FAMILY TRAINING UNDER THE MEDICAID AUTISM BENEFIT: UNDERSTANDING PARENT PERSPECTIVES ON BARRIERS TO ENGAGEMENT

By

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A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

Psychology – Doctor of Philosophy

2021

ABSTRACT

FAMILY TRAINING UNDER THE MEDICAID AUTISM BENEFIT: UNDERSTANDING PARENT PERSPECTIVES ON BARRIERS TO ENGAGEMENT

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Family training, in which providers coach parents to use intervention strategies with their child, is considered evidence-based and best practice for families of children with Autism Spectrum Disorder (ASD). Parents generally value family training, but this service is underutilized in community-settings and many parents report it as an unmet need. Families receiving services through Medicaid have much to gain from family training, as it can increase the accessibility, intensity, and effectiveness of services in a system with limited resources. However, existing research with underserved populations reveals differences in perspectives on underutilization between families and providers and families in the Medicaid system are significantly underrepresented in this research, highlighting the need for a more thorough exploration of perspectives from parents in these communities.

We partnered with eight agencies that provide Medicaid-funded Applied Behavior Analysis (ABA) services to develop this survey-based study and recruit 226 caregivers to participate. Participants were similar to the state-level Medicaid service population in terms of racial and ethnic background, suggesting a representative sample. Our first aim was to better understand caregivers' current experiences with, satisfaction with, and attitudes toward evidence-based family training as part of their child's ABA services. We found that caregiver's experiences with evidence-based family training were limited, but attitudes toward that model were positive; this was unrelated to parent, child, or service characteristics. Satisfaction with

ABA was positively correlated with experiences of family training and other aspects of caregiver involvement in treatment.

Our second aim was to explore caregivers’ perspectives on engagement in family training using Staudt’s (2007) conceptual model of the engagement process, which outlines the influence of provider behaviors on caregiver’s engagement in treatment through family-level logistical, relational, and attitudinal factors. We conducted a multiple, parallel mediation analysis using Staudt’s (2007) model as a guide and found that relationships with providers and attitudes toward treatment played a strong role in caregivers’ readiness to participate in evidence-based family training, while logistical factors, such as stress and external demands, did not. Furthermore, the relationship between supportive provider behaviors and caregiver interest in engagement was fully mediated by relational and attitudinal factors. This suggests that parents’ experience of supportive provider behaviors, such as enabling participation and coordinating care, improved relationships and strengthened positive attitudes about treatment, which in turn increased their motivation to engage in family training. Interestingly, this was only true for caregivers who indicated that their provider engaged in some degree of supportive behavior. These results suggest that providers may benefit from spending more time building relationships with caregivers of the children they serve and supporting the development of positive attitudes towards evidence-based family training.

This dissertation is dedicated to.my parents, family, and friends who have been both patient and supportive throughout my academic journey. It is also dedicated to the families who participated in this project. Your voices have the power to create change and I look forward to continuing to support you in doing so with this and future collaborations.

ACKNOWLEDGEMENTS

I would first like to thank my advisor, Dr. Brooke Ingersoll, for her patience, encouragement, and support throughout my graduate experience; I am so grateful that you provided me the both the support and independence that I needed to grow my skills and develop my own passions. I would also like to thank my lab mates who were an incredible source of friendship and commiseration during my time at Michigan State University – Katherine Pickard, your guidance and mentorship in community engaged research and all thing graduate school was invaluable; Kyle Frost, your statistical knowhow and feedback on my writing was always so helpful; and Diondra Straiton, having you as a partner in this collaboration with Medicaid was an amazing experience. I am also grateful for the insight and feedback provided by my community partners, as well as their efforts and success in recruiting families to participate in this project. Lastly, I want to thank the Organization for Autism Research, who provided funding for this study.

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong, neurodevelopmental disorder characterized by deficits in social communication and interaction along with the presence of restricted and repetitive behaviors (American Psychological Assocaition, 2013). In addition to the core deficits associated with the diagnosis, individuals with ASD experience a variety of co-occurring emotional and behavioral challenges, such as anxiety, depression, attention-deficit/hyperactivity disorder, and intellectual disability (Gurney, McPheeters, & Davis, 2006; Matson, Wilkins, & Macken, 2008; Tregnago & Cheak-Zamora, 2012) and poor long-term outcomes (Billstedt, Gillberg, & Gillberg, 2005; Howlin, Goode, Hutton, & Rutter, 2004). Furthermore, there are greater negative impacts on the families of these individuals compared to families of children with other special healthcare needs, such as reduced quality of life, negative physical and mental health symptoms, and lower levels of life satisfaction (Karst, Hecke, & van Hecke, 2012; Vasilopoulou & Nisbet, 2016). Given the complex challenges for both children and their families, there are higher rates of service use in families of children with ASD compared to other special needs populations (Gurney et al., 2006; Tregnago & Cheak-Zamora, 2012).

Healthcare Disparities in ASD

Despite increased service use, families of children with ASD remain at high risk for unmet service needs. Families of children with ASD compared to families of children with other special healthcare needs have more difficulty accessing needed services (Chiri & Warfield, 2012; Lord & Bishop, 2010; Ruble, Heflinger, Renfrew, & Saunders, 2005; Vohra, Madhavan, Sambamoorthi, & St. Peter, 2014). These families express difficulty accessing experienced professionals who specialize in working with children with ASD due to long waitlists and limited availability (Chiri & Warfield, 2012; Krauss, Gulley, Sciegaj, & Wells, 2003; Liptak et al., 2008), and are more dissatisfied with the services they do receive (Bitterman, Daley, Misra, Carlson, & Markowitz, 2008; Montes, Halterman, & Magyar, 2009).

Challenges with service access and quality are even greater for families of children with ASD from underrepresented groups, included those from lower socioeconomic status (SES) and marginalized racial/ethnic or linguistic backgrounds. Children from lower SES and minority racial-ethnic backgrounds are often diagnosed with ASD much later than their peers (Durkin et al., 2010; Magaña, Lopez, Aguinaga, & Morton, 2013; Mandell et al., 2009; P. Thomas et al., 2012) and experience reduced or delayed access to specialized services (Hodgetts, Zwaigenbaum, & Nicholas, 2015; Magaña et al., 2013; Patten, Baranek, Watson, & Schultz, 2013). Furthermore, families from traditionally underserved and low-SES backgrounds are often less successful in their attempts to gain access to services (Coots, 1998; Trainor, 2010) and experience strained relationships with providers (Burke, 2017; Levine & Trickett, 2000; Shapiro, Monzo, Rueda, Gomes, & Blacher, 2004).

As the healthcare disparities for families of children with ASD are compounded by these demographic risk factors, this population requires special consideration in research on increasing access to quality care. One system for researchers to focus on is the Medicaid system, as it serves a greater proportion of families from low-income and diverse racial, ethnic, and linguistic backgrounds compared to the general population. These populations would benefit from more thoughtful approaches to care that can help to increase access to services when resources are limited, thus reducing healthcare disparities.

Family Training as an Approach to Increasing Access

Given the healthcare disparities seen for families and children with ASD, it is important to understand approaches to treatment that can improve service access and quality, especially for traditionally underserved populations such as those receiving services through Medicaid, and promote the best possible outcomes for all families and children with ASD. One such approach is family training. While family training can describe a variety of approaches to treatment including psychoeducation and care coordination, the particular approach we will focus on going forward is one which provides systematic training in intervention strategies to help a parent accomplish specific goals or outcomes for their child (Bearss, Burrell, Stewart, & Scahill, 2015). This type of family training has been classified as an evidence-based practice that relates to a variety of positive outcomes for families and children. It is also considered a component of comprehensive interventions for children with ASD (Oono, Honey, & Mcconachie, 2013; Wong et al., 2015), especially for young children receiving intensive early intervention services (Maglione, Gans, Das, Timbie, & Kasari, 2012; Schreibman et al., 2015; Zwaigenbaum et al., 2015).

Family training has the potential to increase the effectiveness, intensity, and accessibility of services in a system with limited resources, such as Medicaid. Family training was initially introduced to supplement direct behavioral therapy for children with ASD, increase therapeutic contact, and improve generalization and maintenance of skills across environments (Lovaas, Koegel, Simmons, & Long, 1973). Family training requires fewer hours of direct contact hours, which can increase a provider’s capacity to support more families and extend therapeutic contact throughout the child’s day by supporting parents in using those strategies at home. For example, parents who receive one hour of coaching per week reported using those strategies for 15 hours with their children (Mahoney & Perales, 2005). Additionally, this model can support providers in reaching a greater number of families where access is limited by scarcity of service providers and centers, such as in rural environments (Koegel, Symon, & Kern Koegel, 2002; Meadan, Meyer, Snodgrass, & Halle, 2013). Taken together, utilizing family training in systems like

Medicaid can help to extend limited resources to reach more families by reducing provider time-burden and increasing the population of individuals served, while also maintaining hours of therapeutic contact for children.

Utilization of Family Training in Community Settings

Despite these benefits, family training is underutilized and under-researched in community settings. Hume and colleagues (2005) found that only 21% of families of children with ASD reported receiving any type of family training, despite family training being ranked as the intervention that most strongly contributed to their child's growth, while others have shown that less than 10% of families receive any family training services (Pickard & Ingersoll, 2016; K. C. Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Additionally, lower SES families of children with ASD spontaneously report family training as an unmet need more often than higher SES families, indicating potential disparities in access to family training services (Pickard & Ingersoll, 2016). As these studies focus on family training more broadly, it is unclear how much of this captures parent coaching in interventions strategies compared to more general types of family services, such as psychoeducation, care coordination, advocacy, or other types of support.

In a survey of community providers (Stahmer, 2007), almost all providers indicated including opportunities for parent involvement in their child's ASD treatment, but the type of involvement varied greatly – only 24% offered classes or workshops on specific strategies and only 16% reported providing opportunities for parents to practice with feedback, a key component of effective family training. A better understanding of the current landscape of evidence-based family training practices is necessary to better understand access to this service and clarify what types of involvement opportunities providers are offering to families, as well as what types of involvement parents are interested in pursuing.

It is also important to take into account the barriers to the implementation of evidence-based family training services in community settings. Implementation of services in childhood healthcare is related to a wide variety of factors that span policy, organizational, and individual levels (e.g., Hanson, Self-Brown, Rostad, & Jackson, 2016). These factors are even more complex within a publicly-funded mental health system, such as Medicaid, where there are limited resources and greater needs (Aarons, Hurlburt, & Horwitz, 2011; Aarons, Wells, Zagursky, Fettes, & Palinkas, 2009). One challenge is that research on the implementation of services within community settings focuses more heavily on the policy, organizational, and provider factors than the family-level factors. This is particularly problematic because while family-level factors are a small part of implementation models, provider's perceptions of these factors are a large component of their decision to use family training strategies with caregivers of children with ASD (Chlebowski, Magaña, Wright, & Brookman-Frazee, 2018; Pickard, Kilgore, & Ingersoll, 2016; Stahmer et al., 2019; Straiton, Groom, & Ingersoll, 2020a).

Providers' perceptions of family-level factors, such as perceived interest, family stressors, and external barriers to treatment, are all reported to be significant barriers to their use of family training practices with families of children with ASD (Chlebowski et al., 2018; Pickard, Kilgore, et al., 2016; Stahmer et al., 2019; Straiton et al., 2020a). However, providers and parents disagree about the degree to which family-level barriers play a role in their engagement in services (Chlebowski et al., 2018; Pickard, Kilgore, et al., 2016; Stahmer et al., 2019). This difference in perspective between parents and providers is difficult to interpret, given the limited literature on both parent and provider perspectives on caregiver engagement in family training, as well as the complexities of implementation in underserved communities. To better understand how parents' perspectives influence their access to family training in underserved communities, the following section provides a concrete example of family training as part of children's Medicaid-funded Applied Behavior Analysis (ABA) services in the state of Michigan.

Understanding the influence of perceived barriers in context

The State of Michigan has strengthened directives for increasing caregiver engagement through evidence-based family training as part of quality treatment for all families of children with ASD (Michigan Autism State Council, 2012, 2018). These recommendations were developed alongside insurance changes which allow for the billing of family training services as part of children's Medicaid-funded ABA services. Although policy changes are an important first step to reducing barriers to implementation, this has not led to widespread implementation of family training among families receiving services in this system. An in-depth analysis of billing data in one service region serving 879 children with ASD indicated that 55% of families received a family training session at least once over a six-month period, with those families receiving it every other month on average (Straiton, Groom, & Ingersoll, 2020b). Estimates across all ten Michigan service regions indicated that an average of 65% (range: 45% to 82%) of families received at least one family training encounter per quarter (M. VanDenBerg, personal communication, January 16, 2019).

Despite state-wide directives and billing codes, the amount of family training encounters provided within this region remains in stark contrast to what many evidence-based family training approaches for children with ASD suggest – once or twice weekly meetings held over several months (Casagrande & Ingersoll, 2017a). In addition to low billing rates and intensity of services, follow-up surveys and interviews with the ABA providers who are eligible to bill for family training in these regions showed significant differences in self-reported family training utilization compared to the billing data (Straiton et al., 2020b). When asked directly, 76% of providers reported using family training regularly with their clients with ASD (i.e., at least 1-2 per month for an average client), despite the low billing rates and frequency of services shown in analysis of the billing data. However, it does not appear that providers are offering systematic and evidence-based approach to families when they report using family training which makes this report less informative.

Spontaneous descriptions of family training given by providers did not align with evidence-based family training strategies, such as modeling techniques, allowing caregivers time to practice, and providing performance feedback (Barton & Fettig, 2013; Ruppert, Machalicek, Hansen, Raulston, & Frantz, 2016). Providers most often described family training as psychoeducation for parents, providing skill updates and engaging in progress tracking, or providing general support to the family (Straiton et al., 2020b). Follow-up interviews also indicated that providers may use family training strategies as needed, rather than as a comprehensive and systematic treatment approach, which may account for some of the discrepancy between billing data and self-report.

When asked about factors that influence their use of evidence-based family training strategies, providers reported that their agencies do not prioritize family training, they have limited training in evidence-based strategies, and struggle to engage families. In fact, provider report of family-level barriers such as perceived lack of motivation and engagement were the strongest, unique predictor of providers use of family training strategies alongside the organizational- and provider-level factors (Straiton et al., 2020a). This highlights why a better understanding of parent perspectives is needed. Given the lack of training reported by providers in family training strategies, it is possible that their difficulty with parent engagement is due to provider’s lack of skill rather than a lack of parent interest in family training. Additionally, families may not be aware of what their provider considers family training due to the variety of definitions and they may not perceive the use of evidence-based strategies when used piecemeal. It is also possible that families may not acknowledge receiving family training services, even when providers endorse it as common practice, and that this misunderstanding may contribute to the perception of low parental engagement or motivation by providers.

Given these potential interpretations, it is necessary to better understand parents' experience with and attitudes toward the various components of family training in this Medicaid service system. As such, the first aim of this study is to gather these perspectives from caregivers receiving services within this community. An exploration of parent perspectives within this same system allows for a greater understand of the challenges implementing services in publicly-funded health systems and the interpretation of findings within the context of those challenges. However, given differences between providers and parents perspectives on the degree to which family-level barriers play a role in caregiver engagement in family training services (e.g., Chlebowski et al., 2018; Pickard, Kilgore, et al., 2016), we must also understand parents' perspectives on the process of engagement in family training. Furthermore, perspectives from parents of children with ASD regarding factors that influence their engagement in services are limited, especially among traditionally underserved families such as those in the Medicaid system.

A Conceptual Model of the Engagement Process

Since parent engagement in family training is a significant component of evidence-based family training, caregiver perspectives of these services are important. Additionally, perceived parent engagement and motivation is likely to have a greater impact on providers' use of this service compared to child-directed service models. Thus, the second aim of this study is to obtain parents' perspectives on the family-level factors that contribute to their engagement in family training. Specifically, our goal is to identify and apply a model for caregiver engagement in treatment to parent involvement in family training services for children with ASD. A model that is particularly relevant to this question was developed by Staudt (2007) from the literature around caregiver engagement in treatment for at-risk children, focusing on those in low-income communities or within the welfare system. Staudt's model proposes a process of caregiver engagement in treatment wherein specific family-level factors influence attitudes toward engagement, which is a precursor to engaged behaviors and optimal outcomes; additionally, all of these factors are influenced directly or indirectly by provider practices (see Figure 1).

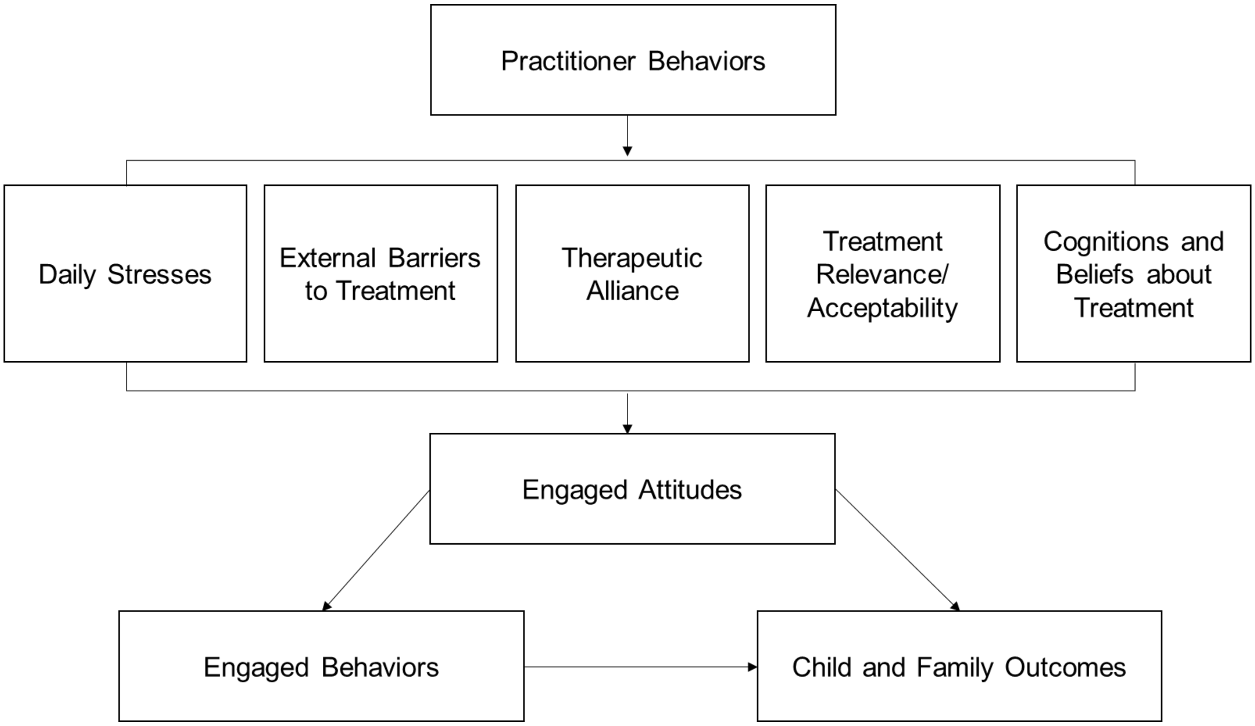


Figure 1.

Conceptual model of the process of parent engagement in treatment.

(Adapted from "Treatment Engagement with Caregivers of At-risk Children: Gaps in Research and Conceptualization," by M Staudt, 2007, *Journal of child and Family Studies, 16*, p190.)

While Staudt's (2007) model of engagement was developed with caregivers of at-risk children receiving community mental health treatment in underserved settings in mind, there are several parallels between these families and those receiving publicly-funded services for children with ASD. First, both sets of children have complex needs which can be supported through family training models as part of best practice (American Academy of Child and Adolescent Psychiatry, 2007; National Autism Center, 2005, 2015; National Research Council, 2001; NICE, 2006; Wong et al., 2015). In fact, there are many conceptual overlaps for parent training models in both communities (e.g., Brookman-Frazee, Stahmer, Baker-Ericzén, & Tsai, 2006).

Second, caregivers of children in both groups have their own healthcare needs that might impact their ability to engage fully in treatment. For example, caregivers of children in the welfare system often receive additional treatment alongside their child due to their own mental health needs (Burns et al., 2010). Similarly, caregivers of children with ASD experience high rates of physical and mental health challenges that require separate attention (Karst et al., 2012; Vasilopoulou & Nisbet, 2016). This is likely to be more pronounced for families in the Medicaid system, who are also more at risk for poor health outcomes related to racial, ethnic, and socioeconomic factors (Adler, Boyce, Chesney, Folkman, & Syme, 1993; Adler N, 1999).

Last, both sets of caregivers are less likely to seek out family training services for themselves; this limits buy-in to services and reduces initial engagement (Yatchmenoff, 2005). Families of at-risk children are often referred to parent training programs through the school or welfare system and providers must work to engage parents who did not seek such services (e.g., Kemp, Marcenko, Hoagwood, & Vesneski, 2009; Shepard, Armstrong, Silver, Berger, & Seifer, 2012). Similarly, families of children with ASD often present with concerns regarding language and communication development and then are referred for ASD-specific evaluation and services

(De Giacomo & Fombonne, 1998; Turygin, Matson, Williams, & Belva, 2014; Twyman, Maxim, Leet, & Ultmann, 2009); this referral may be unexpected and families are unsure of what services they will ultimately receive (Brookman-Frazee, Baker-Ericzén, Stadnick, & Taylor, 2012). Additionally, family training is often a component of and sometimes required in order to access direct services for ASD.

These similarities suggest that Staudt's (2007) model would be useful in understanding the process of engagement in family training for parents of children with ASD. The specific barriers and facilitators to engagement specified in the model are also relevant for families of children with ASD. The barriers to engagement identified in this model include logistical barriers such as family stresses and external barriers to treatment, relational barriers in terms of therapeutic alliance, and attitudinal barriers including beliefs about the acceptability and effectiveness of treatment. These family-level factors are highly relevant for families of children with ASD, especially those in traditionally undeserved communities, who experience greater challenges accessing care (e.., Ruble et al., 2005; Vohra et al., 2014), poor relationships and disagreements with providers about care (e.g., Burke, 2017; Levine & Trickett, 2000; Shapiro et al., 2004), and have limited knowledge of treatment options (e.g., Pickard & Ingersoll, 2016; Stahmer et al., 2019).

This model also includes caregivers' attitudes toward engagement as a critical and separate part of the engagement process than actual behaviors in achieving treatment outcomes. These engaged attitudes represent a readiness and commitment to engage in treatment, which is an important component of engaged behaviors, such as treatment attendance and adherence. These attitudes toward engagement are also highly important in family training, as the model relies heavily on caregiver engagement during sessions for optimal parent learning and the use of strategies outside of sessions to achieve optimal outcomes. Furthermore, the inclusion of provider behaviors in this model highlights the role providers have in establishing collaborative relationships and engaging parents in the process. The following sections briefly review the relevant research around the influence of these model components on parent engagement in treatment, as well as the relevance for family training with caregivers of children with ASD.

Logistical Barriers to Parent Engagement. The first set of potential barriers to engagement in Staudt's (2007) model include daily stresses and external barriers to treatment. Families of children with ASD already experience greater levels of stress compared to other special needs populations (Karst et al., 2012; Vasilopoulou & Nisbet, 2016); this is even more pronounced for low income families (Atharia, Ghaedia, & Mohd Kosnina, 2013; Phetrasuwan & Shandor Miles, 2009). Interventions have been successful in reducing parenting stress by devoting time within family training programs for parents to talk through their personal concerns and challenges (Durand, Hieneman, Clarke, Wang, & Rinaldi, 2013; Prinz & Miller, 1994). Participation in family training programs for children with ASD has also shown decreases in parenting stress and improvement in parent mental health (Coolican, Smith, & Bryson, 2010; Estes et al., 2014; Ingersoll, Wainer, Berger, Pickard, & Bonter, 2016; Turner-Brown, Hume, Boyd, & Kainz, 2016). As such, family stress can contribute to challenges with engagement while providers can help to mitigate those challenges through their own behaviors.

Families, especially those from low-income backgrounds, also have finite amounts of time, energy, and resources to pursue treatments. For example, common barriers include difficulty securing transportation to appointments, finding time to attend sessions due to work or other family obligations, challenges obtaining care for other children, and having a physical or mental health challenge of their own (Fawley-King, Haine-Schlagel, Trask, Zhang, & Garland, 2013; Kazdin, Holland, & Crowley, 1997). These are the type of barriers may be intensified in a family training approach compared to child-directed treatment. Evidence-based family training in ASD is delivered at a relatively high intensity of one to two times per week over the course of several months and has expectations for regular practice between sessions (e.g., Casagrande & Ingersoll, 2017a; Oono et al., 2013), requiring an additional demand on parents' ability to both attend sessions and implement strategies. For example, interviews with caregivers of children with ASD from traditionally underserved cultural, linguistic, and socioeconomic backgrounds highlight significant challenges with attending family services due to work schedules, limited access to transportation, and financial concerns (Pickard & Ingersoll, 2016; Stahmer et al., 2019). Furthermore, given greater access barriers for low-income families of children with ASD (e.g., Ruble et al., 2005), it is likely that logistical challenges would continue to influence engagement in family training engagement within Medicaid. However, the degree to which these barriers are important varies across studies.

In one study on the use of a family training intervention for social communication in children with ASD within a Medicaid setting, parents indeed identified logistical barriers to participation but expressed a greater intention to participate with adaptations and a flexible delivery of the intervention (Pickard, Rowless, & Ingersoll, 2017). However, when adaptations to address logistics are put into place, they have not always shown increased participation. For example, a randomized family training trial focused on recruiting and working with families from traditionally underserved backgrounds found high rates of drop-out despite providing home-based services, having a liberal cancelation policy, and providing transportation or covering costs of attending center-based assessments (Carr & Lord, 2016; Carr et al., 2016; Kasari, Lawton, et al., 2014). Another study found that caregivers of children with ASD are willing to prioritize their involvement in family training - despite logistical challenges - due to its perceived value and importance for their child's growth (Chlebowski et al., 2018; Stahmer et al., 2019). Thus, while logistical barriers may make it harder for parents to participate, it is unclear the role they play in parent engagement in family training and there is a greater need to understand logistical barriers in the context of other types of barriers to engagement.

Relational Barriers to Engagement. The second major component of engagement in Staudt's (2007) model is the therapeutic alliance - the relationships that clients have with their treatment providers. Therapeutic alliance with caregivers is strongly related to engagement and outcomes in childhood mental health treatment broadly (see de Greef, Pijnenburg, van Hattum, McLeod, & Scholte, 2017 for review). It has also been seen as an important component of engagement in and outcomes for parent training for challenging behavior (Kazdin, Holland, & Crowley, 1997; Kazdin & Whitley, 2006; Tolan, Hanish, McKay, & Dickey, 2002). Establishing positive relationships in family training is especially important given the inherent partnership and collaboration required for an approach that focuses on coaching parents to work with their child.

While therapeutic alliance is shown to be an important component of treatment for children broadly, there is little research focusing on the role of therapeutic alliance in family training for children with ASD. One study found that parents actively participating in a family training intervention to manage challenging behaviors for their child with ASD reported strong therapeutic alliance with their providers (Stadnick, Drahota, & Brookman-Frazee, 2013). However, the quality of these therapeutic relationships before treatment begins may affect parents' willingness to engage and limit the ability to grow the relationship through treatment. For example, another study found that parents were hesitant to become involved in family training due to concerns about provider skills and ability to support them, despite an interest in participating in this model of treatment (Brookman-Frazee et al., 2012).

This is unsurprising as relationships between caregivers of children with ASD and their providers are often strained. Families of children with ASD report difficultly communicating with providers (Stoner et al., 2005; Tucker & Schwartz, 2013; Zablotsky, Boswell, & Smith, 2012) and lack confidence in provider's knowledge about ASD services and ability to support them (Brookman-Frazee et al., 2012; Nuske et al., 2018; Tucker & Schwartz, 2013). Together, these challenges reflect poor quality relationships with service providers, which are even more pronounced for demographically at-risk populations (Burke, 2017; Levine & Trickett, 2000; Shapiro et al., 2004; Stahmer et al., 2019), and are likely to interfere with parent engagement.

Improving partnerships is critical for obtaining positive outcomes for families of children with ASD (e.g., Brookman-Frazee & Koegel, 2004; Burke & Hodapp, 2014; Summers et al., 2007) and providers play a significant role in developing those partnerships to support such outcomes. For example, providers who work to establish these relationships in the intake session see improved engagement and outcomes related to care of low income families and children (McKay, Nudelman, McCadam, & Gonzales, 1996; McKay, Stoewe, McCadam, & Gonzales, 1998). Increasing partnership and collaboration during the assessment of ASD also improves the likelihood of family follow-through with recommendations (Jamison et al., 2017; Roth et al., 2016; Tolmie, Bruck, & Kerslake, 2017).

Collaboration with parents throughout treatment also helps to promote positive family and child outcomes. The use of partnership building practices by providers supports ongoing engagement and treatment outcomes by incorporating family values and routines into treatment planning and empowering parents as partners in the intervention process (Brookman-Frazee &

Koegel, 2004; Buschbacher, Fox, & Clarke, 2004; Moes & Frea, 2002). In a study that used a reversal design to switch between an clinician-directed and partnership model of parent coaching for children with ASD, supportive provider behaviors helped parents feel less stressed during sessions, increased their confidence in using strategies, and supported more positive parent-child interactions (Brookman-Frazee & Koegel, 2004). Taken together, the role of providers in establishing strong, positive, and collaborative relationships with parents is a key component of initial and ongoing engagement in services for ASD, that likely extends to family training engagement.

Attitudinal Barriers to Engagement. After overcoming logistical challenges with participation and establishing positive relationships with providers, services must also be viewed as acceptable, relevant, and effective in order for parents to engage. Families who have positive attitudes towards a treatment express greater motivation to participate and have higher rates of attendance and adherence to parent training sessions for behavioral challenges (Kazdin & Wassell, 1999; Mah & Johnston, 2008; Morrissey-Kane & Prinz, 1999; Nock, Ferriter, & Holmberg, 2007; Nock & Kazdin, 2001). Additionally, families are more likely to attend sessions for services in which they express an interest (Bannon & McKay, 2005), while they are not likely to attend or complete treatments that have little perceived relevance or value (Chacko, Wymbs, Rajwan, Wymbs, & Feirsen, 2017). Given the strong body of evidence for engagement in other types of parent training and acceptability of the approach, the role of attitudes toward family training engagement for parent of children with ASD is likely to be no different.

Generally, parents of children with ASD have expressed positive attitudes about their involvement in services, value family training as a component of their child’s care, and feel that family training is effective in supporting their child’s development (Callahan, Henson, & Cowan, 2008; Hume et al., 2005; Mahoney & Filer, 1996; K. C. Thomas, Morrissey, & McLaurin, 2007). Research trials for parent training interventions for ASD have also shown positive parent attitudes about the acceptability and effectiveness of these models (Bradshaw, Steiner, Gengoux, & Koegel, 2015; Brian, Smith, Zwaigenbaum, Roberts, & Bryson, 2016; Lang, Machalicek, Rispoli, & Regester, 2009; Pickard, Wainer, Bailey, & Ingersoll, 2016; Whittingham, Sofronoff, & Sheffield, 2006). However, it has not been shown how directly this level of acceptability relates to engagement in family training outside of research trials and for underserved populations.

Providers play a role in supporting parents' positive attitudes toward treatment through psychoeducation and conversation. Increasing communication about the treatment process and parent expectations has been shown to increased attendance and reduce drop-out for parents of children receiving services in low-income communities (McKay et al., 1996, 1998; Prinz & Miller, 1994). As parents of children with ASD in low-income communities may have limited knowledge of evidence-based treatments (e.g., Pickard & Ingersoll, 2016; Stahmer et al., 2019), providers must support parents in the development of such knowledge. Interventions for low-income caregivers of children with ASD that increase parent knowledge have been effective in in improving attitudes toward treatment and engagement in services (Banach, Iudice, Conway, & Couse, 2010; Kasari, Siller, et al., 2014; Roth et al., 2016; Tolmie et al., 2017), providing support for this as a potential mechanism for increasing engagement in family training for ASD.

The Influence of Provider Behaviors on Engagement in Treatment. The final component of Staudt's (2007) model covers the role that providers have in supporting caregiver engagement. In a review of interventions to increase engagement in child mental health, providers have been successful in increasing engagement through their behaviors (Ingoldsby, 2010; McKay & Bannon, 2004). While each of the previous sections has included specific examples of how provider behaviors impact that barrier in particular, there are also more holistic approaches to care that are related to similar outcomes. One such approach that values this attention to addressing specific family needs, establishing collaborative relationships, and supporting parent empowerment, is family-centered care.

Family-centered care emphasizes the need for flexible service delivery and mutual respect, honesty, and collaboration with the goal of actively involving families in the care of their child. This is a core component of quality care (Committee on Hospital Care, 2012; Kuo et al., 2012) and is related to a variety of positive family and child outcomes for children with special needs broadly (Dunst & Trivette, 2009; Dunst, Trivette, & Hamby, 2007; Kuo, Bird, & Tilford, 2011), as well as for families of children with ASD (Gabovitch & Curtin, 2009). However, families of children with ASD (Brachlow, Ness, McPheeters, & Gurney, 2007; Kogan et al., 2008; Krauss et al., 2003) and families from demographically at-risk backgrounds (Denboba, McPherson, Kenney, Strickland, & Newacheck, 2006; Guerrero, Chen, Inkelas, Rodriguez, & Ortega, 2010; Montes & Halterman, 2011; Ngui & Flores, 2006) are less likely to receive family-centered care.

Family centered care can further be discussed in terms of relational versus participatory help-giving practices. Relational help-giving focuses on building warm and caring relationships with caregivers, while participatory help-giving practices support active caregiver involvement in treatment through a responsiveness to family needs, information sharing, and creating opportunities for parent involvement (Dempsey & Dunst, 2004; Dunst & Trivette, 1996, 2009). These participatory help-giving practices are most similar to those identified by Staudt’s (2007) review and provide benefits beyond relational practices, support the most optimal outcomes, and are most associated with active models of caregiver involvement (Dunst, Boyd, Trivette, & Hamby, 1995, 2002; Dunst et al., 2007; Dunst & Trivette, 1996). This suggests that these behaviors would be most important in supporting caregiver engagement in evidence-based family training for children with ASD.

While Staudt's (2007) model fits with the literature on parent engagement for families of children with ASD and outlines specific provider behaviors that can increase parent participation in treatment, it has not been applied to this population. Additionally, it was proposed as a conceptual model and has not been tested empirically. Given the broader contextual complexities of service implementation in publicly-funded settings, the potential for interactions between components, and limited research on parent engagement in family training for ASD in Medicaid settings, applying this model empirically within this population can support the interpretation of findings within the context of these challenges.

Study Aims

This study will integrate caregiver perspectives into a larger community-engaged research project on provider practices in delivering family training under the Michigan Medicaid Autism Benefit. In addition to developing a better understanding of the use of family training with underserved populations in usual care, exploring caregiver perspectives within this system alongside knowledge of barriers at other levels will provide a more comprehensive view of the role of family-level barriers to engagement. Since the body of research on engagement in family training as part of usual care and in Medicaid settings is limited, the first aim of this study is to understand the current landscape in regard to caregiver's experiences with family training as part of their child's current ABA services, their satisfaction with these services, and their attitudes toward an evidence-based model of family training. The second aim is to explore the perceived barriers and facilitators toward engagement in an evidence-based model of family training and evaluate the influence of provider behaviors, barriers, and facilitators on caregivers’ motivation to participate as proposed by Staudt’s (2007) model of engagement.

METHOD

This research project collected surveys from caregivers of children with ASD receiving ABA services through Medicaid and focused on understanding caregiver perspectives on the care their family receives. On numerous occasions throughout history, researches have taken advantage of and harmed low-income and diverse populations leading up to a culture of mistrust between communities and researchers despite the establishment of strict ethics guidelines and review procedures (e.g., List, 2005; Scharf et al., 2010). For this study we used community engaged research methods that have been shown to support ethical practices when working with low-income and diverse communities, especially when the results of such research have a potential impact on the healthcare that these individuals receive from their communities (e.g., Ejiogu et al., 2011; Higgins & Metzler, 2001; Ross et al., 2010; Wallerstein & Duran, 2006).

Community Partnerships

Table 1 shows a timeline of research activities for establishing and maintaining ethical community academic partnerships as outlined by Ross and colleagues (2010). The degree of participation and responsibility for each research activity varied based on the needs, skills, and desires of community partners and is depicted on a visual continuum as recommended by Doberneck and Dann (2019).

Table 1.

Timeline of engagement activities with degree of participation and responsibility shared by community (C) and research (R) partners marked on a visual spectrum.

Activity		**Date(s)**	**C←————————→R**
Forming the Partnership:	Regional:	May 2017	←—X————————→
	State:	Dec 2018	←————————X——→
	Local:	Jan 2019 – Mar 2019	←—————X—————→
Developing a Joint Work Plan		Sep 2018 – Mar 2019	←—————X—————→
Research Design and Implementation		Sep 2018 – Mar 2019	←————————X——→
The Consent Process		Dec 2019 - Apr 2019	←—————X—————→
Data Collection		Apr 2019 – Dec 2019	←——————————X→
Data	Analysis:	Jan 2020 – Feb 2020	←——————————X→
	Interpretation:	Feb 2020 – Mar 2020	←————————X——→
	Dissemination:	Apr 2020 – future	←—————X—————→
Community Benefits and Sustaining Relationships		Apr 2020 – future	←————————X——→

Forming the Partnership. This research project was developed as part of a broader collaboration through the Michigan Department of Health and Human Services (MDHHS) where we partnered with Medicaid Autism Benefit administrators at the state, regional, and local levels. This partnership was initiated by one regional administrator in May 2017. We then obtained support from state administrators in December 2018. Local administrators were informed about the opportunity between January 2019 and March 2019 through the presentation of current findings at a variety of regional and statewide meetings, information distributed in MDHHS monthly newsletters, and direct contact with regional and local coordinators.

Developing a Joint Work Plan. The partnership was established around a statewide initiative to improve the frequency and quality of family support during ABA services. During the first year of the partnership, partners brainstormed project goals and research questions. A Memorandum of Understanding was developed in September of 2018 to formalize the partnership with regional and state administrations and define specific goals for the overall project (see Appendix A). A partnership letter was developed specifically around the current research project to outline these goals and detail different levels of participation for local administrations in order to help them make an informed and individualized decision about what level of participation would most benefit them (See Appendix B).

Research Design and Implementation. Partners agreed that a survey-based study would be able to address the primary research questions and be the most feasible given resource constraints on both sides of the partnership. The research team drafted the initial survey with content that aligned with the project goals, was appropriate for use in low-income and/or community-based settings, and was supported by previous research. This initial draft was reviewed by a group of stakeholders, including administrators, supports coordinators, ABA providers, and caregivers, to ensure accessible and appropriate content. After revisions, two community providers piloted the survey with several caregivers and provided final edits.

Community partners identified primary recruitment strategies that they felt would result in the greatest reach and anticipated participation. We worked with each individual agency to tailor a recruitment script highlighting project goals and privacy procedures for potential participants, in addition to the informed consent that was included in the survey packet. In-person visits were made to sites to distribute all research materials, discuss the project directly with staff, and troubleshoot potential challenges. For sites where this was not possible, we set up phone calls with staff to discuss participation and mailed all research materials.

All data collection was initiated by non-ABA staff members to prevent conflicts of interest that could arise if ABA providers were involved in recruitment given that caregivers were being asked to report on the quality of their ABA services. Similarly, we wanted to ensure that agencies would not have access to individual responses, and it was agreed that only research staff would have access to raw data. To address these concerns, caregivers were provided envelopes and asked to seal their surveys before returning them to protect their privacy and encourage their honest, unbiased reporting about the quality of their current services.

Applying for Funding. All costs for research materials required to participate were covered with funding provided by the research team and through a grant from the Organization for Autism Research.

The Consent Process. This study was approved by the Michigan State University IRB and considered exempt. Each participating agency also reviewed the study protocol in accordance to their own internal research review process and requirements before beginning.

Data Collection. Information about participant recruitment, retention, and data collection strategies is presented in the following sections.

Data Analysis, Interpretation, and Dissemination. Between April and December of 2019, representatives from each participating agency were encouraged to attend 30-minute monthly calls to discuss ongoing recruitment, preliminary data, and unforeseen challenges. Along with these calls, monthly e-mails were sent out to ensure that information was made available to those who were not available for the calls. After data collection was completed, research partners completed the analysis and initial interpretation. Follow up sessions will be scheduled to present the findings, receive feedback on the interpretation of the data, and identify methods to disseminate findings to both caregivers and providers. Dissemination of findings throughout the project included presentation of the data at regional and statewide meetings for autism benefits coordinators, local professional development conferences, and scientific meetings (see Appendix C). Additionally, articles will be submitted for publication in academic journals and community partners will be invited to co-author.

Community Benefits and Sustaining Relationships. In addition to dissemination of information, the follow-up meetings will focus on next steps for developing training recommendations and other continuing education opportunities, as well as further research projects to help sustain and grow the partnership.

Recruitment

A total of eight community mental health agencies across four service regions were responsible for direct recruitment and data collection. Agency locations varied in terms of urbanization as classified by the National Center for Health Statistics Urban-Rural classification scheme for counties (see Table 2 in Ingram & Franco, 2014). Estimated reach was based on reports from each agency leader regarding the number of families that they expected to have contact with during the recruitment period.

Table 2.

Agency urbanization classifications with reach estimates and participation rates.

County Classification Code	Agencies N	Estimated Reach N	Actual Reach N (% Estimated)	Percent of the total sample
Large Metropolitan	2	160	55 (34.4)	24.4
Medium Metropolitan	2	130	77 (59.2)	34.1
Small Metropolitan	1	60	29 (48.3)	12.4
Micro/Non-Metropolitan	3	120	64 (53.5)	29.2

Recruitment utilized a variety of strategies designed to increase the participation of minority and low-income families, including introducing the study through community partners, conducting data collection in community spaces, and providing immediate compensation to families for their participation (e.g., Ejiogu et al., 2011). First, we identified the recruitment strategies that would result in the greatest reach and anticipated participation based on feedback from community partners. Most agencies (*n*=5) distributed surveys to families during their child’s required annual re-evaluation, when caregivers would be present at for several hours and have time to participate on site. Agencies who served fewer total families (*n*=1) or contracted assessments out to other agencies (*n*=2) utilized case managers to present the opportunity at their next quarterly meeting with families. Next, we worked with each agency to tailor a recruitment script for staff members to share with potential participants in addition to the informed consent that was included in the survey packet. Lastly, participation was completed on site and caregivers were given a $10 gift card by their agency immediately following participation.

Participants

We recruited 226 caregivers (81.9% mothers, 10.6% fathers, 7.4% other) of children with ASD under 21 years of age (Current age in years: *M*=8.70, *SD*=4.12, Range: 1-20; Age of diagnosis in years: *M*=4.47, *SD*=3.47, Range: 1-17) who receive ABA services under the Michigan Medicaid Autism Benefit. Children received an average of 14.92 hours of ABA services per week (*SD*=9.34, Range: 0-40) for 2.01 years (*SD*=1.5, Range: 0-12). These services were primarily provided in center-based (52.7%) or home-based (28.8%) settings, with some children receiving services across both settings (6.6%) or at school (3.1%).

Participants in this study were similar to the general population of individuals enrolled in Medicaid in the state of Michigan in terms of racial and ethnic backgrounds (see Table 2 in Mighigan Department of Health and Human Services, 2017). Racial and ethnic backgrounds for caregivers and children in this study are located in Table 3. Information about caregivers' educational background is located in Table 4.

Table 3.

Caregiver and child racial and ethnic backgrounds.

	Caregiver n (%)		Child n (%)	
	Total	Hispanic	Total	Hispanic
Asian	5 (2.2)	0 (0.0)	5 (2.2)	0 (0.0)
Black	43 (19.0)	2 (0.9)	49 (21.7)	4 (1.8)
Indigenous American	2 (0.9)	0 (0.0)	1 (0.4)	0 (0.0)
White	140 (61.9)	8 (3.5)	122 (54.0)	12 (5.3)
Multiracial	14 (6.2)	3 (1.3)	40 (17.7)	9 (4.0)
*Black/White	8 (3.5)	1 (0.4)	25 (11.1)	4 (1.8)
*Indigenous/White	5 (2.2)	2 (0.9)	9 (4.0)	3 (1.3)
*Indigenous/Black/White	0 (0.0)	0 (0.0)	2 (0.9)	1 (0.4)
*Asian/White	0 (0.0)	0 (0.0)	3 (1.3)	1 (0.4)
*Unknown	1 (0.4)	0 (0.0)	1 (0.4)	0 (0.0)
Unknown	22 (9.7)	2 (0.9)	9 (4.0)	2 (0.9)

*Note: This is a breakdown of individuals reporting multiple identities, thus column totals do not equal 100%.

Table 4.

Caregivers’ highest level of formal education attained.

Highest level completed	n (%)
7th grade or less	6 (2.7)
8th or 9th grade	2 (0.9)
10th or 11th grade	16 (7.1)
High school degree or GED	50 (22.1)
Some college or trade degree	106 (46.9)
4-year college degree	33 (14.6)
Graduate level education	9 (4.0)
Unknown	4 (1.8)

Procedure

Caregivers completed the anonymous survey using a paper-and-pencil packet and returned it to their agency in a sealed envelope. The full survey is shown in Appendix D. On the survey, caregivers were asked to provide basic demographic information about themselves and their child, details about their child’s current ABA services, whether they have been offered or participated in family training as part of ABA, their satisfaction with ABA services, and their current and preferred involvement in ABA services. Caregivers were then asked to indicate the extent to which their ABA provider has used each of seven different evidence-based family training strategies.

Given previous findings that suggest providers in this system may not use evidence-based strategies when they deliver family training and reduced knowledge of evidence-based practices for children with ASD in low-income settings, a one-page informational flyer describing aspects of high-quality, evidence-based family training (Barton & Fettig, 2013; Rush & Shelden, 2011) was embedded in the survey prior to responding to remaining questions about family training (see Appendix D). Caregivers then completed a variety of validated measures that align with Staudt's (2007) model of engagement including their daily stresses and external barriers to treatment, their therapeutic alliance with their ABA provider, their beliefs about the relevance and effectiveness of family training, their attitudes towards engagement in family training, and the degree to which their ABA provider engages in participatory help-giving practices.

MEASURES

Descriptive Measures

Descriptive information was collected around caregiver and child demographics, ABA service characteristics, and experiences with service involvement and family training.

Caregiver, Child, and ABA Service Characteristics. Caregivers were asked to provide details about themselves, their child, and their child's services. Caregivers reported their race, ethnicity, level of education, and relationship to the child about whom they are completing the survey. They provided information about the child receiving ABA services through the Michigan Medicaid Autism Benefit, including their age, race, ethnicity, and age of diagnosis. Finally, they gave details about their child's ABA services, including the location, intensity, and duration of services,

Satisfaction with ABA. Satisfaction with ABA services was evaluated using the three-item Client Satisfaction Questionnaire (CSQ-3; Attkisson & Zwick, 1982).

Involvement in ABA. A total of seven items about involvement were adapted from previous studies exploring caregiver involvement in community-based services for children (Fawley-King et al., 2013; Hume et al., 2005). Three items addressed caregivers' perceived level of current involvement in ABA services, overall satisfaction with their involvement in ABA services, and their preferred level of involvement in their child's ABA services. Four items asked about provider behaviors that support involvement (*I have many opportunities to be involved in my child's ABA; The ABA providers encourage me to be involved in my child's ABA*) and perceptions of whether their own involvement contributes positively to their child's ABA services (*My involvement makes my child's ABA more effective; My involvement in ABA contributes to my child's growth*).

Family Training Experiences. Caregivers were asked about their experiences with family training as part of their child's ABA services. Prior to seeing the evidence-based family training informational handout, caregivers were asked if they have been offered and received family training (either currently or in the past), been offered but declined family training, or never been offered or received family training as part of their child's ABA services. Caregivers then reported how similar the description of evidence-based family training was to the support they receive from their child's ABA supervisor on a 5-point scale from *not at all* to *extremely*, and how often their child's ABA supervisor uses the seven evidence-based family training strategies introduced in the informational handout on a 5-point scale from *rarely/never* to *weekly*.

Model Measures

Seven previously validated measures were used to represent each construct from Staudt's (2007) model of caregiver engagement. Measures were selected based on their validation with families and children with disabilities, as well as the established use of these measures with demographically at-risk populations.

Provider Behaviors. Caregivers rated their perceptions of their ABA providers' supportive behaviors using the Measures of Processes of Care (MPOC-20; King, King, & Rosenbaum, 2004). The MPOC-20 includes 20 items which are rated on a 7-point scale. The MPOC-20 was designed for use with families of children with developmental disabilities and shows good internal consistency (range: α=.77-.88). The MPOC includes five domains, including four focused on provider behaviors (Enabling and Partnership, Providing Specific Information, Coordinated and Comprehensive Care, Respectful and Supportive Care) and one focusing on the agency's behaviors (Providing General Information). We wanted to focus on the behavior of the ABA supervisor and reduce the burden of participation for families, so we dropped the final domain of Providing General Information resulting in a 15-item scale. Additionally, given the role of participatory versus relational help-giving in supporting active participation of caregivers as well as the conceptual overlap between therapeutic alliance and relational help-giving (Dunst et al., 1995, 2002; Dunst & Trivette, 2009), we focused only on the domains related to participatory help-giving practices (i.e., Enabling and Partnership, Coordinated and Comprehensive Care; Dunst & Espe-Sherwindt, 2016; Dunst, Trivette, & Hamby, 2007) as our primary indicator of provider behaviors in Staudt's (2007) model. These items had high internal consistency (α=.95) and the mean was used in analysis.

Daily Stresses. Caregivers completed the Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983) as a measure of their daily stress. The PSS contains statements related to how often events in one's life are perceived stressful based on a 5-point scale from *never* to *very often*. The 4-item version of this measure was used in this study as it has been shown to have similar psychometric properties as the longer scales. Internal consistency was adequate (α =.64) and an overall mean was used in analysis.

External Barriers to Family Training. Caregivers completed the10-item external demands to treatment subscale from the Barriers to Treatment Participation Scale (BTPS; Kazdin, Holland, Crowley, & Breton, 1997). Caregivers were asked to indicate how much they believe each of the barriers would interfere with their ability to participate in family training as described in the informational handout on a 5-point scale from *not at all* to *very much*. The 10-item subscale was previously validated with parents of children receiving services in a community mental health setting and showed good internal consistency (α =.80, Colonna-Pydyn, Gjesfjeld, & Greeno, 2007). Internal consistency in the current study was very good (*α* =.91) and the overall mean was used for analysis.

Therapeutic Alliance. Caregivers reported their relationship with their child's ABA supervisor using the 12-item Therapeutic Alliance Scales for Caregivers and Parents (TASCP; Accurso, Hawley, & Garland, 2013). The TASCP was developed to measure relationships between parents and their child's therapist, validated in a community mental health setting, and predicts engagement in treatments (Accurso et al., 2013). It has also been used for families of children receiving family training in community settings (Stadnick et al., 2013). This measure showed good internal consistency (*α* =.87) and the overall mean was used for analysis.

Treatment Acceptability of Family Training. Caregivers were asked to rate the acceptability and relevance of evidence-based family training using the 8-item Abbreviated Acceptability Rating Profile (AARP, Tarnowski & Simonian, 1992). The AARP has a reduced item count and simplified reading level to make the measure more accessible to families in a community mental health setting. The measure showed good internal consistency (*α*=.93) and an overall mean was used for analysis.

Cognitions and Beliefs about Family Training. Caregivers completed the 6-item Credibility and Expectancies Parent Questionnaire (CEQ-P; Nock, Ferriter, & Holmberg, 2007; Nock & Kazdin, 2001) to evaluate their beliefs about the effectiveness of evidence-based family training. Items were rated on a 5-point scale. The CEQ-P shows good internal consistency (*α*=.79) and predicts treatment attendance and adherence (Nock et al., 2007; Nock & Kazdin, 2001). Internal consistency was high (*α*=.93) and an overall mean was used in analysis.

Motivation to Participate in Family Training. Caregivers reported on their motivation to participate in evidence-based family training using the Parent Motivation Inventory (PMI;

Nock & Photos, 2006). The PMI is a 25-item measure with three subdomains that ask caregivers about their desire for child change (Desire), readiness to change their own behavior (Readiness), and perceived ability to change their own behavior (Ability) on a 5-point scale from *strongly disagree* to *strongly agree.* The PMI has been shown to have good internal consistency and reliability (α=.96; Nock & Photos, 2006). It has been used as a predictor of involvement in family training and shows relationships to treatment attendance and adherence in family training focused on behavior management (Nock & Kazdin, 2005). Since the total score and individual subscales are both valid and reliable indicators (Nock & Photos, 2006), we chose to explore each domain separately to better understand which component of motivation is affected most by the barriers and facilitators in Staudt's (2007) model. Reliability for the desire (α=.90) and readiness (α=.95) subdomains were very good; the ability subscale was adequate (α=.76).

ANALYSIS

Aim 1. Understanding the Current Landscape of Family Training

Current Family Training Experiences. We explored caregivers' perceptions of their current family training access as a part of their child's ABA, alongside the frequency and duration of caregivers' meetings with their child's ABA supervisor who provides the service. We also explored the general similarity of those services to the evidence-based model and the frequency with which their provider used seven specific evidence-based strategies. As caregiver ratings of similarity and frequency of specific strategy use are expected to differ based on family training access, one-way ANOVAs were used to further understand quality of support.

Satisfaction with Services and Involvement. We explored relationships between satisfaction with ABA services and various aspects of caregiver involvement, such as involvement opportunities and overall satisfaction with involvement, using correlations.

Attitudes Toward Evidence-based Family Training. We characterized caregivers' general attitudes towards evidence-based family training strategies as reported on the AARP and CEQ-P. We used the PMI to evaluate their attitudes toward engagement.

Aim 2. Evaluating Staudt's (2007) Model of Caregiver Engagement

Barriers and Facilitators for Engagement. We explored the relationships between provider behaviors (participatory help-giving practices), barriers (daily stresses, external barriers to treatment), facilitators (therapeutic alliance, treatment acceptability, treatment expectancies), and caregivers' engaged attitudes (motivation to participate in family training) using correlations. We did this to check for issues of multicollinearity among the variables, as well as confirming which variables to include in the model based on the relationships proposed by Staudt (2007).

We also ran correlations between these factors and caregiver, child, and ABA service characteristics to check for what variables to include as controls in the model.

Model Analysis. We conducted a multiple mediation path model using SPSS PROCESS Model 4 (Hayes, 2018) to test whether provider behaviors influence caregivers' engaged attitudes through the specified barriers and facilitators suggested by Staudt (2007) as shown in Figure 2. Any characteristics that were significantly correlated with model variables identified in the previous step were included as covariates in the model.

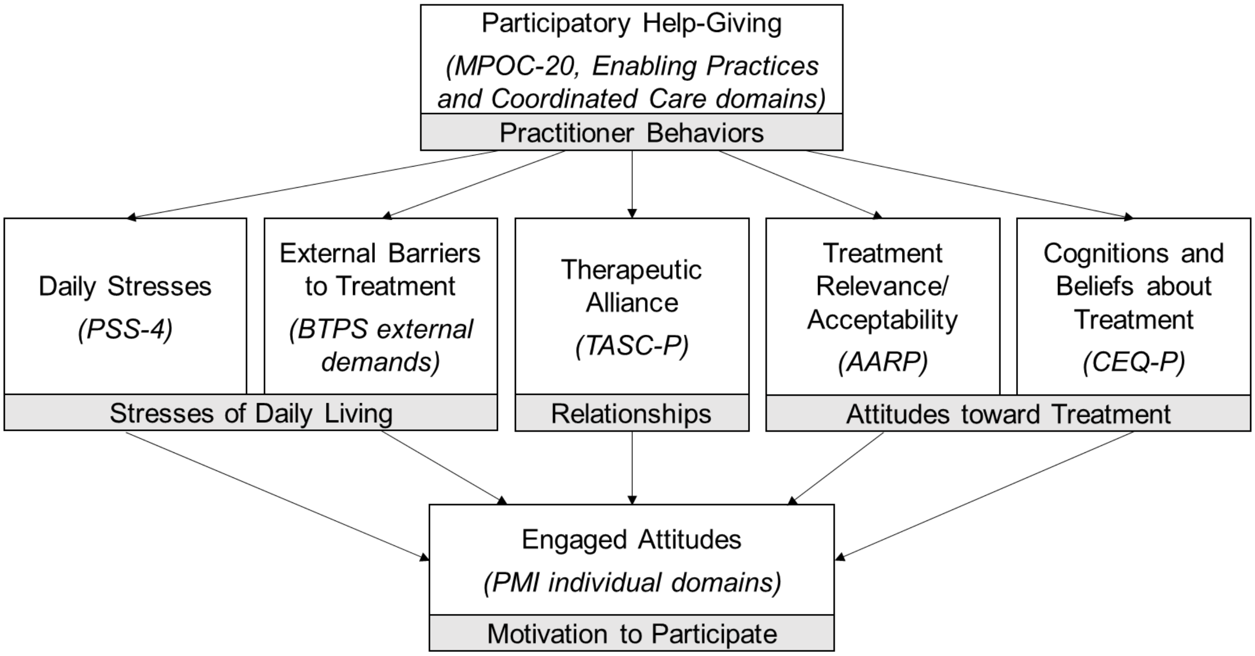


Figure 2.

Staudt's (2007) model of caregiver engagement to treatment with current study measures mapped onto individual components.

Missing Data. We excluded 21 responses (9.3%) from this analysis due to incomplete responses, resulting in a total of 205 complete responses. We defined responses as incomplete when any individual measures central to the main analysis was less than 70% complete. For measures with at least 70% of items completed, responses were averaged based on the number of items completed rather than interpolating missing items.

Power Analysis. Power for a path model is based on maximum likelihood estimation using the N:q rule of thumb, which states that the ideal ratio of subjects (N) to parameters (q) is 20:1 (Jackson, 2003), resulting in a suggested 200 subjects to evaluate Staudt's (2007) model, which is also the minimum number of participants suggested for a valid path analysis (Kline, 2011).

Model Assumptions. *The* four main assumptions of this model are linearity, normality, homoscedasticity, and independence (p 68-71, Hayes, 2018). While this type of analysis is robust to violations of these assumptions and PROCESS includes various methods to mitigate these concerns through bootstrapping and heteroscedasticity-consistent covariance estimators, violations may impact interpretation of findings. To understand the degree to which this is true, we explored our model variables and tested residuals for violations of these assumptions as part of the analysis.

RESULTS

Aim 1. Understanding the Current Landscape of Family Training

Current Family Training Experiences. Most caregivers reported they received family training either currently (*n*=79, 38.2%,) or in the past (*n*=50, 24.2%), while one quarter of families reported that they had not been offered family training services (*n*=51, 24.6%). Less than ten percent of families were offered family training and declined to participate (*n*=20, 9.7%) and seven caregivers (3.4%) did not respond. Families who were currently enrolled in family training were not statistically different from other families in terms of caregiver (*p*'s > .13), child (*p*'s > .10), or ABA service characteristics (*p*'s > .11). There was one agency for whom 80% of the 20 participants reported being enrolled in family training, which was greater than access rates in the rest of the sample ($\chi^2(1,226) = 18.61$, $p < .001$). None of the remaining 7 agencies differed significantly in terms of caregiver reported family training access (*p*'s > .10).

When asked to report how often they met with their child's ABA supervisor, 40.7 % (*n*=92) of caregivers said they met every one to two weeks, 37.6% (*n*=85) of caregivers said they met every one to two months, and 8.0% (*n*=18) said they met less quarterly or less; 13.7% (*n*=31) did not respond. Of families who met either weekly or monthly with their providers, the duration of those meeting is shown in Table 5. Since not all families reported the duration of the meeting, percentages are based on the valid responses for those who reported both a meeting frequency and duration. Meeting length differed based on frequency ($\chi^2(1,4) = 29.02$, $p < .001$). For families meeting weekly or biweekly, half of meetings were over 30 minutes while half were under 30 minutes. For families meeting monthly or bimonthly, most reported longer meetings of one hour or more.

Table 5.

Duration of meetings with ABA supervisor as reported by caregivers.

	Meeting duration (in minutes)				
Meeting frequency	<10	10-20	20-30	30-60	60+
1-2 weeks	18 (25)	7 (9.7)	10 (13.9)	7 (9.7)	30 (41.7)
1-2 months	1 (1.3)	4 (5.3)	5 (6.5)	5 (6.5)	62 (80.5)

Overall, caregivers reported that the support they received from their provider was moderately similar to the evidence-based model (*M*=3.68, *SD*=1.32, Range: 1-5). We then asked about their provider's use of specific strategies regardless of their response about current receipt of family training from *never* to *weekly*. On average, caregivers' reported that their providers used strategies monthly, but this varied widely based on the specific strategy (see Figure 3). Collaboration was the most common strategy, while handouts and materials were provided least often. However, while 41.7% of families reported meeting with their child's ABA supervisor weekly or biweekly, less than half of those reports suggest that their providers used 5 or more of these strategies at each meeting (17.7%), which would be most consistent with the evidence-based model.

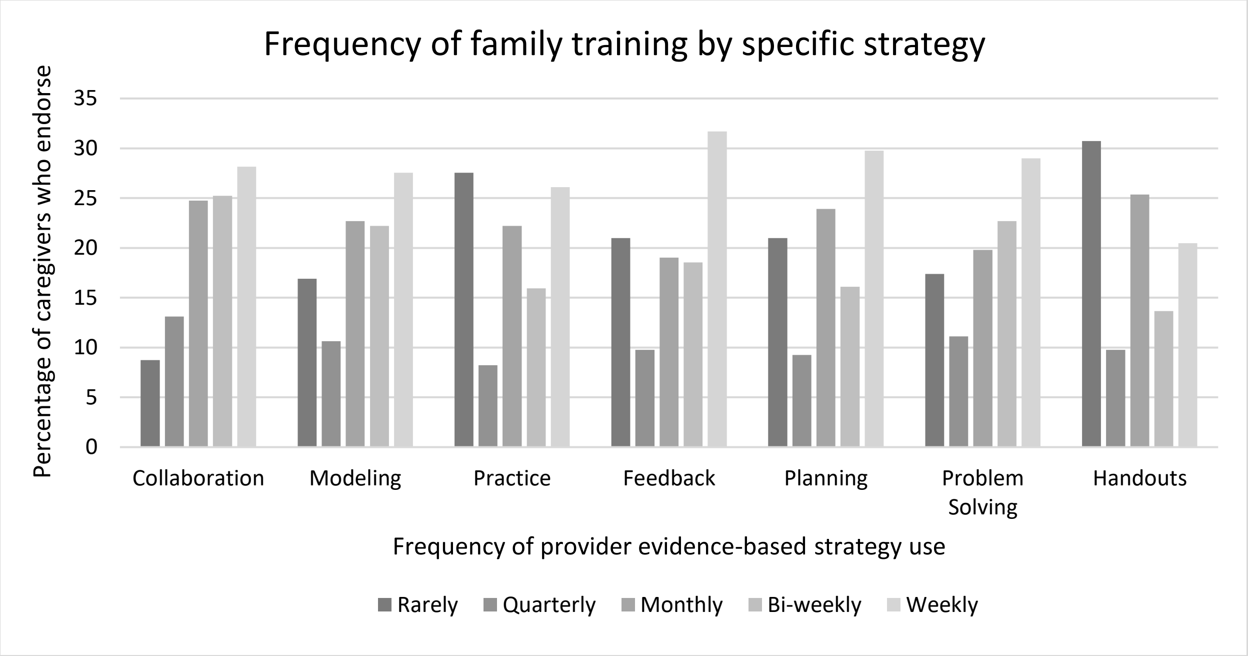


Figure 3.

Caregiver report of the frequency of provider family training use by strategy.

Lastly, we explored caregiver ratings of similarity of current support to evidence-based family training and the frequency of specific strategy use based on their reported access to family training services. Caregiver ratings of the similarity to (ANOVA: $F(3,199) = 14.836$, $p < .001$) and frequency of (ANOVA: $F(3,199) = 15.214$, $p < .001$) evidence-based family training differed based on access to family training as expected. Follow-up t-tests showed that differences were generally consistent with caregivers' report of family training access, such that caregivers who received current family training rated their support to be more similar and frequent, caregivers who endorsed past family training reported less similarity and frequency, and caregivers who were never offered family training reported the lowest level of similarity and frequency (*p*'s < .014). Interestingly, caregivers who declined to participate in family training were not statistically different from families currently or previous enrolled in terms of similarity and frequency of evidence-based family training services (*p*'s > .10) and received support more frequently than families who had never been offered the service (p's < .002; see Table 6 for means and standard deviations).

Table 6.

Means and standard deviations for caregivers' rating of overall similarity to and frequency of evidence-based family training practices used by their provider.

		Similarity		Frequency	
Group	*n*	*M*	*SD*	*M*	*SD*
Current	79	4.29	0.88	3.67	1.05
Past	50	3.48	1.37	3.29	1.32
Declined	20	3.90	0.97	3.82	0.93
Never offered	51	2.88	1.49	2.32	1.31
Total	199	3.69	1.33	3.25	1.30

Satisfaction with Services and Involvement. Overall, families expressed high levels of satisfaction with their ABA services (*M*=3.46, *SD*=0.81, Range: 1-4) and their current involvement in those services (*M*=3.51, *SD*=0.66, Range: 1-4). They felt that their provider supported their involvement (*M*=3.49, *SD*=0.76, Range: 1-4) and that involvement contributed positively to their child's ABA (*M*=3.53, *SD*=0.65, Range: 1-4). Caregivers with more formal education ($r_s = -.108$, $p = .008$), and older children ($r_s = -.182$, $p = .007$) were less satisfied with their ABA services; there were no other correlations between aspects of satisfaction and involvement with caregiver, child, or ABA service characteristics.

Despite high levels of satisfaction with ABA and involvement, a little over half of caregivers reported that they would like to be more involved (*n*=113, 54.6%). Most of the remaining caregivers indicated that they preferred to keep the same level of involvement (*n*=84, 40.6%); only three caregivers (1.4%) reported that they would prefer to be less involved and seven caregivers (3.4%) did not respond.

Satisfaction with ABA was positively correlated with satisfaction with their current involvement in those services ($r_s = .559$, $p < .001$), but not with caregiver's preferred level of involvement ($r_s = -.100$, $p = .148$). Satisfaction with ABA was also positively correlated with provider's family-centered care practices ($r_s = .535$, $p < .001$), perceived similarity of provider's support to evidence-based family training ($r_s = .467$, $p < .001$), and provider's more frequent use of evidence-based strategies ($r_s = .462$, $p < .001$).

Attitudes Toward Evidence-based Family Training. Overall, families reported that evidence-based family trainings strategies were highly acceptable (AARP: *M*=4.11, *SD*=0.81, Range: 1-5), that the strategies would be effective in supporting their child's development (CEQ-P: *M*=4.13, *SD*=0.89, Range: 1-5), and that they would be motivated to participate in this type of service (PMI: *M*=4.21/5, *SD*=0.67, Range: 1-5). These measures of various attitudes towards family training were not correlated with any caregiver, child, or ABA service characteristics.

Aim 2. Evaluating Staudt's (2007) Model of Caregiver Engagement

Barriers and Facilitators for Engagement. We used correlations to check for potential issues with multicollinearity and verify which variables to include in the model analysis (see Table 7). Multicollinearity issues are unlikely given correlations well below a suggested cutoff of 0.80 (Berry & Feldman, 1985). Participatory help-giving practices, our variable representing supportive provider behaviors, was related to all mediators proposed by Staudt (2007) except for daily stress; daily stress was also not related to our outcome of interest. Of the three domains on the PMI, only readiness to engage in treatment was related to participatory help-giving and a majority of mediators. Given this, we dropped the measure of daily stress from our path model and used readiness to participate in family training as our primary outcome.

Table 7.

Exploratory spearman correlations for relationships between variables in the engagement process.

	Participatory Help-giving	Desire	Readiness	Ability
Participatory Help-giving		.018	.197*	.137
Daily Stresses	-.133	.133	-.097	-.124
External Barriers	-.199*	-.100	-.398**	-.181
Therapeutic Alliance	.647**	.105	.323**	.254**
Expectancies	.360**	.239**	.530**	.370**
Acceptability	.302**	.492**	.578**	.484**

Note: *p<.005, **p<.001

We also examined whether any caregiver, child, or ABA service characteristics were correlated to our variables of interest. Mothers reported higher levels of participatory help-giving practices ($r_s = .195$, $p = .005$) and therapeutic alliance ($r_s = .198$, $p = .005$); no other caregiver, child, or ABA service characteristics were related to variables in our model (p's > .183).

Model Analysis. We completed the analysis using Model 4 of the PROCESS macro for SPSS using grand-mean centered variables and including parental role as a covariate.

Missing Data. *We* excluded 21 responses (9.3%) from this analysis due to incomplete responses, resulting in a total of 205 complete responses. Caregivers who did not complete the survey were similar to those who did in terms of education ($\chi^2(6,222) = 5.73$, $p = .45$), race ($\chi^2(4,204) = 3.23$, $p = .52$), ethnicity ($\chi^2(1,171) = .028$, $p = .89$), and caregiving role ($\chi^2(3,225) = 5.44$, $p = .14$). Children were also similar in terms of race ($\chi^2(4,217) = 2.15$, $p= .71$), ethnicity ($\chi^2(1,199) = .30$, $p = .59$), current age ($t(1,220) = .23$, $p = .82$), and age of diagnosis ($t(1,224) = -.045$, $p = .96$). ABA services did not differ in terms of hours per week ($t(1,208) = -.06$, $p = .950$), duration of services ($t(1,212) = 1.69$, $p = .09$), and location ($\chi^2(1,199) = .30$, $p = .59$).

Model Assumptions. We explored the individual measures and model residuals to test the assumptions of normality, heteroscedasticity, independence, and linearity. None the measures met normality assumptions (Shapiro-Wilk Statistics: .881-.932, *p*'s < .001), which is not surprising given all were likert-type measures. External demands, treatment acceptability, and readiness were moderately skewed (BTPS skewness = .66; AARP skewness = -.68; PMI readiness skewness = -.75), while therapeutic alliance, treatment expectancies, and participatory help-giving were more skewed (CEQ skewness = -1.02; TASCP skewness = -1.11; MPOC participatory help-giving skewness = -1.65). Therapeutic alliance and participatory help-giving and treatment alliance were also moderately peaked (TASCP kurtosis = 2.31; MPOC participatory help-giving kurtosis = 2.30), while the tails of other distributions were more normally distributed (kurtosis range: -.54 to .58). In regard to outliers, only the participatory help-giving measure had data points that were more than 2 standard deviations outside the mean. As the data is bounded and these outliers represent important variation in the data, they were kept in the analysis.

Given the challenges with evaluating normality in likert-type data, the model residuals are a more informative test of the assumptions. An analysis of standardized residuals showed that the data contained no outliers (Std. Residual: Min = -3.05, Max = 2.15; Cook's distance: Min = .00, Max = .16), were normally distributed (Shapiro-Wilk = 1.02, *p* > .09), and met the assumptions of collinearity (VIF: Min = 1.00, Max = 2.06; Tolerance: Min = .48, Max = 1.00) and independent errors (Durbin-Watson=1.70). Visual analysis of the partial regression scatterplots does not indicate any non-linear patterns in the data. Visual analysis of the scatterplot between predicted values and residuals suggests no major concerns for heteroscedasticity, although there was some clustering of the data around the ceiling values.

PROCESS includes several measures to mitigate concerns with non-normality and heteroscedasticity. We used bootstrapping (n=5000), which does not make assumptions about distribution of variables. We also included heteroscedasticity-consistent inference, given potential issues with heteroscedasticity based on a visual analysis of residuals. We used HC3 based on recommendations for sample sizes below 250 (Long & Ervin, 1998).

Model Results. External barriers to treatment dropped out of the model as a potential mediator of the relationship between participatory help-giving and readiness to engage in treatment, despite its relationships to readiness to engage in treatment (LLCI: -.0036, ULCI: .0202); the indirect effect of all other mediators remained significant. Unexpectedly, after holding the effect of all other variables constant, the direct effect of participatory help-giving practices on readiness to engage in family training was negative. The final model with regression coefficients and p-values can be found in Figure 4.

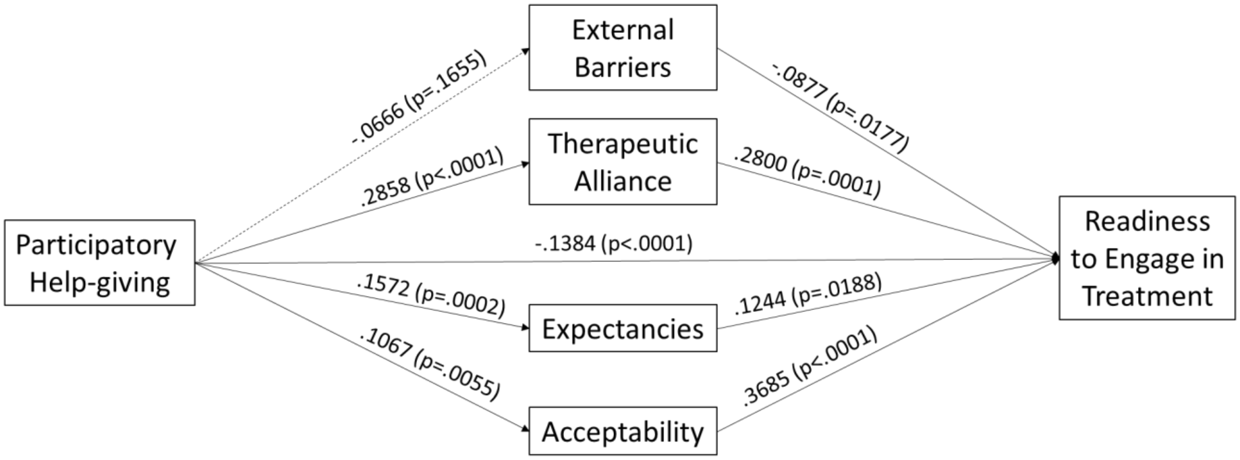


Figure 4.

Multiple mediation model with path coefficients and p values.

Follow-up Analysis. Since the direction of the relationship between participatory help-giving practices and readiness to participate in treatment switched between the correlation and mediation analyses, we conducted a follow-up analysis to explore this unexpected result further.

One possibility is that influential cases affected the results of the model causing this sign switch (e.g., Pek & MacCallum, 2011), given the large number of outliers and significant negative skew on the participatory help-giving scale. It is also possible that the model proposed by Staudt (2007) is only appropriate for those reporting the presence of participatory help-giving practices rather than their absence, since the model was developed around provider interventions that increase engagement. We performed a sensitivity analysis where we split participants based on those who reported low (n=40) and high (n=165) levels of perceived participatory help-giving practices based on responding above or below the middle anchor point of *sometimes*. Children whose caregivers reported low levels of provider participatory help-giving were older at diagnosis ($t(200) = 2.08$, $p = .012$). Mothers were over presented in the high group, while fathers were overrepresented in the low group ($\chi^2(1,3) = 9.53$, $p = .023$). There were no differences in race, ethnicity, caregiver education, or ABA service characteristics between groups.

We re-ran correlations between variables in the model to determine appropriateness of the full model components across groups. While the relationships between variables in the high participatory help-giving group were similar to the full group analysis, the low participatory help-giving group showed a lack of relationship between our primary predictor variable and majority of mediators, despite relationships consistent with the full analysis between the mediators and outcome (See Table 8). Additionally, the relationship between our predictor and outcome across groups was similar is strength but opposite in direction, with the low group reporting a negative relationship between participatory help-giving and readiness to participate in treatment ($r_s = .337$, $p = .01$) and the high group reporting a positive relationship ($r_s = .333$, $p < .001$)

Table 8.

Exploratory spearman correlations between model components across low and high participatory help-giving groups for follow-up sensitivity analysis.

	Low Participatory Help-giving Group (n=40)				High Participatory Help-giving Group (n=165)			
	Participatory Help-giving	Desire	Readiness	Ability	Participatory Help-giving	Desire	Readiness	Ability
Participatory Help-giving		-.244	-.337*	-.163		.065	.333**	.186
Stress	-.154	.023	-.145	-.228	-.118	.165	-.081	-.091
External Barriers	.050	-.338*	-.561**	-.461**	-.264**	-.050	-.356**	-.107
Therapeutic Alliance	.401*	.179	.382*	.271	.511**	.144	.404**	.308**
Expectancies	-.107	.403*	.442**	.123	.339**	.214*	.552**	.421**
Acceptability	-.184	.662**	.419*	.526**	.296**	.471**	.623**	.467**

Note: *p≤.01, **p≤.005

Given the lack of relationship between our primary predictor and the mediators in the low participatory help-giving group, we re-ran the full model with only the participants who reported high levels of participatory help-giving (*n*=165). Again, external barriers to treatment dropped out as a potential mediator (LLCI: -.0096, ULCI: .0592), while all other indirect effects remained significant. In this model, the relationship between participatory help-giving practices and readiness to engage in family training was fully mediated (see Figure 5). Given this change in the model, it appears that individuals who report low-levels of participatory help-giving practices were a poor fit for this model and were highly influential in the initial analysis.

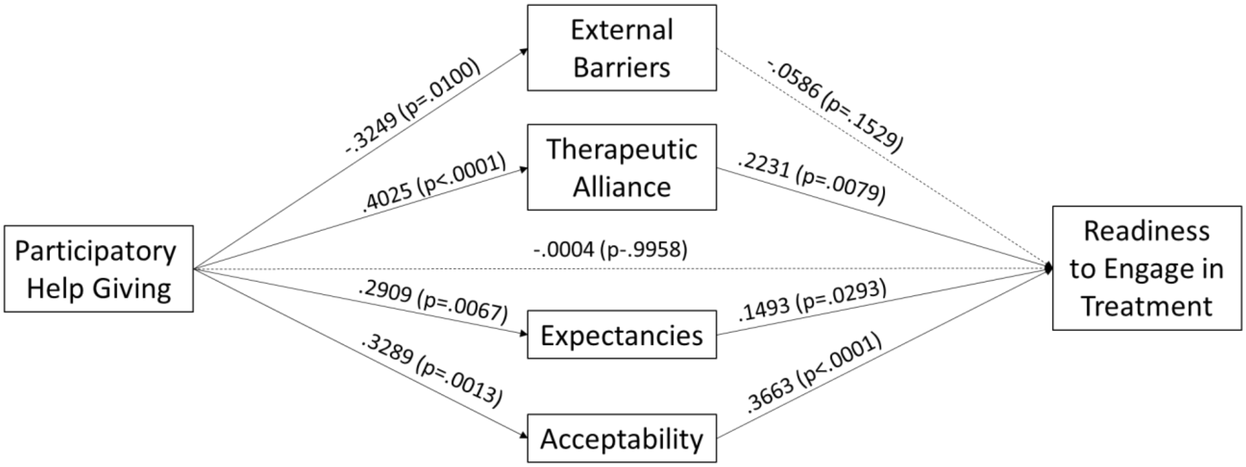


Figure 5. Multiple mediation model with only caregivers who reported positive levels of participatory help-giving behaviors from their provider (n=165).

DISCUSSION

Family training programs have the capacity to increase the accessibility, intensity, and effectiveness of services in systems with limited resources. However, these programs continue to be underutilized in community settings with families of children with ASD and families receiving services through Medicaid are significantly underrepresented in this research. The current study sought to integrate caregiver perspectives into a larger community-engaged research project on family training practices under the Michigan Medicaid Autism Benefit through two research aims. Our first aim was to better understand caregivers' experiences with family training as part of their child's Medicaid-funded ABA services, their satisfaction with these services, and their attitudes toward an evidence-based model of family training. Our second aim was to better understand the influence of various factors on caregivers' perspectives toward participation in evidence-based family training in this population by testing a theoretical model of caregiver engagement in treatment developed by Staudt (2007).

Aim 1. Understanding the Current Landscape of Family Training

Previous caregiver reports of family training as part of usual care have ranged widely across studies, with rates from as low as 8% to as high as 36% of families receiving this service (Hume et al., 2005; Pickard & Ingersoll, 2016; Ruble & McGrew, 2007; K. C. Thomas, Morrissey, et al., 2007). We found higher levels of access to this service than most of the previous studies, with 38% of families reporting current family training. This may represent changes in the service landscape of usual care over the past 15 years. For example, there has been a more explicit focus in state policy on providing family training as part of care for children with ASD in the past decade (e.g., Michigan Autism State Council, 2012, 2018), consistent with best practice recommendations (Maglione et al., 2012; Wong et al., 2015; Zwaigenbaum et al., 2015). Thus, our finding may reflect a positive shift in community practices.

It is also possible that our finding is unique to families receiving publicly-funded services in Michigan. Although some studies show decreased access to services for families of children with ASD from lower socioeconomic backgrounds (e.g., Casagrande & Ingersoll, 2017; Hodgetts et al., 2015; Patten et al., 2013; Pickard & Ingersoll, 2016), others have shown increased access to care for families in Medicaid given limited coverage for autism-specific services through private insurers (e.g., Parish, Thomas, Rose, Kilany, & McConville, 2012; Wang, Mandell, Lawer, Cidav, & Leslie, 2013). Given our focus on a Medicaid system that has emphasized increasing access to family training in policy statements and provides insurance reimbursement for those services as part of ABA (Michigan Autism State Council, 2012, 2018), a higher level of access compared to previous research is understandable. However, this does not address the issue of whether the family training caregivers receive is in line with best practice recommendations.

Evidence-based family training models are typically offered weekly and utilize a combination of evidence-based teaching and coaching strategies (Barton & Fettig, 2013; Ruppert et al., 2016). When caregiver report of family training is narrowed down to those who endorsed meeting with their child’s ABA supervisor on a weekly or bi-weekly basis and endorsed at least 5 of the 7 evidence-based family training strategies just as frequently, rates of family training dropped to 17%. A similar pattern of high apparent rates of family training but limited alignment with evidence-based practices was seen in the billing data (Straiton et al., 2020b) and providers’ report of their own practices (Straiton et al., 2020a) within this system. Billing data suggests that 55% of families have received family training services. However, the average number of sessions billed for those families was one session every other month. Only 3% of families received at least 8 sessions within a 6-month period, which would represent the minimum number of meetings for a lower-intensity evidence-based family training model (e.g., Carter et al., 2011). In terms of providers' report of their own practices, 76% reported providing family training at least monthly with their typical client, but only 5% of the 97 providers who completed the open-ended responses in the survey endorsed using modeling, coaching, and feedback as part of their typical family training session. Taken together, it is unlikely that families are receiving services that align with evidence-based practices despite initial high reports of access.

Caregivers' satisfaction with services is also important as a marker of quality care. Previous research has shown that satisfaction with services is related to aspects of caregiver involvement (Fawley-King et al., 2013; Laws & Millward, 2001; Renty & Roeyers, 2006) and provider's use of family-centered care practices (Rosenbaum, King, Law, King, & Evans, 1998), both of which underlie family training practices. In the current study, we found that greater satisfaction with ABA services was related to both caregivers' satisfaction with their involvement and their perceptions of family-centered care practices similar to previous research. We also found that satisfaction with ABA was related to caregivers' experiences with family training, such that caregivers who felt their provider's support was more similar to the evidence-based model and used the specific strategies more frequently reported greater satisfaction with their ABA services. While general caregiver involvement is an important aspect of overall satisfaction with services, our findings suggest that specific evidence-based approaches to caregiver involvement such as family training are another important component of satisfaction and can support quality care.

After reading a definition of evidence-based family training that emphasizes frequent meetings with an active learning component (i.e., modeling of strategies with opportunities for caregiver practice and coaching), caregivers expressed positive attitudes about the acceptability and effectiveness of these strategies for supporting their child's growth, as well as high levels of motivation to engage in this model of treatment. This interest in pursuing family training is in contrast to providers' report within this same Medicaid system showing that a perceived lack of caregiver motivation and engagement were significant barriers to their use of family training practices (Straiton et al., 2020a). This discrepancy is consistent with previous research on providers' and caregivers' attitudes toward evidence-based family training models (Chlebowski et al., 2018; Pickard, Kilgore, et al., 2016; Stahmer et al., 2019). Given the direct contrast between provider and caregiver report of engagement attitudes in this service system, it is important to explore these differences more closely.

This difference in perspective between caregivers and providers is difficult to interpret, given the limited literature on both caregiver and provider perspectives on engagement in evidence-based family training in usual care, as well as the complexities of implementing services in systems with limited resources such as Medicaid. One possible explanation is that providers are reflecting on perceptions of current family engagement in treatment, while caregivers are responding about their interest in a specific model of future treatment. Engagement and buy-in to treatment have been shown to vary based on the perceived value of the services being offered (Bannon & McKay, 2005; Chacko et al., 2017; Yatchmenoff, 2005). It is possible that caregivers do not find their current opportunities for involvement to be valuable and are not engaged currently, while they would value and engage in a structured, evidence-based approach to treatment in the future. Additionally, motivation may change as caregivers receive family training, especially if providers' knowledge of effective engagement strategies and evidence-based family training models is limited.

Both caregivers and providers have shared concerns about providers' ability to engage and support caregivers in treatment effectively (Brookman-Frazee et al., 2012; Stahmer, Brookman-Frazee, Lee, Searcy, & Reed, 2011; Stahmer et al., 2019). For example, caregivers of children with ASD have reported that they struggle to engage in treatment due to limited confidence in their provider's ability to support them despite positive attitudes toward family training practices (Brookman-Frazee et al., 2012). Given the current report of limited use of evidence-based strategies and influence of limited training on family training implementation in this service system (Straiton et al., 2020a), this difference in perspective between caregivers and providers may accurately reflect a difference in experience.

Taken together with the previous findings, caregivers are reporting low rates of access to evidence-based family training models, but their satisfaction with services is higher with perceived similarity to evidence-based practices. Indeed, caregivers are quite interested in this treatment model. This remains in contrast to providers' reports of caregiver engagement in treatment and additional research is needed. As attitudes are only one aspect of engagement, it is also important to understand these findings in the context of other potential factors.

Aim 2. Evaluating Staudt's (2007) Model of Caregiver Engagement

Our second aim was to better understand what influences caregivers' motivation to participate in evidence-based family training by applying Staudt's (2007) model of caregiver engagement with this population. Staudt's (2007) model outlines the influence of supportive provider practices on caregivers' engagement through five family-level logistical, relational, and attitudinal factors. Exploring the perspectives of families of children with ASD receiving

Medicaid-funded services allows us to interpret our findings within the context of policy-, organizational-, and provider-level barriers to implementation in this same system. An advantage of using this model is that we can understand how each family-level factor influences engagement in the context of each other, as well as how providers' behaviors can support engagement through these factors.

Our data provide preliminary empirical support for Staudt's (2007) model of engagement for caregivers of children with ASD. We found that the relationship between caregivers' positive perceptions of their provider's supportive behaviors and their readiness to engage in family training was fully mediated by therapeutic alliance, treatment acceptability, and beliefs about the effectiveness of treatment. Daily stresses were unrelated to both provider practices and caregiver readiness, while external barriers to treatment were reduced in the presence of supportive provider behaviors, but did not factor into caregivers' readiness to engage in the context of these factors. The limited influence of logistical challenges on caregivers' readiness to engage in treatment was surprising, given the increased levels of stress and external barriers to treatment seen in families of children with ASD from underserved backgrounds (Atharia et al., 2013; Phetrasuwan & Shandor Miles, 2009; Pickard & Ingersoll, 2016; Ruble et al., 2005; Stahmer et al., 2019). There are several potential explanations for this finding.

One potential explanation is that we asked caregivers about whether these logistical barriers would be a concern when participating in a model of evidence-based family training, rather than the degree to which those barriers currently cause challenges with participation in treatment more generally. Given studies that show caregivers are willing to prioritize their involvement in evidence-based family training models despite logistical challenges (Chlebowski et al., 2018; Stahmer et al., 2019), families may minimize the role of these barriers when reporting on a valued future service. Another interpretation is that because we focused only the influence of perceived barriers on engagement attitudes, their effect on motivation for engagement was smaller. While attitudes and intention are well established predictors of behavior (Abraham & Michie, 2008; Ajzen, 1991; Bandura, 1989; Fisher & Fisher, 2002), it is still just a proxy for actual behavior. It is possible that these factors would have a more pronounced effect on engagement behaviors and treatment outcomes, similar to other studies (Kazdin, Holland, & Crowley, 1997; Kazdin & Wassell, 1999).

Another interesting finding was that Staudt's (2007) model only fit for caregivers who perceived a positive degree of supportive behaviors from their child's ABA provider. We found a different relationship between provider behaviors and caregiver attitudes toward engagement in the subset of participants who reported more negative perceptions of their providers' behavior, such that as families perceived lower levels of support they reported greater motivation to participate in family training. Provider behaviors were also unrelated to the logistical and attitudinal factors evaluated. The role of provider behaviors in Staudt's (2007) model was based on interventions that changed provider behaviors to support engagement rather than their typical level of supportive practices. As such, the model may not appropriately represent the experiences of caregivers whose providers do not engage in participatory help-giving practices.

Implications and Recommendations for Practitioners

A variety of evidence-based family training programs exist for ASD that improve both child and family outcomes. However, these programs continue to be underutilized in community settings despite attempts to increase their accessibility (Carr & Lord, 2016; Chlebowski et al., 2018; Pickard et al., 2017; Stahmer & Pellecchia, 2015). Without increasing our understanding of why these programs continue to be underutilized, improving access will continue to be a challenge. Existing research reveals differences in perspectives on the limited use of family training practices between caregivers of children with ASD and their providers, such that providers perceived limited caregiver motivation and engagement while caregivers report high interest and motivation to participate (Chlebowski et al., 2018; Pickard, Kilgore, et al., 2016; Stahmer et al., 2019). Findings from the current study continues to support this discrepancy and extend them to families of children with ASD receiving Medicaid-funded ABA services. As such, it is important to reduce misconceptions held by providers about families' attitudes towards involvement in treatment models such as family training and increase providers' likelihood of offering these opportunities to parents. It is also important for providers to understand how to support ongoing engagement as they use family training models.

Exploring caregivers' perspectives using Staudt's (2007) model of caregiver engagement allows us to understand a variety of reasons why caregivers may not actively engage in family training, weigh each of these barriers and facilitators against each other, and offer a means by which providers can increase caregivers' engagement by reducing the most prominent barriers. We found that caregivers' relationships with their providers and their attitudes toward the acceptability and effectiveness of family training strategies were the strongest predictors of their readiness to participate in evidence-based family training, while daily stresses and external treatment demands had little to no influence on parent engagement attitudes. Providers may benefit from spending additional time with parents explaining the benefits and challenges of engaging in family training, while building collaborative relationships and encouraging parent buy-in prior to the initiation of these services, rather than focusing solely on the logistical barriers to treatment. Low intensity interventions to increase these provider behaviors have been successful in increasing caregiver participation in treatment for at-risk populations (McKay &

Bannon, 2004; Yatchmenoff, 2005). We also found that providers' use of participatory help-giving practices, such as creating opportunities for parent involvement, encouraging active engagement through shared decision making, and coordinating care across providers, supported engagement by improving relationships with parents and their attitudes toward family training. Given the relationship between participatory help-giving practices and active models of parent engagement (Dunst et al., 1995, 2002, 2007; Dunst & Trivette, 1996), additional emphasis on this approach to care is likely to have a significant impact on promoting caregiver engagement in treatment.

In this study we found that only 17% of families received weekly or bi-weekly support that included a combination of evidence-based teaching and coaching strategies, suggesting that providers are not utilizing best practice guidelines for family training. This is unsurprising, as providers within and outside of this system report that they lack training in evidence-based family training models (Stahmer et al., 2019; Straiton et al., 2020b). Providers' lack of training in private payer systems may limit the spontaneous use of family training strategies, but in a system where the use of these practices is required by agency policy, this lack of training likely has a large impact on the quality of services and may create more challenges with engaging caregivers. Providers also report difficult engaging parents in treatment (Straiton et al., 2020a), which may reflect additional lack of skill in working with caregivers more generally. In fact, caregivers of children with ASD often lack confidence in their provider's understanding of ASD and their ability to support them (Nuske et al., 2018; Tucker & Schwartz, 2013), which can lead to hesitance toward engagement in family training practices (Brookman-Frazee et al., 2012). Without the skills to effectively engage families in treatment and use evidence-based family training strategies, providers may inadvertently contribute to the ongoing difficulty establishing positive relationships with families and reflect current issues with engagement in treatment.

Providers can benefit from the use of manualized family training and engagement interventions to support their use of specific evidence-based strategies, provide structure to sessions, and create clear expectations for the treatment process. While engagement strategies are often embedded into family training interventions that target a specific problem or population, there are also manualized interventions that focus on more generalized approaches. For example, the Parent And Caregiver Active Participation Toolkit (PACT), an intervention focused on increasing active engagement and collaboration in services for parents and providers, has been shown to both increase providers' use of engagement techniques and improve parent participation during sessions (Haine-Schlagel, Fettes, Finn, Hurlburt, & Aarons, 2020; Haine-Schlagel, Martinez, Roesch, Bustos, & Janicki, 2018). There are also manuals that cover the active learning components that exemplify evidence-based approach to family training that can be applied regardless of the treatment content (e.g., Rush & Shelden, 2011). Providers who are unable to find a manual that fits their specific expertise can benefit from these content-neutral interventions.

Since the goals of this project were closely aligned with quality improvement efforts that are underway in the Michigan Medicaid system around care for families of children with ASD (Michigan Autism State Council, 2012, 2018) and was conducted in partnership with the agencies that oversee these services, it is our hope that these results can provide a starting point for improving access to and quality of family training services in this system. Stakeholders at the regional and state levels have been a part of this project since its conceptualization and have already begun implementing policy changes and providing training opportunities based on findings from analysis of billing data and provider perspectives (Straiton et al., 2020a, 2020b). Our community partners continue to be invested in the exploration of parent perspectives and implementation of recommendations that will be provided from this study. Furthermore, any changes made across this state-wide system of care can influence changes in policy elsewhere by providing more tangible evidence of the benefits of these models in similar systems.

Limitations

There are several limitations to consider when evaluating the strength and relevance of our findings. First, while our sample was representative of families from the Michigan Medicaid system in terms of racial and ethnic diversity, selection bias is still a concern the generalizability of our findings. Despite attempts to reduce selection bias through integration of the research project into required annual re-evaluations or quarterly case management meetings, providing immediate compensation for participation, and developing recruitment scripts for community providers to introduce the study to all eligible participates, we were unable to evaluate the characteristics of caregivers who did not participate. Staff may have elected not to offer participation to certain families. Additionally, families who were offered the opportunity but chose not to participate may have very different perspectives on engagement in care. Our sample was also restricted to English-speaking families of children with ASD within eight community mental health agencies. As such, we cannot be confident that the views of participants in this study are representative of the general population.

Second, response bias may have influenced our findings. Families in this study reported overwhelmingly positive responses across measures. Despite efforts to protect the anonymity of participant responses and separating data collection from the ABA services they were reporting on, families may have responded in socially desirable ways given the potential impact of negative responses on their services. Additionally, this positive response bias resulted in data that were not normally distributed. While all of the measures we used in this study were previously validated with populations of children with disabilities in underserved settings and our analysis are robust to these violations of normality, negative responders were a highly influential group in the mediation model. Increasing the variation in the data would allow for a more thorough understanding of a range of engagement attitudes.

Third, while we did meet minimum sample size requirements for adequate power, a larger sample would have allowed for more complex analysis and follow-up based on the unanticipated findings from the mediation model. With additional participants and increased variation in responses, more complex models could be evaluated, fit to the data, and compared to alternatives. As such, it is important not to over interpret finding for group of parents experiencing low levels of perceived support from their providers or more negative views on family training and engagement in treatment.

Lastly, our study looked only at attitudes toward engagement rather than engagement behaviors and treatment outcomes. Although attitudes are at the foundation of many theories of behavior change (Abraham & Michie, 2008; Ajzen, 1991; Bandura, 1989; Fisher & Fisher, 2002), we did not have the opportunity to collect more direct measures of behavior such as observations of engagement. Given the limited us of evidence-based family training seen in this population, it is possible that caregivers' attitudes toward could change as they are more exposed to this model of treatment, experience barriers to participation, and better understand the commitment required for optimal outcomes.

Future Directions for Research

Future studies should continue to increase the representation of families of children with ASD from diverse and demographically at-risk backgrounds in research. The use of community-engaged practices in this study showed that these strategies are effective in increasing the participation of families in Medicaid settings. We were able to recruit a diverse range of participants in partnership with community mental health using guidelines that were developed specifically for community engagement for healthcare research (Higgins & Metzler, 2001; Ross et al., 2010; Wallerstein & Duran, 2006). However, given the potential influence of selection and response bias on our findings, researchers should increase their efforts to recruit families who may not be seeking out research participation or who have negative experiences with current care to better understand how they would prefer to be engaged in research given the importance of diverse opinions on improving care in these settings.

It is also important for researchers to provide more information in their studies around how services are being obtained and the type of family training being explored. Insurance status is an important component of access to care for families and individuals with ASD, given the challenges in policy that have historically limited access to autism-specific services (Parish et al., 2012; Wang et al., 2013). Private payer and publically-funded services are likely to show significantly different patterns of access based on policy differences. The type of family involvement is also likely to influence reports of access. We found that access rates dropped by half depending on whether the question of access was a simple yes/no report or based on report of specific evidence-based strategies. There are many ways to engage families of children with ASD in their child’s treatment (Bearss et al., 2015), so researchers should carefully consider what type of family involvement they are evaluating, how parents are likely to access those services, and how they word questions to obtain more accurate information.

Lastly, our study looked only at attitudes toward engagement rather than engagement behaviors and treatment outcomes. As there may be significant differences between parent interest in pursuing family training and their ability to engage in that service, future research should incorporate more objective measures of parent engagement in family training as part of usual care. Additionally, mixed methods research can provide more context for understanding these challenges and interpreting findings by comparing data from multiple sources such as case notes and session observations. Qualitative interviews can also help to continue unpacking the consistent differences between parent and provider report of barriers to caregiver engagement in treatment.

Conclusions

The perspectives of families from underserved backgrounds, such as those receiving services through the Medicaid system, have been significantly underrepresented in research. This study provided an opportunity to give voice to families in the Medicaid system and allowed them to contribute to research with the potential to create change in their communities. Our findings support previous research showing limited access to evidence-based family training in community settings, alongside differences in perspectives on parent engagement in treatment between parents and providers. We found that while there were high levels of reported access to family training services in general, the services were not in line with evidence-based recommendations, consistent with conclusions from billing data and provider perspectives within this same Medicaid system. Additionally, while provider perspectives within this Medicaid system found high perceived family-level barriers to engagement, parents themselves reported relatively few barriers and high motivation to participate in evidence-based family training. Furthermore, parents who reported that their provider engaged in more enabling and supportive practices experienced increased readiness to participate in evidence-based family training, through improvements to the therapeutic alliance and positive attitudes toward treatment.

Given the limited use of evidence-based strategies in usual care and the influence of limited training on family training implementation in this service system, this difference in perspective between parents and providers may accurately reflect a difference in experiences. Where providers may experience a lack of parent engagement due to limited training in engaging parents in treatment and using evidence-based strategies, parents are reporting on their preferred level of involvement and attitudes. Taken together, our findings support ongoing efforts to increase the use of evidence-based family trainings strategies for children with ASD through more structured and comprehensive approaches to treatment that support engagement for both parents and providers.

APPENDICIES

APPENDIX A: Memorandum of Understanding

This Memorandum of Understanding (MOU) sets for the terms and understanding between [redacted agency name] and the Michigan State University (MSU) Autism Lab to examine the utilization and implementation of Family Training through the Autism Benefit.

The Michigan Autism State Plan and Autism State Council emphasize family engagement and involvement as part of quality treatment for families of children with Autism Spectrum Disorder (ASD). One model of engagement and involvement in treatment is family training, which involves working directly with parents to systematically teach them strategies to help their child. Numerous technical review panels have classified family training as an evidence-based practice (EBP) for the treatment of ASD with multiple benefits for both children and family members.

To support the use of family training Michigan’s Medicaid Autism Behavioral Health Treatment/ABA service plan (Autism Benefit) has developed specific billing codes for both group and individual family training. Although an important and necessary step, the availability of these codes has not led to widespread implementation of quality family training among families receiving the Autism Benefit. For example, a review of billing records across mid-Michigan CMH agencies found that over the course of a 6-month period, less than 30% of families received family training services and those that did, received an average of less than 3 hours. A further review of case notes at one location found that the quality of training was often poor, suggesting that family training is not implemented appropriately in the mid-Michigan CMH system.

The purpose of this partnership between [Partner] and the MSU Autism Lab is to:

1) Integrate academic and community expertise in research projects that aim to improve the quality of care for families of children with ASD in the mid-Michigan CMH system
2) Support [Partner] in analyzing the Autism Benefit billing data to ensure compliance with state guidelines of care
3) Provide training opportunities centered around family training for ASD to those within the Michigan CMH system
4) Serve as a foundation for future research-community partnerships in the services of improving care for ASD within CMH

Activities

The above goals will be accomplished by undertaking the following activities by each partner.

[Partner]:	MSU Autism Lab:
• Attend monthly meetings to discuss current progress and next steps	• Attend monthly meetings to discuss current progress and next steps
• Assist with recruitment for research activities examining family training in CMH	• Design and analysis of research activities around family training in CMH
• Access and deidentify Autism Benefit billing data for analysis	• Host webinars or meetings to update stakeholders on project progress
• Provide system-specific knowledge and assistance with data interpretation	• Provide 1-2 trainings on family training best practices to various stakeholders
• Organize training opportunities for CMH	

Reporting

Formal evaluation of the partnership through a short self-assessment and a review of the MOU will occur every 6 months by all parties. The MSU Autism Lab will be responsible for providing the assessment at the appropriate times.

The final products of this project will consist of verbal reports for stakeholders within the CMH system in the form of presentations/webinars, as well as articles submitted for publication in academic journals.

Funding

This project will draw on funds provided by a BCBSM student grant awarded Diondra Straiton for data collection related to provider practices and funds from [Partner] for training opportunities. Future funding opportunities will be sought by both partners as the project grows.

<u>Amendment (4/23/2019)</u>: Additional funding to support collection of parent perspectives was awarded to Karís Casagrande through the Organization for Autism Research Grant Dissertation Award on June 1, 2019.

Agreement

By signing below, we agree to adhere to the terms set above to the best of our abilities for the duration of the partnership. The terms can be re-evaluated and revised at any time.

APPENDIX B: Partnership Letter

The Michigan State University Autism Research Lab has been partnering with various PIHPs and MDHHS to explore Family Training (FT) during ABA services received through the Medicaid Autism ABA Benefit. The purpose of this study is to gain a better understanding of use and quality of FT given the renewed focus on family engagement and involvement as outlined in the *Michigan Autism Spectrum Disorder (ASD) State Plan 2018 Progress Review and Recommendations* released November of 2018.

The 2018 recommendations emphasize providing "direct training and coaching to families to work effectively with the characteristics of ASD (e.g. fascinations, communication, social differences), teach new skills, decrease challenging behaviors, and generalize skills learned in other settings (p. 10)," which is the goal of evidence-based FT. Specific billing codes for FT were developed under the Michigan Medicaid ABA Autism Benefit. However, initial exploration of Michigan Medicaid billing data shows that only about half of families received FT at least once per quarter, with significant differences based on service location.

We would like to invite you to participate in this project as a way to progress towards state standards for family engagement and involvement. This part of the study focuses on adding parent perspectives on FT to information collected from Medicaid billing data and ABA providers' self-reported practices.

Below are some of the ways you can be involved and how involvement can benefit your agency:

1. **Survey and Interview Development**: Make suggestions about factors that contribute to the use of FT in your agency and provide feedback about the content and terminology used in the parent survey or interview prior to recruitment. *The survey may help to assess consumer access to and satisfaction with FT, as required from all region network subcontractors*.

2. **Recruitment**: Provide guidance on recruitment and/or help distribute the survey to parents receiving ABA services within your organization. We would be happy to talk with your staff about how to best connect with the families you serve. *We hope to integrate this survey into your contacts with families, such as during re-evaluations or quarterly reviews.*

3. **Ongoing Project Feedback**: Participate in monthly or quarterly meetings with the MSU Autism Lab and other community partners to provide ongoing feedback for the project. *These meetings will include project updates, challenges, and initial impressions from data collected that can inform your quality improvement procedures.*

4. **Interpretation of findings:** Provide initial reactions to findings and contribute to the interpretation of the data. *Reports of findings for each region will be provided to participating PIHPs.*

If you would like to talk more about this project, please contact Karís Casagrande, MA, via e-mail at casagra3@msu.edu or by phone at 517-432-8031.

APPENDIX C: Outreach and Dissemination Activities

Presentations to inform the community about the project and potential to participate

Date	Audience	Title
01/09/2018	Autism Benefit Coordinators (single region)	Update from MSU Dept. of Psychology on Family Guidance Project
04/10/2018	Autism Benefit Coordinators (single region)	Update from MSU Dept. of Psychology on Family Guidance Project
06/29/2018	Autism Benefit Coordinators (all regions)	Autism ABA Benefit Family Training: Practice, Barriers, and Engagement
9/19/2018	ABA providers and families (single region)	Family Training in the Michigan Medicaid Autism Benefit: Provider and Caregiver Training
11/12/2018	Annual Home and Community Based Waiver Conference attendees	Family Training in the Michigan Medicaid Autism Benefit

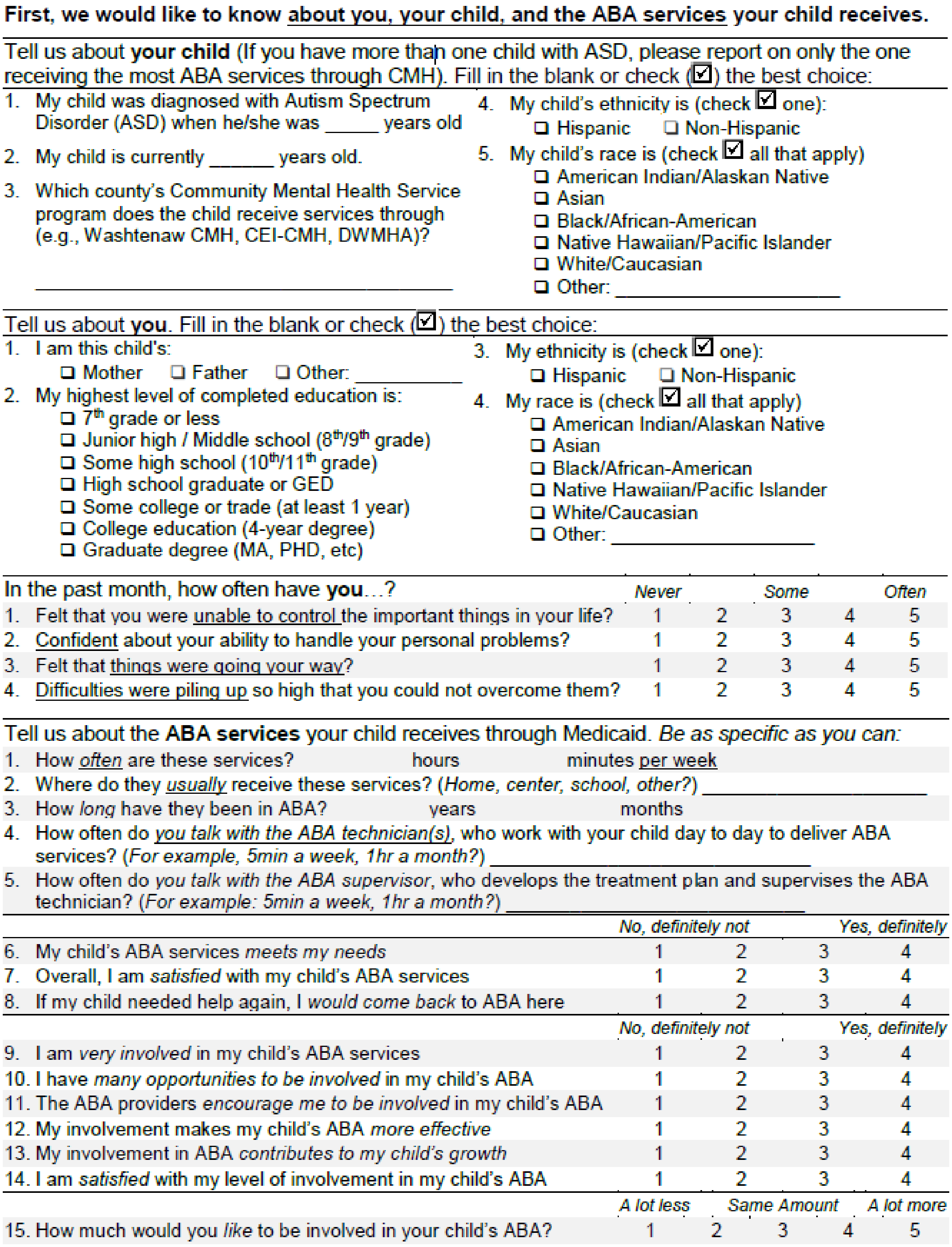
Presentations to report out findings of the partnership

Date	Audience	Title
11/12/2019	Early On Conference	Family Training in Community-Based Early Intervention: Evidence and best practice
04/01/2019	Autism Benefit Coordinators (all regions)	*Presentation canceled due to COVID-19*
05/07/2020	International Society for Autism Research	*Presentation canceled due to COVID-19*
05/13/2020 & 5/20/2020	Autism Benefit Coordinators (participating regions)	Updates on region-specific findings and discussion of dissemination materials for parents and ABA providers.

Informational handouts to disseminate findings to individuals involved in parent training services within Michigan's Medicaid system.

Date	Audience	Description
Ongoing	Benefit coordinators at each CMH	Individualized infographics displaying regional or site-specific findings.
Ongoing	Providers responsible for providing family training	Infographic describing broad findings with specific advice for providers
Ongoing	Families eligible to receive family training services	Infographic describing broad findings with specific advice for caregivers

APPENDIX D: Caregiver survey



First, we would like to know about you, your child, and the ABA services your child receives.

Tell us about **your child** (If you have more than one child with ASD, please report on only the one receiving the most ABA services through CMH). Fill in the blank or check (☑) the best choice:

1. My child was diagnosed with Autism Spectrum Disorder (ASD) when he/she was _____ years old
2. My child is currently ______ years old.
3. Which county's Community Mental Health Service program does the child receive services through (e.g., Washtenaw CMH, CEI-CMH, DWMHA)? ________________________________
4. My child's ethnicity is (check ☑ one):
   ☐ Hispanic ☐ Non-Hispanic
5. My child's race is (check ☑ all that apply)
   ☐ American Indian/Alaskan Native
   ☐ Asian
   ☐ Black/African-American
   ☐ Native Hawaiian/Pacific Islander
   ☐ White/Caucasian
   ☐ Other: __________________

Tell us about **you**. Fill in the blank or check (☑) the best choice:

1. I am this child's:
   ☐ Mother ☐ Father ☐ Other: __________
2. My highest level of completed education is:
   ☐ 7th grade or less
   ☐ Junior high / Middle school (8th/9th grade)
   ☐ Some high school (10th/11th grade)
   ☐ High school graduate or GED
   ☐ Some college or trade (at least 1 year)
   ☐ College education (4-year degree)
   ☐ Graduate degree (MA, PHD, etc)
3. My ethnicity is (check ☑ one):
   ☐ Hispanic ☐ Non-Hispanic
4. My race is (check ☑ all that apply)
   ☐ American Indian/Alaskan Native
   ☐ Asian
   ☐ Black/African-American
   ☐ Native Hawaiian/Pacific Islander
   ☐ White/Caucasian
   ☐ Other: __________________

In the past month, how often have **you**…?	*Never*		*Some*		*Often*
1. Felt that you were unable to control the important things in your life?	1	2	3	4	5
2. Confident about your ability to handle your personal problems?	1	2	3	4	5
3. Felt that things were going your way?	1	2	3	4	5
4. Difficulties were piling up so high that you could not overcome them?	1	2	3	4	5

Tell us about the **ABA services** your child receives through Medicaid. *Be as specific as you can:*

1. How *often* are these services? hours minutes per week
2. Where do they *usually* receive these services? (*Home, center, school, other?*) ____________________
3. How *long* have they been in ABA? years months
4. How often do *you talk with the ABA technician(s)*, who work with your child day to day to deliver ABA services? (*For example, 5min a week, 1hr a month?*) ____________________________
5. How often do *you talk with the ABA supervisor*, who develops the treatment plan and supervises the ABA technician? (*For example: 5min a week, 1hr a month?*) __________________________

	No, definitely not			*Yes, definitely*
6. My child's ABA services *meets my needs*	1	2	3	4
7. Overall, I am *satisfied* with my child's ABA services	1	2	3	4
8. If my child needed help again, I *would come back* to ABA here	1	2	3	4

	No, definitely not			*Yes, definitely*
9. I am *very involved* in my child's ABA services	1	2	3	4
10. I have *many opportunities to be involved* in my child's ABA	1	2	3	4
11. The ABA providers *encourage me to be involved* in my child's ABA	1	2	3	4
12. My involvement makes my child's ABA *more effective*	1	2	3	4
13. My involvement in ABA *contributes to my child's growth*	1	2	3	4
14. I am *satisfied* with my level of involvement in my child's ABA	1	2	3	4

	A lot less		*Same Amount*		*A lot more*
15. How much would you *like* to be involved in your child's ABA?	1	2	3	4	5

Next, we would like to know how you feel about the support you receive from your child's ABA providers. Your providers include *both* the ABA technician(s) and the ABA supervisor.

Here are some questions about your **relationship with** your child's **ABA providers.** Circle how much you agree with each statement:	*Strongly Disagree*		*Neither Agree or Disagree*		*Strongly Agree*
1. I like spending time with my child's ABA providers.	1	2	3	4	5
2. I find it hard to work with my child's ABA providers on solving problems in our lives.	1	2	3	4	5
3. I feel like my child's ABA providers are on my side and try to help me.	1	2	3	4	5
4. I work with my child's ABA providers on solving our problems.	1	2	3	4	5
5. When I'm with my child's ABA providers, I want the sessions to end quickly.	1	2	3	4	5
6. I look forward to meeting with my child's ABA providers.	1	2	3	4	5
7. I feel like my child's ABA providers spend too much time working on our problems.	1	2	3	4	5
8. I'd rather do other things than meet with my child's ABA providers	1	2	3	4	5
9. I use my time with my child's ABA providers to make changes in our lives.	1	2	3	4	5
10. I like my child's ABA providers	1	2	3	4	5
11. I would rather not work on our problems with my child's ABA providers	1	2	3	4	5
12. I think my child's ABA providers and I work well together on dealing with our problem	1	2	3	4	5

In the past year, **how much did your child's ABA providers:**	*Not at all*			*Sometimes*			*To a great extent*
1. Help you feel competent as a parent?	1	2	3	4	5	6	7
2. Provide you with written information about what your child is doing in therapy?	1	2	3	4	5	6	7
3. Provide a caring atmosphere rather than just give you information?	1	2	3	4	5	6	7
4. Let you choose when to receive information and the type of information you want?	1	2	3	4	5	6	7
5. Look at the needs of your "whole" child (e.g., at mental, emotional, and social needs) instead of just physical needs?	1	2	3	4	5	6	7
6. Make sure that at least one team member is someone who works with you and your family over a long period of time?	1	2	3	4	5	6	7
7. Fully explain treatment choices to you?	1	2	3	4	5	6	7
8. Provide opportunities for you to make decisions about treatment?	1	2	3	4	5	6	7
9. Provide enough time so you don't feel rushed?	1	2	3	4	5	6	7
10. Plan together so they are all working in the same direction?	1	2	3	4	5	6	7
11. Treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as "Mom" or "Dad"?	1	2	3	4	5	6	7
12. Give you information about your child that is consistent from person to person?	1	2	3	4	5	6	7
13. Treat you as an individual rather than as a "typical" parent of a child with a disability?	1	2	3	4	5	6	7
14. Provide you with written information about your child's progress?	1	2	3	4	5	6	7
15. Tell you about the results from assessments?	1	2	3	4	5	6	7

Have you ever **received Family Training** (sometimes called Family Guidance), either currently or in the past, as part of your child's ABA services? (check ☑ one):

☐ **Yes**, I am currently receiving it

☐ **Yes**, I received it in the past, but not right now

☐ **No**, it was offered, but I did not want it

☐ **No**, I have not been offered it before

What is Family Training?

Family Training **relies on collaboration** between you and your child's therapist. It is when a provider works with you to **help you feel more confident and skilled in helping your child**. While this looks different depending on your child, **common parts of a good program include**:

Collaboration
Works with you to set goals and track child's progress

Modeling
Demonstrates the strategies for you with your child

Practicing
Gives you time to practice strategies together in session

Feedback
Gives you support as you practice with your child in session

Planning
Helps you plan how to practice the strategies at home

Problem Solving
Helps when using the strategies at home isn't working

Handouts
Provides you with written materials to help you learn

What can I expect from Family Training?

Learning and practicing **require time and effort**, but have lasting benefits for the child and family. For family training to work best, parents **attend weekly sessions** with a therapist over several months. These sessions are **focused on teaching you skills!**

The therapist meets regularly with the family to monitor progress and provide on-going support.

Between sessions, parents practice using the skills they've learned from the therapist.

Vitalsigns
www.cdc.gov/vitalsigns/adhd

What are the benefits?

Supports both the family and the child:

- Transfer skills learned in therapy to the home
- Improve parent-child relationships
- Decrease parent stress
- Increase quality of life

Can help teach your child many skills:

- Problem behaviors
- Talking and listening
- Social skills
- Play and imitation
- Sleeping and eating

Developed by the MSU autism lab

Next, we want to know what you think about the type of Family Training on that handout.

How **similar** is Family Training to the support you receive from:	*Not at all*		*Somewhat*		*Extremely*
1. Your child's ABA technician(s), who work with your child day to day	1	2	3	4	5
2. Your child's ABA Supervisor, who supervises the ABA tech(s)	1	2	3	4	5

How often does your child's **ABA supervisor** use the Family Training strategies from the handout **with you**?	*Rarely/ Never*	*Every few months*	*Once a month*	*A few times a month*	*At least once a week*
1. Collaboration: Work with you to set goals and track progress	1	2	3	4	5
2. Modeling: Demonstrate the strategies for you with your child	1	2	3	4	5
3. Practicing: Allow time for you to practice strategies in session	1	2	3	4	5
4. Feedback: Give you support and feedback as you practice	1	2	3	4	5
5. Planning: Plan and reflect on how you practice at home	1	2	3	4	5
6. Problem solving: Help you figure out how to use the strategies at home when it's hard	1	2	3	4	5
7. Handouts: Provide you with written materials or manuals to help you learn	1	2	3	4	5

Circle **your answer** to the following questions about Family Training:	*None*		*Some*		*A lot*
1. How much sense does Family Training make to you?	1	2	3	4	5
2. How successful do you think it would be in addressing your child's problems?	1	2	3	4	5
3. How sure would you be in recommending it to a friend who's child experiences similar problems?	1	2	3	4	5
4. How much improvement in your child's problems do you really feel will occur from it?	1	2	3	4	5
5. How much do you really *feel* that it will help reduce your child's symptoms?	1	2	3	4	5
6. How much improvement in your child do you really *feel* will occur?	1	2	3	4	5

Circle **how much you agree** with the following about Family Training:	*Strongly Disagree*		*Neither Agree or Disagree*		*Strongly Agree*
1. This is an acceptable treatment for my child's behavior	1	2	3	4	5
2. The treatment should be effective in changing my child's behavior	1	2	3	4	5
3. My child's behavior is severe enough to justify the use of this treatment	1	2	3	4	5
4. I would be willing to use this treatment with my child	1	2	3	4	5
5. This treatment would not have had side effects for my child	1	2	3	4	5
6. I like this treatment	1	2	3	4	5
7. The treatment is a good way to handle my child's problem	1	2	3	4	5
8. Overall, the treatment would help my child	1	2	3	4	5

Circle how often each of these **would be a problem for you** if you participated in Family Training described in the handout:	*Never a problem*		*Sometimes a problem*		*Very often a problem*
1. Treatment taking time away from spending time with my children	1	2	3	4	5
2. Treatment lasting too long (too many weeks)	1	2	3	4	5
3. Being too tired after work to come to a session	1	2	3	4	5
4. Getting a baby-sitter so I can come to the sessions	1	2	3	4	5
5. Having trouble with other children at home, which would make it hard to come to treatment	1	2	3	4	5
6. Scheduling of appointment times for treatment	1	2	3	4	5
7. Crises at home that would make it hard for me to get to a session	1	2	3	4	5
8. Treatment being in conflict with another of my other activities	1	2	3	4	5
9. My job getting in the way of coming to a session	1	2	3	4	5
10. There is always someone sick in my home	1	2	3	4	5

Next, we would like to know how interested you are in Family Training as a way to improve your child's skills or behaviors. (*When it says behavior, you can substitute a different skill that is important to you, such as talking, social skills, sleeping, or eating.*)

Circle **how much you agree** with the following statements:	*Strongly Disagree*		*Neither Agree or Disagree*		*Strongly Agree*
1. It is very important for the well-being of my family that my child changes his behavior	1	2	3	4	5
2. I am willing to work on changing my own behavior as it relates to managing my child	1	2	3	4	5
3. My child's behavior has to improve soon	1	2	3	4	5
4. I am prepared to work through this program every week for several months in order to change my child's behavior	1	2	3	4	5
5. Although the main problem is with my child's behavior, I believe I should work through this program every week	1	2	3	4	5
6. It is very important for the well-being of my child that he changes his behavior	1	2	3	4	5
7. I am willing to change my current parenting techniques and try new ones	1	2	3	4	5
8. I think the benefits of this program will be greater than the costs	1	2	3	4	5
9. I would like my child's behavior to change	1	2	3	4	5
10. I am willing to try parenting techniques even if I think they might not work	1	2	3	4	5
11. I want to be involved in my child's treatment at this point in time	1	2	3	4	5
12. My child will experience many negative outcomes in life if his behavior does not change	1	2	3	4	5
13. I am motivated to practice the techniques I will learn in this program at home with my child	1	2	3	4	5
14. I believe that my child's behavior cannot change without my involvement in treatment	1	2	3	4	5
15. My family will experience many negative outcomes in life if my child's behavior does not change	1	2	3	4	5
16. I am eager to participate in treatment	1	2	3	4	5
17. I believe that changing my own behavior can cause my child's behavior to change	1	2	3	4	5
18. I want my child's behavior to improve	1	2	3	4	5
19. I am motivated to change the way I respond to my child if it will lead to improvement	1	2	3	4	5
20. I believe that I can learn to change my child's behavior	1	2	3	4	5
21. I am motivated to participate in my child's treatment each week	1	2	3	4	5
22. Participation in this program is a top priority in my schedule and that of my child	1	2	3	4	5
23. I believe that I am capable of learning the skills needed to change my child's behavior	1	2	3	4	5
24. I look forward to learning new techniques for managing my child's behavior	1	2	3	4	5
25. I am motivated to work with through this program for one hour each week in order to change my own behavior	1	2	3	4	5

Thank you for participating in our survey!
Please fill out the next page to get your gift card.

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