**Title:** Understanding Caregiver Demographics and Perceptions of Service Access: Insights from an NIH Clinical Trial for Caregivers of Children with Rare Neurogenetic Conditions

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**Introduction:** Caregivers of children with rare neurogenetic conditions (NGCs) experience high levels of stress (Kamga et al., 2020) and report difficulty accessing services that are relevant to their child’s rare condition (Kowanda et al., 2021). Caregivers of children with NGCs also often report feeling less supported than caregivers of children with more commonly occurring disabilities and feel that their own mental health suffers (Kenny et al., 2022). This study sought to describe these experiences among NGC caregivers enrolled in a clinical trial by assessing patterns of community services these caregivers receive and analyzing the degree to which caregivers found this study’s intervention approach favorable to available community services.

**Method:** Data were drawn from Project WellCAST (​​Addressing the WELLbeing of CAregiverS via Telehealth; NCT05999448; R01HD105502-01A1; PI B. Kelleher), an ongoing NIH-funded clinical trial focused on the well-being of caregivers of children with rare neurogenetic conditions (NGCs). This NIH-funded clinical trial conducts four waves. In each wave, caregivers are assigned to participate in a telehealth program (e.g. live mental health therapies, live parent-behavioral training, self-guided resources, and/or peer-to-peer support). Patterns of participant demographics, access to services, and comparison of WellCAST services to community services were described using descriptive statistics.

**Results:** The first three waves of Project WellCAST include baseline data from 346 participants. Caregivers in this sample participated from 46 different states with a mean income of $141,175. Of the 346 caregivers, 85% of them were White, 4% Black or African American, 3% Asian, 1% American Indian or Alaska Native,  and 7% Other or preferred not to describe. Around 73% of caregivers had completed either college (n=134) or graduate school (n=120). Most caregivers were married with an average of 4 family members living in their households. Children in this sample had a range of disorders, including Angelman Syndrome (n=39), Down Syndrome (n=21), Dup15q (n=21), Fragile X Syndrome (n=46), Prader Willi Syndrome (n=70), Williams Syndrome (n=40), an other syndrome (n=78), or an undisclosed diagnosis (n=32). On average, caregivers reported receiving 3 services (SD=1.53, range 1-7). When asked to select all that apply, caregivers reported to have accessed the following services in their communities: Applied Behavior Services (n=27), Occupational Therapy (n=99), Physical Therapy (n=94), Speech Therapy (n=95), General Early Intervention Services (n=104), Special Education Services (n=82), Research-based Clinical Intervention (n=13), or an Other service (n=13). Among caregivers with available outcome data (Waves I-II; Wave III being completed Fall 2024), caregivers receiving the Acceptance and Commitment Therapy, Dialectical Behavior Therapy, Naturalistic Communication Intervention, and RUBI telehealth services, on average, rated the services as better than services they are currently received, while caregivers receiving Culturally Informed Cognitive Behavior Therapy, Durand, or an assortment of resources felt that the WellCAST services were, on average, the same quality as previous services they are currently receiving. When breaking these ratings down by diagnosis category, families with children who had Angelman Syndrome, Fragile X Syndrome, Williams Syndrome, or another syndrome indicated that these services were better than previously accessed services, while families with children who had Down Syndrome, Dup15q, Prader Willi Syndrome, or an unlisted diagnosis rated these services, on average, as the same as previously accessed services.

**Discussion:** Initial results suggest that caregivers of children with NGCs who participated in the first three waves of Project WellCAST represent a wide range of child diagnoses across diverse regions of the United States. A common theme across caregivers is that they were navigating multiple services related to their child’s disability, with most caregivers reporting receiving 3 or more services. This suggests that caregivers are juggling multiple disconnected systems, which has implications for how WellCAST’s personalized health algorithm may help streamline services across systems. On average, caregivers from the first two waves in four of six active treatment arms reported that the services they received in WellCAST were *better* or *much better* than services already available to them in their communities. This finding suggests that in a sample of caregivers already navigating multiple service systems, WellCAST services were a better fit for their child with NGC. Future directions include investigating patterns of service access by family resources and child diagnosis, and factors associated with higher favorability of WellCAST services. In sum, this study is a first step toward defining how past service utilization might relate to caregivers’ experiences in online-based support programs, with the goal of informing the development of personalized health solutions that will best fit the unique needs of families.

**References:**

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