



# SUPPORT SYSTEMS & STRESSORS OF PARENTS/CAREGIVERS OF CHILDREN WITH INTELLECTUAL & DEVELOPMENTAL DISABILITIES

Ann M. Nguyen, PhD, MPH • Jolene Chou, MPH • Jennifer Farnham, MS

## Key Findings

- Over one-third of NJ parents/caregivers reported **feeling lonely and having an insufficient support system**.
- Nearly one-third reported **depression and anxiety**.
- Over one-third experienced **food insecurity**.
- They were **more likely to have all these stressors** compared to parents/caregivers statewide.
- Most felt **very safe** where they lived.

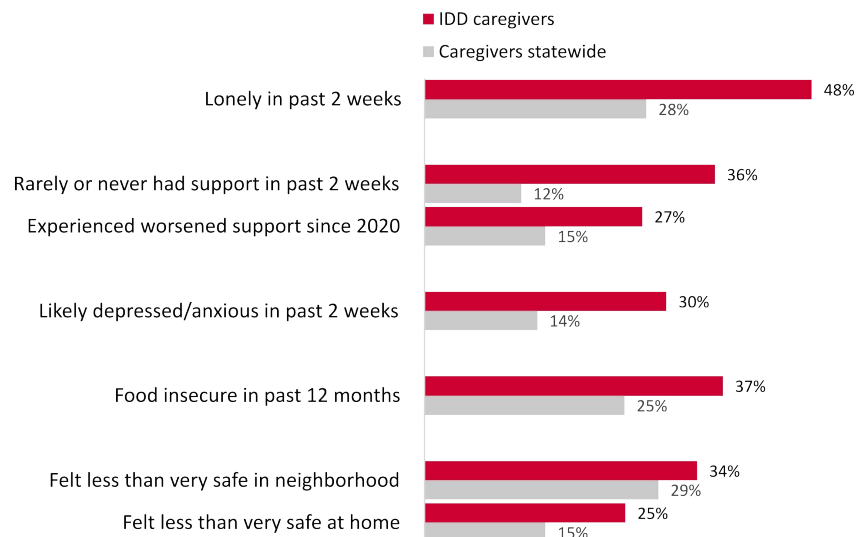
Caring for a child with an intellectual and/or developmental disability (IDD), such as autism spectrum disorder or Down syndrome, can be stressful. Evidence shows that parents and caregivers of children with IDD have higher rates of stress, anxiety, and depression compared to other parents.<sup>1,2</sup>

For these families, stressors heightened during the COVID-19 pandemic, especially in marginalized communities.<sup>3</sup> This Facts & Findings examines the support systems and stressors of parents/caregivers of children with IDD in New Jersey (referred to as “IDD caregivers”) based on 901 respondents to the

Department of Children and Families’ Family Strengths Survey: Caregivers of Children with IDD. To help contextualize findings, responses were compared to caregivers in a 2021 statewide survey of parents/caregivers (referred to as “caregivers statewide”). See Figure 1.

**Many IDD caregivers are caring for more than one child at home**, juggling many household responsibilities and changes throughout the pandemic. Over two-thirds of the IDD caregivers have at least two children in their household, and 20% of respondents have more than one child with IDD.

**Figure 1. Caregiver stressors examined in this report (n=901)**



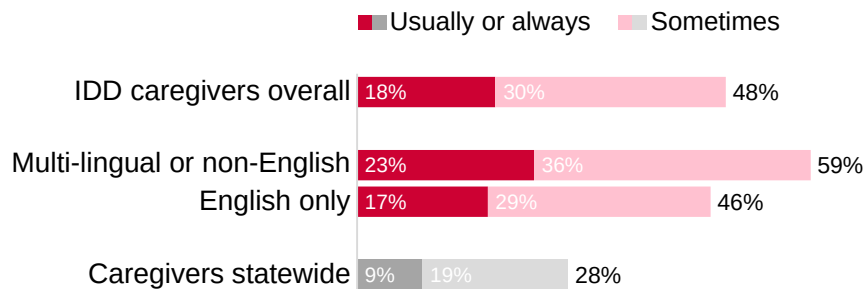
**Source.** Authors' analysis of (1) Department of Children and Families' 2023 Family Strengths Survey: Caregivers of Children with IDD & (2) 2021 Family Strengths Survey: New Jersey Parents and Caregivers.

**One in 5 IDD caregivers experienced loneliness**, having felt “usually” or “always” lonely within the past 2 weeks. They were more likely to report feeling lonely at least sometimes compared to caregivers statewide (48% vs. 28%). See Figure 2.

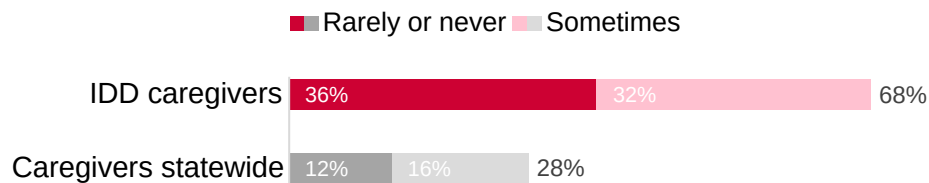
Language barriers may have exacerbated the sense of loneliness: 59% who are multi-lingual or whose primary language is not English reported feeling lonely in the past 2 weeks. They were more likely to feel lonely at least sometimes compared to English-only IDD caregivers.

**Furthermore, over one-third (36%) of IDD caregivers experienced inadequate social support.** They were much less likely to feel socially supported at least sometimes in the past 2 weeks than caregivers statewide (12%) and more likely to report that this support has worsened since 2020 (27% vs. 15%). See Figures 3 and 4.

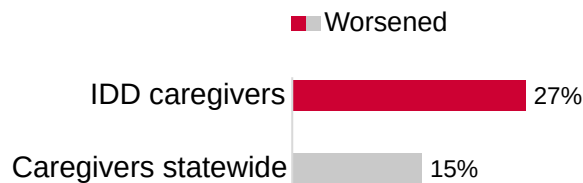
**Figure 2. "Over the past 2 weeks, how often have you felt lonely?" (n=901)**



**Figure 3. "In the last two weeks, when you felt overwhelmed or stressed when caring for or making decisions about the child(ren) in your household, how often did you get the support you needed?" (n=901)**



**Figure 4. Sense of support worsened since March 2020 (n=901)**



**Note.** Measure constructed by comparing the reported level of support "in the last two weeks" vs. "prior to March 2020." **Source.** Authors' analysis of (1) Department of Children and Families' 2023 Family Strengths Survey: Caregivers of Children with IDD & (2) 2021 Family Strengths Survey: New Jersey Parents and Caregivers.

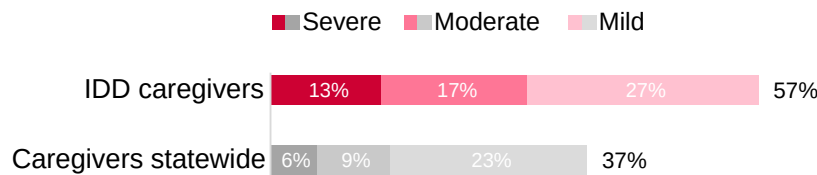
**Depression and anxiety symptoms were prevalent.** About 30% of IDD caregivers reported moderate to severe signs of depression and/or anxiety on the PHQ-4 scale. IDD caregivers were more likely to be depressed and/or anxious than caregivers statewide (15%). See Figure 5.

**Food insecurity was experienced by 37% of the IDD caregivers,** with 12% who reported being “often insecure.” Food insecurity was more common among IDD caregivers than caregivers statewide (25%). See Figure 6.

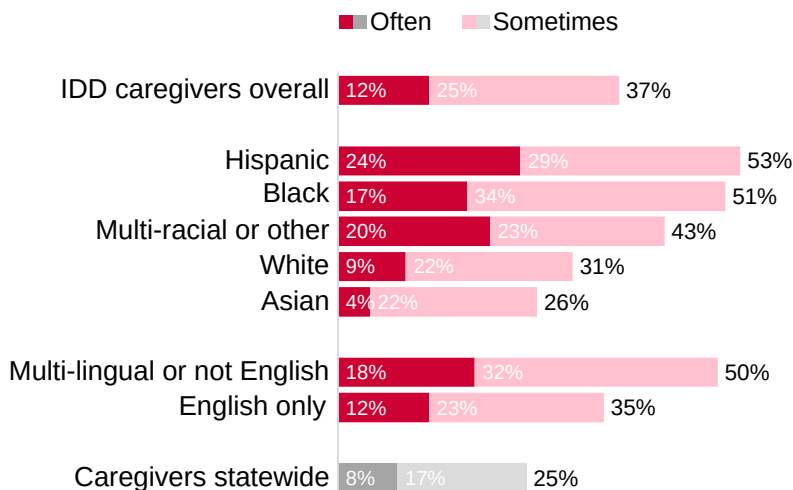
**The experience of food insecurity varied by race/ethnicity and primary language in the household.** Food insecurity was highest among Hispanic (53%) and Black (51%) IDD caregivers compared to White (31%) and Asian (26%); respondents identifying as multi-racial or other fell somewhere in between (43%).

Half of IDD caregivers who are multi-lingual or whose primary language is not English reported food insecurity at least some of the time. They were also more likely to report food insecurity than respondents who spoke only English (35%).

**Figure 5. Depression and anxiety symptoms based on Patient Health Questionnaire-4 (PHQ-4) (n=901)**



**Figure 6. "Within the past 12 months, how often do you 1) worry that your food would run out before you got money to buy more, or 2) feel the food you bought just didn't last and you didn't have money to get more?" (n=901)**

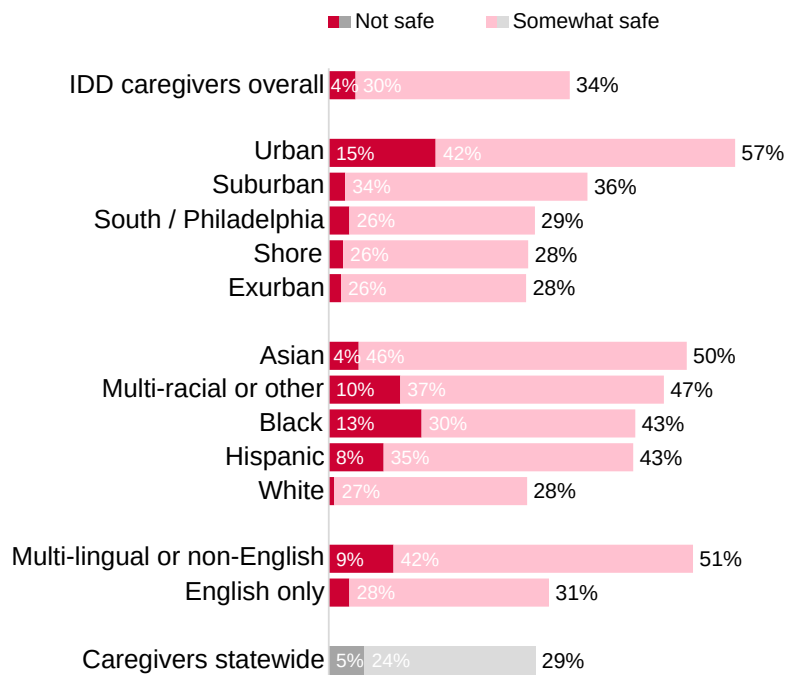


**Note.** For Figure 5, the PHQ-4 has a total score range of 0-12, i.e., Severe (9-12), Moderate (6-8), Mild (3-5), and Normal (0-2). For Figure 6, two survey questions were combined. If the caregiver gave 2 different responses, the higher level of the two was used. **Source.** Authors' analysis of (1) Department of Children and Families' 2023 Family Strengths Survey: Caregivers of Children with IDD & (2) 2021 Family Strengths Survey: New Jersey Parents and Caregivers.

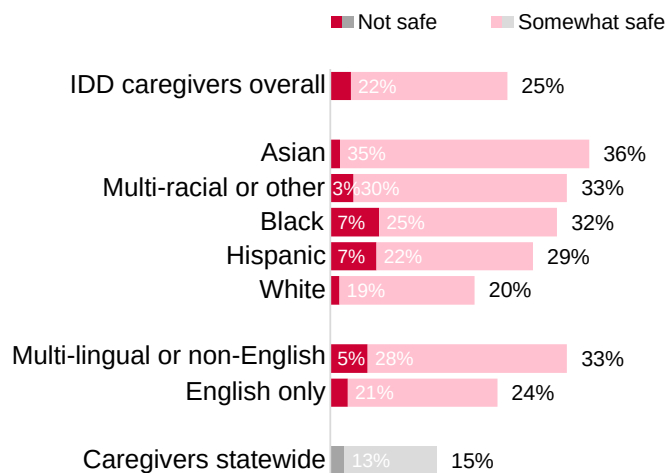
While large majorities of IDD caregivers reported feeling very safe in their neighborhood (66%) and at home (75%), these were less than caregivers statewide (71% and 85%, respectively). **Reported safety varied by region, race/ethnicity, and primary language in the household.** Only 42% of urban residing (Essex and Hudson County) IDD

caregivers reported feeling “very safe” in their neighborhood. Non-White IDD caregivers were less likely to feel “very safe” in their neighborhood and at home. IDD caregivers who are multi-lingual or whose primary language is not English were also less likely to feel “very safe” in their neighborhood and home. See Figures 7 and 8.

**Figure 7. "Overall, how safe do you feel in your neighborhood?" (n=901)**



**Figure 8. "Overall, how safe do you feel in your home?" (n=901)**



**Note.** Urban (Essex, Hudson County); Suburban (Bergen, Mercer, Middlesex, Passaic, Union); Exurban (Hunterdon, Morris, Somerset, Sussex, Warren); South/Philadelphia (Burlington, Camden, Cape May, Cumberland, Gloucester, Salem); Shore (Atlantic, Monmouth, Ocean). **Source.** Authors' analysis of (1) Department of Children and Families' 2023 Family Strengths Survey: Caregivers of Children with IDD & (2) 2021 Family Strengths Survey: New Jersey Parents and Caregivers.

## How the Survey Was Conducted

The Family Strengths Survey: Caregivers of Children with IDD was designed and analyzed by researchers at the Rutgers Center for State Health Policy.

The Eagleton Center for Public Interest Polling conducted the surveys in English via web from November 17, 2022 to October 20, 2023 with a nonprobability sample of 901 New Jersey adults, 18 or older, who are a parent, caregiver, or guardian to a child or young adult (age 0-22) with an intellectual and/or developmental disability.

This survey included 837 adults reached via emails provided by the Department of Children and Families and 64 adults reached through an anonymous link distributed by the Department of Children and Families and their partners. Survey responses were not weighted and are not necessarily generalizable to the state. Findings may be used to inform program planning.

Where feasible, findings were compared to the 2021 Family Strengths Survey: New Jersey Parents and Caregivers, which consisted of 1,449 caregivers weighted to be representative of the non-institutionalized parent population statewide. Findings were stratified by geographic region, race/ethnicity, primary language in the household (English only vs. multi-lingual or non-English), and receipt of Children's System of Care (CSOC) services.

It should also be noted that respondents to the IDD survey were slightly less diverse, older, and more educated than caregivers in the NJ statewide survey. Complete tabulations of survey results are provided in the [online appendix](#).

## About the Family Strengths Survey

Support for the Family Strengths Survey series was provided by the New Jersey Department of Children and Families (NJDCF, [nj.gov/dcf](http://nj.gov/dcf)). Rutgers Center for State Health Policy ([cshp.rutgers.edu](http://cshp.rutgers.edu)) designed and conducted the survey as part of its mission to inform, support, and stimulate sound and creative state health policy in New Jersey and around the nation.

Jennifer Farnham, MS, leads the Family Strengths Survey series; Rutgers Eagleton Center for Public Interest Polling and NJDCF also contributed to the survey's design. This Facts & Findings was prepared by CSHP Senior Research Analyst Jolene Chou, MPH, Jennifer Farnham, MS, and Ann M. Nguyen, PhD, MPH. Additional input was provided by John Palatucci, PhD, MPA. The views expressed in this Facts & Findings are solely those of the authors and do not necessarily reflect the views of NJDCF.

## References

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@RutgersCSHP

[www.cshp.rutgers.edu](http://www.cshp.rutgers.edu)  
[info@cshp.rutgers.edu](mailto:info@cshp.rutgers.edu)

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