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Legislative Advocacy Among Parents of Children with Disabilities

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Abstract

In the past, parents of children with disabilities have spearheaded several policies for individuals with disabilities. However, little is known about their experiences with legislators. To address this gap, focus groups and surveys about legislative advocacy were conducted with 127 parents of individuals with disabilities across four states. The purpose of the study was to explore parent perceptions about experiences with legislative advocacy including the frequency of, strategies for, and barriers to legislative advocacy. Descriptive statistics were conducted to analyze the survey data; constant comparative analysis was used to analyze the focus group data. Participants reported engaging in various forms of legislative advocacy. Participants shared positive and negative experiences of interacting with legislators, including individual and collective advocacy efforts. Some participants did not engage in legislative advocacy due to intimidation. Relationships facilitated legislative advocacy for participants. Implications for future research about legislative advocacy and practices to facilitate legislative advocacy are discussed.

Historically, parents have spearheaded legislative change for their children with disabilities (Turnbull, Shogren, & Turnbull, 2011). Indeed, each time the Individuals with Disabilities Education Act (IDEA) is reauthorized, the Office of Special Education Programs encourages parents of individuals with disabilities to provide input to inform the legislation (Author, 2015). Yet, little generalizable information is known about parent experiences with legislators. In a study of 76 parents of individuals with disabilities, only 3.95% reported engaging in legislative advocacy (Wright & Taylor, 2014). Due to systemic barriers, parents from low-income backgrounds and who are emerging bilingual learners are less likely to engage in legislative advocacy (Trainor, 2010; Author, 2018). Thus, although some parents have made sweeping legislative changes, it is important to understand their legislative advocacy (i.e., methods to impact systemic change such as contacting individuals with decision-making authority, Jackson-Elmoore, 2006) to support all families in engaging in such advocacy. The purpose of this study was to explore the legislative advocacy experiences of parents of individuals with disabilities.

It is important to understand the frequencies of different types of legislative advocacy. Balcazar, Keys, Bertram, and Rizzo (1996) conducted a study of 21 parents of individuals with disabilities who completed a disability leadership program. Although the participants engaged in multiple forms of advocacy, only one participant engaged in legislative advocacy. This participant “was responsible for introducing a bill and encouraging state legislators to pass the bill into law” (p. 347). However, no other information was provided about this participant. Without understanding the frequency and nature of parent efforts, we cannot determine an accurate baseline of legislative advocacy or facilitate advocacy among all families.

It is also important to explore the nature of legislative advocacy. Author (2018) conducted focus groups with parents of individuals with disabilities, exploring their experiences with legislative advocacy. Overall, parents reported mixed experiences – positive, negative and no experiences. Parents with positive experiences reported meeting with legislators who showed concern for their circumstances. Among the parents with negative experiences, they reported that legislators were unresponsive to their concerns. Some parents reported no experiences because of limited knowledge about the legislative process or negative feelings toward legislators. Notably, all Latino participants reported no experiences with legislative advocacy. Unfortunately, this study was limited to one state; it is unclear whether such experiences generalize across states.

It is also critical to understand legislative advocacy strategies. Previous studies have identified several strategies: educating legislators, engaging in collective advocacy, and developing relationships with legislators (Author et al., 2018; Donovan, 1986). Such studies were limited to one state and small sample sizes; thus, it is unclear whether such strategies are generalizable. It is equally important to understand barriers to legislative advocacy. Trainor (2010) conducted focus groups with parents of children with disabilities. None of the parents who were from low-income backgrounds conducted legislative advocacy. Among the parents who conducted such advocacy, participants reported several barriers including: needing knowledge about the legislative process; having a strong social network; needing time; and coping with fatigue from advocacy efforts. This study was limited to one Midwestern state.

Parents have facilitated tremendous legislative changes enabling all children with disabilities to attend public schools and receive supports to forge educational progress. Yet, little generalizable information is known about their legislative advocacy. Indeed, most extant research relies on small samples wherein only a few participants engaged in such advocacy (e.g.,

Trainor, 2010; Wright & Taylor, 2014). To ensure all parents—regardless of geographic location, socioeconomic status or cultural and linguistic background—can engage in legislative advocacy, it is critical to better understand the advocacy process. Our study had four research questions: Among parents of children with disabilities, (1) What is the frequency of legislative advocacy activities?; (2) How do they characterize their legislative advocacy experiences?; (3) What are their strategies for legislative advocacy?; and (4) What are the barriers to legislative advocacy?. Notably, our research questions are broad to have a global understanding of legislative advocacy among a specific population (i.e., parents of children with disabilities). Specifically, we endeavored to understand more global legislative advocacy efforts using established survey scales, for example, to examine general citizenship as well as specific measures and focus group questions to examine legislative advocacy within special education. By exploring both broad legislative advocacy and advocacy specific to special education, we hoped to have a more holistic understanding of the phenomenon of legislative advocacy.

Method

We used a concurrent triangulation design to analyze mixed methods data (Creswell, 2009). Specifically, we collected qualitative (i.e., focus group) and quantitative (i.e., survey) data at the same time. We analyzed the data separately and then compared the data to confirm, cross-validate, and corroborate our findings. This study was part of a larger project examining the efficacy of a parent civic engagement program.

Participants

Participants met these inclusionary criteria: parent of a child with a disability, able to participate in a 6 hr civic engagement training, and willing to complete a survey and participate in a focus group. Overall, 127 parents of children with disabilities were included

in the study. Of the participants, 39.37% ($n = 50$) were from MA, 29.99% ($n = 38$) were from IL, 21.25% ($n = 27$) were from TN, and 9.49% ($n = 12$) were from NH. The majority (86.82%; $n = 111$) of participants was mothers. The sample was racially diverse with 51.94% ($n = 66$) of the participants reflecting racial and ethnic minority backgrounds. See Table 1.

Recruitment

The authors collaborated with the Parent Training and Information Centers (PTI) in Illinois, Massachusetts, New Hampshire and Tennessee, who shared information with parents of children with disabilities about the study. The PTIs distributed flyers and sent emails to their constituents and other family support agencies, including those that served Spanish-speaking families of children with disabilities. Other methods included: email blasts, Facebook posts, and word-of-mouth, though we are unsure of the degree to which these contributed to recruitment. All recruitment materials were available in English and Spanish. All participants received \$20 gift-cards for their participation.

Procedures

First, we received Institutional Review Board approval to begin this study. To register for the civic engagement training, participants completed a survey online or via hard copy, upon request. The survey included the quantitative measures. After completing the survey, the participant was registered for the training. Prior to the training, before receiving any content, participants completed focus groups scheduled to last one hour. After the focus group concluded, the training began. All materials were available in English and Spanish.

Focus groups. All authors facilitated focus groups. Each author has had prior training and experience facilitating focus groups. Each author had previously worked in the special education field; further, three of the authors were also family members of individuals with

disabilities. Each author shared their connection to the disability field at the beginning of the focus group to facilitate rapport. Each focus group had one facilitator and one note-taker. Each focus group was approximately one hr. There were 21 focus groups with, on average, six participants in each. By state, there were seven focus groups in MA, six in IL, six in TN, and two in NH. Notably, of the 21 focus groups, three were conducted in Spanish. The facilitator for the Spanish focus groups was a native Spanish speaker and Latina; notably, two of the authors were Latina and native Spanish-speakers. Additionally, none of the authors facilitated the advocacy sessions; these sessions were only facilitated by the Parent Training and Information Center staff members. Each focus group was audio-recorded using Voice Record software. Each focus group was transcribed verbatim, and the transcripts were used as data. Each Spanish focus group was transcribed (in Spanish) and forward- and back-translated for accuracy checks (Brislin, 1970) by the third and sixth authors who are both Latina and native Spanish speakers.

Field notes and memos. The field notes were written by hand or typed during and after the focus groups. They included descriptive information, such as the date and time, setting, and number of participants in each focus group. Field notes were treated as data along with the focus group transcripts. Researcher memos included reflective information about the focus groups (during data collection), and coding ideas and emerging themes (during data analysis). Researcher memos were discussed during the research team's weekly calls and helped to guide analysis.

Member checks. Regarding trustworthiness of the qualitative methods, we completed first level and second level member checks of the data and analysis for all focus groups in all states (Brantlinger, Jimenez, Klinger, Pugach, & Richardson, 2005). Level-one member check summaries were created at the end of each focus group. The first author briefly read the

summary, and participants offered no changes. After the categories and themes for the focus group data were identified and finalized, a second level member check was used to help authenticate the analysis. Specifically, after reading the transcripts and notes, a two-page summary of each focus group was developed. Each summary was sent to participants via email or phone to determine the accuracy of the summary; participants were instructed to complete a short online survey with any changes they would make to the summaries. Of the 127 participants, 120 participants responded and agreed with their respective focus group summaries. No changes were suggested.

Measures

Broad Civic Engagement Scale (Lopez et al., 2008). This scale assesses civic engagement via 19 questions which contribute to three subscales: electoral activities (e.g., voting, campaign contributions), civic activities (e.g., community problem solving, active membership in a group or association) and political activities (e.g., contacting officials, protesting). In previous studies, the reliability of the subscales has been high (ranging from .64 to .76, Sessa, Grabowski, & Shashidhar, 2013). In this study, each subscale had high reliability: electoral activities (alpha = .82), civic activities (alpha = .85), political activities (alpha = .86).

Special education legislative advocacy scale (Author, 2017). With eight items pertaining to special education legislative advocacy activities, the responses were dichotomous: no (0) or yes (1). Items included: visiting a legislator, e-mailing a legislator, speaking to a support group, writing to the newspaper about special education, telling other parents about special education policy, other forms of civic engagement, sharing information about the IDEA reauthorization, and calling a legislator. In a prior study with parents of children with disabilities, the scale had

strong reliability (Kuder-Richardson coefficient = .63, Author, 2017). In this study, the Kuder-Richarson coefficient = .75.

Focus group protocol. The focus group protocol was semi-structured so that participants could freely speak about legislative advocacy. The focus group protocol was developed based on extant literature about special education (Turnbull, Shogren, & Turnbull, 2011; Author, 2017) and legislative advocacy (Author, 2017; Trainor, 2010; Wright & Taylor, 2014). The focus group was piloted in English and Spanish with parents of individuals with disabilities. Only minor changes were made (e.g., changes to the wording, change of the order of questions). See Appendix A for the focus group protocol.

Analyses

Within the concurrent triangulation design, the two types of data were analyzed separately and then compared and integrated. Analyses for the surveys included descriptive statistics. Specifically, frequencies, means, ranges, and standard deviations were conducted for each scaled measure and individual items.

The focus group transcripts and field notes were coded inductively using a multi-stage process to identify participant perspectives on legislative advocacy. Two of the authors--who had facilitated some of the focus groups and were familiar with them--independently coded each of the focus group transcripts. First, they each read the same six (~30% of the total) transcripts to familiarize themselves with the data. Then, independently, they used constant comparative analysis (Creswell, 2013; Glaser & Strauss, 1967) to code the same six transcripts. Using a line-by-line approach, they examined each piece of data (i.e., each line). Each piece of data was highlighted and notated with a phrase. A line may have multiple codes if the line included multiple concept or ideas. Then, they met to discuss their individual codes resulting in 100 open

codes; they compared the codes for redundancy and to agree on the same terminology. This resulted in the creation of a codebook with 64 codes organized into five categories: Perspectives on Legislative Advocacy, Experiences with Legislative Advocacy, Strategies for Legislative Advocacy, Barriers to Legislative Advocacy, and Perspectives on Legislators. After developing the codebook, they independently coded the remaining 15 transcripts. While the codebook facilitated coding consistency, the coders also looked for new codes and categories in the remaining 15 transcripts that may not have emerged in the first six. Again, the coders met to discuss coding of the remaining 15 transcripts, resolve discrepancies, and in particular, to update the codebook with new codes and categories. Notably, the coders added several new codes but not new categories. Upon confirming the codes, the researchers focused on the broader categories and themes (Braun & Clarke, 2006). Using the coded data as a guide, the coders wrote detailed researcher memos for each focus group, identifying the key topics that were discussed and noting the topics (when possible) that were discussed by two or more participants.

Results

Below, we provide the findings with respect to each research question. Regarding the frequency of legislative advocacy activities, we first provide the quantitative survey results. Within these survey results, we provide the responses to the open-ended questions on the surveys. For the remaining research questions, we provide the qualitative findings.

Frequency of Legislative Advocacy Activities

Regarding the special education legislative advocacy activities, the mean number of activities was 2.60 ($SD = 2.11$, ranging from 0 to 7). The most frequently conducted special education legislative advocacy activity was emailing a legislator about special education (44.09%, $n = 56$), whereas only 16.453% ($n = 21$) reported having written to newspaper or other

media outlet about the IDEA reauthorization. With respect to electoral advocacy activities, on average, participants conducted 11.02 activities ($SD = 3.00$, ranging from 6 to 18). Among the most frequent electoral advocacy activities, 66.14% ($n = 84$) of participants reported that they were always registered to vote. See Table 2. Regarding civic advocacy activities, on average, participants reported conducting 19.26 activities ($SD = 4.86$, ranging from 9 to 27). Further, more than half of the sample reported engaged in volunteerism as a civic advocacy activity. Lastly, with respect to political advocacy activities, on average, participants reported conducting 16.67 activities ($SD = 4.89$, ranging from 9 to 27). See Table 3. Within the special education legislative advocacy activity and the electoral advocacy scale, participants were able to write an “other” response. There were 188 write-in responses. Across special education and electoral advocacy, participants reported: attending events, political advocacy, and online advocacy. For special education advocacy, participants reported joining social movements. For electoral advocacy, participants reported generic volunteerism and fundraising. See Table 4.

Parent-Legislator Interactions

“I don’t know where to start.”: No interactions. Some participants did not have experience with legislative advocacy. A parent from Massachusetts reported feeling unprepared to interact with their legislator: “I don’t know what to say yet. So, I got to learn how to do that eventually.” Likewise, a mother from New Hampshire expressed her uncertainty related to interacting with her legislator, “I don’t know where to start. I think that’s my problem.” Although most participants reported feeling intimidated and uncertain, several other participants expressed no need to engage in legislative advocacy as they were more focused on meeting their children’s needs. For instance, a mother from Illinois shared:

I went the legal route, so I already established getting her out of public school and in private placement...so I tried to go with the school, and I took it to the next level with the attorneys, so I didn't even bother with legislators.

A mother of a child with autism who also resided in Illinois, similarly questioned whether legislative advocacy was worth the time and energy:

Now, we go to legislators, right. Do I decide to put a bunch of energy into advocating to get more money? Do I really think that would happen? I love and advocate for my son...I want to advocate for families. So, bringing it back to legislators... I just don't know if the legislators fit into it.

“They are people, you know?”: Individual interactions. Several participants described their experiences interacting with legislators on an individual basis via calling, emailing, writing letters, meeting in-person and testifying at legislative hearings. While describing their individual interactions, some participants reported they were in contact “regularly” or “all the time” with their legislators, sharing their concerns and information, such as research reports to educate their legislators about disability related issues. Moreover, participants commented on the human nature of legislative advocacy. Specifically, participants emphasized that legislators are people too—and thus, families should not feel intimidated by them. A mother from New Hampshire reported: “I have contacted lots of legislators, and they're people, you know?...Don't be scared. You know, they put their pants on one leg at a time, like everybody else.” Moreover, some participants believed it was their civic duty to voice their concerns and educate their legislators. For example, a New Hampshire mother reported:

I speak to them [legislators] regularly. Yes. I send in reports, I send in different things, I

send in ‘Look at this, look at that’. I want people to look at it. The way I kind of see it is, if I don't vote and I don't say what I think, I don't have the right to complain, and I want the right to complain.

“It is easier if you have a few other parents.”: Collective interactions. Several participants spoke about not knowing how to approach their legislators and feelings of intimidation. Thus, some participants described their experiences advocating in groups. They described receiving peer support to conduct legislative advocacy and, subsequently, feeling empowered. A parent from Massachusetts reported that many families may find legislative advocacy intimidating, however: “...it’s easier if you have a few other parents go with you, kind of help you go through the language and everything.” A parent from Massachusetts echoed this experience and expanded upon the support received by a collective approach:

Well I took a leadership series [at the PTI], so the first time I ever contacted a representative or a state senator was through them which was great because they really lead you step-by-step on the process and you really had the support behind you and of course when you’re in the southeast region you have other people that probably have the same senator or maybe even representative with you so you’re not going there alone.

When participants spoke about a collaborative approach, in some instances, they emphasized the importance of holding legislators accountable. A participant from Illinois suggested that legislators are not accountable because special education does not have collective advocacy for disability-specific issues: “It [special education] is not a well-organized lobby [so] there’s no pushback, they don’t feel the heat of it.” This sentiment was reverberated in other focus groups in Illinois. Another parent from Illinois suggested, “There needs to be a big not-for-

profit that is specifically for special education [advocacy]. . . because, if not, nothing is ever going to change. It won't change.”

Strategies for Legislative Advocacy

Reaching out to legislators. Some participants shared experiences of contacting legislators to express their concerns. A participant from Massachusetts shared:

I've knocked on doors. I've gone to the state house, I've gone, and I've talked to some legislators to affect change and pass bills all the time. I think it's like, some of them will just let you talk to the representative or the staffer. Some of them will take the time to talk with you and listen, especially they want to hear those stories.

Another participant from Massachusetts shared her experiences with going to Washington D.C. to meet with legislators to prevent a program for children with disabilities from being defunded. She stated: “I actually went to Washington D.C. because I was like ‘My son is not going to lose his ability to have peer connections with reading’ . . ., and they saved the program.” Participants also reported contacting legislators although they received mixed responses from the legislators. A mother of a child with a disability from Massachusetts shared, “It's been sort of a meet and greet in the community, reminding them who I am and who I represent, um, but hand delivering a letter in the office, no response.”

Using personal touch with their child with a disability. Some participants reported offering anecdotes and bringing their children to legislative advocacy events as useful strategies. In this way, participants reported that their advocacy may be memorable to the legislators. A participant from Tennessee shared, “I took my daughter and just met with them. . ., I said [to the legislator] keep [her daughter's name] and me in mind when you make legislation.” Some participants reported being unable to attend legislative advocacy events due to childcare needs.

In response, several other participants suggested that they bring their children for the memorable effect on legislators. A participant from Illinois shared, “We went down to Springfield [capital]. I think my daughter was in 7th or 8th grade, and we went to Springfield [for] the breakfast meeting that we had, and the kids were passing out flyers and all that.”

Building relationships with legislators and staff. Participants shared that building rapport with the legislators and their staff facilitates advocacy. A mother from Massachusetts shared her experiences in working through the connections that she discovered about the legislators: “I know that my senator has a grandson with autism. So, it’s like working through those connections.” A mother who reported many experiences advocating for her child in Massachusetts shared a strategy of researching the staff members of a legislator; this helped her understand their roles:

I feel like a lot of time, it’s figuring out who their staffer is, because they [legislators] might not be reading it..., if there are 200 letters or faxes or emails or phone calls from their district about the same thing, their staffers are going to flag that for them.

Finding some commonalities on a personal level between the parents and the legislators, such as religion, was mentioned as well. A parent in Tennessee reported:

So when I found out he [legislator] was a Christian... I was like oh okay. So just kind of leading from those things. . . , doing research, find that little niche and put it in their bio and kind of use that to our advantage.

Participants also shared that building a positive relationship with legislators and expressing their gratitude towards legislators would help. For example, a mother from Massachusetts stated, “sort of thanking them at every opportunity. . . , just thank you so much for what you’ve done, for the legislation you’ve pushed.”

Barriers to Legislative Advocacy

Logistical barriers. Participants reported facing several logistical barriers when conducting legislative advocacy. These included childcare (as described above), time, and distance. For example, a mother from Massachusetts left her job to become a full-time advocate for her son with Down syndrome. She reported:

Parent A: I left my job so that I could essentially become an educational advocate for my son...I'm taking him out of school to go to the Down syndrome advocacy day next week so that's like my first foray into advocacy but I'm thinking as he's a teenager now, having him become a part of that process, that you know what, it's okay if he misses a day of school to go visit his state legislators.

Parent B: Yeah. Time is a barrier.

A mother from Tennessee stated the long drive to her state capital to meet with legislators precluded her advocacy: "Well, they're [legislators] all in Nashville. So, I called Memphis to see if they had an office... That's still a two to three-hour drive... so, that's the only barrier."

Systemic barriers. Due to the lack of state funding, participants described having a sense that legislative advocacy would be ineffective. A mother from Massachusetts stated:

I think that so much of it is tied to the foundation budget. Honestly, unless we could change the budget so many of these issues aren't going to be fixed because it's an unfunded mandate. What are you going to do?

A mother from Illinois reported: "It's a numbers game. It's a money game. Illinois is bankrupt." Notably, at the time, Illinois had lacked a state budget for three years. In combination with the logistical barriers, legislative advocacy did not seem worth it to some of the participants due to the systemic barriers.

Knowledge barriers. Some participants reported having little knowledge about legislative advocacy. Accordingly, participants were unsure how to conduct legislative advocacy. A mother from Massachusetts reported that it was intimidating to approach legislators: “I think a big obstacle for me is just, it’s a little intimidating to think how much I need to learn about an area to be able to talk persuasively to a legislator.” Similarly, a mother from Illinois stated that she did not have enough understanding of the legislative process to speak to her legislators about changes. The participant stated: “I mean, I want to participate as a citizen [in legislative advocacy] ...I want to learn how to do that [speak to legislators] but yeah, I don’t know.”

Power differential. Participants reported that the initial contact with legislators was intimidating. For example, participants in New Hampshire stated:

Parent A: They absolutely are [people, too], but it’s getting that initial contact. Like it’s intimidating because they’re almost like, it took going to PIC [Parent Information Center, the NH PTI] before I understood the educational terms. Now you want me to understand the political terms on top of that? Well, guess what? I don’t know them and so I’m afraid of looking like a fool when I talk to a legislature, just to put that out there. That is my fear and I know it might not be a rational fear but to talk to a legislature to try and communicate what my issues are, my concerns are, I’m already not a very good communicator but to do that on a different level that I’m not familiar with is scary.

Parent B: They [legislators] are [intimidating]!

Similarly, a mother from Tennessee stated contacting legislators can be intimidating especially if parents are focusing on making changes to specific bills and legislators ask specific questions. She further stated, “And it’s really intimidating for parents to advocate to legislators...it’s intimidating and frustrating.”

Anti-immigrant perspective. Participants in the Spanish-speaking focus groups reported that the stigma around immigration prevented their legislative advocacy. Participants reported that anti-immigrant perspectives and policies complicated and diminished their legislative advocacy. Consider participants in a Spanish-speaking focus group in Tennessee:

Parent A: Estamos viviendo en Tennessee y Tennessee ha estado legislando leyes contra los inmigrantes... desafortunadamente, la legislatura no esta haciendo mucho por las minorías y eso se agrega al tema actual del racismo de inmigración que esta administración no es algo que nadie sepa, es algo que vemos todos los días en la televisión...es un momento muy difícil para las leyes y para las minorías.

Parents B, C, D: Eso es muy cierto. (Todos los participantes asintieron en acuerdo).

Parent A: We are living in Tennessee and Tennessee has been legislating laws against immigrants. Unfortunately, the legislature is not doing much for the minorities and that is added to the current issue of the immigration racism that this administration is not something that nobody knows, it's something we see every day on television...it is a very difficult time for the laws and for minorities.

Parents B, C, D: That is very true. (All participants nodded in agreement)

Similarly, a mother from Tennessee described being fearful to contact her state's legislators because of her immigration status:

Tenemos es que tenemos miedo de los legisladores porque no somos de este país. En este país somos inmigrantes y todo eso está sucediendo ahora mismo. Hay mucho miedo y horror al hablar con un legislador. Es todo por miedo y no quieres que pase algo —estar separado de tus niños.

We are afraid of the legislators because we are not from this country. In this country, we

are immigrants and everything that is happening right now. There is a lot of fear and horror to go talk to a legislator. It's because of fear and you don't want something to happen—being separated from your children.

Discussion

This study had three main findings. First, this study suggests that many parents are engaging in legislative advocacy; however, such activities varied. The most common activities included contacting legislators, voting, and volunteering. Contacting legislators and voting activities align with prior research showing that parents often spearhead legislative advocacy initiatives (Turnbull et al., 2011). Volunteering aligns with prior research demonstrating that parents of children with disabilities often volunteer for disability causes (Balcazar, Keys, Bertram, & Rizzo, 1996). Prior studies about legislative advocacy suggested that parents of children with disabilities infrequently engage in legislative advocacy (Trainor, 2010; Wright & Taylor, 2014). However, such studies did not include volunteering or voting as methods of legislative engagement even though such activities are considered civic and electoral legislative advocacy activities (Lopez et al., 2008). Thus, the definition of legislative advocacy may need to be broadened in future studies to include electoral, political, and civic advocacy methods to accurately capture the advocacy of parents of children with disabilities.

Second, participants had varied involvement with legislators ranging from no involvement to individual and collective advocacy. Each of these experiences has important implications. For example, participants' feelings about their civic duty influenced their legislative advocacy. Prior research has discussed individual advocacy as an expectation for parents of children with disabilities (Kalyanpur, Harry, & Skrtic, 2000). Similarly, there may also be an expectation of legislative advocacy among parents of children with disabilities. In

addition, some parents reported lacking knowledge to engage in legislative advocacy. This barrier is reminiscent of the frequently discussed power differential between parents and education professionals (Leiter & Krauss, 2004). This study suggests that the power differential may be expanded to legislative advocacy.

There were specific barriers among Spanish speaking families including: anti-immigrant rhetoric, discrimination, and stigma. Indeed, discrimination and stigma are common barriers among Spanish-Speaking families when advocating for their own children (Magaña, 2000). However, the current polarizing political climate may further exacerbate this barrier especially among Spanish-speaking families with legislators—individuals who may harness policymaking power to deport undocumented families (Johnson, 2008). Thus, it seems that such barriers are increasingly relevant and require policy and research attention.

Lastly, relationships facilitated legislative advocacy for participants. Participants emphasized that relationships with legislators were critical for promoting their disability-related issues. This finding is consistent with the literature about the value of social networking for facilitating parental (Author, 2016) and legislative advocacy (Trainor, 2010; Wright & Taylor, 2014). Most advocacy trainings focus on increasing empowerment and knowledge among parents of children with disabilities (Magaña et al., 2015). However, this study suggests that relationship-building may be a critical element for effective advocacy. In light of this, practitioners should consider addressing relationships in advocacy trainings.

There are a few limitations worth noting. Although the sample was diverse, they only represent a small, highly-educated portion of the population across four states. Further, given that participants were also registered to attend an advocacy training and were recruited using Parent Training and Information Centers, the participants may not be representative. Also, children with

traumatic brain injury were not represented in the sample. Thus, there may be limited transferability of the findings. Second, the use of qualitative methods for studying this phenomenon is not intended to be generalized. Therefore, the findings of this study represent the experiences and perceptions of these particular participants, at this given time, and may not be generalized to a larger population of parents outside of this sample. Additionally, the Broad Civic Engagement Scale has marginal reliability; thus, there may be concerns of its use as a scaled measure among parents of children with disabilities.

Directions for Future Research

Future studies should examine different types of advocacy activities. For example, participants reported the importance of personal contact with legislators but also reported frequently conducting online advocacy (e.g., advocacy via social media). Research should examine whether there is a differential impact of in-person versus online advocacy. Given the increasing online presence of advocacy activities (Chalmers & Shotton, 2016), it is timely to examine whether such activities are effective. Further, because that parents of children with (versus without) disabilities devote greater time to childrearing (Smith et al., 2006) and, thus, have less time to conduct legislative advocacy, it is important to understand whether social media can be an effective but less time-intensive advocacy method.

Future research should also examine the potential impact of cultural and linguistic background, type of disability, and child age on legislative advocacy. Although we took detailed field notes, we could not confidently identify the ethnicity, type of disability, or age of the child of each participant's quotes in the focus groups. Thus, we cannot discern differences in barriers with respect to ethnic groups or child age. However, prior research suggests the culturally and linguistically diverse parents face greater systemic barriers in advocacy (Trainor, 2010). Thus,

research is needed to determine whether such barriers exist for certain cultural groups with respect to legislative advocacy. Additionally, research is needed about the type of disability. In the past, parents of children with intellectual disability have primarily conducted legislative advocacy efforts (Turnbull, Shogren, & Turnbull, 2011); it is unclear whether the type of disability influences the frequency of and experiences with legislative advocacy. Finally, research is needed about the age of the child. Parents of younger children are just beginning to navigate disability policy (Author, 2017); as such, they may be less likely to engage in legislative advocacy efforts. Indeed, legislative advocacy may be a phenomenon that requires longitudinal research to determine how it changes as the child ages.

Implications for Practice

One implication of this study relates to the PTIs, federally-funded centers that mostly offer trainings about special education rights and individual advocacy. However, as documented throughout the history of special education legislation (Turnbull, Shogren, & Turnbull, 2011), it is critical for parents to conduct legislative advocacy. PTIs should consider offering trainings about legislative advocacy. Such trainings would need to target the barriers to legislative advocacy, as identified in this study. For example, the training would need to offer ways to overcome intimidation, to find time to conduct legislative advocacy, and to learn about the legislative process. Admittedly, some of these barriers may be easier to overcome than others. For example, the training could include information about the legislative process to increase parent knowledge. Also, the training may include stipends to help with childcare and transportation so parents have time to conduct legislative advocacy. However, it may be more difficult to address fear, intimidation, and stigma among participants. Regardless, as parents are better informed about legislative advocacy, they are more likely to effect systemic change.

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Table 1.

Participant Demographics

Characteristic	% (N = 127)
Educational Background	
Some high school	6.29% (8)
High school graduate	7.87% (10)
Some college	17.32% (22)
College graduate	30.71% (39)
Graduate degree	37.79% (48)
Annual Household Income	
Less than \$15,000	11.02% (14)
Between \$15-29,999	9.45% (12)
Between \$30-49,999	16.53% (21)
Between \$50-69,999	14.17% (18)
Between \$70-99,999	19.69% (25)
Over \$100,000	22.83% (29)
Missing	6.29% (8)
What is your marital status?	
Married	66.93% (85)
What is your ethnicity?	
White	48.03% (61)
African American	19.69% (25)
Hispanic or Latino	19.69% (25)
Asian American	4.72% (6)
Other	7.87% (10)
What is your preferred language?	
English	89.92% (114)
Spanish	10.08% (13)
Which type of disability does your child have?*	
Autism Spectrum Disorder	48.06% (62)
Learning disability	37.21% (48)
Speech/language impairment	37.21% (48)
Developmental delay	32.28% (41)
Intellectual disability	27.91% (36)
Emotional/behavioral disorders	24.03% (31)
Health condition	18.60% (24)
Multiple disabilities	12.60% (16)
Blind/visual impairment	7.75% (10)
Deaf/hearing impairment	6.98% (9)
What is the gender of your child?	
Male	63.77% (81)
Female	32.28% (41)
Missing	3.93% (5)

*Percentages do not add up to 100% as participants could choose multiple types of disabilities

Table 2.

Frequency of Special Education Legislative and Electoral Advocacy Activities

<i>Have you conducted the following special education legislative activities...</i>			
	Yes, I have		
Engaged in another form of special education legislative advocacy (write-in)	47.24% (60)		
E-mailed a legislator about special education	44.09% (56)		
Told another parent about the IDEA reauthorization	36.22% (46)		
Called a legislator about special education	33.86% (43)		
Visited a legislator about special education	33.86% (43)		
Spoken to a parent support group about the IDEA reauthorization	32.28% (41)		
Written to the newspaper (or alternate form of media including Facebook, Twitter, etc.) about the IDEA reauthorization	16.54% (21)		
<i>Have you conducted the following electoral advocacy activities...</i>			
	No, never	Yes, usually	Yes, always
Are you registered in your election district?	13.38% (17)	13.38% (17)	66.13% (84)
Do you vote in national and local elections?	13.38% (17)	29.92% (38)	48.82% (62)
Have you volunteered for a political organization or candidate running for office?	62.20% (79)	20.47% (26)	10.24% (13)
Have you given money to a candidate, political party, or organization that supported candidates?	59.06% (75)	24.41% (31)	8.66% (11)
When there is an election taking place, do you try to convince people to vote for or against one of the parties or candidates or not?	42.52% (54)	41.73% (53)	7.87% (10)
Do you wear a campaign button, put a sticker on your car or place a sign in front of your house?	50.39% (64)	33.07% (42)	7.87% (10)

Table 3.

Frequency of Civic and Political Activities

	No, never	Yes, but not within the last 12 months	Yes, within the last 12 months
<i>Civic Activities</i>			
Worked together with someone or some group to solve a problem in the community where you live	16.54% (21)	22.83% (29)	52.75% (67)
Volunteered or done any voluntary community service for no pay	13.38% (17)	18.11% (23)	60.63% (77)
Volunteered with a religious group	34.65% (44)	22.05% (28)	33.86% (43)
Volunteered with an environmental organization	51.18% (65)	29.92% (38)	11.02% (14)
Volunteered with a civic or community organization involved in health or social services	32.27% (41)	16.54% (21)	56.69% (72)
Volunteered with any other group	23.62% (30)	21.26% (27)	45.67% (58)
Personally walked, ran, or bicycled for a charitable cause—this is separate from sponsoring or giving money to an event	29.92% (38)	30.71% (39)	31.50% (40)
Besides donating money, have you ever done anything else to help raise money for a charitable cause	24.41% (31)	26.77% (34)	40.16% (51)
<i>Political Activities</i>			
Contacted a newspaper or magazine to express your opinion on an issue	58.27% (74)	18.89% (24)	13.38% (17)
Called in to a radio or television talk show to express your opinion on a political issue even if you did not get on the air	68.50% (87)	11.81% (15)	10.24% (13)
Take part in a protest, march, or demonstration	43.31% (55)	21.26% (27)	23.62% (30)
Signed an e-mail petition about a social or political issue	23.62% (30)	27.56% (35)	38.58% (49)
Signed a written petition about a political or social issue	31.50% (40)	22.05% (28)	35.43% (45)
Not bought something from a certain company because you disagree with the social or political values of the company that produces it	22.83% (29)	20.47% (26)	46.46% (59)
Bought something because you like the social or political values of the company that produces it or provides it	29.13% (37)	17.32% (22)	44.09% (56)
Worked as a canvasser—going door to door for a political or social group or candidate	70.87% (90)	14.17% (18)	4.72% (6)

Table 4.

Write-in responses for special education and electoral advocacy activities

Themes	Examples	Sample Quotes
Online advocacy (special education and electoral advocacy)	Social media; Sent e-mails to other parents to increase electoral involvement; Facebook conversations; online disability groups	<p>“You have to post it everywhere, on a website, on Facebook, on Twitter, every platform... so information is getting to people”</p> <p>“I started a separate Facebook social media advocacy page within our community”</p> <p>“We are putting out information mostly through social media also with email so people can empower themselves”</p>
Attended events (special education and electoral advocacy)	Attended: local meetings, town meetings, school committee meetings, educational and law programs	<p>“I’m on the school committee”</p> <p>“I joined the Parent-Teacher Organization and started talking about building a special education parent advisory council working with the school”</p> <p>“I went to the conference myself, I grabbed all the information and I gave them to the teacher.”</p>
Generic volunteerism (electoral advocacy only)	Participated in: a cancer walk, phone banking, canvassing, door knocking, and yogathons	<p>“I started my own non-profit”</p> <p>“I have done events together, where particularly in budget years, I’ll try to help organize with other parents in my area”</p>
Fundraising (electoral advocacy only)	Coordinated fundraising events; sold goods and donated the proceeds; organized fundraising receptions.	<p>“I’m going to pay my #35 and go [to a fundraiser breakfast]”</p>
Political advocacy (special education and electoral advocacy)	Filed due process; Spoke with gubernatorial candidate; Conducted a rally for special education; Spoke at a city council meeting; Spoke to State Board of Education; Wrote to the state general assembly.	<p>“I was a part of the affidavit for the ISBE investigation”</p> <p>“If you’re born as a person with multiple difficulties, you automatically are political, and your advocacy starts right there.”</p>
Starting/joining a movement (special education advocacy only)	Joined: grassroots movement about dyslexia; “Families Organizing for Change” committee; special education parent advisory council.	<p>“I ran for the Special Education Advisory Council. I’m chair of that Parent Advisory Council.”</p>

Appendix A Focus Group Protocol

Introduce yourself. Briefly describe your connection to the field and the project. Specify your connection to family advocacy especially. I want to thank all of you for coming. I hope that each of you enjoys our discussion. I'm going to go over some ground rules before we start. We hope that this will be a lively discussion among all of us. We ask that you respect the **confidentiality** of the information that is shared here so that everyone can feel open to exchange your opinions, feelings, and beliefs. We also ask that the information discussed here will stay here and not be shared with others outside of the room. **If you need to get up** in the course of the conversation, feel free to do so. This is an informal discussion, so if you need to leave the room for a while, or if you have to get up and get a drink or you need to move around a little bit because you get stiff, feel free to do that. Last, there are **no right or wrong answers** here. We want to hear different points of view, so if your view on a topic differs from the views of others around the table, we need to hear that too. Group members do not have to agree, but everyone should listen respectfully as others share their views.

1. When you think about special education and the services your child receives, what would you change?
2. Do you feel like you can affect change for your own child's services?
 - a. How have you (or could you)?
 - b. What are the barriers?
3. Do you feel like you can affect change in the special education system (for other children with disabilities)?
 - a. How have you (or could you)?
 - b. What are the barriers to affecting systemic change?
4. How do you feel when interacting with school professionals (educators, administrators)?
 - a. Do you initiate contact with school professionals? For what reasons?
 - i. If yes, how did you contact them and what was the result of the contact?
 - b. Do you feel that they listen to your concerns?
 - c. What barriers do you face in contacting school professionals?
5. How do you feel about legislators (people who write and pass laws, usually politicians and elected officials)?
 - a. Have you ever contacted a legislator? Why?
 - i. If yes, how did you contact them and what was the result of the contact?
 - b. Do you feel that they listen to your concerns?
 - c. What barriers do you face in contacting legislators?
6. How do you feel about this advocacy expectation for parents in special education?
 - a. How do you feel about the advocacy expectation for your own child?
 - b. How do you feel about the advocacy expectation for systemic change?
7. Is there anything else you would like to add?