Title: Respite Care among Parents of Children and Adults with Autism Spectrum Disorder

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Introduction: Although all parenting is associated with some stress, parents of children and adults with autism spectrum disorder (ASD) report greater than average levels of parenting stress. Parents of children with ASD experience greater stress than even parents of children with other intellectual and developmental disabilities (Hoffman et al., 2009), likely due to challenging behaviors associated with ASD (Griffith et al., 2010). Some families rely on informal sources of support to provide temporary breaks in caregiving, however others rely on more formalized services such as respite care. Respite care refers to any service that provides parents with a temporary relief in caregiving duties (Mullens et al., 2002). Although a considerable amount of research was conducted on respite care when it was first introduced after individuals with disabilities were relocated from institutions to community settings, this service has received relatively little empirical attention in recent years. This study aimed to understand to what extent parents of children and adults with ASD use respite care services as well as their level of satisfaction with finding and keeping a quality provider. Among those who had never used respite care services, this study aimed to identify potential barriers to access.

Method: Parents of children and adults with ASD were recruited through the Simons Powering Autism Research for Knowledge (SPARK) database, an autism research databased composed of individuals with autism and their family members living in the U.S. A random sample of 3,517 parents in the database were invited to participate in this study, of which 849 gave permission to be contacted by the research team. A total of 629 parents consented to the study, with 539 completing the survey. The online survey consisted of questions about a) family background, b) definition and use of respite care, c) frequency, cost and setting for services, d) time use during respite care, e) finding providers, and f) characteristics of providers. Parents also completed measures of activities of daily living (Waisman Activities of Daily Living; Maenner et al., 2013) and behavior problems (Scales of Independent Behavior-Revised; Bruininks et al., 1996). For the purposes of this study, respite care was defined as any break in caregiving provided by a respite care provider, personal care attendant or babysitter (who is not a family member) outside of parent work hours. Participants were primarily women (96%) and 42 years of age on average (SD=8.43). More than half were married (66%), over a third identified as non-white (36%), and the average number of children was 2.5 (SD=1.39). The target children/adults with ASD were mostly boys/men (79%) and 12 years of age on average (SD=5.79). Over a third (39%) were identified as non-white.

Results: Less than half (46%) of parents were very familiar with the concept of respite care, although most (86%) agreed that a temporary relief in caregiving was very important to the well-being of parents of children/adults with ASD. Approximately one third (31%) of participants had never used any form of respite care for their child with ASD. White parents were more likely to never use respite care than non-white parents (p = .03), although age, family income, parent education, number of children and marital status were unrelated. The most commonly identified barriers included an inability to find a respite care provider (82%) and the lack of ability to pay for a respite care provider (74%). Among those who had used respite care services, most accessed this service only occasionally (58%) or monthly (13%). The majority (71%) of respite care services took place in the home, although some reported using a friend or relative’s home (28%) or a camp (14%). Most parents (70%) reported receiving financial support for respite service at some point, but less than half (48%) never had to pay out of pocket for respite. Parents were most likely to run errands, spend time with a spouse/partner, clean or cook while receiving respite care. The greatest perceived benefit of respite was to the self, followed by the spouse/partner, the child with ASD, and other siblings.

Discussion: To the best of our knowledge, this is the largest study on the use of respite care among parents of children and adults with ASD in the U.S. Findings suggest that most, but not all, parents have accessed respite care at some point during their child’s lifetime, however regular access to affordable respite care was rare in this sample. These findings suggest that families lack information on where to find providers as well as how to pay for their fees. Most parents reported tending to housework while receiving respite care, with the exception of a focus on spending time with a partner.
References:


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