




Parent Perceptions of the Advocacy Expectation in Special Education

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Abstract

Although the Individuals With Disabilities Education Improvement Act (IDEA) mandates parent participation in their children's education programs, the implementation of IDEA results in parent effort beyond participation, specifically, an expectation of advocacy. To date, research on the advocacy expectation is mixed, with some parents perceiving advocacy as an obligation to ensure appropriate services for their children, whereas others argue it is unreasonable and has cultural dissonance, disadvantaging some parents. We examined parent perspectives of the advocacy expectation in special education through 19 focus groups with 127 parents of children with disabilities across four states. Findings included a nuanced understanding of the advocacy expectation, with participants reporting the importance of advocacy and some describing that advocacy was part of their social role. However, under adversarial circumstances with school personnel, participants described feeling overwhelmed because the advocacy expectation felt more difficult than it needed to be. We discuss implications for policy and practice.

Parents of individuals with disabilities have been indispensable advocates in the history of federal special education law in the United States.¹ Indeed, parents organized and engaged in advocacy that contributed to passage of the Education for All Handicapped Children Act of 1975, enabling millions of children with disabilities to attend school and receive a free appropriate public education. Renamed the Individuals With Disabilities Education Act (IDEA) in 1990, IDEA (2004) mandates parental participation as a key provision, requiring school personnel to give parents opportunities to be involved in their children's individualized education program (IEP), subsequently strengthening parents' role in their children's education (Yell, 2016).

Despite passage of IDEA, parents continue to advocate for appropriate services for their children with disabilities (Dinnesen & Kroeger, 2018). Although it describes "participation," the implementation of IDEA has resulted in parent effort far beyond mere participation.

In a seminal article about advocacy, Kalyanpur and colleagues (2000) wrote that the field has witnessed the development of an advocacy expectation that "assumes that parents will choose to participate in the decision-making process, make their service preferences known, and seek redress if these requests are not responded to" (p. 122). Although parent participation is mandated in IDEA and results in positive student outcomes (Turnbull et al., 2015), we also consider Mlawer's (1993) question: "Is it possible that, by attempting to help parents become skilled educational advocates for their children, we have created an advocacy expectation that makes life even

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more difficult for many parents, families, and children?" (p. 106). In this study, we sought to address this question by examining parent perspectives of the advocacy expectation in special education through 19 focus groups with 127 parents of children with disabilities across four states.

Parent Participation in IDEA

IDEA's parent participation principle sought to involve parents in educational decision making and to protect the rights of parents and their children with disabilities. Under IDEA (2004), parents must be provided the opportunity "to participate in meetings with respect to the identification, evaluation, and educational placement of the child, and the provision of a free appropriate public education to such child" (20 U.S.C. § 1415). *Participation* has been defined as family interactions in both formal and informal educational settings with school personnel regarding children with disabilities (Trainor, 2010b). This may include written notice of IEP meetings, the right to participate as a team member during IEP meetings, and access to interpreters (IDEA, 2004). "Participation" refers to a wider range of interactions and activities that may or may not include advocacy (Trainor, 2010a). *Advocacy* is defined as speaking and acting on behalf of another person or group of people to help address their preferences, strengths, and needs (Wolfensberger, 1977). Engaging in educational decision making and pursuing dispute resolution tactics if one's rights are not upheld (IDEA, 2004) reflect a transition from participation to advocacy.

The Advocacy Expectation in Special Education

IDEA's parent participation mandate may have contributed to the advocacy expectation (Kalyanpur et al., 2000). The advocacy expectation may also be due to the tendency for schools to focus on compliance with IDEA more than providing each student with an education program designed to meet their needs (Phillips, 2008). Thus, parents need to pursue what is in the best interest of their child by advocating

for appropriate services. In addition, IDEA's funding contributes to the need for parent advocacy. Although Congress determined the federal government would fund up to 40% of the excess costs of educating children with disabilities, federal funding has not exceeded 15% (Congressional Research Service, 2019). The underfunding of IDEA prevents appropriate evaluation, leads to a lack of appropriate services being provided, promotes segregation of students with disabilities from their peers, and contributes to the lack of qualified personnel (National Council on Disability, 2018). In response to these challenges, parents may feel compelled to advocate. In addition, parents may feel the need to advocate when their voices are not heard, decisions are being made for them, and their children are not receiving needed services (Hess et al., 2006; Salas, 2004). In fact, advocacy and special education are considered by many parents to go hand-in-hand (Phillips, 2008).

The advocacy expectation may not always align with what some parents want, nor is it reasonable for some parents (Mlawer, 1993). To date, research is mixed, with some parents perceiving advocacy as an obligation to ensure access to services for their children (Dinnesen & Kroeger, 2018; Wang et al., 2004), whereas others argue it is unreasonable and has cultural dissonance, situating some parents at a disadvantage (Kalyanpur et al., 2000; Trainor, 2010a). In a study of parents' perceptions of their advocacy and its impact on their lives, parents reported their advocacy enhanced understanding of their child's disability, their rights, and the educational system; involved conflict that necessitated "fighting"; and caused stress, which adversely affected family dynamics (Wang et al., 2004). Despite the negative ramifications of their advocacy, parents still reported the need to advocate. Even though the advocacy expectation is commonly acknowledged in special education (Trainor, 2010a), little research has examined it.

Cultural Dissonance of the Advocacy Expectation

It would be inauthentic to ignore the role that social and cultural capital play in the advo-

cacy expectation. Social capital entails relationships that afford the exchange of information, and cultural capital includes dispositions and knowledge that inform how an individual advocates (Bourdieu, 1986). Indeed, some research suggests that parents experience disadvantage if they do not possess the social and cultural capital most valued by school professionals. For example, Trainor (2010b) found that parents of high socioeconomic status (SES) were more likely to communicate about their children's needs using jargon, and White parents were more likely to refer to published knowledge about disability, which both led to more successful advocacy. In comparison, Latinx, Black, and Native American parents and parents of low SES were more likely to advocate in terms of their child as an individual, which school professionals valued less. School professionals were also more likely to share insider information with White parents, which aided their advocacy efforts.

Trainor's (2010b) research aligns with prior literature suggesting the advocacy expectation disadvantages culturally and linguistically diverse (CLD) families, families of color, and families of low SES (Kalyanpur et al., 2000). Collaborative partnerships between CLD families and school professionals remain infrequent due to school professionals' assumptions of deficits in CLD families and cross-cultural misunderstandings or differences related to perceptions of disability, goals for students with disabilities, and caregiver roles (Harry, 2008). CLD families may not share the cultural values of individual rights and freedom of choice upon which the advocacy expectation is based; thus they may struggle to meet it (Kalyanpur et al., 2000). For example, immigrant parents from countries without special education services may not be aware of their child's rights under IDEA, and parents from cultures that value harmony may not voice their disagreements with school professionals. Such differences may be stigmatized and lead to deficit thinking and discrimination due to systemic racism (Yosso, 2005). CLD families of children with disabilities often face the intersectional effects of racism and ableism that act in

interconnected ways against those with multiple minoritizing identities (Annamma et al., 2013).

Theoretical Framework

Traditional uses of social and cultural capital theory tend to be deficit oriented and often focus on the lack of such capital among marginalized groups (Yosso, 2005). To adhere to a strengths-based approach, we considered a different framework for this study. Due to the importance, yet exclusionary nature, of social and cultural capital for parent advocacy in special education, we utilized Yosso's (2005) community cultural wealth framework. Based in critical race theory, this framework explicitly acknowledges that CLD families face systemic barriers limiting their multiple forms of capital being recognized by dominant groups (e.g., White education professionals), often leading to disempowerment (Harry, 2008). Rather than seeking to understand and value the capital families have, school professionals often emphasize their own technical special education knowledge, which many CLD families may not initially possess (Trainor, 2010b). This disconnect results in the barriers described already, which perpetuate the ethnocentric assumption that CLD families are unable and uninterested to participate in their children's education. Yosso's framework helps us by both identifying the systemic barriers faced by CLD families and recognizing the forms of capital CLD families possess rather than assuming they are deficient in the social and cultural capital valued by the dominant groups.

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We recognize that our use of Yosso's (2005) framework is novel in its extension to parents of children with disabilities. We did so because over half of our sample reflected traditionally underrepresented racial and ethnic

groups who may experience individual and systemic racism. Further, we contend that in the context of special education, parents of children with disabilities risk marginalization due to discrimination by proxy in which they may be viewed as lesser by school professionals due to being parents (versus professionals) and, specifically, parents of children with (versus without) disabilities. Though parents may not have disabilities themselves, school professionals who hold a deficit orientation toward disability may generalize that to parents, and this may result in a deficit view of families, especially CLD families. Notably, the advocacy expectation exacerbates the potential for this discrimination because parents need to engage as professionals during the IEP process.

The nature of the advocacy expectation may yield positive results for many children with disabilities but also disadvantages families that are unable or unwilling to meet the expectation. Although some parents feel a sense of obligation to advocate for their children, others argue that the advocacy expectation may not be reasonable or fair to parents. Despite these challenges, limited extant literature exists related to parents' perceptions about the expectation to advocate for their children. Given the importance of the topic and the mixed findings of limited extant research, the following research questions guided the design of this study: How do parents of children with disabilities feel about the expectation that they will advocate for their children? What does the advocacy expectation entail for parents of children with disabilities?

Method

The exploratory nature of this study required a qualitative research design. Specifically, we engaged in a constructivist grounded theory study utilizing grounded theory methods but with interpretive analysis informed by the theoretical framework rather than testing of a theory (Creswell, 2013; Harry et al., 2005). This study was part of a larger project investigating the effectiveness of a parent civic

engagement program meant to educate parents of children with disabilities about how to engage in legislative advocacy for the next IDEA reauthorization.

Participants

This study included 127 parents of children with disabilities. Participants were primarily mothers of children with disabilities (86.82%; $n = 111$). The sample was racially diverse with 51.94% ($n = 66$) of the participants reflecting traditionally underrepresented racial and ethnic backgrounds. Geographically, 39.37% ($n = 50$) were from Massachusetts, 29.99% ($n = 38$) were from Illinois, 21.25% ($n = 27$) were from Tennessee, and 9.49% ($n = 12$) were from New Hampshire. See Table 1 for additional information.

We collaborated with one Parent Training and Information Center (PTI) in each state to recruit participants via criterion sampling. Inclusionary criteria were (a) parenting a school-age child with a disability, (b) participating in a civic engagement program, and (c) being willing to complete research measures. Each PTI distributed flyers describing the civic engagement program and the study. We also collaborated with community agencies that served Spanish-speaking families of children with disabilities. Recruitment materials were in English and Spanish. Participants received a \$20 stipend. We obtained institutional review board approval.

Procedures

Civic engagement program. The program was offered twice in each state, once in May and June and once in September. To register, each participant completed a consent form and a survey that included a family demographic questionnaire. The surveys and training materials were translated into Spanish using the translation/back-translation method (Brislin, 1970). Participants were then invited to attend an in-person, 6-hr civic engagement program. At the beginning of the program (before receiving any content), participants completed

Table 1. Participant Demographics ($N = 127$).

Characteristic	% (n)
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)
\$15,000–\$29,999	9.45 (12)
\$30,000–\$49,999	16.53 (21)
\$50,000–\$69,999	14.17 (18)
\$70,000–\$99,999	19.69 (25)
Over \$100,000	22.83 (29)
Missing	6.29 (8)
What is your marital status?	
Married	66.93 (85)
Not married	33.07 (42)
What is your ethnicity?	
White	48.03 (61)
Black or 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?^a	
Autism Spectrum Disorder	48.06 (62)
Learning disability	37.21 (48)
Speech/language impairment	37.21 (48)
Intellectual disability	27.91 (36)
Emotional/behavioral disorders	24.03 (31)
Health condition	18.60 (24)
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)

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

a 1-hr focus group that was the first activity of the program. After the focus groups concluded, the training portion of the program occurred. The second author developed the program; the first and second authors trained PTI staff to conduct the program. The program included a broad review of core IDEA

principles, details of past IDEA reauthorizations, and prompts to facilitate discussion about potential changes to IDEA. Conversations were dictated by topics the families raised. The program included methods to advocate for systemic change, culminating in individual legislative advocacy testimonies.

Focus group protocol. We scheduled focus groups before the training so the training content would not influence the participants' responses and also as an icebreaker activity for participants. The focus group protocol was established based on a review of the literature regarding advocacy among families of children with disabilities (Burke & Sandman, 2017), parent motivation to affect systemic change (Gutiérrez, 1990), and types of advocacy (Trainor, 2010a). It was piloted in English and Spanish with parents of children with disabilities, resulting in minor changes (e.g., wording of questions). The final protocol had six open-ended questions with follow-up probes: "When you think about special education and the services your child receives, what would you change?" "Do you feel like you can affect change for your own child's services?" "Do you feel like you can affect change in the special education system (for other children with disabilities)?" "How do you feel when interacting with school professionals?" "How do you feel about legislators?" and "How do you feel about the advocacy expectation for parents in special education?"

Each focus group had one facilitator, six participants on average, and a length of at least 60 min. We conducted 21 focus groups: seven in Massachusetts, six in Illinois, six in Tennessee, and two in New Hampshire. Two focus groups from Illinois were omitted from the analysis because facilitators did not have time to ask the final question about the advocacy expectation. We did not define "advocacy expectation" when we asked the final question but clarified that it meant "the expectation that parents need to advocate for appropriate services" when participants asked for clarification. Three focus groups were conducted in Spanish. Two Latina authors, both native Spanish speakers, facilitated the Spanish focus groups. Researchers wrote descriptive field notes, including group details, participant reactions, emerging themes, and interview summaries. Each focus group was audio recorded and transcribed verbatim. Spanish focus groups were transcribed using forward- and back-translation. We had

207,028 total words (404 pages) of transcription data and 14,395 words (74 pages) of field notes.

Data Analysis

The data from the demographic questionnaire were used to describe the participants. Focus group data were analyzed inductively using a multistage coding process to systematically categorize data and iteratively develop themes. Researchers independently read each transcript (in line-by-line format) to familiarize themselves with the data. In pairs, researchers coded an assigned section (e.g., Question 6) for all transcripts. Within pairs, researchers independently coded six transcripts, utilizing constant comparative analysis (Glaser & Strauss, 1967). Each line of data was examined and compared with other data. If the line of data represented a distinct concept or idea, it was given a code; if the line of data represented an idea from an established code, it was given the same code. A line could have multiple codes if it represented multiple concepts. Each researcher pair compared codes, resolved differences (e.g., wording of codes) via discussion, and developed a codebook to recode the first six transcripts and code the remaining transcripts. This resulted in 104 open codes that were eventually refined (e.g., combining similar codes) to 49 categorical codes. Researchers developed coding summaries highlighting patterns within and across focus groups. The research team discussed coding summaries during weekly meetings, which resulted in organizing the codes into nine categories. Discussions included grouping codes that were applied to data units reflecting similar situations or perspectives. This iterative approach strengthened the quality of analysis via repetitive and structured examination of data with constant feedback from the team.

Once the data were categorized by code, the next stage included systematically reviewing codes and categories within and across focus groups. We double-checked the coding by having a new researcher pair code each focus group using the same process. Discrepancies

were presented to the research team and discussed until consensus. We refined and confirmed categories such that each had internal homogeneity and external heterogeneity (Braun & Clarke, 2006). This involved combining several categories with overlapping data into a larger category (e.g., participants' negative and positive emotions), which reflected deeper analysis and the beginning of thematic development. We also considered focus group representativeness by determining the percentage of focus groups in which each code was applied. This helped us to note whether a high-frequency code was used a lot in one conversation, which would reflect its importance for a particular focus group, or if it was discussed across most focus groups and thus a recurrent topic. See Table 2 for code frequency (i.e., number of times a code was used) and code representativeness (i.e., percentage of total focus groups in which a code was used) (Sandelowski, 2001).

During the final stage of analysis, we focused on the conceptual level of themes by noting relationships between and among codes and categories (Braun & Clarke, 2006). To do this, we utilized Saldaña's (2016) second-cycle coding methods of pattern coding and focused coding. Pattern coding facilitates abstraction by condensing the data units organized by descriptive codes in many categories to pattern codes representing key themes in fewer categories. Through pattern coding, we organized our nine categories into eight themes (see Table 2). Focused coding structures the pattern coding by considering the most frequent codes with which to develop connections and confirm themes. With focused coding, we refined the themes into four main themes and four supporting themes. Recognizing that the themes did not quite capture all that the participants were doing to meet the advocacy expectation, we utilized Yosso's (2005) framework in the analysis to organize the main and supporting themes. By highlighting the participants' agency and advocacy through their different types of capital, Yosso's framework also suggests an alternative way for school personnel to view and interact with parents.

Trustworthiness

With regard to quality indicators of interview studies (Brantlinger et al., 2005), we selected appropriate participants based on specific criteria, developed reasonable interview questions based on the literature and piloted in English and Spanish, recorded and transcribed all focus groups verbatim, and maintained confidentiality. We also utilized multiple measures to establish credibility of data analysis: first- and second-level member checks, collaborative work, investigator triangulation, and researcher reflexivity (Brantlinger et al., 2005). First-level member check summaries were created after each focus group. Each facilitator read the summary to member check their initial impressions. Participants did not offer any changes. Second-level member checks were conducted to support authenticity of the data analysis and interpretation. After reading transcripts and field notes, we generated a summary of each focus group. The summaries were sent to participants, and they were asked to complete an online survey to confirm or change the summary. The majority (94.5%) of participants responded. They did not request changes to the focus group summaries. We utilized collaborative work and investigator triangulation by including multiple researchers and using peer debriefing. The first two authors designed and conducted all aspects of the study with substantial collaboration from the other authors. Peer debriefing (e.g., discussing coding patterns, themes) occurred during weekly calls.

Critical to qualitative research, researcher reflexivity was utilized to ensure awareness of our values and biases related to the study. The first two authors have siblings with disabilities; the second author is the parent of a child with a disability. Given their familial experiences, the authors may have biases favoring families (versus schools) with respect to advocacy. The research team was diverse regarding identity; each had conducted prior research with families. We approached the study valuing family-school collaboration and recognizing the importance of parent advocacy in special education. We reminded ourselves to remain grounded in the data and

Table 2. Type of Capital, Themes, Code Representativeness, and Code Frequency.

Type of capital	Themes	Codes	Representativeness	Frequency
Resistant capital	The AE should not be so difficult to meet; the AE is difficult due to school factors	More collaboration with school is needed	78.9%	62
		Meeting the AE is difficult	68.4%	38
		Too much is expected of parents	63.2%	36
		Requires parents to be assertive	57.9%	24
		Shouldn't have to fight	52.6%	25
		Family perceived negatively by school	52.6%	19
		Not enough on schools	47.4%	56
		AE feels overwhelming	47.4%	17
		Requires discipline	36.8%	12
		AE feels frustrating	31.6%	13
		AE enforced by schools	26.3%	8
		Families need to hold schools accountable	26.3%	7
		Effort yields limited results	21.1%	9
Navigational capital	The AE places considerable demands on parents; the AE comes with other requirements	Requires additional learning	68.4%	46
		Requires substantial sacrifices	63.6%	32
		Sought external supports/solutions	57.9%	22
		Inflexible special education system	52.6%	17
		AE is consuming	47.4%	9
		AE is guilt-inducing	31.6%	9
Aspirational capital	Parents feel galvanized by the AE	Responsibility as parent of child with disability	63.2%	19
		Motivation to meet the AE	47.4%	20
		High stakes	42.1%	12
Familial capital	AE is also a duty to other families	A duty to other children with disabilities/families	68.4%	21
		Worthy of effort	31.6%	10
Social capital	Parents view AE as their duty—advocacy role	A mission and lifestyle	26.3%	7
		Parents of children without IEPs don't have to advocate as much	15.8%	6
Linguistic capital	Results in inequities	Inequitable	42.1%	12

Note: AE = advocacy expectation; IEP = individualized education program.

to support interpretation with extant literature to adhere to the study's methodology.

Findings

The thematic findings reflect the most common patterns in the data. Participants reported that meeting the advocacy expectation felt more difficult than it should be. The challenges of the advocacy expectation were exacerbated by a lack of collaboration with school personnel. The advocacy expectation also resulted in inequities for families who struggled to advocate due to systemic barriers. Despite these challenges, participants were motivated by a sense of duty to advocate for their children and other families' children. As such, participants enacted Yosso's (2005) resistant, navigational, aspirational, familial, social, and linguistic capital.

Resistant Capital: "It's So Much More Difficult Than It Needs to Be"

Participants manifested *resistant capital* by fighting not only for appropriate services for their children but to hold school personnel accountable. Yosso (2005) describes resistant capital as "knowledges and skills fostered through oppositional behavior that challenges inequality" (p. 80). To meet the advocacy expectation, participants engaged in an inherently unequal dynamic in which they need to participate as professionals while simultaneously being devalued as nonprofessionals. Across all focus groups, the majority of participants emphasized that engaging in advocacy ranged from unpleasant to burdensome and proved to be a predominantly negative experience because of its excessive demands. Representative of many participants, a parent from Massachusetts explained,

I don't mind being expected to advocate for my child at all. . . . I would expect that I would be the advocate. What I did not expect and don't like is that it's so much more difficult than it needs to be.

Participants reported the excessive demands of advocacy took a significant toll on them. A

parent from Illinois stated, "I said when I laugh and make jokes about it, [I] have to because you'll cry [if not]." This theme includes two subthemes: (a) wanting more cooperation and collaboration from school personnel and (b) a sense that too much was expected of them.

Needed more collaboration with school: "We feel like they view us as an annoyance." Participants stressed that the advocacy expectation felt so burdensome because they did not experience collaboration and cooperative problem solving with school personnel. Instead of being collegial, the majority of participants described the IEP process as adversarial. For example, a parent from Massachusetts stated, "You don't get heard at the IEP meeting. Whether or not they're supposed to make decisions under the law at the meeting with you, the decision has been made before you walk in the door." Participants reported fighting for services during meetings rather than collaboratively discussing IEPs as equal team members. A parent from Tennessee described, "Sometimes those conversations happen where parents are bullied and forced to—'You have to medicate your child,' 'You have to do this'—instead of it being a conversation. It's a demand or request." Thus, participants reported meetings felt like contentious, high-stakes negotiations.

In response to the lack of collaboration and adversarial nature of meetings, participants demonstrated resistant capital through disciplined effort and assertiveness. A parent from Massachusetts explained, "It takes extreme discipline for you to keep active and involved." Increasing their discipline and assertiveness contributed to the overall sense of participants resisting and trying to change an unfair system. A parent from Illinois stated, "I think until the parents get pissed off enough and demand change, that's the only way change is going to happen."

Along with the adversarial nature of these meetings, participants reported receiving mixed messages in that they were theoretically equal team members, but school personnel perceived them negatively when they

advocated. A parent from Tennessee suggested the contentious nature of meetings could be worse when parents were known as strong advocates: "It becomes adversarial sometimes before the meeting even starts, especially with the parent who knows a little bit more. So it's almost like you're shot in the foot before you even get started." Other participants observed negative repercussions of their advocacy, such as a parent from Massachusetts: "As a parent, I feel like the bad guy when I have to advocate for my child. I shouldn't be the bad guy for having knowledge to get my child an education." In addition to being perceived negatively for advocating, several participants described having their input in meetings ignored by school personnel, as a parent from Massachusetts described: "So I think that we're expected to do a lot of advocating and then that continually, 'Well, you're not the expert.'" Such mixed messages were confusing and frustrating to participants. Participants described an "us-them" dynamic between parents and school personnel rather than a collaborative team. Participants were dismayed that despite their advocacy, there were still school barriers to overcome. A parent from New Hampshire stated, "We feel like they view us as an annoyance. They don't view us as a help to the system."

A sense that too much was expected: "It shouldn't just rely on the parents." Without the expected collaboration from school personnel, participants reported that too much was expected of them. Participants indicated being overwhelmed as the most common feeling associated with the advocacy expectation. A parent from Tennessee stated, "I think sometimes as a special-needs parent that you're so overwhelmed, you just don't know what to do or where to start." Participants described engagement beyond typical advocacy actions (e.g., attending meetings, communicating with school personnel). For example, another parent from Tennessee explained,

It [advocacy] should be done, but we have to be the watchdogs to make sure they're [school personnel] doing what they're supposed to. So

we have to, but it shouldn't just rely on the parents to make sure the schools are doing what they should be doing.

Similarly, a parent from New Hampshire stated, "We shouldn't be the checks and balances, but that's how it feels. . . . Couldn't you [school] just follow the law?" Beyond participating on the IEP team, participants reported they needed to monitor school personnel regarding IEP development and delivery of services. Such additional work focused on school accountability resulted in parent frustration, as a parent from New Hampshire described: "I was angry at first. I mean, I have my own career, but now I have to learn your career to make sure that you're doing your career. That's really irritating."

Navigational Capital: "It's Like a Fourth Job!"

Reflective of Yosso's (2005) *navigational capital*, or "skills of maneuvering through social institutions" (p. 80), participants emphasized additional requirements and substantial sacrifices to meet the advocacy expectation. They described a pattern of recognizing the need to do more than only attend the IEP meeting and to prepare themselves to do so. The most common requirement was the amount of learning the advocacy expectation entails. Parents acquired professional knowledge in special education, general education, and related services. Participants believed the amount of self-education the advocacy expectation demanded was excessive, such as a parent from New Hampshire who stated, "I feel like we should have a degree in special education."

The demands of learning this information manifested as a learning curve for the parents. Part of that learning curve was recognizing the need to advocate, as a parent from New Hampshire described:

I was that parent that went to the IEP meeting and thought they were just going to give him everything he needed, and it was less than a year later that I'm scratching my head going, "Now I know what they meant," like, there's a little bit of a learning curve to it.

A parent from Tennessee explained how she prepared for IEP meetings once she learned her rights: "I asked for a week in advance so I could see the IEP. I wasn't understanding nothing my first time." Participants described guilt as a negative consequence of the learning curve due to missed opportunities to advocate for their children's services. A parent from Massachusetts admitted, "I'm still learning how to be an effective advocate for my kid, and I struggle and I have a lot of guilt that I trusted for too long and just waited, and I should have been more aggressive earlier."

To meet the advocacy expectation, participants described making substantial sacrifices. The most significant sacrifice was the amount of time spent learning about their rights and advocating. A parent from Massachusetts described that the time commitment was akin to a full time job:

I cannot believe that when they did the law that was the intent. That it's such an incredibly parent-driven process, and if you fight, you get, and if you don't fight, your kids are not getting what they need. I mean, I'm going to so many trainings. It's so frustrating. I don't want to. It's like a second job. It's like a fourth job!

Some parents tried to balance their advocacy and daily caregiving with their actual jobs, whereas others left their jobs to devote time to the advocacy expectation. Thus, in addition to time, some participants sacrificed employment and income for the advocacy expectation.

In addition to self-education and substantial sacrifices, participants described problem-solving techniques, such as finding supports and services outside of school. Participants secured external services (e.g., tutors, therapies) for their children that were not offered or delivered in school, brought special education advocates to meetings, consulted with attorneys, and engaged in legislative advocacy to change school policies. A parent from Massachusetts explained, "You have to go around the school system. We're finding all these alternative ways and connecting up and creating. I don't feel like, through the system, it [advocacy] was successful at all."

Aspirational Capital: ". . . Because He Is Capable of Learning"

Despite the challenge of meeting the advocacy expectation, participants felt galvanized by it and viewed it as integral to parenting children with disabilities. Notably, participants were motivated by high expectations and visions of success for their children. Yosso (2005) describes this *aspirational capital* as the "ability to maintain hopes and dreams for the future, even in the face of real and perceived barriers" (p. 77). Participants viewed the advocacy expectation as their duty to facilitate as much progress as possible for their children. A parent from Massachusetts explained,

I feel like I have to do every single thing that I can for my child to the *n*th degree. Otherwise, I'm letting him down. So, I spend all of my time, all of my money, all of my effort, all of my emotional everything. I have to do all of this because I can't let him down, and I have to give him as much opportunity as I possibly can within my power.

Because of their high expectations for their children, participants reported the advocacy expectation was worthy of their efforts, as a parent from New Hampshire stated:

I decided a long time ago that it [advocacy] was worth it. I want to work 40 hours a week, and then spend another 40-plus [hours] advocating for him, and it's just my life. I'm not going to let all of those pieces stand in my way for him because he is capable of learning.

Participants were also motivated to meet the advocacy expectation when they recognized the negative consequences of not doing so. Parents from Illinois discussed the importance of advocacy to improve educational outcomes for their children to resist the school-to-prison pipeline. Parents from Massachusetts highlighted the importance of advocacy to maintain appropriate services, prompting one parent to state, "If we weren't there, they would just trample our kids."

Familial Capital: “We’re All in This Thing Together”

Participants embodied *familial capital* by continuing to advocate not only for their children but also for others’ children and systemic change. Yosso (2005) describes familial capital as extending beyond kinship to refer to “community well-being” (p. 79). Participants reported the advocacy expectation was part of their duty to other families; their efforts were a result of their collective identity as parents of children with disabilities. A parent from Tennessee explained, “What helps my child will ultimately help yours. Most definitely, we’re all in this thing together. We all want the same goal.” Participants suggested sharing IEPs and experiences with each other so they would know what services were available and how to address various problems. Prior negative experiences (e.g., legal dispute) fueled some participants’ advocacy so others would not have similar experiences. A parent in Massachusetts explained,

This [advocacy] is going to impact everyone else at this level, too. I’m not the only one . . . and that sort of just springboards that action because I can’t sit there and watch it [having to fight for services] happen again and again and again.

Participants conveyed a shared commitment to helping other families.

Social Capital: “We Parents Need to Collaborate and Work Together”

Participants described a common pattern of developing and utilizing *social capital* when they realized they needed more support to help them meet the advocacy expectation. Yosso (2005) defines social capital as “networks of people and community resources . . . [that] can provide both instrumental and emotional support” (p. 79). In Massachusetts, participants joined their local Special Education Parent Advisory Councils; in other states,

participants sought to connect with other parents of children with disabilities for guidance, mentorship, and camaraderie. A parent from Tennessee explained, “I’m just trying to do what I can and go and meet different people and learn more and more.” A parent from Massachusetts suggested that even more collaboration among parents would be helpful in alleviating some of the excessive demands of the advocacy expectation:

We parents need to collaborate and work together because you know what? Whatever is affecting my kid in class is going to affect your kid and your kid (*pointing around room*). I haven’t seen that collaboration, and the school is not supporting the efforts.

Advocacy as a social role: “. . . the most important job we have.” Related to their social capital, participants described embodying advocacy as a social role and valuing it as an important part of their identities. For example, a parent from Illinois introduced herself with pride as a “strong advocate.” Across focus groups, participants described advocacy as a duty, mission, and lifestyle. A parent from Massachusetts explained, “It [advocacy] is a full-time job and the most important job we have.” Another parent from Massachusetts added, “It is lifelong work.” Participants were motivated by the advocacy expectation and proud to advocate. A parent from New Hampshire shared, “Some parents step up and some don’t. I’m glad to say that I step up.”

Although participants were motivated to assume the advocacy role, some participants felt it was unfair compared with parents of children without disabilities. A parent from Massachusetts explained,

I think it’s incredibly unfair that we have to do this. I don’t want to do this. I mean, other parents don’t have to do this, right? I go to the [Parent–Teacher Association] and everybody is talking about field trips and, you know, get money from cookies. I want to care about that. I don’t want to care about IEPs and “Is my son part of the classroom?” and “Are his rights respected?”

Such realizations caused some participants to wish they could focus only on parenting, as one parent from Illinois stated: "As a parent, I really don't want to be an advocate. I want to be able to parent my child." Although participants felt the demands of the advocacy expectation were unfair, especially compared with parents of children without disabilities, they took pride in the advocacy role and all of their consistent efforts on behalf of their children and others' children.

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Linguistic Capital: "Even if It's Hard for Them to Understand Me"

Participants discussed inequities inherent to the advocacy expectation. Recognizing the demands of the advocacy expectation and the substantial sacrifices to meet those demands, participants stressed that it led to an inherently unfair situation because some families faced systemic barriers to advocacy. In particular, immigrants and emerging bilingual learners encountered disadvantages others did not. Participants described that school personnel did not recognize or value their perspectives, which reflect *linguistic capital*. Yosso (2005) describes linguistic capital as "intellectual and social skills attained through communication experiences in more than one language and/or style" (p. 78). A parent from Massachusetts, an immigrant herself, stated,

Yes, immigrant parents are having a hard time. They don't understand the language; they don't even know why their kids are having an IEP. Parents don't know about their rights. Parents don't know that the kids can get support. The IEPs are not being translated in their own language, and if a parent wants or tries to advocate for their own kids, [here] comes retaliation. Happened to me this year twice. I know a parent who was being retaliated [against] and was deported to his home country.

In addition to a fear of retaliation, participants also emphasized the racism they encountered while trying to advocate for their children, as a parent from Tennessee stated: "Prejudice is still living. Still alive and well. And we should be the last group of parents to be like, 'Oh no, you can't come in here and have a say with me,' because we all experience the same thing."

Participants reported enduring a lack of linguistic access to meetings and the materials needed to engage meaningfully during meetings. For example, a parent from Tennessee stated, "*A veces, los traductores, no conocen los términos de la educación especial y eso realmente afecta la interpretación* [At times, the translators, they do not know the terms from special education and then that really affects the interpretation]." Regarding linguistic access, participants specified needing materials translated into their preferred language and professional language interpreters during meetings as well as longer meetings to account for interpretation. Participants stressed that linguistic inaccessibility conveys disrespect, as a parent from Massachusetts explained:

I'm a Latina woman and I have been treated with respect sometimes and treated with disrespect many, many, many times. The times that I was treated with respect and everything was done right was when my daughter was in a private school because they knew what they were doing. They [public schools] didn't have the respect. I had to use my husband who is American, and I always put him in front in order for him to advocate. For me otherwise, they would not listen to me.

Recognizing the challenge of such additional barriers, a parent from Massachusetts stressed,

You guys [other focus group participants] have a very hard time advocating for your own kids. You know your rights, you speak the language, some of you know how to advocate, and still you have problems. Imagine the Latino parent, immigrant. Knowing the language is a privilege.

Despite inequities, participants reported persisting with the advocacy expectation. A

parent from Tennessee emphasized advocating for her daughter with her limited English skills:

Puedo hacerte miles de preguntas e ir con diferentes personas y esforzarme al máximo. Diles que quiero esto y que quiero esto. Incluso si les cuesta entenderme. Pero quiero esto para mi beneficio de los demás. No solo para mí [I am able to ask you thousands of questions (points to daughter) and go with different people (school personnel) and strive as I can. Tell them (school personnel) I want this (service for my daughter), and I want this (service for my daughter). Even if it's hard for them (school personnel) to understand me. But I want this for my benefit and the benefit of others. Not only for me].

Discussion

This study examined perceptions of the advocacy expectation in special education with a diverse sample of parents across four states utilizing Yosso's (2005) community cultural wealth framework. Our first research question inquired how parents feel about the expectation that they advocate for appropriate services for their children. Participants reported positive experiences with advocacy, embracing the advocacy expectation as a duty to their children. Participants' advocacy reflected aspirational capital through high expectations for their children and motivation to advocate for their children's academic and social progress. Participants felt galvanized by the advocacy expectation because it enabled them to strive for high-quality and appropriate services for their children. Notably, some participants described that advocacy was part of their social role and that they were proud to engage in this advocacy role. These findings are consistent with prior research suggesting there may be positive effects of parent advocacy (Burke et al., 2019) and that parents view advocacy as a means to improve their children's services (Boshoff et al. 2017; Wang et al., 2004). Whereas prior studies emphasize positive effects of advocacy for children with disabilities, this study extends the literature to parents, suggesting that parent advocacy capitalizes on aspirational and social capital. The advocacy role can result in benefits of agency

and positive identity for parents of children with disabilities.

However, participants emphasized that the advocacy expectation was too much to ask when school personnel did not collaborate with them or uphold their mandated responsibilities. Under adversarial circumstances, participants described feeling overwhelmed and frustrated by the advocacy expectation because it felt unequal and much more difficult to enact than it needed to be. Moreover, the consistent advocacy required of participants becomes more apparent when contrasted with the involvement of parents of children without disabilities, which is typically measured by attendance at singular events (e.g., open house) and learning activities at home or in the community (Oswald et al., 2018). Indeed, families of children with disabilities (compared with families of children without disabilities) are more involved in securing educational services that should be provided without such advocacy (Haines et al., 2017; Welchons & McIntyre, 2015).

Parents recognize that advocacy may include occasional disagreements and differences of opinion (Wang et al., 2004). Yet, participants faced predetermination of services and placement, mixed messages about participating in meetings (e.g., viewed negatively when advocated), and little accountability by school personnel to do what was discussed in meetings. Participants indicated that adversarial struggles and "fighting" for services occurred regularly. These findings are consistent with prior studies showing that school personnel can prevent equitable participation between families and schools due to deficit views of families and children, use of jargon and other complex language, and contexts of conflict rather than collaboration (Bacon & Causton-Theoharis, 2013; Boshoff et al. 2017). Due to such barriers from school personnel, parents have described a need for persistent advocacy (Dinnesen & Kroeger, 2018). In this study, participants demonstrated resistant capital by fighting for appropriate services for their children and continuing to advocate, especially when school personnel did not collaborate with them or comply with IDEA. Our findings suggest the advocacy

expectation itself may be understandable, but the circumstances surrounding it may challenge families to fulfill the obligation.

Our second research question focused on what the advocacy expectation requires of parents. Participants enacted navigational capital when they persevered, problem solved, and continued to advocate for appropriate services amid school barriers in a system they perceived to not work as it should. Participants made sacrifices, particularly of their own time and resources, to engage in self-education to meet the advocacy expectation. This is consistent with prior research finding that parents acquired new knowledge in order to advocate (Bacon & Causton-Theoharis, 2013; Boshoff et al., 2017; Burke & Hodapp, 2016; Rossetti et al., 2018; Trainor, 2010a). Additionally, participants attended meetings with someone else (e.g., special education advocate, spouse or partner) and consulted with attorneys. These strategies are also consistent with prior research (Bacon & Causton-Theoharis, 2013; Wright & Taylor, 2014). This study extends the literature by finding that participants' advocacy included securing external supports and services for their children, solving unexpected problems due to school barriers, and engaging in systemic advocacy to help other families avoid the challenges they faced. Such strategies helped them assert individual agency within the institutional constraints of the special education system.

Participants stressed that their social networks supported them to meet the advocacy expectation and that they looked to help others do the same. Thus, participants' advocacy included and benefited from social capital. Other studies have found that parents are committed to supporting each other within their social networks (Dinnesen & Kroeger, 2018; Solomon et al., 2001). Yet, such networks have tended to exclude CLD families (Harry, 2002). Thus, we were encouraged by participants' emphasis on familial capital, the recognition of—and concern for—a larger community of families of children with disabilities. Participants recognized not all families advocate due to personal circumstances and systemic barriers and were motivated to advocate for systemic changes on their behalf.

This new finding represents one lever for systemic change to better support equitable participation by all families.

Systemic change in special education is warranted, as this study confirms extant research finding that the advocacy expectation disadvantages CLD families due to differences in values, lack of linguistic accessibility, and lack of cultural responsiveness by school personnel (Harry, 2008; Kalyanpur et al., 2000; Kibria & Becerra, 2020; Rossetti et al., 2018; Trainor 2010a). Participants described both experiencing such inequities and being aware that others experienced them. As in prior research, the emotional labor of advocacy amid the intersectional effects of racism and ableism resulted in a taxing burden on families (Kibria, 2020). Participants stressed that school personnel need to begin supporting CLD families by recognizing and valuing linguistic capital.

Limitations

Though the study included a diverse sample, participants registered to attend an advocacy training; thus, the findings may reflect perspectives of parents who were aware of and had time to attend the training. Indeed, one finding was that participants embrace the advocacy role; this may not be true of parents who did not attend the training. Regarding procedures, we did not track participant comments during focus groups. Accordingly, we were unable to disaggregate and compare participants' perspectives by specific variables, such as family ethnicity, child age, type of disability, and support needs of the child. Although our findings were representative across the diverse sample and did not indicate variance across subgroups, extant research finds differences in school-based family involvement and participation in IEP meetings by race and ethnicity (Wagner et al., 2012; Zhang et al., 2011), SES (Wagner et al., 2012), and culture (e.g., acculturation, English language ability; Turney & Kao, 2009). Additionally, our first focus group question implied a negative view of special education and may have set a critical tone for focus groups. Our rationale for using this question was solely as an icebreaker to start a rich discussion.

Directions for Future Research

Future research should examine parent perspectives with the goal of exploring patterns especially regarding CLD families. Families of color (compared with White families) report lower rates of participation and satisfaction with their involvement in IEP meetings (Wagner et al., 2012). Across the range of CLD families, there may be differences in advocacy related to cultural norms, views of disability, awareness of special education policy and practice, linguistic access, and communication (Harry, 2008; Rossetti et al., 2018). Additionally, child age and level of support needs should be examined. Regarding child age, family advocacy may change in elementary school as academic demands shift (Burke et al., 2016), and advocacy may transfer from family to student once the student becomes transition aged (Kohler et al., 2017). Regarding supports, family involvement may be lower in families of students with maladaptive behavior (Newman, 2004). Families may inherently be more involved in educational decision making in the lives of students who require family support in all areas of life (Wehmeyer et al., 2016).

Notably, advocacy is a two-way system. It is insufficient to examine only family perspectives, thereby excluding school perspectives. We found the nature of the family–school partnership (i.e., adversarial or collaborative) impacted perceptions of the advocacy expectation. This study suggests a need to include all stakeholders to understand the advocacy phenomenon. How do special educators, service providers, paraprofessionals, and administrators perceive family–school collaboration and their responsibility to advocate for children with disabilities and their families? Facilitators of and barriers to family–school partnerships should be further explored, especially in relation to teacher and administrator preparation programs in higher education.

Implications for Policy

This study supports the historical and ongoing importance of IDEA's (2004) parent participation mandate. Parents should continue to be

afforded opportunities to be involved as equal decision makers on their children's IEP teams. However, to address the excessive demands of the advocacy expectation and the inequities endured by CLD families, the burden of advocacy should be shared. Increased monitoring at local, district, and state levels could ensure more accountability in service delivery. Parents need feasible options for formal advocacy and dispute resolution because enacting procedural safeguards can be costly, require professional knowledge, and take time and resources (Burke & Goldman, 2015). In the next IDEA reauthorization, policy makers should consider new ways to ensure advocacy for children with disabilities, especially children of color with disabilities, who can be doubly marginalized (Annamma et al., 2013; Rossetti et al., 2020). Phillips (2008) proposes providing an out-of-district advocate to each child receiving special education services. Alternately, school personnel could incorporate advocacy into their work (Trainor, 2010b; Wang et al., 2004). Ultimately, the point is not to weaken the advocacy expectation but to bolster advocacy for children without inflicting greater burden on families.

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Implications for Practice

Our findings indicate that the special education system places too great a burden on families. The excessive demands of the advocacy expectation would be eased if school personnel consistently actualized collaborative family–professional partnerships (FPPs) with all families. FPPs can mediate parents' need to engage in advocacy because families may not feel the need to “fight” for services

when working in unison with professionals (Goldman & Burke, 2017; Turnbull et al., 2015). The development of FPPs that collectively empower families and school personnel requires guidelines to proactively structure family–professional interactions and remain focused on children’s needs (e.g., the sunshine model; Haines et al., 2017).

Notably, Yosso’s (2005) community cultural wealth framework provides a model for school personnel to value families’ capital as they partner with them. As such, specific practice implications can be aligned with the six types of capital. For example, if school personnel recognized resistant capital as a form of advocacy, they may not react defensively and perpetuate adversarial meetings. Extant research indicates FPPs are facilitated by teachers demonstrating commitment (to the student and parent), competence (in one’s role), equality (as decision makers), and frequent communication (Blue-Banning et al., 2004; Rodriguez et al., 2014). If these things were happening, families could collaborate with teachers rather than utilize their navigational capital to secure services on their own. School administrators should capitalize on parents’ aspirational capital by structuring the IEP process to begin with parents teaching school personnel about their children’s strengths, interests, and needs. Participants’ aspirational capital included high expectations for their children and an asset-based rather than deficit-oriented approach. Further, schools and districts should proactively ensure all families are aware of their rights and prepared for IEP meetings by improving the readability of IEPs and the procedural safeguards. Recognizing the importance of parents’ social and familial capital, teachers should facilitate such networks by connecting parents with each other and facilitating parents to contact their PTIs. Valuing linguistic capital can be an integral part of a school’s process to begin to dismantle systemic racism and ableism and to foster respectful individual interactions with all families (Annamma et al., 2013). An easily targeted recommendation—and one mandated by IDEA (2004)—is to ensure linguistic accessibility of meetings via professional interpreters and translated

materials (Rossetti et al., 2018, 2020). Principals and other school leaders can foster inclusive schools by explicitly addressing the intersectionality of race and disability (Annamma et al., 2013). Finally, educators must be prepared to enact these changes; thus teacher preparation should include methods for developing FPPs (Haines et al., 2017) and cultural responsiveness (Harry, 2008).

By valuing and recognizing parents’ unique forms of capital, school professionals can strengthen FPPs and ameliorate the advocacy burden described by parents. Lessening this burden through structural changes to policy and practice may allow parents to *participate* in their children’s educational decision making, as IDEA intended. Educational systems, not parents, should accept the burden of the advocacy expectation to ensure appropriate services.

Note

1. Recognizing the diversity of families, we refer inclusively to parents, legal guardians, and other primary caregivers as “parents” throughout this article.

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