UNDERSTANDING HEALTH CARE DISPARITIES AMONG FAMILIES OF CHILDREN WITH ASD: THE ROLE OF ADVOCACY, EMPOWERMENT, AND PARENT-PROFESSIONAL PARTNERSHIPS

By

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ABSTRACT

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Children with Autism Spectrum Disorder (ASD) utilize a greater number of health care services compared to children with other developmental disabilities. Despite this, children with ASD remain at high risk for unmet service needs, which are compounded by differences in SES. Additionally, these families experience low levels of service satisfaction and poor relationships with their service providers, prompting them to engage in advocacy on behalf of their child. This study aimed to understand the contributions of advocacy, empowerment, and parent-professional partnerships to service disparities in families of children with ASD using parental education as a proxy for SES. First, a quantitative measure of advocacy specific to this population was validated. Second, the relationship between education and service outcomes in families and children with ASD was confirmed. Third, possible mediators of service disparities were examined. Finally, predictors of parent advocacy were explored. The results of the current study strengthen claims in the literature that families of children with ASD experience high levels of unmet needs which are exacerbated by low levels of education, and that parent-professional partnership plays a role in explaining these service disparities. As such, increasing parent-professional partnerships through family-centered care and professional training may help to reduce service disparities and improve satisfaction with care for families and children with ASD. Additionally, advocacy and empowerment should be researched further, as they appear to have important roles in helping families of children with ASD access services.

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by persistent deficits in social communication and interaction, as well as restricted and repetitive patterns of behaviors and interests (American Psychiatric Association, 2013). The prevalence of ASD is increasing (Blumberg et al., 2013), with most recent estimates suggesting that it affects 1 in every 68 children (Centers for Disease Control and Prevention, 2014). This increasing rate of diagnosis is compounded by the fact that children with ASD have complex service needs. Specifically, children with ASD tend to exhibit more challenging behaviors (Matson, Wilkins, & Macken, 2008) and experience a higher number of concurrent behavioral and emotional disturbances (Gurney, McPheeters, & Davis, 2006) compared to other children with special health care needs (CSHCN; e.g., behavioral or conduct problems, intellectual or developmental disability, anxiety or related disorders, ADHD, depression, chronic medical conditions, etc.). In addition, families of children with ASD experience increased stress (Burke & Hodapp, 2014; Duarte, Bordin, Yazigi, & Mooney, 2005; Koegel et al., 1992) and decreased quality of life (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Lee, Harrington, Louie, & Newschaffer, 2008) compared to families of children with other developmental disabilities, such as Down Syndrome.

As a result, families of children with ASD utilize a greater number and range of health care services than other families of CSHCN (Gurney et al., 2006; Tregnago & Cheak-Zamora, 2012). For example, based on the National Survey of Children’s Health, parents report that their children with ASD experience more physical health concerns, are more likely to use prescribed medications (and if so, for long-term use), attend more emergency and non-emergency physician visits, and receive increased counseling and therapy services than children without ASD (Gurney et al., 2006).

Despite their more complex health needs and increased service use, children with ASD remain at an especially high risk for unmet service needs compared to other CSHCN (Chiri & Warfield, 2012). The rate of service use by families and children with ASD is much lower than expected given the high prevalence rate of ASD (Ruble, Heflinger, Renfrew, & Saunders, 2005). Difficulty accessing services may be due to a limited number of qualified professionals who specialize in working with children with ASD (Ruble et al., 2005; van Eys & McLaughlin, 2002), resulting in long waitlists, difficulty obtaining referrals, and issues securing appointments with experienced and skilled professionals (Chiri & Warfield, 2011; Krauss, Gulley, Sciegaj, & Wells, 2003). These factors lead families to feel more dissatisfied with the services they do receive compared to families of other CSHCN (e.g., Bitterman, Heflinger, Northrup, Sonnichsen, & Schilling, 2008; Liptak et al., 2006; Montes, Halterman, & Magyar, 2009). This discrepancy between service needs and service use may also be due in part to the increased financial costs required to provide care to children with ASD compared to other CSHCN (Tregnago & Cheak-Zamora, 2012; Wang, Mandell, Lawer, Cidav, & Leslie, 2013; Wang & Leslie, 2010).

Historically, insurance coverage has not been provided for ASD-specific services (Chang et al., 1998; Stuart, 2011; van Eys & McLaughlin, 2002). This lack of coverage leads to increased out-of-pocket costs for families (Järbrink, Fombonne, & Knapp, 2003; Ganz, 2007; Montes & Halterman, 2008), which continue despite recent insurance reforms to make service coverage for children with ASD more comprehensive (Stuart, 2011; Wang et al., 2013). Moreover, the burden of caring for a child with ASD often causes parents to quit, change, or refuse jobs (Leiter, Krauss, Anderson, & Wells, 2004; Liptak et al., 2008) resulting in a substantial loss of income (Montes & Halterman, 2008), making it even more difficult for families to afford these services. As these financial stressors accumulate, families of children with ASD report increased issues accessing and obtaining appropriate care (Krauss et al., 2003).

Issues with service access and unmet needs are further compounded by differences in SES. ASD is less likely to be diagnosed in children from low-SES backgrounds (Durkin et al., 2010; Thomas et al., 2011). When these children are identified, diagnosis occurs much later (Thomas et al., 2011) and their families access less early intervention and ASD-specific services than their high-SES peers (Magaña, Lopez, Aguinaga, & Morton, 2013). Access to care may also be affected by the ability to physically access available services. For example, low-SES families have difficulty accessing the transportation necessary for their children with ASD to attend services (Zeman, Swanke, & Doktor, 2011). These families often lack the resources and flexibility in their daily schedules to seek out and to obtain additional services for their children with disabilities (Coots, 1998; Trainor, 2010a). In addition, low-SES families are less knowledgeable about available ASD services (Pickard & Ingersoll, 2016), which may make them less likely to seek out additional services compared to their high-SES peers (Porterfield & McBride, 2007). As early, specialized intervention is one of the best predictors of successful outcomes for children with ASD (Johnson & Meyers, 2007; Meyers & Johnson, 2007), delayed or forgone access to specialized care can be expected to lead to poorer long-term outcomes for the child and their family. Indeed, children with ASD from low-SES backgrounds tend to be more severely affected than children from high-SES backgrounds (Liptak et al., 2008; Mayes & Calhoun, 2011; Thomas et al., 2011). Taken together, it is clear that the service needs of families and children with ASD are not being met, especially for families from low-SES backgrounds.

This link between health outcomes and SES is not unique to ASD. In general, children from low-SES households have greater unmet health care needs and poorer overall health outcomes (Bradley & Corwyn, 2002; Kataoka, Zhang, & Wells, 2002; Newacheck, Hughes, Hung, Wong, & Stoddard, 2000). There are a number of behavioral, psychological, and social factors that may help explain the relationship between education and access to care (Adler et al., 1994; Adler & Ostrove, 1999; Bradley & Corwyn, 2002; Williams, 1990), which also apply to families of children with ASD and other developmental disabilities (Coots, 1998; Magaña et al., 2013; Trainor, 2010b). As families and children with ASD are already at increased risk, it is important to understand how these mechanisms may further impact service disparities in this population more specifically. Three possible psychosocial mechanisms that are relevant for service access in families of children with ASD are explored: advocacy, empowerment, and parent-professional relationships, respectively.

Behavioral mechanism: Advocacy

Parent advocacy involves acting on behalf of one's child with special needs to resolve issues, obtain services, or promote change. Parent advocacy is seen as an essential aspect of ensuring quality of life and protecting the rights of individuals with intellectual and developmental disabilities (American Association on Intellectual and Developmental Disabilities & The Arc, 2010). For example, parents may attend workshops to learn about their child's special needs, read about special education rights, learn effective communication strategies, build relationships with their child's service providers, ask questions about the services their child receives, and engage in procedural safeguards when their child's needs are not being met. Advocacy may help to reduce service disparities in families of children with special needs by improving access to services through increasing knowledge, communication and problem-solving skills, and involvement in decision making (Coots, 1998; Trainor, 2010a), making it an essential skill for families of children with ASD who have high levels of unmet needs and dissatisfaction with service providers.

Given their difficulty accessing and affording appropriate services, as well as their dissatisfaction with the services they do receive, it is perhaps not surprising that parents of children with ASD are more likely to advocate for services compared to families of other CSHCN in order to meet their needs (Burke & Goldman, 2015; Mueller & Carranza, 2011). However, not all types of advocacy are successful (Coots, 1998; Trainor, 2010a). Low-SES families are less likely to utilize effective strategies when approaching providers and advocating for additional or unmet service needs (Coots, 1998; Trainor, 2010a); this is especially clear within the school system. For example, parents from low-SES backgrounds will often accept basic services suggested by the school, instead of independently seeking out or suggesting additional services that are individualized to the child (Coots, 1998). Low-SES families are also more likely to use intuition about their child's perceived strengths and weaknesses when advocating, instead of using more concrete information, such as assessment data and diagnostic status which is often more powerful with professionals (Trainor, 2010a). Additionally, families from diverse backgrounds feel that schools are not responsive to their child's needs (Levine & Trickett, 2000) and that they have a negative view of parents and their children (Shapiro et al., 2004), which reduces their likelihood of initiating or engaging in future advocacy actions (Harry, Allen, & McLaughlin, 1995). Taken together, SES may have an influence on whether parents engage in advocacy, and if so, whether the types of advocacy strategies they utilize are effective. Thus, parent advocacy may be an important mechanism to explain differences in service access among low-SES families with ASD. If so, helping low-SES families engage in more successful advocacy strategies may help to reduce service disparities among low-SES families.

There is evidence that training parents in advocacy skills, such as communication skills and problem-solving strategies, can lead to increased service attainment and satisfaction with received services for families of a child with a disability (Balcazar, Keys, Bertram, & Rizzo, 1996; Gross, 1996; Siller, Reyes, Hotex, Hutman, & Sigman, 2014; Wright & Taylor, 2014). Additionally, participation in advocacy training is related to improvements in family well-being, self-esteem, and parental self-efficacy (Dixon et al., 2001; Siller et al., 2014; Wright & Taylor, 2014). However, engaging in advocacy has been shown to lead to increased emotional and financial stress, decreased support, and feelings of alienation and isolation (Burke & Hodapp, 2014; Ewles, Tessen, & Minnes, 2014; Fazil, Wallace, Singh, Ali, & Bywaters, 2004; Resch et al., 2010; Shapiro et al., 2004). Given these risks, it is necessary to explore how advocacy may be involved in the relationship between SES and service disparities for families of children with ASD compared to other possible mechanisms before urging parents to take action on behalf of their child.

Psychological mechanism: Empowerment

While advocacy is used to describe concrete behaviors such as attending workshops or engaging procedural safeguards, psychological empowerment reflects a feeling of control over one’s life and an ability to effectively meet one’s own needs through personal action or collaboration (Dempsey & Foreman, 1997). Empowerment is directly related to improved family and child outcomes (Cunningham, Henggeler, Brondino, & Pickrel, 1999). Empowerment can help reduce worry and displeasure associated with caring for an individual with a mental illness (Dixon et al., 2001), as well as increase family functioning, parent-professional partnerships, and satisfaction with services (Resendez, Quist, & Matshazi, 2000). In parents of children with ASD, increased levels of empowerment were related to improved parental self-efficacy (Puttahraksa, Tilokskulchai Sitthimongkol, Prasopkittikul, & Liknapichitkul, 2006) and fewer parent mental health and child behavior problems (Weiss, Cappadocia, MacMullin, Viecili, & Lunsky, 2012). On the other hand, low levels of empowerment are related to alienation, increased stress, and poor family functioning (Nachshen, 2004; Scheel & Rieckmann, 1998).

Given that families from low-SES backgrounds are less likely to be aware of effective services that are available for their children (Pickard & Ingersoll, 2016), they may not be confident in the types of services their child may benefit from. In fact, low-SES families are less likely to report having unmet needs, despite receiving fewer services (Porterfield & McBride, 2007). Parents who completed an intervention designed to increase empowerment felt more confident in their skills and more knowledgeable about how to navigate the mental health care system (Bickman, Heflinger, Northrup, Sonnichsen, & Schilling, 1998), which may make empowerment an important independent predictor of the ability to access services in low-SES families.

Social mechanism: Parent-Professional Partnerships

In addition to decreased access to satisfactory services, families of children with ASD are less likely to receive family-centered, comprehensive, and well-coordinated care than other families of CSHCN (Brachlow, Ness, McPheeters, & Gurney, 2007; Kogan et al., 2008; Krauss et al., 2003). This is particularly problematic given that family-centered care (which focuses on support, mutual respect, and collaboration between parents and professionals) promotes parent-professional partnership, positive family and child outcomes, and access to high quality health care services (American Academy of Pediatrics Committee on Hospital Care, 2012; Bickman et al., 1998; Dempsey & Keen, 2008). Furthermore, parents from low-SES backgrounds are less likely to experience family-centered care (e.g., Guerrero, Chen, Inkelas, Rodriguez, & Ortega, 2010; Montes & Halterman, 2011), making parent-professional partnerships an important factor when examining SES-related health disparities in families of children with ASD.

Parents who have high quality parent-professional partnerships are likely to be more satisfied with their current services and less likely to express a high level of unmet service needs (Burke & Goldman, 2015; Summers et al., 2007; Trainor, 2010b; Wang, Mandell, Lawer, Cidav, & Leslie, 2004). Low-SES families of children with ASD are less satisfied with their service providers and the services they receive (e.g., Hidalgo, McIntyrem & McWhirter, 2015). Additionally, the quality of parent-professional partnerships affects family and child outcomes in families of children with ASD (e.g., Brookman-Frazee, 2004; Burke & Hodapp, 2014; Summers et al., 2007). For example, when clinicians engaged parents in the treatment process by collaborating on treatment targets, techniques, and opportunities for implementation, parents of children with ASD experienced less stress and had better quality parent-child interactions than in a clinician-directed treatment process; children were also more responsive and appropriately engaged during these interactions (Brookman-Frazee, 2004). Unfortunately, families of children with ASD generally experience less collaboration and more dissatisfaction with the services they do receive (e.g., Liptak et al., 2006; Montes et al., 2009), which may indicate poor relationships with providers. These families report feeling less confident in their provider’s expertise and are more critical of their provider’s knowledge and qualifications when compared to families of children with physical or intellectual disabilities (Liptak et al., 2006). For example, families of children with ASD are likely to disagree with their providers about needed services (Sperry, Whaley, Shaw, & Brame, 1999) and are more likely to seek out alternative treatments (Levy &

Hymen, 2005). Due to their difficulty accessing and affording appropriate services, as well as their dissatisfaction with the services they do receive, families of children with ASD often have poor quality relationships with their providers. As low-SES families of children with ASD are even less likely to experience quality parent-professional partnerships, it may be an important mechanism in understanding service disparities.

Study Aims

As families have a finite amount of time, energy, and resources, it is important to understand what factors influence a family's ability to access services; advocacy, empowerment, and parent-professional partnerships all appear to play important roles in child and family outcomes, and may be important mechanisms for explaining service disparities among low-SES families of children with ASD. Unfortunately, many studies on advocacy do not give clear definitions of the expected behaviors or training components, but focus instead on parental perceptions and related outcomes such as knowledge, attitudes, and services. Additionally, much of the research on the outcomes and risks associated with parent advocacy relies on qualitative information (e.g., Fazil et al., Levine & Trickett, 2000, Shapiro et al., 2005; Trainor, 2010a). This makes it difficult to understand the relative contributions of specific advocacy behaviors versus empowerment and parent-professional partnership to service outcomes in families of children with ASD.

While specific advocacy training programs improve service outcomes in families of children with ASD (e.g., Siller et al., 2014), they often involve multiple components, some which include specific advocacy behaviors, but also address empowerment and parent-partnerships. Empowerment is seen as highly related to advocacy (Dixon et al., 2001; Wright & Taylor, 2014), making it difficult to disentangle the effects of the actual behaviors from the attitudes that parents may have. For example, empowerment trainings for families of children with ASD often involve direct instruction on navigation and advocacy within the health system, as well as how to build positive partnerships with providers (e.g., Puttahraksa et al., 2006). Additionally, trainings that are meant to target parent-professional partnerships also address family empowerment, communication skills, and problem solving strategies (e.g., Bickman et al., 1998; Murray, Ackerman-Spain, Williams, & Ryley, 2011). To disentangle the effects of specific behaviors from other related constructs such as empowerment and parent-professional partnerships, it is necessary to have appropriate measures of advocacy behaviors.

Upon reviewing the literature for advocacy in parents of children with developmental disabilities, only three quantitative measures of advocacy were found: the Family Advocate Service Checklist (FASC; Davis, Gavazzi, Scheer, & Uppal, 2011), Parent Advocacy Scale (PAS; Nachschen et al., 2001), and Special Education Rights and Advocacy Scale (Burke & Hodapp, under review). The FASC (Davis et al., 2011) was developed as an advocacy tracking tool that measure the frequency, duration, mode, purpose, and location of advocacy behaviors. This tool was meant to be used by professional parent advocates tracking their work with families, so the utility of the FASC for research purposes or with families has not been determined. The PAS (Nachshen, Anderson, & Jamieson, 2001) is a structured interview for parent advocacy across five domains given by Balcazar and colleagues (1996): membership in organizations, role in organizations, number of advocacy actions, focus of actions, and how parents feel about their roles in advocacy and their community. While this measure has acceptable psychometric properties in families of children with developmental disabilities, including ASD, the interview format makes it more difficult to use and code in a large-scale study. The Special Education Rights and Advocacy Scale (Burke & Hodapp, under review) is a rating-scale questionnaire that is more specifically geared towards parent advocacy in special education. However, parents of children with ASD advocate in many systems, not just in the school. As a result, it was necessary to develop a quantitative measure of advocacy behaviors that captures the breadth of advocacy behaviors that parents of children with ASD are likely to engage in. Additionally, a rating scale format as compared to an open-ended interview would make the tool more accessible and versatile for use in future research.

In response to these concerns, the **first aim** of this study was to create a measure of advocacy that captures the range of behaviors that parents of children with ASD are likely to engage in. As children with ASD receive services from many organizations and many advocacy behavior scales are open-ended, current advocacy behavior scales do not capture an adequate range of behaviors or are not suitable for surveys. The final scale of behaviors was based on existing measures and validated within the context of the study. The **second aim** was to better understand the relative quantitative contributions of education, advocacy, empowerment and parent-professional partnerships to service outcomes in families of children with ASD given the complex relationships among the variables of interest and a primarily qualitative body of literature. Education was chosen over other strategies to approximate SES such as income and occupation (Hollingshead, 1975; Krieger, Williams, & Moss, 1997; Shavers, 2007) because it is not dependent on parental age (Shavers, 2007) and is stable among families of children with disabilities (Seltzer et al., 2001). Additionally, while education is one of the most common measures of SES (Krieger, Williams, & Moss, 1997; Shavers, 2007), each factor can have different effects on health outcomes (e.g., Winkleby , Jatulis, Frank, & Fortmann, 1992). As such, this article will talk specifically about the effect of education on health care disparities. This project aims to replicate previous research using a new measure of advocacy and answer the following three questions: 1) Does parental education predict service outcomes? 2) Do parent advocacy, empowerment, or parent-professional partnership explain the relationship between parental education and service outcomes? 3) What predicts engagement in parent advocacy?

METHODS

Participants

Parents of a child with ASD (including Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified) between the ages of 3 and 22 were invited to participate in this study. Flyers describing the study were distributed via email to families by established, Michigan-based networks for parents of children with special needs, including the Association for Children's Mental Health of Michigan, Autism Alliance of Michigan, Michigan Alliance for Families, and Mid-Michigan Autism Association. Information about the study was also posted publically on each group's website and posted to local social media forums for parents of children with ASD. In addition, community service providers working in low-income intermediate school districts (ISDs) were identified using the Small Area Income and Poverty Estimates school district data (U.S. Census Bureau, 2014). Interested providers posted flyers, forwarded information directly to families, or made materials available to families on site. All research materials and methods were approved by the Michigan State University IRB.[1]

Two-hundred seventy seven individuals initiated participation in the study. A total of 35 participants were excluded as they did not identify themselves as a parents (*n*=7) or attempt all survey measures (*n*=28). Of those who did not complete the study, only six (21.4%) provided any partial data; thus a comparative analysis of completers and non-completers could not be

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[1] The study was also submitted to two Community Mental Health (CMH) review boards in order to recruit from underrepresented populations; however, CMH internal review was not completed within the timeframe of this project.

performed. Missing item-level data on rating scales was imputed using group means before summing the rating scales; this was only necessary for 15 items total across two rating scales. Missing demographic data were not imputed. The final sample consisted of 242 parents (76% mothers; see Table 1 for parent characteristics) with a child with ASD between 3 and 20 years of age (*M*=9.85, *SD*=4.06; 87.2% male; see Table 2 for child characteristics). The families were receiving services in 44 different states: 36% from Michigan, 8% from California, 5% from New York, and less than 5% for all other states individually. Most families completing the study heard about it from a friend or family member (25%), saw it online (24%), saw a flyer (18%), received an e-mail (17%), or heard about it from a professional or provider (11%).

Measure Development

For two of the primary constructs, service use and parent advocacy, there were no existing measures appropriate for surveying families of children with ASD. Thus, the first step was to develop measures of these constructs. As part of the development process, both measures were given to five professional advocates and/or service providers. Recommendations informed edits to the content and organization of the measures. One of the service providers focused specifically on ensuring the content would be clear to low-income families receiving services within the community mental health system. After addressing recommendations from professionals, four families completed the measures and a brief feedback phone call. The finalized scales took into account both parent and professional recommendations.

The Services Inventory (Summers et al., 2007) was modified to better capture interventions used by families of children with autism. The original Services Inventory is made up of 27 child- and family-oriented services that are commonly used by children with special needs; eight additional services were added to the questionnaire based on the common service needs of parents of children with ASD (e.g., Bono, Daley, & Sigman, 2004; Hess, Morrier, Heflin, & Ivey, 2008; Pickard & Ingersoll, 2016; Ruble et al., 2005). Four services that were not relevant for children with ASD (e.g., transportation and mobility services, hearing and vision services) were removed and an additional four services were combined into one option. The final scale included 28 different child- and family-focused services (see Appendix A).

To develop a quantitative measure of parent advocacy behaviors relevant for families with ASD, an initial set of advocacy actions was gathered from current advocacy interviews and scales for families of children with developmental disabilities, including the Family Advocate Service Checklist (FASC; Davis et al, 2011), Parent Advocacy Scale (PAS; Nachschen et al., 2001), and Special Education Rights and Advocacy Scale (SERAS; Burke and Hodapp, under review), as well as general advocacy programs, interventions, and guidelines for families of individuals with disabilities. Compiled behaviors from the above sources were simplified by combining like items and discarding items that are not applicable to this population. Additionally, as parents of ASD interact with a large number of service systems (Gurney et al., 2006), responses to certain items were requested in each of four settings: school system, insurance coverage, intervention services, medical care. The resulting Autism Advocacy Scale is presented in Appendix B.

Procedure

Participating parents completed the study using the online survey software Qualtrics; three families requested a paper copy of the survey. Paper surveys were entered into Qualtrics by the author and double checked by a member of the research staff. The survey was piloted on five families to ensure that the flow and content was appropriate for this population before being distributed. Parents had access to the survey for 1 week; excluding outliers (*z*-score > 3.5; *n*=2), average completion time for the online survey was 27.63 minutes. See Table 3 for an overview of all measures given, the order of administration, and reliability of individual scales.

Measures

Parent Demographics. Parents provided basic demographic information about themselves including their gender, race/ethnicity, employment status and job, level of education, marital status, yearly family income, and state of residence.

Parental Education. Parental level of education was used as an indirect measure of SES. Parental education was measured on a 7-point scale ranging from less than 7th grade education to graduate degree. Parents with less than a 4-year college education were considered less educated (N=92, 37.9%), and those with a 4-year college education and higher were considered more educated (N=151, 62.1%).

Child Characteristics. Parents also provided information about their child's age, gender, race/ethnicity, and symptom severity. Symptom severity was measured using the Autism Behavior Checklist (ABC; Krug, Arick, & Almond, 1980a, 1980b). The ABC measures symptoms of autism and related difficulties through endorsements of 57 yes/no questions. Item endorsements are scored based on perceived symptom severity. For example, a "yes" response to an item symptom deemed less severe would be scored as a 1, while a more severe symptom endorsement would be scored as a 4. A total severity score was calculated by summing all items. Cronbach's alpha (1951) indicated acceptable internal consistency within the current population (α=0.81), which is consistent with reliability estimates in the literature (e.g., Krug et al., 1980b; Rellini, Tortolani, Trillo, Carbone, & Montecchi., 2004; Volkmar et al., 1988).

Service Use. A modified version of the Services Inventory (Summers et al., 2007) was used to measure service use, needs, adequacy, and satisfaction. Parents were asked to indicate whether they receive, need but do not receive, or do not need each of 28 services. The services were broken down into three categories of services: 1) common intervention services for children with ASD, such as applied behavior analysis (ABA), speech therapy, and special education; 2) ancillary services, such as primary or specialty medical care, case or medication management, and residential treatment services; and 3) family support services, such as respite care, assistance paying bills, and parent-training. For each service they reported receiving, parents were asked to indicate how many hours they received (less than 1 hour a week; 1-5 hours a week; 6-14 hours a week; 15 or more hours a week) and how satisfied they were with service (not satisfied, somewhat satisfied, satisfied). Service adequacy was measured as the ratio of total services received to the total number of services needed and received. As service adequacy is based on parental perceptions of what services are needed, additional information about received services was gathered to determine if parental perceptions were consistent with more objective measures, such as service hours or total number of services received. The relationship between these variables was high (hours: r=.74, p<.001; services received: r=.85, p<.001), indicating that parents' perceptions of service adequacy were consistent with the amount of services they received.

Parent Advocacy. The Autism Advocacy Scale was used to measure parent engagement in advocacy behaviors. Parents were asked how often they engage in 12 advocacy actions on a 5-point scale from *never* to *very often*. Seven of these actions were subdivided into four different advocacy areas (school system, insurance coverage, intervention services, medical care) resulting in a total of 33 items. Higher scores are indicative of greater engagement in specific advocacy behaviors. Internal reliability obtained for this measure was good (Cronbach's α=.95). Additional analysis was done to examine the validity of the measure, as well as the underlying factor structure (See *Results*).

Parent Empowerment. The Family Empowerment Scale (FES; Koren, Dechillo, & Friesen, 1992) measures empowerment in families of children with emotional, behavioral, or mental disabilities. The FES contains 34 statements related to attitudes, knowledge, and behaviors regarding family, systems, and community level advocacy. Parents are instructed to rate each statement on a 5-point scale from not true at all to very true. Koren and colleagues (1992) conceptualized a four factor model of empowerment (systems-level advocacy, knowledge, competence, and self-efficacy); Singh and colleagues (1995) performed an independent validation that found four similar factors. Based on the inter-correlation of the individual factors (r=.63-.77, Koren et al., 1992; r=.62 to .71, Singh et al., 1995), an overall sum score of empowerment is used in analysis. Internal consistency was high (Cronbach's α=.93) and consistent with established levels (e.g., Koren et al., 1992; Singh et al., 1995).

Parent-professional Partnership. The Family-Professional Partnership Scale (FPPS; Summers et al., 2005) was used to measure the quality of the parent-professional partnership. Parents were asked to rate the provider with whom they interacted most frequently. The scale consists of 18 items rated on a 5-point scale from *very dissatisfied* to *very satisfied*. These items are related to professional skills, commitment, respect, trust, communication, and equality for both child and family relationships. The overall sum of the relationship quality is used in analysis and indicated good internal consistency (Cronbach's α=.92), consistent with established estimates (e.g., Summers et al., 2005; Summers et al., 2007).[2]

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[2] The Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983) was also administered as a measure of global stress. However, internal consistency was unacceptably low (α=.48) compared to established estimates (α=.78; Cohen et al., 1988), indicating that this measure may not be appropriate to use in this population. As such, it was dropped from analysis.

RESULTS

Summaries of parent and child characteristics are located in Table 1 and Table 2 respectively. Despite recruitment efforts aimed at increasing the racial and socioeconomic diversity of participants (e.g., multiple means of participation, targeting community agencies, providing monetary compensation, developing community partnerships; Ejiogu et al., 2011), parents were primarily White, non-Hispanic (n=200; 82.6%), and the majority had obtained a college degree or higher (n=151, 62.4%). It should be noted that our sample included no participants at the lowest educational levels (e.g., less than high school); of families without college degrees (n=91), the majority reported having attended as least some college or trade school (n=75, 81.4%). While this sample is less diverse than some (e.g., Mandell et al., 2007; Thomas et al., 2012), it is similar to many survey-based studies in families of children with ASD (e.g., Liptak et al., 2008; Matson et al., 2008; Sperry et al., 2010; Weiss et al., 2012).

Participating parents were mostly mothers (n=184; 76%). Independent samples t-tests indicated that mothers rated their children as being less severe (M=69.25, SD=24.75) compared to fathers (M=77.95, SD=21.29; $t(240)$=2.40, p=.019, d=.38). Mothers also reported lower quality parent-professional partnerships (Mothers: M=70.79, SD=9.53; fathers: M=76.12, SD=6.44; $t(240)$=3.98, p<.001, d=-.66) and service adequacy (Mothers: M=0.38, SD=0.24; fathers: M=0.59, SD=0.31; $t(240)$=5.35, p<.001, d=.76). There were no differences in advocacy behaviors (p=.955, d=.01), empowerment (p=.219, d=-.18), income (U=4687, p=.203, r_{rb} =.10), or education (U=5232, p=.808, r_{rb}=.03) between mothers and fathers (see Table 4). There were also no significant differences in parental responses based on racial-/ethnic background (ps>.379; see

Table 5).

Children were primarily male (*n*=212, 87.2%), with an average age of 9.85 years (*range*: 3-20 years; *SD*=4.06). While boys and girls did not differ in current age (*p*=.317) or age of diagnosis (*p*=.309), girls were rated as more severe (*M*=84.53, *SD*=20.86) than boys (*M*=69.64, *SD*=24.09; *t*(239)=3.22, *p*=.001, *d*=.66). The majority of parents reported that their child was diagnosed with ASD (*n*=163, 67.4%). Other children were diagnosed with Autistic Disorder (*n*=55, 22.7%), Asperger's Syndrome (*n*=21, 8.3%), or PDD-NOS (*n*=3, 1.2%). The mean age of diagnosis was 3.9 years (*range*: 1-12 years; *SD*=1.72). Children had a mean severity score of 71.62 (*range*: 31-150, *SD*=24.26). In terms of symptom severity, 12.3% of children were borderline (ABC: 20-44), 44.4% were mild (ABC: 45-69), and 43.2% were moderate-to-severe (ABC: ≥70) based on the cutoff values suggested by Oro, Navarro-Cavillo and Esmer (2014). There was a small, but significant inverse relationship between age and ABC severity score (*r*=-.187, *p*=.004).

Aim 1

The first aim was to example the psychometric properties of the Autism Advocacy Scale. Reliability, factor structure, and validity were investigated within the context of the full study.

Reliability. The final scale consisted of 33 items and had a Cronbach's alpha of .95, indicating high internal consistency. All but two items (1c. I talk with other parents about interventions or services for children with ASD; 2c. I search online for information about interventions of services for children with ASD) had an item-remainder corrected correlation of .45 or greater (1c=.284; 2c=.104), indicating that they are not as closely tied together with the other items. Removal of those two items did not noticeably improve internal consistency (Δα=.003), so they were left in for further analysis.

While high internal reliability is one indicator of a unidimensional measure, it is possible that advocacy behaviors differ across systems. For example, a parent might advocate for their child in the school system but feel less comfortable doing so for medical care or insurance coverage. It is also possible that individuals would want to use this measure of advocacy within a particular service system. As such, reliability within each service system was examined. Internal consistency was good and item-remainder corrected correlations were .40 or greater for three out of four service systems: education (α=.865), insurance (α=.805), intervention (α=.672), medical care (α=.847). While removal of items 1c. and 2c. improved both internal consistency (α=.718; Δα=.046) and item-remainder correlations (all greater than .36) for the intervention subscale, this change does not create a significant improvement and has no theoretical justification.

Factor analysis. An exploratory factor analysis (EFA) examined whether there were any underlying factors within the AAS as families may advocate differently across service systems or modalities (e.g., in person, online). EFA followed the suggested guidelines of Osborne and Costello (2009). As responses to the AAS items were normally distributed and the individual factors were likely to correlate, principle axis factoring and direct oblimin rotation were utilized. The Kaiser-Meyer-Olkin measure of sampling adequacy was .934 and Bartlett test of sphericity was significant (*p*<.001), indicating that the data structure is appropriate for an EFA.

A two factor solution appeared to be most appropriate based on visual examination of the scree plot, as an increased number of factors did not explain a large amount of additional variance (see Figure 1). These first two factors accounted for 49.63% of the variance in the data. However, eigenvalues greater than 1.0 suggest that there are up to 6 possible factors in the data, which explain 66.37% of total variance (see Table 6). All but two items correlated most strongly with the first factor (see Table 7), making a two or six factor solution difficult to interpret without accounting for highly correlated factors. It is important to note that these two items were also the two items with low item-remainder corrected correlations (1c and 2c). After accounting for the correlation between factors by using a rotated solution, the two factor solution indicated that item groups 4, 6, and 7 (calling organizations, utilizing specialists or other individuals) loaded primarily on factor one and item groups 1, 2, 3, 5, and 8 (talking to other parents, searching online, attending workshops, reading official documents, and participation in organizations) loaded primary on a second factor (see

Table 8). Furthermore, the six factor solution revealed factors that primarily reflected individual item groupings on the AAS (See Table 9). Given that factors were more likely to represent individual item groupings rather than theoretical aspects of advocacy behaviors, and all but two items loaded on a single factor, a single factor solution is most appropriate.

Validity. Face and content validity was established through piloting with parents, professional advocates, and service providers, as well as exploring existing measures, trainings, and literature about parent advocacy behaviors (see *Methods)*. Convergent validity was established by examining the AAS's relationship with a subset of items on the FES. The FES includes questions about attitude, knowledge, and behaviors at the family, systems, and community levels. As the AAS is a behavioral measure of advocacy, it would be expected that responses on the AAS would be similar to systems and community behaviors. The correlation between total scores on the AAS and this sub-total on the FES is significant (r=.344, p<.001), indicating some level of convergent validity.

Concurrent validity was established by looking at the relationship between the AAS total score and other study measures (see Table 10 for correlation matrix). Advocacy was positively correlated with empowerment (r=.312, p<.001), but not related to parent-professional partnerships (*r*=.041. *p*=.521) or education (*r*=.044, *p*=.492). This lack of relationship is surprising given that qualitative data suggests that advocacy is often more common among more educated families (e.g., Coots, 1998; Nachschen et al., 2001; Trainor, 2010a) and often results from poor relationships with providers (Burke and Goldman, 2015; Trainor, 2010b; Wang et al., 2004). Additionally, some quantitative studies have found that advocacy is positive correlated with education (Nachschen et al., 2001) and negatively correlated with parent-professional partnerships (Burke and Goldman, 2015). Additionally, a negative correlation with advocacy was found for both service adequacy (*r*=-.214, *p*=.001) and child symptom severity (*r*=-.247, *p*<.001).

The negative correlation between advocacy and service adequacy was unexpected, but likely explained by the fact that the data were cross-sectional. For example, families who are currently engaging in high levels of advocacy may be doing so because their current services are inadequate. Previous studies suggesting that advocacy leads to increased service adequacy have used qualitative reports or longitudinal analyses. Thus, it would be expected that increased advocacy would be related to improved service adequacy over time. Additionally, children are required to meet a certain severity cut-off in order to receive reimbursement for services through insurance. Families whose children are less severe may find they need to advocate more in order to meet the service needs of their child. Lastly, the overall sample was highly educated, so it may not represent the true relationship between education and advocacy in the population.

Aim 2

Given the complex relationships among the variables of interest and a primarily qualitative body of literature, this project aims to replicate previous research using this measure of advocacy and answer the following three questions: 1) Does parental education predict service outcomes? 2) Do parent advocacy, empowerment, or parent-professional partnership explain the relationship between parental education and service outcomes? 3) What predicts engagement in parent advocacy?

All analyses were completed using hierarchical regression in IBM SPSS 22; mediation analyses were completed using the PROCESS macro developed by Hayes (2013). To examine whether any indirect effects were significant, a 95% confidence interval was obtained using the bootstrapping method and percentile-corrected confidence estimates to account for possible inflated Type I error (Fritz, Taylor, and MacKinnon, 2012; Hayes & Scharkow, 2013). To account for significant theoretical and statistical associations between parental relationship to child, child age, and child symptom severity and the variables of interest, these variables were entered as controls in Step 1 of each regression analysis or entered as covariates within PROCESS. Additional covariates were entered based on significant correlations to variables of interests as needed. Non-categorical predictor variables were centered on the grand mean to aid in interpretation. All variables were reliable (α's > .83) and normally distributed (skewness < 2; kurtosis < 2) with no outliers (*z*-scores < 3.5).

Does parental education predict service outcomes? This first question examined whether parental education was associated with the service outcome variables using a series of hierarchical linear regressions. After controlling for demographic factors as described above, education was significantly associated with number of services received (β=0.176, *t*(237)=2.95, *p*=.004), number of services needed but not received (β=-0.232, *t*(237)=-3.84, *p*<.001), service adequacy (β=0.232, *t*(237)=3.92, *p*<.001), and service satisfaction (β=.154, *t*(237)=2.57, *p*=.010) above and beyond the effects of the control variables (ΔR^2=0.024 - 0.054; see

Table 11). Taken together, these findings replicate prior research demonstrating that families with less formal education have more difficulty accessing needed services and are less satisfied with the services they do receive than more educated families. The data do not support previous findings that less educated families report fewer service needs despite their use of fewer services (e.g., Porterfield & McBride, 2007), but rather that their unmet needs are greater (*M*=14.68, *SD*=6.87) than their more educated peers (*M*=11.35, *SD*=7.37).

Do parent advocacy, empowerment, or parent-professional partnership explain the relationship between parental education and service outcomes? The next question addressed whether parent advocacy, parent empowerment, and/or parent-professional partnerships could help explain the association between parental education and our primary service use variable, overall service adequacy. As advocacy and empowerment were negatively related to service outcomes (see Table 10 for correlations), they were not included as mediators; the pattern of relationships would not be interpretable in the model. Thus, we examined whether the quality of the parent-professional partnership partially or fully mediated the association between parental education and perceived service adequacy. To do this, we conducted regression analyses using SPSS PROCESS to assess each component of the proposed mediation model, controlling for relevant demographic factors (child age, symptom severity, and parental role), empowerment, and advocacy. The total effect of education on service adequacy was significant (B=.066, SE=.016, *t*(233)=4.15, *p*<.001, 95% C.I.=.035-.099), such that more educated parents reported greater adequacy of services received for their family. It was also found that education was positively related to the quality of the parent-professional partnership (B=1.77, SE=.551, *t*(233)=3.22, *p*=.002, 95% C.I.=.69-2.86). Lastly, the quality of the parent-professional partnership was positively associated with service adequacy (B=.012, SE=.002, *t*(233)=6.69, *p*<.001, 95% C.I.=.008-.015), such that parents who reported a higher quality parent-professional partnership with their child’s primary intervention provider indicated greater service adequacy.

When controlling for the parent-professional partnership, the relationship between education and service adequacy was reduced in magnitude (B=.046, SE=.015, *t*(233)=3.05, *p*=.003), suggesting partial mediation. Results indicated that the indirect effect was significantly different than zero (B=.021; 95% C.I. =.007 - .037), suggesting that the quality of the parent-professional partnership partially mediates the relationship between parental education and service adequacy (see Figure 2).

What factors influence engagement in parent advocacy? As advocacy appears to be an outcome of poor service adequacy rather than a predictor, this next question examined was which factors are associated with engagement in parent advocacy. As only empowerment and service adequacy were related to advocacy behaviors (see Table 10 for correlations), parent-professional partnership and parental education were only included as controls in this model. Hierarchical linear regression was used to examine the extent to which parent empowerment and service adequacy are associated with parent advocacy, as well as whether these two variables interact in predicting parent advocacy. In step 1, we entered control variables as described above. In step 2, we entered parent empowerment and service adequacy. Finally, in step 3, we entered the product of parent empowerment and service adequacy. The regression model with independent predictors was significant and accounted for 17.1% of the variance in advocacy behavior above and beyond the control variables ($p<.001$). Service adequacy ($p=.001$) and empowerment ($p<.001$) each significantly predicted advocacy behaviors. However, the interaction between empowerment and service adequacy did not reach significance ($\Delta R^2=.012$, $p=.070$; see Table 12), indicating that they function as independent predictors of advocacy behaviors.

DISCUSSION

Despite existing literature examining the roles of advocacy, empowerment, and parent-professional relationships on service outcomes in families of children with ASD, the current study was the first to examine their contribution to service outcomes concurrently. This is especially important given the overlap in definitions among these factors. For example, definitions of empowerment have often included references to advocacy behaviors and collaborations with professionals, in addition to attitudes and beliefs (e.g., Dempsey & Foreman, 1997; Zimmerman & Warschausky, 1998). While advocacy has historically been seen as a component of empowerment (Koren et al., 1992; Nachshen et al., 2004), they are best understood separately (Nachshen & Jamieson, 2000) as they have different effects on service outcomes (e.g., Bickman et al., 1998; Curtis & Singh, 1998). Additionally, parental involvement in education has often been utilized as a measure of positive family-school partnerships (Epstein et al., 1996). As empowerment and parent-professional relationships have close ties to advocacy behaviors, it is important to explore how each of these concepts is related to service outcomes independently in order to provide best practice recommendations for addressing service disparities in families of children with ASD.

One challenge addressed by the current study was that the definition and measurement of advocacy has differed across the literature, shifting between attitudes, perceptions, and behaviors measured through both qualitative and quantitative means. Additionally, advocacy trainings feature a broad array of topics and many studies define advocacy as the result of training, knowledge of techniques, or perceived involvement with the system, while very few measure engagement in advocacy through concrete behaviors (e.g., Balcazar et al., 1996; Davis et al., 2010; Siller et al., 2014). Thus, it is difficult to conclude whether advocacy behaviors themselves or the broader changes in knowledge, partnerships, or attitudes lead to positive outcomes. Given this, it was necessary to design a measure of advocacy behaviors appropriate for families and children with ASD in order to better understand the relative contributions of advocacy, empowerment, and parent-professional partnership to service outcomes in this population.

The resulting Autism Advocacy Scale isolated specific behaviors that parents may engage in on behalf of their child with ASD based on existing literature, advocacy trainings, and feedback from parent and professional advocates. The final scale consisted of eleven statements about advocacy behaviors, such as talking with other parents, attending workshops, or calling agencies for information, with seven items repeated for four different service systems: school system, insurance coverage, intervention services, and medical care. Parents were asked to report how often then engaged in each of these behaviors on a five-point scale from *never* to *very often*. While engagement in advocacy behaviors was related to empowerment as expected, it did not relate to parent-professional partnership or parental education, despite findings in the literature that families with lower levels of education are less likely to engage in advocacy (Burke and Goldman, 2015, Coots, 1998; Nachschen et al., 2001; Trainor, 2010a) and advocacy often results from poor relationships with providers (Burke and Goldman, 2015; Trainor, 2010b; Wang et al., 2004). This is especially surprising given that two of these studies utilized the Special Education Rights and Advocacy Scale (Burke and Goldman, 2015) and the Parental Advocacy Scale (Nachschen et al., 2001), off of which the current measure was based. Additionally, the correlation between advocacy and service adequacy was negative, while most studies report positive correlations. There are several possible explanations for this contradictory set of findings.

First, participants in this study were highly educated and represented a restricted sample of families of children with ASD. Burke and Goldman (2015) completed their study using a national sample, while Nachshen and colleagues (2001) recruited through local service providers. In contrast, almost all participants in the current study were recruited through online information, support, or advocacy groups targeted towards families of children with disabilities. Parents who belong to such groups may be more knowledgeable about the services available for their child, more motivated to find alternative services, and more likely to advocate on behalf of their child to access those services, resulting in less variability across participants. In fact, higher levels of advocacy activities (Balcazar et al., 1996) and education (Mandell & Salzer, 2007) are related to increased membership in these types of organizations. Additionally, this study was only available to families with proficiency in English. Advocacy and its correlates may look different in groups with limited English proficiency. For example, Latino families may feel especially alienated in the advocacy process, due to poor communication skills and relationships with service providers (Levine & Trickett, 2008; Shapiro et al., 2004). Taken together, it is likely that participants in this study were already engaged in high levels of advocacy and show less variability in behaviors based on education compared to the general population of families of children with ASD. While this restriction is common in research on families and children with ASD, it is possible that results from this study would not be generalizable to families with fewer years of formal education (Aguinis and Whitehead, 1997). Future research with a more representative sample may show different patterns of relationships.

Second, the advocacy measure may be reflective of differences in family’s perceptions about their advocacy behavior. Despite attempts to separate the behavioral components from parental attitudes to create a more objective measure of advocacy, families were asked to rate their involvement on a five-point scale from *rarely* to *often*. Responses to this question are likely based on expectations. For example, families may have different perceptions of what engaging in advocacy *often* means based on their knowledge of advocacy and the other individuals in their support networks who may or may not engage in similar behaviors; a frequency rating may have been a more objective. Additionally, there was no way to determine whether advocacy attempts were successful outside of overall service adequacy. Given literature that suggests families from disadvantaged backgrounds engage in less-successful advocacy attempts (e.g., Coots, 1998; Trainor, 2010a), they may engage in the same level of behaviors, but with less success. Thus, while the measure was designed to capture behavioral features of advocacy, it may still have been influenced by additional factors which alter how it relates to other variables of interest.

Third, the data collected were aggregated and cross-sectional, which likely affects the pattern of relationships. Participants rated their relationship with providers across all service systems, rather than within an individual system (e.g., school system, insurance coverage, intervention services, medical care), which may have caused the effects of parent-professional partnership on advocacy to wash out. Burke and Goldman (2015) explored the relationship between advocacy and parent-professional partnerships within the school system only. Furthermore, the relationships between service access, advocacy, empowerment, and parent-professional relationships are likely longitudinal and reciprocal. For example, empowerment has been shown to be both an outcome of advocacy training (Dixon et al., 2001) as well as an important component in the decision to advocate (Wright and Taylor, 2014). Additionally, families who experience poor relationships with their child’s service providers are more likely to advocate in order to get their child’s needs met (Burke & Goldman, 2015; Trainor, 2010b; Wang et al., 2004); on the other hand, engaging in advocacy itself can contribute to poor relationships with service providers (Resch et al., 2010). It would be also expected that advocacy relates to higher service adequacy over time, while families who are currently engaging in high levels of advocacy are doing so because their current services are inadequate. Without gathering data longitudinally, it becomes difficult to understand what the true pattern of relationships are among these variables.

The second aim of this study was to replicate previous research using this measure of advocacy in order to better understand how parental education, advocacy, empowerment, and parent-professional partnerships impact service outcomes in families of children with ASD. In general, families participating in the current study expressed high levels of unmet service needs compared to previous research in families of other CSHCN using the Services Inventory (Summers et al., 2005; Summers et al., 2007). Parents reported that they received 43% of needed family and child services, while Summers and colleagues (2007) found that families received 72% of needed services. Furthermore, parents in the current study reported that they received 8 different services on average, while Summers and colleagues (2007) found most families received 4 or fewer services total. These findings lend support to previous research which shows that children with ASD utilize greater services (Gurney et al., 2006; Tregnago & Cheak-Zamora, 2012), while simultaneously experiencing higher levels of unmet needs (Chiri & Warfield, 2012; Ruble et al., 2005) compared to families of other CSHCN. Given the differential outcomes for families of children with ASD compared to other CSHCN, the current study sought to better understand the effect that education has on service disparities in this population, as well as various mechanisms that may underlie how families of children with ASD access services.

Service outcomes in families with ASD participating in this study were further exacerbated by difference in parental education. While more educated families reported that 48%

of their service needs were met, this dropped to 36% in less educated families. Additionally, families who had less formal education received fewer service hours and were less satisfied with the services they received. Overall, less educated families experienced poor service outcomes compared to their more educated peers, supporting previous research that SES impacts health outcomes for children generally (e.g., Bradley & Corwyn, 2002), as well as within families of children with ASD (Magaña et al., 2013). As service adequacy is a ratio of received services to total needed and received services, the actual number of needed services was examined to address concerns that less educated families may report fewer service needs overall, despite similar levels of need (Porterfield & McBride, 2007). However, this was not the case; families with less formal education reported a greater number of needed services compared to their more educated peers. It is possible that methodological differences are responsible for this. Porterfield and McBride (2007) calculated unmet service needs for children with a variety of special needs by asking if there was any time that they child needed care from a specialty doctor but did not receive it, while the current study asked parents to indicate their unmet needs by giving them a list of possible services and requesting that they mark specific services as received or needed. Giving parents a list of possible services may have cued parents to report more service needs compared to asking an open-ended question.

As there were significant differences in service access among more and less educated families of children with ASD, further analyses addressed whether advocacy, empowerment, or parent-professional partnership mediated this relationship. Although it was predicted that all three variables would relate to both parental education and service outcomes, only the quality of the parent-professional partnership was significantly correlated with both. Furthermore, parent-professional partnership served as a partial mediator of the relationship between parental education and service outcomes, indicating that improving parent-professional partnerships in low-SES families may reduce service disparities in this population. Given that there are generally low levels of satisfaction and partnership in care for families of children with ASD (e.g., Chiri & Warfield, 2012; Liptak et al., 2006), specialized trainings have already been developed for both parents and professionals that show success in improving parent-professional relationships in the ASD community (e.g., Murray et al., 2011), making parent-professional relationships a promising target for improving service outcomes in this population.

In addition to the limitations discussed previously, other barriers to service access that impact families of children with ASD were not controlled for or evaluated as possible mediators of this relationship. Several families commented on different barriers to care that limit their access, despite attempts to advocate on behalf of their child. For example, location (e.g., rural, suburban, urban) has a strong impact on the amount of difficulty families face in accessing service providers (Murphy & Ruble, 2012). One family in the current study expressed that they drive 86 miles each way to receive some services, making it challenging to attend multiple times per week. Furthermore, several families mentioned the difficulty of getting a medical diagnosis, which provides greater access to services, compared to an educational classification of autism, which only provides access to school-based services. Future studies should ask families to provide a ZIP code in order to classify the level of available services in their area, as well as whether their diagnosis came from the school or a medical professional.

Lastly, this study sought to understand the relationship between service outcomes and advocacy behaviors. As factors associated with successful advocacy could not be explored due to the negative relationship between advocacy and service outcomes, this study instead examined what factors influence engagement in advocacy behaviors. Results suggest that empowerment is a strong independent predictor of engagement in advocacy behaviors in the face of poor service adequacy. Additionally, the interaction between service adequacy and empowerment approached significance. Given the limitations in the study that may have influenced the relationships seen, it is worth considering what an interaction would mean in the context of the data. Parents who are more empowered may be more likely to initiate advocacy attempts when faced with poor service adequacy. However, as not all advocacy attempts are successful, it is important to understand what factors contribute to success. It has been suggested that empowerment may serve as a potential moderator in differentiating successful from unsuccessful advocacy attempts (Nachshen & Jamieson, 2000; Wang et al., 2004), such that parents who are empowered may be more confident in their advocacy abilities, resulting in more successful advocacy actions and greater access to services for their child with ASD. However, empowerment is a reflection of perceived ability to meet needs, rather than true ability; in communities where services are limited and difficult to access, increased empowerment may not relate to improvements in services and can actually increase feelings of alienation and stress (Riger, 1999). Furthermore, parents who advocate in the context of high quality parent-professional relationships may be more successful in their attempts (Trainor, 2010) or may not need to engage in advocacy, as they are likely to be more satisfied with their current services (Burke & Goldman, 2015; Summers et al., 2007; Wang et al., 2004). The current study found that advocacy was related to poor service adequacy in a cross-sectional sample; it was not possible to examine whether empowerment or parent-professional relationships might increase or decrease the success of advocacy (i.e. greater service adequacy). Future research using a longitudinal design is necessary to examine the relationship between advocacy and changes in service adequacy over time. Such research could also examine factors that interact with advocacy to produce optimal service outcomes and minimize stress.

Taken together, these results highlight the importance of systematic changes in the provision of services for families of children with ASD. Despite higher levels of advocacy in this population (Mueller & Carranza, 2011) and recent insurance reforms (Stuart, 2011; Wang et al., 2013) aimed to improve access to services, this study strengthened claims in the literature that families of children with ASD continue to face a high level of unmet service needs and low levels of service satisfaction that are exacerbated by parental education. Results suggest that improving parent-professional partnerships, particularly in low-SES families of children with ASD, may help increase service access in this population.

Historically, parents of children with ASD have reported poor relationships with their providers across a number of different domains (Brachlow et al., 2007; Kogan et al., 2008; Krauss et al., 2003) and low-SES families experience even greater disparities in family-centered care (Guerrero, et al., 2010; Montes & Halterman, 2011). As high quality parent-professional relationships relate to family-centered care (AAP Committee on Hospital Care, 2012; Bickman et al., 1998; Dempsey & Keen, 2008), lead to greater efficacy of intervention services, and relate to greater satisfaction with services (Brookman-Frazee, 2004), changes should be made to ensure that families of children with ASD receive the same levels of family-centered care as other CSHCN to reduce disparities in service outcomes.

Additionally, parental engagement in advocacy to address poor service adequacy is highly related to levels of family empowerment. While it was not possible to determine whether empowerment improved the success of advocacy, the interaction between service adequacy and empowerment was trending towards significance, indicating that the contribution of empowerment to advocacy should be explored further. Future research should examine these relationships in a more representative sample, as well as evaluate their effects longitudinally in order to provide the best recommendations to families of children with ASD and ensure the greatest likelihood of success in pursing appropriate services.

APPENDICES

APPENDIX A

Services Inventory

Instructions: Below are some commonly used **interventions** for **children with ASD.**

For **each service** listed, please indicate **whether** your child: 1) **Receives** this service; 2) **Needs** this service, but does not receive it; or 3) **Does not need** this service (e.g., child is not old enough, family does not have this specific need).

For the **services you receive**, mark **how many hours you receive**, if it is **enough**, and **how satisfied** you are with the service.

Please think about your experiences **over the last 6 months**. We are interested in services that are ***provided or supervised by a professional.***

1. In-home intensive intervention (e.g., ABA/DTT, DIR/Floortime)

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

2. Clinic-based intensive intervention (e.g., ABA/DTT, DIR/Floortime)

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

3. Physical and/or occupational therapy

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

4. Speech and/or language therapy

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

5. Special education services (e.g., classroom aide, inclusion support, IEP/IFSP)

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

6. Counseling and psychological therapy

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

7. Behavior support or management

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

8. Social skills training or group

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

9. Sensory intervention

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

10. Other (please describe):

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

Next are some commonly used **services** for **children with ASD.**

For each service listed, please indicate **whether** your child: 1) **Receives** this service; 2) **Needs** this service, but does not receive it; or 3) **Does not need** this service (e.g., child is not old enough, family does not have this specific need).

For the services you receive, mark **how many hours you receive**, if it is **enough**, and **how satisfied** you are with the service.

Please think about your experiences **over the last 6 months**. We are interested in services that are ***provided or supervised by a professional.***

---

1. Coordination of services (e.g. case management)

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

2. Primary medical care (e.g., health and wellness, sick visits, urgent care)

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

3. Medication management

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

4. Specialist medical care

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

5. Community Living Services (CLS)

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

6. Residential Treatment

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

7. Assistive and augmentative communication (e.g., Picture Exchange Communication System [PECS])

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

8. Transition services

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

9. Employment services

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

10. Self-care support (example: help with dressing or bathroom use)

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

11. Complementary and alternative medicine

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

12. Other (please describe):

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

Next are some commonly used **services** for **families** of children with special needs.

For each service listed, please indicate **whether** your child: 1) **Receives** this service; 2) **Needs** this service, but does not receive it; or 3) **Does not need** this service (e.g., child is not old enough, family does not have this specific need).

For the services you receive, mark **how many hours you receive**, if it is **enough**, and **how satisfied** you are with the service.

Please think about your experiences **over the last 6 months**. We are interested in services that are ***provided or supervised by a professional.***

1. Child care

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

2. Respite Care

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

3. Money to help pay bills

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

4. Transportation

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

5. Parent Support Groups

___ **Receive** this service →
___ **Need** this service, but do not receive it
___ **Do not need** this service

1. How **often** do you receive this service?
___ Less than 1 hour a week ___ 6-14 hours a week
___ 1-5 hours a week ___ 15 or more hours a week

2. Do you receive **enough** of this service?
___ Some, but not enough ___ Enough ___ More than we need

3. How **satisfied** are you with this service?
___ Not satisfied ___ Somewhat satisfied ___ Satisfied

6. Counseling	
___ **Receive** this service →	1. How **often** do you receive this service?
___ **Need** this service, but do not receive it	___ Less than 1 hour a week ___ 6-14 hours a week ___ 1-5 hours a week ___ 15 or more hours a week
___ **Do not need** this service	
	2. Do you receive **enough** of this service? ___ Some, but not enough ___ Enough ___ More than we need
	3. How **satisfied** are you with this service? ___ Not satisfied ___ Somewhat satisfied ___ Satisfied
7. Parent or family training, education, or skills	
___ **Receive** this service →	1. How **often** do you receive this service?
___ **Need** this service, but do not receive it	___ Less than 1 hour a week ___ 6-14 hours a week ___ 1-5 hours a week ___ 15 or more hours a week
___ **Do not need** this service	
	2. Do you receive **enough** of this service? ___ Some, but not enough ___ Enough ___ More than we need
	3. How **satisfied** are you with this service? ___ Not satisfied ___ Somewhat satisfied ___ Satisfied
8. Information support (e.g., about specific disabilities, where to get services, legal rights)	
___ **Receive** this service →	1. How **often** do you receive this service?
___ **Need** this service, but do not receive it	___ Less than 1 hour a week ___ 6-14 hours a week ___ 1-5 hours a week ___ 15 or more hours a week
___ **Do not need** this service	
	2. Do you receive **enough** of this service? ___ Some, but not enough ___ Enough ___ More than we need
	3. How **satisfied** are you with this service? ___ Not satisfied ___ Somewhat satisfied ___ Satisfied
9. Other (please describe):	
___ **Receive** this service →	1. How **often** do you receive this service?
___ **Need** this service, but do not receive it	___ Less than 1 hour a week ___ 6-14 hours a week ___ 1-5 hours a week ___ 15 or more hours a week
___ **Do not need** this service	
	2. Do you receive **enough** of this service? ___ Some, but not enough ___ Enough ___ More than we need
	3. How **satisfied** are you with this service? ___ Not satisfied ___ Somewhat satisfied ___ Satisfied

Adapted from the Services Inventory (Summers et al, 2005).

APPENDIX B

Autism Advocacy Scale

Instructions: Advocacy is what a caregiver does to gain knowledge, solve problems, get services, or make changes in their child's life and community. Below are examples of how a caregiver may advocate for their child with special needs. Click the response that best describes how often you do that behavior.

	Never	Almost Never	Some times	Fairly Often	Very Often
1. I talk with other parents about…					
… special educations rights, laws, and/or procedural safeguards.	0	1	2	3	4
… insurance coverage for children with ASD.	0	1	2	3	4
… interventions or services for children with ASD.	0	1	2	3	4
… primary and/or specialty medical care for children with ASD.	0	1	2	3	4
2. I search online for information about…					
… special educations rights, laws, and/or procedural safeguards.	0	1	2	3	4
… insurance coverage for children with ASD.	0	1	2	3	4
… interventions or services for children with ASD.	0	1	2	3	4
… primary and/or specialty medical care for children with ASD.	0	1	2	3	4
3. I attend workshops to learn about…					
… special educations rights, laws, and/or procedural safeguards.	0	1	2	3	4
… insurance coverage for children with ASD.	0	1	2	3	4
… interventions or services for children with ASD.	0	1	2	3	4
… primary and/or specialty medical care for children with ASD.	0	1	2	3	4
4. I call organizations or agencies to ask for information					

	about…					
	… special educations rights, laws, and/or procedural safeguards.	0	1	2	3	4
	… insurance coverage for children with ASD.	0	1	2	3	4
	… interventions or services for children with ASD.	0	1	2	3	4
	… primary and/or specialty medical care for children with ASD.	0	1	2	3	4
5.	I read official documents or policy statements on…					
	… special educations rights, laws, and/or procedural safeguards.	0	1	2	3	4
	… insurance coverage for children with ASD.	0	1	2	3	4
	… interventions or services for children with ASD.	0	1	2	3	4
	… primary and/or specialty medical care for children with ASD.	0	1	2	3	4
6.	I have a professional advocate, attorney, or specialist….					
	… attend meetings about my child's special education plan.	0	1	2	3	4
	… help me with insurance coverage for my child with ASD.	0	1	2	3	4
	… help me get interventions or services for my child with ASD.	0	1	2	3	4
	… help me find primary and/or specialty medical care for my child with ASD.	0	1	2	3	4
	… write letters on my behalf to improve my child’s services and/or quality of life.	0	1	2	3	4
7.	I have someone else (not a professional advocate, attorney, or specialist)…					
	… attend meetings about my child’s special education plan.	0	1	2	3	4
	… help me with insurance coverage for my child with ASD.	0	1	2	3	4

	… help me get interventions or services for my child with ASD.	0	1	2	3	4
	… help me find primary and/or specialty medical care for my child with ASD.	0	1	2	3	4
8.	How often do you…					
	... participate in organizations or groups that improve the lives of children with special needs?	0	1	2	3	4
	... donate to organizations or groups that improve the lives of children with special needs?	0	1	2	3	4
	... help with fundraisers and/or events that improve the lives of children with special needs?	0	1	2	3	4
	... make phone calls, go to meetings, or write letters/e-mails to improve your child's services and/or quality of life?	0	1	2	3	4

Adapted from the FASC (Davis et al, 2011), PAS (Nachschen et al., 2001), and SERAS (Burke and Hodapp, under review).

APPENDIX C

Tables

Table 1. *Primary Care Giver Characteristics*

	N (%)
Relationship to Child	
Mother	184 (76.0%)
Father	58 (24.0%)
Education	
Less than 12th grade	0 (0.0%)
High school/GED	16 (6.6%)
Some College	75 (31.0%)
4-year College Graduate	119 (49.2%)
Graduate degree	32 (13.2%)
Income	
Less than $10,000	2 (0.8%)
$10-20,000	39 (16.1%)
$20-30,000	45 (18.6%)
$30-50,000	92 (38.0%)
$50-75,000	29 (12.0%)
$75-100,000	16 (6.6%)
Greater than $100,000	16 (6.6%)
Race	
White	200 (82.6%)
Black	15 (6.2%)
Asian	21 (8.7%)
Bi/Multi Racial	2 (0.8%)
Other	4 (1.7%)
Ethnicity	
Hispanic	4 (1.7%)
Non-Hispanic	238 (98.3%)
Marital Status	
Single	52 (21.5%)
Divorced/Separated	99 (40.9%)
Widowed	12 (5.0%)
Married	77 (31.8%)
Single, living w/ partner	2 (0.8%)

Table 2. *Child Characteristics*

	***M* (*SD*)**
Age (in years)	9.85 (4.06)
Age of diagnosis (in years)	3.89 (1.72)
	N (%)
Gender	
Male	211 (87.2%)
Female	30 (12.4%)
Missing	1 (0.4%)
Diagnosis	
ASD	163 (67.4%)
Autistic Disorder	55 (22.7%)
Asperger's Syndrome	21 (8.7%)
PDD-NOS	3 (1.2%)
Race	
White	198 (81.8%)
Black	16 (6.6%)
Asian	20 (8.3%)
Bi/Multi Racial	5 (2.1%)
Other	3 (1.2%)
Ethnicity	
Hispanic	8 (3.3%)
Non-Hispanic	234 (96.7%)

Table 3. *Overview of survey measures and order of administration*

Measure	**Number of Items**	**α**
Child Demographic Information	7	–
Parent Demographic Information	10 (+5 if married or partnered)	–
Autism Advocacy Scale	33	.95
Services Inventory	28 (+3 follow-up questions)	–
Family-Professional Partnership Scale	18	.92
Family Empowerment Scale	34	.93
Perceived Stress Scale	10	.49
Autism Behavior Checklist	57	.81

Table 4. *Differences in response patterns for mothers versus fathers*

	Mothers		**Fathers**				
Measure	***M(*SD*)***	***n***	***M(*SD*)***	***n***	***t(240)***	***p***	***d***
ABC	69.25 (24.75)	184	77.95 (21.29)	58	2.40	.017	.38
AAS	114.57 (21.41)	184	114.74 (18.15)	58	0.06	.955	.01
FES	132.46 (15.91)	184	129.47 (16.88)	58	-1.12	.219	-.18
FPPS	70.79 (9.53)	184	76.12 (6.44)	58	3.98	<.001	-.66
Adequacy	0.38 (0.24)	184	0.59 (0.31)	58	5.35	<.001	.76
	Mean rank	***n***	***Mean rank***	***n***	***U***	***p***	r_{rb}
Income	122.07	181	110.31	58	4687	.203	.097
Education	123.10	184	119.71	58	5232	.808	.028

Table 5. *Differences in response patterns for White Non-Hispanic parents versus parents of other racial and ethnic backgrounds*

	White Parents		**Non-White Parents**				
Measure	***M(*SD*)***	***n***	***M(*SD*)***	***n***	***t*(241*)***	***p***	***d***
ABC	70.65 (23.96)	194	74.10 (25.43)	48	0.88	.379	-.14
AAS	114.66 (20.67)	194	114.40 (20.74)	48	-0.08	.937	.01
FES	132.13 (15.92)	194	130.17 (17.18)	48	-0.75	.451	.12
FPPS	72.02 (9.24)	194	72.25 (8.93)	48	0.16	.877	-.03
Adequacy	0.43 (0.27)	194	0.42 (0.27)	48	-0.43	.669	.04
	Mean rank	***n***	***Mean rank***	***n***	***U***	***p***	r_{rb}
Income	119.55	191	121.78	48	4498.5	.836	-.018
Education	120.84	194	124.19	48	4527	.747	-.028

Table 6. *Total variance explained by the factor model*

	Initial Eigenvalues		
Factor	Total	% of Variance	Cumulative %
1	13.069	39.603	39.603
2	3.310	10.030	49.633
3	1.654	5.013	54.646
4	1.535	4.653	59.299
5	1.187	3.597	62.896
6	1.149	3.483	66.379

Extraction Method: Principle Axis Factoring.

Table 7. *Unrotated matrix of the AAS factors with Eigenvalues greater than 1.0*

	Factor					
	1	2	3	4	5	6
AAS1_ed	.507	.435				
AAS1_ins	.458	.320				
AAS1_int		.505	.353			
AAS1_med	.563	.362	.362		-.367	
AAS2_ed	.590	.348			.347	
AAS2_ins	.494					
AAS2_int		.569				
AAS2_med	.470	.399		.335		
AAS3_ed	.759					
AAS3_ins	.707					-.351
AAS3_int	.647					-.326
AAS3_med	.787					
AAS4_ed	.710					
AAS4_ins	.639					
AAS4_int	.476			.384		
AAS4_med	.672			.442		
AAS5_ed	.588	.326				
AAS5_ins	.554					
AAS5_int	.489		-.441			
AAS5_med	.626		-.480			
AAS6_ed	.785					
AAS6_ins	.777	-.350				
AAS6_int	.711	-.387				
AAS6_med	.760	-.345				
AAS6_letter	.782	-.326				
AAS7_ed	.711					
AAS7_ins	.676	-.357				
AAS7_int	.716	-.407				
AAS7_med	.736	-.418				
AAS8_org	.473					
AAS8_donate	.490					
AAS8_help	.640					
AAS8_contact	.461					

Extraction Method: Principle Axis Factoring.
Correlations < .30 are not shown

Table 8. *Rotated pattern matrix for a two factor AAS*

	Factor	
	1	2
AAS1_ed		.670
AAS1_ins		.531
AAS1_int		.607
AAS1_med		.590
AAS2_ed		.621
AAS2_ins		.506
AAS2_int	-.406	.603
AAS2_med		.608
AAS3_ed	.406	.501
AAS3_ins	.466	.363
AAS3_int	.323	.454
AAS3_med	.505	.420
AAS4_ed	.537	
AAS4_ins	.493	
AAS4_int		
AAS4_med	.511	
AAS5_ed		.599
AAS5_ins		.490
AAS5_int		.462
AAS5_med	.321	.416
AAS6_ed	.775	
AAS6_ins	.850	
AAS6_int	.836	
AAS6_med	.834	
AAS6_letter	.829	
AAS7_ed	.731	
AAS7_ins	.781	
AAS7_int	.853	
AAS7_med	.875	
AAS8_org		.502
AAS8_donate		
AAS8_help	.387	.374
AAS8_contact		.395

Extraction Method: Principle Axis Factoring.
Rotation Method: Oblimin with Kaiser Normalization.
Correlations < .30 are not shown

Table 9. *Rotated pattern matrix of AAS factors with Eigenvalues greater than 1.0*

	Factor					
	1	2	3	4	5	6
AAS1_ed				-.369	-.442	
AAS1_ins					-.544	
AAS1_int					-.749	
AAS1_med					-.834	
AAS2_ed		.312		-.513		
AAS2_ins		.508				
AAS2_int	-.407	.544				
AAS2_med		.586				
AAS3_ed						-.458
AAS3_ins	.354					-.487
AAS3_int						-.477
AAS3_med	.369					-.416
AAS4_ed	.444					
AAS4_ins	.457	.378				
AAS4_int		.492				
AAS4_med	.478	.521				
AAS5_ed			-.520			
AAS5_ins			-.725			
AAS5_int			-.824			
AAS5_med			-.826			
AAS6_ed	.717					
AAS6_ins	.762					
AAS6_int	.770					
AAS6_med	.740					
AAS6_letter	.734					
AAS7_ed	.728					
AAS7_ins	.764					
AAS7_int	.839					
AAS7_med	.837					
AAS8_org				-.505		
AAS8_donate						
AAS8_help	.381					
AAS8_contact				-.343		

Extraction Method: Principle Axis Factoring.
Rotation Method: Oblimin with Kaiser Normalization.
Correlations < .30 are not shown

Table 10. *Correlation table for control variables (child age and symptom severity) and variables of interest (service adequacy, advocacy, empowerment, parent-professional partnership)*

	Advocacy	Child age	Symptom severity	Empowerment	Parent-Professional Partnership	Service Adequacy
Child age	.102					
Symptom Severity	-.247***	-.187**				
Empowerment	.312***	.082	-.311***			
Parent-Professional Partnership	.041	-.002	-.241***	.220***		
Service Adequacy	-.214***	.134*	.096	-.149*	.409***	
Education	.044	.077	-.094	.060	.200*	.219***

*p<.05, **p<.01, ***p≤.001

Table 11. *Multiple regressions for the effect of education on different service outcomes, including number of services received, number of services needed, overall service adequacy, and service satisfaction.*

Services Received

Predictor	**β**	***t***	R^2	ΔR^2	**Δ F**	***p***
Step 1			.132	---	12.08	.000
Child age	.146	2.41*				
Symptom severity	.119	1.94				
Parent role	-.311	-5.17***				
Step 2			.163	.031	8.676	.004
Education	.176	2.95**				

Services Needed

Predictor	**β**	***t***	R^2	ΔR^2	**Δ F**	***p***
Step 1			.089	---	7.07	.000
Child age	-.083	-1.35				
Symptom severity	-.071	-1.14				
Parent role	.281	4.61***				
Step 2			.142	.054	15.05	.000
Education	-.232	-3.84***				

Table 11 (con't)

Service Adequacy

Predictor	**β**	***t***	R^2	ΔR^2	**Δ F**	***p***
Step 1			.131	---	11.91	.000
Child age	.136	2.28*				
Symptom severity	.094	1.54				
Parent role	-.323	-5.44***				
Step 2			.184	.053	15.37	.000
Education	.232	3.92***				

Service Satisfaction

Predictor	**β**	***t***	R^2	ΔR^2	**Δ F**	***p***
Step 1			.141	---	12.97	.000
Child age	.076	1.27				
Symptom severity	-.245	-4.02***				
Parent role	-.297	-4.96***				
Step 2			.165	.024	6.70	.010
Education	.154	2.57*				

Table 12. *Multiple regression for the effect of service adequacy and empowerment and their interaction on advocacy behaviors, controlling for child age, symptom severity, parental role, education, and parent-professional partnership.*

Advocacy

Predictor	**β**	***t***	R^2	ΔR^2	**Δ F**	***p***
Step 1			.068	---	3.42	.005
Child age	.078	1.267				
Symptom severity	-.134	-1.988*				
Parent role	-.109	-1.673				
Education	.068	1.094				
Parent-professional partnership	-.016	-.218				
Step 2			.171	.103	14.54	.000
Service Adequacy	-.246	-3.39***				
Empowerment	.240	3.67***				
Step 3			.182	.012	3.32	.070
Interaction	-.115	-1.821				

APPENDIX D

Figures

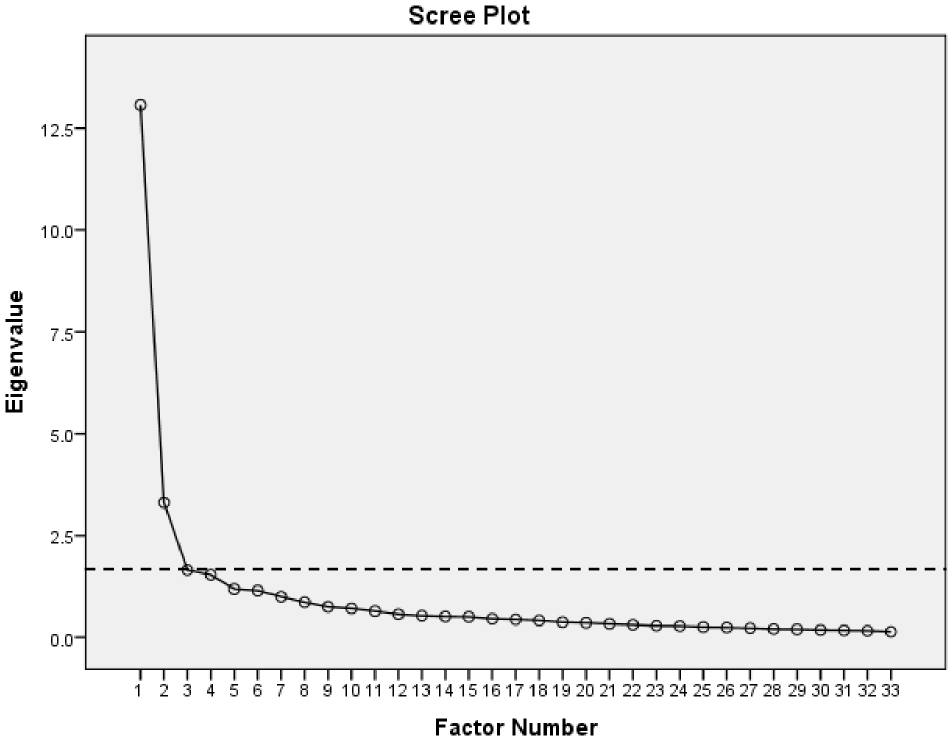

Figure 1. Scree plot from SPSS exploratory factor analysis indicating a two factor solution based on visual inspection.

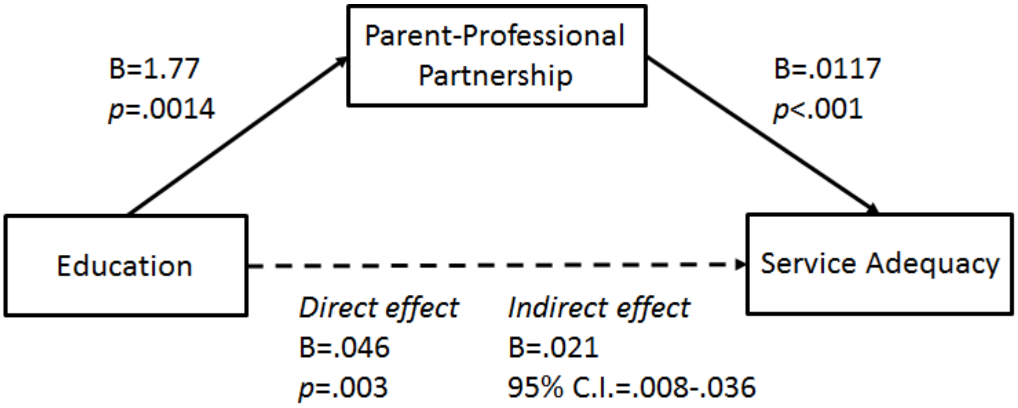

Figure 2. Indirect effect of education on service adequacy through parent-professional partnership.

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