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Exploring Patterns of Advocacy and Well-Being of Parents of Children with Intellectual and Developmental Disabilities

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Abstract:	Advocacy is often an expectation for parents of children with intellectual and developmental disabilities (IDD). However, little is known about how advocacy may impact parent well-being, including stress, family dynamics, and marital relationships. To this end, the purpose of the study was to explore the pattern between positive and negative advocacy experiences of parents of children with IDD and the well-being of: parents, families, and marriages. Semi-structured interviews were conducted with 38 parents of children with IDD. Regardless of the nature (i.e., positive or negative) of the advocacy experience, participants reported that advocacy increased their stress. When the advocacy experience was positive, some participants reported improved family quality of life.

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Abstract

Advocacy is often an expectation for parents of children with intellectual and developmental disabilities (IDD). However, little is known about how advocacy may impact parent well-being, including stress, family dynamics, and marital relationships. By exploring the effects of advocacy on well-being, interventions can be implemented to support both the advocacy and well-being of parents of children with IDD. To this end, the purpose of the study was to explore the pattern between positive and negative advocacy experiences of parents of children with IDD and the well-being of: parents, families, and marriages. Semi-structured interviews were conducted with 38 parents of children with IDD. Regardless of the nature (i.e., positive or negative) of the advocacy experience, participants reported that advocacy increased their stress. When the advocacy experience was positive, some participants reported improved family quality of life. Also, regardless of the nature of the advocacy experience, some participants reported feeling frustration within their marital relationships. Implications for future research and practice are discussed.

Exploring Patterns of Advocacy and Well-Being of Parents of Children with Intellectual and Developmental Disabilities

The Individuals with Disabilities Education Act (2004) emphasizes the importance of parent involvement as an essential component of the special education process for children with intellectual and developmental disabilities (IDD). In addition, advocacy is an expectation for parents of children with disabilities (Trainor, 2010). Notably, advocacy can help families access needed services for their children with IDD (Burke et al., 2016; Cohen, 2013). Parent advocacy can be characterized in many ways, but ultimately the purpose of advocacy is to yield a desired outcome for the individual one is advocating for (Wolfersberger, 20001; Turnbull et al., 2016). Advocacy can be proactive or reactive (Turnbull et al., in press). Regarding the former, a parent may advocate to prevent conflict. With respect to the latter, a parent may advocate in response to their child not receiving a needed service.

The vast majority of research about advocacy focuses on the effect on the child (Turnbull et al., 2016). However, when parents advocate, there may be an impact on parent well-being. For example, advocacy may increase maternal stress (Burke & Hodapp, 2014) and reduce family quality of life (Wang et al., 2004). In a study of 16 Latina mothers of children with autism spectrum disorder (ASD), all participants reported that advocacy was stressful (Rios et al., in press). However, it is unclear how the nature of the advocacy experience (e.g., positive or negative) may relate to parent well-being including stress, and familial and marital relationships. Such constructs are important as parents of children with (versus without) IDD report worse family quality of life (Blacher et al., 2005; Magaña & Smith, 2008) and less marital satisfaction (Risdal & Singer et al., 2004). The purpose of this study was to explore the pattern between positive and negative advocacy experiences and the well-being of parents, families, and marriages.

Advocacy experiences may affect parent well-being. Among parents of children with IDD, the bulk of research about parent well-being has focused on stress. Compared to parents of children without IDD, parents of children with IDD experience greater stress (Hayes & Watson, 2013). Parenting stress, and, more broadly, well-being is important. When parents are less stressed, they may have the energy to access services for their children with IDD (Geenen et al., 2003; Trainor, 2010). However, when parents are stressed, they are more likely to have less effective parenting strategies (e.g., parent's ability to structure an organized home environment; Coldwell et al., 2006). Although most research has focused on child maladaptive behavior as a predictor of parenting stress (e.g., Neece et al., 2012), some extant research has found that parent advocacy can contribute to parenting stress (Burke & Hodapp, 2014). However, such research has not examined whether the type of advocacy experience (e.g., if the parent has a positive advocacy experience leading to a successful outcome or a negative experience which does not lead to the intended outcome) relates to parent well-being. It is important to better characterize the relation between the type of advocacy and parent well-being to identify ways to improve parent advocacy experiences.

Further, it is important to explore the pattern between family well-being and parent advocacy experiences. Within the past decade, research has begun to examine family qualify of life (i.e., positive social involvement and opportunities to achieve personal potential, Wang et al., 2004), which offers a more balanced understanding of the positive and negative aspects of raising a child with IDD (Kyzar et al., 2016). Although limited, research suggests there is a negative pattern between advocacy and family quality of life. In a sample of 104 parents of children with IDD, Wang and colleagues (2004) examined advocacy, family quality of life, and stress. They found that advocacy caused stress for parents of children with IDD and negatively impacted family quality of life. However, they did not examine whether the nature of the advocacy experience related to family well-being.

Notably, while the primary goal of advocacy is to ensure access to services and supports for the child with IDD (Turnbull et al., 2016), no empirical research has directly examined whether advocacy impacts marital relationships. Research suggests that having a child with IDD can add stress to the marital relationship (Gerstein et al., 2009). Poor quality marital relations have negative implications for the child with IDD and their family. In a study of families of children with ASD, when marital quality was poor, parents were significantly more prone to depression and their children demonstrated greater behavior problems (Langley et al., 2017). To develop interventions to improve marital quality, it is important to parcel out the stressors to the marital relationship. Although the marital relationship was not directly examined, Rios and colleagues (2020) found that mothers of children with IDD often felt unsupported by their husbands in their advocacy efforts. Conversely, mothers who brought their spouses to individualized education program (IEP) meetings reported less stress. Research is needed to directly explore the potential pattern between advocacy and marital relationships.

Advocacy is critical for parents of children with IDD. Yet, little research has examined the relationship between advocacy and well-being. By exploring the pattern between advocacy and well-being, interventions can be developed and tested to support both the advocacy and well-being of parents of children with IDD. Using qualitative interviews, this study had three research questions: Among parents of children with IDD, (1) how do parents report the effects of their advocacy on their well-being?; (2) how do parents report the effects of their advocacy on their family well-being?; and (3) how do parents report the effects of their advocacy on their marital relationships?.

Method

Participants

This study included 38 parents of children with IDD. Inclusionary criteria required participants to be older than 18 years of age and have advocated for their child with IDD. The mean age of the participants was 46.68 (*SD* = 9.98 years). Regarding educational background, most (73.6% or *n* = 28) participants completed college. Altogether, 30% of participants reflected minority backgrounds. Specifically, 21% (*n* = 8) of participants were Latina, 7% (*n* = 3) of participants were Black, and 2% (*n* = 1) were Asian. On average, the children of the participants were 12.04 years of age (*SD* = 4.60, range from 3.5 to 20). Participants reflected three states in the United States. Notably, two of the participants chose to conduct their interview in Spanish; the remaining interviews were conducted in English. See Table 1.

Recruitment

Participants were recruited through a variety of methods, including social media, word-of-mouth and email. Additionally, we collaborated with Parent Training and Information Centers (PTIs) and parent support groups in Illinois; these agencies shared the recruitment flyer with their constituencies. All recruitment materials were available in English and Spanish. Each participant received a $30 gift card after completing the interview and a $10 gift card after completing the member check (i.e., participant validation of the interview). There were no pre-determined criteria for the number of participants; recruitment was ongoing until saturation was reached as indicated by the redundancy of themes (Bowen, 2008).

Procedures

Prior to conducting the interviews, this study was approved by the University Institutional Review Board. Interested individuals contacted the research team. During the screening, we asked individuals whether they met the inclusionary criteria. If they met the criteria, we explained the consent form. Data were collected in two ways: a demographic questionnaire and a semi-structured interview protocol. Participants were given the option of completing the interview in-person or over the phone; all participants chose the phone. Research has indicated that in-person and phone interviews may generate the same results (Sturges & Hanrahan, 2004). The demographic questionnaire collected information about each participant including their: age, gender, race, occupation, and number of children with and without disabilities.

The interview protocol was developed based on literature about special education advocacy (e.g., Trainor, 2010; Turnbull et al., 2016) and parent well-being (e.g., Burke & Hodapp, 2014; Wang et al., 2004). After developing the initial interview protocol, to evaluate the validity and composition of the interview questions, experts in qualitative methodology and special education advocacy as well as 10 parents of children with disabilities reviewed the protocol and provided feedback. Based on their feedback, minor revisions were made (e.g., small wording changes, revising the order of questions). The revision was then piloted with two parents of children with disabilities in English and Spanish, respectively. Following the pilot, additional small wording changes were made to the protocol. See Appendix A for the protocol. Notably, each participant described one positive experience and one negative experience.

Prior to beginning the interview, each interviewer introduced herself, her personal and professional relation to disability and advocacy and the purpose of the study. Notably, each author has a personal and professional connection to disability thereby facilitating rapport and trust with the participants (O'Toole, 2013). Specifically, at the beginning of each interview, the interviewers disclosed their backgrounds as special education teachers as well as family members of individuals with disabilities. The interviewer received informed consent before beginning the interview. Then, to build trust, the interviewer reminded the participant of their anonymity to help them feel comfortable sharing their advocacy experiences.

Each interview lasted between 23 and 90 min (*M* = 54.30; *SD* = 18.49). All interview questions were asked to each participant. During the interviews, descriptive field notes were taken (e.g., the interviewer recorded the tone of the participant). Reflective field notes were also taken, documenting the insights of the interviewer. At the end of each interview, the interviewer summarized the interview to conduct an initial level of member checking. All interviews were audio recorded and transcribed verbatim, for a total of 515 single-spaced pages of transcripts (i.e., 258,855 words). The authors then listened to the recordings along with each transcript to correct any errors.

Translation. First, each interview was transcribed verbatim by the second author with the assistance of the third author—both authors are native Spanish speakers. After each interview was transcribed, the interviews conducted in Spanish were back translated into English. The second author then compared the transcript with the Spanish audiotape. The forward/back translation is a commonly used method with interviews recorded in another language to ensure the quality and accuracy of each interview (Brislin, 1970). The second author checked each transcript for accuracy by listening to the audio recording while she read the transcript.

Data Analysis

We utilized constant comparative analysis (Glaser & Strauss, 1967) and emergent coding (Patton, 2002) to code the interview transcripts and field and reflective notes. Two research team members independently coded the positive advocacy experiences and two research team members independently coded the negative advocacy experiences. For the purpose of this study, “positive” advocacy experiences were characterized as “successful” outcomes for the child. “Negative” advocacy experiences were characterized as “unsuccessful” outcomes for the child. First, we read each transcript multiple times to familiarize ourselves with the data (Tesch, 1990). Then, using a line-by-line approach, we coded all text related to advocacy experiences and well-being. Each piece of data were compared with the other data (Creswell, 2003), highlighted, and annotated with a specific phrase. Each new piece of data were then compared with previously coded data to check if the new data were considered a new idea or can be coded as an existing code. Once all data were coded, each set of two research team members created a codebook for positive and negative advocacy experiences, respectively. Then, each pair of team members used the codebook to re-examine the data. During this process, we determined whether new codes should be added to the codebooks. Using the codebook, we found 64 codes. We compared codes to discuss any possible issues or necessary clarifications. After checking the codes, the codes were grouped into categories and organized into themes grounded in the data. After all of the transcripts and notes were coded, we discussed the similar and different themes for positive and negative advocacy experiences with respect to each research question. To measure and ensure reliability, we met to discuss and compare findings. We used Miles, Huberman & Saldaña’s (2014) intercoder agreement formula to reach 100% consensus. All disagreements were resolved through discussion until we reached consensus. To minimize bias, the authors kept detailed field notes throughout the research process (Maxwell, 2005). The first and third authors listened to the audio recordings of each interview to ensure the notes were accurate and to avoid bias. To search for additional biases and ensure the findings accurately reflected the participant’s perspectives, we listened to the audio recordings multiple times and took detailed notes. Finally, the second author consulted with co-authors regularly.

Credibility and trustworthiness

This study met several of the quality indicators for trustworthiness (Brantlinger et al., 2005). In addition to conducting brief member check (Level One) at the end of each interview, we also conducted a Level Two member check. Specifically, after each interview was transcribed and coded, participants were emailed a summary of their individual interview and asked to validate, add or make changes to their individual summaries. We received responses from all participants; no major changes were suggested. By providing member checking, participants were able to assess the validity of the findings (Guba & Lincoln, 1989). In addition to the member checks, we debriefed with one another throughout data collection and data analysis. Notably, detailed interview notes were used to further ensure the trustworthiness of the findings. Further, to refine themes, we searched for negative cases during data analysis (Brantlinger et al., 2005). We also conducted triangulation by comparing the field and reflective notes, demographic questionnaire data, and transcripts.

Findings

Regardless of the nature (i.e., positive or negative) of the advocacy experience, participants reported that advocacy increased their stress. When the advocacy experience was positive, some participants reported improved family quality of life. Also, regardless of the nature of the advocacy experience, some participants reported feeling frustration within their marital relationships.

Pattern Between Advocacy and Parent Well-being

Regardless of the nature of the advocacy experience, some participants reported feeling anger and stress. Regarding only negative advocacy experiences, some participants reported feeling depressed. Conversely, only with respect to positive advocacy experiences, some participants reported feeling happy and/or peaceful.

Anger

For both positive and negative advocacy experiences, various participants (*n* = 23) reported feeling anger. Bianca successfully advocated for her nine-year-old son with multiple disabilities to continue to receive occupational therapy and speech therapy. While Bianca was ultimately successful in advocating for her son, she stated that the advocacy took too long to be successful. While her son ultimately received appropriate services, the length of the advocacy process angered her: “I was so angry. I was so stressed out that I couldn’t sleep at night. I mean, it was just so upsetting. It was one of the most stressful time of my life that they [school personnel] were just willing to give up on him [son].” After her unsuccessful advocacy experience, Catherine felt angry because school personnel called Catherine daily to pick up her son because of his behavior. Catherine requested behavioral supports for son but her advocacy was unsuccessful. This experience made Catherine angry because she felt the school was not providing her son with the necessary supports to be successful in the classroom. Because the school would not consider her requests for behavioral supports, Catherine decided homeschooling her son was appropriate. Catherine further stated, “With the negative experience, we [parents] were really angry.”

Stress

Many participants (*n* = 11) reported stress when advocating for their children during positive *and* negative advocacy experiences. Ariana, the mother of a 20-year-old with a learning disability, recalled advocating for her son. She advocated for an educational consultant to help her son learn to read. While she was successful in her advocacy, this positive advocacy experience was stressful. Ariana reported, “The educational consultant often refers to me as having post-traumatic stress disorder from the experience in the grade school. It was horrible. Just constant battling to try to get him what he needed…it was a stressful household.” With regard to a negative advocacy experience, Stephanie unsuccessfully advocated for her daughter with ADHD to have an IEP goal addressing executive functioning. The team disagreed with Stephanie’s proposed goal. When describing the effect of this advocacy on her well-being, Stephanie reported, “I just think I’m really tired. I’m really overwhelmed and I’m stressed.”

Depressed

In regards to negative advocacy experiences, some participants (*n* = 8) reported feeling depressed. In middle school, Norma unsuccessfully advocated for her son with ASD to receive a one-on-one aide. Because her advocacy was ineffective, Norma reported feeling depressed: “I think I’m in this low state of depression. I think my quality of life was lessened from this whole experience of having a special needs kid.” Similarly, Brittni, the mother of a 3-year-old with ASD, reported unsuccessfully advocating for physical therapy. After each advocacy effort, Brittni’s daughter was denied physical therapy. She reported, “It’s very draining—just takes up all my day trying to call in between my work hours, on my lunch break trying to get in that phone call to get my daughter her needed services …it is depressing and sad all the time.”

Happy

Only with respect to positive advocacy experiences, some participants (*n* = 6) reported being “happy”. Toni successfully advocated for her son with ID to receive compensatory speech services after her son’s speech therapist was absent for several months. Toni stated, “I was just happy that he [son] was getting the services that he was entitled to here [at school].” Similarly, Catherine, the mother of an eight-year-old son with ASD and ADHD, successfully advocated for a change of placement. After moving her son to a different school, both Catherine and her son were happy: “I’m happy because of the new parents, new kids—I think it’s an excellent program. He’s [son] happy.” Thus, when their advocacy yielded the desired outcome, some participants reported being “happy”.

Pattern between Advocacy and Family Well-being

For some participants, regardless of the nature of the advocacy, participants reported that advocacy increased stress within their families. Notably, for some participants, only positive advocacy experiences yielded positive effects on family well-being.

Advocacy Increased Family Stress

Some participants (*n* = 13) reported that positive and negative advocacy experiences negatively impacted their family well-being. Specifically, participants reported advocacy created stress for their families. Linda, the mother of a son with ASD, recalled advocating for her son to be evaluated for an IEP. Linda and her husband hired an attorney to assist in their advocacy. While Linda was successful in receiving an evaluation, her advocacy was stressful for the family; she reported, “We [family] were stressed. It was hard. It was just very difficult to see your kid struggle…and not get any answers from anybody even when we were trying to ask [for help].” Some participants described that negative advocacy experiences stressed the family. Maria, the mother of three children with ASD, reported unsuccessfully advocating for a change of placement. Instead of her son being moved to a smaller classroom, he was moved to a larger classroom in another district. The move was stressful for her family. She reported, “It’s very stressful being around here [my home].”

Positive advocacy experiences positively impacted family dynamics

Some participants (*n* = 7) reported that their positive advocacy experiences positively impacted family well-being. Jamie, the mother of a six-year-old son with ASD, advocated for her son to repeat preschool due to his delays. The school refused. After persistently advocating, Jamie's son was retained in preschool. Jamie stated, "It [positive advocacy experience] was also a great experience on our family because we get to see our son thriving and happy for a year instead of going through a year of transitions that were difficult." Similarly, Cristina, the mother of a fourteen-year-old son with a learning disability, advocated for her son to be moved from his alternative school to his neighborhood school. The school agreed. Cristina reported stated, "[This experience was] positive. It was a good outcome [for my family] in the sense of building professional relations with them [school personnel]."

Pattern between advocacy and marital relationships

Regardless of the nature of the advocacy experience, some participants reported feeling frustration within their marital relationships. Notably, only for positive advocacy experiences, some participants reported united marital relationships whereas other participants reported no effect on their marital relationships.

Advocacy Created Frustration within Marital Relationships

For some participants (*n* = 7), both positive and negative advocacy experiences resulted in frustration in marital relationships. In recalling a negative advocacy experience, Amber advocated for her 19-year-old daughter with multiple disabilities to be included in extracurricular activities. Being the only parent advocating for her daughter caused frustration within her relationship with her spouse. Amber stated, "This piece [of advocacy] I feel like it did—I mean, it certainly had an effect on my relationship. I mean, it's just the level of chronic irritation. He [husband] doesn't get all these disability issues and advocacy the way I do." Similarly, in her successful advocacy experience, Stephanie advocated for her daughter with a processing disorder to receive proper accommodations in the classroom. While Stephanie was successful in getting her daughter the appropriate accommodations to help her be successful in the classroom, Stephanie reported that she and her husband would argue about the accommodations her daughter needed and this put stress on her marriage. Stephanie further stated, "We may argue and it's stressful at the time…and, that's really stressful at times for me." In addition, Lisa successfully advocated for her 10-year-old son with multiple disabilities to receive a proper evaluation for dyslexia. While Lisa was successful in advocating for her son, the experience brought a lot of frustration within her marriage in trying to understand what was best for their son. In addition, the prolonged evaluation for their son also brought more frustration. Lisa further stated, "There's a lot of frustration between my husband and I…"

Positive Advocacy Experiences Helped Unite the Marital relationship

Some participants (*n* = 8) reported that their positive advocacy experiences resulted in more unity within their marital relationships. Lucy, the mother of two children with disabilities, reported that her positive advocacy experience brought her husband and her closer together. Specifically, Lucy successfully advocated for her daughter to participate in science classes. Lucy stated, "My husband and I, we are definitely a team on all these issues…I think these kinds of things [advocacy]--if nothing else, they bring us together because it makes us talk about these things." Similarly, Shira, a mother of a son with a learning disability, reported a closer marital relationship after she successfully advocated that her son to receive an evidence-based reading program. Shira stated, "[advocacy affected my husband and I] positively. We are more united."

No effect on marital relationship

Some participants (*n* = 4) reported that their negative advocacy experience had no major effects on their family. In regards to her negative advocacy experience, Cristina unsuccessfully advocated for her son with behavioral issues to not receive in-school suspension during math class. Because Cristina's son was failing math, she believed this was unfair. However, even though this was a negative advocacy experience, Cristina reported that it had no major effects on her relationship with her husband. Cristina further stated, "I don't see any [major effects]. There was no effect." Similarly, Diana unsuccessfully advocated for her daughter to be evaluated for an IEP. However, the school did not want to conduct an evaluation. While Diana was unsuccessful in this experience, Diana stated that there were no major effects on her marriage. Diana further stated, "I think I would say the same thing…it didn't really have an impact."

Discussion

In this study, we explored the pattern between advocacy and well-being of the: parent, family, and marital relationship. We had three main findings. First, regardless of the nature of the advocacy experience, the majority of participants reported feeling stress and anger. This finding is consistent with previous research which has found that advocacy is stressful for parents (Burke et al., 2019; Rios et al., in press). This study extends the literature by suggesting that—regardless of the nature or result of the advocacy—the advocacy experience was stressful. Perhaps unsurprisingly, negative advocacy experiences may stress or anger parents. However, it is surprising that positive advocacy experiences can also be stressful. Notably, it may not be that the actual advocacy was stressful but rather the need to advocate was stressful. Research suggests that parents often advocate due to negative experiences with school professionals (Burke & Hodapp, 2016). Thus, it may be that the context requiring advocacy was stressful for parents.

This finding is important for two reasons. This finding suggests there may be positive and negative implications of successful advocacy. Prior research has demonstrated that when parents of children with IDD successfully advocate, parents feel more empowered (Burke et al., 2019) and their children demonstrate improved access to services (Taylor et al., 2017). However, such positive effects may be paired with negative effects on parent well-being. Also, this finding suggests that future research is needed to identify which aspects of advocacy may trigger stress and anger. From this study, it seems that the nature of the advocacy experience may not tell the whole story in relation to parent well-being. Future research should explore other facets of advocacy including: the number of advocacy attempts, the school's response to advocacy, and the duration of advocacy. Such other dimensions may impact parent well-being.

Second, regardless of the nature of the advocacy, participants reported that advocacy increased stress within their families. As suggested by prior research, there is a pattern between parent advocacy and maternal stress (Burke & Hodapp, 2014; Burke, Lee, & Rios, 2019) as well as between parent advocacy and family quality of life (Wang et al., 2004). Future research should more closely characterize this pattern. For example, given that this study (and other research) has found a pattern between advocacy and stress, it could be that greater family stress is a result of increased maternal stress (which stems from advocacy). Indeed, prior research has suggested that maternal stress impacts family dynamics (Johnson et al., 2011; Valdez et al., 2013). However, it could also be that advocacy directly impacts family well-being. Research is needed to more closely examine these patterns.

Third, regardless of the nature of the advocacy experience, some participants reported feeling frustration within their marital relationships. To some extent, this finding is expected given the roles of mothers. Mothers (versus fathers) tend to be the primary advocates for their children with IDD (Burke & Hodapp, 2014). Further, mothers (versus fathers) tend to fulfill most of the caregiving for their offspring with IDD (Magaña et al., 2004). However, although mothers fulfill many caregiving responsibilities, spousal support is critical to maternal well-being (Cohen et al., 2014). In addition, when fathers are more involved in advocacy, mothers report their advocacy may be more effective (Burke et al., 2017). Thus, by including both parents in advocacy, there may be positive effects for the marital relationship and the advocacy itself.

Limitations

Although an important jumping off point to exploring the pattern between advocacy and well-being, this study has several limitations. First, the sample was highly educated and primarily comprised of mothers of children with IDD. Although mothers are often the individuals who conduct advocacy for their children with disabilities (Burke & Hodapp, 2014), this limits the transferability of findings. Second, we did not ask participants about their household (e.g., same gender couples, single parents). Participant advocacy experience may differ in relation to their background. Notably, we did not examine the differences or patterns of advocacy in regards to child's disability or the race/ethnicity of the parents.

Directions for Future Research

There are several implications for future research. First, more open-ended research is needed to investigate advocacy experiences. Based on prior research (e.g., Turnbull et al., 2016), we characterized advocacy as depending on the outcome for the child. However, families may have more fluid definitions of advocacy which do not entirely hinge on the child outcome. For example, the duration of the advocacy process may influence parents' characterization of advocacy. Indeed, some participants reported positive advocacy experiences even though the advocacy took years to result in positive outcomes for their children. The resources and effort expended may also relate to the characterization of the advocacy experience. In this study, some participants relied on paid attorneys and advocates and the utilization of due process hearings; such expensive and time-consuming advocacy efforts may also impact parents' characterization of advocacy. To this end, future research should be intentionally open-ended so parents can construct their own meanings of "positive" and "negative" advocacy.

Additionally, research is needed to more closely examine the pattern between advocacy and parent well-being. Such research should examine the relation between advocacy and depression as well as other mental health constructs (e.g., anxiety; Baker et al., 2005; Magaña & Smith, 2008). Indeed, prior research suggests that parents of individuals with (versus without) IDD have worse mental health (Blacher et al., 2005; Magaña & Smith, 2006). It is important to determine whether advocacy may be a predictor of other mental health constructs. By closely examining the relation between advocacy and parent well-being, we can have a better understanding of the effects of advocacy on parents.

Also, research is needed to flesh out the effects of positive advocacy experiences on parent well-being. In this study, some participants reported positive advocacy experiences even though that advocacy increased stress within their families. This finding may suggest a tradeoff in advocacy—parents perceive advocacy as successful as long as it yields positive results for their children even though it may negatively impact parent well-being. Notably, some research suggests that parents, especially Latino parents, prioritize the health of their children with IDD over their own health (Magaña & Ghosh, 2010). Future research should explore whether this phenomenon is occurring and its long-term effects on parent mental and physical health.

Implications for Practice

This study also has several implications for practice. When describing both negative and positive advocacy experiences, participants often reported negative effects on parent and family well-being. As advocacy trainings become more common (Burke, 2013), they may need to address not only special education policy and non-adversarial advocacy skills but also parent coping strategies with negative advocacy experiences. Specifically, parent advocacy trainings may need to include content about how parents can cope with their own advocacy experiences; special education advocacy trainings for advocates may need content about how advocates can support the well-being of families during the advocacy process.

In addition, practitioners should target mothers and fathers in their advocacy trainings. In most advocacy trainings, mothers (versus fathers) tend to be primary participants (e.g., Burke et al., 2016; Taylor et al., 2017). However, the role of fathers should not be minimized. By encouraging the attendance of couples in advocacy efforts, there may be a mitigating effect on parent overall well-being (including maternal stress) and the quality of the marital relationship.

School professionals should connect parents with resources to be educated and empowered to advocate for services. Specifically, practitioners should encourage parents to contact PTIs, federally-funded centers designed to educate and empower parents to ensure their children with disabilities receive needed school services. In addition, practitioners may consider encouraging parents to bring someone with them to IEP meetings.

Last, practitioners should develop strong partnerships with families. Family-school partnership is an essential component of the special education process for children with disabilities (IDEA, 2004). If there are strong family-professional partnerships, then professionals and families may engage in ongoing, honest communication. Because advocacy is a tenet of family-professional partnerships (Haines et al., 2017), advocacy would persist in these partnerships but advocacy may be more positive and less adversarial.

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Table 1

Participant Demographic Information

Participant	Gender	Education	Annual income	Marital status	Race	Total # of children	Child: gender	Child: age	Child: disability
Stephanie	Female	College degree	Over $100,000	Married	White	2	Female	10	SLD
Norma	Female	Graduate school	Over $100,000	Married	Latino	1	Male	14	SLD/EBD
Stacy	Female	Graduate school	Over $100,000	Married	White	1	Male	6	ID/ASD/Speech/LD/DD
Joanne	Female	College degree	$50,000-$69,999	Married	White	1	Male	15	ID/Speech/LD/DD
Sylvia	Female	Graduate school	$30,000-$49,999	Married	White	4	Female	15	ID/SLI
Alicia	Female	Graduate school	Over $100,000	Married	White	1	Female	15	ID/ASD/Speech/OI

Lupe	Female	Some college	$30,000-$49,999	Married	Latino	1	Male	6	ASD
Linda	Female	College degree	Over $100,000	Married	White	1	Male	13	ASD
Hannah	Female	Graduate school	Over $100,000	Married	White	1	Male	14	SLD/EBD
Bianca	Female	Graduate school	Over $100,000	Married	Asian American	1	Male	9	ID/ASD/Speech/DD/Deaf
Lisa	Female	Graduate school	$50,000-$69,999	Married	White	1	Male	10	Cerebral Palsy
Cristina	Female	Graduate school	$70,000-$99,999	Divorced	White	1	Male	14	ASD
Christine	Female	Graduate school	$30,000-$49,999	Divorced	White	1	Male	9	EBD
Janet	Female	College degree	Over $100,000	Never married	White	1	Female	12	SLD

Betty	Female	College degree	Over $100,000	Married	White	1	Male	18	ASD/Deaf/Health Condition
Claudia	Female	Some college	$30,000-$49,999	Married	African American	2	Male	12	ASD
Maria	Female	High school degree	$50,000-$69,999	Married	Latino	2	Male	7	ASD
Angela	Female	-	Less than $15,000	Married	Latino	1	Male	11	ASD
Jessica	Female	Some high school	$15,000-$29,999	Separated	Latino	1	Female	4	ASD
Jennifer	Female	High school degree	$50,000-$69,999	Married	Latino	1	Male	12	SLI/ASD

Delia	Female	Some high school	$30,000-$49,999	Married	Latino	1	Male	8	ASD
Martin	Male	High school degree	$50,000-$69,999	Married	Latino	1	Male	17	ASD
Bethany	Female	Graduate school	Over $100,000	Married	African American	1	Female	13	ID/ASD/Speech/LD/DD/EBD
Julia	Female	Graduate school	$70,000-$99,999	Married	White	1	Male	12	ID/LD/Deaf/Health Condition
Lauren	Female	College degree	$50,000-$69,999	Married	White	3	Male	10	SLI/ASD
Amber	Female	Graduate school	Over $100,000	Married	White	1	Female	19	ID/ASD/DD
Deborah	Female	Graduate school	$70,000-$99,999	Separated	White	1	Female	11	ID/Speech/LD/DD/Blind/OI

Melanie	Female	Graduate school	Over $100,000	Married	White	1	Female	5	Speech/Blind/OI
Savannah	Female	College degree	$70,000-$99,999	Married	African American	1	Female	20	LD
Aaron	Male	College degree	$70,000-$99,999	Married	White	2	Male	3.5	ASD/EBD
Leilani	Female	College degree	$30,000-$49,999	Divorced	White	1	Female	17	DD/Health Condition
Layla	Female	College degree	$50,000-$69,999	Married	White	1	Female	5	OI
Ariana	Female	College degree	Over $100,000	Married	White	1	Female	20	SLD
Catherine	Female	Some college	Less than $15,000	Never married	White	1	Male	8	ASD/DD/EBD
Christian	Male	Graduate school	Over $100,000	Married	White	1	Female	18	ID/ASD/Speech/DD/Health Condition

Elizabeth	Female	Some college	-	Married	White	1	Female	16	SLI/Health condition
Addilyn	Female	Graduate school	Over $100,000	Married	White	1	Female	10	ID/ASD/Speech
Lucy	Female	Graduate school	Over $100,000	Married	White	2	Female	19	ID/SLI

Note: All participants names are pseudonyms. SLD= specific learning disability; ASD = autism spectrum disorder; EBD = emotional behavioral disorder; ID = intellectual disability; SLI = speech/language impairment; DD = developmental delay; OI = orthopedic impairment

Appendix A

Interview Protocol

Advocacy means speaking on behalf of your child with a disability to address their needs.

a. Think of a time that you had a positive advocacy experience (i.e., a time that you advocated for your child and it resulted in desired change). Can you walk me through your successful advocacy process from beginning to end?
    i. Why was this experience a positive experience of advocacy?
    ii. Does anything stand out about this experience?
    iii. What advocacy strategies did you use?
    iv. What was the result?
    v. Is there anything else you wish you had done?
    vi. Is there anything you wish would've happened?
    vii. What was the outcome of this experience on your child? On you? On your family? On your partnership with the school?
b. Think of a time that you had a negative advocacy experience (i.e., a time that you advocated for your child and it did not result in your desired change). Can you walk me through your unsuccessful advocacy process from beginning to end?
    i. Why was this experience a negative experience of advocacy?
    ii. Does anything stand out about this experience?
    iii. What advocacy strategies did you use?
    iv. What was your intended result? What was the actual result?
    v. Is there anything else you wish you had done?
    vi. How did you cope with this experience?
    vii. What was the effect of this experience on your child? On you? On your family? On your partnership with the school?
c. What prompted you to participate in this study? What made you interested?