

# Development and Validation of the Facilitators and Barriers to Health for Young Children With Down Syndrome (FaB Health Ds) Survey

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Approximately half (47.8%) of all children (2-18 years) with Down syndrome (Ds) are obese [1]. Children with Ds also face increased risk for prediabetes and obstructive sleep apnea syndrome [2]. To develop meaningful interventions to prevent obesity, we must understand behavioral mechanisms that contribute to obesity. Children with Ds and their families face unique barriers to healthy habits, including functional limitations, behavioral problems, and limited social support [3]. It is not clear how these barriers impact daily routines.

**PURPOSE:** In order to better understand the nutrition, physical activity, sedentary behavior, and sleep of young children with Ds, we designed and validated a survey (FaB Health Ds) to gain a better understanding of facilitators and barriers to health.

**METHOD:** This descriptive study used an iterative Delphi approach to design and validate the FaB Health Ds survey. To be included, parents had to be > 18 years of age, have a child aged 1-5 years with Ds. We conducted a rigorous search of existing tools that examine healthy habits during early childhood and identified, developed, and categorized potential items according to a blueprint to ensure coverage of all areas of interest. In order to estimate content validity, a team of four experts in the fields of occupational therapy, public health, psychology, and medicine provided two rounds of feedback including general feedback on flow and comprehensiveness as well as rating each items' relevance and clarity. Items that were not considered relevant by > 2 experts were removed and content validity was calculated at the scale-level. The expert validated survey was then trialed by a group of parent stakeholders (n = 5) who provided additional feedback on relevance, clarity, and comprehensiveness. Modifications were made prior to a pilot study to determine reliability using internal consistency. We developed a scoring algorithm and calculated internal consistency of the FaB Health Ds using SPSS, version 27. Descriptive statistics, such as means and frequencies, were also reviewed for key areas of interest based on the World Health Organization (WHO) obesity prevention recommendations for young children.

**RESULTS:** Based on two rounds of expert review, the content validity index for FaB Health Ds indicated excellent content validity (CVI = .90). Cronbach's alpha indicated excellent internal consistency ( $\alpha = .92$ ) in an initial pilot trial (n = 30). Ninety-five parents completed the survey over a 6-month period. Most parents (73%) reported that their child did not consume the WHO recommended 5 servings of fruits and vegetables each day (M = 4.3, range = 0 to 6). Per parent report, children were meeting WHO recommendations for physical activity by spending, on average, 1.6 hours in moderate/vigorous and 5.9 hours in light activity per day. However, parents reported children spending more than an hour per day using screens (M = 1.5, range 0-10 hours) and having mobility restrained (e.g., in a stroller or car seat; M = 1.2; range = 0-6). On average, parents reported children were getting 11.4 hours of sleep per day, with 69% meeting the WHO recommendation of 11-14 hours per day (range = 4 to 15 hours).

**CONCLUSION:** FaB Health Ds demonstrated excellent content validity and internal consistency. Preliminary results indicate that nutrition and sedentary behaviors may be priority areas for intervention to prevent obesity among young children with Ds.

**IMPACT STATEMENT:** Occupational therapists (OTs) have unique skills to help families of young children with Ds overcome barriers related to feeding and sedentary behavior. Promoting health for young children with disabilities represents an emerging area of practice and research in which OTs can make a lasting impact.

## References

1. Basil, J. S., Santoro, S. L., Martin, L. J., Healy, K. W., Chini, B. A., & Saal, H. M. (2016). Retrospective study of obesity in children with Down syndrome. *The Journal of pediatrics*, 173, 143-148. <https://doi.org/10.1016/j.jpeds.2016.02.046>
2. Magge, S. N., Zemel, B. S., Pipan, M. E., Gidding, S. S., & Kelly, A. (2019). Cardiometabolic risk and body composition in youth with down syndrome. *Pediatrics*, 144(2). <https://doi.org/10.1542/peds.2019-0137>
3. Khetani, M., Graham, J. E., & Alvord, C. (2013). Community participation patterns among preschool-aged children who have received P art C early intervention services. *Child: care, health and development*, 39(4), 490-499. <https://doi.org/10.1111/cch.12045>