

The well-being of mothers of adolescents with developmental disabilities in relation to medical care utilization and satisfaction with health care

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Abstract

Parents of children with disabilities have been found to be more likely to experience stress and depressive symptoms than parents of typically developing children as a result of the increased challenges inherent in their parenting role. This study investigated the utilization of and satisfaction with adolescent health care services reported by mothers and their relation to maternal well-being. Participants included 73 mothers and their adolescents with developmental disabilities who had been recruited as infants and toddlers from early intervention programs to participate in a longitudinal investigation, the Early Intervention Collaborative Study. Data were collected through parent reports and structured assessments with adolescents. Regression analyses were conducted to test whether utilization and maternal satisfaction with care related to maternal depressive symptoms or parenting stress after controlling for child and family characteristics. The results demonstrated that both utilization and maternal satisfaction with health care added unique variance in predicting lower levels of maternal stress and depressive symptoms.

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The collaborative relationship between parents of children with developmental disabilities and their children's physicians has been found to be central to parent satisfaction with children's health services (Galil et al., 2006; Horrell, MacLean, & Conley, 2006). Parents' satisfaction with their children's health care is valuable to examine not only because of its association with

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compliance and continuity of care (Albrecht & Hoogstraten, 1998; Hickson & Clayton, 2002; Lewis, Scott, Pantell, & Wolf, 1986; Mah, Tough, Fund, Douglas-England, & Verhoef, 2006; Squier, 1990) but also because children's physicians are often the professionals to whom parents turn regarding developmental concerns (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004). The parent–physician relationship and the frequency of medical visits are likely to have particular salience in situations where a child has developmental disabilities and related special health care needs (Committee on Children with Disabilities, 1999). Indeed, in analyses based on the National Health Interview Survey, Newacheck and Halfon (1998) reported that children with disabilities (and presumably their parents or caregivers) have three times the rate of physician contacts compared to children without disabilities. Parent satisfaction with the health care their children with disabilities receive has been investigated recently with respect to the qualities of health care providers that are valued by parents and the unmet needs of families (Liptak et al., 2006; Warfield & Gulley, 2006). Little is known, however, about the implications of levels of utilization of services or parent satisfaction with children's care on the well-being of these caregivers themselves. This research gap exists despite much empirical evidence on the importance of parent well-being to parenting competence (e.g., Downey & Coyne, 1990; Leung & Slep, 2006). Developmental models of the determinants of parenting (Belsky, 1984) as well as family system models of functioning (Minuchin, 2002; Patterson, 1991) place the psychological well-being of primary caregivers, conceptualized as low levels of parenting stress and depressive symptoms, as central to their functioning as competent parents.

Although most parents are likely to feel challenged in some aspects of their parenting role, many studies have indicated that the stress reported by primary caregivers of children with developmental disabilities is often greater and more variable than that reported by caregivers of typically developing children (Baker et al., 2003; Dyson, 1991; Hodapp, 2002; Roach, Orsmond, & Barratt, 1999). Some research has suggested that parental stress varies by the type of disability of the child (Blacher, Neece, & Paczkowski, 2005; Duarte, Bordin, Yazigi, & Mooney, 2005). For example, parents of children with Down syndrome have often been found to experience less parenting stress than parents of children with other types of disabilities (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Most, Fidler, Laforce-Booth, & Kelly, 2006). Child gender has also been related to parental stress in some studies, but the relation is inconsistent (e.g., Scher & Sharbany, 2005; Shin et al., 2006). Most of those studies, however, have focused on parenting stress during the early childhood years. The few longitudinal investigations of parents of children with developmental disabilities indicate that aspects of parenting stress, especially those related to the child's adjustment, increase significantly from early through middle childhood (Hauser-Cram et al., 2001; Orr, Cameron, Dobson, & Day, 1993).

Greater parenting stress has been associated with a range of behavior problems, inadequate peer social networks, and multiple medical needs among adolescents with developmental disabilities. Behavior problems are more likely to occur in children and youth with disabilities than in those who are developing typically (Baker, Blacher, & Olsson, 2005; Tonge, 1999) and these problems often increase dramatically in the adolescent period (Jacobson, 1990). In a sample of adolescents and young adults with Down syndrome, autism, or fragile X syndrome, Abbeduto et al. (2004) found that the most consistent predictor of maternal well-being was the youth's behavior. Adolescents who have difficulty regulating their own behavior tend to have poor social relationships (Merrell, Johnson, Merz, Johnson, & Ring, 1992) resulting in inadequate peer networks. Additionally, adolescents with developmental disabilities may require multiple visits to pediatricians and specialists due to special health care needs related to, for example, seizure disorders, cardiac anomalies, or poor mobility (McPherson et al., 1998). These

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