

Communicating with Health Care Providers: Perceptions of Parents of Children with
Autism Spectrum Disorders

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Both parents and providers identify difficulties with their communication interactions in pediatric health care, especially around child development. Autism Spectrum Disorder (ASD) is one of the most common childhood developmental delays, but little is known about the communication processes that occur during the diagnostic period between parents and providers. The purpose of the study was to identify key elements, barriers to, and facilitators of the communication process between parents and health care providers during the diagnostic period for a child recently diagnosed with ASD. Parents were recruited from throughout the U.S. from ASD parent and community organizations and research networks. The study utilized a mixed methods design with semi-structured, one-on-one interviews and the administration of a demographic survey and standardized measures of mental health and family-centered care with 31 parents. The interviews uncovered major themes related to barriers and facilitators of communication process at both the provider and systems level, as well as parents' initial concerns and actions taken, provider reaction to parent concerns, and outcomes of the communication process. Facilitators included parents reporting providers listened to

them, elicited their concerns, were respectful, were knowledgeable, treated parent like a partner, as well as systems issues that resulted in providers having direct communication and enough time to spend with parents. Barriers included the provider not treating parent as a partner, not listening, lack of knowledge about ASD, not giving parents information, along with systems issues resulting in providers not having enough time with parents, long wait times for diagnosis, insurance issues, and indirect communication. The majority of parents rated the diagnostic process as stressful (71.0%) and that they experienced moderate to severe symptoms of depression and anxiety (54.8%). A statistically significant inverse correlation was observed between parent reports of the number of key elements of communication and reported stress ($r_s = -.43$, $p=0.016$). The results of this study can be used by health care providers to help guide the communication that occurs with families during this time, as well suggest possible areas of intervention for future research.

Approved

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