



Measuring the involvement in family life of children with autism spectrum disorder: A DBPNet study

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ABSTRACT

Background: Children with Autism Spectrum Disorder (ASD) have social and communication deficits that impair their involvement in family life. No measures of child involvement in the family have been validated for the ASD population.

Aim: To evaluate the validity of a measure of Family Involvement (FI) of children ages 5–12 with ASD.

Method: Parents of children ages 5–12 with ASD (n = 114) completed FI items from the PROMIS® pediatric Family Relationships item bank in computerized adaptive testing (CAT) format, as well as measures of ASD symptom burden, parenting stress, and parental depression. Medical record review provided child intelligence or developmental quotient. A reference sample (n = 236) closely matching the ASD sample in age and gender was created from the national standardization sample, and underwent a simulated CAT.

Results: The CAT precisely and efficiently measured parent-reported FI of children with ASD. Average FI scores were lower among children with ASD (M = 46.3, SD = 7.1) than children in the reference sample (M = 52.5, SD = 9.1). A "dose response" decrease in FI was observed as ASD severity increased. Increased parenting stress was associated with lower FI. No relationship between FI and child IQ was found.

Conclusion: The FI items captured FI among children ages 5–12 with ASD with acceptable precision. Reduced FI among children with ASD, particularly those with higher symptom severity, suggests validity of the items in this population.

What this paper adds?

- There is a need for valid outcomes measures for children with developmental and behavioral conditions, including autism spectrum disorder (ASD).
- Child involvement in family life may be an important outcome given that core symptoms of ASD limit a child's participation in

Abbreviations: ASD, Autism Spectrum Disorder; ADOS, Autism Diagnostic Observation Schedule; CARS, Childhood Autism Rating Scale; CAT, Computerized Adaptive Testing; IQ, Intelligence Quotient; PROMIS, Patient Reported Outcomes Measurement Information System; PSI-SF, Parenting Stress Index-Short Form; SRS-2, Social Responsiveness Scale, 2nd Edition

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family activities, often to the detriment of family functioning.

- The Family Involvement item bank measured involvement of children with ASD in their family life with acceptable precision and efficiency.
- Higher autism symptom burden correlated with lower child involvement, suggesting preliminary validity of the item bank.
- The item bank's use of computerized adaptive testing (CAT) reduced respondent burden and increased efficiency of measurement without sacrificing precision.

1. Introduction

The National Institutes of Health's Patient Reported Outcome Measurement Information System (PROMIS®) was established in 2004 with the goal of creating and disseminating valid, reliable, efficient, and precise measures of health-related qualities (e.g. physical functioning, depression, mobility, etc.). Many measures have been developed for use within the pediatric population (Forrest et al., 2012). Fifteen items, created during the development process of the Family Relationships measure (Bevans et al., 2017), had been previously identified as dealing specifically with the behavioral, or observable, ways in which children demonstrate their involvement in family activities and with other family members, rather than more subjective or affective experiences of belonging to one's family. The resulting 15-item Family Involvement (FI) item bank, validated independently, allows parents to report efficiently and precisely the level of family involvement they perceived their children to demonstrate.

FI is defined as the consistency and quality of children's interactions with parents and family members. FI is a complex, bidirectional construct that captures both the child's and the family's involvement with each other, and includes the qualities of engagement (being paid attention to by family), participation (spending time together and being involved in activities with family), enjoyment (deriving pleasure and having fun with family); and communication (family is available and willing to listen and talk; child feels understood in interaction with family).

The FI item bank, as a derivative of a larger work by the PROMIS project, retains unique qualities demonstrated by measures developed using similar methodology. The item bank measures a unidimensional construct of FI, confirmed through factor analyses detailed later in this manuscript. Each item was calibrated using item response theory (IRT) models, allowing each item response to convey information that probabilistically predicts a responder's level of the trait being measured. This allows the items to be delivered using computerized adaptive testing (CAT), which administers items one at a time, using each previous response to suggest the subsequent item that may best allow increasingly precise measurement of the trait. The result is a measure that can precisely and efficiently capture the trait being measured, offering advantages over measures developed using classical test theory (Forrest et al., 2012).

There is an urgent need for valid and efficient outcomes measures for children with developmental conditions (Blum et al., 2012). As part of the effort to address this need, we sought to evaluate the validity of the FI item bank for children with Autism Spectrum Disorder (ASD). ASD is a complex neurobiological disorder characterized by social and communication deficits and restricted, repetitive behaviors. Having a child with ASD can negatively impact family functioning and caregiver well-being (Davis & Carter, 2008; Karst & Van Hecke, 2012; Khanna et al., 2011; McStay, Trembath, & Dissanayake, 2014; Montes & Halterman, 2007). Children with ASD engage in fewer family recreational activities and chores than typically developing children, and the activities in which they do engage tend to be more solitary (Reynolds, Bendixen, Lawrence, & Lane, 2011; Solish, Perry, & Minnes, 2010). Children with social and communication difficulties may participate in less varied activities with fewer numbers of people (Hilton, Crouch, & Israel, 2008). Externalizing and, to a lesser extent, internalizing behavior problems in children with ASD can negatively affect family relationships and overall family functioning (Sikora et al., 2013). Caregivers have reported decreased sense of attachment with their children with ASD, which was related to the child's functional impairment as well as with parenting stress (Goodman & Glenwick, 2012). Caregivers also report being less able to talk with their child with ASD about important topics, which contributes to decreased family connectedness and caregiver psychological functioning (Montes & Halterman, 2007). Given that ASD symptoms have thus been shown to limit a child's ability to engage and participate in family activities, an instrument that can assess family involvement of a child with ASD would be a useful outcome measure.

For this project, we specifically focused on FI, or the behavioral aspects of family relationships, because a heterogeneous condition like ASD that affects social and communication skills may make the subjective expression of family relationships (i.e. sense of belongingness) a more difficult outcome to capture without more in-depth investigation. Although the items in the FI measure were developed and validated in a general population, their applicability to children with ASD has not been established. However, recent data have suggested that other measures developed using similar methodology do show preliminary validity in the ASD population (Toomey et al., 2016).

Our principal objective was to evaluate the precision and validity of the parent-report FI items for children aged 5–12 years with ASD. To assess the construct validity of FI in an ASD population, we determined whether FI varied as expected in relation to child- and family-specific characteristics. As social, communication, behavioral, and functional difficulties have been shown to reduce participation in family activities and family connectedness, we hypothesized that higher ASD symptom burden and lower child IQ (as a marker of functional status) would be related to lower parental report of a child's involvement with his or her family. We also hypothesized that higher parental stress, which is related to decreased sense of parental attachment and child-parent interactions, would also be related to lower reports of child family involvement.

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