Title: Using Focus Groups to Guide Measure Development for Behavioral Inflexibility in Developmental Disabilities

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Introduction: Children with developmental disabilities, such as Autism Spectrum Disorder (ASD), often display inflexible and rigid patterns of behavior. Behavioral inflexibility (BI) is thought to be one factor underlying a range of behaviors in ASD, such as restricted and repetitive behaviors (RRBs) and limited social interaction abilities. While BI is included within the DSM-5 conceptualization of ASD, there are very few measures that sufficiently capture the spectrum of BI and its impact on family functioning. The overall goal of our project is to develop a caregiver-report measure of BI for children with developmental disabilities, which is sensitive to change over time and with intervention. This poster details the application of qualitative methodology in the initial development of our caregiver-rated measure of behavioral inflexibility. Qualitative methods are essential for obtaining first person perspectives, and thus can play a role in item development for caregiver report measures.

Method: Caregivers of children with ASD (ages 2-17), and providers who work with children with ASD, were invited to participate in a series of focus groups at three sites (UNC-Chapel Hill, Ohio State University and Vanderbilt University). We also purposefully sampled for caregivers of girls with ASD. A total of 30 caregivers and 25 clinicians participated in 7 focus groups between September and November 2015.

Focus group guides were used to provide structure and common probes across the different groups and sites. These guides were designed to elicit discussions on (a) examples and triggers of BI; (b) impact of BI on working with the child/family activities; and (c) adjustments/strategies used by caregivers/clinicians to manage BI. The focus groups were recorded and audio files were professionally transcribed. Thematic analysis was applied to identify patterns (or “themes”) across the transcripts. Four coders completed line by line coding of two transcripts to generate about 650 initial codes. After checking for duplication and overlap, 155 codes formed the basis of our master codebook. All remaining transcripts were coded by two independent coders using the master codebook. Data saturation was achieved as only 30 additional codes were added after all transcripts were coded. In addition to apply for both inductive and deductive coding, frequency counts were calculated to examine the most common codes across transcripts. Web-based teleconferences were held to maintain coder consistency and consensus.

Results: Following coding of all seven transcripts, codes were condensed into 85 combined codes under broader categories. Three overarching themes emerged: (1) Impact of BI on child and family functioning (subthemes: child activity; family functioning; positive and negative aspects; social impact; and need for structure and predictability); (2) Manifestation of BI in daily life (subthemes: consistency issues; cognitive aspect; long-term variability; environmental changes; and inflexibility in action); (3) Strategies used to address BI (subthemes: multiple strategies; maintaining structure; and having a plan). No differences emerged between the themes generated by caregivers and clinicians with the exception that clinicians shared more opinions regarding the measurement of BI. Further, no differences emerged in the frequency of codes or themes from the focus group of caregivers of girls with ASD.

The most common child codes related to the child reacting physically/aggressively or with SIB (N = 43), BI impacting their social relationships (e.g. insisting on talking about certain topics with peers; N=29), inflexibility over the way things are done (e.g. can only complete a task one way; N = 46) and inflexibility surrounding the environment (e.g. where items are placed, insisting on certain routes to school; N = 28). The overlap between BI and anxiety was frequently referenced (N = 26), as was improvement with age (N = 44) and how children could be flexible at times (N = 36). Common caregiver codes included the need to be flexible because of their child’s needs (N = 25), the importance of maintaining routine/structure (N = 48) and the need to prepare others in advance because of the child’s BI (N = 39).
Discussion: The goal of our focus groups was to ensure our final measure (the Behavioral Inflexibility Scales) has sufficient content validity (the extent to which an instrument measures the domain of interest) and was relevant to the sample population. Together with a comprehensive review of relevant measures, investigators used our focus group data to generate 38 candidate items for a caregiver-report measure of behavioral inflexibility. The focus groups were particularly influential in revealing the impact of BI on families and the extent to which caregivers and clinicians have to accommodate for BI in daily life. Focus groups are the first step in a series of steps toward the development of the Behavioral Inflexibility Scale.