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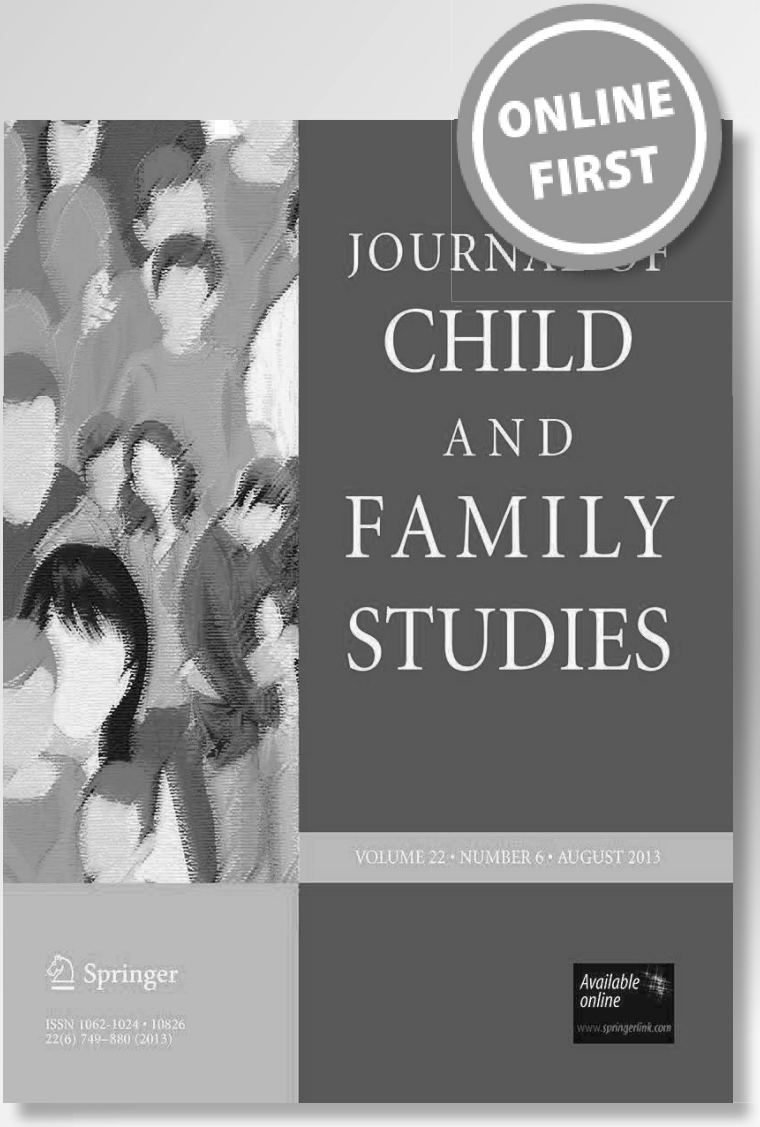

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ORIGINAL PAPER

Enablers of Behavioral Parent Training for Families of Children with Autism Spectrum Disorder

Tracy J. Raulston[1] · Meme Hieneman[2] · Nell Caraway[3] · Jordan Pennefather[3] · Naima Bhana[1]

Abstract

Objective Children with autism spectrum disorder (ASD) are at an increased risk to develop problem behavior, which can have deleterious effects on child and parental well-being. Because of this, parents are often provided with Behavioral Parent Training (BPT). However, attrition rates in BPT are high, and there is a relative dearth of research investigating factors that influence parental engagement in BPT.

Methods We ran seven semi-structured online focus groups with a total of 30 parents of children with ASD and related disabilities. Parents were interviewed in order to gain a greater understanding of variables that enable or pose barriers to parental engagement in BPT. An inductive qualitative analysis was conducted by two independent authors.

Results Our analyses revealed three themes indicating the need for (a) supportive, professional feedback; (b) accessible, flexible, and affordable training; and (c) social-emotional support and community connection in BPT for parents of children with ASD.

Conclusions Results from this study suggest that parental engagement in BPT for children with ASD may be enhanced if it is relevant to the needs of families, facilitated by responsive professionals, flexible, and readily accessible. Additionally, parents may benefit from BPT that includes social and emotional support, such as assistance connecting with other families and evidence-based strategies to manage the stress associated with parenting a child with ASD and challenging behavior.

Keywords Autism spectrum disorder · Behavioral parent training · Parental engagement · Support · Families

Autism spectrum disorder (ASD) is characterized by social-communication deficits (e.g., difficulties with language, emotions, and relationships) and repetitive behavioral patterns (e.g., insistence on sameness, difficulties with transitions) (American Psychiatric Association 2013). As a result, children with ASD and related disabilities are at an increased risk of developing problem behavior including aggression, non-compliance, self-injury, and elopement (Baghdadli et al. 2003; Hartley et al. 2008; Kanne and Mazurek 2011). Reported prevalence of problem behavior in children with ASD has varied in the literature, with recent estimates ranging between 35.8 to 94.3% (Baghdadli et al. 2003; Bodfish et al. 2000; Hartley et al. 2008; Murphy et al. 2009). These problem behaviors can present early in childhood (Wallace and Rogers 2010) and persist into adulthood (Lowe et al. 2007). Problem behavior can have deleterious effects on children's social-emotional and academic outcomes (Kuhlthau et al. 2010). Child problem behavior can also have negative effects on family members, and in particular, parents. In fact, the relationship between child problem behavior and parenting stress is bidirectional, thus mutually escalating or deescalating over time (Lecavalier et al. 2006; Neece et al. 2012). Interventions to address child behavior problems in families of children with ASD and related disabilities are critical for the family system as a whole (Wong et al. 2015).

Fortunately, there is a robust literature base indicating that interventions rooted in the science of applied behavior analysis (ABA; e.g., antecedent manipulation strategies, functional communication training, differential reinforcement) are effective in reducing problem behavior and increasing adaptive behaviors (e.g., communication, self-help skills) for children with ASD (National Autism Center 2015; National Professional Center on Autism Spectrum

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Disorders 2014; National Research Council 2001). ABA-based interventions are often delivered by behavior technicians in treatment centers or structured sessions in the child's home setting (Klintwall and Eikeseth 2014). These delivery methods are highly effective for child outcomes including significant improvements in behavior and functioning (Eikeseth 2009; Howlin et al. 2009; Rogers and Vismara 2008); however, the generalizability and sustainability of these methods may be compromised. For example, ABA service providers typically provide minimal systematic training to parents (Love et al. 2009). Thus, it is unclear how well the skills children learn through ABA-based therapies transfer to various family routines (e.g., shopping trips, community and church activities, visits to relatives' and friends' homes).

A growing body of research suggests that parents of children with ASD and other developmental disabilities can be taught to be effective change agents thereby implementing ABA-based interventions in their family home setting (Durand et al. 2012; Fettig and Barton 2014; Gerow et al. 2017). Parents of children with developmental disabilities have also been successfully trained to use strategies grounded in ABA and social learning theories (e.g., adapted Incredible Years Program) in group formats (McIntyre 2008a, 2008b). The results of these interventions have included increases in child adaptive behavior, decreases in child problem behavior, improved parental efficacy, and reductions in parental stress (Dababnah and Parish 2016; Durand et al. 2012; Frantz et al. 2017; Gerow et al. 2017; McIntyre 2008a; 2008b).

Early studies focused on behavioral parent training (BPT) adopted a procedural approach to training in which parents were taught to use strategies such as praise, rewards, timeout, contingency contracts, and data-based monitoring (Serketich and Dumas 1996). Over the years, it has become evident that parents can take a more active role in designing, implementing, and monitoring the outcomes of interventions. In recent studies, parents have been taught to recognize the possible purposes (i.e., operant functions) their children's behavior serves and to employ function-based interventions (Dunlap et al. 2018; Durand et al. 2012; McIntyre 2008a, 2008b). Best practice recommends that parents be empowered and taught skills that build their capacity to manage their children's behavior and embed instruction into their everyday routines (Division for Early Childhood 2014; Turnbull and Turnbull 2017).

Although BPT has been shown to be efficacious, a research-to-practice gap persists (Dingfelder and Mandell 2011). For those families who do receive BPT, it is estimated that approximately half drop out before completion (Chacko et al. 2016). This rate of attrition is worrisome, yet there is little research examining why this is the case. There are several plausible reasons for compromised engagement in parent training programs including socioeconomic status (Carr et al. 2016; Croen et al. 2017), geographical limitations (Ingersoll et al. 2017, Lindgren et al. 2016), lack of time, and competing life demands such as work schedules (McConnell et al. 2015). High levels of stress could also compromise initial engagement with BPT, as well as adherence with the strategies learned in BPT (Allen and Warzak 2000; Carr et al. 2016; Osborne et al. 2008).

Moore and Symons (2011) surveyed parents of children with ASD and found the following variables to be significantly associated with adherence with behavioral interventions: (a) agreement between couples on how and when to use strategies, especially reinforcement; (b) parent perceptions including their effectiveness as a behavior agent of change (i.e., self-efficacy); (c) confidence that the intervention strategies would produce meaningful outcomes; and (d) acceptance of child in family and community life. McConnell et al. (2015) found that contextualization (e.g., degree to which interventions could be embedded into daily routines) significantly predicted parents' treatment adherence after controlling for child age and disability severity. The aforementioned correlational findings provide a basis for likely enablers and barriers to BPT. More research is needed to further understand factors that contribute to the success and failure of BPT.

Because parents are the primary support system for their children with ASD and offer the greatest guidance throughout their young lives, it is vital to understand what variables affect their ability to access and participate in BPT. Quantitative studies have explored demographic factors that may affect participation (Carr et al. 2016; Croen et al. 2017), as well as suggested hypotheses to explain variations in parent responding during evaluations of BPT (Allen and Warzak 2000), but these do not provide an in depth understanding of issues that contribute to engagement.

We utilized an implementation science conceptual framework to guide the formulation of our research questions and data collection methods. Implementation science is the study of factors that influence the effective adoption and integration of evidence-based interventions into practice (The National Implementation Research Network 2015). A central tenet of implementation science involves investigating how to diffuse evidence-based innovations. Diffusion, in this instance, refers to how practices are (a) communicated by professionals, (b) adopted and implemented by natural change agents (e.g., parents), and (c) sustained over time within social systems (Rogers 2003). Implementation science stresses that interventions should fit the perceived needs, values, and beliefs of stakeholders. Additionally, implementation science emphasizes the importance of understanding relationships between partners in systems, including those of professionals and consumers

– in this case, the parents themselves (Fixsen et al. 2005). Given this emphasis, implementation scientists commonly use qualitative methods of inquiry. Specifically, focus groups have been frequently utilized by implementation scientists to gain insight into knowledge users' experiences and perspectives with the adoption of an evidence-based practice. Focus groups allow homogeneous strangers with similar experiences, yet not too closely linked together, to tell their stories (Palinkas 2014). Thus, the purpose of the current study was to explore enablers, and by contrast barriers, of BPT from the perspective of parents of children with ASD. We sought to answer two overarching research questions: (1) What variables appear to enable parental engagement in BPT and (2) What variables appear to pose barriers to parental engagement in BPT?

Method

Participants

Following Institutional Review Board approval, parents of children with ASD were recruited to participate in this study through nationwide distribution flyers to centers serving children with ASD and via Facebook advertisements. To participate in the study, parents were required to (a) have a high-speed Internet connection and (b) be parenting a child with ASD or a related disability. Their child had to (a) live primarily in the parent's home and (b) have a history of engaging in frequent challenging behavior. For two of the later focus groups, we targeted parents who had experience with BPT by adding this to our recruitment flyers and advertisements. Parents provided informed consent by signing an online Qualtrics® form and completed an online demographics survey. Eligible parents were then invited to attend a focus group based on their availability.

Table 1 displays participant demographics. A total of 30 parents participated with 26 of those being mothers (86.67%). The mean age was 37.39 years old ($SD = 4.67$). A range of educational levels was reported. Seven of the parents had a master's degree or higher (23.33%). Ten of the parents had a bachelor's degree (33.33%). Twelve had an education level lower than a bachelor's degree (40%). Twenty-one reported their race as White/Caucasian (70%), three as Black/African American (10%), one as Asian (3.33%), and three reported more than one race (10%). Two parents reported their ethnicity as Hispanic (6.67%), with the remaining 28 reporting non-Hispanic (93.33%). Annual household income ranged from $10,000–$100,000 +, with the majority of the sample reporting incomes above $40,000 (76.67%). All parents reported that their child ($M = 6.82$ years old; $SD = 2.57$) had behavioral challenges. Twenty-six of the children were reported to have a formal ASD diagnosis or special education eligibility (86.67%), whereas the others reported that their children had related disabilities. Parents lived in 13 different states, across various regions, and two were from Canada. The parents participating in this study represented a diversity of backgrounds and experience necessary for effective qualitative research.

Table 1 Participant demographic characteristics

	$N = 30$
Parent sex (female)	86.67%
Parent age in years – *M*	37.39
Parent race	
White/Caucasian	70.00%
Black/African American	10.00%
Asian	3.33%
More than one race	10.00%
Parent ethnicity	
Hispanic	6.67%
Non-Hispanic	93.33%
Parent education level	
Lower than bachelor's degree	40.00%
Bachelor's degree	33.33%
Master's degree or higher	23.33%
Total family income range	
10,000–19,999	3.33%
30,000–39,999	20.00%
40,000–49,999	16.67%
50,000–59,999	13.33%
60,000–74,999	13.33%
75,000–99,999	23.33%
100,000+	10.00%
Child age in years – *M* (*SD*)	6.82 (2.57)

Procedure

The current study was a part of a larger investigation conducted by a small business in the Pacific Northwest region of the United States aimed to develop and evaluate a parent training program to improve child behavior and reduce parenting stress for families of children with ASD. During the design phase of this investigation, seven focus groups using semi-structured interviews were conducted online via Google Hangouts. Focus groups were used in the current study because they allowed for exploration of experiences and perspectives across participants, creating depth and credibility of understanding of the issue at hand (Palinkas 2014). Such understanding of enablers for BPT cannot be gleaned through incidental interactions or secondary interpretations of quantitative studies. We employed a content analysis, which is a pragmatic, qualitative methodological

approach to examine a topic and gain an understanding of "what works" starting with inductive logic derived from a review of the literature (Cho and Lee 2014).

The seven semi-structured focus groups were conducted to obtain information on a host of items to gather data on how parents access information to help their child's behavior, while also addressing their own needs and stress. The focus groups were moderated by the second author (co-principal investigator of the clinical trial), with support of a product researcher who managed logistics and assisted in probing additional information. The lead moderator was a doctoral-level behavior analyst with more than 30 years of experience working with children with ASD and their families, including providing BPT. Neither moderator had previous contact with the parents. The groups were observed by the first and third authors, who noted subtleties in the interaction and context.

The focus groups were conducted online via Google Hangouts during afternoons and evenings.

Measures

A script for introducing the focus group and a list of questions and timelines were prepared in advance. Moderators reviewed the purpose of the session and ground rules to encourage participants to speak freely, share the floor with other participants, minimize interruptions, and protect confidentiality. Moderators then introduced each question and probed for deeper understanding of the responses, rotating their attention among the participants. At the end, the moderators summarized the discussion. The questions of interest for the current analysis included open-ended items related to potential enablers to accessing acceptable, beneficial parent training to improve child behavior and reduce parenting stress. Example interview questions included (a) How do you go about choosing particular resources or programs related to your child with autism; (b) How do you determine if a program is relevant and trustworthy; (c) What, if any, trainings related to your child's behavior have you sought or attended; (d) What did you like most about the program; and (e) What, if any, barriers or frustrations did you experience? Follow-up probe questions varied depending on the organic direction of the discussion. For example, if a parent indicated that she attended formal (e.g., manualized) BPT, the moderator asked one or more of the following questions: (a) What information was covered during the course(s); (b) How was the material presented (when, how long, where, with whom); (c) What information did you find to be most and least beneficial, Why; (d) What experiences/activities did you find to be most and least beneficial, Why; or (e) What, if any, obstacles did you experience related to using the strategies you learned?

Data Analyses

Audio recordings of each focus group were captured. Interviews lasted ~90 min each and were conducted from December 2015 to May 2016. The focus group audio files were transcribed by a professional captioning and court reporting service. The data from the transcripts were analyzed and synthesized using an iterative content analysis process focusing on the research questions. The process involved data reduction and display and drawing of conclusions and verification (Miles and Huberman 1994). We began by coding themes within individual transcripts and then compared and consolidated the themes across the focus groups.

The first and second authors independently analyzed each transcript by cycling through the text to (a) eliminate extraneous information, (b) label responses, and (c) categorize each response. Extraneous information was defined as off-topic discussion (i.e., not pertaining to the questions) such as personal anecdotes and conversations about particular providers. The labels were no more than four words in length, concisely capturing the gist of each response. Next, the first and second authors utilized inductive analysis to independently derive themes (i.e., statements of meaning derived from the data) from the response categories. During this triangulation process, themes were gradually consolidated, omitting redundancy and ensuring the most salient ideas were included. The third author analyzed 33% of transcripts, independently coding themes for reliability. When a disagreement in themes was found, the first and third authors met and discussed until an agreement was reached. The themes were shown to be reliable. Next, the first, third, and fifth authors pulled quotes from the text to illustrate each theme. Once completed, the second author completed a final review of themes and quotes to ensure that the labels and descriptions were aligned and that redundancy across themes was eliminated.

Results

The transcripts produced a total of 4943 lines of text. Three major themes emerged related to the aforementioned overarching question of interest, including identifying enablers and barriers to BPT from parents' perspectives. These themes included (a) individualized and supportive professional feedback; (b) accessible, flexible, and affordable training; and (c) social-emotional support and connection to community. The descriptive labels of the emergent themes are presented as enablers; however, it should be noted that the explanations and quotes are illustrative of both examples and nonexamples (i.e., barriers) of the theme.

Individualized and Supportive Professional Feedback

Parents reported feeling overwhelmed with information available online and needed help determining where to start. Parents reported needing feedback from a professional with expertize in behavior support. Parents tended to refer to behavior in terms of the topography (i.e., form), demonstrating that they did not always recognize, at least initially, behavioral functions. Many parents began investigating problem behaviors or particular interventions with online searches and expressed that they needed support and feedback from a professional with whom to brainstorm and assist in determining what was right for their family. In the following quote, a parent described frustrations she experienced:

> "So it gets a little frustrating when you don't have that sort of contact with someone to work out problems, issues. So a lot of it's just trial and error, and then working with my husband, trying to figure out what's driving it. But it would be nice to keep in contact with someone who might have a better understanding of problem behaviors, or you know, can give me some feedback, or just ask more specific questions about what you think might be causing it."

Parents also expressed needing individualized approaches specific to their child, rather than general information. As indicated in the quote below, many parents mentioned needing to have someone who would provide guidance tailored to their circumstances:

> "It's nice to have somebody that you check in with and that you're kind of -- like, you can go over things with. That's what I find with a lot of these other programs, that it was just all information, that there's no interaction. And it was -- after a while, you just lose interest and you don't really -- you don't know how to apply what you're learning unless you kind of bounce the ideas off of somebody else."

Parents also communicated that the way in which professionals interacted with them was important. They specified a need for the professional to be non-judgmental and collaborative, rather than taking an expert point-of-view as described in the following quote:

> "It needs to be somebody who is ready to be very collaborative; who is willing to try new things; like < parent's name removed > said, who's not judgmental at all; somebody who's willing to work with the families and not just command us from on high kind of thing. It has to be somebody who's willing to work in a partnership with us. And in terms of gut instinct, that's my thing. If I feel that you're willing to be a partner in the process, then fine, you're willing to come on board. If that's not the vibe I'm getting from you, then stay away."

In the following quote, a parent commented on a frustrating experience with a professional behavior analyst taking an expert stance:

> "…So it's like, I know what I'm doing, and then I've been receiving comments like, 'Yeah, I studied like seven years to be BCBA,' and yeah, okay, I'm just a mom. But I know my child since he was born. So I think that's not really working, from the parent's side."

In the next quote, a parent spoke about a professional making sure that the recommended strategies aligned with the families' parenting style:

> "…they were always like, 'Are you good with this? Is this along your parenting style?' And just sort of always checking back and making sure I was comfortable with that. It was good, because we had other scenarios where it was just, 'This is the theory. This is going to have to work.'"

Overall, this theme suggests that parents wanted individualized, supportive feedback from a professional with expertize in causes, or functions, of their child's challenging behavior. Further, parents reported needing this feedback on an ongoing basis to brainstorm their specific challenges and help them apply behavioral strategies.

Accessible, Flexible, and Affordable

The second theme that emerged from the transcripts includes needing BPT to be (a) accessible; (b) flexible (i.e., for the learning activities to fit within their busy schedules); and (c) affordable (e.g., covered by their child's insurance). A few parents reported that they completed online training that was designed for behavior technicians taught by Board Certified Behavior Analysts (BCBAs). One parent described a positive experience she had completing a Registered Behavior Technician (RBT) course that involved online narrated presentations with weekly in-person quizzes:

> "…I wanted to say that I also took an RBT course. Because I saw such a discrepancy between what I learned at < research cite retracted > and what I was getting through the state -- you know, what we were

qualified for through the state. And I wanted to make sure how I could be implementing closer to what I was getting through < research site retracted > . That was more of what I wanted, so I did the RBT course. And that helps me in figuring out more the FBA -- you know, functional behavior assessment type, the precursor behaviors, and the antecedents and all that."

Other parents indicated that such programs were not an option for their family due to the cost. Many parents reported that they would not be able to participate BPT programs unless it was covered by their child's insurance.

"We've pursued other trainings. In the past year, though, we've looked at trainings, but haven't been able to because of cost, and that they're only offered in a location where you have to fly to [laughs]. So some of those that we would like to pursue are just not accessible to us and available or cost, you know. We just can't afford to do them."

"I did a look a little bit into some web-based trainings, but they were cost prohibitive. I mean, there is one that's through the local college here, but it's like a graduate certificate program. And I would have been interested in doing it, but it's a little costly."

Some parents expressed a desire to participate in self-directed online BPT programs. These programs would allow parents to access the training materials when they were able (i.e., as it fit into their schedule). Because of competing demands and child problem behavior, parents indicated that the training materials needed to be delivered in a way that was flexible, allowing for changes, pausing, and review.

"I think another key for me is being able to self-pace any kind of course or training or instruction, and also being able to self-schedule. Because a lot of times, if it's a phone call on a Tuesday at 7:00, you can't always do that. You might have a kid who's having a meltdown right at that time, or a husband with a last-minute meeting or whatever, whatever. And then also just being able to self-pace. We have some stretches of time that are better than others, you know? Or sometimes I can't get to it until 10 o'clock at night after everybody's finally asleep or whatever. So flexibility is super key in going through any kind of training."

The parents who participated in the focus groups clearly wanted to access training that would benefit their children and families. As busy parents supporting children with behavioral challenges, they emphasized the importance of being able to participate in BPT without significant disruption in their family lives.

Social-Emotional Support and Connection to Community

Parents reported needing help with the stress associated with their child's challenging behavior. Multiple parents reported seeing therapists because of the stress from their child, stating that their therapists had suggested scheduling time for self-care and social support opportunities such as getting together with friends, having a date night with their spouse, or short weekend getaways. Parents also indicated that they needed assistance communicating with their child's teachers as well as other family members about their child and ASD, in general. In the following quote, a parent described her and her husband's need for self-care and social support:

"I'm seeing a therapist for that, trying to get back into mindfulness. I took a vacation by myself with my friends. And we were able to find a babysitter who is also a special needs teacher, so that it's been three years in the making that I've had any kind of making -- even thinking about any kind of stress relief… My husband is part of a special needs' dad group. I have one other participant who lives in the area, so I have one other friend who has a child with ASD. I am looking for support groups now because, yeah, I'm trying to find one."

In the next quote, a parent describes a positive experience of informal social connection created through her son's ABA center.

"One of the things that kind of plays off what he just said is we received an invite to a birthday party of a child at the ABA center whose parents we had never met before, but they invited pretty much everybody to come. And I think one of the very first times we got to meet other parents who were in similar situations. And it was kind of a one-time thing, and we didn't really keep in touch. But I think just that one incident and that one person reaching out and getting all of the parents together at the center was very -- it was helpful for me, and it was very laid back and very informal."

After follow-up probe questions from the moderator, the parent continues to tell how this birthday party experience allowed her to connect with parents with whom she could

relate, and how this differed from talking with parents with children who were older.

> "I had met with parents who had older children who had been on this journey for a lot longer. But because they were all birthdays, all the kids who were there were pretty much between the same ages -- it was the whole time in ABA, so they were all between three and six, really. There were parents who were in the same place as us. I think a lot of the organizations that I had met with before through -- whether it was the Autism Society of < state retracted > or the special needs Facebook groups or things that I had already been a part of…It wasn't quite the same thing. I think, they have a wealth of knowledge, but they don't necessarily relate to where you are on your journey."

Parents appreciated being socially connected with others during BPT, especially with groups of parents who were experiencing similar difficulties parenting a child with challenging behavior. Parents indicated that the way in which information was delivered was important, and they wanted to feel supported.

> "Actually, I think I remember most of the people. There was a lot of -- you get into a group where you're able to ask questions without the fear of getting a negative response, and I think that's actually what I remember most, is not necessarily what they were teaching but how they were teaching it. It just -- I don't know. That's the part that I remember most is being able to talk to people and have a conversation. Again, in the autism community, it tends to be so isolated, and it felt a little less isolated."

Finally, parents mentioned relying on social media for support. This was important due to their limitations in attending events in person and the flexibility of access. They found safety in these internet communities.

> "Yeah, Facebook has been -- surprisingly, it's been a good thing. And I know sometimes it's not so great, but for me with not having family around or a lot of friends around, that's my outlet. And it's been a great support system."

In this final theme, parents emphasized the value of mental health supports and social networks. Parenting a child with behavioral challenges can cause social isolation and stress, and parents reported needing to purposefully take time to rejuvenate and be connected to a community.

Discussion

In this qualitative study, we obtained information regarding enablers and barriers of BPT from parents of children with ASD and related disabilities via focus groups. An iterative content analysis yielded three themes indicating the need for (a) supportive, professional feedback; (b) accessible, flexible, and affordable training; and (c) social-emotional support and community connection.

Although BPT can be effective in strengthening parental self-efficacy and skills needed to intervene effectively with their children's behavior (McIntyre 2008a, 2008b), in real-world practice BPT programs are plagued by high attrition rates (Chacko et al. 2016) and failure of parents to follow through with strategies (Allen and Warzac 2000). This nonadherence points to barriers in adoption and implementation, demanding that we attend thoroughly and constructively to issues that will better enable parental engagement.

Each of the themes identified in this study aligns with and expands upon existing literature. First, although some parents may be able to understand and independently implement behavior support strategies learned in BPT, many require support to apply the approaches within their daily routines and overcome challenges (Fettig and Barton 2014; Lucyshyn et al. 2015; Moes and Frea 2002; McIntyre and Brown 2016). The way in which professionals provide this support is also important. An extensive body of literature describes characteristics of parent-professional collaboration (e.g., supportive stance, mutual trust, and shared decision-making) that lead to the most positive outcomes (Madsen 2007).

Second, parents of children with disabilities and challenging behavior – including those with ASD – often need BPT, but unfortunately, qualified professionals are at a premium. In addition, the cost of programs can be prohibitive and a variety of other barriers to obtaining training such as work schedules, childcare responsibilities, and time and travel demands pose challenges (Ingersoll et al. 2017; Lindgren et al. 2016). Parents need to be able to access BPT in a variety of ways and on their own time. In response, a number of researchers are exploring other options for service delivery, including group training (McIntyre 2008a, 2008b), online consultation (Machalicek et al. 2016, Wacker et al. 2013), and self-directed programs (Ibanez et al. 2018; Ingersoll et al. 2016; Ingersoll et al. 2017).

Third, parents of children with ASD and challenging behavior are often under considerable stress that may interfere with their ability to implement the strategies taught via BPT (Dabrowska and Pisula 2010; Totsika et al. 2011). High levels of stress may be ameliorated by offering social-emotional support and greater connection

to community. Informal and formal social support has been demonstrated as a protective factor for these families (Boyd 2002, McIntyre and Brown 2016). Finally, there is emerging research on the benefits of combining BPT with cognitive-emotive practices such as acceptance-based therapies (Blackledge and Hayes 2006), optimism training (Durand et al. 2012), and mindfulness (Singh et al. 2014).

Conceptual and Theoretical Frameworks

The results of this study align with existing conceptual and theoretical frameworks that have been proposed for improving child behavior and lives of families. Lucyshyn et al. (2009) put forward an ecological model of behavioral intervention for families that emphasizes assessment of the multiple layers of influence in family environments. Incorporated into this model is an understanding of parent–child interaction, based on coercive family process theory (Patterson 1982), and of the broader ecology of family life, based on ecocultural theory (Bernheimer et al. 1990). Family routines as the unit of analysis and intervention, and making strategies fit within this context, are emphasized.

Hieneman and Fefer (2017) described how positive behavior support, which is an application of ABA and BPT that stresses implementation by typical caregivers, within natural settings and in the context of regular routines, can be implemented. In their article, Hieneman and Fefer distilled the key features of effective practice – lifestyle enhancement, assessment-based interventions, and comprehensive proactive, educative, and functional interventions that fit within family life. These features can readily be adopted by families and frame evidence-based intervention in home and community settings.

Finally, our findings highlight some variables that may affect the adoption and sustainability of behavioral strategies learned through BPT. The Consolidated Framework for Implementation Science Research (CFIR) comprises the following domains: intervention, inner and outer settings, the individuals involved, and the process by which implementation is accomplished (Damschroder et al. 2009). In the current study, theme one (individualized and supportive feedback) and two (accessible, flexible, and affordable) support the idea that interventions – in this case BPT – need to be adaptable and consider cost. Theme three (social-emotional support and connection to community) addresses the outer and inner settings domain, and in particular, the families' needs and resources as well as networks and communications. By interviewing critical change agents in BPT – the parents of children with ASD – we were able to learn more about parents' knowledge and beliefs of this evidence-based practice.

Strengths, Limitations, and Directions for Future Research

This study offers insight regarding the potential enablers and barriers to BPT for families of children with ASD and related disabilities, emphasizing needs for those whose access to services may be constrained by logistical issues (e.g., availability of providers, cost of training). It also highlights the need for adjunctive support to help parents overcome barriers and more fully adopt interventions. Key take-aways are that BPT needs to (a) be relevant to the needs of families; (b) be flexible and readily accessible (e.g., being able to access training on their own time); (c) be facilitated by responsive professionals; and (d) provide social and emotional support (e.g., assistance connecting with other families who have similar circumstances, evidence-based guidance to manage the stress associated with parenting a child with ASD and challenging behavior).

Well-designed qualitative research is characterized by selection of a representative sample of participants, consistency in the use of protocols and analysis procedures, and contextualization of the results. Whereas our sample had several of these attributes, we must also acknowledge limitations. Our sample included a limited number of parents of younger children with ASD and related disabilities. The parents selected may have been more experienced, motivated, and technically savvy than the typical population. The parents were well-distributed nationally and represented different educational and socioeconomic levels, but also somewhat homogeneous in terms of racial and ethnic diversity. Given these limitations, it is still likely that the findings have relevance for this population. Findings also may have implications for a broader range of populations as similar concerns have been raised by parents of children with attention deficit hyperactivity disorder (ADHD) and other behavioral disorders (Kumpfer and Alvarado 2003; Substance Abuse and Mental Health Services Administration 2011).

Our recruitment method had inherent sampling bias, which was influenced by the fact that the small business (IRIS Educational Media) conducted the study. Participants were recruited from local agencies that had contact with members of the research team as well as from a broader national sample. Given this, the local individuals may have been exposed to similar approaches and perspectives. More tech-savvy participants (i.e., those with access to high-speed internet) were purposefully recruited because (a) the focus groups were held online and (b) IRIS Educational Media develops multimedia training resources. Questions could have been shaped by interests related to developing viable products and marketing, which is why the primary moderator was on contract, rather than a staff member. Because the questions were presented a bit differently across focus

groups, our results may have varied. Some parents offered more input than others, regardless of our efforts to moderate the discussion. And, finally, the online focus group format may have been novel and awkward for some parents. These methodological issues certainly may have influenced the participants' responses.

In terms of the analysis, it is important to acknowledge that researcher judgment can affect the themes identified in a qualitative analysis. The first and second authors were professionals experienced in BPT who may have had preconceived notions regarding effective practice. That said, significant efforts were made throughout the content analysis process to clarify and validate themes and limit our interpretations regarding the information obtained. Although it would have been beneficial to conduct member checks to clarify participant perspectives and strengthen the credibility of the findings, we were unable to do so as this was not included in the informed consent process approved by the Institutional Review Board. Because of this limitation, we employed triangulation across three data analysts. Additionally, the focus groups were run across a 5-month period and included 30 parents. Prolonged engagement, triangulation across multiple data sources, and employment of multiple data analysts provide sufficient evidence of the credibility of the findings and our interpretation.

There are several important implications for research. First, there is a relative dearth of research uncovering the perceived enablers and barriers to accessing BPT, adopting and implementing evidence-based behavioral strategies, and perhaps most importantly, sustaining and adapting strategies across time. Future research should continue to investigate, both qualitatively and quantitatively, what malleable factors affect families' experiences with BPT. Such studies may help researchers understand how to decrease the likelihood of attrition from BPT programs. Further, these studies could also elucidate ways that caregivers can be supported during BPT. For example, it may be important to include psychoeducational programming within BPT, including how parents can access informal and formal social-emotional supports within their communities, or even connect families together on social media.

A greater understanding of how to incorporate training in these malleable protective factors within low-resourced and underserved communities is especially warranted. Treatment adherence for parent-implemented social-communication interventions in low-resourced families of children with ASD has been found to be significantly predicted by parental stress (Carr et al. 2016). Carr et al. recommend that parent training for low-income populations be delivered in homes or neighborhoods, be available in the evenings and/or weekends, and accommodate families' preferred language. These recommendations align with theme two (accessible, flexible, and affordable) of our findings. It is imperative that the field understands more about the unique enablers and barriers for engagement in BPT for low-resourced families, especially given disparities in identification and access to services (Liptak et al. 2008) and the bidirectional relationship between child problem behavior and parental stress (Neece et al. 2012).

Future BPT research should involve actively recruiting diverse parents who range on various characteristics including but not limited to: (a) sex and gender, (b) age (c) socioeconomic status (including education and income), (d) race and ethnicity, (e) geographical location (including internet stability), (f) comfort with technology, (g) religious and spiritual views, or (h) mental health risk. These parental characteristics are likely to influence views and perspectives and may affect engagement in BPT. Such efforts may help uncover patterns that affect differential responding to BPT programs. Group experimental designs, for example, if properly powered, could detect moderating variables. Finally, it would be useful to study the perspectives of individuals who have started BPT and dropped out to understand reasons for attrition as well as interview those who were unable to access it.

Research Involving Human Participants

Oregon Research Institute provided Institutional Review Approval for the current study. Informed consent was obtained from all individual participants included in the study.

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Author Contributions T.J.R.: collaborated with the design, recruited participants and executed the study, conducted data analyses, and wrote the paper. M.H.: designed and executed the study, conducted data analyses, and collaborated in writing the paper. N.C.: designed and executed the study, conducted data analyses, collaborated with writing the paper. J.P.: collaborated with the design and writing the paper. N.B.: conducted data analyses, collaborated in the writing and editing of the final manuscript.

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Compliance with ethical standards

Conflict of interest This research was funded in part by a grant from the National Institutes of Health (2R44MH102845-02). IRIS Educational Media developed a parent training product using results from this study. Additionally, the first author received leadership grant funds from The U.S. Department of Education Office of Special Education Programs. The remaining authors declare that they have no conflict of interest.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. 5th edn. Washington, DC: Author.

Allen, K. D., & Warzak, W. J. (2000). The problem of parental nonadherence in clinical behavior analysis: effective treatment is not enough. *Journal of Applied Behavior Analysis*, *33*, 373–391.

Baghdadli, A., Pascal, C., Grisli, S., & Aussilloux, C. (2003). Risk factors for self-injurious behaviours among 222 young children with autistic disorders. *Journal of Intellectual Disabilities Research*, *47*, 622–627.

Bernheimer, L. P., Gallimore, R., & Weinser, T. S. (1990). Ecocultural theory as a context for the individual family service plan. *Journal of Early Intervention*, *14*, 219–233.

Blackledge, J. T., & Hayes, S. (2006). Using acceptance and commitment training in the support of parents of children diagnosed with autism. *Child and Family Behavior Therapy*, *28*, 1–18.

Bodfish, J. W., Symons, F. J., Parker, D. E., & Lewis, M. H. (2000). Varieties of repetitive behavior in autism: comparisons to mental retardation. *Journal of Autism and Developmental Disorders*, *30*, 237–243.

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, *17*, 208–215.

Carr, T., Shih, W., Lawton, K., Lord, C., King, B., & Kasari, C. (2016). The relationship between treatment attendance, adherence, and outcome in a caregiver-mediated intervention for low-resourced families of young children with autism spectrum disorder. *Autism*, *20*, 643–652.

Chacko, A., Jensen, S. A., Lowry, L. S., Cornwell, M., Chimklis, A., Chan, E., Lee, D., & Pulgarin, B. (2016). Engagement in behavioral parent training: review of the literature and implications for practice. *Clinical Child and Family Psychology Review*, *19*, 204–215.

Cho, J. Y., & Lee, E. H. (2014). Reducing confusion about grounded theory and qualitative content analysis. Similarities and differences. *The Qualitative Report*, *19*, 1–20.

Croen, L. A., Shankute, N., Davignon, M., Massolo, M. L., & Yoshida, C. (2017). Demographic and clinical characteristics associated with engagement in behavioral health treatment among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *47*, 3347–3357.

Dababnah, S., & Parish, S. (2016). Incredible Years Program tailored to parents of preschoolers with autism: pilot results. *Research on Social Work Practice*, *26*, 372–385.

Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual and Developmental Disability Research*, *54*, 266–280.

Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implementation Science*, *4*, 1–15.

Dingfelder, H. E., & Mandell, D. S. (2011). Bridging the research-to-practice gap in autism intervention: an application of diffusion of innovation theory. *Journal of Autism and Developmental Disorders*, *41*, 597–609.

Division for Early Childhood (2014). DEC recommended practices in early intervention/early childhood special education 2014. Retrieved from http://www.decsped.org/recommendedpractices.

Dunlap, G., Strain, P., Lee, J. K., Joseph, J., & Leech, N. (2018). A randomized controlled evaluation of Prevent-Teach-Reinforce for young children. *Topics in Early Childhood Special Education*, *37*, 195–205.

Durand, V. M., Hieneman, M., Clarke, S., Wang, M., & Rinaldi, M. L. (2012). Positive family intervention for severe challenging behavior: a multisite randomized clinical trial. *Journal of Positive Behavior Interventions*, *15*, 133–143.

Eikeseth, S. (2009). Outcome of comprehensive psycho-educational interventions for young children with autism. *Research in Developmental Disabilities*, *30*, 158–178.

Fettig, A., & Barton, E. E. (2014). Parent implementation of function-based intervention to reduce children's challenging behavior: A literature review. *Topics in Early Childhood Special Education*, *34*, 49–61.

Fixsen, D. L., Naoom, S. F., Blasé, K. A., Friedman, R. M., & Wallace, F. (2005). *Implementation research: A synthesis of the literature*. Tampa, FL: University of South Florida, Louis de la Parte Florida Mental Health Institute, The National Implementation Research Network (FMHI Publication #231).

Frantz, R., Hansen, S. G., & Machalicek, W. (2017). Interventions to promote well-being in parents of children with autism: a systematic review. *Review Journal of Autism and Developmental Disorders*, *5*, 1–20.

Gerow, S., Hagan-Burke, S., Rispoli, M., Gregori, E., Mason, R., & Ninci, J. (2017). A systematic review of parent-implemented functional communication training for children with ASD. *Behavior Modification*, *42*, 335–363.

Hartley, S. L., Sikora, D. M., & McCoy, R. (2008). Prevalence and risk factors of maladaptive behaviour in young children with autistic disorder. *Journal of Intellectual Disability Research*, *52*, 1–11.

Hieneman, M., & Fefer, S. A. (2017). Employing the principles of positive behavior support to enhance family education and intervention. *Journal of Child and Family Studies*, *26*, 2655–2688.

Howlin, P., Magiati, I., & Charman, T. (2009). Systematic review of early intensive behavioral interventions for children with autism. *American Journal on Intellectual and Developmental Disabilities*, *114*, 23–41.

Ibanez, L. V., Kibak, K., Swanson, A., Wallace, L., Warren, Z., & Stone, W. L. (2018). Enhancing interactions during daily routines: a randomized controlled trial of a web-based tutorial for parents of young children with ASD. *Autism Research*, *11*, 667–678.

Ingersoll, B., Shannon, K., Berger, N., Pickard, K., & Holtz, B. (2017). Self-directed telehealth parent-mediated intervention for children with autism spectrum disorder: examination of the potential reach and utilization in community settings. *Journal of Medical Internet Research*, *19*, 1–11.

Ingersoll, B., Wainer, A. L., Berger, N. I., Pickard, K. E., & Bonter, N. (2016). Comparison of a self-directed and therapist-assisted telehealth parent-mediated intervention for children with ASD: a pilot RCT. *Journal of Autism and Developmental Disorders*, *46*, 2275–2284.

Kanne, S. M., & Mazurek, M. O. (2011). Aggression in children and adolescents with ASD: prevalence and risk factors. *Journal of Autism and Developmental Disorders*, *41*, 926–937.

Klintwall, L., & Eikeseth, S. (2014). Early and intensive behavioral intervention (EIBI) in autism. In V. B. Patel, V. R. Preedy, & C. R. Martin (eds), *Comprehensive guide to autism* (pp. 117-137). New York, NY: Springer.

Kuhlthau, K. A., Kahn, R., Hill, K. S., Srilakshmi, G., & Ettner, S. L. (2010). The well-being of parental caregivers of children with disabilities. *Maternal and Child Health Journal*, *14*, 155–163.

Kumpfer, K. L., & Alvarado, R. (2003). Family-strengthening approaches for the prevention of youth problem behaviors. *American Psychologist*, *58*, 457–465.

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism

spectrum disorders. *Journal of Intellectual Disability Research*, *50*, 172–183.

Lindgren, S., Wacker, D., & Suess, A. (2016). Telehealth and autism: treating challenging behavior at lower cost. *Pediatrics*, *137*, 167–175.

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in diagnosis and access to health service for children with autism: data from the National Survey of Children's Health. *Journal of Developmental & Behavioral Pediatrics*, *29*, 152–160.

Love, J. R., Carr, J. E., Almason, S. M., & Petursdottir, A. I. (2009). Early and intensive behavioral intervention for autism: a survey of clinical practices. *Research in Autism Spectrum Disorders*, *3*, 421–428.

Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K., & James, W. (2007). Challenging behaviours: prevalence and topographies. *Journal of Intellectual Disability Research*, *51*, 625–636.

Lucyshyn, J. M., Binnendyk, L., Fossett, B., Cheremshynski, C., Lohrmann, S., Elkinson, L., & Miller, L. (2009). Toward an ecological unit of analysis in behavioral assessment and intervention with families of children with developmental disabilities. In W. Sailor, G. Dunlap, G. Sugai & R. Horner (Eds.), *Handbook of positive behavior support* (pp. 73–106). Baltimore: Paul H. Brookes.

Lucyshyn, J. M., Fossett, B., Bakeman, R., Cheremshynski, C., Miller, L., Lohrmann, S., & Irvin, L. K. (2015). Transforming parent-child interaction in family routines: longitudinal analysis with families of children with developmental disabilities. *Journal of Child and Family Studies*, *24*, 3526–3541.

Machalicek, W., Lequia, J., Pinkelman, S., Knowles, C., Raulston, T., Davis, T., & Alresheed, F. (2016). Behavioral telehealth consultation with families of children with autism spectrum disorder. *Behavioral Interventions*, *31*, 223–250.

Madsen, W. C. (2007). *Collaborative therapy with multi-stressed families: Second edition*. New York, NY: The Guilford Press.

McConnell, D., Parakkal, M., Savage, A., & Rempel, G. (2015). Parent-mediated intervention: adherence and adverse effects. *Disability and Rehabilitation*, *37*, 864–872.

McIntrye, L. L. (2008a). Adapting Webster-Stratton's incredible years parent training for children with developmental delay: findings for a treatment group only study. *Journal of Intellectual Disability Research*, *52*, 1176–1192.

McIntrye, L. L. (2008b). Parent training for young children with developmental disabilities: randomized controlled trial. *American Journal on Mental Retardation*, *113*, 356–368.

McIntyre, L. L., & Brown, M. (2016). Examining the utilization and usefulness of social support for mothers with young children with autism spectrum disorder. *Journal of Intellectual & Developmental Disability*, *43*, 93–101.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative Data Analysis*. 2nd edn. Thousand Oaks, CA: Sage Publications.

Moes, D. R., & Frea, W. D. (2002). Contextualized behavioral support in early intervention for children with autism and their families. *Journal of Autism and Developmental Disorders*, *32*, 519–533.

Moore, T. R., & Symons, F. J. (2011). Adherence to treatment in a behavioral intervention curriculum for parents of children with autism spectrum disorder. *Behavior Modification*, *35*, 570–594.

Murphy, O., Healy, O., & Leader, G. (2009). Risk factors for challenging behaviors among 157 children with autism spectrum disorder in Ireland. *Research in Autism Spectrum Disorders*, *3*, 474–482.

National Autism Center. (2015). Findings and conclusions: National Standards Project, Phase 2. Retrieved from http://www.nationalautismcenter.org/resources.

National Implementation Research Network. (2015). Implementation science defined. Retrieved from http://nirn.fpg.unc.edu/learn-implementation/implementation-science-defined

National Professional Development Center on Autism Spectrum Disorders. (2014). Evidence based practices for children, youth, and young adults with autism spectrum disorder. Retrieved from http://autismpdc.fpg.unc.edu.

National Research Council. (2001). *Educating children with autism*. Washington, DC: The National Academies Press.

Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: A transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities*, *117*, 48–66.

Osborne, L. A., McHugh, L., Saunders, J., & Reed, P. (2008). Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum. *Journal of Autism and Developmental Disorders*, *38*, 1092–1103.

Palinkas, L. A. (2014). Qualitative and mixed methods in mental health services and implementation research. *Journal of Clinical Child & Adolescent Psychology*, *43*, 851–861.

Patterson, G. R. (1982). *Coercive family process*. Eugene, OR: Castalia.

Rogers, E. (2003). *Diffusion of innovation*. 5th edn. New York, NY: Free Press.

Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child & Adolescent Psychology*, *37*, 8–38.

Serketich, W. J., & Dumas, J. E. (1996). The effectiveness of behavioral parent training to modify antisocial behavior in children: A meta-analysis. *Behavior Therapy*, *27*, 17–186.

Singh, N. N., Lancioni, G. E., Winton, A. S. W., Karazsia, B. T., Myers, R. E., Latham, L. L., & Singh, J. (2014). Mindfulness-based positive behavior support (MBPBS) for mothers of adolescents with autism spectrum disorder: Effects on adolescents' behavior and parental stress. *Mindfulness*, *5*, 646–657.

Substance Abuse and Mental Health Services Administration. (2011). *Interventions for disruptive behavior disorders: evidence-based and promising practices*. HHS Pub. No. SMA-11-4634, Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

Totsika, V., Hastings, R. P., Emerson, E., Lancaster, G. A., & Berridge, D. M. (2011). A population-based investigation of behavioural and emotional problems and maternal mental health: associations with autism spectrum disorder and intellectual disability. *Journal of Child Psychology and Psychiatry*, *52*, 91–99.

Turnbull, R., & Turnbull, A. (2017). Family engagement: An analysis of IDEA Part C and B requirements. Retrieved from: https://eclkc.ohs.acf.hhs.gov/sites/default/files/video/attachments/inclusion-handout.pdf.

Wacker, D. P., Lee, J. F., Padilla Dalmau, Y. C., Kopelman, T. G., Lindgren, S. D., Kuhle, J., & Waldron, D. B. (2013). Conducting functional communication training via telehealth to reduce the problem behavior of young children with autism. *Journal of Developmental and Physical Disabilities*, *25*, 35–48.

Wallace, K. S., & Rogers, S. J. (2010). Intervening in infancy: Implications for autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, *51*, 1300–1320.

Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., & Schultz, T. R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: a comprehensive review. *Journal of Autism and Developmental Disorders*, *45*, 1951–1966.