Title: Comparing Endorsements of Self-Injurious Behavior across Two Questionnaires for Parents of Individuals with Rett Syndrome and MeCP2 Duplication

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Introduction: Self-injurious behavior (SIB) is an issue that affects between 5-15% of individuals with intellectual and developmental disabilities (IDD), and can have profound impacts on the quality of life for individuals and their caregivers (Didden et al., 2012; Ruef & Turnbull, 2002). Questionnaires can be useful in the measurement of SIB because they are an efficient and cost-effective way of evaluating SIB for a multitude of purposes, and as such, a number of different tools have been developed. However, relatively little attention has been paid to the degree to which different measures result in the same prevalence estimates of SIB within and across groups. The purpose of this study was to compare endorsements of SIB on two measures that have been used to identify individuals with and without SIB in recently published studies, the Aberrant Behavior Checklist (ABC) and the Diagnostic Assessment for the Severely Handicapped – II (DASH-II), to determine if endorsements of SIB would be the same or similar across measures in a sample of parents of individuals with Rett syndrome (RTT) and MeCP2 duplication.

Method: A convenience sample of 42 parents of individuals with RTT (N=27) and parents of individuals with MeCP2 duplication (N=15). Parents were involved in a larger study and were included in this analysis if they had completed both the ABC and the DASH-II. The ABC includes three general items relating to SIB (i.e., “Does physical violence to self”) that are rated on a severity scale from 0 to 3 as part of the irritability subscale. The modified DASH-II SIB subscale includes six topography-specific subscales rated on a frequency scale of 0 to 2. Simple agreement between the questionnaires was calculated by comparing parents who endorsed at least one SIB item (i.e., subscale score ≥1) on the two questionnaires.

Results: Ten participants (23.8%) endorsed at least one item on the ABC, and 27 (62.3%) endorsed at least one item on the DASH-II. The overall agreement of parent endorsement of SIB on both questionnaires was low across the combined sample (59.5%), with agreement somewhat better among parents of individuals with RTT (66.7%) compared to MeCP2 duplication (46.7%).

Discussion: These results suggest that prevalence estimates of SIB based on parent report measures may be affected by the questionnaire selected, and potentially by participant characteristics. This finding indicates that identification of SIB may be more open to interpretation than is typically acknowledged. One limitation of the study is that the rating scales used may not reflect the most appropriate, or most frequently used scales for identifying SIB in this population. Nevertheless, these scales, along with several other published and ad hoc measures, are being used as measures of SIB by researchers, and additional research is needed to identify the specific factors that affect caregivers’ responding if such instruments are to be used to classify participants in group for research, diagnostic, or treatment purposes.

References/Citations: