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Topic: Build child, family and community relationships that promote child development and learning.

Golnick, A, Maccabee-Ryaboy, N., Scal, P., Wey, A., & Gaillard, P. (2012). Shared decision making: Improving care for children with autism. *Intellectual and Developmental Disabilities*, 50, 322-331.

Context

The interpersonal relationship between primary medical care professionals (e.g., physicians) and parents of children with autism spectrum disorder (ASD) can vary depending on the physicians' knowledge of ASD and their approach to involving families in making decisions about the care of the child. The ability of a physician to (a) understand how the condition impacts family adjustment, (b) provide information on ASD, and (c) explain the numerous treatment options can affect the families' satisfaction with medical services. Parents have reported concerns with the lack of engagement in shared decision making (SDM) when consulting with physicians. These concerns can exacerbate stress and adjustment problems often associated with parents of children with ASD. SDM is a specific tool that can be used in family-centered care to strengthen family functioning, empower parents, and increase parental satisfaction.

Purpose of Study

The purpose of the study was to determine the extent to which parents of children with ASD reported being involved with SDM. It was hypothesized that parents who were more involved in SDM were more likely to be satisfied with health care services, better informed of controversial issues and the treatment options for ASD.

Method

A researcher-developed instrument regarding access, use, and satisfaction with primary medical care and decision making was completed by 128 parents of children with ASD ages 3 to 18. The researchers analyzed the association of SDM with parent satisfaction and perceived guidance on controversial issues and treatment options.

Results

Parents with the highest levels of SDM reported greater satisfaction with the quality of their child's health care and receiving more guidance on treatment options and controversial issues.

Discussion

The quality of the relationship between primary medical care providers and parents has a significant impact on how families adjust to having a child with ASD. SDM can serve to ameliorate the stress often associated with medical care and treatment options for ASD. Researchers recommend that medical care providers find ways to increase the level of parent involvement in decision making about their child's care and selection of treatment options. Medical providers who support and respect the parents' contributions to the care of their children and provide information about the controversial issues associated with treatment of ASD can reduce the tensions often reported between providers and parents. Future research is needed on how SDM can be implemented in practice and studied by comparing a control group of parents (not receiving a SDM approach) and a treatment group of parents (receiving a SDM approach).

About *Research-to-Practice Briefs*

Research-to-Practice Briefs provide summaries of key studies that inform practice related to early childhood special education. The series is designed specifically to support community college faculty who prepare candidates to work with children with special needs in the early childhood setting.

About the ACCEPT Project

The ACCEPT (Advancing Community College Efforts in Paraprofessional Training) Project is a federally-funded cooperative agreement between the U. S. Department of Education Office of Special Education Programs (OSEP) and the University of North Carolina at Charlotte College of Education. The focus of this effort is the inclusion of special education content in the coursework and experiences provided within the associate degree program in early childhood education at targeted state-supported community colleges in North Carolina.

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