# 2021 Gatlinburg Conference Poster Submission

**Title**: Development of the Facilitators and Barriers to Health for Young Children with Down Syndrome Survey: FaB Health Ds

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**Introduction**: **Obesity disproportionately impacts children with Down syndrome**. Children with Down syndrome demonstrate a higher prevalence of obesity than typically developing peers and those with other developmental disabilities.[1] In fact, approximately half (47.8%) of all children (2-18 years) with Down syndrome are obese.[2] Overweight children have increased risk of obesity and poor cardiovascular health as adults. Children with Down syndrome also face increased risk for type 2 diabetes[3] and obstructive sleep apnea syndrome.[2] Despite genetic and disease-specific influences, obesity is preventable. To develop meaningful interventions to prevent obesity, we must understand behavioral mechanisms that contribute to rapid weight gain observed in children with Ds within the first five years of life. Children with Down syndrome and their families face unique barriers to healthy habit formation, including functional limitations, behavioral problems, and limited social support.[4] It is not clear how these barriers impact routines and whether barriers to healthy behavior vary based on socio-economic factors. As part of a mixed methods study to better understand the nutrition, physical activity, sedentary behavior, and sleep of young children with Down syndrome, we designed and validated a survey (FaB Health Ds) to gain a better understanding of facilitators and barriers to health within this population of children vulnerable to weight gain.

**Method**: We conducted a rigorous search of existing tools that examine facilitators and barriers to nutrition, physical activity, and sleep (e.g., presence or absence of accessible programs, competing family demands, physical and behavioral skills) during early childhood. Identified tools were reviewed by the first author (Caldwell) who categorized and developed potential items based on a blueprint for survey areas (facilitators, barriers, and descriptives in the areas of nutrition, physical activity, sedentary behavior and sleep). Next, an iterative Delphi process was used to validate the measure. First, 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, length, wording, and comprehensiveness as well as rating each items' relevance and clarity. Items that were not considered relevant by $\geq$2 experts were removed from the FaB Health tool and content validity was calculated for the overall tool at the scale-level. Then, The expert validated tool was trialed by a group of parent stakeholders (n=5) who had a child with a disability (n=2), or were parents of young children who also had significant experience working with children with disabilities as a clinician (n=2) or educator (n=1). This group completed the survey and provided feedback on the relevance, clarity, and comprehensiveness of the survey. Additional modifications were made to the REDCap web-based survey prior to a pilot study to determine reliability using internal consistency. To be included, parents had to be $\geq$ 18 years of age, have a child aged 1-5 years with Down syndrome, and consent to participation. 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 scale-level content validity index indicated excellent content validity for the entire scale (CVI = .90). We recruited 30 participants to pilot the FaB Health Ds survey. Cronbach's alpha was excellent for the entire scale ($\alpha$ = .92). Preliminary results indicate that parents report their young children with Down syndrome eat, on average, 4.6 servings of fruits and vegetables per day (range = 1 to 6). Notably, this is under the WHO recommendation of 5 servings per day and 70% of children in this sample are not meeting this recommendation based on parent report. Young children were spending, on average, 1.3 hours per day in moderate to vigorous activity and 6 hours per day in light physical activity, exceeding WHO recommendations for physical activity. Additionally, 85% of participants met WHO recommendations for sedentary behavior ($\leq$60 minutes of screen time and $\leq$60 minutes being restrained per day) based on parent report. Our sample was just below the recommendation of 11 hours of quality sleep per 24-hour period, averaging 10.8 hours per day, with nearly half (46%) reporting <11 hours of quality sleep.

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

Additional data is needed to make inferences to the larger population and data collection is ongoing with widespread distribution of the FaB Health Ds survey, now that it has been validated.

**References:**

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