Experiences of Family-Centered Care among Parents of Toddlers with ASD Concerns

Catherine Dick

A thesis
submitted in partial fulfillment of the
requirements for the degree of

Master of Science

University of Washington
2020

Committee:
Wendy Stone
Shannon Dorsey

Program Authorized to Offer Degree:
Psychology

University of Washington

Abstract

Experiences of Family-Centered Care among Parents of Toddlers with ASD Concerns

Chair of the Supervisory Committee:

Wendy Stone

Department of Psychology

Family-centered care is an approach to healthcare that considers the needs and priorities of the whole family. Accessing family-centered care may be of particular importance when concerns for ASD are present, given the central role that healthcare providers play in the diagnostic process, as well as parents' high levels of stress during this period. This study compares experiences of family-centered care across two groups of parents: those with concerns about autism for their toddlers (ASD) and those concerned about other developmental issues (DEV). We also compare experiences with family-centered care across two systems of care frequently accessed by both groups: primary care and Part C Early Intervention. Across domains of family-centered care, there were no differences between concerns groups. Parents experienced a higher degree of family-centered care with Early Intervention providers compared with primary care providers in three of five domains of family-centered care that measured 1) provision of general information, 2) coordinated and comprehensive care, and 3) respectful and supportive care.

Parents of children with autism spectrum disorder (ASD) are often the first to express concerns about their child's behavior or development, typically around 18 months of age (Conrood & Stone, 2004). Parents' concerns about their child's development have been shown to be valid in predicting later developmental diagnoses, including ASD (Glascoe, 2001, Sacrey et al., 2015). Once parents become concerned, an optimal path forward would include a timely ASD evaluation, and early ASD-specialized intervention, for which a formal ASD diagnosis is often a prerequisite. ASD can be reliably diagnosed by a clinician by approximately 24 months of age (Lord et al., 2006; Pierce et al., 2019), and ASD-specialized early intervention improves developmental and behavioral outcomes for toddlers (Dawson et al., 2010; Ingersoll, 2010; Kasari et al., 2015; Landa et al., 2010; Wetherby et al., 2014). Receipt of ASD-specialized intervention during toddlerhood is especially impactful given sensitive periods of development that occur early in childhood, when the brain is most plastic (Dawson, 2008).

However, the reality of this path from concerns to a diagnosis and services is complex. Once parents begin to have ASD concerns for their young child, they face many obstacles in the process of accessing a diagnostic evaluation and ASD-specialized services in the community (Lappé et al., 2018; Mandell, Novak, & Zubritsky, 2005). Recent estimates indicate that the median age of ASD diagnosis in the United States is 4.33 years (Baio et al., 2018); thus, parents who have ASD concerns for their child experience, on average, a delay of 2 years between the time they first become concerned about their child's development, and an eventual ASD diagnosis (Sansosti et al., 2012). Parents experience this delay as extremely stressful (Deschamps et al., 2020, Siklos & Kerns, 2007), and report feelings of uncertainty, helplessness, and worry for their child (Moh & Magiati, 2012).

During this period prior to a diagnosis, parents navigate several systems of care. Two systems of care parents often access during the time between first concerns and diagnosis are a) health care (i.e., primary care) and b) Birth-to-3 (i.e., early intervention [EI]) services. The health care and Birth-to-3 systems have distinct roles, and employ providers from different disciplines, yet families rely on both systems to address early concerns about their child's development. Both systems can be instrumental in families' access to a timely diagnosis and individualized, developmentally appropriate interventions for their child. The complex path between first concerns, a diagnosis, and services relies on effective interactions between a family and providers in these systems. Importantly, beyond providers' role in moving families forward logistically in the process of accessing a diagnosis and services, the *quality* of parents' experiences with providers during this process can impact parents' stress during an already uncertain and difficult time. For example, less perceived collaboration with health care providers (e.g., pediatricians and psychologists) during the diagnostic process has been associated with increased parenting stress (Moh & Magiati, 2012).

Family-centered care is recommended as a best practice approach in the health care system and in Birth-to-3. Family-centered care is characterized by a collaborative partnership between parent and provider in order to provide optimal care for the child within the unique family context. Family-centered care, in contrast to professional-centered or child-centered approaches, takes into account the needs and priorities of the whole family, and is based on the premises that: 1) parents know their children best and want the best for their children; 2) each family is different and unique; 3) optimal child functioning occurs within a supportive family/community context; and 4) the child is affected by stress and coping of other family members (Rosenbaum et al., 1998). This translates into provider behaviors such as: engaging in shared decision-making with parents, identifying the child's strengths and needs, sharing information with the family, communicating clearly, respecting and trusting parents, and considering the psychosocial needs of all family members (Rosenbaum et al., 1998). When families have access to care that is family-centered, parents are more satisfied with care, parents are less stressed, and it results in improved child outcomes (Rosenbaum et al., 1998). Providing family-centered care may also benefit healthcare providers by strengthening parent-provider alliances, increasing patient and family adherence to treatment, improving clinical-decision making, and increasing provider satisfaction (American Academy of Pediatrics, 2003; Auslander, Thompson, Dreitzer, & Santiago, 1997). However, translating family-centered care from theory to practice has resulted in variability in the implementation of this approach (Goldfarb et al., 2010; Kuo et al., 2012).

In health care, the role of the primary care provider (PCP) for families with young children is to conduct well-child visits at specified ages for the purpose of developmental monitoring and referral, and provide medical care for children on an as-needed basis. The American Academy of Pediatrics (AAP) recommends that well-child visits in early childhood occur at 12, 15, 18, 24, 30, 36, and 48 months of age (AAP, 2019). Primary care providers are tasked with developmental "surveillance," or the ongoing process of identifying children who may be at risk for developmental delay over time, and developmental "screening," or using standardized screening tools at specified intervals to assess current developmental risk (Johnson et al., 2007). The AAP recommends ASD screening at both 18- and 24-month well-child visits (AAP, 2019). If developmental risk is identified, PCPs should make referrals for further evaluation and services. Family-centered care has been advocated for in the health care system as a key component of the "medical home" (AAP, 2002). In the medical home model, primary care is considered the hub of all aspects of a child’s care, from which the PCP refers to other specialties or community resources as needed (AAP, 2002). Along with being family-centered, the AAP states that a medical home should be accessible, continuous over time, comprehensive, coordinated, compassionate, and culturally effective (AAP, 2002). The medical home model is considered best practice for the provision of comprehensive pediatric primary care, in particular for the ongoing care of children with special health care needs (AAP, 2002).

The Birth-to-3 system offers federally-funded early intervention services to infants and toddlers with developmental delays and/or disabilities through Part C of the Individuals with Disabilities Education Act (Part C IDEA, 2004). The terms “Part C Early Intervention” and “Birth-to-3” are often used interchangeably to refer to this system; here, the term *early intervention* (EI) will be used. When families have developmental concerns for their child, including concerns about ASD, they are often engaged with EI. Children can receive an array of services through EI, including speech, physical, and/or occupational therapies, and these services are typically delivered in the home. Importantly, EI is a time-limited service that is available until children are 3 years old. Family-centered care has been integral to the mission of IDEA Part C Early Intervention since its inception. In EI, once it has been determined that a child is eligible for services, an assessment process, and collaboration with the family yields an Individualized Family Service Plan (IFSP) that details services the family will receive. Services are also typically provided in the child’s “natural environment,” often the family home.

The degree to which care is family-centered within, and across, these two systems has the potential to greatly impact the family’s path from first ASD concerns to an evaluation and services. For example, in the medical system, breakdown in provider-parent communication is frequently a barrier to early identification of ASD. Parents often first express ASD concerns about their toddler to the child’s primary care provider, and the provider’s response to parent concerns can either facilitate or delay an ASD diagnosis (Zuckerman, Lindly, & Sinche, 2015). When primary care providers respond proactively to parents’ ASD concerns (e.g., conduct developmental tests, make specialist referrals), children receive ASD diagnoses earlier than when providers’ responses are reassuring, passive, or dismissive (e.g., say it is too early to tell, advise a wait-and-see approach; Zuckerman, Lindly, & Sinche, 2015). Parents’ concerns about their child’s development have been shown to be valid (McMahon et al., 2007), yet parents commonly report receiving reassuring or passive provider responses, which leads to delays in diagnosis, as well as anger and frustration for parents during an already challenging time (Ryan & Salisbury, 2012; Zuckerman, Lindly, & Sinche, 2015).

In EI, families have access to services for their child prior to a formal ASD diagnosis, and the degree to which these services are family-centered (i.e., take into account the child’s individual needs as well as the family’s strengths and challenges), is critical to encourage the child’s developmental progress during these early years. Some research has indicated that EI providers self-report a higher degree of provision of family-centered care compared to providers in other systems of care (developmental evaluation centers, health departments; McWilliam, Snyder, Harbin, Porter, & Munn, 2000). However, there is a dearth of empirical work that examines parents’ perceptions of family-centered care in the EI setting. Providers taking parent concerns seriously and engaging in shared-decision making with families in both systems may facilitate a plan of action that leads to a timely diagnosis and developmentally appropriate, individualized services.

Families of children with ASD, even compared to children with other special health care needs, have complex needs and require a high degree of care coordination and support, but they are even less likely to access FCC (Brachlow et al., 2007). Families of children with ASD report being less likely to receive family-centered health care, and are less likely to be satisfied with their child's care (Liptak et al., 2006; Kogan et al., 2008). Families of children with ASD who *do* perceive their care to be family-centered report higher satisfaction with their primary care provider's ability to address the child's ASD-specific needs as well as associated conditions (Carbone et al., 2013). In addition, data from the 2016 National Survey of Child's Health indicate that access to family-centered care among families of children with ASD significantly reduces the odds of having unmet healthcare needs for the child (Karpur, Lello, Frazier, Dixon & Shih, 2018). It is not yet known if the disparity in access to family-centered care between families of children with ASD and families of children with other special healthcare needs (e.g., developmental delay) exists during the pre-diagnostic period, while parents have concerns about these disorders for their toddlers, prior to a diagnosis.

Family-centered care is an important component of quality care that supports both child and parent well-being. It is critical to understand parents' experiences of family-centered care in the systems they access, particularly as parents develop ASD concerns for their toddler and pursue an evaluation and services. The current study compares experiences of family-centered care across two groups of parents: those with concerns about ASD for their toddlers prior to a diagnosis, and those with other developmental concerns for their child (DEV), as well as families' experiences of family-centered care across two systems frequently accessed by both groups: primary care and EI. In addition, families in the current study represented a diverse community sample, which is critical given that difficulties in access to care are exacerbated for families from minority backgrounds (Baio et al., 2018).

Three research questions were addressed: (1) Do parents with ASD concerns vs. DEV concerns differ in their ratings of family-centered care from community providers?; (2) Do parents' ratings of family-centered care differ between their primary care providers (PCPs) and EI providers?; and (3) Does the type of parent concern for the child (i.e., ASD or DEV) moderate the relation between provider type and parent experience of family-centered care?

Method

Participants

Data were collected as part of an ongoing longitudinal, community-based study designed to expedite access to early, specialized services for toddlers for whom there are ASD concerns through provider training. The study includes parents, PCPs, and EI providers in four diverse counties in a Northwestern state. All data for this study were collected from parents *before* the community-based providers received training in ASD-specialized screening and intervention.

Families were recruited to the larger study by participating PCPs and EI providers, who handed out informational flyers and/or sent out email blasts to families of children within the eligible age range. Consistent with the goals of the larger study, different age eligibility criteria were used for children recruited from PCPs (i.e., 16-20 months old) and EI providers (i.e., 16-33 months). Eligibility for the ASD Concerns group and DEV Concerns group was determined via a telephone screening interview conducted with parents prior to the initiation of research procedures. Parents in current study (N=59; PCP-recruited: n=12, EI-recruited: n=47) comprise the subset of families enrolled in the larger study who: (1) had either ASD or DEV concerns for their child, and (2) completed a measure of family-centered care about *both* their PCP and EI providers during their first study timepoint. This study included 37 parents of children with ASD concerns and 22 parents of children with DEV concerns. Families were included in the ASD

Concerns group if they reported that: (1) they, a family member, or a healthcare professional had concerns about ASD (n=28), (2) the toddler screened at-risk for ASD (n=1), or had an ASD diagnosis (n=5), or (3) the parent indicated specific concerns about their toddler's social interaction, *in combination with* concerns about his or her language/communication, motor development, toy play, or sensory behaviors (n=3). Families were included in the DEV Concerns group if the parent endorsed concerns in any of the developmental areas (i.e., social interaction, language/communication, motor development, toy play, sensory behaviors, other) without meeting criteria for ASD concerns. Families in which the child had a severe medical condition (e.g. cerebral palsy, deafness) were excluded from the study.

Concerns groups did not differ on any key child or parent demographic variables (Table 1), including: age of child in months (ASD: *M*=28.03, DEV: *M*=25.77); parent age in years (ASD: *M*=32.70, DEV: *M*=34.91); child sex (ASD: 65% male, DEV: 77% male); child race (ASD: 86.5% white, DEV: 68.2% white); child ethnicity (ASD: 27.0% Hispanic, DEV: 27.3% Hispanic); parent education (ASD: 29.7% 4-year college or more, DEV: 22.7% 4-year college or more; *p*s range from 0.11-0.54).

Procedure

Parents of children who met the screening criteria were sent an online consent form to complete. Upon consent, families received an online survey with a battery of questionnaires that included measures used in the current study. Families were compensated $20 for completion of an online survey. Parents of children in the larger study were sent the questionnaires every three months until their child was 36 months of age. For the purpose of this study, data from only the first study timepoint were used.

Measures

Family Demographic Information Form

Participants completed a brief demographic questionnaire that assesses relevant parent and child demographic variables, such as age, race, ethnicity, parent education, household income, and languages spoken in the home.

Measure of Processes of Care (MPOC-20)

The MPOC-20 (King, King & Rosenbaum, 2004; Table 2) is a parent self-report questionnaire that assesses the extent to which families experience specific behaviors of healthcare providers across five domains of family-centered care: Enabling and Partnership, Coordinated and Comprehensive Care, Respectful and Supportive Care, Providing General Information, and Providing Specific Information. This measure was chosen given its extensive use among families of children with special healthcare needs, including ASD (Carbone et al., 2013; Cunningham & Rosenbaum, 2014; Hodgetts et al., 2013). It demonstrates adequate internal consistency (α=.63-.92), and demonstrates concurrent validity (r=.35-.61) with a measure of patient satisfaction, the Client Satisfaction Questionnaire (King, King & Rosenbaum, 2004; Larsen et al., 1979). All families completed two MPOC-20 questionnaires about their experiences of family-centered care during the previous 3-month period: one for their PCP, and one for their EI provider.

Enabling and Partnership (3 items) measures the extent to which providers encourage parent involvement in the receipt of information and in treatment decisions. Providing General Information (5 items) measures the extent to which providers offer general information about child development, health issues, and community resources. Providing Specific Information (3 items) measures the extent to which providers offer individualized information about the child's health and progress, and share results from assessments. Coordinated and Comprehensive Care

(4 items) measures the extent to which providers look at the needs of the "whole" child and provide consistent care across treatment teams. Respectful and Supportive Care (5 items) measures the extent to which providers treat parents as equals and provide a caring and supportive atmosphere. Parents rate each item on a 7-point Likert scale to indicate the degree to which families experience specific provider behaviors. A rating of 1 indicates "Never," a rating of 4 indicates "To a Moderate Extent, and a rating of 7 indicates to "To a Very Great Extent". Subscale scores were computed by calculating the average rating of items included in that subscale, with higher scores indicating a greater degree of FCC.

Analyses

A 2(Concerns group; between-subjects) x 2(Provider type; within-subjects) mixed-design ANOVA was used for each of the five MPOC-20 subscales to evaluate the impact of type of parent concern and type of provider on parent experience of family-centered care for each domain.

Results

No significant differences between the ASD and DEV concerns group were found for any of the MPOC-20 scales (*p*s range from .07-.71). There were significant main effects of Provider type on three of five MPOC-20 scales (see Figure 1). Parent ratings were significantly higher for EI providers than for PCPs in the areas of: Providing General Information (EI: *M*=5.48, PCP: *M*=4.90; *F*=6.964, *p*=.011); Coordinated and Comprehensive Care (EI: *M*=6.12, PCP: *M*=5.71; *F*=7.213, *p*=.009) and Respectful and Supportive Care (EI: *M*=6.14, PCP:*M*=5.67; *F*=11.409, *p*=.001). No significant differences were found between EI providers and PCPs in the areas of Enabling and Partnership (EI: *M*=5.94, PCP: *M*=5.62; *F*=3.483, *p*=.067), and Providing Specific

Information (EI: *M*=5.78, PCP: *M*=5.64; *F*=0.626, *p*=.432). There were no significant interactions between Provider type and Concerns group for any MPOC-20 scale.

Discussion

This study is the first to: 1) compare parent ratings of family-centered care across health care and EI; and 2) compare ratings of family-centered care between families who have concerns about ASD or other developmental concerns for their toddler. Results revealed that parents' experiences of family-centered care did not differ between parents who had ASD concerns and parents who had other types of developmental concerns for their toddlers for any of the scales. Additionally, the type of concerns parents had for their toddler did not moderate the relation between provider type and parent ratings of family-centered care. However, our results did reveal that across the concerns groups, parent ratings of family-centered care were higher for EI providers than for PCPs in three of the five domains: Providing General Information, Coordinated and Comprehensive Care, and Respectful and Supportive Care. In contrast, no significant differences in ratings for the EI providers and PCPs were found for the other two MPOC-20 domains: Enabling and Partnership, and Providing Specific Information. Differences in parent ratings of family-centered care between PCPs and EI providers suggest that Part C Early Intervention may be a system that is uniquely positioned to provide family-centered care; yet it is encouraging that mean ratings of providers in both systems were relatively high in the current study compared to much of the literature (Carbone et al., 2013).

These results likely reflect differences in training and philosophy between medical practice and early intervention, as well as system-level factors. Family-centered care has been integral to the mission of IDEA Part C Early Intervention since its inception. In EI, an Individualized Family Service Plan (IFSP) is developed upon entry to EI by a team that includes at minimum the family, the child's providers, and a service coordinator. It outlines services to be provided to the child, and states the family's resources, priorities, and concerns. It is periodically reviewed by the team, taking into consideration the child's progress and changes to the family's situation or preferences. This process, fundamental to EI, is inherently family-centered, and is likely highly related to the domain of Coordinated and Comprehensive Care. In contrast, for health care, the movement toward family-centered care has required a conceptual shift from historically considering the physician as the expert, to considering the family as an equal partner in care (Kuo et al., 2012). While family-centered care has been promoted in primary care through the advancement of the medical home, it is not implemented universally. Several barriers to family-centered care in PCP practices have been identified, including: lack of understanding of family-centered care principles; limited knowledge of how to translate guidelines of family-centered care into practice; and provider attitudes and competencies (Bamm & Rosenbaum, 2008; Beatson, 2008; Kuo et al., 2012). In one qualitative study examining parent and provider perspectives on the medical home, while many pediatricians described their role as being advocates, care coordinators, and referral sources, few pediatricians saw themselves as providers of comprehensive ASD care (Carbone, Behl, Azor & Murphy, 2010). Many described challenges with care coordination, and acknowledged lack of understanding of community resources for families of children with ASD (Carbone et al., 2010). A minority of PCPs may believe that family-centered care undermines their professional authority (Bamm & Rosenbaum, 2008).

System-level factors, such as the setting in which care is provided, the frequency of contact with families, and the time available during visits may also explain the advantage for EI compared to primary care in provision of family-centered care. For example, EI providers serve children and families in the child's natural environment, which is often the family home. As such, they have unique access to the family's living conditions, interactions between family members, and family strengths and challenges. These factors may also foster a closeness not available in other contexts. EI providers may see families weekly, whereas PCPs may see families once every few months for well-child visits. Beyond frequency of contact, each EI visit is likely to be longer than a single visit to primary care, which is, on average, 14.5 minutes for a well child visit (Migongo et al, 2012). Length of primary care visits is likely to impact the domain of Respectful and Supportive Care (e.g., parents having enough time to talk and not feeling rushed). Additionally, the time that is required of PCPs to provide coordinated care, a key component of family-centered care, can go well beyond the amount that is reimbursed by insurance (Antonelli & Antonelli, 2004). These systemic factors may hinder, but need not prohibit, provision of family-centered care in primary care settings. However, the manner in which it is approached within these constraints will necessarily differ across the two service delivery systems.

Family-centered care is a broad construct with several components, which may translate into different provider behaviors in primary care compared to EI. The results of this study may suggest possible directions for improving family-centered care in primary care settings. PCPs should be offered relevant continuing education, both related to family-centered practices, and caring for families of children with ASD. Specific emphasis should be placed on treating the parent as an individual and taking their concerns and preferences seriously. Families may also benefit from the development and distribution of materials in their primary care practice that help them learn about child development and available community resources.

Several factors may contribute to the relatively high ratings across systems of care in the current study, compared to the broader literature. First, the current study included families of toddlers; previous research indicates that families of young children with ASD experience higher family-centered care than families of older children with ASD (Hodgetts et al., 2013). Families of young children have support from EI until age 3, which could contribute to this finding. Additionally, families who have ASD concerns for their young toddler, but do not yet have a diagnosis, have yet to experience the arduous process of seeking ASD-specialized services for their child, which could impact their experience within systems of care. The parent ratings in the current study may be elevated to the extent to which they represent providers who chose to participate in the larger study. Unfortunately, we are unable to track the exact number of enrolled providers that parents rated in the current study, but the possibility exists that the providers may be a particularly motivated group who provide a high degree of family-centered care relative to other community providers. Importantly, while mean ratings were relatively high in the current study compared to previous research, variability is apparent in parent ratings (see Figure 1).

We expected to find a difference in ratings of family-centered care between parents with ASD concerns and parents with other developmental concerns for their toddler, given previous findings that families of children with diagnosed ASD are less likely to experience health care that is family-centered, comprehensive, and coordinated compared to families of children with other special health care needs (Brachlow et al., 2007; Kogan et al., 2008). Families of children with ASD are also less likely to be satisfied with their child's health care (Liptak et al., 2006). Importantly, in the current study, the between-subjects main effect of Concerns type used smaller samples than did the within-subjects main effect of Provider type; thus, it is possible that this comparison was under powered to detect an effect. Replication with larger samples is needed.

As noted above, the current study was limited by a small sample size, and by inclusion of providers who chose to participate in the larger study. Given that a proportion of providers that families rated were enrolled in the larger study, the results may not generalize to a broader sample of providers in the community. Though, if enrolled providers represent a group motivated to provide family-centered care, we would expect lower mean ratings in a broader community sample of providers, highlighting the importance of continuing to advance family-centered care. Additionally, this study lacks demographic information about the providers rated by parents, as not all providers were enrolled in the larger study. Future research should examine ratings of family-centered care as they relate to the series of steps involved in screening, referral, and accessing a diagnostic evaluation and ASD-specialized services.

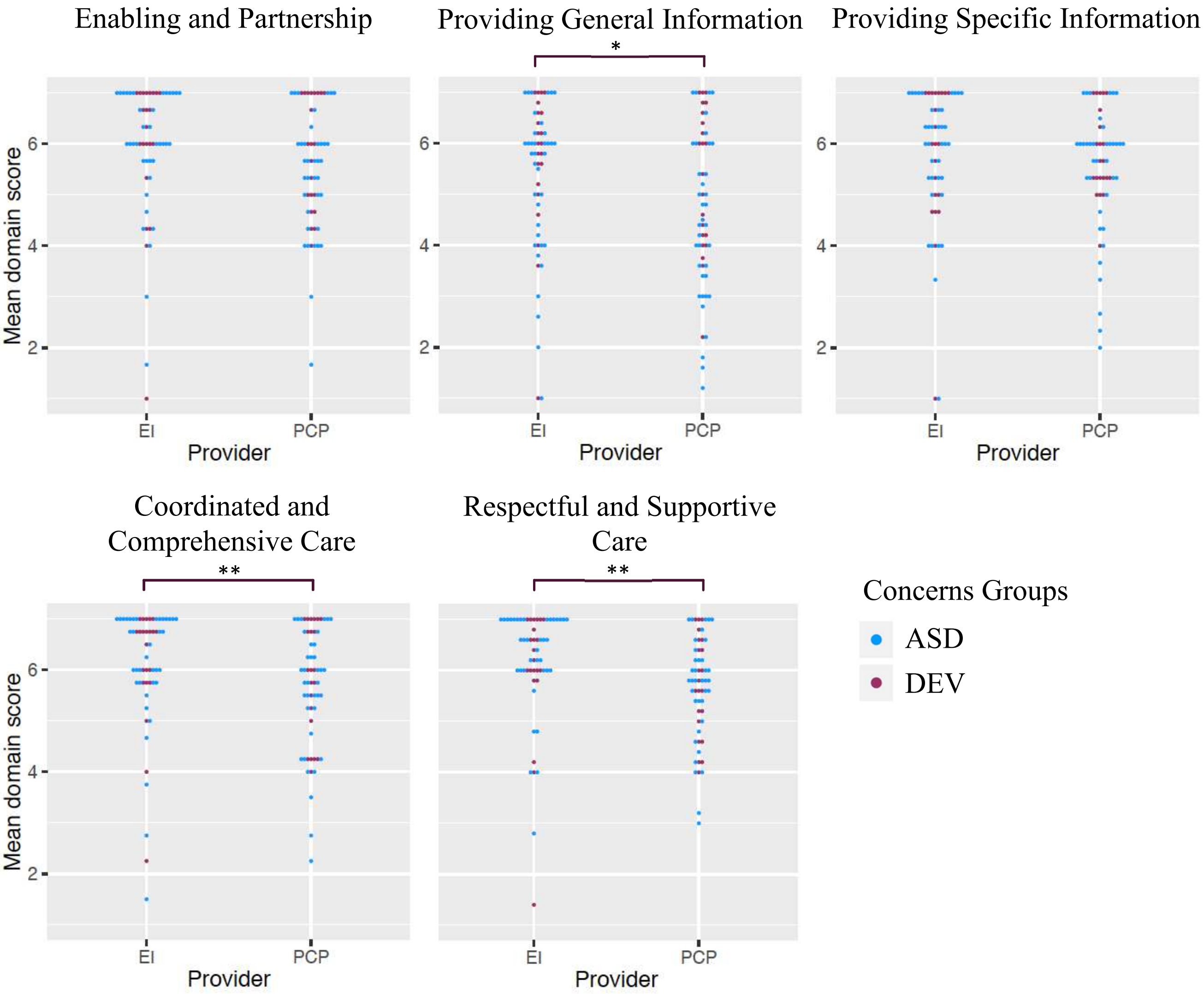
Table 1. Demographics of Parent Concern Groups

	ASD	**DEV**
Child age in mos. M *(SD)*	28.03 *(4.98)*	25.77 *(5.53)*
Child sex (% male)	64.9	77.3
Child race (% white)	86.5	68.2
Child ethnicity (% Hispanic)	27.0	27.3
Parent age in years, M*(SD)*	32.70 *(8.55)*	34.91 *(7.10)*
Parent education level (%)		
Less than high school	5.4	4.5
High school or GED	16.2	13.6
Trade/vocational school, Associate's degree, or some college coursework	48.6	59.1
4-year college	24.3	4.5
Master's degree	5.4	4.5

Table 2. MPOC-20 Domains and Items

Domain	Items
Enabling and Partnership	Providers let you choose when to receive information and the type of information you want to receive
	Providers fully explain treatment choices to you
	Providers provide opportunities for you to make decisions about treatment
Providing General Information	Practice gives you information about the types of services offered at the organization or in your community?
	Practice has information available about your child's health issues (e.g., its causes, how it progresses, future outlook)?
	Practice provides opportunities for the entire family to obtain information
	Practice has information available to you in various forms, such as a booklet, kit, video, etc.?
	Practice provides advice on how to get information or to contact other parents (e.g., organization's parent resource library)?
Providing Specific Information	Providers provide you with written information about health matters related to your child
	Providers provide you with written information about your child’s progress
	Providers tell you about the results from assessments
Coordinated and Comprehensive Care	Providers look at the needs of your “whole” child (e.g., at mental, emotional, and social needs) instead of just physical needs
	Providers make sure that at least one team member is someone who works with you and your family over a long period of time
	Providers plan together so they are all working in the same direction
	Providers give you information about your child that is consistent from person to person
Respectful and Supportive Care	Providers help you to feel competent as a parent
	Providers provide a caring atmosphere rather than just give you information
	Providers provide enough time to talk so you don’t feel rushed
	Providers treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as “mom” or “dad”)
	Providers treat you as an individual rather than as a “typical” parent of a child

Figure 1. MPOC-20 Domain Scores by Provider Type



Note: MPOC-20 scores range from 1-7, where higher scores represent higher ratings of family-centered care in a domain. Each data point represents the mean domain score for a provider, rated by a parent. $*p < .05$, $**p < .01$

References

American Academy of Pediatrics Committee on Practice and Ambulatory Medicine, Bright Futures Periodicity Schedule Workgroup. "2019 Recommendations for Preventive Pediatric Health Care." Pediatrics, vol. 143, no. 3, 2019, doi:10.1542/peds.2018-3971.

American Academy of Pediatrics Committee on Hospital Care Institute for Family-Centered Care (2003). Policy statement: Family-centered care and the pediatrician's role. *Pediatrics, 112*, 691–696.

American Academy of Pediatrics Committee on Practice and Ambulatory Medicine, Bright Futures Periodicity Schedule Workgroup (2019). 2019 Recommendations for Preventive Pediatric Health Care. *Pediatrics*, *143*(3).

American Academy of Pediatrics Medical Home Initiatives for Children With Special Needs Project Advisory Committee (2002). The medical home. *Pediatrics*, *110*, 184-186.

Antonelli, R.C, & Antonelli, D.M. (2004). Providing a medical home: The cost of care coordination services in a community-based, general pediatric practice. *Pediatrics,113*(5), 1522-8.

Auslander, W. F., Thompson, S. J., Dreitzer, D., & Santiago, J. V. (1997). Mothers' satisfaction with medical care: Perceptions of racism, family stress, and medical outcomes in children with diabetes. *Health and Social Work, 22*, 190-199.

Baio, J., Wiggins, L., Christensen, D. L., et al. (2018). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2014. Morbidity and Mortality Weekly Report Surveillance Summaries, 67(6), 1–23.

Bamm, & Rosenbaum. (2008). Family-Centered Theory: Origins, Development, Barriers, and Supports to Implementation in Rehabilitation Medicine. *Archives of Physical Medicine and Rehabilitation, 89*(8), 1618-1624.

Beatson, J. (2008). Walk a mile in their shoes: Implementing family-centered care in serving children and families affected by autism spectrum disorder. *Topics in Language Disorders, 28*(4), 309-322.

Brachlow, A. E., Ness, K. K., McPheeters, M. L., & Gurney, J. G. (2007). Comparison of indicators for a primary care medical home between children with autism or asthma and other special health care needs: National survey of children's health. *Archives of Pediatrics and Adolescent Medicine, 161*(4), 399–405.

Carbone, P. S., Behl, D. D., Azor, V., & Murphy, N. A. (2010). The Medical Home for Children with Autism Spectrum Disorders: Parent and Pediatrician Perspectives. *Journal of Autism and Developmental Disorders*, *40*(3), 317–324. doi: 10.1007/s10803-009-0874-5

Carbone, P.S., Murphy, N.A., Norlin, C., Azor, V., Sheng, X., Young, P.C. (2013). Parent and pediatrician perspectives regarding the primary care of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*, 964-972.

Coonrod, E. E., & Stone, W. L. (2004). Early Concerns of Parents of Children With Autistic and Nonautistic Disorders. *Infants & Young Children, 17*(3), 258-268. doi:10.1097/00001163-200407000-00007

Cunningham, B.J., & Rosenbaum, P.L. (2014). Measure of Processes of Care: A review of 20 years of research. *Developmental Medicine and Child Neurology., 56*(5), 445-452.

Dawson, G. (2008). Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. Development and Psychopathology, 20(3), 775–803. doi: 10.1017/s0954579408000370

Deschamps, T. D., Ibañez, L. V., Edmunds, S. R., Dick, C. C., & Stone, W. L. (2020). Parenting stress in caregivers of young children with ASD concerns prior to a formal diagnosis. Autism Research, 13(1), 82–92. doi: 10.1002/aur.2213

Glascoe, F. P. (1999). The value of parents' concerns to detect and address developmental and behavioural problems. *Journal of Paediatrics and Child Health, 35*(1), 1-8. doi:10.1046/j.1440-1754.1999.00342.x

Goldfarb, F. D., Devine, K., Yingling, J. T., Hill, A., Moss, J., Ogburn, E. S., . . . Pariseau, C. (2010). Partnering With Professionals: Family-Centered Care From the Parent Perspective. *Journal of Family Social Work, 13*(2), 91-99. doi:10.1080/10522150903487081

Hayes, S. A., & Watson, S. L. (2012). The Impact of Parenting Stress: A Meta-analysis of Studies Comparing the Experience of Parenting Stress in Parents of Children With and Without Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 43*(3), 629-642. doi:10.1007/s10803-012-1604-y

Hodgetts, S., Nicholas, D., Zwaigenbaum, L., McConnell, D. (2013). Parents’ and professionals’ perceptions of family-centered care for children with autism spectrum disorders across service sectors. *Social Science & Medicine, 96,* 138-146.

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).

Ingersoll, B. (2010). Brief Report: Pilot Randomized Controlled Trial of Reciprocal Imitation Training for Teaching Elicited and Spontaneous Imitation to Children with Autism.

Journal of Autism and Developmental Disorders, 40(9), 1154-1160. doi:10.1007/s10803-010-0966-2

Johnson, C. P., & Myers, S. M. (2007). Identification and evaluation of children with autism spectrum disorders. Pediatrics, 120(5), 1183–1215. doi: 10.1542/peds.2007-2361

Karpur, A., Lello, A., Frazier, T., Dixon, P. J., & Shih, A. J. (2018). Health Disparities among Children with Autism Spectrum Disorders: Analysis of the National Survey of Children's Health 2016. *Journal of Autism and Developmental Disorders, 49*(4), 1652-1664. doi:10.1007/s10803-018-3862-9

Kasari, C., Gulsrud, A., Paparella, T., Hellemann, G., & Berry, K. (2015). Randomized comparative efficacy study of parent-mediated interventions for toddlers with autism. *Journal of Consulting and Clinical Psychology, 83*(3), 554-563. doi:10.1037/a0039080

King, S., King, G., & Rosenbaum, P. (2004). Evaluating Health Service Delivery to Children With Chronic Conditions and Their Families: Development of a Refined Measure of Processes of Care (MPOC−20). *Children's Health Care,33*(1), 35-57. doi:10.1207/s15326888chc3301_3

Kogan, M.D., Strickland, B.B., Blumberg, S.J., Singh, G.K., Perrin, J.M., van Dyck, P.C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics, 122*(6).

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-Centered Care: Current Applications and Future Directions in Pediatric Health Care. *Maternal and Child Health Journal,16*(2), 297-305. doi:10.1007/s10995-011-0751-7

Landa, R. J., Holman, K. C., O’Neill, A. H., & Stuart, E. A. (2010). Intervention targeting development of socially synchronous engagement in toddlers with autism spectrum disorder: A randomized controlled trial. *Journal of Child Psychology and Psychiatry, 52*(1), 13-21. doi:10.1111/j.1469-7610.2010.02288.x

Lappé, M., Lau, L., Dudovitz, R. N., Nelson, B. B., Karp, E. A., & Kuo, A. A. (2018). The Diagnostic Odyssey of Autism Spectrum Disorder. *Pediatrics, 141*(Supplement 4). doi:10.1542/peds.2016-4300c

Larsen, D. L., Attkisson, C. C., Hargreaves, W. A., & Nguyen, T. D. (1979). Assessment of client/patient satisfaction: Development of a general scale. *Evaluation and Program Planning*, *2*(3), 197–207. doi: 10.1016/0149-7189(79)90094-6

Leiter, V. (2004). Dilemmas in sharing care: Maternal provision of professionally driven therapy for children with disabilities. Social Science and Medicine, 58(4), 837–849.

Liptak, G.S., Orlando, M., Yingling, J.T., Theurer-Kaufman, K.L., Malay, D.P., Tompkins, L.A., Flynn, J.R. (2006). Satisfaction with primary health care received by families of children with developmental disabilities. *Journal of Pediatric Health Care, 20*(4), 245-252.

Lord, C., Risi, S., Dilavore, P. S., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism From 2 to 9 Years of Age. *Archives of General Psychiatry, 63*(6), 694. doi:10.1001/archpsyc.63.6.694

Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors Associated With Age of Diagnosis Among Children With Autism Spectrum Disorders. *Pediatrics, 116*(6), 1480-1486. doi:10.1542/peds.2005-0185

McWilliam, R.A., Snyder, P., Harbin, G.L., Porter, P., Munn, D. (2000). Professionals' and families' perceptions of family-centered practices in infant-toddler services. *Early Education and Development, 11*(4), 519-538.

Migongo, A. W., Charnigo, R., Love, M. M., Kryscio, R., Fleming, S. T., & Pearce, K. A. (2012). Factors relating to patient visit time with a physician. *Medical Decision Making: an International Journal of the Society for Medical Decision Making*, 32(1), 93–104.

Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders, 6*(1), 293-303. doi:10.1016/j.rasd.2011.05.011

Pierce, K., Gazestani, V. H., Bacon, E., Barnes, C. C., Cha, D., Nalabolu, S., . . . Courchesne, E. (2019). Evaluation of the Diagnostic Stability of the Early Autism Spectrum Disorder Phenotype in the General Population Starting at 12 Months. *JAMA Pediatrics, 173*(6), 578. doi:10.1001/jamapediatrics.2019.0624

Rosenbaum, P., King, S., Law, M., King, G., Evans, J. (1998). Family-centred service. *Physical & Occupational Therapy in Pediatrics, 18*(1), 1-20.

Ryan, S., & Salisbury, H. (2012). 'You know what boys are like': Pre-diagnosis experiences of parents of children with autism spectrum conditions. *British Journal of General Practice, 62*(598). doi:10.3399/bjgp12x641500

Sacrey, L. R., Zwaigenbaum, L., Bryson, S., Brian, J., Smith, I. M., Roberts, W., . . . Armstrong, V. (2015). Can Parents' Concerns Predict Autism Spectrum Disorder? A Prospective Study of High-Risk Siblings From 6 to 36 Months of Age. *Journal of the American Academy of Child & Adolescent Psychiatry, 54*(6), 470-478. doi:10.1016/j.jaac.2015.03.014

Sansosti, F. J., Lavik, K. B., & Sansosti, J. M. (2012). Family Experiences Through the Autism Diagnostic Process. *Focus on Autism and Other Developmental Disabilities, 27*(2), 81-92. doi:10.1177/1088357612446860

Siklos, Susan, & Kerns, Kimberly A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities., 28*(1), 9-22.

Wetherby, A. M., Guthrie, W., Woods, J., Schatschneider, C., Holland, R. D., Morgan, L., & Lord, C. (2014). Parent-Implemented Social Intervention for Toddlers With Autism: An RCT. *Pediatrics, 134*(6), 1084-1093. doi:10.1542/peds.2014-0757

Zuckerman, K. E., Lindly, O. J., & Sinche, B. K. (2015). Parental Concerns, Provider Response, and Timeliness of Autism Spectrum Disorder Diagnosis. *The Journal of Pediatrics*, *166*(6). doi:10.1016/j.jpeds.2015.03.007