Satisfaction With Primary Health Care Received by Families of Children With Developmental Disabilities

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ABSTRACT

Objective: To evaluate the perceptions of families of children with developmental disabilities regarding their primary care physicians and to determine if differences exist for different conditions.

Methods: Mailed survey to families of children who had autism, physical disabilities (cerebral palsy or spina bifida) and mental retardation that included the Multidimensional Assessment of Parental Satisfaction for Children with Special Needs.

Results: One hundred twenty-one families responded. Families rated physicians highest on their ability to keep up with new aspects of care and on their sensitivity to the needs of children. Parents had the lowest ratings for the primary care physicians' ability to put them in touch with other parents, understanding of the impact of the child's condition on the family, ability to answer questions about the child's condition, and information and guidance for prevention. Physicians' knowledge about complementary and alternative medicine and their qualifications to manage developmental disabilities ranked worse than neutral. Families with a child with autism had more spontaneous negative comments and rated their primary care physicians lower on several aspects of care. They requested more information on complementary and alternative medicine and more support in the community.

Discussion: Families of children with developmental disabilities demonstrate dissatisfaction with several aspects of health care that can serve as areas for intervention by their health care providers. Families of children with autism in particular articulate dissatisfaction and voice unmet needs. J Pediatr Health Care. (2006) *20*, 245-252.

Children with special health care needs (McPherson et al., 1998) have complex medical needs. The American Academy of Pediatrics (AAP) and Maternal and Child Health Bureau (MCHB) have stated, "All children with special health care needs will receive regular ongoing comprehensive care within a medical home" provided by the primary care physician

(MCHB, 2004, p. 1). In describing the medical home, the AAP has stated that it should be "accessible, continuous, comprehensive, family centered, coordinated, and compassionate. It should be delivered or directed by well-trained physicians who are able to manage or facilitate essentially all aspects of pediatric care" (AAP, 2003, p. 1).

Patient satisfaction is an important measure of quality of care (Donabedian, 1992). The patient's perspective in defining the quality of health care is increasingly being used to develop policies for service delivery and financing. Evaluating patient satisfaction can enhance the involvement of patients and families in decisions that concern them (self-management) (Law et al., 2003; Rosenbaum, King, Law, King, & Evans, 1998; Wagner, 1998). Also, satisfaction with medical encounters is related to outcomes such as adherence (compliance) with medical regimens (Auslander, Thompson, Dreitzer & Santiago, 1997; Freed, Ellen, Irwin, & Millstein, 1998; Oermann, Swank, & Sockrider, 2000; Parhiscar & Rosenfeld, 2002).

Based on clinical experience, it was hypothesized that families who have a child with autism would be less satisfied with primary care than families of children with other conditions. In addition to our clinical impressions, a number of studies have documented higher than typical levels of stress for families who have a child with autism (Duarte, Bordin, Yazigi, & Mooney, 2005; Koegel et al., 1992). In one study, families who had children with autism had higher levels of stress than did families who had children with cystic fibrosis (Bouma & Schweitzer, 1990). Holroyd and McArthur (1976) found that, in comparison with mothers of children with Down syndrome, mothers of children with autism were more upset and disappointed with their child and more anxious about obtaining appropriate services. In addition, families of children with autism have a high utilization of complementary and alternative therapies (Levy & Hyman, 2005), suggesting dissatisfaction with conventional care. Finally, significant differences between parental perception and professional assessments of the cognitive level of children with autism have been documented (Geiger, Smith, & Creaghead, 2002), suggesting at least some discord between these parents and professionals. The purpose of this study was to evaluate the perceptions of families with a child with a developmental disability regarding their primary care physicians and to determine if differences exist for families who have children with different conditions.

METHODS

The sample for this survey included patients who currently receive services at the Kirch Developmental Services Center, Golisano Children's Hospital, University of Rochester Medical Center. This program provides care to children who have physical disabilities such as spina bifida and cerebral palsy, as well as developmental disabilities such as autism and mental retardation. Individuals with these four conditions were identified through a centralized database, and surveys were mailed to them. Children were classified as having mental retardation only if they did not have autism as well.

Families were identified from a database of encounters from the previous 12 months. Three hundred surveys were mailed to the homes of these families during the winter of 2003-2004: 100 to families with a child with a physical disability (50 each to families with a child who had cerebral palsy and spina bifida), 100 to families with a child with autism, and 100 to families with a child with mental retardation (without autism). Surveys were color coded by diagnosis. A raffle was used to try to increase the return rate. Reminder cards were sent 4 weeks after the initial mailing.

Survey Instrument

The survey was designed to be completed by the child's primary parent and was reviewed prior to the survey by nonstudy parents and professionals for clarity, language, ease of completion, and length of time for completion. It was translated into Spanish to encourage greater subject response. The Spanish version of the survey was printed on the reverse side of the English version. Participants were able to complete the survey within 10 to 15 minutes. The mailing consisted of a letter of introduction, a consent form, the survey, a self-addressed stamped envelope for survey return, and a separate stamped postcard that families could return to be entered in a drawing for five cash prizes. The study was approved by the University of Rochester Research Subjects Review Board.

The Survey consisted of three parts: (a) demographic information, (b) the Multidimensional Assessment of Parental Satisfaction (MAPS) for Children with Special Needs (Ireys & Perry, 1999), and (c) general questions regarding health care. The MAPS for Children with Special Needs (Ireys & Perry)

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