

The child care crisis disproportionately affects children with disabilities ^[1]

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Excerpted from introduction

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.¹ 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.² 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.³ This lack of investment in child care, coupled with poor oversight and enforcement of antidiscrimination 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.

Region: United States ^[3]

Tags: inclusion ^[4]

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