Stories of Strength and Strain: Exploring Caregiver Burnout to Enhance Care for People Navigating Intellectual and Developmental Disabilities at CA-START San Diego

INTRODUCTION

Caregivers supporting people with intellectual and developmental disabilities (IDD) and co-occurring mental health conditions frequently encounter high levels of stress that can lead to burnout. The emotional, physical, and financial toll of caregiving effects not only caregivers' well-being but also the care they provide. We know that caregiver burnout exists across the board when it comes to caregivers of people navigating IDD. If caregivers are impacted, those they care for are impacted. Therefore, by identifying and addressing caregiver burnout, we can enhance the entire system of care. The extent to which we pinpoint how various factors contribute to their burnout in an effort to find targeted supports based on their specific caregiver burnout profile is critical. Research demonstrates that unmanaged caregiver burnout has significant implications for both caregivers and the people they support, particularly people navigating IDD. Chronic stress can lead caregivers to provide inconsistent and less effective care due to emotional exhaustion, physical fatigue, and systemic barriers. This decline in caregiving quality not only affects the caregivers' well-being but also leads to adverse outcomes for people with IDD, including delayed developmental milestones, increased presenting challenges, and reduced engagement in therapeutic activities (Hastings et al., 2016). Addressing the factors that drive burnout is an essential part of creating sustainable caregiving environments and protecting the long-term well-being of people with dual diagnoses. This study investigates burnout factors among caregivers engaged in the CA-START San Diego program, which supports people navigating dual IDD and mental health diagnoses. Using survey insights, this research aims to unpack the contributors to caregiver burnout, with an emphasis on actionable strategies and targeted interventions that can alleviate their experiences and improve the overall system of care. By analyzing caregiver profiles and identifying high-impact stressors, this study seeks to inform solutions that enhance the caregiving dynamic, safeguard the well-being of people with IDD and mental health needs, and build a more responsive, effective support system.

REVIEW OF THE LITERATURE

Caregivers often experience high levels of emotional exhaustion, particularly when supporting people with dual diagnoses. Research by Zuna et al. (2020) revealed that caregivers managing both IDD and mental health conditions face heightened levels of anxiety and depression compared to those caring for people with IDD alone. This emotional strain stems from the constant demands of providing care, managing complex presentations, and navigating fragmented systems.

The physical burden of caregiving includes assisting with daily activities, managing crises, and maintaining a vigilant presence. Dhiman et al. (2023) found that caregivers of people with dual diagnoses reported significantly higher rates of stress-related physical health issues, such as sleep disturbances and cardiovascular problems. These physical demands compound the emotional toll, increasing the risk of long-term health consequences.

Financial challenges are a leading source of stress for caregivers. Many incur out-of-pocket expenses for therapies, equipment, and other critical services. Research by Chou et al. (2009) highlighted reduced employment opportunities among caregivers, while Baumgartner et al. (2022) identified the prevalence of financial hardship, including difficulty affording essential services like respite care and transportation.

The complexity of navigating service systems is a significant stressor. Caregivers often describe their frustration with delays, limited access to resources, and the lack of coordination between providers. Burke and Heller (2021) noted systemic gaps that exacerbate stress, such as the limited availability of respite care and inadequate crisis management supports.

Caregivers frequently manage crises involving self-harm, aggression, or other severe presenting challenges. Thompson et al. (2024) demonstrated how these high-intensity situations contribute to emotional exhaustion and secondary trauma. The irregular nature of crises often leaves caregivers feeling ill-equipped and unsupported.
Direct support professionals face distinct challenges that include maintaining professional boundaries, managing documentation, and dealing with work-life imbalance. Research by Chung et al. (2022) highlighted low wages, insufficient training, and the emotional demands of caregiving as contributing factors to high turnover rates and burnout among paid caregivers.

Caregivers from culturally diverse backgrounds face unique stressors, including language barriers and cultural stigmas surrounding disabilities and mental health. Martinez-Leal et al. (2022) emphasized the importance of culturally responsive services, noting that unmet cultural needs often intensify caregiver burdens.

Research Questions: 1. What are the most impactful factors contributing to caregiver burnout for both paid and natural caregivers within the CA-START San Diego program? **2.** How do these factors differ between paid caregivers and natural supports? **3.** What specific challenges reported by caregivers point to unmet needs or highlight areas for intervention?

METHODOLOGY

Participant Recruitment and Survey Design

A total of 31 caregivers participated in the study, including 28 natural supports (family members) and 3 paid caregivers. Recruitment was conducted via email invitations sent to primary caregivers of enrolled in the CA-START San Diego program. These caregivers provided care to managing dual IDD and mental health diagnoses.

Two data collection tools were utilized:

1. **Quantitative Component**:
    - A 37-item, literature-informed survey was designed to measure contributors to caregiver burnout, including emotional strain, physical fatigue, financial challenges, and systemic barriers.
    - Caregivers rated each factor's impact on a 0–3 Likert scale, with higher scores reflecting greater impact.
2. **Qualitative Component**:
    - Open-ended questions were included to capture deeper insights into factors contributing to caregiver burnout that were not explicitly covered in the survey. These responses provided rich, qualitative data about systemic barriers, unmet needs, and opportunities for improvement.

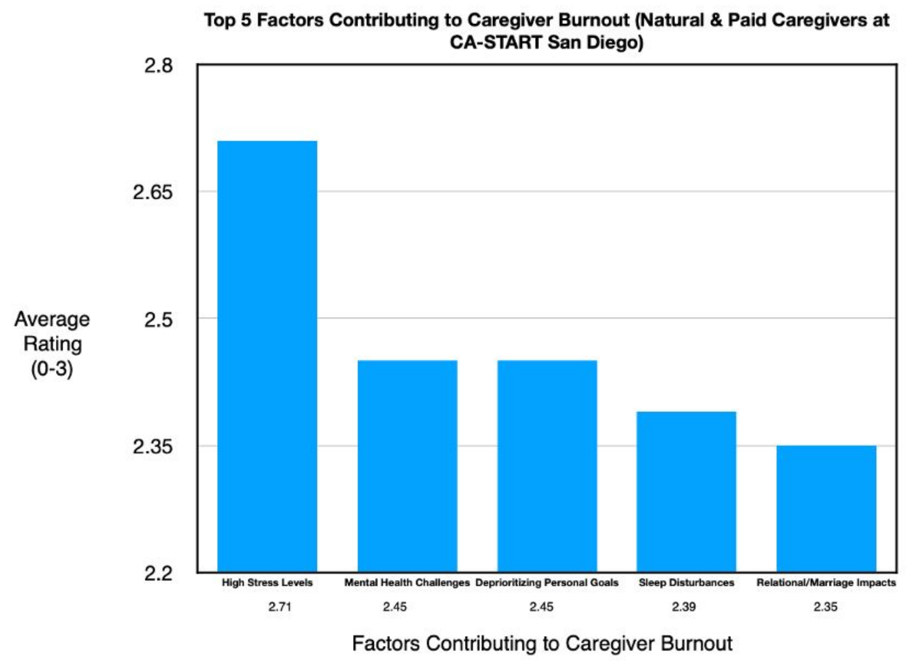
Additionally, the Family Experiences Interview Schedule (FEIS) was utilized to gain further understanding of caregiver interactions with service systems, focusing on identifying systemic barriers and exploring opportunities for enhanced support.

Data Analysis

-Quantitative data was analyzed using descriptive statistics to identify the prevalence and intensity of key burnout factors. Comparative analyses were conducted to assess differences between responses from natural supports and paid caregivers.

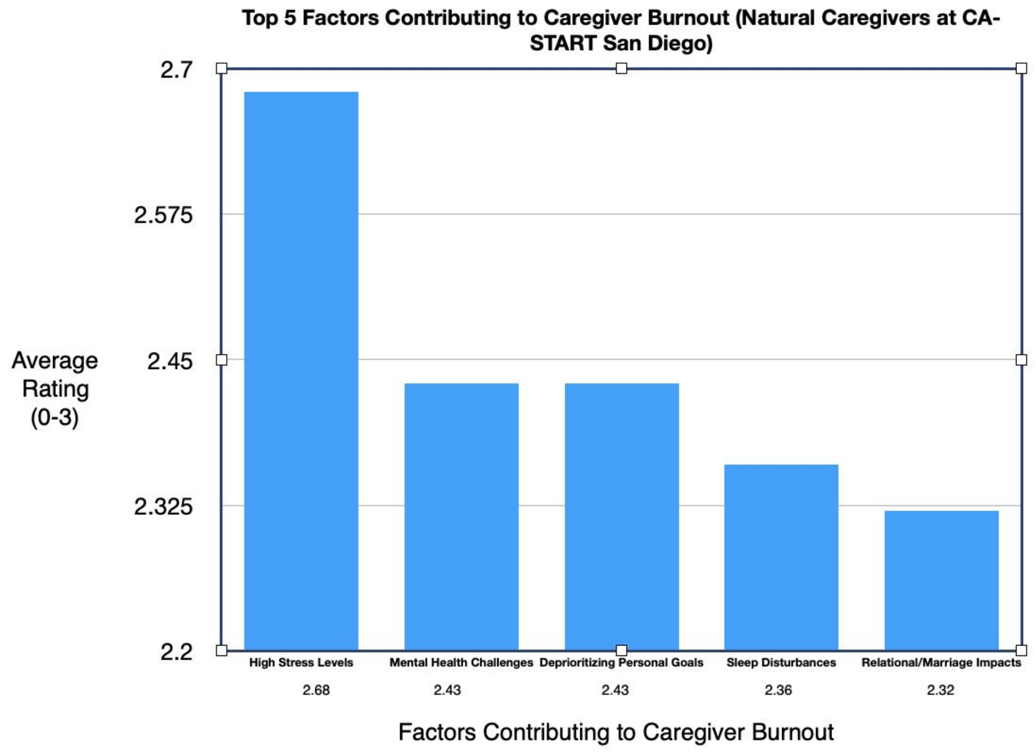
-Qualitative data, particularly from the FEIS and open-ended responses, underwent thematic coding. This process involved reviewing caregiver narratives to extract recurring themes, which were then categorized into overarching groups such as barriers to services, suggestions for improvement, specific needs, and positive feedback. The integration of qualitative insights with quantitative findings enabled a multidimensional perspective on caregiver burnout.

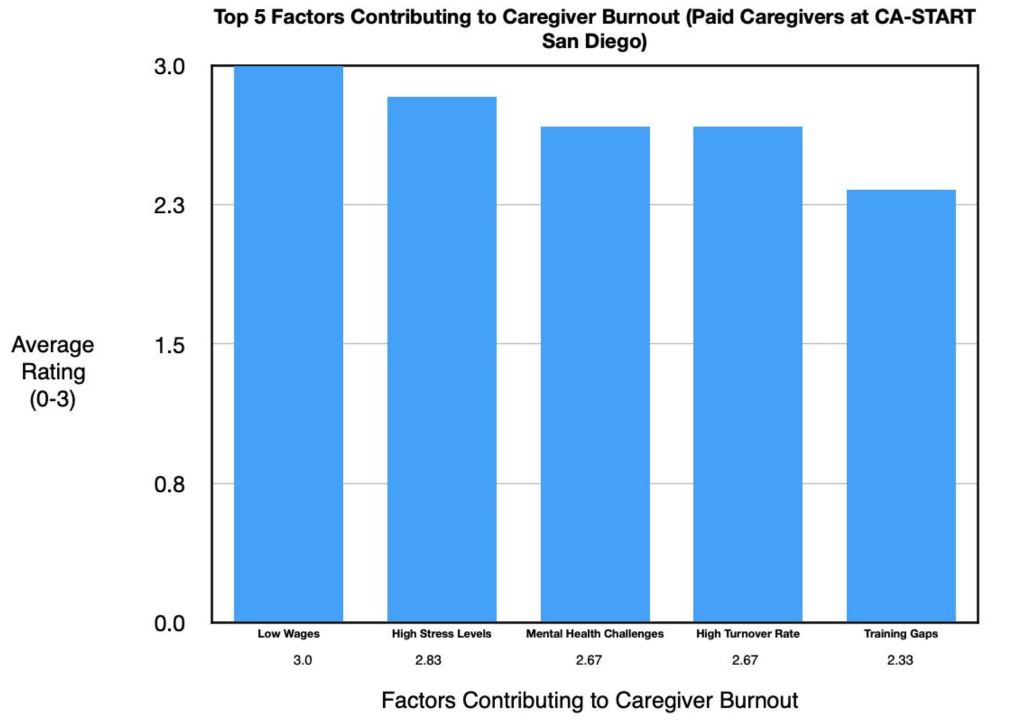
RESULTS



REFERENCES

Baumgartner, J. N., et al. (2022). Financial strain among caregivers of people with developmental disabilities: A systematic review. Journal of Applied Research in Intellectual Disabilities, 35(2), 379-393.
Burke, M. M., & Heller, T. (2021). Family caregiving of people with intellectual and developmental disabilities: Experiences with service systems. Research in Developmental Disabilities, 108, 103822.
Chung, W., et al. (2022). Understanding turnover among direct support professionals: A mixed-methods study. Intellectual and Developmental Disabilities, 60(1), 20-34.
Chou, Y. C., et al. (2009). Employment and financial burden of families with preschool children with disabilities in Taiwan. Journal of Intellectual Disability Research, 53(11), 950-961.
Dhiman, V., et al. (2023). Physical health outcomes among caregivers of people with dual diagnosis: A longitudinal study. Journal of Applied Research in Intellectual Disabilities, 36(1), 228-239.
Martinez-Leal, R., et al. (2022). Cultural competency in intellectual disability services: A qualitative study of caregiver experiences. Journal of Policy and Practice in Intellectual Disabilities, 19(1), 78-89.
Thompson, L., et al. (2024). Crisis management experiences of caregivers supporting people with intellectual disabilities and mental health needs. Journal of Mental Health Research in Intellectual Disabiliti
17(1), 1-18.
Zuna, N., et al. (2020). Mental health among caregivers of children with intellectual and developmental disabilities: A systematic review. Journal of Intellectual Disability Research, 64(8), 590-610.





Qualitative Insights on Caregiver Burnout (Open-Ended Survey Responses)

(The open-ended survey responses specifically explored additional factors contributing to caregiver burnout, providing deeper insight into their challenges and experiences).

Natural Caregivers:

- Fear for the future. *"You worry every day about what will happen to them when you're not around."*
- Emotional exhaustion from constant caregiving. *"You forget who you are outside of caring for them."*
- Social isolation due to a lack of understanding from others. *"Friends don't get it. They stop inviting you because they don't understand your life."*
- Limited access to resources, with long waitlists and few local options.

Paid Caregivers:

- Low pay and workplace instability. *"It feels like we're replaceable, not valued."*
- Insufficient training, particularly for crisis situations. *"We're expected to handle situations we haven't been trained for."*

Qualitative Insights on Caregiver Burnout (FEIS Data, Qualitative narrative responses – advice)

Systemic Barriers

-Access Challenges: Navigating services was described as draining. *"It feels like a maze. Every time you think you're making progress, a new hurdle appears."* Long wait times and a lack of specialized providers added to frustrations. *"We drive hours just to see someone who doesn't even specialize in cases like ours."*

-Crisis Response Gaps: Emergency options were seen as inadequate. *"The police are your only choice in a crisis, but they're not trained for mental health issues."* Another shared, *"The ER stabilized him and sent us home. We were left on our own, terrified about what was next."*

Cultural Challenges

-Language Barriers: Limited bilingual resources placed extra burdens on families. *"I had to rely on my teenage daughter to translate. It felt unfair to her."*

-Stereotypes and Misunderstandings: Caregivers felt judged based on race or culture. *"They see my accent and think I'm ignorant. I just want good care for my child."*

Positive Feedback

-Empathetic Support: Some caregivers praised their caseworkers. *"She treated us like we mattered. That made all the difference."*

-Effective Programs: Services that taught management strategies made a lasting impact. *"They gave us tools to manage triggers and treated my child with dignity. For the first time, I felt hope."*

-Crisis Hotlines: Many found emotional relief from helplines. *"Talking to someone at my breaking point kept me going."*

DISCUSSION, LIMITATIONS AND FUTURE RESEARCH

This study offers a comprehensive understanding of caregiver burnout by integrating findings from quantitative survey data, open-ended survey responses, and FEIS qualitative comments. It identifies systemic challenges, caregiver struggles, and actionable strategies for improvement, with explicit attribution to each data source.

Factors Implicated in Caregiver Burnout

Emotional and Physical Strain

Quantitative survey data highlighted that natural caregivers experience significant emotional and physical exhaustion, with stress levels rated 2.68/3.0, mental health challenges (2.43/3) and sleep disturbances (2.36). Deprioritization of personal goals was rated very highly (2.43/3). Open-ended survey responses echoed this reality, as one caregiver reflected, "You forget who you are outside of caring for them." The survey further revealed how caregiving often caused caregivers to reshape their priorities, with personal and professional goals deprioritized at 2.43/3.0. This sentiment was poignantly articulated in an open-ended response, "I used to want more children but it is impossible now to even imagine balancing this dream with my reality."

For paid caregivers, systemic issues emerged prominently in the quantitative survey. High turnover was rated (2.67/3) and Inadequate training was rated at 2.33/3.0, while low wages received the highest burden rating of 3.0/3.0. Open-ended survey responses added depth to these findings, as one paid caregiver shared, "We're expected to handle situations we haven't been trained for," emphasizing their perceived lack of preparation.

Systemic Barriers

FEIS qualitative comments revealed significant challenges navigating fragmented and inconsistent systems. Caregivers frequently cited frustrations with long wait times, provider shortages, and logistical hurdles. One rural caregiver shared, "We drive hours just to see someone who doesn't even specialize in cases like ours." Minority caregivers highlighted additional barriers, including language gaps and cultural insensitivity. FEIS comments included one parent's account, "I had to rely on my teenage daughter to translate during crucial meetings." Another caregiver described experiencing bias, stating, "They see my accent and think I'm ignorant. I just want good care for my child."

Gaps in Crisis Management

Both open-ended survey responses and FEIS qualitative comments emphasized severe deficiencies in crisis response systems contributing to caregiver burnout. Many caregiver respondents noted their reliance on inappropriate emergency services like the police during crises. One FEIS comment explained, "The police are your only choice in a crisis, but they're not trained for mental health issues." Another caregiver shared frustration with inadequate follow-up, stating, "The ER stabilized him and sent us home. We were left on our own, terrified about what was next."

Social Isolation and Emotional Toll

Quantitative survey data pointed to a high prevalence of social isolation among caregivers, particularly among natural caregivers. Open-ended survey responses detailed the effects of this isolation, with one caregiver stating, "I have no friends because my life is so chaotic." FEIS qualitative comments further emphasized the need for societal awareness and support, as caregivers advocated for "educating communities" to reduce stigma and foster a more inclusive environment.

Recommendations for Systemic Improvement

Based on insights across all data sources, the study suggests several strategies to address these challenges:

-Expand Respite Services – Quantitative survey data underscored the need for consistent breaks to alleviate caregiver exhaustion, while open-ended responses highlighted the toll of unrelenting, 24/7 caregiving; Support Paid Caregivers – Survey findings revealed concerns over low wages and insufficient training, with open-ended responses highlighting feelings of being undervalued and unsupported; Develop Tailored Crisis Interventions – FEIS qualitative comments stressed the importance of specialized teams equipped to manage IDD and mental health crises, reducing dependence on unsuitable emergency services like the police; Enhance Cultural Competency – FEIS insights highlighted barriers faced by minority caregivers, suggesting hiring bilingual staff, providing cultural training, and ensuring services meet diverse needs; Streamline Service Navigation – FEIS findings pointed to the need for centralized case management systems to simplify access to fragmented resources and alleviate administrative burdens on caregivers.

Limitations: 1.Sample Size and Composition 2. Geographic Specificity 3. Self-Selection Bias 4. Cross-Sectional Nature

Future Research: This data provides a vital foundation for advancing research within CA-START programs, with a primary focus on understanding caregiver burnout. Future initiatives will center on analyzing and categorizing caregiver burnout profiles to identify the distinct challenges faced by various caregiver types. The ultimate goal is to develop targeted interventions tailored to these profiles, offering precise and effective support for caregivers.

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