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HEALTH & HEALTH CARE ACCESS OF CHILDREN WITH INELLECTUAL & DEVELOPMENTAL DISABILITIES

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Key Findings

- Almost **60% of children with IDD** had reported **health of "very good" or "excellent."**
- Some children with IDD **(11%) cannot get access to needed mental health care**.
- **Half reported access challenges for mental health** care and care services in general.
- **Most have contacted CSOC**, and **58% of them have received services**.
- For those who received **CSOC services**, a majority found these services **well-designed and are satisfied**.

Children and youths with intellectual and development disabilities (IDD) are a large and growing population,[1] who often have higher prevalence of chronic conditions[2] and mental health needs[3] than typically developing children. The COVID-19 pandemic created numerous health care challenges for children across the U.S., including a disproportionate impact on children with IDD.[1]

The State of New Jersey offers an array of health services for children with IDD through its Children's System of Care (CSOC). It is important to examine the health of children with IDD – in light of the direct and indirect effects of the pandemic – to ensure service needs are met and gaps closed.

This Facts & Findings describes the health and health care access of 1,110 children with IDD in New Jersey based on web survey responses to the Department of Children and Families' Family Strengths Survey: Caregivers of Children with IDD. Compared to the National Survey of Children's Health, this survey sample appeared to have worse health and less access to health care than the child population in New Jersey.[4]

Despite the adverse effects of the pandemic on children across New Jersey, **the majority of children with IDD were in "very good" (38%) or "excellent" (21%) health in 2023,** as reported by their parents and caregivers. See Figure 1a.

About 1 in 10, however, were in "fair" or "poor" health, indicating that there are opportunities to improve access to services for children with IDD.

Nearly half of children with IDD "always" or "usually" had difficulties with daily activities. For over one-third (37%) of children with IDD, this adversity had "a great deal" of impact on their ability to do things that other children their age can do. See Figures 1b-c.

Figure 1a. **"In general, how would you describe this child's health?" (n=1,110)**

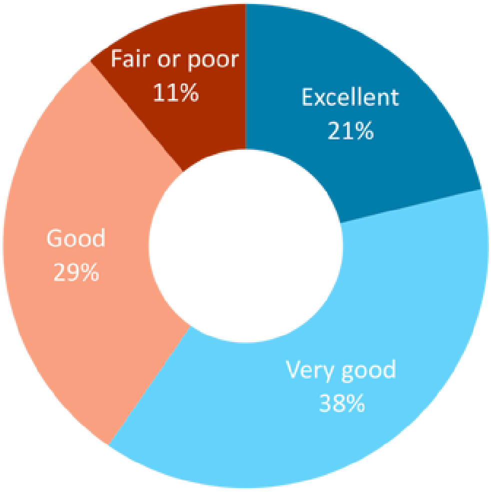


Figure 1b. **"During the past 12 months, how often have this child's health conditions or problems affected his or her ability to do things other children his or her age do?" (n=1,110)**

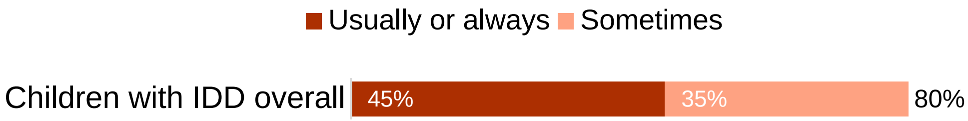


Figure 1c. **"To what extent do this child's health conditions or problems affect his or her ability to do things?" (n=1,110)**

Note. Figure 1a values do not add up to 100% due to rounding. **Source.** Authors' analysis of the Department of Children and Families' 2023 Family Strengths Survey: Caregivers of Children with IDD.

About half of the children with IDD had trouble getting access to care. 22% reported they are "always" frustrated with getting access to services in the past year, and another 23% reported being "usually" frustrated. See Figure 2a.

Access to mental health care was particularly challenging for children with IDD. One out of 10 could not get mental health care even though they needed it. Among those who needed mental health care, 42% said that it was "very difficult" to "impossible" to get treatment. See Figures 2b-c.

There was some variation in access to mental health care by household primary language and region. Those in multi-lingual or non-English households were nearly twice as likely to report not receiving but needing mental health care compared to primarily English-speaking households. See Figure 2b.

About half of those living in the Exurban (Hunterdon, Morris, Somerset, Sussex, and Warren County) and South/Philadelphia (Burlington, Camden, Cape May, Cumberland, Gloucester, and Salem County) regions said it was "very difficult" or "impossible" to get mental health care. See Figure 2c.

Figure 2a. **"During the past 12 months, how often were you frustrated in your efforts to get services for this child?" (n=1,110)**

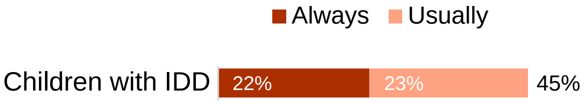


Figure 2b. **"During the past 12 months, has this child received any treatment or counseling from a mental health professional?" (n=1,110)**

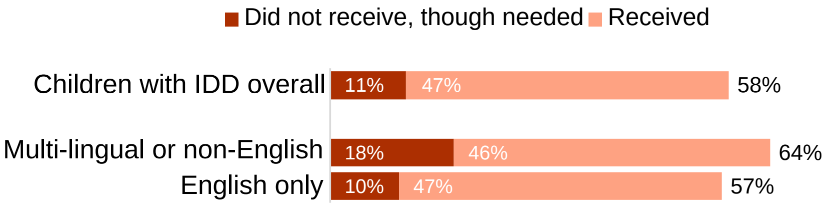
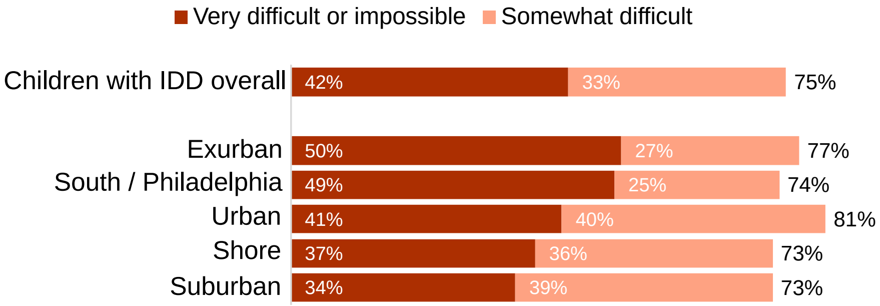


Figure 2c. **Among those who received or needed treatment (n=646): "How difficult was it to get the mental health treatment or counseling that this child needed?"**



Note. Mental health professionals include psychiatrists, psychologists, psychiatric nurses, and clinical social workers. 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 the Department of Children and Families' 2023 Family Strengths Survey: Caregivers of Children with IDD.

CSOC is a readily available and valued source of care for many children with IDD. It was reported that most (83%) of the children with IDD had contact with the Children's System of Care (CSOC).

Among those who contacted CSOC, over half (58%) received CSOC services. Notably, contact with CSOC could mean a number of things, including contacting CSOC for information only. See Figure 3a.

Access to CSOC services is not equal across the regions, however. Urban-residing children (Essex and Hudson County) report the lowest levels of receiving CSOC services.

Among those who received CSOC services, a large majority found these services well-designed at least some of the time (86%) and are at least somewhat satisfied (76%). Opportunities remain to continue enhancing the reach and quality of these services. See Figures 3b-c.

Figure 3a. Among those age 3-22 and who had contact with CSOC (n=907): "We received one or more therapeutic services (mobile crisis visit, other services), respite services, or financial support for camp."

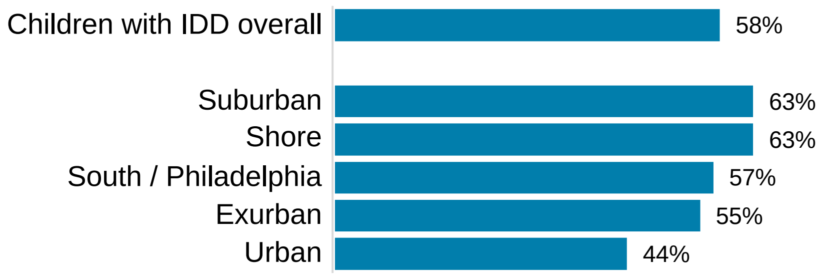


Figure 3b. Among those who received CSOC services (n=526): "How often have CSOC/PerformCare's services been well-designed to meet the needs of your child?"

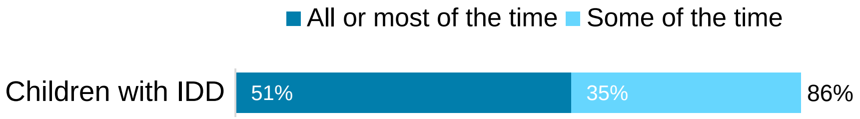
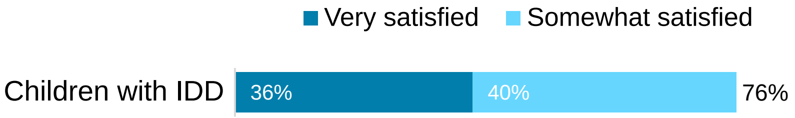


Figure 3c. "Overall, how satisfied are you with CSOC/PerformCare?" (n=1,110)



Note. Contact with CSOC could mean a number of things, including contacting CSOC for information only. Additional analyses found that mental and social well-being is similar between caregivers who received CSOC services and those who did not. 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 the Department of Children and Families' 2023 Family Strengths Survey: Caregivers of Children with IDD.

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.

The 901 survey respondents answered reported on the health and health care access of 1,110 children with IDD. Survey responses were not weighted and are not necessarily generalizable to the state. Findings may be used to inform program planning.

Findings were stratified by geographic region, race/ethnicity (using the parent/caregiver's race/ethnicity, which has limitations), primary language in the household (English only vs. multi-lingual or non-English), and receipt of Children's System of Care (CSOC) services.

Small numbers made some stratifications not possible or unstable. 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). Rutgers Center for State Health Policy (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.

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