



Title: Evaluation of the PROMIS® Pediatric Family Involvement Measure in Children with Autism Spectrum Disorder: A DBPNet Study

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Background: The NIH Patient Reported Outcomes Measurement Information System (PROMIS®) has developed a parent-report measure of a child's family involvement. The core symptoms of Autism Spectrum Disorder (ASD) impact participation in family activities and overall family functioning; thus, family involvement is an important potentially measurable outcome. The PROMIS measure has not yet been evaluated in children with ASD.

Objective: To evaluate the PROMIS Family Involvement parent-report measure for children with ASD.

Design/Methods: Subjects were parents of 5-12-year-old children from three academic medical centers who met DSM-IV or DSM-5 criteria for ASD and scored in the ASD range on the Autism Diagnostic Observation Schedule or Childhood Autism Rating Scale. Parents completed via computer a demographic form, the PROMIS Family Involvement (FI) measure, the Social Responsiveness Scale 2nd Ed. (SRS-2), the Parenting Stress Index 4th Ed. Short Form (PSI-SF), and the PROMIS Adult Depression measure. The FI measure was administered using computerized adaptive testing, which minimizes the number of items administered while maintaining precision as measured by the standard error of measurement (SEM); a SEM of 0.32 translates to a reliability coefficient of 0.9. The FI measure gives T-scores normed on a US sample of typically developing children (mean=50, SD 10).

Results: Fifty-three parents have completed the study measures. The average child age was 8.3 years. The FI T-scores were normally distributed (mean=45.4, SD 6.6, 95% CI [43.6,47.2], range 29.3-58.5). A higher level of ASD symptoms on the SRS-2 correlated with lower FI ($r=-0.4$, $p=0.003$). The FI and the PSI-SF total score were inversely correlated ($r=-0.27$, $p=0.05$) as were FI and the Parent-Child Difficult Interaction subscale of the PSI-SF ($r=-0.37$, $p=0.006$). There was no correlation detected between FI T-scores and child age, IQ, or parental depression. The SEM ranged from 0.26 to 0.32, with 50 participants requiring 5 or fewer of 15 FI items to achieve such level of precision.

Conclusions: The PROMIS FI measure may efficiently (i.e. few items required to measure the construct) and precisely measure family involvement in 5-12-year-old children with ASD. Higher ASD severity and parent-child difficulties correlated with lower FI.

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