**Title**: Comparison of therapies and services utilized by children with Down syndrome with medical co-occurring conditions

**Authors**: Rebecca Bernstein1, BA; Kristine Wolter-Warmerdam1, PhD ABD, MA; Allison Meyer1,2, PhD

**Introduction**: Children with Down syndrome (DS) make up 1 out of 640 live births in the United States (CDC.gov, 2024); many of which are born with or develop to have differing levels of complex medical needs (Hickey et al., 2012). Due to this variability, many children with DS receive several types of therapeutic services and treatments that can overlap with one another. Families with children that have higher numbers of medical co-occurring conditions report difficulty managing the different services and will focus on a few areas while putting others to the side, including mental and behavioral health supports (Justin et al., 2022; Osborn, 2020; Calwell et al., 2023). Our preliminary review aims to identify the use of mental and behavioral health services for children with DS in relation to their medical diagnosis complexity and other therapies or services utilized.

**Method**: Through a retrospective review of caregiver responses from a clinic initiative survey, we analyzed data for the use of mental and behavioral health services and the impact of medical comorbidity numbers. Responses for 170 children with DS (Mean age= 9.5; male=57.1%, English speaking=78.8%; Spanish speaking=21.2%) that received care through a multidisciplinary clinic specializing in DS were reviewed. The survey asked questions on current services utilized (mental/behavioral health and medical based therapies/services), caregiver opinion on mental health, and caregiver interest in learning about mental health. Demographics and medical co-occurring conditions were merged with the results. Children with DS were classified into two groups: low level of co-occurring medical conditions (0-15.99) and high levels of co-occurring (16+) medical conditions. These groups were defined by a median split of the number medical co-occurring conditions (median=16) Frequencies are reported and chi-square tests were completed between medical co-occurring conditions and reported therapies and services from the caregiver survey.

**Results**: All participants (n=170) had at least one co-occurring medical condition identified (mean=16.02; median=16; range=3-33). Over half (51.8%) of the families reported that their child used mental or behavioral health therapies (psychological medication management, individual therapy, group therapy, or other) compared to 96.5% using other medical therapy services (applied behavior analysis, occupational therapy, physical, speech, or other). Both groups of medical co-occurring conditions reported using less mental and behavioral health therapies than other therapies and services, with the vast majority accessing one type of service alone (i.e., only psychiatric medication, only mental health intervention; high=78.4%; low=74.4%). Approximately half of the families (n=87; 51.2%) reported no prior conversation with a provider regarding their child’s mental health needs. However, 60.0% of caregivers expressed being “interested” or “very interested” in learning about mental and behavioral health, with the high medical group indicating a similar interest in comparison to the low medical group.

**Discussion:** There were no significant differences between the high and low medical complexity groups for use of mental and behavioral health services. There is an overall high interest in learning about mental and behavioral health regardless of whether families are already accessing mental and behavioral health services. However, current literature indicates that individuals with high reports of co-occurring medical conditions do have difficulties accessing care supports (Calwell et al., 2023; Osborn, 2020). Because many individuals with DS already have high medical complexity, this population may access or approach mental and behavioral health services differently. Future guidance for this focus would be to identify the barriers which families are facing in accessing behavioral and mental health services and identify if there is a connection between this and medical complexity.Data collection is ongoing.

**References:**

Caldwell, A. R., Kim, Y., Alshahwan, N., Vellody, K., Bendixen, R. M., Renz, K., ... & Must, A. (2023). Parental perception of facilitators and barriers to health among young children with down syndrome: a qualitative study. Frontiers in Pediatrics, 11, 1155850.

Hickey, F., Hickey, E., & Summar, K. L. (2012). Medical update for children with Down syndrome for the pediatrician and family practitioner. Advances in pediatrics, 59(1), 137-157.

Justin, A. Y., Bayer, N. D., Beach, S. R., Kuo, D. Z., & Houtrow, A. J. (2022). A national profile of families and caregivers of children with disabilities and/or medical complexity. Academic Pediatrics, 22(8), 1489-1498.

Kuo, D. Z., Melguizo-Castro, M., Goudie, A., Nick, T. G., Robbins, J. M., & Casey, P. H. (2015). Variation in child health care utilization by medical complexity. Maternal and child health journal, 19, 40-48.

Lee, E. Y., Neil, N., & Friesen, D. C. (2021). Support needs, coping, and stress among parents and caregivers of people with Down syndrome. Research in Developmental Disabilities, 119, 104113.

Menear, K. (2007). Parents' perceptions of health and physical activity needs of children with Down syndrome. Down Syndrome Research and Practice, 12(1), 60-68.

Osborn, R., Roberts, L., & Kneebone, I. (2020). Barriers to accessing mental health treatment for parents of children with intellectual disabilities: A preliminary study. Disability and rehabilitation, 42(16), 2311-2317.

Sie Center for Down Syndrome, Children’s Hospital Colorado

2 University of Colorado School of Medicine, Department of Pediatrics