Digital Commons @ Assumption University

Education Department Faculty Works

Education Department

2019

The Perceptions and Goals of Special Education Advocacy Trainees

Samantha E. Goldman
Assumption College, s.goldman@assumption.edu

Meghan M. Burke
University of Illinois at Urbana-Champaign

Maria P. Mello
St. John's University

Follow this and additional works at: https://digitalcommons.assumption.edu/education-faculty

Part of the Special Education and Teaching Commons

Recommended Citation

The Perceptions and Goals of Special Education Advocacy Trainees

Samantha E. Goldman[1], Meghan M. Burke[2], & Maria P. Mello[3]

[1]Assumption College, Department of Education, Worcester, MA

[2] University of Illinois at Urbana-Champaign, Department of Special Education, Champaign, IL

[3] St. John's University, Department of Education Specialties, Queens, NY

Corresponding Author:
Samantha Goldman
Assumption College, Department of Education
500 Salisbury St.
Worcester, MA 01609
s.goldman@assumption.edu
508-767-7125

Abstract

Although the field of special education advocacy is growing, little is known about the perceptions and goals of individuals who participate in advocacy trainings. It is important to understand why individuals want advocacy training to design more effective programs and determine whether training meets participant expectations. In this study, we evaluated the perceptions of 142 participants who completed the Volunteer Advocacy Project (VAP), a special education advocacy training. Using participants' responses to open-ended questions on the VAP application, we examined the perceptions of caregivers and professionals to understand their motivations for becoming advocates, their plans for using their newfound knowledge and skills, and their perceptions of the attributes of special education advocates. Findings indicated some key differences between caregivers and professionals in their reasons for becoming advocates and plans for using their newfound knowledge and skills. Participants wanted to become special education advocates to help their own child (if they were caregivers) and to help others. Participants planned to use their newfound knowledge and skills to advocate and to provide service to the community at three levels depending on their role: school, community, and state/national. Finally, regardless of role, participants perceived warmth, competence, and grit to be necessary attributes of successful advocates. Implications for research and practice are discussed.

Keywords: advocacy, caregivers, professionals, special education, disability

The rights of parents of children with disabilities to participate in decision-making processes and hold schools accountable are established in the Individuals with Disabilities Education Act (IDEA), the U.S. federal special education law. However, understanding the law and acting on their rights is a complex and often overwhelming task for parents (Mueller, 2015). To support parents in understanding and exercising their rights, the field of special education advocacy has emerged. Special education advocates are trained individuals who do not offer legal advice, but rather provide support and guidance for families as they navigate the special education process (Goldman, Burke, Mason, & Hodapp, 2017). Although recommended for inclusion in the next reauthorization of IDEA (Wakelin, 2008), limited research exists about the special education advocacy process, advocacy training, and advocates themselves. Additionally, due to a shortage of trained special education advocates (Phillips, 2008), parents are often unable to connect with advocates in their geographic areas when they need support. Therefore, there is a need for advocacy training and research on how the training and advocacy processes work.

One special education advocacy training, called the Volunteer Advocacy Project (VAP), has a burgeoning research base regarding its training components and subsequent advocacy process (e.g., Burke, Goldman, Hart, & Hodapp, 2016a; Burke, Mello, & Goldman, 2016b; Goldman et al., 2017; Burke & Goldman, 2017). Established in Tennessee in 2008, the VAP is a 36-hour training that provides weekly sessions across a range of topics relevant for special education advocates. Many sessions relate to IDEA (i.e., eligibility and evaluation, individualized education plans, least restrictive environment, extended school year, discipline and behavior, transition, assessment, and procedural safeguards), while some sessions are focused on skills and topics needed to successfully work with families and schools (e.g., cultural diversity, non-adversarial advocacy, characteristics of disabilities). The VAP is offered at

multiple sites across the state, with participants either attending the training live at the main location, or via webcast at one of the satellite sites. Regardless of site, the VAP training has been successfully implemented with positive outcomes in terms of participant learning (i.e., increase in knowledge about IDEA) and increased participant comfort with advocacy from pre- to post-training (Burke et al., 2016a). As of 2012, VAP graduates were advocating in nearly half of the school districts across the state (Burke et al., 2016b). Yet, little is known about the individuals who are interested in completing the VAP and becoming special education advocates. By understanding who is participating in the VAP and why they want to be special education advocates, we can ensure that the VAP (and other advocacy programs) are designed to effectively meet the expectations of the participants who can then proceed to advocate for others.

Parent advocacy is considered to be necessary to access needed services for one's child (Nachsen, Anderson, & Jamieson, 2001); indeed, parents may be the best advocates for their children (Wakelin, 2008). Caregivers have unique perspectives and understanding of raising a child with a disability and working with the school on the child's behalf (Trainor, 2010). However, many caregivers struggle to advocate for their own child due to, for example: a lack of special education knowledge, a power imbalance with the school, and procedural barriers (Trainor, 2010). As a result, it is critical to train professional advocates (Wakelin, 2008).

Although some advocacy training is limited to parents of individuals with disabilities (e.g., Taylor et al., 2017), the VAP is open to any person interested in becoming an advocate (Burke et al., 2016a). Therefore, it is important to gain an understanding of why participants are interested in completing the VAP, and whether participants from different backgrounds (i.e., caregivers vs. non-caregivers) differ with regard to their reasons for participation. For example, the reasons why a caregiver wants to become an advocate may relate to their own struggles

navigating the special education system for their own child (Nachsen et al., 2001; Trainor, 2010). In contrast, professionals who are not caregivers of children with disabilities may have different motivations for becoming advocates. Professionals may be looking for training opportunities to become better at their jobs, or may be trying to advance their careers. Although there is not currently a certification or licensure for special education advocates, professional non-attorney advocates can engage in activities that support families and may help them avoid the use of legal representation (Phillips, 2008). Further, professionals use may their completion of an advocacy training as a rationale for charging families for their advocacy assistance (Burke, 2013). Therefore, for the VAP, which includes both caregivers and non-caregiver trainees, it is important to learn why different people are interested in participating—specifically, whether their motivations relate to one child, to their own career, or to the broader disability population (Nachsen et al., 2001).

Beyond understanding why individuals participate in an advocacy training, when designing advocacy training it is also important to understand how advocates plan to use the skills and knowledge they gain from the training. All VAP graduates are asked to volunteer, pro bono, as an advocate for four families. However, beyond this requirement, there remains much to explore about how program graduates use their newfound skills and knowledge. Preliminary research with a sample of VAP graduates from 2009-2012 has indicated promising outcomes, with more than half of graduates advocating for at least one family in the first four years following program completion (Goldman et al., 2017). The advocacy activities of these VAP graduates included those that were 'family-focused' (e.g., coordinating a parent support group) and those that were 'school-focused' activities (e.g., completing a record review). However, parents (versus school personnel) were significantly more likely to advocate post-training

(Goldman et al., 2017). Thus, it is possible that caregivers have different expectations of post-advocacy engagement than professionals.

Caregivers and professionals may also differ in what they consider to be attributes of successful advocates. In general, much research and theory has shown that people differentiate each other according to two dimensions: warmth and competence (Fiske, Cuddy, & Glick, 2007). Warmth includes traits such as being helpful, sincere, and understanding, while competence relates to terms such as knowledgeable, intelligent, and skilled (Fiske et al., 2007; Wojciszke, 1994). However, it is unknown whether special education advocates are judged according to these same constructs, and if caregivers and professionals differ in their perspectives. For example, although caregivers and teachers share similar perceptions of how parents advocate, they have different perspectives regarding the outcomes of advocacy at school (Burke et al., 2017). Thus, while caregivers may use their personal experiences with special education to frame their views of successful advocates, professionals may view the required attributes of successful advocates differently, and this should be considered when providing training.

Given the limited understanding of the perceptions and goals of special education advocates and the burgeoning field of special education advocacy, it is crucial to better understand the perspectives and goals of advocacy training participants. By learning about trainee goals, advocacy training can be specifically designed or revised to meet these needs. Additionally, by exploring trainees' expectations of the advocacy program, we can determine whether the program meets their needs; this should aid in sustaining the advocacy training. Further, by comparing the perspectives of caregivers to professional participants, we can discern whether an advocacy training can meet both sets of expectations. In this study we addressed three research questions: (1) Why do individuals want to become special education advocates?,

(2) After completing the special education advocacy training, how do individuals plan to use their newfound knowledge and skills?, and (3) What do individuals perceive as the necessary attributes to be a successful special education advocate? Across all research questions, we examined differences between caregiver and professional responses.

Method

Sample

In this study, there were 142 applicants who applied to and completed the VAP training from 2014-2016 (see Table 1). Participants were mostly female (94.4%) and White (73.9%). Overall, 70% ($n = 100$) were caregivers for individuals with disabilities; of these 100 caregivers, 46 also had paid or volunteer jobs in a disability-related field. More than half of the sample had college or graduate degrees. Although participants came from across the state, most were from non-rural counties (United States Department of Agriculture, 2013) and lived in the top five metro areas in TN; specifically, 41.5% ($n = 59$) attended the VAP live at the host site in Nashville, while the remaining trainees participated through distance sites closer to their homes.

Procedures

All participants applied for and completed the VAP, a 12-week training for special education advocates. The training was offered through the state University Center on Excellence in Developmental Disabilities (UCEDD) and was facilitated by the first and third authors. This study, along with other methods of data collection related to the training, were reviewed and approved by the university Institutional Review Board.

Recruitment. The recruitment process for the VAP began each year in July and continued for approximately six weeks, or until one week before the training began in August. To recruit participants, paper and electronic flyers, created by program coordinators, were

disseminated through disability organizations across the state. Disability organizations included, for example, local chapters of The Arc, Autism Speaks, Autism Society, Down syndrome Associations, and the state Parent Training and Information Center (PTI). Former program graduates and site coordinators were also forwarded the flyer and the link and asked to share the training information. The recruitment flyer, all e-mails, and the VAP website contained an embedded link to an online application form.

Application process/data collection. An online application form was created through REDCap (Research Electronic Data Capture), a secure, password-protected survey platform (Harris, Taylor, Payne, Gonzalez, & Conde, 2009). Paper applications were available upon request. Both paper and electronic versions of the application were identical to those used in previous years of training (i.e., 2008 - 2013). The application consisted of multiple choice and short answer demographic questions relating to: location, level of education, occupation, race/ethnicity, gender, and role. This section was followed by six open-ended questions about the applicant's interest in participating in the training, including: (1) What interests you in becoming an advocate? Why do you want to participate in this project?; (2) What is your personal connection to the disability field?; (3) Have you had any experience advocating for families of children with disabilities?; (4) What do you think are the necessary attributes to be a successful advocate?; (5) How would you describe yourself and your family?; and (6) What would you like to get out of participating in this project? How do you think you will you apply the knowledge you will have gained from this project?. There was no character limit for the responses. On average, responses were 45 words, with a range from 28 words for responses to Question 3 to 64 words for Question 1.

Acceptance into training. After respondents completed the VAP application, the VAP

coordinators (first and third authors) reviewed all applications to determine eligibility.

Participants were accepted into the training if they were: (a) 18 years of age or older, (b)

committed to completing the 12-week training with minimal or no absences, (c) committed to

volunteering as an advocate for four families after completing the training, (d) able to access any

of the available training sites across the state, and (e) paid or requested a waiver for a $35 fee for

materials.

Data Analysis

For this study, completed applications for the 142 participants from 2014-2016 were

combined and exported to an Excel spreadsheet. Only contact information, such as address and

phone number, was removed. All other application information was included so that multiple

sources of information (e.g., responses to different questions about participant role, professional

experience, and connection to the disability field) could be triangulated during the data analysis

process. The first and second author then used constant comparative analysis to code participant

responses to three of the open-ended application questions: (1) What interests you about

becoming an advocate for families of children with disabilities? Why do you want to participate

in this project?; (2) What would you like to get out of participating in this project? How do you

think you will apply the skills and knowledge you will have gained from this project?; and (3)

What do you think are the necessary attributes to be a successful advocate?. These responses

were triangulated with other data from the application, such as demographic information and

responses to other open-ended questions that did not directly answer our research questions (e.g.,

"What is your personal connection to the disability field?"). The first and third author who

facilitated the training were personally familiar with many of the participants and were able to

use informal notes and anecdotes about participants as an additional data source to triangulate

with open-ended responses (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005).

To code responses to the three open-ended questions, the first and second author independently read all 142 responses and coded all text that related to the research questions using emergent coding (Patton, 2002). The authors then compared their codes, discussed disagreements, and each re-analyzed the data to see if any additional codes emerged. During coding, the authors also used information about the participant's role (i.e., caregiver and/or professional in the disability field) to identify differences in perceptions. After multiple iterations of this constant comparative coding process, the authors agreed on final themes and sub-themes grounded in the data for each research question. These themes were sent to the third author for review and approval.

Word cloud. When coding responses to the third research question (i.e., attributes of successful advocates), the authors utilized a word cloud as a tool to supplement the abovementioned data analysis procedures. A word cloud helps to produce basic descriptive information by visually representing how frequently words are used in participant responses (Cidell, 2010). It is considered an acceptable tool for preliminary analysis as well as for validation, to confirm findings and the interpretation of findings (McNaught & Lam, 2010). Because of the nature of this question and the types of responses provided (i.e., often words/attributes rather than full sentences), this supplementary tool seemed appropriate to aid in exploring, interpreting, and displaying the answer to our third research question.

To create the word cloud, the authors used wordclouds.com, an online program. The authors uploaded a text file containing all participant responses to the relevant application question. To ensure that the word cloud showed the most frequently occurring words of importance (McNaught & Lam, 2010), the authors combined words with common stems (e.g.,

passion and passionate), removed stop words (e.g., and, but), removed words repeated directly

from the question (e.g., advocate, attribute), and removed other words that did not answer the

question (e.g., son, disabilities, can, general). Once the word cloud was created, the authors

adjusted the settings so that the most frequently used words were visible, with their size equated

with word count. The authors also were able to view a list of words with corresponding word

counts that were used as an additional source of information for data triangulation.

Trustworthiness

The authors incorporated multiple design elements to safeguard the trustworthiness of

outcomes in terms of credibility, transferability, dependability, and confirmability (Brantlinger et

al., 2005). First, all three authors were uniquely and closely connected to the disability field and

the advocacy training. Specifically, each author had facilitated the VAP at some point and had

significant experience in the field of special education. Multiple coders were involved

throughout the data analysis process to ensure that different perspectives and interpretations were

explored. Peer debriefing was also used throughout the study to promote the confirmability of

findings. Additionally, the authors triangulated multiple methods of analysis, sources, and

investigators to ensure that findings represent the respondents' viewpoints. Further, by including

and analyzing responses from all 142 program graduates over three training cohorts, the authors

were able to analyze variability across participant roles and promote the dependability of the

findings over time and participants.

<div align="center">

Findings

</div>

We identified three main findings. First, participants wanted to become special education

advocates to help their own children (if they were caregivers) and to help others. Participants

planned to use their newfound knowledge and skills to advocate and to provide service at three

levels: (1) school, (2) community, and (3) state/national. Finally, participants perceived warmth, competence, and grit to be necessary attributes of successful advocates. These findings and corresponding themes which, to some extent, differ by participant role (i.e., professional vs. caregiver), are further described below, according to research question.

Reasons for Completing an Advocacy Training

  To help myself. Many participants described wanting to develop skills and gain knowledge from the VAP to benefit themselves and their families. Notably, there were distinct subthemes with respect to caregivers and professionals (see Figure 1).

  Caregivers. Many caregivers acknowledged their desire to first help their own children before advocating for other families. Simply stated by the mother of a 10-year-old with autism spectrum disorder (ASD): "I know how overwhelming navigating the school system is. I would love to be able to help other parents, but I have to be able to help my family first." Other caregivers reported being able to concurrently advocate for their own children and others. A self-advocate with a child with ASD reported, "If I can get educated and help not only my family but others, as well then I would truly love to help." Notably, caregivers were diverse in their experience advocating for their own children, including individuals who were: beginning the advocacy process; continually advocating for their own child; reporting successful past advocacy efforts for their child; and preparing for their future advocacy needs.

  Professionals. Some participants reported that the VAP would help them reach professional goals. For example, a doctoral student in a counseling program reported wanting to learn more about school services before completing her degree. A mother of a child with ASD who was also an administrative assistant reported, "We recently formed a chapter of The Arc in our county. I presently serve as president of the chapter. We are trying to train as soon as

possible before parents begin to call needing assistance." Similarly, a mother of a 5-year-old with special healthcare needs who was also a service coordinator reported, "I want to prepare for my next position as a family advocate." Notably, several retirees or "empty-nesters" expressed the goal of becoming volunteer advocates to fill their time and fulfill their passions. Stated by a retired grandparent: "Retired from 34 years with the [state] Department of Developmental Disabilities. Miss it." Thus, the VAP was viewed as a way for participants to gain knowledge and skills to move into professional roles related to supporting individuals with disabilities.

Help others. Although all participants reported wanting to help others, caregivers and professionals framed this desire through their unique lens of experience.

Caregivers. Many caregivers reported a desire to support other families of children with disabilities. As stated by a mother of a child with cerebral palsy:

> I would like to be the voice for families struggling through the system. There are too many areas of the unknown for families to learn about so that their child can get better care. The opportunities are out there and I would like to share and support those in need. We need to give of ourselves to help others take control of their lives.

Help others avoid my negative experience. Beyond the broad goal of helping others, some caregivers reported having negative experiences advocating for their own child's educational rights and lacking an advocate to help them. These caregivers reported wanting to help other families avoid similar negative experiences. A single mother of a 14-year-old son with ASD reported, "I never want a parent to feel like I did. Alone. My first IEP meeting I was completely lost and felt intimidated. I want to help families to not feel that way." Similarly, a mother of three children with disabilities, reported, "I would love to spare others the stress, frustration, and heartache we experienced."

Pay it forward. Other caregivers had been successfully helped by an advocate; these caregivers wanted to do the same for other families. A mother of a child with ASD reported:

Advocacy has touched our lives personally. I believe hiring an advocate when my son entered the school system completely changed the trajectory of his progress. As a parent of a child with a disability, I know that having an advocate provides you with a newfound hope and strength to continue moving forward even when it seems overwhelming and hopeless. I want to help others in that same way.

These caregivers wanted to "pay it forward" because they felt fortunate to have benefited from an advocate during their own experiences navigating the school system for their children.

Professionals. Those with a professional connection to the disability field also reported wanting to complete the VAP to better support children with disabilities and their families, but framed this goal through their professional experiences. For example, some participants described wanting to do better at their current job/volunteer work in the disability field as a result of completing the VAP; others described wanting to complete the training to be able to better advocate for their clients in other contexts or beyond their typical job responsibilities.

Improve skills in current employment. Individuals who hoped to better serve their clients in their current job described wanting to develop skills through the VAP that related to their work responsibilities. For example, a Certified Psychological Assistant reported:

I am very interested in helping children with disabilities… I would like to participate in order to be able to better serve my clients and be able to give them as much information as possible.

Similarly, a parent representative for the state autism organization shared:

I am on the phone with parents of children on the autism spectrum all the time… While I

know a good bit about the laws and regulations I would like to be more fully informed so I know the information I am imparting is current and completely accurate. This would really help me do my job better!

Some of these professionals described their desire to ameliorate the challenges of families of children with disabilities that they observed through their jobs. A special education supervisor with 15 years of experience described how she tried to address the concerns of families: "I have heard horror stories from parents who have moved into our county and who had difficulties or problems with schools in other areas." In contrast, other participants wanted to complete the VAP to understand the perspectives of families of children with disabilities in order to do their jobs better. A retired educator shared her desire to better understand "the other side"—or families' perspectives: "In my work as a CASA volunteer I see a need to understand more about this area from the other side as I was directly involved in my time as an Assistant Principal." Additionally, some professionals mentioned the need to stay current on constantly changing disability policy and regulations and to stay inspired about their work. A self-advocate and mother to 21-year-old twins with disabilities who had been providing advocacy services professionally for 14 years shared: "I see the VAP filling the gap (need for refresher courses) to stay current and the best advocate I can be… I need a booster shot from VAP to keep me current and provide me with fuel to keep my fire burning."

Better advocate for clients. Many participants who worked with individuals with disabilities and families hoped to better advocate for the rights of their clients, beyond their typical job responsibilities. A speech-language pathologist reported:

I would like to become an advocate for families of children with disabilities to learn how to better guide my families through the different processes experienced by these

families… I wish to gain a deeper understanding [of service delivery systems] to both

better guide the families with whom I work, as well as relate to them as they advocate for

their children. I believe my completion of this project will give me access to the

necessary knowledge to become an effective advocate for the families and children with

whom I work.

Other professionals made similar statements about wanting to address the advocacy needs of

individuals with disabilities. For example, one participant--a father of an adult with disabilities

who had become a special education teacher after retiring from a software company--explained,

"I'm always wanting to learn more about helping families and individuals with navigating

through paperwork, rights, and knowing the correct information for resources and supports

available for families of children with disabilities." These participants were focused on

advocating for clients beyond their typical job responsibilities and contexts.

Using Acquired Skills and Knowledge

Participants planned to use their newfound skills and knowledge in two main ways:

advocating for families and providing service to the community. Some differences between the

expectations of caregivers and professionals were noted (see Figure 2).

Advocate. Aligned with the mission of the VAP, participants wanted to advocate after

completing the training. A few caregivers highlighted their need to first advocate for their own

children; however, nearly all caregivers expected to advocate for other families in addition to

their own offspring. As stated by a mother with three daughters with disabilities: "Certainly, I

will apply what I learn in my daughters' 504 and IEP meetings, but I also intend to share my

knowledge with friends and neighbors who need assistance. Indeed, I know of several families I

could immediately assist..." Professionals similarly communicated the desire to become

advocates for others. A professional caretaker for a child with ASD who had a degree in special education shared that:

> When I found this program I was so thrilled because I thought of all the people/families I would be able to help! I personally know so many families with children who have special needs that would greatly benefit from having an advocate break the barriers in front of them. There is so much to learn from this program and I am grateful I can be the one to take it all in and use it to help others!

Below are subthemes found across caregivers and professionals within the theme of advocating for other families.

Educate and empower. Many participants reported specifically planning to educate and empower families. For example, a professional who worked for a statewide disability organization wrote: "[disability organization] works to educate and empower our families. Completing this course will give us greater knowledge in fulfilling our mission." A mother of an adult with a learning disability wrote about her future advocacy work: "I want people to know what their rights are and to understand there is nothing wrong in requiring that their rights be respected and their needs met." Altogether, many participants shared their desire to help others gain information about their child's rights (i.e., educate) and support caregivers in becoming active participants in decision-making for their children (i.e., empower).

Help navigate the service delivery system. Participants wanted to help families navigate the special education process. A vocational rehabilitation director with over 20 years of experience and two children and a spouse with disabilities shared: "I have a passion for helping adults and children with disabilities by helping them successfully navigate an often complex network of agencies and systems." Other examples of navigation described by participants

included: providing families with advice and instructions; being able to correctly apply the law to craft a plan; attending meetings with families; and observing students.

Help access services. Many participants wrote about helping students obtain needed services to forge educational progress. A mother of a 7-year-old with Down syndrome who was actively involved in the disability community shared that her daughter received excellent school services and that: "…every child in the state should have the opportunities she has… All children should receive the services and accommodations they need regardless of school or school system." A few participants specifically reported that they wanted to help families receive a free and appropriate public education (FAPE). For example, a participant who was a pastor and mother of a child with ASD attended IEP meetings with friends and planned to: "…continue to develop relationships with parents of children struggling to get FAPE. I will attend meetings, participate in conversations, and commit to helping children receive FAPE."

Provide affective support. Some participants wanted to provide families with comfort and emotional support, both within and outside of IEP meetings. A parent of a young child with ASD shared: "I want to provide comfort to those parents feeling scared or alone or failing in their search for assistance." A former teacher who had multiple relatives (i.e., a child, sibling, and spouse) with disabilities explained that she understood the "frustration and fear of feeling as if there is no one to help" and wanted to "help parents find ways out of the darkness of feeling the world is against them…"

Provide service to the community. Participants expressed a desire to provide "service to the community" with the skills and knowledge gained from the training. Service was described across three levels: school/service system; local community; and statewide/national. However, there were differences between caregivers' and professionals' plans.

School/service system. Both caregivers and professionals expressed a desire to build stronger family-professional partnerships, but in different ways. Caregivers focused on improving family-professional communication. For example, a stay-at-home mom of two children with ASD reported: "My hope is to help teachers and parents communicate more effectively." In contrast, professionals focused on training their colleagues, interns, and students to develop positive relationships with families. A former teacher who had experience working with pre-service teachers reflected on the lack of trust between educators and parents and expressed her desire to: "…teach the students teachers to not only 'teach' the students identified with a disability, but also how to further advocate for the student and family correctly… to develop positive working relationships between the school, community, and families."

Local community. Only caregivers reported planning to use their advocacy skills within their local communities. Specifically, they hoped to expand disability supports in their communities by creating support groups and building a network of advocates. As stated by an individual with multiple family members with disabilities, "My ultimate desire is to take the information given and pour it back into the community."

Support groups. Some caregivers reported that existing support systems for caregivers of individuals with disabilities were lacking in their communities; after completing the training, they hoped to organize support groups to help other caregivers feel less isolated and to build a community. A custodial grandmother who cared for her two grandchildren with disabilities and was a surrogate parent for students in her school district, shared: "I have found as a grandparent raising teens I don't know how to fit into support groups with much younger parents well. I would like to see a group being formed for grandparents raising grandchildren with disabilities."

Advocacy networks. Caregivers also hoped to use their newfound skills to expand

advocacy networks in their communities. A parent of a child with ASD shared that she: "…would also like to meet other people interested in advocating as a means to form a support team for advocates in my area." Another mother, whose child was recently diagnosed with a disability, stated: "I hope to use the skills I gain to help those in my area and become more familiar with and work with the parent advocacy groups in my city." Some caregivers shared that they were unable to connect with an advocate when they needed one for their own child; they hoped to remedy this problem by expanding the number of trained advocates. A grandmother who helped care for her young granddaughter with Rett syndrome stated: "I believe our county has a great need for special needs advocates and I intend to help fill that need, not only as an advocate, but as someone who encourages others to become advocates."

     State-wide/national. At the broadest level, some caregivers described a desire to impact state or national policy for individuals with disabilities. A mother of three daughters with disabilities shared her goal: "In a more general sense, I want to work toward reform of special education in Tennessee, because I see the special education trend heading in the wrong direction." Other caregivers mentioned federal policy changes. They envisioned impacting policy changes by: lobbying, contacting the media, and working with legislators. A stay-at-home mother to 10-year-old twins with cerebral palsy and Fragile X syndrome shared: "I would like to gain knowledge to take the advocacy skills I have to the next level. I have been communicating with legislators regarding disability issues and would like to acquire a greater skill set to advocate for change."

Attributes of a Successful Advocate

     All participants, regardless of role, identified the following attributes: (1) warmth toward families; (2) competence in advocacy; and (3) grit to achieve the best outcome for the child. The

words used in response to this question are depicted in the form of a word cloud in Figure 3.

Warmth. Many participants described the need to be understanding and compassionate

to families. A pre-service special education teacher whose son had been diagnosed with multiple

disabilities shared: "I feel it is important to be able to understand and have compassion for how

stressful having a child with a disability can be on a family." Participants also described the need

to be patient with families, offering support and encouragement. As reported by a graduate

student in Child Studies and Applied Behavior Analysis, attributes included: "Patience and

kindness to work with parents who might be confused and emotional." Overall, participants

identified attributes that related to developing warm, understanding relationships with families.

Competence. Most participants reported that advocacy required competence--

specifically, being *knowledgeable*, *skilled*, and *professional*. Encompassing these sub-themes of

competence, a professional and family member of multiple individuals with disabilities

explained, "To be a successful advocate, one must have…excellent communication skills (both

oral and written), good negotiation skills, and a strong working knowledge of the systems and

laws that apply in which they are advocating."

Knowledgeable. Participants most frequently referenced being knowledgeable as an

attribute for being a successful advocate. They described the importance of being knowledgeable

about: the law; the special education system; different types of disabilities; and information

about resources and services for families. As stated by a stay-at-home mother who had advocated

for her two sons with dyslexia:

> First and foremost, a successful advocate must understand the laws of the land. Ten years
>
> ago I probably wouldn't have said that first. I would have listed attributes such as
>
> compassion. I know, through my own experience, that unless you understand the specific

learning differences, have strong recommendations for qualified professionals, and

understand the laws of the land, not much will be accomplished.

Skilled. Participants also expected advocates to be skilled as: listeners; communicators;

team members; and problem solvers. Participants referred to these skills with respect to

interacting with families and schools. For example, being an effective listener included both

"listening to all sides" and listening to the family's needs because "each family's wants and

needs are different so listening to them will be very important." Similarly, participants reported

that successful advocates should be skilled, articulate communicators who could explain

concepts to families and facilitate family-school communication. A family member of multiple

individuals with disabilities (i.e., a sibling, in-law, spouse, and three children) stated: "An

advocate should be able to be clear and facilitate effective communication… An advocate needs

to be able to work effectively with a family to explain their options, their rights, and prepare the

family well before meetings."

Participants also reported that advocates should be skilled, effective team members who

are able to creatively problem solve and compromise or negotiate when appropriate. As stated by

a retired special education supervisor: "I also think that it is necessary to be an involved team

player. Compromise and fairness do not always walk hand in hand but both parties can still leave

the table feeling good about what they have done and accomplished." A parent who described

her son as "disabled by the world's standards," explained that a successful advocate should use:

"…peaceful, resolute, out of the box solution based thinking."

Professional. Participants also reported that advocates should be professional, including

attributes such as *objective*, *dependable*, *respectful*, and *prepared*. The mother of two sons with

disabilities listed the following attributes: "a 'cool head', non-confrontational attitude; the ability

to keep calm and take a minute to think before speaking; it is essential to 'do your homework' prior to any meetings and be as prepared as possible to address any outcome." A family member of an individual with a disability who also had worked in the disability field explained: "I think successful advocates provide factual information, are flexible and objective… Advocate should seek out and provide accurate, reliable information to families so that they may best serve their children under all circumstances."

Grit. Regarding grit, frequently used terms included: *passionate*, *persistent*, and *strong*. Many participants wrote that advocates need to be committed to and passionate about working for the rights of individuals with disabilities. A mother of a child with ASD wrote: "To be a successful advocate you have to be passionate about what you are advocating for… and have a desire to truly help others." Beyond passion, participants described a need to persist in the face of challenges. They described advocates as motivated and determined to achieve the best possible outcome for the child, acknowledging that "advocacy is not an easy path." A mother of triplets, two of whom were diagnosed with communication disorders, explained the importance of persisting "…to make sure that everything that can be done for a child with a disability is being done so that the child receives the best education possible." To persevere, participants acknowledged the need to be *assertive* and *confident*, willing to "stand for what's right" and "be the voice for those who aren't able." A mother who was a family counselor and had a son with fetal alcohol syndrome described the need for an advocate to be: "…courageous enough to speak up, not settle for less than what the child should have."

Discussion

In this study, we examined the perceptions of advocacy training participants about their goals for the training. We also were able to examine differences between the perceptions of

caregivers and professionals. We had three main findings that related to our research questions

about trainees': reasons for wanting to become advocates; plans after completing the advocacy

training; and perceptions of the necessary attributes of successful advocates.

First, advocacy training participants may have self-serving and externally motivated

reasons to become advocates. For caregivers, this could include advocating for their own

children and for other families; for professionals, this could include attaining future career goals

and better supporting current clients. Thus, although most participant responses aligned with the

"pay it forward" component of the VAP (i.e., advocating for four other families), the training

also helped participants in their personal and professional goals, for caregivers and professionals,

respectively. To date, the effects of advocacy training programs for other families have been

studied (e.g., Goldman et al., 2017; Jamison et al., 2017). However, research has not yet

examined how advocacy training programs may influence advocacy among the participants in

personal (i.e., advocating for their own children with disabilities) and professional (i.e.,

advancing their careers) ways. With respect to the former, given that parent advocacy is often

necessary to access services (Nachsen et al., 2001; Wakelin, 2008), it is important to determine

whether advocacy training helps caregivers advocate for their own offspring. Regarding the

latter, research is needed to determine whether advocacy training may be helpful for

professionals to advance their careers. Although there is no national special education advocacy

certificate or license, if participants, namely professionals, are completing advocacy training with

this professional goal, it is important to develop systems to manage and regulate advocacy

training and professional advocacy.

Second, advocacy training participants hoped to use their newfound knowledge and skills

to help families of children with disabilities and, with respect to caregivers, to affect systemic

change. Previous research indicates that VAP graduates have gone on to advocate for other

families of children with disabilities (e.g., Goldman et al., 2017) and that VAP advocates use an

advocacy process with certain consistent components (e.g., educate and empower, provide

affective support; Burke & Goldman, 2017). However, the desire to impact systemic change is a

new finding with respect to special education advocacy training. It has been well-documented

that parents of children with disabilities spearheaded the passage of the Education for All

Handicapped Children Act (i.e., the initial federal special education law; Turnbull, Shogren, &

Turnbull, 2011). However, in the most recent IDEA 2004 reauthorization, individual parents

provided only 4% of public feedback (York, 2005). Thus, it may be that advocacy training

should include content about affecting systemic change (e.g., legislative advocacy). However,

this desire to use knowledge and skills gained through the training to advocate at a level beyond

the service system was not expressed by professionals. It is unknown whether professionals are

less interested in advocating for such changes, or whether they already engage in systemic

advocacy professionally. Thus, more research is needed to determine whether it is worthwhile

for advocacy training to address advocating for systemic change.

      Finally, this study demonstrated that perceived attributes of successful advocates by both

caregivers and professionals included: warmth; competence; and grit. Previous research has

documented the importance of the universal dimensions of warmth and competence (Fiske et al.,

2007); these findings confirmed and expanded on the importance of warmth and competence for

advocates. However, grit was a newfound attribute. Duckworth and colleagues (2007) defined

grit as perseverance toward achieving long-term goals. Although grit has been noted as an

important attribute for teacher retention (Robertson-Kraft & Duckworth, 2014), it has not yet

been applied to special education advocates. Especially given that advocacy is often necessary to

access services (Wakelin, 2008) and that advocates are often requested by families that are experiencing challenges in receiving services from the school, it seems important to consider grit in future research about advocates and advocacy training.

Although important, this study has several limitations. First, the sample was primarily White; however, this sample accurately mirrored the racial/ethnic demographic of Tennessee (United States Census Bureau, 2017). Further, this sample was limited to the state of Tennessee and one particular advocacy training; thus, the findings may have limited transferability. Additionally, although there was no character limit for VAP application responses, interviews may present a more open-ended forum for participants to share their reasons and expectations for an advocacy training program. Given this method (i.e., analyzing written open-ended application responses), we were not able to utilize certain qualitative procedures, such as member checking, which could further establish the trustworthiness of our findings (Brantlinger et al., 2005). Further, in this study, we were only able to analyze participants' self-reported plans and goals; we did not follow up with participants to see if their reported plans aligned with their actual post-training advocacy. Thus, our findings are a jumping off point for examining post-training advocacy.

Implications for Research and Practice

More research should be conducted to determine the impact of advocate attributes on advocate, family and child outcomes. Research is needed to determine if the warmth, competence, and grit perceived as necessary attributes by VAP participants actually relate to post-training advocacy and, correspondingly, influence child and family outcomes. For example, although having a strong identity as an advocate post-training is related to higher rates of continued advocacy (Goldman et al., 2017), it is not known how other attributes correlate with

post-training advocacy. Further, while limited research has been conducted to investigate the impact of advocacy on child and family outcomes (e.g., Jamison et al., 2017), no researchers have examined how the attributes of an advocate may influence child and family outcomes; this research is needed to identify which attributes are key to improving outcomes. Put simply, the goal of advocacy training is to support families in the special education process; it is therefore critical to know which factors relate to successful advocacy. If researchers replicate the finding that emerged from the perceptions of VAP participants, training should be designed to promote warmth, competency, and grit. To date, it seems that researchers have only designed studies to examine the effects of advocacy training on competence (e.g., knowledge and skills; Burke et al., 2016a).

Research is also needed to examine how advocacy may differ when caregivers advocate for their own families versus for other families. This study demonstrated that caregivers expect advocacy training to help them advocate for their own offspring with disabilities as well as other families. Research should be designed to investigate this finding to determine whether an advocacy training helps an advocate's own offspring as well as other families' of children with disabilities. Advocacy by caregivers can take a wide range of forms, such as advocating for the needs of one's individual child to advocating much more broadly for the needs of all individuals with disabilities (Nachsen et al., 2001). Trainor (2010) identified four types of parent advocacy including: relying on intuition; using knowledge of the child's disability; using special education knowledge; and using knowledge of educational systems to advocate for systemic change. In contrast, special education advocates may conduct school-focused advocacy activities (e.g., record reviews, attending IEP meetings) and family-focused advocacy activities (e.g., meeting with families; Goldman et al., 2017). Research is needed to determine whether caregivers who

graduate from advocacy training programs use different advocacy methods depending on whether or not they are advocating for their own offspring versus other families. Further, practitioners who conduct advocacy training may consider revising the content to reflect differences in parent advocacy for one's own child and advocacy for other families.

In addition, these findings should be considered in light of unauthorized practice of law. With special education advocacy training, policymakers and practitioners may be concerned that special education advocates blur the line of practicing law without being attorneys (Burke, 2013). This study suggests that advocates fulfill unique tasks that are unlike attorneys. For example, in this study, participants reported that advocates provide affective support to families and must demonstrate warmth—these traits do not align with the responsibilities of an attorney. Paired with other research indicating that advocates provide affective support (Burke & Goldman, 2017), this study further suggests that advocates are not practicing law, and that training specific to professional special education advocacy is needed.

In conclusion, this study provides initial insight into the perceptions of caregivers and professionals who completed a special education advocacy training. Our findings can be used to design effective advocacy training and ensure that trainees' goals and expectations are met. Although more research is needed to understand how participants' intentions translate into actions, our findings elucidate trainee expectations, plans for post-training advocacy, and perceptions of advocate attributes. With this preliminary understanding of the differences and similarities between the perceptions of caregiver and professional trainees, it is important to continue to conduct research about special education advocacy to improve training, advocacy, and child outcomes.

Compliance with Ethical Standards

Conflict of Interest: All authors declare that they have no conflict of interest.

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: A waiver of informed consent was approved by the university Institutional Review Board because the research involved no more than minimal risk to the subjects, the waiver did not adversely affect the rights and welfare of the subjects, and the study did not involve procedures for which written consent is normally involved outside the research context. Participants provided consent by answering 'yes' to a question regarding participation in research and providing an electronic signature by typing their name.

References

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative

    studies in special education. *Exceptional Children, 71*, 195-207.

    doi:10.1177/001440290507100205

Burke, M. M. (2013). Improving parental involvement: Training special education advocates.

    Journal of Disability Policy Studies, 23, 225-234.

Burke, M. M., Goldman, S. E., Hart, M. S., & Hodapp, R. M. (2016a). Evaluating the efficacy of

    a special education advocacy training program. *Journal of Policy and Practice in*

    Intellectual Disabilities, 13, 269-276. doi: 10.1111/jppi.12183

Burke, M. M., Mello, M. P., & Goldman, S. E. (2016b). Examining the feasibility of a special

    education advocacy training program. *Journal of Developmental and Physical*

    Disabilities, 28, 539-556. doi: 10.1007/s10882-016-9491-3

Burke, M. M., & Goldman, S. E. (2017). Documenting the experiences of special education

    advocates. *The Journal of Special Education, 51,* 3-13. doi: 10.1177/0022466916643714

Burke, M. M., Meadan-Kaplansky, H., Patton, K. A., Pearson, J. N., Cummings, K. P., & Lee, C.

    (2017). Advocacy for children with social-communication needs. Perspectives from

    parents and school professionals. *The Journal of Special Education,* 1-10.

    doi: 10.1177/0022466917716898

Duckworth, A. L., Peterson, C., Matthews, M. D. & Kelly, D. R. (2007). Grit: Perseverance and

    passion for long-term goals. *Journal of Personality and Social Psychology, 92*, 1087-

    1101. doi:10.1080/00223890802634290

Fiske, S. T., Cuddy, A. J., & Glick, P. (2007). Universal dimensions of social cognition: Warmth

    and competence. *Trends in Cognitive Science, 11*, 77-83. doi: 10.1016/j.tics.2006.11.005

Goldman, S. E., Burke, M. M., Mason, C. Q., & Hodapp, R. M. (2017). Correlates of sustained

      volunteering: Advocacy for students with disabilities. *Exceptionality, 25*, 40-53.

      doi: 10.1080/09362835.2015.1064420

Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research

      electronic data capture (REDCap)- A metadata-driven methodology and workflow

      process for providing translational research informatics support. *Journal of Biomedical*

      Information, 42, 377-381. doi:10/1016/j/jbi.2008.08.010

Individuals with Disabilities Education Improvement Act, 20 U.S.C. § 1400 et seq. (2004).

Jamison, J. M., Fourie, E., Siper, P. M., Trelles, M. P., George-Jones., J., Grice, A., …

      Kolevzon, A. (2017). Examining the efficacy of a family peer advocate model for Black

      and Hispanic caregivers of children with autism spectrum disorder. *Journal of Autism*

      and Developmental Disorders, 47, 1314-1322. doi:10.1007/s10803-017-3045-0

McNaught, C., & Lam, P. (2010). Using Wordle as a supplementary research tool. *The*

      Qualitative Report, 15, 630-643. Retrieved from http://nsuworks.nova.edu/

      tqr/vol15/iss3/8

Mueller, T. G. (2015). Litigation and special education. The past, present, and future direction

      for resolving conflicts between parents and school districts. *Journal of Disability Policy*

      Studies, 26, 135-143. doi: 10.1177/1044207314533382

Nachsen, J., Anderson, L., & Jamieson, J. (2001). The Parent Advocacy Scale: Measuring

      advocacy in parents of children with special needs. *Journal on Developmental*

      Disabilities, 8, 93-105. Retrieved from https://oadd.org/journal/volume-8-number-1/

Patton, M. Q. (2002). *Qualitative evaluation and research methods*. Thousand Oaks, CA: SAGE.

Phillips, E. (2008). When parents aren't enough: external advocacy in special education. *The Yale Law Journal, 117*, 1802–1853. Retrieved from http://digitalcommons.law.yale.edu/ylj/vol117/iss8/3

Robertson-Kraft, C., & Duckworth, A. L. (2014). True grit: Trait-level perseverance and passion for long-term goals predicts effectiveness and retention among novice teachers. *Teachers College Record, 116,* 1-27. Retrieved from http://www.tcrecord.org/Content.asp?ContentId=17352.

Taylor, J. L., Hodapp, R. M., Burke, M. M., Waitz-Kudla, S. N., & Rabideau, C. (2017). Training parents of youth with autism spectrum disorder to advocate for adult disability services. *Journal of Autism and Developmental Disorders, 47*, 846-857. doi:10.1007/s10803-016-2994-z

Trainor, A. A. (2010). Diverse approaches to parent advocacy during special education home-school interactions. *Remedial and Special Education, 31*, 34-47. doi:10.1177/0741932508324401

Turnbull, H. R., Shogren, K. A., & Turnbull, A. P. (2011). Evolution of the parent movement: Past, present, and future. In J.M. Kauffman & D.P. Hallahan (Eds.), *Handbook of special education* (pp. 639-653). New York, NY: Routledge.

United States Department of Agriculture (2013). *Rural-urban continuum codes*. Retrieved from https://www.ers.usda.gov/data-products/rural-urban-continuum-codes/

United States Census Bureau. (2017). *Quickfacts: Tennessee*. Retrieved from http://www.census.gov/quickfacts/tn

Wakelin, M. M. (2008). Challenging disparities in special education. *Northwestern Journal of*

    Law & Social Policy, 3, 263-288. Retrieved from https://scholarlycommons.law.

    northwestern.edu/njlsp/vol3/iss2/6

Wojciszke, B. (1994). Multiple meanings of behavior: Construing actions in terms of

    competence or morality. *Journal of Personality and Social Psychology, 67*, 222-232.

    doi:10.1037/0022-3514.67.2.222

York, L.A. (2005). *Descriptive analysis of comments obtained during the process of regulating*

    the reauthorization of the Individuals with Disabilities Education Act of 2004

    (unpublished dissertation). Denton, Texas. University of North Texas.

Table 1

Participant Demographics (N = 142)

Characteristic	% (*n*)
Gender	
Female	94.4% (134)
Male	5.6% (8)
Race/Ethnicity	
White	73.9% (105)
African-American	12.0% (17)
Latino	4.9% (7)
Asian-American	1.4% (2)
Other	0.7% (1)
Educational Background	
High school graduate	7.0% (10)
Some college	26.1% (37)
College degree	25.4% (36)
Graduate degree or higher	37.3% (53)
Missing	4.2% (6)
Role*	
Caregiver for a child with a disability	70.4% (100)
Mother	92.0% (92)
Father	4.0% (4)
Grandparent	3.0% (3)
Other	1.0% (1)
Person with a disability	2.8% (4)
School personnel	9.2% (13)
Non-school service provider in disability field	21.8% (31)
Graduate student	5.6% (8)
Cohort	
Fall 2014	26.1% (37)
Fall 2015	33.1% (47)
Fall 2016	40.8% (58)
Home County	
Davidson	16.9% (24)
Hamilton	10.6% (15)
Knox	7.7% (11)
Shelby	17.6% (25)
Williamson	10.6% (15)
Other	36.6% (52)

*Total does not sum to 142 because respondents selected all responses that applied.
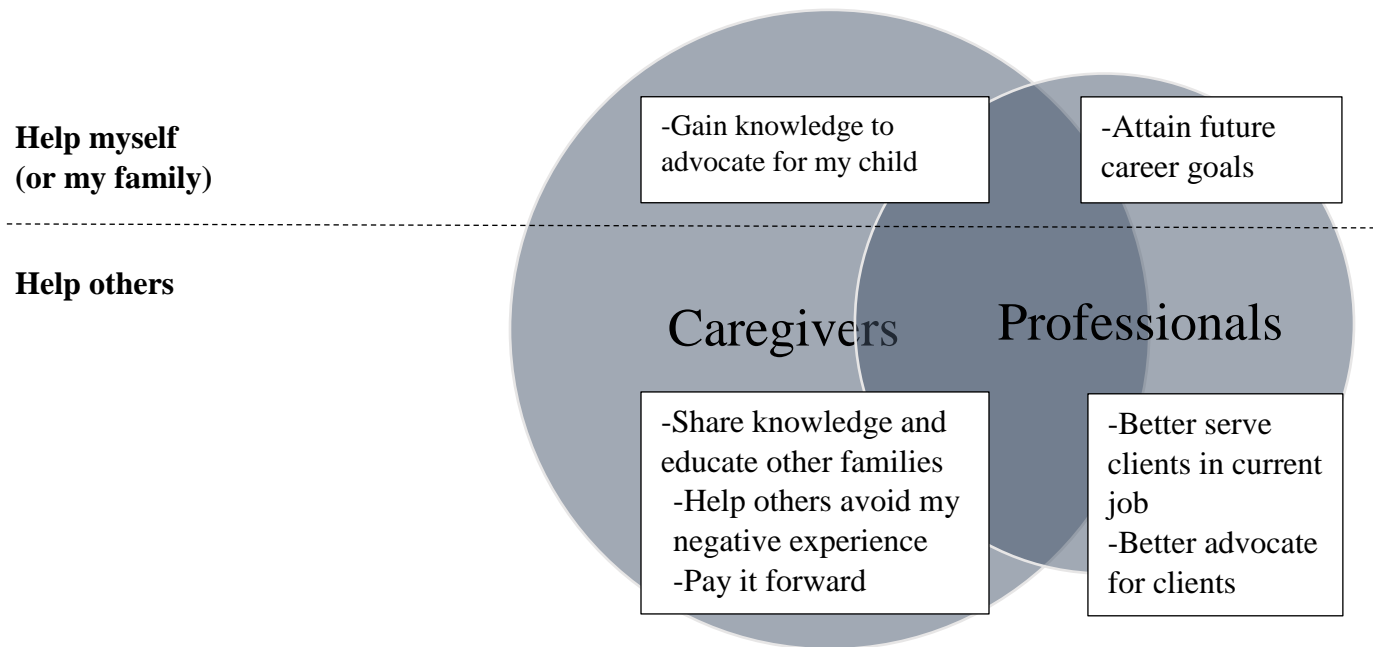
**Help myself
(or my family)**

Help others

-Gain knowledge to
advocate for my child

-Attain future
career goals

Caregivers   Professionals

-Share knowledge and
educate other families
 -Help others avoid my
 negative experience
 -Pay it forward

-Better serve
clients in current
job
-Better advocate
for clients

Figure 1. Research question one themes separated for caregivers and professionals.

Theme 1: Advocate

Knowledge and skills learned during advocacy training lead to:

Advocate for:	
Own family/child	Other individual children/families by: -Educating and empowering -Helping families navigate the special education process -Helping families access needed services -Providing affective support
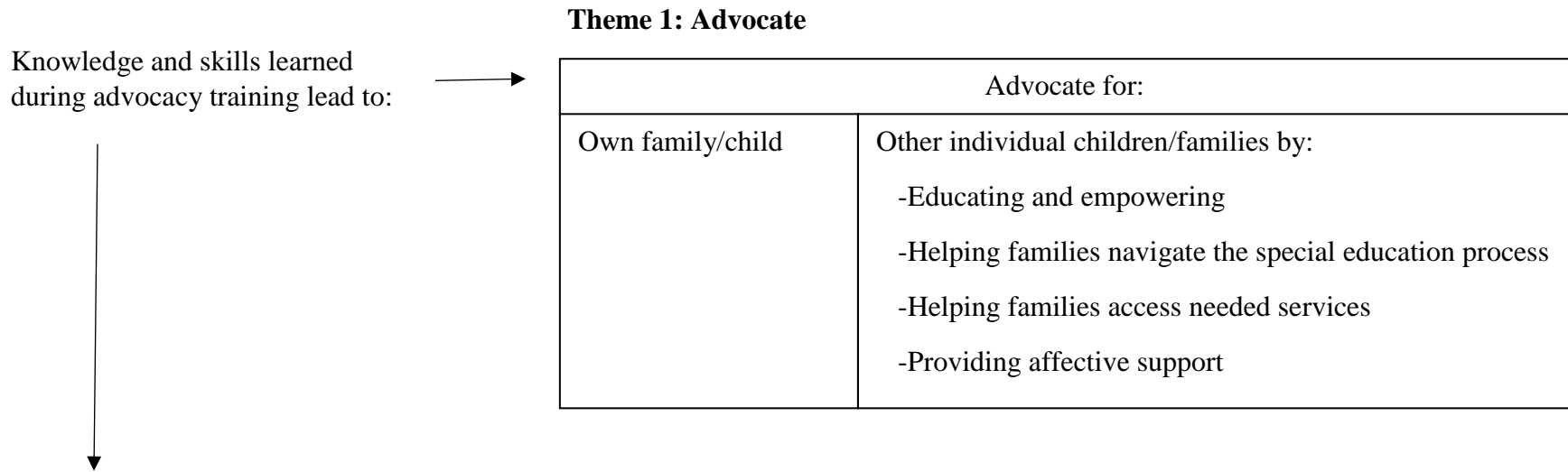
Theme 2: Provide "service" to the community

	Level		
	School/Service System	Local Community	State-Wide/National
Caregivers	Build family-professional partnership → Promote communication	Expand disability supports/network → Support groups / Advocacy supports and services	Impact policy change
Professionals	Train professionals		

Figure 2. Research question two themes separated for caregivers and professionals.

Figure 3. Word cloud of advocate attributes.