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Parents' and professionals' perceptions of family-centered care for children with autism spectrum disorder across service sectors

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ABSTRACT

Family-centered care (FCC) has been linked with improved parent and child outcomes, yet its implementation can be challenging due to family, professional, organizational and systemic factors and policies. This study aims to increase knowledge and understanding of how families with children with autism spectrum disorder (ASD) experience FCC in Alberta, Canada. 152 parents with a child with ASD completed the Measure of Processes of Care, separately for each utilized service sector, and 146 professionals working with persons with ASD completed the Measure of Processes of Care – Service Providers. Additionally, in-depth interviews were conducted with a sub-sample of 19 parents, purposefully sampled for diversity in child and family characteristics. Data were collected in 2011. Descriptive and inferential statistics were used to analyze quantitative data. Interview transcripts were analyzed using grounded theory constant comparison methods, yielding a data generated theoretical model depicting families' experiences with FCC over time and across service sectors. There were no statistically significant differences in FCC scores across service sectors, but statistically significant differences in FCC scores between parents' and professionals' were found. Qualitative data revealed positive experiences and perceptions of receiving FCC from professionals "on the ground" across sectors, but negative experiences and perceptions of FCC at the systems level (i.e., administration, funders). These broad experiences emerged as a core theme "System of Exclusion", which integrated the key themes: (1) "The Fight", (2) "Roles and Restrictions of Care", and (3) "Therapeutic Rapport". Professionals and service providers can use findings to ensure that services reflect current conceptualizations of FCC, and decision and policy makers can use findings to recognize systemic barriers to implementing FCC and inform policy change.

Introduction

Autism Spectrum Disorder (ASD) presents a wide range of manifestations and symptoms, with clinical diagnoses determined based on behavioral criteria including impaired social interaction and communication skills, and restrictive and stereotyped behaviors (e.g., preoccupation, rigidities). Co-morbidities include aggression, impulsivity, anxiety, depression, selective feeding, sleep disturbances, sensory sensitivities, seizures, and cognitive delay (American Psychiatric Association, 1994). Thus, the need for resources, supports and services for persons with ASD and their families often occurs daily and across the lifespan, and can vary considerably between persons with ASD, and over time (Mulligan, Steel, MacCulloch & Nicholas, 2010).

Given the pervasive impact that a diagnosis of ASD can have on the daily lives of persons with ASD and their families, treatment and supports for people with ASD should address the needs of the entire family. Family-centered care (FCC) is a broadly defined practice philosophy in which parents and service providers work in partnership, and supports and services coincide with changing needs and priorities of the family. Families are given choice and control over treatment decisions, based on the premise that families are the constant in the child's life and are best suited to determine their child's needs (Woodside, Rosenbaum, King & King, 2001). FCC has been linked with increased parent satisfaction, decreased parent stress, and improved child outcomes (King, King & Rosenbaum, 2004; Woodside et al., 2001). However, disconnects exist between the values and principles that are supported in theory and the realities of everyday practice (Kilmer, Cook &

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Munsell, 2010; Liptak et al., 2006; McWilliam, Snyder, Harbin, Porter & Munn, 2000). Challenges to implementing FCC include family, professional or organizational factors, such as role stress (Beatson, 2008; MacKean, Thurston & Scott, 2005), limited resources (Beatson, 2008), a lack of training or comprehensive understanding of FCC (MacKean et al., 2005; McWilliam, Maxwell & Sloper, 1999), and systems-level policies and procedures that restrict the provision of FCC (Beatson, 2008; Bruns, Sather, Pullman & Stambaugh, 2011; Kilmer et al., 2010; Kogan et al., 2008; MacKean et al., 2005; McWilliam et al., 2000; O'Neil, Palisano, & Westcott, 2001). This paper aims to increase knowledge and understanding of how families of children with ASD experience FCC across service sectors and over time, and how families' and professionals' perspectives of the provision of FCC align.

FCC across service sectors

Although implementing FCC can be challenging, many medical, allied health, education, social and community services recognize its merits and advocate an FCC philosophy (King et al., 2004). Accordingly, perceptions of FCC have been evaluated across a range of environments in which health services occur. A reasonable assumption is that challenges associated with implementing FCC would vary based on service sector because of differing foci, priorities and policies between school (educational), home or community (e.g., church, grocery store) (community), and hospital or clinic (medical) settings. However, very little research has compared perceptions of FCC among sectors (i.e., medical, educational, community) through which services are provided in the context of caring for people with ASD or other populations.

The core symptoms of ASD are not "medical" per se (i.e., exclusive to physical health), so interventions usually occur outside of a medical setting. For example, services for children with ASD are often provided in schools, which are unlikely to practice FCC, especially as children get older (Dyke, Buttigieg, Blackmore & Ghose, 2006; McWilliam et al., 1999). Type of agency (i.e., early intervention, health) has been found to most strongly predict professionals' perceptions of providing FCC to young children and their families, with more positive perceptions for home-based early intervention services than developmental evaluation clinics or a health department (McWilliam et al., 2000). Families' perceptions of receiving FCC varied by service delivery model and service location for processes related to enabling and partnership, coordinated and comprehensive care, and respectful care, but not for the provision of information (King et al., 2004). A hospital-based, interdisciplinary program that treated a specific health care need received higher ratings than services provided for a broad array of health care needs across rehabilitation centers, hospitals, clinics and schools. However, perceptions of FCC across multiple services received simultaneously by a given family were not directly compared.

Parents' versus professionals' perspectives of care

MacKean et al. (2005) investigated conceptualizations of FCC from the perspectives of parents of children with developmental disorders (including ASD) who received, and health care professionals who provided, services through a large children's hospital in Canada. Parents stressed the importance of relational competencies of health care providers (e.g., caring, communication), whereas professionals focused on their roles as information-givers. Overall, parents' reported that their roles in their child's care management were not determined collaboratively; rather, responsibility for care was delegated to parents when parents really desired more help from health-care providers. Overall, parents felt that services reflected an interpretation of FCC defined by experts without parents' input. Leiter (2004) also concluded that determining the "right mix of maternal-professional effort" (p. 846) in implementing FCC is challenging in the context of significant variability in child, family and service characteristics.

Elementary school services were perceived to be less family-centered by parents than teachers (McWilliam et al., 1999). However, similarities in parent and service provider perspectives of FCC for children with physical disabilities have been found (Dyke et al., 2006; Raghavendra, Murchland, Bentley, Wake-Dyster & Lyons, 2007). In these studies, parent ratings were highest for the extent to which they were treated respectfully and poorest for the provision of information they received. Similarly, service providers in both studies rated their provision of respectful and supportive care most highly, and rated their provision of general information lowest. Parents and professionals also both highly rated perceptions of FCC for children with physical disabilities in early intervention settings, but expressed concerns that institutional policies were barriers to implementing FCC (O'Neil et al., 2001). However, these studies were not specific to families of children with ASD.

Studying the distinct needs and experiences of families of children with ASD may be important because their perceptions of disability and their experiences with supports and services often differ from parents of children with other disabilities (Kogan et al., 2008). Of concern, the limited research available on FCC for families of children with ASD suggests that services are often not perceived to be family-centered (Beatson, 2008; Kogan et al., 2008; MacKean et al., 2005). This is surprising because FCC is particularly well suited to complex service needs, common with persons with ASD (Beatson, 2008).

This study aims to: (1) evaluate perspectives of families' of children with ASD in receiving FCC across service sectors; (2) evaluate perspectives of professionals across sectors in providing FCC to families of children with ASD; and, (3) compare parent versus professional perceptions of FCC for children with ASD. We also analyzed perceptions of FCC based on child's age, previously shown to influence perceptions of FCC (Woodside et al., 2001). We hypothesized that: (1) parents would perceive services provided through the community sector (i.e., home-based services) as more family-centered than services provided through the health and education sectors; (2) parents with preschool-aged children would perceive higher levels of FCC than parents of older children; (3) professionals working in the community sector would report providing higher levels of FCC than professionals working in health and education sectors; and, (4) parents and professionals would report similar areas of relative strengths and challenges in the provision of FCC.

Methods

This study represents a subset of data from a larger, mixed-methods study investigating the processes by which families navigate systems of care for young persons with ASD. The Health Ethics Review Board at the affiliated university approved the study. Data were collected in 2011.

Participants

Parents with a child with ASD up to 18 years old ($n = 152$; see Table 1) were recruited from Alberta, Canada, including $n = 86$ surveys returned from a random sample of families registered with the ASD clinic in Edmonton (32% response rate), and $n = 66$ returned from parents recruited through snowball sampling with assistance from Autism Societies throughout Alberta. Responses were anonymous. Parents could provide their contact information