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# The Child Care Crisis Disproportionately Affects Children With Disabilities

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By Cristina Novoa January 2020



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# Introduction and summary

**Authors' note:** *The disability community is rapidly evolving to using identity-first language in place of person-first language. This is because it views disability as being a core component of identity, much like race and gender. Some members of the community, such as people with intellectual and developmental disabilities, prefer person-first language. In this report, the terms are used interchangeably. Direct quotes are lightly edited for clarity and length but otherwise use the speakers' preferred terms.*

With a full-time job and a school-aged child as well as newborn twins, Alexis knew she was going to need child care. After several days in the neonatal intensive care unit—like many twins, her babies were born prematurely and needed extra care—the hospital discharged them with no specialized support or instructions. As her babies grew, however, Alexis noticed that one showed some muscle weakness on one side; rolling to the left was difficult, as was holding a bottle with both hands. As she prepared to return to work, she wondered: Could interventions like physical therapy help her baby? And how would that affect the kind of care the infant would need?

Across the country, Missy asked herself altogether different questions. With four children at home—two preteen stepsons, a 7-year-old and a 3-year-old—juggling multiple school and child care schedules could be overwhelming. She was fairly satisfied with her child care now that her youngest child was enrolled in preschool—a program for which her child is eligible under the Individuals with Disabilities Education (IDEA) Act—but challenges remained. Educators at the inclusive preschool were comfortable handling her child's adaptive equipment, unlike staff at their previous center. Still, the program ended by 2 p.m., leaving her to wonder who would watch her preschooler in the afternoon when she has to work. Could she squeeze some additional work hours into her early mornings and watch her child after school?

Like most parents, Alexis and Missy want to see their children thrive. Child care is critical to this vision. Reliable, quality child care provides children with nurturing interactions that their growing brains and bodies need while allowing parents to

pursue the employment and educational opportunities that undergird a family's economic security.<sup>1</sup> But parents of children with disabilities face meaningful obstacles to accessing this care.

The United States has failed to invest in child care for decades, leading to a dearth of affordable, high-quality options. Ableism—the intentional or unintentional discrimination against people with disabilities—further compounds the child care crisis. Nationwide, more than half of people live in child care deserts, or areas where the number of children under the age of 5 far outstrips the number of available child care slots.<sup>2</sup> However, because many of those openings are in programs that are inaccessible to children with disabilities, the share of disabled children effectively living in child care deserts is likely higher. Programs operate on slim budgets that scarcely cover staff salaries, leading experienced early educators to seek better-paying jobs elsewhere. But early childhood special education teachers—some of whom are paid far below their general education peers—may be especially likely to leave.<sup>3</sup> This lack of investment in child care, coupled with poor oversight and enforcement of anti-discrimination laws designed to protect people with disabilities, mean that too many children are left out of care.

This report examines families' child care experiences when they have children ages 0 to 5 with disabilities and offers policy solutions that are critical to supporting these families. Although the term “disability” applies to a diverse community of individuals representing a broad array of conditions and experiences, people with disabilities often face similar barriers to full participation in social programs and institutions, including child care. Using quantitative data from two nationally representative surveys—the 2016 Early Childhood Program Participation Survey (ECPP) and a combined sample of the 2016–2018 National Survey of Children's Health (NSCH)—as well as qualitative interviews conducted in fall 2019 from a diverse sample of parents across the United States, the report's analyses demonstrate that families face significant obstacles to finding appropriate child care arrangements. (see Appendix for full methodology) To ensure their children's care, parents develop complicated arrangements involving formal and informal caregivers, often with significant consequences for careers, financial well-being, and family life.

Key findings from the analysis include:

- ECPP data show that, compared with parents of nondisabled children, a larger proportion of parents with disabled children experience at least some difficulty finding care (34 percent vs. 25 percent) and are unable to find care (34 percent vs. 28 percent).

- Both ECPP survey data and interview data show that parents face numerous barriers to care, including a lack of available slots, scheduling challenges, and concerns about quality.
- Interviewed parents reported patching together help from extended family, child care centers, special education preschool, and nurses and home health aides, as well as making significant changes to their jobs to provide care.
- An analysis of NSCH data shows that, compared with parents of nondisabled children, parents of young children with disabilities are three times more likely to experience job disruptions because of problems with child care.
- The consequences of not finding care extend far beyond job disruptions; many interviewed parents reported greater financial strain, health challenges, and increased stress.

It is important to note that families in which parents are themselves disabled face additional barriers to care. Although this report focuses only on children with disabilities, future research is needed to fully understand these families' experiences.

## Why analyze multiple data sources?

Disability affects how children interact with multiple programs and systems, including child care, education, and health care. With unique emphases on early education and health, respectively, the ECPP and the NSCH provide complementary survey data about families' experiences navigating these systems. Because these datasets use nationally representative samples, findings can be generalized to the United States' entire childhood population.

Supplementing these quantitative data with qualitative findings tells an even richer story of parents' experiences with child care. Whereas quantitative survey data provide information about number and frequency—for example, how many child care arrangements a family uses or how often a pre-K program calls a father to pick up his autistic child because of challenging behavior—qualitative data shed light on the meaning behind those events.<sup>4</sup> For example, interviewing the father may reveal that after a month of weekly calls, he feels the program no longer welcomes his family, and he sees little choice but to find a new arrangement.<sup>5</sup> (see the Appendix for additional information on the data sources)

# Disability in early childhood

Early childhood is a period of rapid development across physical, cognitive, social, and behavioral domains. Sometimes, however, this development follows an unexpected pattern, and children are diagnosed with a disability or delay.<sup>6</sup> These children—representing an estimated 15 percent of the United States’ childhood population—are protected by three civil rights laws: the Individuals with Disabilities Education Act (IDEA), the Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act.<sup>7</sup> To educate parents about their rights, the Office of Special Education Programs\* supports nearly 100 Parent Training and Information Centers and Community Parent Resource Centers across U.S. states and territories. These parent-led groups operate at the state level to support and inform families.<sup>8</sup> Despite these protections and resources, families still struggle to find appropriate child care and early learning opportunities for children when their growing brains and bodies could most benefit.

The IDEA guarantees early intervention (EI) services for infants and toddlers as well as a free and public education beginning in preschool. These two programs are called Part C and Part B, respectively, in reference to the legislative text.<sup>9</sup> Importantly, the IDEA stipulates that children with disabilities should be in general education settings whenever possible—a practice known as inclusion.<sup>10</sup> Although these programs help children access critical developmental and educational supports, they were developed during a period of relatively low labor force participation for mothers and were not designed with working parents’ needs in mind.<sup>11</sup> For example, EI covers nursing and medical services, various therapies, and parent education, but it does not include child care for infants and toddlers—a group for whom child care options are especially scarce.<sup>12</sup> Reliable, enriching care opportunities become more available once a child becomes eligible for preschool special education at the age of 3, but most states’ programs operate on an academic calendar that leaves families to scramble for care to cover summer and other out-of-school hours.<sup>13</sup>

Importantly, the IDEA specifies that children are eligible for services only if they are diagnosed with a specific condition enumerated in the law.<sup>14</sup> However, the law allows states considerable discretion in determining eligibility criteria for diagnoses of those conditions.<sup>15</sup> As a result, a family in Arkansas with a 3-year-old enrolled in preschool special education could find their child no longer eligible for a similar program if they move to neighboring Texas, a state with different, narrower eligibility criteria.<sup>16</sup> In light of declining federal dollars for IDEA early childhood programs, states are further narrowing their eligibility criteria and focusing their dwindling resources on serving smaller shares of children.<sup>17</sup>

In contrast to the IDEA, the ADA and Section 504 of the Rehabilitation Act define disability broadly as a physical or mental impairment that substantially limits a person's major life activities.<sup>18</sup> Both laws prohibit discrimination against individuals with disabilities, including disabled children and disabled adults in need of child care. Specifically, the ADA stipulates that child care programs cannot exclude children with disabilities unless including them would require a “fundamental alteration of the program” and that programs must make “reasonable modifications” to integrate disabled individuals. Because these terms are open to interpretation—and because child care programs often operate with razor-thin margins that make financing accommodations difficult—children with disabilities are often excluded.<sup>19</sup>

# Findings from the analysis

CAP's analysis identified families' obstacles to child care; illuminated the patchwork of care that families with disabled children often use; and highlighted the consequences that these families face if they cannot find care.

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## Families' obstacles to child care

"Just in general, finding child care is hard. And trying to find child care for two is even harder. Then trying to find one for a child with special needs that's in the perfect location—it's even harder still." —**Alexis**

### A shortage of care

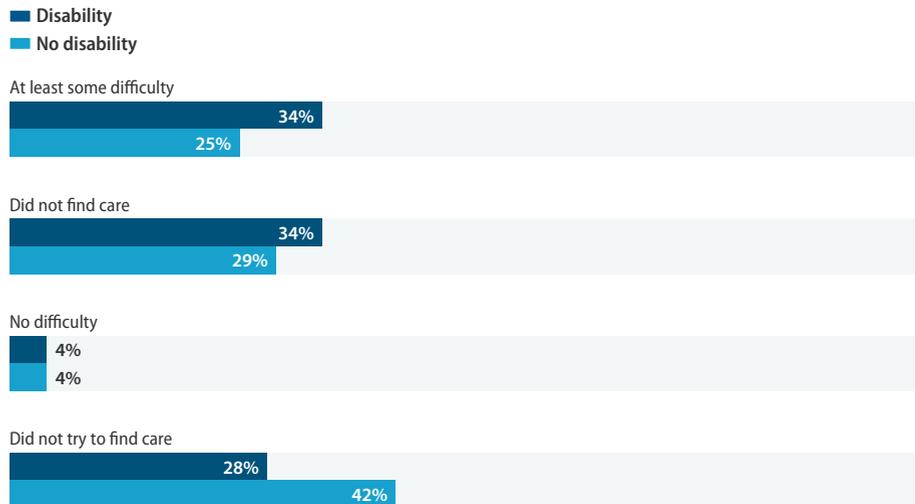
Child care is difficult to find for all families; evidence from the ECPP suggests that it is especially difficult for families of children with disabilities. Whereas the share of families reporting no difficulty finding care was similar across families with nondisabled children and families with disabled children, a larger proportion of parents with disabled children experienced at least some difficulty finding care (34 percent vs. 25 percent) and were unable to find care (34 percent vs. 28 percent).

Across the United States, parents of children with disabilities were also significantly more likely than parents of nondisabled children to report a lack of available slots as their main difficulty in finding care—12 percent vs. 8 percent. This finding likely masks variation across states, given that the way each state determines eligibility likely affects the difficulty parents' have finding care.

FIGURE 1

## Parents of children with disabilities struggle to find child care

Estimated percentage of families reporting difficulty finding child care in 2016, by child's disability status



Source: Author's analysis of National Center for Education Statistics "2016 National Household Education Survey: Early Childhood Program Participation Survey," available at <https://nces.ed.gov/nhes/dataproducts.asp#2016dp> (last accessed January 2020).

Qualitative interview data support this finding and reveal other challenges. Throughout interviews, parents recalled tenaciously looking for child care before their child's birth. Alexis described frequent calls to providers to find care: "Sometimes you got to be the advocate. If I become a nuisance, hey! I'm a nuisance for a reason." Interviews also revealed that as children's needs became clear, many parents were compelled to revise their plans. For families of disabled children, restarting the search process is more burdensome than simply starting at the bottom of a waitlist; they must find programs that fit their child's needs, even as they are learning what those needs are. One first-time mother, who had already visited several programs throughout her pregnancy, described a discouraging second visit to a child care program after her child was born:

*I asked [the provider], "Would you take a child with complex medical needs?" And the response was, "As long as it doesn't disrupt the classroom." And it just sunk my heart into my stomach because I have a 4-month-old. I don't know what this was going to look like at six months. I've no clue what 2 looks like for him.*

## Quality and safety concerns

Beyond availability of slots, interview data reveal that parents were concerned about child care providers' experience or knowledge serving children with disabilities. For example, parents of Deaf children who were interviewed noted an absence of providers in their communities who were fluent in American Sign Language while remarking how important it is for children's language and social development to communicate in their language.<sup>20</sup> In contrast, Alexis and other parents of children with complex medical needs worried about providers' ability to ensure their children's well-being and physical safety, especially in environments where providers must divide their attention among multiple children. Given her child's limited speech, Alexis noted having to be extra "careful" in choosing trusted providers who understood her child's other ways of communicating. Less sensitive providers or providers who are stretched thin by watching large numbers of children may be less attuned to the nonverbal cues that some children use to communicate their needs.

Less frequent, but still important, were instances in which attitudinal or environmental barriers discouraged families from attending a program. Several parents expressed frustrations about program policies, noting how these often violated the principle of inclusion. Examples included barring children from specific activities such as playing outdoors on hot days or inappropriately holding children back with younger peers. Physical barriers exist as well. As a mother of two toddlers, including one with a physical disability that makes climbing steps difficult, Alexis had to eliminate any program without easy ground floor access or elevators. Parents were quick to note that these types of barriers constitute illegal forms of discrimination, and several parents described filing complaints or undertaking legal action. Having this legal recourse, however, did not help parents address their immediate child care needs. Moreover, several parents recognized that following through with these complaints was possible because they had access to resources—including existing connections to legal professionals and financial resources to pay legal fees—unavailable to all families. Although filing a complaint could eventually help families gain access to care, it was often a laborious and expensive process that not all families could undertake.

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## A patchwork of care

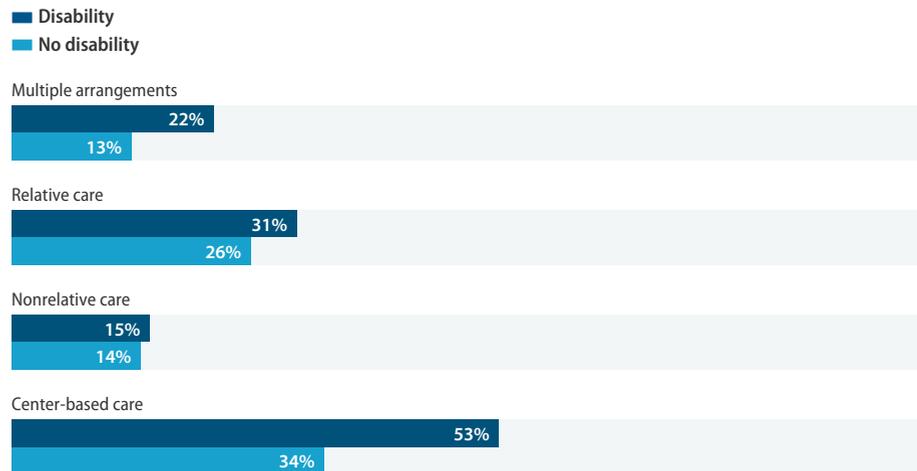
“I wake up around 4:30 a.m. or so and come down to my desk and work for a while (before my child is awake). Without my parents helping out . . . I’m not sure what I’d do.” —Missy

### Multiple child care arrangements

ECPP data reveal that children with disabilities are significantly more likely than non-disabled children to receive care from multiple sources (22 percent vs 13 percent).

**FIGURE 2**  
**Parents of children with disabilities use multiple kinds of child care arrangements**

Estimated percentage of families regularly using different child care arrangements in 2016, by child's disability status



Source: Author's analysis of National Center for Education Statistics "2016 National Household Education Survey: Early Childhood Program Participation Survey," available at <https://nces.ed.gov/nhes/dataproducts.asp#2016dp> (last accessed January 2020).

Interview data complement survey findings by capturing more fully how families of children with disabilities weave together multiple sources of care as well as their preferences for different types of care. Interviewees often reported relying on extended family or chosen family for child care.<sup>21</sup> In Missy's case, although her child has been enrolled in a child care center since infancy, her retired parents live nearby and provide regularly scheduled care several times a week. Other interviewees described relying on a network of nearby grandparents, aunts, uncles, and close friends—several of whom were still in the workforce—to provide last-minute care. Even sporadic care from family is critical; several interviewees described extended visits from out-of-town grandparents to help provide child care, especially during stressful moments such as hospitalizations.

Almost half of interviewed parents reported regularly using center-based programs as part of their patchwork of care. However, center-based programs do not always meet families' needs. Several interviewees—especially parents whose children have complex needs—also reported using nurses and aides, some of whom accompanied children in child care.

## Nurses, home health aides, and child care

Some children with disabilities may need around-the-clock care from a nurse or home health aide. To help, the federal government allows states to pay for these children's in-home care with Medicaid through a waiver, even if the children would not otherwise qualify for Medicaid.<sup>22</sup> Having a nurse or home health aide available to help take care of their child gives parents more freedom to work or go to school. However, as some parents noted in their interviews, the role of these providers is mainly to attend to children's physical health needs rather than their overall development. To ensure that children benefit from enriching, developmentally appropriate activities while also receiving one-on-one professional care, some families in the Medicaid waiver programs enroll children in child care with a nurse or aide to provide additional support. Despite having the potential to be a tremendous source of support, interviews suggest that eligible families often find out about these programs late and experience numerous challenges in securing and keeping these services, including onerous application processes, restrictive child care program policies, and rapid staff turnover. Future research is needed to better understand the role these supports play in families' child care arrangements.

### Parental care arrangements

Nearly all interviewees reported one or more parent devoting significant time to child care. Reasons for doing this included concerns about children's health or safety in group settings, scheduling constraints, program costs, and frustration with care options. Before Missy's child started preschool, Missy stayed home with her two days a week due to challenges scheduling therapy appointments—sessions required pulling her child out of care several times a month—concerns about program costs, and disappointment in the quality of care. “Ugh, I don't miss the schedule juggling we had before preschool,” she explained in an interview. Even so, a shortened school day prevents her from working typical hours. “He gets dropped off by the bus at 2:15 p.m.,” she said in an interview, “so we still need to be home in the afternoon.” To accommodate her child's care, Missy works part time from home, squeezing in work during odd hours and weekends while her child is asleep or in another adult's care.

Parent care took many forms beyond those Missy used. One option that families utilized was staggering adults' work schedules. For example, Alexis' partner, who worked night shifts, watched their twins during the day for a full year while Alexis worked. Another option was parental care supported through paid job-protected leave—a benefit that many families lack. Although most parents interviewed were fortunate to have some form of leave through benefits such as vacation and paid sick days, disability insurance, and parental leave, they reported exhausting every available option in order to care for their children. Importantly, parents needed to take time off work to care for their child long past the first 12 weeks of life that some current paid leave proposals would cover for parents of new children.<sup>23</sup> Anticipating the need to take time off later, some mothers with employer-provided time off, such as disability or paid sick time, reported returning to work early in order to “save” their time off. Despite these challenges, this sample is relatively privileged; only 19 percent of U.S. civilian workers currently have paid family leave through their employers, and only 40 percent have short-term disability coverage.<sup>24</sup>

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## Consequences of not finding care

“There were nights we’d be in bed and just cry because it was just hard.”—Alexis

### Career sacrifices

Survey data suggest that child care struggles can affect the careers of parents with disabled children. Many parents of young children report leaving their job, not taking a job, or making significant changes to their job due to problems with child care. Using a combined sample of NSCH data from 2016–2018, CAP estimates that more than 2 million parents of young children—nearly 1 in 10—make at least one of these career sacrifices each year. This number rises to nearly 1 in 5, or 18 percent, for parents of children with disabilities. It is important to note that these figures do not take into account demographic or family characteristics that could contribute to the likelihood of parents experiencing child-care-related career disruptions. Controlling for demographic characteristics such as children’s race and gender as well as parents’ education levels, the odds of making a career sacrifice were three times higher for parents of children with disabilities than parents of nondisabled children. Considering the disproportionately high rates of poverty among people with disabilities, the additional resources that children with disabilities often need, and the onerous process of securing disability benefits for children, driving parents out of the workforce will likely exacerbate economic inequalities between families of disabled and nondisabled individuals<sup>25</sup>.

Interview data echo this finding and show that both mothers and fathers experience job disruptions. All interviewees identified as mothers and remarked upon their own career sacrifices, which reflects the fact that women are often the primary caregivers in their families.<sup>26</sup> In addition, several mothers noted that their male partners also experienced significant changes to their work as a result of child care problems. Approximately one-third of interviewees noted that their partners scaled back or changed their work hours, while two reported that their children's fathers had left the workforce to provide child care. At least one mother noted that her husband lost his job after having to request scheduling accommodations too frequently.

#### Other consequences of not finding child care

Interviewed parents who reported avoiding advancement opportunities or neglecting to pursue different jobs due to child care problems often said that they felt frustrated or stranded in their careers. Interviews also revealed that parents' career sacrifices spill into other aspects of family life. For example, leaving the workforce or scaling back work hours reduces family income at a time when families are often shouldering other high costs associated with caring for their children. As Alexis acknowledged, it's "not always just child care; it's finding somewhere to live that is hard . . . It's buying the right shoes [for my child's disability]."<sup>27</sup> Beyond specialized shoes, Missy also described purchasing or modifying equipment for her child to use at the child care center to participate in group activities: floor mats to cushion her child's head during a fall, a tricycle she modified herself, and a black blanket to reduce visual clutter and allow her child to participate in activities that would otherwise be too overwhelming.<sup>28</sup> On average, families of children under the age of 5 already spend about 10 percent of total family income on child care—more than the 7 percent that the U.S. Department of Health and Human Services considers affordable.<sup>29</sup> This figure, however, does not capture purchases such as shoes and adaptive equipment that disabled children must often have to participate in care. A reduction in income without a corresponding reduction in child care spending would mean that families have even less money to cover other necessities.

Despite their love for their children, several parents interviewed said that they felt stressed, exhausted, and isolated at times due to a lack of support. To care for their children and continue to meet their work responsibilities, several parents reported sacrificing sleep to make up work or provide care. Most parents remarked that their lack of sleep affected their moods or relationships, and one interviewee connected her husband's rare, life-threatening reaction to a common virus with the wear and tear on his body brought on by stress and sleep deprivation.

## Policy solutions

Child care—including child care for children with disabilities—suffers from years of chronic underinvestment. Indeed, federal funding for child care has remained largely stagnant over the past 15 years.<sup>30</sup> Meanwhile, policymakers and program leaders at all levels have neglected to implement practices and policies that would ensure care is truly accessible to all. As a result, children lose out on valuable education and early intervention services that help them thrive, and parents lose out on a dependable care arrangement that allows them to pursue meaningful opportunities, including further education and stable employment. Federal action is needed to help ensure that families of children with disabilities have access to the resources they deserve.

Congress can address many of the challenges raised in this report by taking the following actions.

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### Invest in child care by passing the Child Care for Working Families Act

Fixing the child care system requires a comprehensive approach such as that offered by the Child Care for Working Families Act, a bill introduced by Sen. Patty Murray (D-WA) and Rep. Bobby Scott (D-VA).<sup>31</sup> In addition to making child care more reliable and affordable for all families through significant investments in the child care system, the act includes several provisions to ensure that child care is high quality and inclusive of all children, including those with disabilities.

First, it would increase the supply of accessible care by requiring states to use resources to expand inclusive child care options; creating a new funding stream to provide early intervention services in child care settings; and allowing providers to use funds to construct or renovate facilities to improve accessibility.<sup>32</sup> If these provisions were in place now, parents like Missy would not have to pull their children out of care for several hours a month to receive services. And child care programs could upgrade their facilities with automatic doors and elevators to be more accessible to families like Alexis'. Second, the bill would require consumer education for parents

to help them choose appropriate child care providers.<sup>33</sup> Such a provision would help assuage the stress felt by first-time mothers beginning their child care searches anew in the wake of their infants' diagnoses. Finally, the bill would increase pay for the entire early childhood workforce, enabling programs to recruit and retain highly skilled educators and provide training opportunities specifically on caring for children with disabilities. These changes would improve the quality of care provided to all families, including those with disabilities.<sup>34</sup>

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## Support children's right to education and developmental supports by adequately funding the IDEA and fully enforcing civil rights protections

Despite civil rights protections enshrined in laws such as the IDEA and the ADA, children with disabilities often fail to receive the services to which they are entitled. This is partly due to a steady erosion of funding. After adjusting for inflation, today's per-child funding for young children with disabilities is between one-half and one-third what it was 25 years ago.<sup>35</sup> States have responded to these funding shortages by narrowing IDEA eligibility criteria and serving fewer children.

To ensure that children receive the services they need, Congress should significantly increase funding for IDEA early childhood programs—early intervention and preschool special education. The Funding Early Childhood is the Right IDEA Act would increase funding incrementally for early childhood IDEA programs to a total of \$2.95 billion across both programs by 2024. This is approximately three times more than the 2019 funding level of \$861 million.<sup>36</sup> Policymakers should also expand the capacity of the U.S. Department of Education's Office for Civil Rights to investigate and address violations of the IDEA, the ADA, and the Rehabilitation Act's Section 504 in schools and early learning settings.

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## Bolster parent caregiving through progressive work-family policies

Parents of children with disabilities may need more time off work or greater workplace flexibility to manage the health and caregiving needs of their children. This is especially true for parents who work in low-wage jobs, which are less likely to offer benefits such as paid leave and scheduling flexibility. Work-family policies such as paid family and medical leave, paid sick days, and workplace flexibility can help address the inequities in access to paid time off.

Parents of children with disabilities often need time off work throughout their children's early years—whether it is to care for a newborn at home or be with their toddler in the hospital. Indeed, the findings of this analysis echo previous CAP research showing that more than one-quarter of caregiving leaves taken under the Family and Medical Leave Act were taken to care for a seriously ill child.<sup>37</sup> Paid family and medical leave would provide workers access to up to 12 weeks of job-protected leave each year to welcome a new child, recover from a serious medical condition, or care for a seriously ill family member. Comprehensive paid family and medical leave, such as that proposed in the Family and Medical Insurance Leave Act, would allow parents to return to work when they are ready, increasing the likelihood that they will return—and continue to earn similar or higher wages—after a child is born.<sup>38</sup>

A paid sick days policy would also help parents who need short-term leave from work to care for themselves or an ill family member or seek preventive care. It could be especially useful for parents of children with disabilities, who may need to bring their child to many health care or therapy appointments. Federal legislation such as the Healthy Families Act would enable most workers across the country to earn up to seven paid sick days per year to recover from an illness, care for a sick family member, or access medical care.<sup>39</sup> By making it easier for parents to take paid time off work, these policies would help parents like Alexis and Missy care for their children without risking their jobs.<sup>40</sup> Supporting parents' ability to work and maintain their wages while providing care to loved ones can in turn reduce financial strain and emotional stress for families.

Predictable and flexible scheduling is also critically important to help parents of children with disabilities—especially parents in low-wage and hourly jobs—juggle work, child care, doctors' appointments, and unplanned family emergencies. Policies such as the Schedules That Work Act would protect workers who ask for workplace flexibility and would require employers to post schedules two weeks in advance.<sup>41</sup> This would allow workers to plan child care arrangements and health care appointments or request leave to manage caregiving.

# Conclusion

Most parents in the United States depend on child care to maintain an often-fragile balance between work and family life. Although a shortage of affordable, high-quality care is an issue for all families, it disproportionately affects families of children with disabilities. Families like those of Missy and Alexis face additional barriers to accessing child care, with greater consequences for their careers, family finances, and personal well-being.

Child care in the United States is sorely in need of investment and reform. In order to ensure the full participation of children with disabilities and their families—a community that could particularly benefit from the stability and support that high-quality child care can provide—policymakers must ensure that this care is accessible and appropriate for children with disabilities.

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## About the author

**Cristina Novoa** is a senior policy analyst for Early Childhood Policy at the Center for American Progress.

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*\*Correction: February 7, 2020: This report has been updated to reflect that the Office of Special Education Programs—not the Administration for Children and Families—supports nearly 100 Parent Training and Information Centers and Community Parent Resource Centers across U.S. states and territories.*

# Appendix

This report presents findings from the author’s analysis of the 2016 Early Childhood Program Participation survey (ECPP); a combined multiyear sample of the National Survey of Children’s Health (NSCH); and interviews with parents of children with disabilities conducted in fall 2019.

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## Early Childhood Program Participation Survey

The ECPP was administered as part of the 2016 National Household Education Surveys Program and collected data specifically about children who had not yet started kindergarten.<sup>42</sup> The ECPP includes data from 5,837 households and is a nationally representative survey, representing 21.4 million children from birth to age 5. The survey asks parents to respond to questions about their child, including whether they have a disability, their child’s participation in early childhood education programs, and characteristics of their child’s household and family members. Parents report on only one child for the survey, even if there are other children in their home.

The author’s analysis of the survey focused on comparisons between parents of children with and without disabilities. The author used a binary variable provided by the ECPP indicating whether the target child currently has a disability. The analysis examined several key questions from the survey, including:

- “How much difficulty did you have finding the type of child care or early education program you wanted for this child?”
- “What was the primary reason for the difficulty finding child care?”
- “Is this child now receiving care from a relative other than a parent or guardian on a regular basis, for example, from grandparents, brothers or sisters, or any other relatives?”

- “Is this child now receiving care in your home or another home on a regular basis from someone who is not related to him/her?”
- “Is this child now attending a day care center, preschool, or prekindergarten not in a private home?”

To determine whether being in multiple child care arrangements differed by disability status, the author used the last three variables to construct a new variable.

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## National Survey of Children’s Health

The U.S. Census Bureau’s National Survey of Children’s Health (NSCH) is a nationally representative survey providing rich data on children’s physical and mental health, access to quality health care, and the child’s family and community context.<sup>43</sup> The NSCH—which has been administered annually since its redesign in 2016—is the only national and state-level survey on the health and well-being of children and families. Households were contacted at random to identify those with one or more children under 18 years old. In each household, one child was randomly selected to be the subject of the survey. Surveys were administered via web and paper-based instruments sent to parents, and results are weighted to represent the population of noninstitutionalized children from birth to the age of 17.<sup>44</sup>

To increase the analytic sample, the author combined data across the most recent three years of surveys: 2016, 2017, and 2018. Combining multiple years and leveraging this large sample size allowed the author to produce reliable estimates for rare outcomes such as parents of children with disabilities leaving the workforce.<sup>45</sup> Individual-year survey weights were adjusted in order to reflect an average annual population. The dataset was then restricted to children ages 0–5. The combined dataset resulted in a total of 29,231 observations, including 2,035 children ages 0–5 with disabilities. The weighted sample represents 23.5 million young children nationwide, including nearly 1.5 million children with disabilities.

The author’s analysis of the NSCH focused on comparisons between parents of children with and without disabilities on one key question: “During the past 12 months, did you or anyone else in the family have to quit a job, not take a job, or greatly change your job because of problems with child care for this child?” The author used an NSCH-provided variable for whether the child received IDEA services in order to identify whether the child had a disability.

The analysis then used logistic regression with survey weights to predict the odds of parents making a career sacrifice based on a child's disability status. As the outcome of interest—a career disruption—was a dichotomous variable, a logistic regression was most appropriate. Survey weights adjust the estimates to be nationally representative. Regression models controlled for several child and family characteristics that could also affect the likelihood of being suspended or expelled. These included a child's gender, race, home language, and the family poverty ratio.

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## Interviews with families

Throughout the report, the author examines interviews conducted with parents of children with disabilities from October 10 to October 31, 2019. The author recruited eligible parents online through a Google form shared with CAP partners, inviting a smaller sample to participate. In extending invitations, the author considered children's disability or diagnosis, striving for diversity in the sample, as well as families' geographic, racial, and socioeconomic/educational diversity. The children of parents in the sample represent a broad array of disability diagnoses, including Down syndrome, deafness, Autism, cerebral palsy, and various types of complex medical needs. The final sample was too small to identify differences by race, socioeconomic status, or diagnoses; it consisted of 17 parents representing 13 states. All self-identified as female, and eight identified as white/Caucasian. Compared with the general population, the sample was highly educated: Nine reported having master's or professional degrees; two had bachelor's or college degrees; two had associate degrees; three had some college coursework; and one did not provide information.

After informing participants of how their responses would be used and having participants sign an informed consent form, the author conducted a semistructured interview lasting approximately 45 minutes. Topics included barriers to care, types of child care arrangements used, and the effect of child care challenges on participants' families. Interviewees were paid a small stipend of \$25 in exchange for their participation, and the interviews were recorded and transcribed with their consent. The author analyzed transcriptions for common themes.

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## Endnotes

- 1 Child care is especially critical for mothers; 64 percent earn a significant portion of their families' incomes and need child care to support their employment. See Sarah Jane Glynn, "Breadwinning Mothers Continue To Be the U.S. Norm" (Washington: Center for American Progress, 2019), available at <https://www.americanprogress.org/issues/women/reports/2019/05/10/469739/breadwinning-mothers-continue-u-s-norm/>.
- 2 Rasheed Malik and others, "America's Child Care Deserts in 2018" (Washington: Center for American Progress, 2018), available at <https://www.americanprogress.org/issues/early-childhood/reports/2018/12/06/461643/americas-child-care-deserts-2018/>.
- 3 In New York City, for example, special education teachers working at community-based organizations that are part of Pre-K For All—the city's free preschool program for 4-year-olds—might earn \$30,000 less than general education teachers in the same classroom. The children served in these community-based organizations are often public school children who are placed in these schools after all other public settings have been considered. See Tom McAlvanah "Salary disparities are hurting special education students too," NYN Media, July 20, 2018, available at <https://nynmedia.com/content/salary-disparities-are-hurting-special-education-students-too/>; Christina Veiga, "Same classroom, different salaries: Special education pre-K teachers earn dramatically less than their general education co-teachers," Chalkbeat, January 2, 2020, available at <https://chalkbeat.org/posts/ny/2020/01/02/same-classroom-different-salaries-special-education-pre-k-teachers-earn-dramatically-less-than-their-general-education-co-teachers/>.
- 4 Hirokazu Yoshikawa and others, "Mixing Qualitative and Quantitative Research in Developmental Science: Uses and Methodological Choices," *Developmental Psychology* 44 (2) (2008): 344–354, available at <https://www.baruch.cuny.edu/facultyhandbook/documents/YoshikawaWeisnerKalil-Way2008DP.pdf>.
- 5 This is a "soft" expulsion, where a program's practices leave a family little choice but to withdraw their child. See Abby Schachner and others, "Preventing Suspensions and Expulsions in Early Childhood Settings: An Administrator's Guide to Supporting All Children's Success" (Menlo Park, CA: SRI International, 2016), available at <http://preventexpulsion.org>.
- 6 Disability, especially when so much of a child's development is in flux, is a complex term. Development occurs across a continuum, with some children functioning above or below what is expected for a given age in a domain. At some point along this continuum, a child's ability may fall far enough below what is expected that she is considered to have a disability or a delay. This approach has been criticized because in practice, policy, rather than science, dictates where that point is drawn. Moreover, disability is moving toward a framework emphasizing the role of environmental and attitudinal barriers in impeding individuals' full participation in society. See Kathleen Hebbeler and Donna Spiker, "Supporting Young Children with Disabilities," *The Future of Children*, 26 (2) (2016): 185–205, available at <https://www.jstor.org/stable/43940587?seq=1>; and Azza Altiraifi, "Advancing Economic Security for People With Disabilities" (Washington: Center for American Progress, 2019), available at <https://www.americanprogress.org/issues/disability/reports/2019/07/26/472686/advancing-economic-security-people-disabilities/>.
- 7 Paul H. Lipkin and Jeffrey Okamoto, "The Individuals With Disabilities Education Act (IDEA) for Children With Special Educational Needs," *American Academy of Pediatrics* 136 (6) (2015), available at <https://pediatrics.aappublications.org/content/pediatrics/136/6/e1650.full.pdf>.
- 8 Center for Parent Information and Resources, "About Parent Centers Serving Families of Children with Disabilities," available at <https://www.parentcenterhub.org/the-parent-center-network/> (last accessed January 2020).
- 9 Part B contains provisions relating to the education of school-aged children as well as a state grants program for preschool children with disabilities (Part B Section 619). Part C and Part B 619 are considered the IDEA's two early childhood programs. See Kyrie E. Dragoo, "The Individuals with Disabilities Education Act (IDEA) Funding: A Primer" (Washington: Congressional Research Service, 2019), available at [https://www.everycrsreport.com/files/20190829\\_R44624\\_c85f49a0d2b1c25913346932a5bf6b9c30831c8d.pdf](https://www.everycrsreport.com/files/20190829_R44624_c85f49a0d2b1c25913346932a5bf6b9c30831c8d.pdf).
- 10 Amanda Morin, "Least Restrictive Environment (LRE): What You Need to Know," Understood, available at <https://www.understood.org/en/school-learning/special-services/special-education-basics/least-restrictive-environment-ire-what-you-need-to-know> (last accessed January 2020).
- 11 In 1975, the year that the IDEA's predecessor legislation passed, 39 percent of mothers with children under the age of 6 were in the labor force. That figure rose to 65 percent by 2017. See U.S. Department of Labor, "Mothers and Families: Labor Force Participation," available at [https://www.dol.gov/wb/stats/mother\\_families-text.htm](https://www.dol.gov/wb/stats/mother_families-text.htm) (last accessed January 2020).
- 12 Steven Jessen-Howard and others, "Understanding Infant and Toddler Child Care Deserts" (Washington: Center for American Progress, 2018), available at <https://www.americanprogress.org/issues/early-childhood/reports/2018/10/31/460128/understanding-infant-toddler-child-care-deserts/>.
- 13 Maryland Developmental Disabilities Council, "Barriers to Quality Child Care & Out of School Time Activities in Maryland" (Baltimore: 2012), available at [http://www.md-council.org/wp-content/uploads/2017/09/BarrierstoQuality\\_ChildCare\\_2012FINAL.pdf](http://www.md-council.org/wp-content/uploads/2017/09/BarrierstoQuality_ChildCare_2012FINAL.pdf).
- 14 The IDEA includes 13 disability categories. See Andrew M.I. Lee, "The 13 Disability Categories Under IDEA," Understood, available at <https://www.understood.org/en/school-learning/special-services/special-education-basics/conditions-covered-under-idea> (last accessed January 2020). The IDEA also allows states to use the category of "developmental delay," although states broadly differ in how they assess and define developmental delay. Moreover, not all states have opted to use this category. See Lipkin and Okamoto, "The Individuals With Disabilities Education Act (IDEA) for Children With Special Educational Needs"; and Early Childhood Technical Assistance Center, "Part B, Section 619 Eligibility," available at <https://ectacenter.org/topics/earlyid/partbelig.asp> (last accessed January 2020).
- 15 Ibid.
- 16 In 2016, 11.7 percent of preschoolers in Arkansas received special education—nearly three times the share of preschoolers Texas served (3.9 percent). No evidence suggests that these differences are the result of states' different populations. Instead, they result from different policy choices. See U.S. Department of Education, "40th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2018" (Washington, 2018), available at <https://www2.ed.gov/about/reports/annual/osep/2018/parts-b-c/40th-arc-for-idea.pdf>.
- 17 Dragoo, "The Individuals with Disabilities Education Act (IDEA) Funding."

- 18 Civil Rights Division, "A Guide to Disability Rights Laws" (Washington: U.S. Department of Justice, 2009), available at <https://www.ada.gov/cguide.htm>; and Lipkin and Okamoto, "The Individuals With Disabilities Education Act (IDEA) for Children With Special Educational Needs."
- 19 The exception includes child care services that are controlled by religious entities such as churches, mosques, or synagogues, which are not covered under the ADA. See U.S. Department of Justice Civil Rights Division, "Commonly Asked Questions About Child Care Centers and the Americans with Disabilities Act," available at <https://www.ada.gov/childqanda.htm> (last accessed January 2020).
- 20 Amanda Howerton-Fox and Jodi L. Falk, "Deaf Children as 'English Learners': The Psycholinguistic Turn in Deaf Education," *Educational Sciences* 9 (2) (2019), available at <https://www.mdpi.com/2227-7102/9/2/133/htm>.
- 21 This finding echoes an earlier CAP analysis highlighting the important role of chosen family for individuals with certain disabilities. See Katherine Gallagher Robbins and others, "People Need Paid Leave Policies That Cover Chosen Family" (Washington: Center for American Progress, 2017), available at <https://www.americanprogress.org/issues/poverty/reports/2017/10/30/441392/people-need-paid-leave-policies-that-cover-chosen-family/>.
- 22 Beginning in the early 1980s, the federal government introduced Medicaid waiver programs to help families receive professional care at home as an alternative to institutionalization. These programs "waive" normal Medicaid rules—most often how income is calculated—in order to extend services to children who may not otherwise qualify. Most waivers in use today are 1915(c) Home and Community Based Services, which provide services such as in-home care from nurses or home health aides to help children with disabilities live at home. Other common waivers include the Tax Equity and Fiscal Responsibility Act/Katie Beckett Program, 1115 demonstration waivers, and state-based programs. Kids' Waivers "What Is a Waiver?," available at <https://www.kidswaivers.org/> (last accessed January 2020).
- 23 Diana Boesch "Rhetoric vs. Reality: Not All Paid Leave Proposals Are Equal" (Washington: Center for American Progress, 2019) available at <https://www.americanprogress.org/issues/women/reports/2019/10/10/475625/rhetoric-vs-reality-not-paid-leave-proposals-equal/>.
- 24 U.S. Bureau of Labor Statistics, "Table 31. Leave benefits: Access, civilian workers, March 2019," available at <https://www.bls.gov/ncs/ebs/benefits/2019/ownership/civilian/table31a.pdf> (last accessed January 2020); U.S. Bureau of Labor Statistics, "Table 16. Insurance benefits: Access, participation, and take-up rates, private industry workers, March 2019," available at <https://www.bls.gov/ncs/ebs/benefits/2019/ownership/private/table16a.pdf> (last accessed January 2020).
- 25 National Council on Disability, "National Disability Policy: A Progress Report" (Washington: 2017), available at [https://ncd.gov/sites/default/files/NCD\\_A%20Progress%20Report\\_508.pdf](https://ncd.gov/sites/default/files/NCD_A%20Progress%20Report_508.pdf).
- 26 Sarah Jane Glynn "An Unequal Division of Labor: How Equitable Workplace Policies Would Benefit Working Mothers" (Washington: Center for American Progress, 2018), available at <https://www.americanprogress.org/issues/women/reports/2018/05/18/450972/unequal-division-labor/>.
- 27 Missy's interview echoed this finding, noting that "finding shoes to fit is a literal nightmare" and that the only shoes that fit her toddler were expensive name-brand sneakers she would not have otherwise bought.
- 28 Missy noted, however, that although her family offered to buy equipment such as floor mats and bean bag chairs to allow her child to participate more fully in child care activities, their center ultimately deemed these as potential tripping hazards for other children. This illustrates the type of considerations and trade-offs child care programs face.
- 29 Rasheed Malik, "Working Families Are Spending Big Money on Child Care" (Washington: Center for American Progress, 2019), available at <https://www.americanprogress.org/issues/early-childhood/reports/2019/06/20/471141/working-families-spending-big-money-child-care/>.
- 30 Rebecca Ullrich, Stephanie Schmit, and Ruth Cosse, "Inequitable Access to Child Care Subsidies" (Washington: Center for Law and Social Policy, 2019), available at [https://www.clasp.org/sites/default/files/publications/2019/04/2019\\_inequitableaccess.pdf](https://www.clasp.org/sites/default/files/publications/2019/04/2019_inequitableaccess.pdf).
- 31 Child Care for Working Families Act, S. 568, 116th Cong., 1st sess. (February 26, 2019), available at <https://www.congress.gov/bill/116th-congress/senate-bill/568/text>.
- 32 Ibid. Importantly, early intervention services for infants and toddlers can currently be delivered in child care settings, but not all programs support this. The Child Care for Working Families Act would create a dedicated funding stream to deliver early intervention in these settings.
- 33 Ibid.
- 34 Ibid.
- 35 Funding Early Childhood is the Right IDEA Act, H.R. 4107, 116th Cong., 1st sess. (July 30, 2019), available at <https://www.congress.gov/bill/116th-congress/house-bill/4107>; Dragoo, "The Individuals with Disabilities Education Act (IDEA) Funding."
- 36 First Five Years Fund, "IDEA Early Intervention and Pre-school Programs," July 29, 2019, available at <https://www.ffyf.org/idea-early-intervention-and-preschool-programs/>.
- 37 Diana Boesch, "Paid Family and Medical Leave Must Be Comprehensive to Help Workers and Their Children" (Washington: Center for American Progress, 2019), available at <https://www.americanprogress.org/issues/women/reports/2019/07/16/472026/paid-family-medical-leave-must-comprehensive-help-workers-children/>.
- 38 Elizabeth Washbrook and others, "Public Policies, Women's Employment after Childbearing, and Child Well-Being," *The B.E. Journal of Economic Analysis & Policy* 11 (1) (2011): 1–42, available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3769194/pdf/nihms474288.pdf>; Charles L. Baum II and Christopher J. Ruhm, "The Effects of Paid Family Leave in California on Labor Market Outcomes," *Journal of Policy Analysis and Management* 35 (2) (2016): 333–356, available at <https://onlinelibrary.wiley.com/doi/abs/10.1002/pam.21894>.
- 39 Healthy Families Act, S. Res. 840, 116th Cong., 1st sess. (March 14, 2019), available at <https://www.congress.gov/bill/116th-congress/senate-bill/840>.
- 40 FAMILY Act, S. 337, 115th Cong., 1st sess. (February 7, 2017), available at <https://www.congress.gov/bill/115th-congress/senate-bill/337>; Jane Farrell and Sarah Jane Glynn, "The FAMILY Act: Facts and Frequently Asked Questions" (Washington: Center for American Progress, 2013), available at <https://www.americanprogress.org/issues/economy/reports/2013/12/12/81037/the-family-act-facts-and-frequently-asked-questions/>.
- 41 Katherine Gallagher Robbins and Shirin Arslan, "Schedules That Work for Working Families," Center for American Progress, December 18, 2017, available at <https://www.americanprogress.org/issues/poverty/news/2017/12/18/444245/schedules-work-working-families/>; Schedules That Work Act, H. R. 5004, 116th Cong., 1st sess. (November 8, 2019), available at <https://www.congress.gov/bill/116th-congress/house-bill/5004?s=3&r=4>.
- 42 National Center for Education Statistics, "2016 National Household Education Survey: Early Childhood Program Participation Survey" (Washington: U.S. Department of Education, 2018), available at <https://nces.ed.gov/nhes/dataproducts.asp#2016dp>.

43 2016–2018 data are from the U.S. Census Bureau, “NSCH Data,” available at <https://www.census.gov/programs-surveys/nsch/data.html> (last accessed January 2020).

44 Health Resources and Services Administration, “Data Users: Frequently Asked Questions: 2018 National Survey of Children’s Health,” available at <https://mchb.hrsa.gov/data/national-surveys/data-user> (last accessed January 2020).

45 U.S. Census Bureau, “2018 National Survey of Children’s Health: Guide to Multi-Year Estimates” (Washington: U.S. Department of Commerce, 2019), available at <https://www2.census.gov/programs-surveys/nsch/technical-documentation/methodology/NSCH-Guide-to-Multi-Year-Estimates.pdf>.

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