Utilization of and Experience with Respite Care Among Families with Children with IDD

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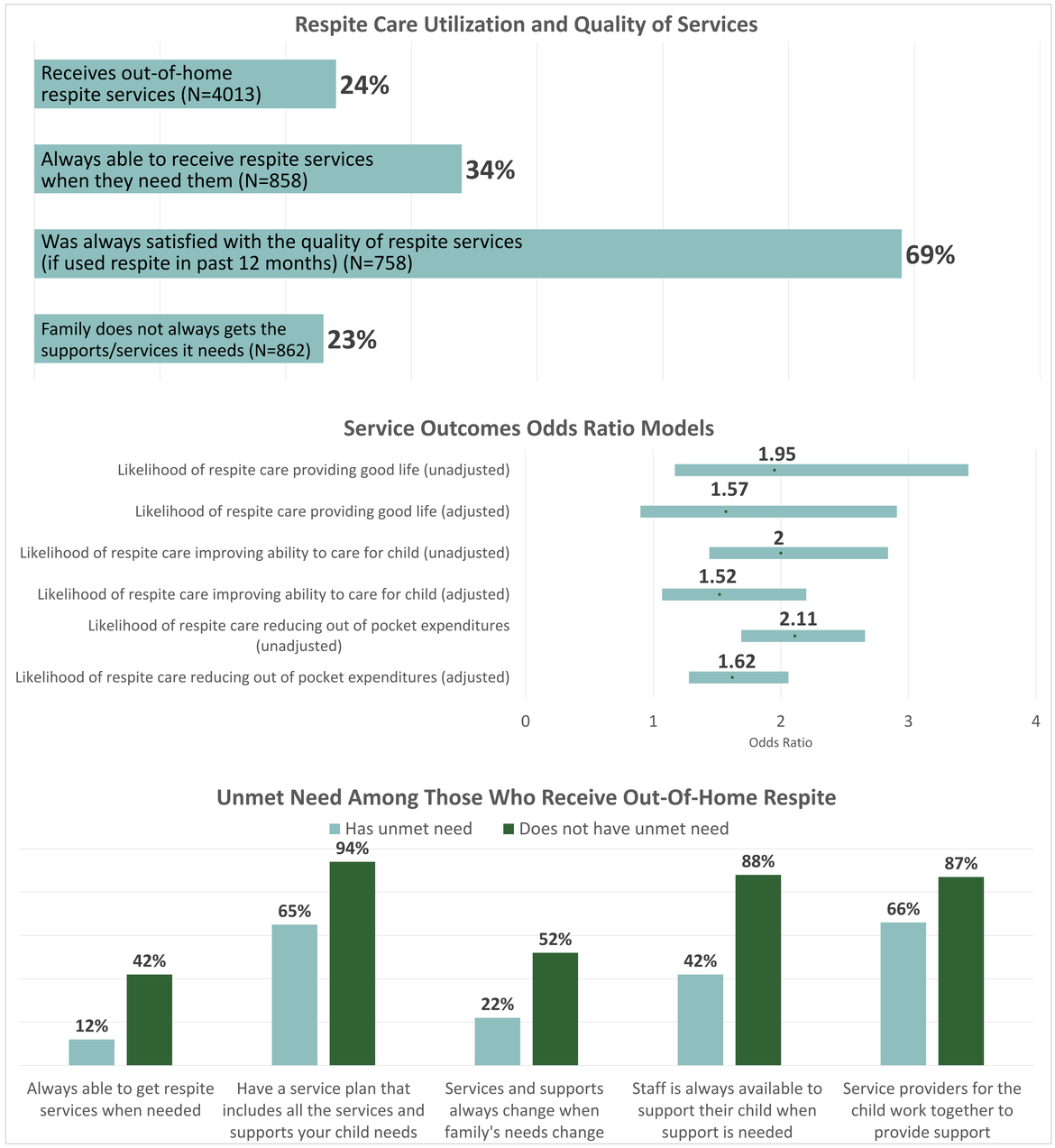
Introduction

- Respite care, usually a temporary service that provides short term relief for family members, is an invaluable service for many families. An upwards of 59 million family caregivers in the United States provide for adults and children with disabilities, providing over 1 trillion dollars of unpaid care.
- Often delivered in home or facility-based setting, respite care for families with children can look like recreational camps
- Respite care has been shown to improve family caregivers' quality of life, societal outcomes, and reduce costs of care.
- However, access to respite care can vary depending on various state policies and payment rates
- The National Core Indicators – Intellectual and Developmental Disability (NCI-IDD) Child Family Survey (CFS) is a survey tool to establish a set of performance and outcome indicators for disability service systems with results and national benchmarks of system level performance reported annually
- **We utilize the CFS data to identify trends, outcomes, and areas of improvement for respite care in LTSS services accessed amongst families with children with intellectual/developmental disabilities (I/DD).**

Methods

- **The NCI-IDD CFS 2024-25 data includes 4,113 respondents from ten states;** each state drew from a random sample of at least 1000 families who had a child with an IDD living in the home and received at least one service
- Respondents indicated whether they receive out-of-home respite as part of their state funded DD services
- In addition to looking at rates of utilization of respite services, we used bivariate associations to examine the relationship between respite and outcomes in satisfaction, quality of life, and expenditures
- Logistic regression models analyzed the associations in service outcomes and utilization of respite care while controlling for age, income, education, level of support needs, and if caregiver or another family member are paid to provide support
- Finally, areas of improvement were identified for accessing and utilization of respite services, service planning, and coordination for those who reported unmet respite care despite receiving out-of-home respite services

Results



Discussion

- Overall, 24% (N = 4,013) of people report receiving out of home respite care as a service/support received from the ID/DD State Agency
- Of those receiving out-home respite care services, 34% (N = 858) are always able to receive respite services when needed and 69% (N = 758) report they were always satisfied with the quality of respite services
- **Those who receive out of home respite care services reported were:**
  - **Significantly more likely to report that services and supports are improving the ability to care for their child (aOR =1.52, CI [1.07-2.2])**
  - **Significantly more likely to report that services and supports reduced their family's out-of-pocket expenses for their child's care (aOR = 1.63, CI [1.28,2.06])**
  - No significant differences between likelihood that services and supports are helping their child live a good life (aOR = 1.57, CI [0.90,2.91])
- **Despite this, of those receiving out-of-home respite care, 23% (N=862) still do not get the supports and services they need**
- Out of those who report receiving out-of-home respite care but also unmet need, 57% (N = 202) still needed additional respite care
- Families that receive respite services but have unmet need compared to those that don't have unmet need report significantly lower rates of having a service plan that includes all services and supports, always being able to get respite services, have staff available to support their child when needed, or service providers work together to provide support

Conclusions and Future Directions

- CFS data continues to demonstrate that providing respite care for family caregivers can be a reliable way to improve children's quality of life, improve family member's ability to provide care, and reduce out of pocket expenses.
- However, it also suggests that even amongst those that access respite care, some are still not getting adequate supports
- This study also points at further considerations for quality improvement as states seek ways to reduce Medicaid-funded supports

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