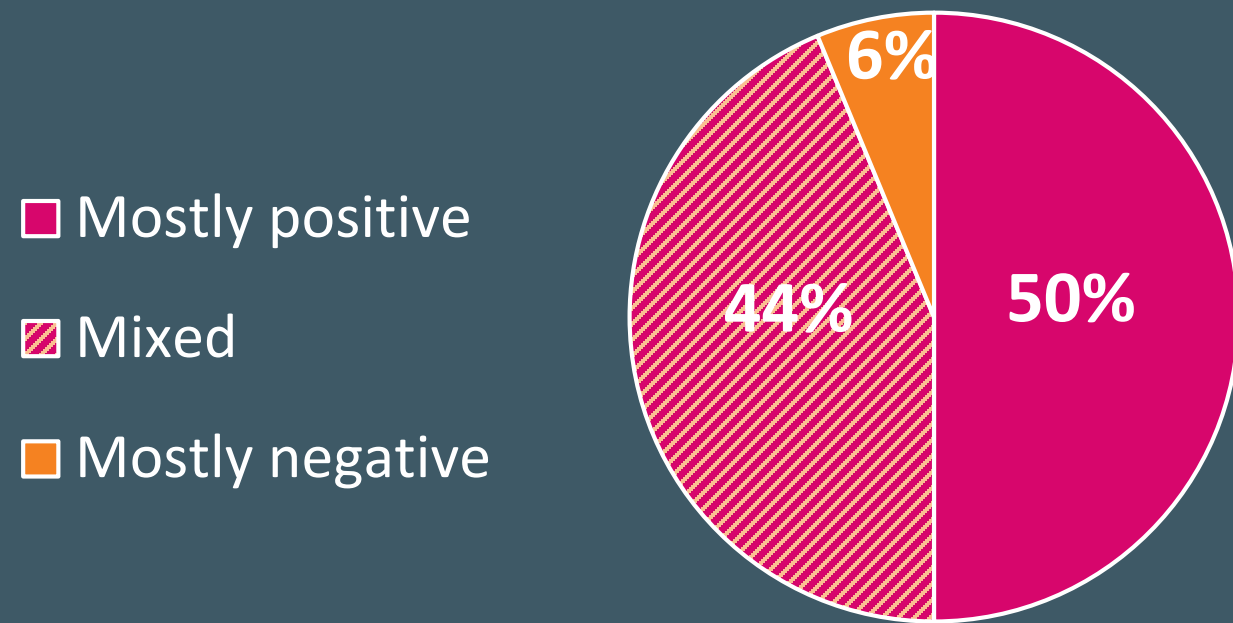
An easier way to identify providers that will actually enroll and support their child

“Receiving [lists of] actual child care providers who have experience with children with developmental delays.”

– parent of child with asd

Many Parents had Positive Child Care Experiences

Parent's Overall View of Child's Care Experiences



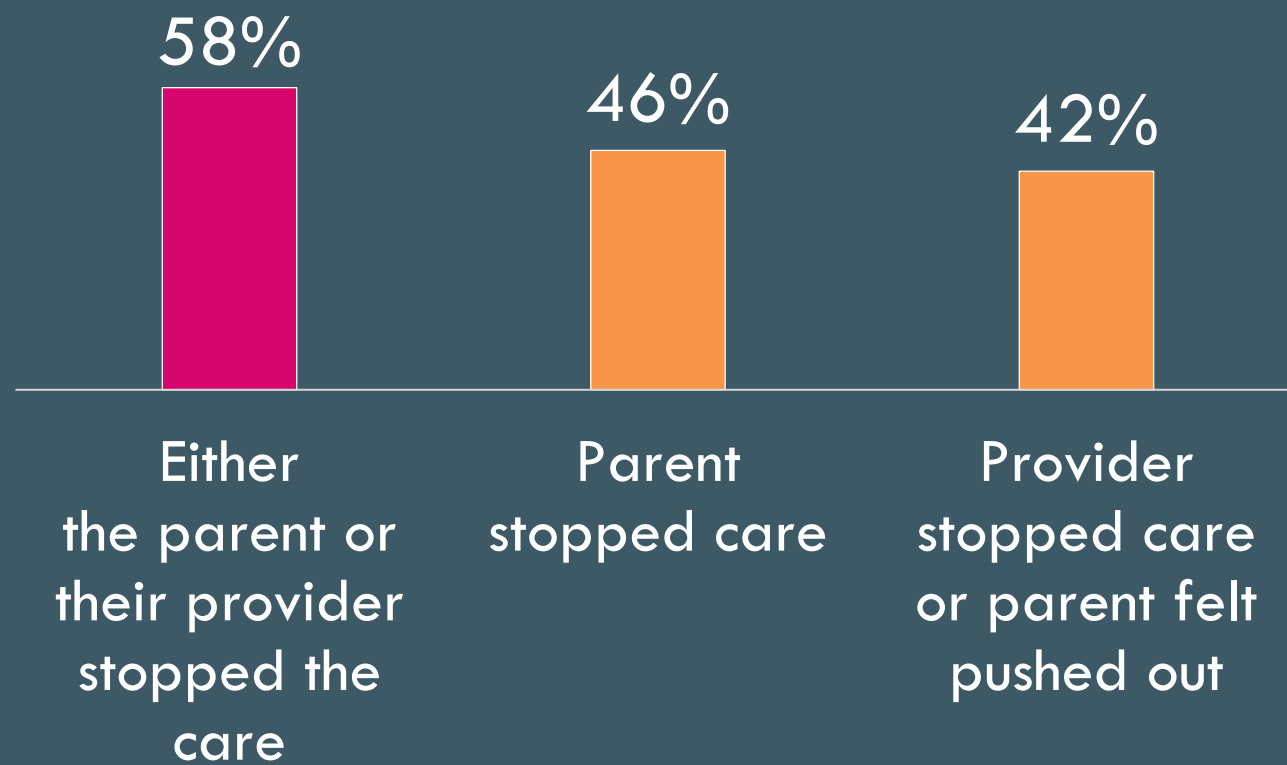
Caring and Patient: *“They don't get frustrated and don't give up on her.”*

Supported child's development: *“Our child has learned so much...and even started eating more, which has been a challenge since birth.”*

Good communication: *“We met monthly to discuss my son's progress and made goals.”*

Willing to give care a try: *“Did not discriminate against him. Even though she doesn't have training...she did allow him to still enroll.”*

Yet, Most Parents Have Had Child Care that Did Not Work Out



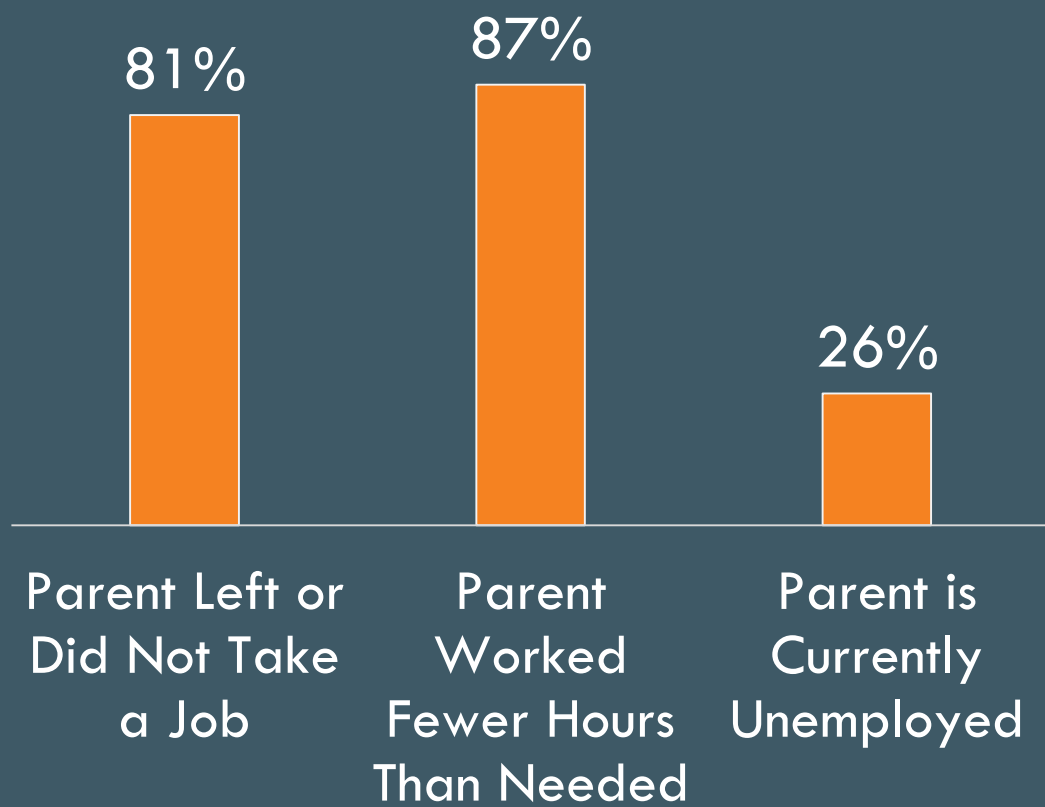
Parents Wish Their Providers Were:

Better Prepared: *“I feel like he is just being babysat and they are not able to work with him on the things he struggles with.”*

More Patient & Respectful: *“When he struggled with sensory overload, feeding issues and such, they complained and were not compassionate.”*

Had More Staff: *“I wish there could be an additional aide throughout the day.”*

Impacts of Child Care Difficulties on Families



Financial Impacts

- Loss of income
- Unable to meet expenses
- Homelessness (7 parents)

Other Impacts

- Parent stress & worry
- Poor physical health/ lack of rest
- Stress on their marriage
- Children lose out on social opportunities

“Well, we are homeless....I would get to work and they would be calling me to come and get him.”

“I can only work part time...I barely can afford any extra clothes or things that any of us need.”

“My son is affected because he makes friends and then later when he has an episode is removed from the programs.”

Provider Experiences



Providers: Who Responded?

113 Chicago Child Care Centers (21%)

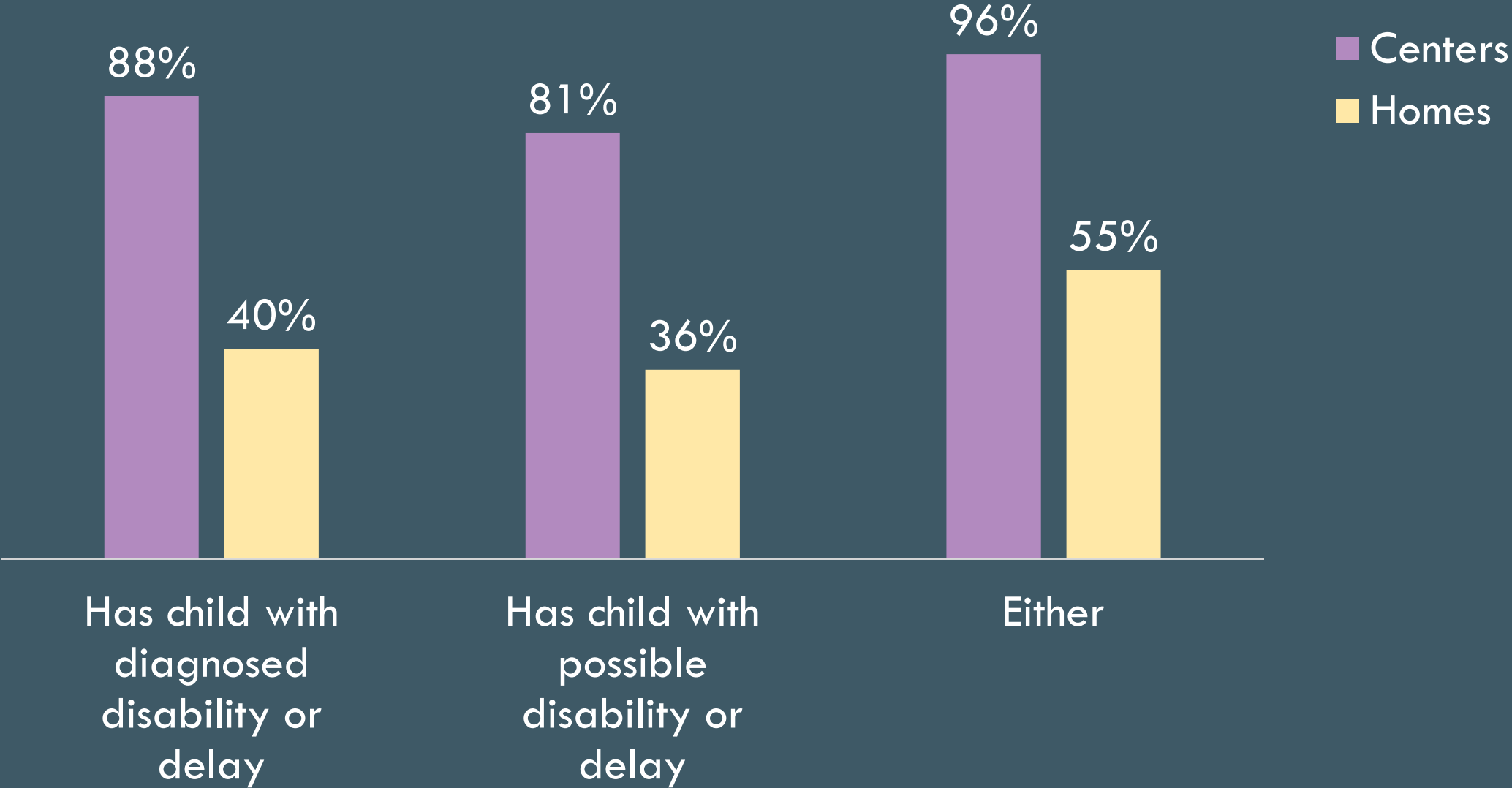
- Good mix in terms of size, for-profit status, & location & funding

356 Chicago Licensed Homes (27%)

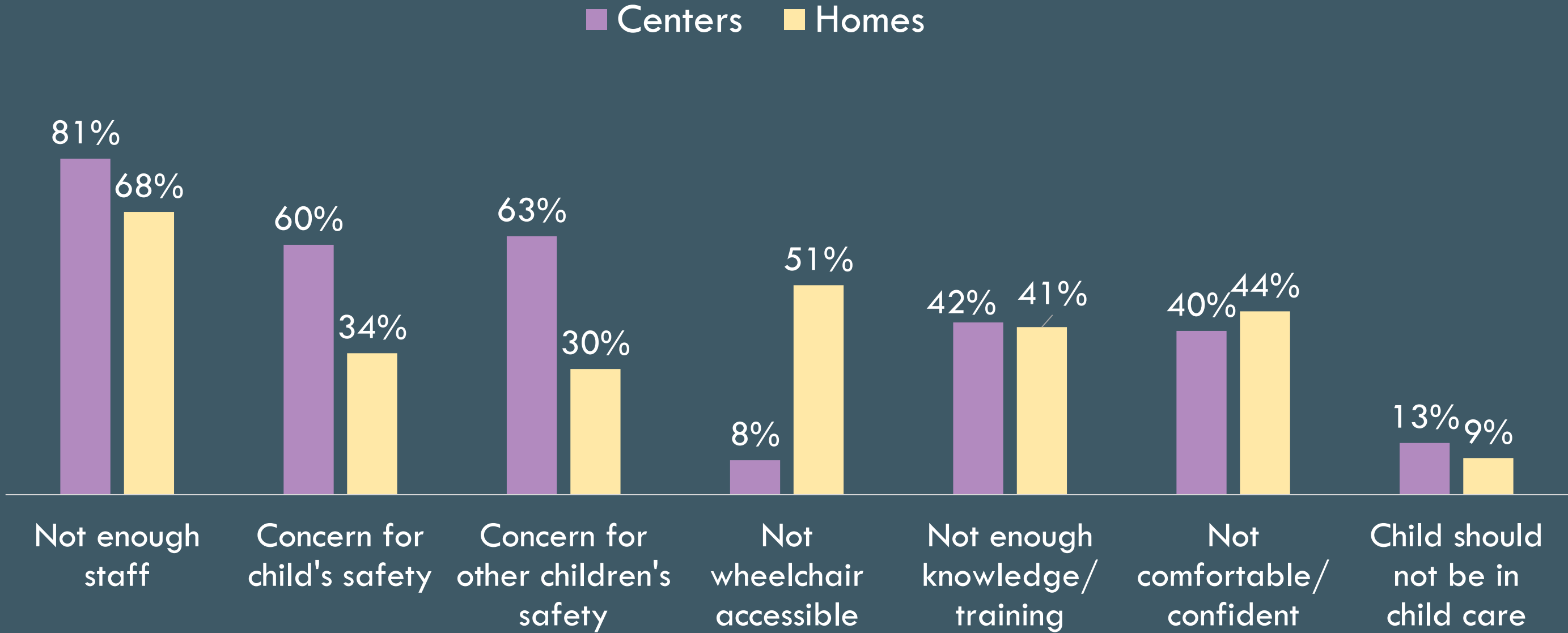
- 74% have at least one assistant
- 81% in the field for 10+ years
- Most have CCAP children



Who is Caring for Children with Disabilities?



Reasons Providers Could Not Accommodate a Child



Examples of Children Providers Could Not Serve

because could not accommodate the child's needs

"The child required someone to always be with him... He would bang his head on the floor, run off, or hurt other children."

- Center provider

"The children were very aggressive with other children and staff. I was worried someone would get hurt. Also, we didn't have the space to allow the children to explore because they did not like to sit down."

- Home provider

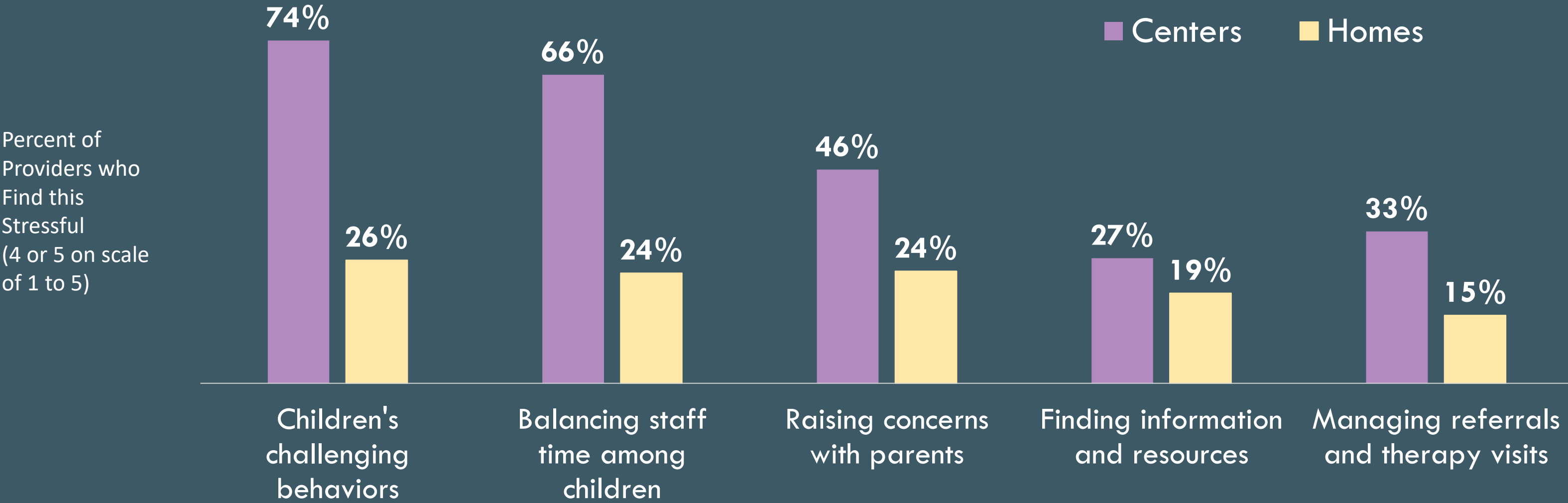
"He cried ALL DAY long. I have another kid in my care that doesn't like noise so it was bad. He didn't want me near him to look at him or touch him..."

- Home provider

"We are not equipped to do certain things like wound care for a wheelchair-bound child or tube feedings for the child."

- Center provider

Sources of Stress Related to Caring for Children with Disabilities & Delays



Providers' Staffing Challenges

Many providers cannot afford more staff than the minimum required.

Extra staff who have special education qualifications are even less affordable.

"We need a person that has specialized training, especially with children with behavior issues. An extra set of hands is nice but not enough."

-Center

Impact of not having additional staff:

- Families are turned away
- Children not receiving optimal amount of support
- Providers burning out
- Some programs reducing number of children enrolled, which means less income

"The children need so much supervision that it kinda leaves the other children vulnerable. One of the kids with autism doesn't sit down and is constantly moving. He tries to get into the baby's play pen."

-Home provider

Challenging behaviors

Provider examples:

- “Physically aggressive children who cannot regulate or follow a schedule.”
- “Screaming, kicking and biting.”
- “Behavioral outburst due to [being] overstimulated.”
- “Behavioral needs that impact the child's ability to join the group and engage in group activities.”

“Some people just don't understand, I went to bed for 3 months crying and debating if I wanted to continue down this career path and it was only one kid but he was a violent nonverbal kid. I was so scared for the other kids until I couldn't allow him to hurt any of my other children so I had to let them go.”

-Home provider

Providers' Training Challenges

1) Availability

Providers who can usually find the training they are looking for



2) Cost of training and of substitutes for the classroom

"We currently can only do what is on Gateways because it is free training."
- center provider

3) Trainings are not specific or practical enough

"The training courses...are generally offering the already-tried strategies."
- center provider

"[Having] the theory is not enough...I need support for ideas to use with the child or what materials I can offer that child."
- home provider

Providers Like Idea of On-site Coaching or Support

- More specific to the child and situation
- Better learning style for some caregivers
- Especially useful when a child first enrolls or is diagnosed

Provider Challenges with Connecting Children to Services

- Parents not willing to get child evaluated
- Families' long wait times for Early Intervention
- Providers need more information to refer a family
- Providers would like more collaboration with Early Intervention and Early Childhood Special Ed

"Families are hesitant and afraid. They fear a child will be labeled. They may still be in the denial stage" - home provider

"It would be great if we knew what the process is in our school district for helping parents get the information for Special Education services." - center provider

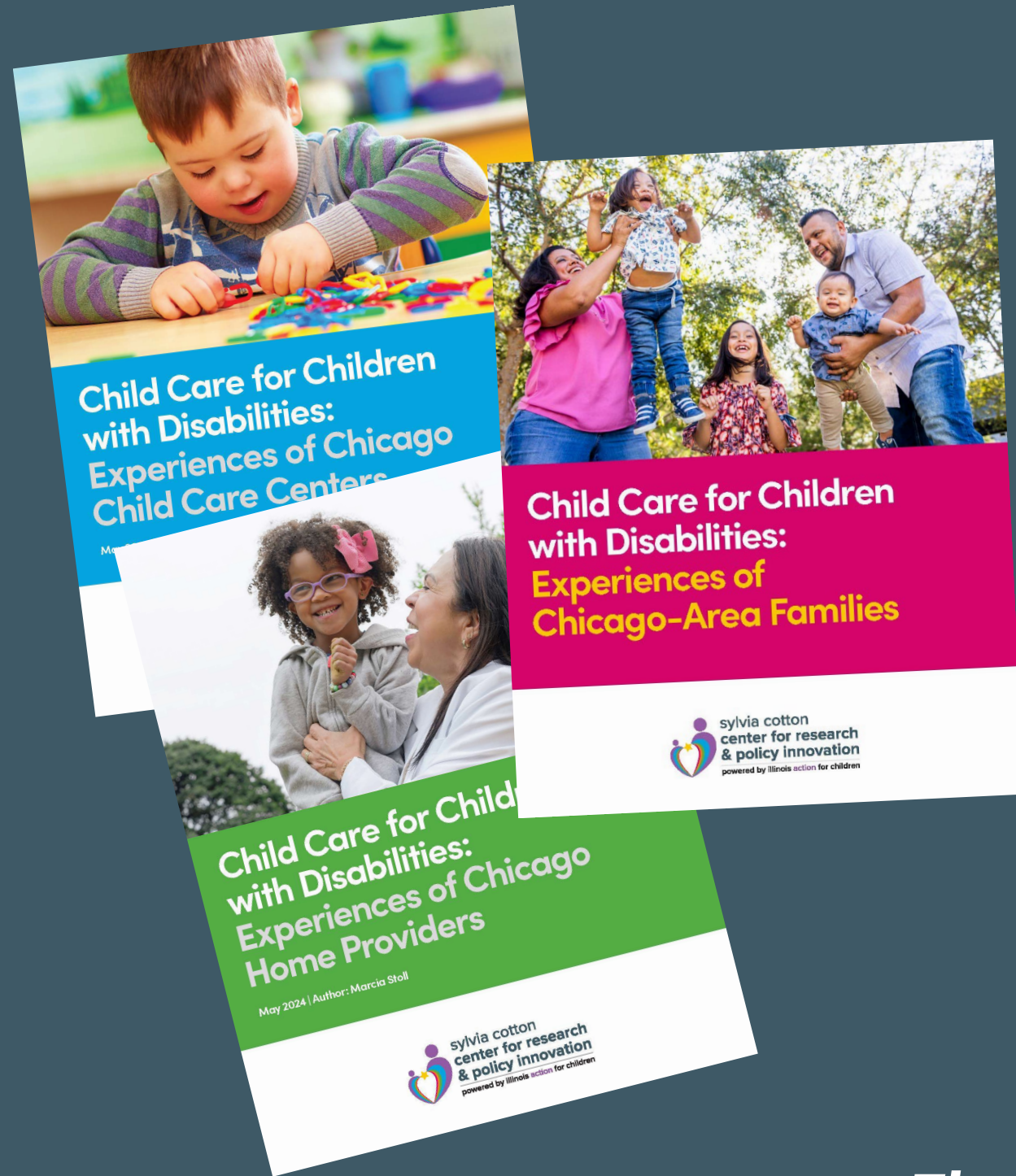
"There is a pretty big disconnect between CPS and the center. I have worked in other communities where there has been more of a cooperating partnership to create continuity between the 2 programs." - center provider

Recommendations



Ways We Can Invest in Our Early Childhood System

- 1. Offer families more support with their search for child care**
- 2. Address provider staffing levels**
- 3. Support ongoing training and preparedness of child care workforce**
- 4. Support child care programs with cost of adaptive equipment & facility upgrades**
- 5. Offer families full-day preschool and Special Education at single location**
- 6. Increase funding to expand Early Intervention workforce**
- 7. Encourage collaboration between child care and Early Intervention and Early Childhood Special Education**
- 8. Continue to educate providers on the benefits of inclusion**



Thank you!

Contact: Marcia Stoll
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Find our reports here:

www.actforchildren.org/about/research-data/reports

Thank you to Start Early for funding and supporting this research.