

Families Requesting Advocates for Children with Disabilities:

The Who, What, When, Where, Why and How of Special Education Advocacy

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### Abstract

Because parents face barriers in advocating for their children within the special education system, some families request help from a special education advocate. In this study, we evaluated the perceptions of caregivers who requested advocacy support to understand why, for whom, when, and where the advocacy services were needed; how the advocate helped; and what the outcomes of the advocacy process were and which variables related to better outcomes. We conducted structured interviews with 36 families who had requested help and connected with an advocate over a 3-year period. Compared to national norms, families were more likely to request an advocate if their child had ASD, was in elementary school, and lived in non-rural areas. Family requests were most often for: advocate attendance at IEP meetings; help to resolve disagreements with the school concerning supports and services; and information about school services and parental rights. Most advocate assistance was for a short duration, although a longer duration process, advocate attendance at meetings, and more intensive advocate assistance were all related to better outcomes. Most participants were satisfied with the advocate and with the end-result of the advocacy process. Findings are discussed in terms of implications for future research and practice.

*Keywords:* special education advocacy, caregivers, communication, school

### Families Requesting Advocates for Children with Disabilities:

#### The Who, What, When, Where, Why, and How of Special Education Advocacy

Although federal law has long determined that children with disabilities have the right to a free, appropriate public education in the least restrictive environment, the specific actions required to turn such rights into reality have not always been followed. Partly to address this issue, the Individuals with Disabilities Education Act (IDEA) accords to parents a central role, as they are the “accountability mechanism” for their child’s education. In fulfilling this role, parents (and caregivers more generally) often need to advocate on behalf of their child with school personnel (Wang, Mannan, Poston, Turnbull, & Summers, 2004).

Unfortunately, parents are often reluctant to advocate, feeling themselves at a disadvantage when dealing with their child’s school. In most cases, they lack essential knowledge of the individualized education program (IEP) process, which becomes exacerbated by the higher reading levels required to comprehend such laws (Dinnesen & Kroeger, 2018). Parents may also feel intimidated by the professional status of other IEP team members, as well as by the specialized knowledge and field-specific terminology that such personnel possess. Many parents are also reluctant to request additional special education services and, even among those who do, such requests are often denied (Leiter & Krauss, 2004). On a more philosophical level, Kalyanpur, Harry, and Skrtic (2000) highlight the “equity expectation”—that parents and school personnel are equal. This expectation conflicts with the higher status given to school personnel’s (supposedly objective) professional knowledge as compared to parents’ (supposedly subjective) personal knowledge about their child. All such factors work together to present barriers to parents and other caregivers advocating on behalf of their own children.

Given such difficulties, there is a need for special education advocates who can support families in navigating the special education process and advocating on behalf of the child (Mueller, 2016). Various programs have been developed to educate advocates about special education law, the IEP process, and parent rights. One such program, the Volunteer Advocacy Project (VAP), involves a 36-hr training on topics related to special education law (e.g., IEPs, evaluations, extended school-year services, least restrictive environment) and advocacy skills (e.g., working with culturally diverse families, non-adversarial advocacy; Author, 2013). Each program graduate is asked to volunteer as an advocate for at least four families after completing the training. To date, the VAP has been shown effective in boosting attendees' knowledge and comfort in special education advocacy (Authors, 2016a) and in producing advocates that support many families after training completion (Authors, 2017a). However, this growing body of research has asked questions only about the perceptions of the advocates themselves, not those of the families that have received support from an advocate.

Less examined have been the basic facts of caregiver requests for support from a special education advocate, including the contents of advocacy requests and the exact nature of what caregivers are calling about. We do not know why caregivers request advocates as opposed to utilizing other formal or informal dispute resolution procedures. Although data are available on the sources of disputes when families utilize due process (e.g., placement, IEP; Mueller & Carranza, 2011), it is not known if families request advocates for similar reasons. We also do not know if families more often reach out for support from an advocate once a conflict has already developed, or if they instead act proactively to learn their rights.

Additionally, we know only a little about what might be called the “who, when, and where” of special educational advocacy. In formal mediation processes, parents of children with

autism spectrum disorder (ASD) are markedly “over-represented” in terms of due process hearings and lawsuits (Mueller & Carranza, 2011; Zirkel, 2011), but it remains unclear whether these families also more often request advocacy services. Similarly, we know some of the characteristics of families that advocate on behalf of their own child (i.e., child, parent, and family-school characteristics; Authors, 2016c), but have not examined the child and school characteristics of those who are requesting external support from a trained advocate.

In addition, important questions persist as to the advocacy process itself, or the “how” of advocacy. How and how often, for example, do families and advocates communicate, what types of activities do advocates engage in, and how long does the advocacy process last? Granted, the trained advocates themselves report engaging in activities that are either “family-focused” or “school-focused” (Authors, 2017a). Family-focused advocacy activities include tasks such as communicating with the family over the phone or in person, while those that are school-focused involve actively engaging with the school by, for example, communicating directly with the school or helping the family to do so. Advocates also report following a 5-step process that often ends with supporting parents at IEP meetings (Authors, 2017b). At present, however, how caregivers perceive this process and how they desire the advocacy to proceed remains unclear.

Finally, few studies have examined the results of the advocate’s efforts, especially as perceived by the caregivers who requested these advocates in the first place. These outcomes may include both positive and negative results. For example, parents who engage in advocacy activities on their child’s behalf—including learning their educational rights by navigating the internet or calling agencies—often have the worst experiences in terms of attaining services (Authors, 2016c). In one of few extant studies, Kirkland and Bauer (2016) interviewed school administrators to understand their perceptions of the effect of special education advocates.

Administrators reported that advocates significantly influenced their decisions about special education. Notably, their study did not examine advocacy effects from the perspective of the families who worked with advocates. However, some studies have shown that, according to both caregivers' and school personnel perceptions, alternative dispute resolution procedures can result in improved relationships and in a decreased likelihood of needing to use other more formal dispute resolution procedures, such as due process (Author, 2018).

This study, then, utilized calls to the VAP for advocacy services to determine basic information about the process of educational advocacy as seen by families of children with disabilities. We specifically asked four main questions: For caregivers who requested an advocate, what were their perceptions of (1) Why a special education advocate was needed?; (2) For whom, when, and where were the advocacy services needed?; (3) How the advocate helped?; and (4) What were the outcomes of the advocacy process and which variables related to better outcomes?

## **Method**

### **Participants**

Participants included 36 individuals who contacted the VAP to request an advocate over a 3-year period (August 2014- July 2017), and then contacted their assigned advocate.

Respondents were mostly mothers (see Table 1) who lived in 17 counties across a southeastern state. Participants were referred to or found information about the VAP through such community resources as disability organization websites and newsletters and a university-affiliated disability information-and-referral center.

### **Procedures**

**Advocate requests and linkage.** All participants called or e-mailed the VAP coordinator to request an advocate from August 2014 to July 2017. Although advocacy requests were spread throughout the academic year, most requests were made in August, September, and February ( $n = 11$ , 10.8% in each month). A designated graduate student (first and third authors) fielded all calls/e-mails and returned missed calls/e-mails within 24 hours. After speaking with the caller to obtain additional information about their advocacy needs, the graduate student contacted a VAP graduate/advocate to: (a) confirm that they lived in the family's area, if possible, (b) ask if the advocate was willing to work with the family, and (c) ensure they were comfortable and/or familiar addressing the advocacy needs reported by the caller. If the advocate agreed, the participant was then given the advocate's contact information and told that the advocate would be expecting to hear from them in the near future.

**Phone interviews.** Structured phone interviews were conducted to follow-up with individuals who called to request a VAP advocate during a 3-year period. Three graduate research assistants (RAs) were trained to use an interview script and to record participant responses directly in a secure online survey platform (Research Electronic Data Capture [REDCap]; Harris et al., 2009). All study procedures and materials were approved by the university Institutional Review Board.

Once trained, RAs were assigned participants to contact via phone or e-mail. To ensure advocates had time to help families resolve issues, contact was not attempted until at least six months after the initial advocate request. Each participant was called and/or e-mailed up to three times to attempt contact. As shown in Figure 1, our database included 102 individuals who requested a VAP advocate from August 2014 to July 2017; we were able to reach 60 of these individuals. Reasons for being unable to reach a participant included: a disconnected phone

number, full voicemail, or no response to three e-mails and/or voicemails. If a participant answered the call or e-mailed to schedule a time to speak, then the RA explained the study, asked if the participant remembered calling the VAP and contacting an advocate, and obtained verbal consent before continuing with the phone script. Participants were eligible to complete the phone interview if: a) they provided verbal consent, b) they reported contacting the VAP advocate, and c) it had been at least 6 months since they requested the VAP advocate. If the participant met all inclusion criteria ( $n = 36$ ), the RA then proceeded through the phone script, recording the participant's answers in the REDCap form. Open-ended notes sections were included on the form so that the RA could record field notes or responses that did not correspond with available options. Phone interviews lasted between 6 and 132 minutes with an average call length of 27 minutes and a median of 21 minutes.

### **Measure**

We developed a 17-item structured interview script using the extant literature about special education advocacy (e.g., Authors, 2017a; 2017b) and conflict resolution (e.g., state complaint, due process; Mueller & Carranza, 2011; White, 2014). In addition to basic participant demographics, the measure was used to gather information about: a) child characteristics (i.e., "Who, When, and Where"); b) reasons for requesting an advocate (i.e., "Why"); c) advocacy process (i.e., "How"); and d) outcomes (i.e., "What"). Response formats included: multiple choice, multiple selection, yes-no, and open-ended format.

**Child characteristics.** Participants were asked several multiple-choice questions relating to "Who?" (i.e., the child's gender, disability, and special education eligibility category [if receiving services] at the time of the advocate request), "When?" (i.e., the child's age and grade) and "Where?" (i.e., type of school and school district).

**Reasons for requesting an advocate.** Next, participants were asked what prompted them to request an advocate (i.e., “Why”); additional probe questions were asked to categorize the type of advocacy needed. Participants were also asked about their relationship with the school at the time of the advocate request and at present (i.e., at the time of the interview), rated on a scale from 1, *very poor*, to 5, *very good*.

**Advocacy process.** To identify how advocates supported families, participants were asked about what happened after they were given the advocate’s contact information. Participants answered yes-no questions about communication, guided by “family-focused” advocacy activities that advocates reported using in a previous study (Authors, 2017a). These activities included: 1) talking over the phone, 2) e-mailing, and 3) meeting in person with the advocate. If participants answered yes to any of these questions, they were asked how many times they engaged in each type of activity. Participants were also asked yes-no and open-ended questions about the types of actions the advocate did to help, guided by the “school-focused” advocacy activities (Authors, 2017a) and advocacy process (Authors, 2017b). These included: reviewing records, attending meetings, communicating directly with the school, and helping the family communicate with the school. Finally, participants were asked about the duration of time for which they worked with the advocate and if they were still in touch.

**Advocacy outcomes.** To address participants’ perspectives of advocacy outcomes (i.e., “What”), participants were asked multiple choice, yes-no, and open-ended questions about the end-result of the advocacy process and whether they were satisfied with the advocate and with the outcome. The interview was ended by asking the participant, “Is there anything I didn’t ask you that you would like to tell me?”

## **Analyses**

After all interviews were completed, the data were reviewed. First, basic descriptive statistics (e.g., percentages, medians, means, and ranges) were used to answer the research questions and determine if the results were normally distributed. Due to the small sample size and non-normal distributions, we used non-parametric statistics to further explore the relations between variables. These statistics included Spearman's rho to evaluate the correlation between process variables ("How"), Wilcoxon Matched-Pairs Test to compare the change in the relationship with the school over time, and Fisher's Exact Probability Test to answer our final research question about the relation between categorical variables from the advocacy process ("How") and advocacy outcomes ("What"). We also used chi-square one-sample tests to compare the child characteristics represented in this sample to those of the 2015 U. S. public school population (U. S. Department of Education, 2017; U. S. Department of Education, 2018).

## Results

### **The Reasons for Requesting Advocates: "Why" of Advocacy Requests**

Participants requested an advocate for a variety of reasons. Most commonly, they wanted an advocate to attend an IEP meeting with them ( $n = 12$ , 33.3%). Participants also requested an advocate due to a disagreement about the amount or type of services, supports, and accommodations provided for the child or because they were more generally seeking information and wanted to learn about their rights ( $n = 6$ , 16.7% for each reason). See Table 2 for other reasons for requesting an advocate, which were cited by four or five respondents each.

Participants reported that their relationship with the school at the time when they requested an advocate was, on average, *adequate* ( $Mdn = 3$ ,  $M = 2.84$ ,  $SD = 1.32$ ), with a range from *very poor* to *very good* (i.e., range: 1-5).

### **Child Characteristics of Advocacy Requests**

**“Who.”** The children of participants were approximately half male and half female (see Table 1). Almost half of participants who requested a VAP advocate had a child with ASD ( $n = 16, 44.4\%$ ); this proportion is over four times the percentage of children in the U.S. who receive special education services under the eligibility category of ASD (9%; U.S. Department of Education, 2018), one-sample  $\chi^2(1) = 154.2, p < .0001$ . The remaining participants had offspring with various other types of high- and low-incidence disabilities. Conversely, the numbers of calls from parents of children with specific learning disability (SLD) were disproportionately low,  $\chi^2(1) = 18.54, p < .001$ . Though the most common category for receiving special education services in the US, no caregivers of children with identified SLD used an advocate (see Table 1).

**“When.”** Although the child’s age at the time of the request spanned most of the school-age years (i.e., 2-16 years old), almost half of these students ( $n = 17, 47.2\%$ ) were in elementary school (see Table 1). Children were, on average, 9 years old ( $Mdn = 8, M = 8.65, SD = 3.99$ ) and in third grade. The most common child ages when the advocate was requested included: 7-years-old ( $n = 6, 16.7\%$ ), 3-years-old ( $n = 4, 11.1\%$ ), and 9-years-old ( $n = 4, 11.1\%$ ). While the age of special education services under IDEA Part B ranges from 3 to 21 years, two children were still receiving early intervention services (IDEA Part C) when their families requested advocacy support. No students in this sample were above 16 years of age and only 8.2% were in their high school years (compared to 30% in high school in the U.S. school population),  $\chi^2(2) = 16.55, p < .001$ . See Table 1.

**“Where.”** Almost all students attended public school ( $n = 33; 91.7\%$ ) in 16 districts (out of 119) across the state. A quarter of all requests ( $n = 9$ ) were for students attending school in the most populous city in the state—and the main site of the VAP—followed by five requests (13.9%) from participants whose child attended school in the next most populated city in the

same metropolitan area. The remaining requests were distributed across other districts throughout the state, including both rural areas and major cities.

### **The Advocacy Process: “How” Advocates Helped Caregivers**

**Modality and frequency of communication.** The 36 participants who contacted the VAP advocate received support in a variety of ways: by phone, e-mail, and in-person. On average, participants communicated with the advocate in two of these ways ( $Mdn = 2$ ,  $M = 1.92$ ,  $SD = 0.87$ , *range: 1-3*). However, 12 participants reported using all three modes of communication with the advocate. Specifically, almost all participants ( $n = 35$ , 97.2%) communicated with the advocate by phone; only about half ( $n = 17$ , 47.2%) reported communicating with the advocate through e-mail or meeting in person. Those who connected by phone or e-mail reported communicating with the advocate three times, on average, during the advocacy process (*range: 1-15*). However, those who met in-person ( $n = 17$ ) only did so, on average, one time, with a range from one to seven times. A large majority of participants ( $n = 29$ , 80.6%) reported that they did not have any trouble contacting their assigned advocate.

**Advocacy activities.** Participants reported that advocates helped them by engaging in a range of activities including: reviewing records, communicating with the school—or helping the participants to do so themselves—and attending meetings. Almost half of participants ( $n = 15$ , 41.7%) shared school records with the advocate for review. On average, advocates reviewed one record (*range: 0-4*), with the most common types of records reviewed being IEPs and evaluations (each indicated by 10 participants). Nine advocates (25%) helped the participants to communicate with the school, while six advocates (16.7%) communicated directly with the school on behalf of the family. Additionally, nine advocates (25%) attended at least one meeting with the participant, with six attending one meeting and three attending two. On average,

advocates supported participants by engaging in one of the above advocacy activities ( $Mdn = 1$ ,  $M = 1.08$ ,  $SD = 1.32$ ,  $range: 0-4$ ) although some participants ( $n = 16$ , 44.4%) did not report using any of the above activities. The more modes of communication used (i.e., e-mail, phone, and in person), the higher the number of advocacy activities in which the respondent engaged (i.e., record review, attend a meeting, help communicating with the school, direct communication with the school),  $r_s(36) = .74$ ,  $p < .001$ .

**Length of advocacy process.** Most participants ( $n = 29$ , 80.5%) received advocacy support for a month or less (see Table 2). Only three (8.3%) were still in contact with the advocate at the time of the follow-up call (7, 12, and 22 months after the initial request). The number of modes of communication and the number of advocacy activities were both positively correlated with working with the advocate for longer amounts of time,  $r_s(36) = .42$ ,  $p = .012$  and  $r_s(36) = .66$ ,  $p < .001$ , respectively.

### **Outcomes of the Advocacy Process: “What”**

The most commonly reported end results were: compromise between the family and school ( $n = 9$ , 25.0%) and the school giving the family what they asked for ( $n = 8$ , 22.2%; see Table 2). Participants reported significant improvements to their relationship with the school from the time the advocacy request was made to the time of the follow-up call, Wilcoxon test,  $Z = 3.42$ ,  $p = .001$ . However, eight participants (22.2%) reported an outcome with ongoing conflict (i.e., family and school continue to disagree). Additionally, 10 participants (27.8%) reported that, since requesting an advocate, their child had to change schools due to ongoing disagreements with the school or continuing to be unhappy with the quality of services provided for their child.

In general, participants were satisfied with outcomes in terms of: the advocate ( $n = 30$ , 83.3%) and the end-result of the advocacy process ( $n = 26$ , 72.2%). Most participants were

satisfied with both the end-result and the advocate ( $n = 23$ , 63.9%). However, seven participants (19.4%) reported being satisfied with the advocate, but not with the end-result.

### **Relation between Process and Outcomes**

**Mode of communication and outcome.** No significant relations occurred between the ways in which participants and advocates communicated and the outcomes of the advocacy process (i.e., satisfaction, end result, or change in partnership).

**Advocacy activity and outcome.** Participants who reported that the advocate communicated directly with the school were much more likely to indicate an end-result of “compromise” (i.e., I got some, but not all, of what I advocated for; 66.7% vs. 16.7%, respectively), Fisher’s test,  $p = .024$ . Similarly, all participants ( $n = 9$ ) who reported that an advocate attended a meeting with them were satisfied with the end result compared to only 63.0% ( $n = 17$ ) of those who did not bring the advocate to a meeting, Fisher’s test,  $p = .039$ . Finally, all of those who reported that an advocate attended a meeting with them reported an improvement in their relationship with the school, compared to 48.0% of those who did not, Fisher’s test,  $p = .025$ . No other characteristics of the advocacy activities were significantly related to the outcome.

**Length of advocacy process and outcome.** In terms of the time spent working with the advocate, of those who had help from the advocate just once, only 45.5% were satisfied with the end result, compared to 84.0% of those who received help from the advocate more than once, Fisher’s test,  $p = .039$ . Similar patterns were seen for satisfaction with the advocate (63.6% and 95.8%, respectively), Fisher’s test,  $p = .026$

### **Discussion**

Although advocacy trainings are becoming more common (Author, 2013), little is known about the advocacy requests and experiences of families of children with disabilities. To ensure that advocacy trainings and advocates themselves are meeting the needs of families, it is important to understand advocacy requests and the advocacy process through the eyes of families. To this end, this study featured three main findings.

First, families most often requested an advocate when the child had ASD and attended public school in non-rural areas. In several prior studies, children with ASD have been found to be over-represented in due process cases (Mueller & Carranza, 2011), with parents of these children more likely to exercise the rights accorded to them under IDEA (Zirkel, 2011). This same trend seems to exist for advocacy, with caregivers of children with ASD most frequently requesting and then contacting a VAP advocate for support. Children whose parents requested advocates also more often attended schools in non-rural districts. This finding of greater advocacy requests from non-rural families mirrors the use of other types of alternative dispute resolution procedures, such as facilitated IEP meetings, which are also clustered in urban areas (Author, 2018). This finding seems a cause for concern, especially since VAP advocates were available in almost half of the state's school districts (Authors, 2016b) and since families of children with disabilities living in rural areas face unique, systemic barriers in accessing services (Mello et al., 2016). Even so, these advocacy requests stemmed from a small percentage of districts, mostly from a non-rural part of the state. Additional barriers may therefore exist for families in requesting and accessing advocacy services in rural areas.

Second, some caregivers requested an advocate for reasons that are similar to those identified in the literature about formal dispute resolution procedures (Mueller & Carranza, 2011; White, 2014). For example, the second most commonly cited reason for requesting an

advocate was due to disagreement over the type and amount of services and supports provided for the child. However, many caregivers requested an advocate when their child was young (i.e., in elementary school) and some reported that they were seeking support proactively before an issue arose or to have someone on “their side of the table” at an IEP meeting. In order to educate themselves and to obtain desired outcomes for their child’s education, caregivers seem to be using advocates early in the child’s education and the special education process. In contrast, due process complaints are usually filed when the child is older (Mueller & Carranza, 2012) and when there is no alternative for resolving a dispute between the school and family.

Third, in terms of how advocates support families, advocate attendance at IEP meetings seems more important to caregivers than other advocacy activities. Previous research indicates that advocates follow a prescribed and linear process; within this process, attendance at an IEP meeting is the final step (Author, 2017b). For many families, however, advocate attendance at an IEP meeting may be a primary goal; for them, this single activity may outweigh other advocacy steps. Still, for most participants, the advocacy process was brief, usually only involving one of several “school-focused” advocacy activities (including attending meetings), and was successful in terms of caregiver perceptions of satisfaction with the advocate and the outcome of the advocacy process.

However, this finding must be considered in relation to another finding—that when the advocacy process was longer, it was more likely to be successful. More research is needed to understand the relation between the length of the advocacy process and outcomes. On the one hand, advocates may be educating and empowering families to advocate on their own (Authors, 2017b); families may thus not need a long advocacy process. On the other hand, some families may need more support to achieve their desired goals.

**Implications for Research**

More research is needed to disentangle the relation between the advocacy process and outcomes, particularly relating to the outcome of family-school partnerships. In this study, most families reported improved school partnerships after working with an advocate, especially when the advocate attended a meeting with them. Yet previous research has noted a mixed relation between advocacy and family-school partnerships, particularly depending on the role of the respondent and the type of advocacy (i.e., a parent advocating on behalf of their own child vs. trained special education advocate advocating for someone else's child). For example, in a national sample of parents of children with disabilities, the authors (2016) found that parent advocacy negatively correlated with self-report of family-school partnerships. In contrast, educators and administrators have reported that advocacy has positive effects (Burke et al., 2018; Kirkland & Bauer, 2016). Viewed through the experiences of caregivers who requested an advocate, this study provides additional support for the idea that using special education advocates at IEP meetings may build partnerships and minimize conflict (Mueller, 2016). Further studies are needed to examine the convergence of the perspectives among parents, teachers, administrators, and advocates themselves. These stakeholders, each of whom has different responsibilities and priorities, may not perceive the outcomes of IEP meetings in the same way (Author, 2018).

In addition, longitudinal and high-quality experimental studies are needed to make statements about the effects of using an advocate, especially concerning how different characteristics of the advocacy process (i.e., the "How") relate to child, parent, and family outcomes. From this study, advocacy may be effective in improving family-school partnerships, as well as in meeting the expectations of families. Without a control group, however, one cannot

discern whether such changes can be attributed to the advocate. For example, some families reported having to change their child's school in the interval between the advocacy call and the follow-up interview due to ongoing conflict. Future research should include a randomized controlled trial (RCT) to determine the effect of an advocate. Notably, Jamison and colleagues (2017) used an RCT to evaluate the effectiveness of an advocacy training with parents of individuals with ASD. They found that parents who worked with advocates were more likely to receive timely evaluations and supports. As a next step, researchers should consider following the procedures of Jamieson and colleagues to conduct more rigorous trials evaluating the effect of special education advocates.

Perhaps relatedly, research is needed to explore other correlates of outcomes. For example, studies are needed that consider the match between the advocate and the family. In this regard, Magaña and colleagues (2015) conducted an intervention study with Latina mothers of children with disabilities. As part of the study, they emphasized the importance of matching Latina mothers with other Latina mothers of children with disabilities; the connection of being from the same cultural background as well as having shared experience in raising a child with a disability was designed to facilitate their partnership. Within research on outcomes of psychotherapy as well, studies are replete with examples of how clients show better outcomes when they are also matched with clinicians in terms of demographic, life-experience, and other characteristics, thereby producing better (and beneficial) therapeutic alliances (Martin, Garske, & Davis, 2000). In recent years, studies have explored this issue from the client's perspective, first asking clients which personal characteristics they deem important in a therapist and then determining whether such therapist characteristics subsequently produce better outcomes (Noyce & Simpson, 2018). Future studies should similarly consider whether shared elements between

trained special education advocates and the families requesting their assistance might lead to better outcomes. Although advocates recognize the importance of shared experiences with families (Authors, 2018), more research is needed to understand families' perspectives on this matter.

### **Implications for Practice**

Findings from this study also lead to recommendations for practice. Specifically, organizations that link families with advocates should consider tracking the experiences of families who request an advocate at set time-points. In our study, of the 53 participants who consented to participate, only 36 reported having any contact with their advocate. Why was there no follow-up contact among the remaining 17 individuals? By tracking all participants who request advocacy assistance, practitioners can better understand why some individuals did not contact their advocate and, depending on the reason, address this issue in the linkage process, as well as during advocate training. It may be, for example, that some families seek support during a moment of crisis and then do not follow up with an advocate when they cannot access this support immediately. Instead, families may simply be seeking information about their rights and the law (as many participants indicated); rather than connecting the caller with someone else, organizations may be able to triage these calls and directly provide information immediately.

Providers of advocacy services should also consider tracking families both to understand the correlates of successful outcomes and to learn why some families may be dissatisfied with their advocate and the advocacy process. For example, the VAP program is a 36-hr training over a 12-week period; some VAP graduates may not yet be comfortable or experienced enough to attend IEP meetings in the role of an advocate (Authors, 2016b). Alternatively, dissatisfaction may be explained by a poor "fit" between the advocate and caregiver. By following up to ask

caregivers about their satisfaction (or lack thereof) with the advocacy process and the advocate, practitioners may be able to improve the training and process of linking families to advocates.

### **Limitations**

This study also had several limitations that should be noted. First, our sample size was small and a bigger sample may have yielded more power to test different correlates of advocacy outcomes. Relatedly, the small sample size was a result of difficulty in reaching some of the families that requested an advocate. Our study would have been improved if we had been able to collect data from all 102 individuals who originally requested an advocate from the VAP. We do not know if the experiences of participants were different than those who we were unable to reach or who were unwilling to participate in the interview. Such families may differ in their satisfaction with the advocacy process or in other unmeasured characteristics, such as caregiver level of education or race/ethnicity. Each of these potential problems limits the generalizability of our findings.

Still, despite these limitations, this study begins the process of understanding the specifics of families' advocacy use. Until now, we have known little about families' experiences when working with a special education advocate, as opposed to advocating for their own child. Although preliminary, in this study we identified reasons for requesting an advocate, specific child characteristics, and relations between process and outcome variables. As such, our findings provide a greater understanding of how the advocacy process works and whether families' needs and expectations are being met. Ultimately, if we are going to help parents serve as the "accountability mechanism" for their children's federally guaranteed educational rights, we need to understand the specifics—the who, what, where, when, why and how—of obtaining and using advocates throughout the special education process.

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## FAMILIES REQUESTING ADVOCATES

Table 1

*Participant and Child Descriptives*

Characteristic	% (n)	% of US school-age population
<b>Role</b>		
Mother	80.6% (29)	
Father	8.3% (3)	
Grandparent	8.3% (3)	
Legal guardian	2.8% (1)	
<b>County</b>		
Non-rural	83.3% (30)	
Rural	16.7% (6)	
<b>Child gender</b>		
Male	55.6% (20)	
Female	44.4% (16)	
<b>Child grade</b>		
Early Intervention	5.6% (2)	n/a
Pre-K	13.9% (5)	3%
Elementary School	47.2% (17)	45%
Middle School	25.0% (9)	22%
High School	8.3% (3)	30%
<b>Child diagnosis*</b>		
ASD	44.4% (16)	9%
ADHD (Other Health Impairment)	16.7% (6)	14%
Intellectual Disability	8.3% (3)	6%
Speech/Language/Processing Impairment	8.3% (3)	20%
Hearing Impairment	5.6% (2)	1%
Multiple Disabilities	5.6% (2)	2%
Cerebral Palsy (Orthopedic Impairment)	5.6% (2)	1%
Mental Health/Bipolar	5.6% (2)	n/a
TBI	2.8% (1)	<0.5%
Gifted	2.8% (1)	n/a
Specific Learning Disability	0% (0)	34%

*Note.* ASD=autism spectrum disorder; ADHD= attention-deficit/hyperactivity disorder; TBI= traumatic brain injury. US population child grade percentages from U. S. Department of Education, National Center for Education Statistics. (2017). Enrollment in public elementary and secondary schools by level and grade. Retrieved on January 1, 2019 from [https://nces.ed.gov/programs/digest/d17/tables/dt17\\_203.10.asp](https://nces.ed.gov/programs/digest/d17/tables/dt17_203.10.asp). US student disability categories from U.S. Department of Education, Office of Special Education Programs. (2018). *Children and youth with disabilities*. Retrieved on January 1, 2019 from [https://nces.ed.gov/programs/coe/indicator\\_cgg.asp](https://nces.ed.gov/programs/coe/indicator_cgg.asp)

\*Based on IDEA eligibility category or medical diagnosis. Does not sum to 100% because respondents identified all that applied.

## FAMILIES REQUESTING ADVOCATES

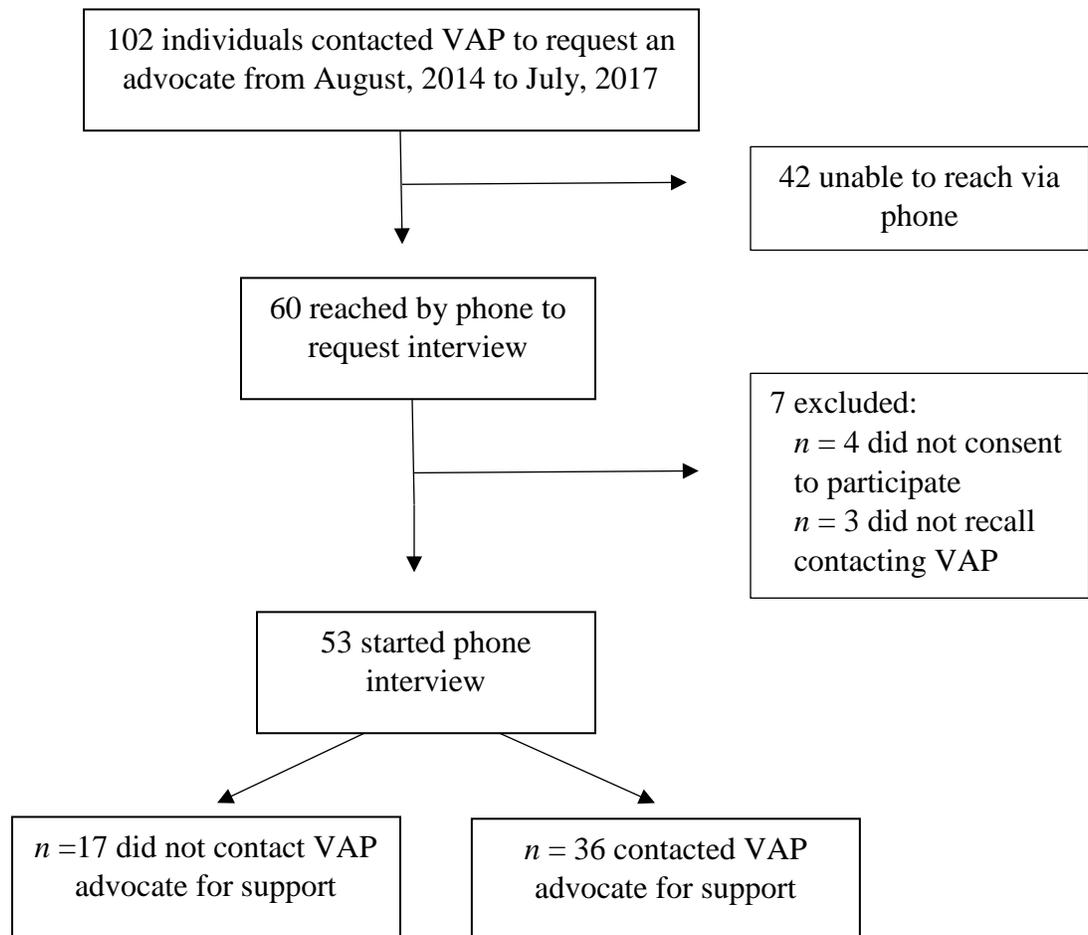
Table 2

*Advocacy Reason (Why), Process (How), and Outcome (What) Descriptives*

Variables	% (n)
<b>Why: Reasons*</b>	
IEP meeting	33.3% (12)
Disagreement over amount or type of services and supports	16.7% (6)
Being proactive/wanted to learn and know rights	16.7% (6)
Transition to new school/service delivery system/state	13.9% (5)
Placement	13.9% (5)
Disciplinary/behavioral issue	11.1% (4)
Compliance	11.1% (4)
Other	11.1% (4)
<b>How: Advocacy Process Length</b>	
One meeting/phone call	30.6% (11)
A couple of weeks	30.6% (11)
A month	19.4% (7)
A few months	16.7% (6)
A year or longer	2.8% (1)
<b>What: Outcomes*</b>	
Compromise (I got some but not all of what I asked for)	25.0% (9)
The school gave me what I asked for	22.2% (8)
Collected the information I was looking for	13.9% (5)
Continued to disagree, but I accepted it or circumstances changed	13.9% (5)
Continue to disagree and plan on pursuing further (e.g., due process, administrative complaint)	8.3% (3)
Worked together to find a solution all were happy with	8.3% (3)
Advocate helped to understand why what the school was providing was appropriate	8.3% (3)
Other	16.7% (6)

\*Does not sum to 100%- respondents identified all that applied.

## FAMILIES REQUESTING ADVOCATES



*Figure 1.* Participant inclusion flowchart.