Child Care for Children with Disabilities: Experiences of Chicago-Area Families

May 2024 | Author: Marcia Stoll

sylvia cotton
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This report is dedicated to the parents who so generously shared their time and experiences in our survey.

Thank you to Start Early for funding this important research.

Many people offered valuable consultation during this project. We apologize to anyone inadvertently left out.

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Introduction

Over the years, Illinois Action for Children has supported thousands of parents as they looked for child care for their children with disabilities. Our consultants too often have witnessed parents struggling to find care that can support their children's needs. Several years ago, our Research Team followed parents as they searched for care, including eight parents of children with disabilities. We heard stories of parents missing work, children missing opportunities and high levels of parent anxiety related to difficulty finding child care.[1]

Our current research draws on parent AND child care provider experiences to explore the challenges of finding and providing child care for children with disabilities in more depth. *It is clear that parents and providers want the same thing — for all children to have care where they feel welcome and supported to develop to their full potential —* but our current child care system simply does not have enough resources to make this a reality. We hope this project provides insight into what investment is needed in Illinois child care to ensure that every family, regardless of a child's abilities, can access quality care.

This is one of three reports that capture the experiences of families, child care home providers and centers. This report focuses on families.[2] In August 2023, Illinois Action for Children invited parents across the Chicago area to take a survey about their experience finding and using child care for their children with disabilities and developmental delays. The results follow.

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[1] Searching for child care: Stories of Cook County mothers: Report on child care in Cook County 2020, Illinois Action for Children. https://bit.ly/cookcountymotherstories

[2] You can find other reports in this series at https://www.actforchildren.org/about/research-data/reports/child-care-for-children-with-disabilities

About the Families

Recruitment for the survey occurred mainly through emails to parents who used Illinois Action for Children's referral service to find child care for their child with special needs. Flyers were also shared through community organizations that serve parents of children with disabilities or delays. In total, 121 parents took the survey.

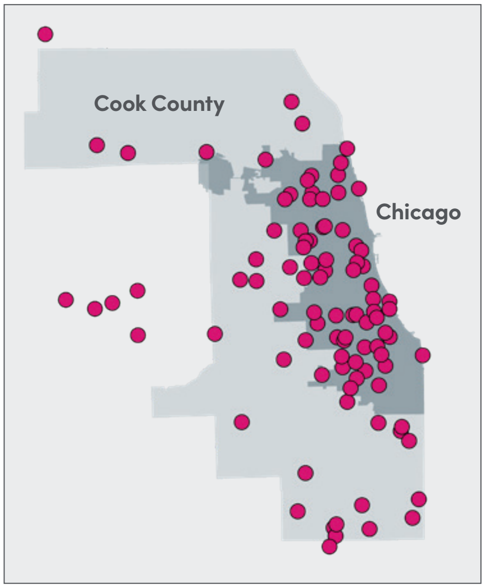
Three quarters of the parent respondents were single parents, and a quarter were in two-parent households. Nearly half of the parents identified as Black or African American, 21% as Latino/a and 12% as White. The majority of parents (58%) live in Chicago while 42% live in a Chicago suburb.

A significant portion of families (29%) have more than one child with a disability or developmental delay. These parents selected a focal child for this survey. Among all parents, two thirds focused their responses on a child aged 0 to 5 (most commonly a 3- to 5-year-old) and a third on a school-age child.

FAMILY CHARACTERISTICS

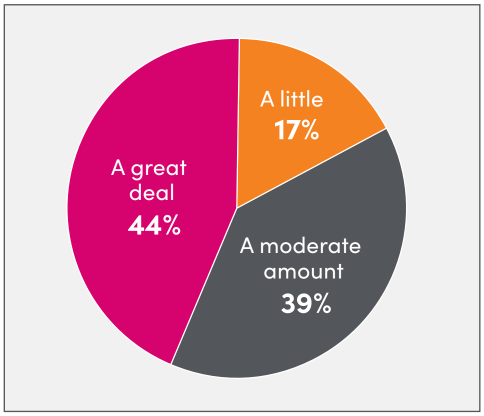
Household Type	
Single parent	76%
Two parents	24%
Parent Race or Ethnicity	
Black or African American	46%
Latino/a	21%
White	12%
Asian	2%
American Indian/Alaskan Native	2%
No response	24%
Location	
Chicago	58%
Suburb	42%
Has multiple children with disabilities or developmental delays	
	29%
Age of Child with Disability or Developmental Delay (focal child of survey)	
0 to 2	19%
3 to 5	47%
6 to 12	34%

WHERE FAMILIES LIVE



Parents reported how much extra adult support their child with a disability or developmental delay needs in daily life compared to other children their age. The most common response was "a great deal" (44%) followed by "a moderate amount" (39%) and "a little" (17%).

AMOUNT OF EXTRA ADULT SUPPORT THEIR CHILD NEEDS IN DAILY LIFE (N=120)



Extra Supports the Children Need While in Child Care

Parents listed a range of types of extra support that their children need in child care. Some children need only a little help with certain activities, or as one parent said, "just patience and extra understanding." Other children depend much more on their caregiver, with some requiring constant one-on-one assistance. One parent said her daughter "needs assistance in every activity all the time. Without that she won't be able to do anything on her own."

The types of support children need vary. Many parents said their children need extra supervision, particularly during outdoor play. Children need help with self-care, such as with eating, using the restroom or diaper changing. Children with a feeding tube need their provider to feed them through this method and help ensure the tube stays safely in place during play. Some children need help moving because they cannot walk. Others need help identifying and regulating their emotions so they do not harm themselves or others. Children with speech delays or who are nonverbal need assistance with communication, either through devices, visual charts or sign language. Finally at least one child requires the administration of medication.

Parents' Search for Child Care

Reflecting on their most recent search for child care, three out of four parents said finding care was difficult or, more commonly, very difficult.

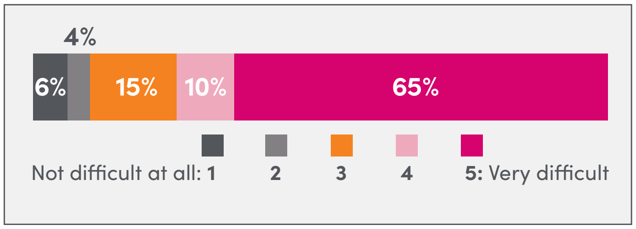
In fact, **only half of parents were successful in finding and enrolling their child with a disability or developmental delay into child care.**

The success rate was lower among families seeking care for school-age children: only 39% found care.[3]

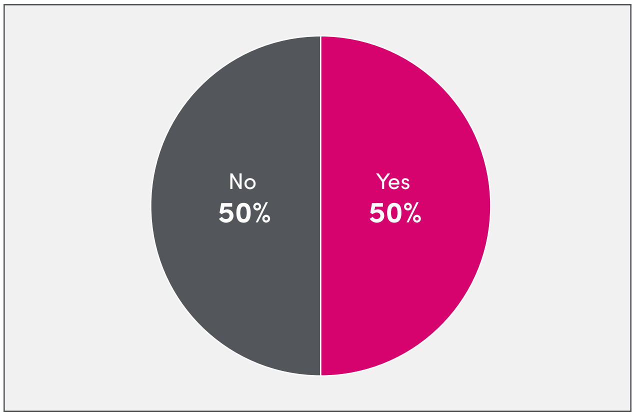
Most parents either required (63%) or preferred (25%) that their child care provider have training or experience with their child's disability. Among the half of parents who found care, 63% selected a provider with some training or experience. Another 9% said their provider was willing to be trained.

The top three ways that parents found care were through online searches, word of mouth and a Child Care Resource and Referral agency, most likely Illinois Action for Children.

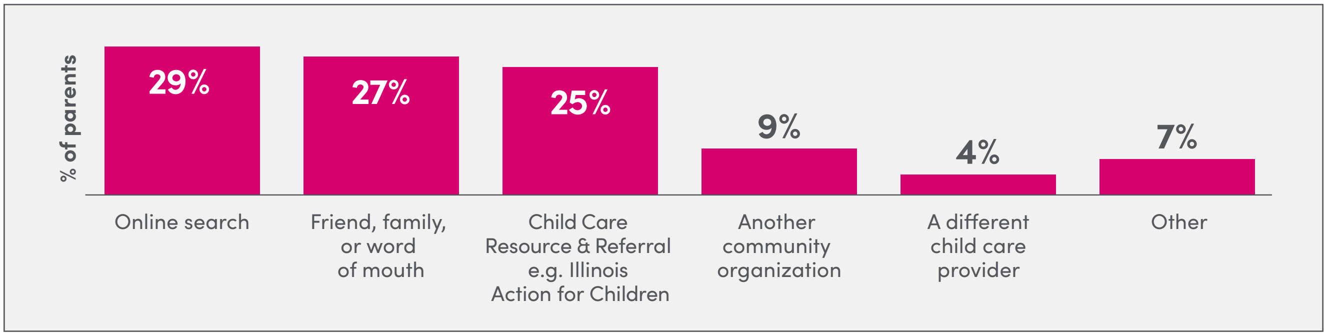
HOW DIFFICULT WAS FINDING CARE, ON A SCALE OF 1 TO 5? (N=121)



WERE PARENTS ABLE TO FIND & ENROLL THEIR CHILD IN CARE? (N=121)



HOW PARENTS FOUND THEIR CHILD CARE (N=56)



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[3] Given the study size, this percentage is not statistically different from the 56% of parents of younger children who found care.

Parents' challenges with finding care

A few parents who had positive experiences finding care commented on what they found helpful. They appreciated the quick timeframe of getting their child in care, being able to spend time observing during program visits, and resources that they received from their Early Intervention program.

The large majority of parents (85%) said their child's disability or developmental delay made it more challenging to find child care. Parents encountered what they perceived as a general unwillingness to serve children with disabilities, a lack of trained providers, programs being unable or unwilling to accommodate specific needs of their children, and affordability issues. Some children who enrolled in programs were asked to leave shortly after.

Types of challenges reported by parents:

- **Programs were not able/willing to care for the child because of their disability or delay.** Parents did not always receive a specific reason why a program could not accommodate their child beyond that the child had a disability. As one parent said, "Once I told them my child has autism they said immediately they can't take special kids." Some parents interpreted this as a lack of interest in children with disabilities or a dislike for providing this care. Providers were not always direct with parents. One parent said, "Child care centers ghosted us after learning of my child's disability" while another said, "They always put her on the waitlist."

> **"Child care centers ghosted us after learning of my child's disability."**

- **Programs lacked training to handle the child's needs.** In some cases, it was the parent who determined that a provider did not have enough knowledge or experience to support their child. In other cases, the program gave this as their reason for not enrolling the child. Providers told some parents that their programs did not have a person "certified" to care for their child.

> **"I was always honest with the provider and told them my son was autistic, and I was always told they don't have enough staff or training in that area and cannot accommodate me. I honestly felt discriminated against…The day care he goes to right now was sort of a last resort for me. I had no options and I work, I'm a full time single mom."**

- **Programs would or could not provide g-tube feeding or administer seizure medication.** Parents of children needing g-tube feeding said most programs will not provide it, but parents occasionally found one that could or was willing to learn. One said of her daughter: "She should be getting a G tube feed for lunch but we had to work around that. We called 32 daycare providers and found 1 that would take her. The other ones usually said they could not meet her needs, or they were full (I will obviously never know if that is true)." Another parent could not find a provider to give her son seizure medication. Programs told her they were not qualified to do so, and those that had nurses available were not affordable to her even with child care assistance from the state.
- **Programs want children to be toilet trained.** This was a common barrier named by parents. As one parent said, "at [age] 4 no day cares wanted her with a diaper."
- **Programs would/could not accommodate the child in other ways.** One parent said most places are not equipped for wheelchair access, while another said her child does not like certain foods but programs "are very strict about food or outside food." Another parent said of her son, "he couldn't be placed with children his age because of his physical limitations, but because of his age couldn't be with younger children."
- **Programs lacked staff to care for their child.** Parents were told that programs did not have enough teachers available to work with their child and could not afford to hire extra staff.

- **Parents had difficulty finding accredited or trustworthy programs.** Some parents wanted programs with certain credentials such as NAEYC accreditation and found these options limited. Others found it hard to find a program they felt comfortable with and confident that their child would get the care and attention needed.
- **Family income was a barrier to enrolling.** Some parents who received state child care assistance had difficulty finding programs that accepted these payments. Another parent said, "I make too much for Head Start and they were full."
- **Children enrolled but were soon asked to leave.** Some families found child care but their children were "kicked out" after a short time. One parent said, "A lot of places couldn't deal with him."

Laws Governing Child Care Programs and Service of Children with Disabilities

Americans with Disabilities Act (ADA)[4]

The ADA prohibits child care programs (both centers and homes) from excluding children with disabilities unless the child's presence would pose a direct threat to the health or safety of others or require a fundamental alteration of the program. Child care providers must make reasonable modifications to their policies and practices to integrate children.

Illinois law on suspension and expulsion in early childhood education[5]

Under this law, child care and other early education programs may not expel children ages 0 to 5 because of their behavior. Programs instead must draw on community resources to address the child's behavioral needs. Only after taking documented steps to address the behavior can they, if necessary, work with the family on a "planned transition" to a different child care setting.

What would make finding care easier

Parents who had trouble finding care commented on what would have made their search easier. Parents want lists of programs that will actually enroll and support their child and a greater supply of providers who are trained, are affordable, and have smaller settings or nurses present.

What parents say would make finding care easier:

- **Referrals or lists of providers**
  - Lists of providers that accept children with specific disabilities and providers that have experience or training with specific disabilities
  - Lists that include information on cost of care & whether transportation is offered
  - Lists or referrals that are provided by a professional or organization that the parent is connected to such as their Early Intervention coordinator or pediatrician.

> **"There needs to be a listing of child care facilities that do have skilled teachers for children with disabilities."**

- **Recommendations or references from family, friends or other parents**
- **More trained and willing providers**
  - "If all daycares are required by the State of Illinois to be licensed with handling children with disabilities."
  - "Having more people certified with working with people with disabilities."
  - "More schools for ABA [applied behavior analysis]."
- **More options, particularly with smaller group sizes**
  - "More Head Start centers with open seats for parents with higher incomes."
  - "More centers that have smaller class setting with multiple teachers."
  - "Give more licenses to small daycares, they can take [care] of them better then big centers."

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[4] https://www.ada.gov/topics/child-care-centers/

[5] https://oecd.illinois.gov/suspension-and-expulsion-resources.html

- **More programs with nurses**
  - "If there was a staff nurse there to care for him the way I do at home."

> **"Just giving care for her a try. It's not a lot. Most places just didn't want to deal with her."**

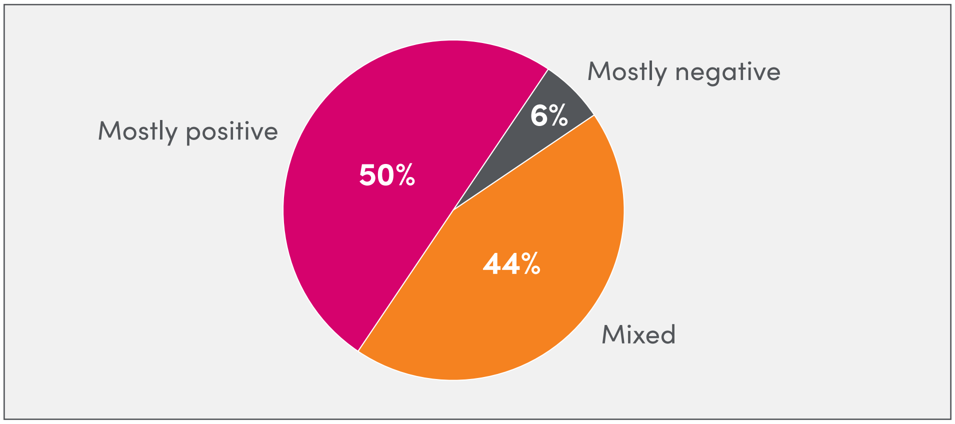
- **More affordable care options**
  - "There should be daycares that specialize in developmental delays that provide discounts… The assistance should go to these kids, not just super low income households. I don't qualify despite paying these higher rent prices. But if I was unemployed my child could go for free."
  - "More cost effective options."
  - "Pay one parent while the other parent goes off to work."

Families' Child Care Experiences

Approximately three quarters (72%) of parents taking the survey have used child care on a regular basis for their child who has a disability or developmental delay. These parents told us about their experiences.

Half of parents said their child's overall child care experience (across all providers) has been mostly positive. Only 6% said their experience has been mostly negative, and 44% felt it has been mixed.

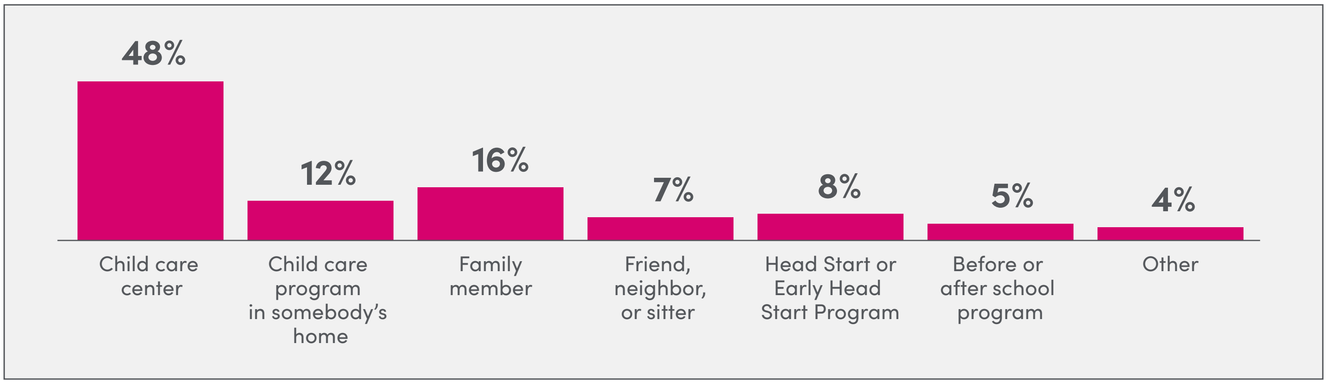
HOW PARENTS DESCRIBE THEIR CHILD'S OVERALL CHILD CARE EXPERIENCE (N=80)



Child care arrangements used by families

More than half of parents (61%) reported that their most recent, primary child care was center-based. These parents mainly used child care centers (48%), but also Head Start (8%) and before- or after-school programs (5%). About a third of parents (35%) primarily used home-based care, most commonly family members (16%) but also home-based child care programs (12%) and friends, neighbors or sitters (7%). School-age children were particularly likely to be in home-based care (52%), especially care by a family member, friend, neighbor or sitter.

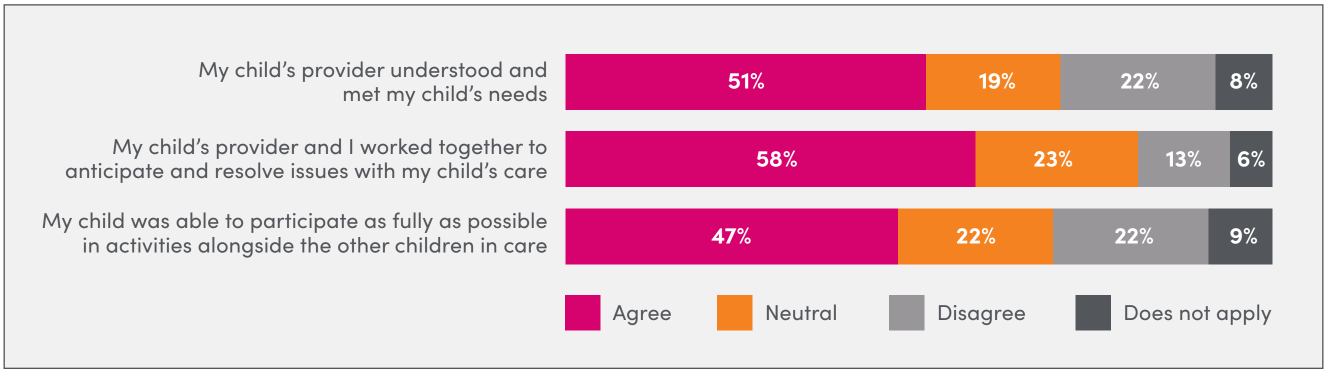
MOST RECENT PRIMARY CHILD CARE ARRANGEMENT FOR CHILD WITH DISABILITY OR DEVELOPMENTAL DELAY (N=85)



More parents had positive opinions of their most recent primary child care than negative opinions.

- **51%** agreed that their child's provider or teacher understood and met their child's needs; 22% disagreed (the remaining parents were neutral or said the question does not apply)
- **58%** agreed that their child's provider or teacher partnered with them to anticipate and work through any issues with their child's care; 13% disagreed
- **47%** agreed that their child was able to participate as fully as possible in activities alongside the other children in care; 22% disagreed.

PARENT'S OPINION OF THEIR MOST RECENT PRIMARY CHILD CARE ARRANGEMENT FOR THEIR CHILD WITH A DISABILITY OR DEVELOPMENTAL DELAY (N=79)



Parents were more likely to agree with these statements if their child needed only "a little" or "a moderate amount" of extra support rather than "a great deal."[6] In addition, the subgroup of parents who used family members for care were more likely to say their provider understood and met their child's needs (89%) compared to families overall (51%), as were parents who used a program in somebody's home (67%).

What Parents Appreciate About their Child Care

Many parents had positive things to say about at least one of their child care experiences. We asked them to name something a child care provider did particularly well in meeting their child's needs. The majority described how their provider was caring and patient with their child.

What providers did particularly well:

Providers were caring and patient

- "They don't get frustrated and don't give up on her. Even when she can't express her emotions or feelings. They seem very patient."
- "Ensuring my son felt included in all the activities and being patient as well as understanding when my son had tantrums due to his autism."
- "[They] gave her a little extra time to do certain things. Were gentle with her."

> **"My Mom was the best by far. She was very accommodating and respectful of my wishes and just mothering him, being understanding and patient."**

Providers were willing to work with their child

- "Just accepted my son and did not discriminate against him. Even though she [the provider] doesn't have training with children who have special needs, she did allow him to still enroll."
- "They have been open to learning how to use his g-tube and ways that he can participate in daycare activities."

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[6] The greater likelihood to agree is not statistically significant across all three measures.

Integrated the child with other children

- "Letting him be more involved with the other children."
- "My child is integrated with other children without special needs."

Helped their child learn

- "They helped him learn how to feed himself."
- "She's actually learning. She can walk, [a] few words can be said. She can use utensils."

Had good communication with the parent

- "She was open to any suggestions given to us by her therapists. She was also open to any suggestions I had."
- "One [provider] was very sensitive to their needs and communicated with me regularly about challenges and techniques she used."

Understood and met the child's needs

- "Prepared food that my child likes."
- "They read and understood his IEP."[7]

What Parents Wish Was Different About Their Care

The key things that parents wish were different about their child care was for their provider to be better prepared to work with their child, to have more patience and respect for their child, and to have more staff.

Providers better prepared: This was the top wish from parents. They discussed how a lack of knowledge and training made it difficult for staff to manage their child, which at times led to the child being sent home. It also meant children did not get enough support with their development. One parent said, "I feel like he is just being babysat and they are not able to work with him on the things he struggles with." Several other parents, too, wished their providers worked with their children on their goals or had more appropriate activities to meet their child's goals or needs. Finally, lack of training sometimes meant parents had to be the ones to educate staff. Some found this tiring, though one parent wished there was more opportunity for it.

> **"Anytime we have someone to care for our child we have to do the teaching to that other person....it is quite overwhelming to have to manage other adults to care for your child."**

Patience and respect: Parents also wished providers had more patience, understanding and tolerance with their children. One parent wished providers were "not discriminating or frowning upon children who can't help themselves." Another parent agreed: "The care provider was rude about his developmental delay and repeatedly spoke to others about his disability and not me."

> **"What I wish was different was that my child was in a child care facility with other children instead of being cared for by someone alone."**

More staff: Parents saw how programs' lack of staff affected their ability to give children enough support. Some wished an additional aide could be in the classroom to offer their child support. One parent said extra staff would allow her son to "attend field trips like the other kids without me having to be present and miss work."

Parents also wished their child care included transportation services, was lower cost, had more flexible hours, and was more flexible with allowing the child's therapist to serve the child at the program.

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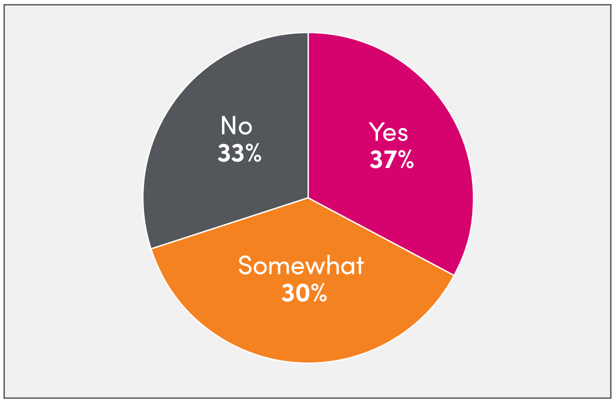
[7] IEP stands for Individualized Education Program. It is the agreed upon service plan for children ages three and older eligible for Special Education services. It outlines what services and supports a child needs and is entitled to receive through the school district, as well as goals for their development. Ideally, child care providers would help support children in meeting these goals.

When Providers Are Unable to Meet the Children's Needs

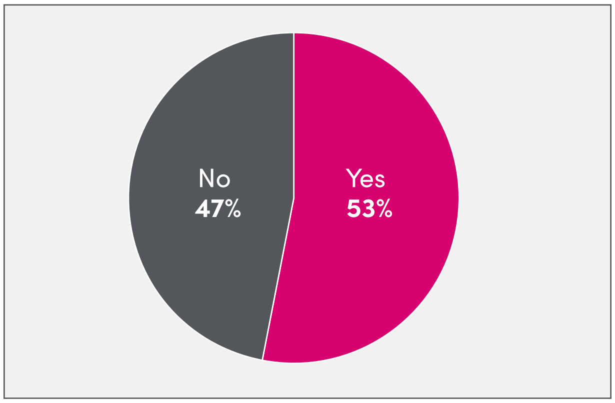
When providers have difficulty caring for a child, parents might have to consider finding new care or may worry that their provider will stop caring for their child. We asked parents if their child care provider ever expressed difficulty caring for their child.

- 37% of parents said yes, their provider expressed having difficulty, and another 30% said *somewhat*. A third said no.
- **Just over half of parents (53%) worried their provider might stop caring for their child due to difficulties providing care.**
- In fact, 42% of parents said a provider did stop providing care or the parent felt pushed out.
- Also, 46% of parents said there was an instance when they chose to stop care with a provider because the provider was not meeting their child's needs.
- **Overall, 58% of parents had an experience where either they or their provider stopped the care because the provider could not meet their child's needs.**

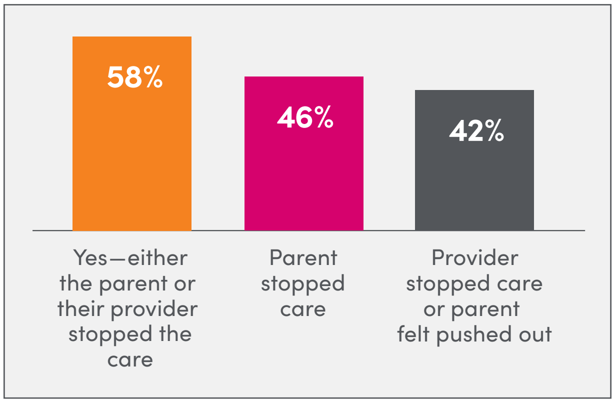
HAS A PROVIDER EVER EXPRESSED DIFFICULTY CARING FOR YOUR CHILD? (N=79)



DID YOU WORRY THAT YOUR PROVIDER MIGHT STOP CARING FOR YOUR CHILD? (N=79)



HAS A PROVIDER EVER EXPRESSED DIFFICULTY CARING FOR YOUR CHILD? (N=79)



Parents whose children need "a great deal" of extra support were more likely to experience these challenges. Fifty-five percent said *yes* a provider expressed having difficulty caring for their child, and a full 73% said either they or one of their providers stopped care because the provider could not meet their child's needs.

Experiences where their child's needs were not met or the provider had difficulty caring for their child. Parents explained more about their child care difficulties. Some described their child being asked to leave a program because of the child's behavior and/or the program's lack of staff to attend to the child; instances when programs did not or could not accommodate parent wishes; and staff not connecting with their child or not communicating well with the parent.

Programs unable to manage the child

- "Provider basically told me that there was nothing else she can do with him so I have a find him somewhere else as of immediately."
- "My son was so frustrated that he started biting teachers and other peers so we had a meeting with the principal and they expelled my son."

> **"[They] had my child enrolled for 2 to 3 days and told me he couldn't come back because their teachers were not equipped for kids with disabilities but cookie cutter kids."**

- "They underestimated how overwhelming taking care of my child is."
- "The child care center basically committed to caring for her. Then turned around and kept sending her home for having diarrhea despite the many letters and plan of care her doctor wrote out explaining that diarrhea is a normal and, unfortunately, life-long reality for children who live with short gut."

Children not getting the care the parent wanted

- "Our first in home daycare, the provider refused to use his equipment (special tomato chair, Benik vest) and did not allow therapists to do sessions during daycare. She was not open to meeting about his needs and/or hearing suggestions from his therapists for what he needed."
- "One teacher at a previous center simply ignored my child seemingly because she didn't want to deal with the challenges of caring for her."

> **"Some teachers get irritated or frustrated with him."**

- "When he struggled with sensory overload, feeding issues and such, they complained and were not compassionate. They also were not willing to train their employees."
- "...They never put effort into helping me potty train him especially since he has a speech delay."
- "Sometimes bullying happens and no one is aware, and it makes it look like your child is being disruptive. But if they can't communicate and defend themselves, their surroundings get hyper in their mind and [my son] will wander off or lash out with aggression, and by that time it's too hard to come back from."

Programs not staffed to meet the child's needs

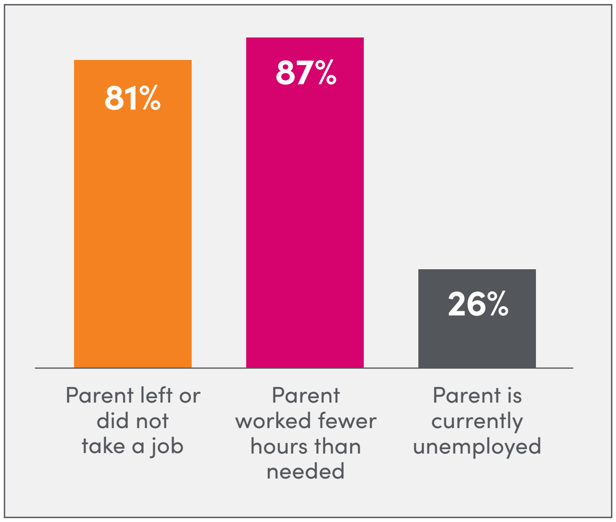
- "[The center] could not meet my child needs and do [not] have the proper staff to look after him. She told me he was a safety concern because he climbed into things."
- "She told me that he was a challenge [that] she could not handle at the moment, she needed more staff."
- "The center dis-enrolled him causing me to lose my full-time job and decline in income. The staff were not able to provide the necessary attention my child needed due to being understaffed and overcrowded with children."

Families' Financial Well-Being and Child Care

The large majority of parents experienced negative impacts to their employment because they could not find child care for their child with a disability or delay.

- **81%** of parents or their spouse/partner have had to leave a job or not take a job because they could not find child care.
- **87%** of parents said they or their partner have worked fewer hours than desired because of lack of child care.
- **26%** of parents said either they or their partner was currently unemployed because of lack of child care.

IMPACT OF LACK OF CHILD CARE ON PARENT



In their comments, parents explained the financial impact on their family of not having child care.

Not being able to work

- "I had to quit my 19½ year job to care for my son after he got of out the [neonatal intensive care unit]…so my income changed a lot since then."
- "We are forced into being a one-income household when we need two incomes due to me having to be a stay-at-home mom to care for my neurodiverse children."
- "I have not been able to hold a job for the past 5 years because I have been refused child care."

Not being able to work the amount of hours needed

- "I used to make 160k a year. I now work part time and make maybe $15k a year."
- "Due to the lack of childcare availability for my special needs child, my husband had to find a new job at night, and his new job gets paid less and has less hours worked."
- "I can only work part time. I'm paying [a friend] to take care of my children…I barely can afford any extra clothes or things that any of us need."

> **"Jobs don't understand that sometimes your children come first."**

Missing work

- "My child requires an assistant [for the] majority of the day, she can't articulate what she needs. At the last few daycares I had to drop everything most times and assist or pick up my child."
- "I've missed some days and over exhausted all my sick days. I missed some days without pay and lost out paying people out of pocket."

Becoming homeless (reported by seven parents)

- "Lack of childcare has cost me everything. I was recently evicted from my house from lack of work, behind on all bills, and cannot overall provide a stable home for my children."
- "Well we are homeless. I was trying to work to get us off the streets, but with the child care not being able to do their part I'm now stuck with my child 24/7…I would get to work and they would be calling me to come and get him."

Could not pay bills and meet living expenses

- "I am unable to bring in monies that pay my car note, cell phone, utilities, school cost and childcare. My husband now pays for everything and is struggling."

> **"It is very difficult to be able to work more hours, and this affects the entire family economically and emotionally."**

- "I have been in and out of working the last year because when I ask personal family or friends to watch my son they can't handle him and I end up having to quit. I struggle with diapers and or sometimes food by the end of the month. I owe back rent almost $10,000. I will be in debt for a long time which affects me getting a house."

Extra Child Care Costs

Extra child care costs related to a child's disability or delay can also stress a family financially. Some parents said their program charged extra fees for supplies, diapering and other accommodations. One parent said, "Our copayment was $150 a month, but this daycare charges $150 a week because extra accommodation like feeding him like a baby."

Other parents provided supplies to their child care providers. One bought special equipment when the provider did not have it. Another provided food because her child is a picky eater. Some parents mentioned buying special toys or a weighted blanket for child care.

Other Aspects of Families' Well-Being and Child Care

We asked parents how their child care experiences have positively or negatively affected them, their child or others in their family.

When child care works, children thrive and parents have peace of mind.

Parents expressed how their positive child care experiences benefited their children and themselves. Their children were able to have social experiences, other supportive adults in their life, and opportunities to learn and grow.

> "Our child has learned so much from being in day care, and can now read and communicates better, and even started eating more, which has been a challenge since birth."

> "It has allowed my child to be in surroundings with other kids her age to learn and grow. And to slowly become more comfortable in the real world outside of our house."

Parents also described their peace of mind knowing their child was in trusted hands.

> "Knowing my child had a care giver that supported and wanted to see him thrive as much as me, made me feel less stressed at work knowing I was able to leave him for several hours a day and he wasn't being mistreated."

Poor child care experiences affected the mental and even physical health of children and parents.

Parents with child care challenges described the negative impact on children's social opportunities. Also, two parents said that instances when their child was restrained resulted in bruises or trauma for their child.

> "It negatively impacted my daughter not being able to be around other children and attend school like her sibling. She truly felt left out and often blamed herself."

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

> "Child care providers were hostile towards our child. He was prevented from interacting with other kids by being isolated in a different room strapped into a chair. This was traumatizing to our child."

Parents reiterated the financial toll that child care struggles had on their family. They also described their stress and worry over whether their child was well cared for while they work. Some discussed the physical and mental exhaustion from not getting a break from their child, and how difficult it is to watch their child being treated differently. They said the impacts touch the entire family, including their other children and their marriage.

> "In every aspect of life it has affected me negatively. I don't get sleep, I'm crabby, my health is not good, I don't have energy and I've put on weight."

> "It was very sad and difficult to go day to day seeing that because they're different they don't have same opportunities as the others."

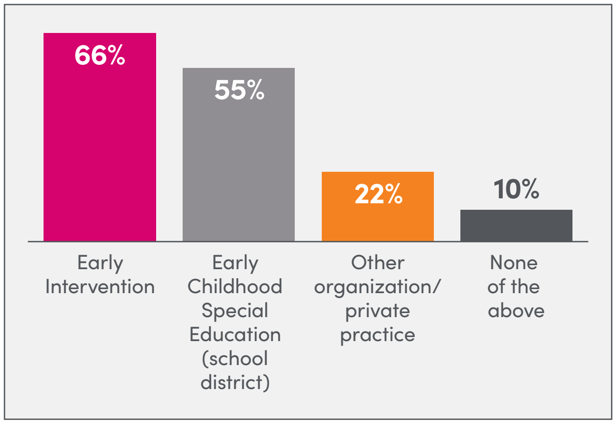
> "It affects you, because you can't work or you work under a lot of stress. You are always worried about how your child will be, if the school is prepared to help him, if they will have patience with him, in short, it is difficult."

> "Even when I am sick I can't rest because [there is] no one to take care of them."

Children's Support Services & Child Care

Most children under age six who are diagnosed with a disability or developmental delay are eligible for Early Intervention (ages 0 to 3) or Early Childhood Special Education (ages 3 to 5). These programs provide children with services such as speech, physical or occupational therapy. In fact, 84% of parents taking our survey said their child participated in at least one of these programs. When private-pay services are included, 90% said their child has received some type of services.

CHILD HAS RECEIVED REGULAR THERAPY SERVICES THROUGH THIS PROGRAM (N=110)



Conflicts between Services and Child Care

Sometimes the receipt of these services conflicts with parent employment or child care and this prevents children from getting needed developmental supports.

Early Intervention services for children ages 0 to 3 can be provided at a child care program if the parent chooses and the provider is willing. This is important for working parents who might otherwise have difficulty scheduling therapy sessions. Early Childhood Special Education services for children ages 3 to 5, however, are currently provided primarily at the school district. Parents who want or need to use child care for the remainder of the day may need to secure their own transportation between the two programs, depending on whether their child is eligible for district transportation as specified in their Special Education service plan (their IEP). Transporting their child can pose a challenge for parents.

Among parents surveyed, only a small portion – 7% – said they had to decline Early Intervention or Early Childhood Special Education services that their child was eligible for because the services conflicted with their work or child care. Conflicts stemmed from the following:

- Hours of therapy were not convenient
- Parent lacked transportation between the child's school and child care
- Provider was not willing to have therapists at their home child care program
- Therapists were not consistent or reliable

Two parents explained:

> "We didn't have daycare in the town where we live, and the local school only offers a part time program. With both of us working, we couldn't logistically transport our child to school and daycare so we kept her in daycare."

> "...Because it's a home daycare she refused to have people come to her house to provide services. I have to apply for 1 hour of vacation time to get home in time for his weekly speech sessions. I had to decline development therapy because they don't fit my schedule."

Half of these parents said their child was able to get the services they needed through another program outside of Early Intervention or Early Childhood Special Education.

How Child Care and the Child's Therapy Can Work Better Together

Parents reported ways their child's therapy services and child care could work better together. Parents' most common responses are the following:

Transportation being provided: Many parents wished for improved transportation options. One said, "We were told that we don't qualify for bussing services through the school district, but that would be immensely helpful so my child could receive therapy at school rather than multiple visits to private therapists each week." Another parent wished the child care provider could take her child to therapy: "I had to leave work to take her to therapy from daycare or skip daycare some days which ultimately caused me to lose my job for having to leave for the betterment of my child every day."

Longer programs: Other parents wished their school's Early Childhood Special Education program was longer or had wrap-around child care. "I wish the program was longer and he could have lunch, I have to leave work to transport him to daycare to be on time to eat lunch."

More information sharing: Some parents wanted more communication between the special education program or their therapist and the child care program: "A better way to share information with daycare providers and for them to apply different things to his everyday care." Parents also wished to receive more information themselves. "Just wish for better communication if something's wrong and activity ideas to do at home with my child to help him."

Better location options: A few parents wished their child's services could be delivered at their child care program. The parent of a 3-year-old said, "Having to choose between childcare and making sure she has the proper therapies has been extremely difficult. It would be wonderful to have both at a facility or have more providers willing to accommodate children in her situation." A parent of a two-year-old described the challenge of receiving Early Intervention services without having a home: "I am transient. It is difficult to do in home visits without a home."

Better scheduling options: A few parents had difficulties scheduling services at times that worked for them. One said, "I have had difficulty finding service providers that are able to provide services while my child is in daycare."

Final Words: What Parents Want Others to Know About Raising a Child with a Disability or Developmental Delay in our Child Care System

"It takes a lot of advocacy on the parent's behalf and determination to ensure your child receives the best of care."

"It's very difficult for a single mom with no family to raise 2 children with developmental delays. I cry every day because I don't know what to do to help them and help myself…"

"Our children want to be happy… and make friends, and when there are not a lot of programs out there for them, they are left with not getting the proper help they need to grow and be as successful as their counterparts. It makes it hard for them to understand themselves and the world."

"Family support makes all the difference in the world."

"Every day is different, it takes patience and a lot of time, and a whole lot of love. IT TAKES A VILLAGE."

"It's difficult but worth it. However learning the system is a full time job in itself."

"It's challenging to watch someone you love so dear at heart and sometimes not understand what or how they may feel due to their disability. I worry every day that he is not getting the tools and help he needs to succeed. Sometimes I feel lost because I'm not sure of the best thing to do to help my son. To all moms, you are not alone."

"It's important that you work as a team so all the caregivers and providers are all on the same page about your child's growth and development."

"It is incredibly difficult. Even in a big city like Chicago where there are many daycare options."

"It gets better as they get older."

"You are your child's voice and it's important you be vocal about your child's needs."

"Don't ever compare your child to anyone else's child because yours is special and a gift and is very smart in the most unique way possible."

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