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Family-centered care practices in a multidisciplinary sample of pediatric professionals providing autism spectrum disorder services in the United States[☆]

Lillian M. Christon^{*}, Barbara J. Myers

Virginia Commonwealth University, United States

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ABSTRACT

Family-centered care (FCC) has not been studied extensively in the field of autism spectrum disorders (ASD), but has been highlighted as a critical component of practice with youth with ASD. The aim of this study was to examine predictors (e.g., the theory of planned behavior, [TPB]) of providing family-centered care (FCC) services to youth with ASD in pediatric professionals from a range of disciplines. A multidisciplinary (e.g., medicine, psychology, education, etc.) sample of professionals ($N=709$) who endorsed providing services to youth with ASD in the United States was recruited from online provider listings, listservs, etc. Hierarchical multiple regressions examined the relationship of demographic and TPB predictors to professionals' self-reported FCC practices. Professionals reported a high degree of using FCC in their practice with youth with ASD. Attitudes and perceived behavioral control predicted self-reported FCC practices, while subjective norms did not. Experienced practitioners reported using FCC practices in spite of not having necessarily received FCC training. Discipline differences were evident in rates of reported FCC. The Theory of Planned Behavior is helpful in understanding FCC practices and attention should be given to training professionals in FCC as they work with youth with ASD. Implications and future directions are discussed.

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1. Family-centered care practices in a multidisciplinary sample of pediatric professionals providing autism spectrum disorder services

Family-centered care (FCC) is an approach to planning and delivering care that promotes collaborative partnerships between care providers, pediatric patients, and families. FCC is an important component of professionals' practice with youth with chronic conditions (Johnson, 2000), including youth with autism spectrum disorder (ASD; Gabovitch & Curtin, 2009). In FCC, professionals establish a supportive relationship with the children's caregivers and family, as they design services to fit individual child and family values and needs (Rogers & Vismara, 2014). The literature on intervention

Abbreviations: ASD, autism spectrum disorder; FCC, family-centered care; TPB, theory of planned behavior.

[☆] The work presented was conducted at Virginia Commonwealth University, Department of Psychology, 806 West Franklin Street, P.O. Box 842018, Richmond, VA 23284 2018, United States.

^{*} Corresponding author. Present address: Medical University of South Carolina, Department of Psychiatry and Behavioral Sciences, Division of Behavioral Medicine, 67 President Street, MSC 861, Charleston, SC 29425 United States.

E-mail address: christon@musc.edu (L.M. Christon).

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utilization tells a story wherein children with ASD use more services than typically developing children and require more interventions than children with other special healthcare needs (e.g., chronic illnesses, other emotional or behavioral problems; [Montes, Halterman, & Magyar, 2009](#)). With more services being used, attention must be given to the quality of the services delivered to children with ASD, and the extent to which they are delivered in a FCC fashion. This study examines professionals' FCC practices with children with ASD, an area in which limited research has been done.¹

The core concepts of FCC are treating patients and families with respect and dignity, sharing information with patients and families, encouraging patients and families to participate in care and decision-making, and collaborating in implementation and delivery of care (e.g., [Committee on Hospital Care, 2003](#)). In FCC, professionals explore a family's preferences, provide the family with the necessary information to make educated decisions about the care for their child, and attend to psychosocial aspects of care ([Bensing, 2000](#); [Harbin et al., 2000](#); [Roberts & Magrab, 1991](#)). Hallmarks of FCC also include building the motivation, self-empowerment, and self-efficacy of families ([Bensing, 2000](#)). Further, FCC acknowledges the importance of adopting a family-systems, developmental, and multidisciplinary approach to care, "in which the perspectives of various professionals are integrated to provide the best understanding of the child, the family, and the culture" ([Roberts & Magreb, 1991, p. 145](#)).

Involving caregivers and family members in services is necessary for children with ASD given the need for coordinated delivery, both to increase opportunities for teaching and skill generalization across multiple settings ([White, 2012](#)), and to aid in the intervention decision-making process. Based on caregiver report of intervention use, children with ASD have been estimated to use, on average, between four ([Goin-Kochel, Myers, & Mackintosh, 2007](#)) to seven ([Green et al., 2006](#)) interventions (e.g., pharmacological, behavioral, educational, diet-based, speech, etc.) at any given point in time. Further, ASD interventions exist in abundance and run the gamut in terms of empirical support. Families rely on professionals' information and support as one important component in their decision-making about treatments ([Carbone et al., 2013](#); [Christon, Mackintosh, & Myers, 2010](#)). Families are likely to be involved with multiple professionals from different disciplines throughout their child's development. Professionals must actively engage in a dialogue with families to better understand their preferences and values, while providing general and specific information about interventions and their research support.

Benefits of FCC can include improved family adherence to a child's set of interventions ([Woodside, Rosenbaum, King, & King, 2001](#)), increased caregiver well-being ([King, King, Rosenbaum, & Goffin, 1999](#)), reduced family emotional distress, increased coping and adjustment, and increased family satisfaction with the child's care ([Carbone et al., 2013](#); [Gabovitch & Curtin, 2009](#)). FCC approaches may influence child outcomes by increasing the self-efficacy of the caregivers and improving relationships between caregivers and professionals ([Dunst, Trivette, & Hamby, 2007](#)). FCC has been linked to increasing caregivers' positive judgments of child behavior and confidence in managing their child's care ([Dunst et al., 2007](#)), as well as improved collaborative decision-making with better information available for providers ([Committee on Hospital Care, 2003](#)).

Despite these benefits, some literature has indicated that professionals may not consistently practice FCC in working with children with ASD ([Gabovitch & Curtin, 2009](#)). Families of children with ASD report receiving less FCC than do families of children with other emotional/behavioral/developmental problems ([Kogan et al., 2008](#); [Gabovitch & Curtin, 2009](#)). FCC has been reported as less prevalent for children with ASD compared to children with other medical conditions (e.g., asthma) even after controlling for condition severity, personal characteristics, and insurance status ([Brachlow, Ness, McPheeters, & Gurney, 2007](#)). One possibility is that due to the pervasiveness and severity of symptoms in ASD, children with ASD and their families may need a higher level of FCC than children with other chronic medical, developmental, and psychiatric conditions; professionals may struggle to meet this need.

There are a number of possible barriers to using FCC. Barriers discussed across literatures include a lack of training or knowledge, a fear of offending families, and a lack of knowledge of resources within the community that might meet the family's needs ([Harbin et al., 2000](#)). Professionals' attitudes and perceptions about FCC may impact their use of FCC. [Rosenbaum, King, Law, King, and Evans \(1998, p. 14\)](#) point out that shifting to a FCC perspective may cause some professionals to feel devalued, unskilled, or no longer like the "revered authorities" in their discipline. [Wagner et al. \(2005, p. S11\)](#) provide the following perspective on barriers to family- or patient-centered care for medically oriented professions: ". . . Professionals by virtue of their culture, training, social dominance, job stress, and other factors are traditionally inclined to be controlling . . . From this perspective, the problem is professional attitudes and behaviors that must be altered."

Professionals also may have little organizational support, a lack of time, and a lack of funding or insurance coverage for practicing FCC ([Gabovitch & Curtin, 2009](#)). Spending additional time with youth/families to tailor interventions or address complex psychological, physical, medical, or behavioral needs is challenging for many professionals ([Gabovitch & Curtin, 2009](#)), given that they may not be paid for additional time spent and they may have other patients waiting. Even in educational settings with public funding, the cost of serving children with ASD is enormous; little funding is provided for additional services and time ([Shattuck & Grosse, 2007](#)). Another systems-level challenge of implementing FCC is that the

¹ The literatures drawn from in this introduction include the disciplines included in this study: (a) education (including behavioral specialists); (b) medicine and nursing; (c) occupational therapy and physical therapy; (d) psychology; (e) social work; and (f) speech language pathology and audiology.

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