Parent leadership and civic engagement: Suggestions for the next Individuals with Disabilities

Education Act (IDEA) reauthorization

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Abstract

Although parent involvement is a cornerstone of the Individuals with Disabilities Education Act (IDEA), few individual parents of children with disabilities participate in civic engagement to voice their suggestions for the next IDEA reauthorization. To address this gap, a civic engagement training was conducted with 95 parents of children with disabilities across four states. At the end of the training, participants completed videotaped testimonials voicing their suggestions for the next IDEA reauthorization. Participant suggestions clustered around three themes: expanding IDEA to address specific concerns; adding text to provide specificity and clarity in IDEA; and implementing the current version of IDEA. Implications for research and policy are discussed.

Keywords: parent advocacy, civic engagement, IDEA reauthorization, disability

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Education Act (IDEA) reauthorization

The Individuals with Disabilities Education Act (IDEA, the federal special education

law) was last reauthorized in 2004 and will be updated again within the next five years,

presenting a long-overdue opportunity to improve the education of over six million children with

disabilities (Burke & Sandman, 2014; School Superintendents Association, 2013). During an

IDEA reauthorization, the Office of Special Education Programs (OSEP) strives to include

stakeholders in the legislative process (Gartin & Murdick, 2005). As parental participation is a

core IDEA principle and parents are experts on their children (Turnbull, Turnbull, Erwin,

Soodak, & Shogren, 2011), OSEP is especially interested in input from parents of children with

disabilities. In fact, parent advocacy significantly contributed to the initial passage of IDEA (i.e.,

P.L. 94-142) in 1975, as well as to its subsequent reauthorizations in 1983, 1986, 1990, 1997,

and 2004 (Turnbull, Shogren, & Turnbull, 2011). However, during the last IDEA

reauthorization, individual parents provided only 3.82% ($n = 288$) of the public comments (York,

2005); in addition, parents comprised only 18% of the witnesses ($n = 65$) at Congressional

hearings about IDEA (Turnbull et al., 2011). In comparison, parents comprised 34% of the

witnesses at Congressional hearings about IDEA during the 1997 reauthorization and 43% of the

witnesses at Congressional hearings about IDEA during the 1990 reauthorization (Turnbull et al.,

2011). Further, few parents reported advocating for legislative changes. In a survey study with

400 parents of children with disabilities, only 3.95% ($n = 3$) participated in legislative advocacy

(Wright & Taylor, 2014). Unfortunately, their study did not include a racially diverse sample.

Indeed, culturally and linguistically diverse (CLD) parents may feel especially

disempowered to advocate (Magaña, Lopez, Aguinaga, & Morton, 2013). This may be especially

true with respect to legislative advocacy. Burke and colleagues (2018) conducted focus groups with 49 parents of children with disabilities. The focus groups were conducted in English and Spanish. In contrast to the White, English-speaking parents of children with disabilities, all of the Latinx, Spanish-speaking families reported no legislative advocacy experience. The lack of legislative advocacy among CLD parents is critical. Given that CLD families face greater systemic barriers in navigating special education and voicing their concerns to professionals (Geenen, Powers, & Lopez-Vasquez, 2001), it is important to convey their suggestions for the next IDEA reauthorization. Thus, the purpose of this study was to examine the suggestions of primarily (but not exclusively) CLD parents of children with disabilities for the next IDEA reauthorization.

Parents of children with disabilities may want to expand IDEA to include specificity and clarity regarding certain provisions. Burke and Sandman (2014) conducted a civic engagement training with 49 parents of children with disabilities. At the end of the training, parents completed videotaped testimonials about their suggestions for the next IDEA reauthorization. Of their suggestions, the majority (73.47%) were related to adding supports or specificity to IDEA. Related to adding supports, participants wanted IDEA to include a provision requiring applied behavior analysis services and regulating class size. With respect to specificity, participants wanted IDEA to add clarifications about: transition planning, the least restrictive environment (LRE), and eligibility for learning disabilities. Notably, their study was limited to one state.

Parents may also request that states simply comply with IDEA mandates. Notably, 28 out of 50 states did not meet IDEA Part B requirements according to an analysis of State Performance Plans and Annual Performance Reports (U.S. Department of Education, 2017). Parents residing in these states may be more interested in compliance with existing IDEA

provisions than revising the IDEA. The issue of compliance may also be especially poignant for

CLD families. According to IDEA, non-native English-speaking parents of children with

disabilities are legally entitled to have language interpreters at IEP meetings. However, many

CLD parents of children with disabilities report not having access to language interpreters during

meetings, including Latinx families (Povenmire-Kirk, Lindstrom, & Bullis, 2010), Chinese

families (Rossetti et al., 2018), Korean families (Cho & Gannotti, 2005), Vietnamese families

(Rossetti et al., 2018), and Haitian families (Rossetti et al., 2018).

      Additionally, it is critical to examine patterns among suggestions for the next IDEA

reauthorization. For example, there may be unique suggestions with respect to the racial and

ethnic background of parents. CLD (versus White) children with disabilities are more likely to:

experience suspensions (Krezmien, Leone, & Achilles, 2006) and receive fewer services

(Magaña et al., 2013). Parental input can inform policy changes to decrease such disparities.

Given such disparities, CLD (versus White) families may have different suggestions for the next

IDEA reauthorization. Also, there may be differences with respect to household income.

Families of individuals with disabilities are disproportionately more likely to live in poverty

(Emerson, 2007). Thus, additional expenses can exacerbate the financial solvency of these

families. To this end, low-income (versus high-income) families may express different

suggestions for the IDEA reauthorization. For example, low-income may want IDEA to provide

more high-quality services for their children so they do not have to pay out of pocket. Finally,

the type of disability may impact suggestions for the IDEA reauthorization. For example,

families of children with autism spectrum disorder (ASD, versus other disabilities) are more

likely to file due process (Mueller & Carranza, 2011). Thus, families of children with ASD may

have unique suggestions for the next IDEA reauthorization.

Given the disparities in services and outcomes for children—especially CLD children—with disabilities, it is necessary to solicit the feedback of parents for the upcoming IDEA reauthorization. To this end, we conducted a civic engagement training with parents of children with disabilities across four states. At the end of the civic engagement training, 95 participants completed testimonials conveying their suggestions for the next IDEA reauthorization. We analyzed these testimonials to answer two research questions: (1) What are parent suggestions for the next IDEA reauthorization? (2) Are there any patterns between parent suggestions and cultural and racial background, household income, state of residence, or disability of the child?

Method

The exploratory nature of this study's research questions necessitated a qualitative research design. This study was part of a larger project examining the efficacy of a parent civic engagement program. The project's purpose was to educate parents of children with disabilities to conduct legislative advocacy for the next IDEA reauthorization. Extant research indicated a need for parent advocacy programs with a broad focus (e.g., civic engagement) and a geographically, racially and culturally diverse sample of parents (Goldman & Burke, 2017). The civic engagement program was conducted in collaboration with a Parent Training and Information Center (PTI) in each of four states with whom we had prior professional relationships (IL, TN, MA, and NH).

Participants

The participants in this study were 95 parents of children with disabilities. With respect to geographic diversity, 43.2% ($n = 41$) were from Massachusetts, 26.3% ($n = 25$) were from Illinois, 20% ($n = 19$) were from Tennessee, and 10.5% ($n = 10$) were from New Hampshire. The participants were primarily mothers of children with disabilities (86.3%, $n = 82$) and over half

reflected racial and/or ethnic minority backgrounds. Specifically, 22.1% of the participants

identified as Black ($n = 21$), 18.9% as Latinx ($n = 18$), 7.4% as Other (e.g., two races; $n = 7$),

6.3% as Asian ($n = 6$), and 44.2% as White ($n = 42$). Inclusionary criteria were: being the parent

of a child with a disability, participating in the 6 hr civic engagement program, and completing

research activities, including the legislative advocacy testimonial.

In total, 127 parents of children with disabilities participated in the 6 hr civic engagement

program; 95 participants completed the legislative advocacy testimonial. Some participants could

not complete the testimonial as they needed to leave the training early for personal reasons (e.g.,

medical appointment, childcare) or they did not want to be videotaped. Notably, there were no

significant demographic differences between those who attended the civic engagement program

and those who completed legislative advocacy testimonials (see Table 1).

Procedures

The authors' Institutional Review Boards approved all procedures.

Civic engagement program. The 6 hr civic engagement program was offered twice in

each of the four states. Based on the preference of the PTI in each state, the program was offered

during one day with lunch separating the two halves of the program, or it was offered across two

half days. The program was offered in English and Spanish. The program was developed by the

second author; the first and second authors trained each PTI or related agency to conduct the

program in each state. The civic engagement program included content about past IDEA

reauthorizations as well as prompts to facilitate discussion about potential changes to IDEA.

Specifically, the program included a broad review of core principles and components of IDEA

followed by discussion of ways that each might be changed. The participants determined the

content of the discussion. In addition, the program included content about methods to advocate

for systemic change, culminating in the legislative advocacy testimonies. For more information

about the civic engagement program, see Burke and Sandman (2014).

Data collection. Data were collected from the participants in conjunction with the 6 hr

civic engagement program. Before beginning the program, participants completed a

questionnaire answering demographic questions such as their: annual household income, racial

and/or ethnic background, state of residence, and type of disability of the child. At the end of the

civic engagement program, participants developed their own three min testimonials detailing

their suggestions for the IDEA reauthorization using a "Hook, Line, and Sinker" (Walsh &

Kuriansky, 2009) format that was taught during the program. The participants were provided

with numerous sample testimonials during the program. In the sample testimonials, the

participants identified the: a) hook (i.e., introduction of the person providing the statement and

their child/family); b) line (i.e., presentation of a problem); and c) sinker (i.e., suggestion for how

to resolve the problem). After reviewing the sample testimonials, the participants were given the

"Hook, Line, and Sinker" worksheet (see Appendix A) and 30-45 min to individually write their

own legislative advocacy testimonials. Participants were videotaped with the choice of reading

their testimonial or speaking extemporaneously; most read their testimonials. If they opted out of

the video, we took a photo of their written testimony. Research assistants transcribed the videos

and photos of the testimonial sheets. The transcripts and corresponding videos were used as data.

The length of the videos, on average, was 1:33 min (*SD* = 59 sec, ranging from 0:33 sec to 5:57

min). In total, we received 73 video recordings and 22 written testimonials.

Data analysis

The testimonials were analyzed using a multi-stage coding process to: (a) identify the

participants' suggested changes to IDEA, (b) generate descriptive codes for the participants'

suggested changes to IDEA, and (c) generate categorical codes for the type of requested change to IDEA. Two independent coders coded each testimonial. The first author coded all of the testimonials, and four trained research assistants (i.e., three doctoral students, one graduate student) each coded ¼ of the testimonials. Initially, each coder independently read the transcripts of each testimonial to gain familiarity with the data (Bogdan & Biklen, 2003) before engaging in the multi-stage process, described below.

To identify the participants' suggested changes to IDEA, each coder read their testimonials looking to identify distinct suggestions. When participants described multiple suggested changes, we coded each separately. Since two independent coders coded each testimonial, we were then able to compare lists of identified suggestions and resolve discrepancies through multiple discussions. There were 17 discrepancies in which one of the coders identified a specific request for change in the IDEA but the other coder did not. We discussed the discrepancies until agreement, including 12 of these and excluding five. The majority of the 12 that were included consisted of multiple suggested changes within the same statement, thus the discrepancies were largely due to a coder missing one distinct suggestion among several. Of the five that were excluded, four statements were ultimately deemed too general or indirect to qualify as a specific request (e.g., "Not every student needs same thing with anxiety."), and the remaining one was off-topic. These discrepancies reflected a coder extrapolating a suggestion from a general statement. This process resulted in 180 distinct participant suggestions for change in the IDEA. All but two participants included at least one suggested change. The inter-coder reliability at this stage was 91.4%.

The second stage included inductively generating codes that described each of the participants' recommended changes to IDEA. We used open coding and a constant-comparison

approach in which each code was compared with existing codes to determine whether the new

data reflected an existing code or a new idea (Creswell, 2013; Glaser & Strauss, 1967). The

coding process proceeded iteratively with multiple group meetings to discuss the descriptive

codes, resolve discrepancies by consensus, and categorize the descriptive codes. The initial 98

descriptive codes were refined and then organized into seven categories. The categories were

reviewed multiple times for internal homogeneity and external heterogeneity, such that the data

within each category were connected in meaningful ways (i.e., descriptively similar or

thematically linked) and distinct from the data in other categories (Patton, 2002). This led to the

development of sub-categories in most of the categories. For example, the category about

Individualized Education Programs (IEP) was divided into two sub-categories of IEP Process

and IEP Document. The broad category about Special Education Services was divided into two

sub-categories of Quality of Services and Eligibility for Services, and the latter sub-category was

further divided into two sub-categories of Extend Ages of Eligibility and Add

Disability/Eligibility Category.

Once the categories were established, the final step in the data analysis was to code each

participant suggestion according to the type of requested change to the IDEA. After discussion of

the descriptive codes, the research team identified and used three categorical codes for the type

of requested change to IDEA: Expand (i.e., add services and/or mandates to the IDEA),

Implement (i.e., comply with existing IDEA requirements), and Specify/Clarify (i.e., provide

further explanation or guidelines about IDEA requirements to enhance service delivery and/or

compliance). Each of the coders used these to independently code the same testimonials they

previously coded. Thus, all testimonials were, again, coded by two independent coders. The

fourth author then compared each set of codes across all testimonials for reliability and spoke

with each author to resolve discrepancies. Out of the 180 participant suggestions, there were 148

agreements and 32 discrepancies for an inter-coder reliability of 82.2%. Overall, each data unit

reflected a distinct participant suggestion for change in the IDEA that was inductively coded

with a descriptive code, categorized descriptively and/or thematically (e.g., IEP, Special

Education Services), and coded with one of three a priori categorical codes reflecting the type of

requested change to the IDEA (i.e., Expand, Implement, Specify/Clarify).

To address the second research question, we examined the data for patterns across

cultural and racial background, annual household income, state of residence, and disability of the

child. Specifically, we created data sets with the categorical codes and the descriptive sub-codes

organized by each of the following participant variables: race/ethnicity, annual income, and

child's disability. We examined frequencies of the categorical codes and descriptive sub-codes

within each of the participant variables, comparing to the overall findings and across each of the

groups. We discussed these and other descriptive patterns numerous times before presenting to

the rest of the research team.

Trustworthiness and credibility

To establish credibility and trustworthiness, the researchers engaged in member checks,

investigator triangulation, and peer debriefing (Brantlinger, Jimenez, Klingner, Pugach, &

Richardson, 2005; Lincoln & Guba, 1985). To ensure accuracy of the participants' suggested

changes to the IDEA, the third author captioned and edited all of the videos and we sent the

captioned videos to each participant. We also sent the transcripts of the written testimonials to

each participant. There were no requested changes from any of the participants.

In addition, this study utilized investigator triangulation by incorporating multiple

researchers and peer debriefing. This was a collaborative study across four states; the first two

authors collectively designed and conducted all aspects of this study with significant

collaboration and support from the remaining authors. Peer debriefing occurred during the

regular weekly researcher meetings to: discuss progress, address concerns, and resolve

discrepancies during data analysis. All researchers had worked with families in some capacity

(e.g., special education teacher, PTI staff member) and were knowledgeable in special education

policy and practice, and in home-school collaboration and family engagement. The first three

researchers were experienced in qualitative coding methods and trained the other researchers in

the study's procedures. Additionally, the first three authors also provided critical feedback about

data analysis procedures and interpretation of findings during all researcher meetings.

Findings

The participants offered 180 distinct suggestions for the next IDEA reauthorization. Their

requested changes fell into three categories: expansion or addition of services and mandates

(47.22%), appropriate implementation of existing mandates (40%), and specification or

clarification of existing mandates (12.78%). While expansion requests were the most prevalent

of the three, combining the other two categories of requested changes indicates that over half of

the requested changes emphasized strengthening existing mandates by implementing them

appropriately and clarifying gray areas. The seven descriptive themes comprising the content of

the requested changes to IDEA included: special education services (22.78%), funding of IDEA

(18.89%), IEPs (17.22%), parent support (12.78%), school accountability (12.78%), inclusive

education/LRE (7.78%), and educator training (5.56%). These descriptive themes were

distributed across the three categories of the types of requested changes (see Table 2). Below, we

detail these categories and themes, and then explore the patterns with cultural and racial

background, income, state of residence, and disability of the child.

Expand: Add Services or Mandates to IDEA

    Special education services. The participants' requested changes emphasized expanding IDEA mandates related to eligibility for services ($n = 12$) and quality of services ($n = 7$). Regarding eligibility, participants wanted more transition support as evidenced by some participants ($n = 7$) requesting that services be extended to age 26 while two participants requested that transition services begin earlier than age 16 or 14 (depending on the state). For example, a mother stated, "I am really concerned that the age gap of children protected under IDEA isn't long enough, and I would like for you to consider extending the scope of IDEA to the age of 26 because disability is lifelong and it doesn't magically disappear when a child turns 21." Also related to eligibility, several participants ($n = 3$) requested the addition of new categories of eligibility including Attention-Deficit/Hyperactivity Disorder (ADHD) as its own category, as well as "Twice Exceptional" as a new category. Regarding the latter, a participant stated, "Current legislation lacks the appropriate accommodations for twice exceptional learners. Specific language, funding, and practices for the identification and achievement of twice exceptional children needs to be addressed and instituted in [district]."

    Regarding quality of services, several participants ($n = 4$) described a need to add mandates that would result in more appropriate academic services, such as requiring Universal Design for Learning (UDL) in all instruction and increasing the number of educators (e.g., teachers, paraprofessionals). Other participants ($n = 3$) requested mandates that would emphasize more than just academic support and progress. Two suggestions included requiring social emotional learning curricula for all students and voice output communication aids for all non-verbal students. Regarding the latter, a participant stated: "I believe that it is critical that every non-verbal child be provided an output device to voice their concerns."

IEPs. The participants requested adding mandates related to the IEP process ($n = 16$).

Specifically, the most frequent suggestions related to changing IEP timelines ($n = 6$). Suggested

changes to timelines included: receiving the agenda and evaluation results seven days prior to the

IEP meeting, receiving an IEP draft 10 days prior to the IEP meeting, instituting a 20-day

timeline for receiving IEPs translated into the family's preferred or native language, and

shortening the 60-day time period for conducting evaluations. These suggestions were generally

supportive of additional time for parents to review materials. A participant stated, "The

completed evaluation should be provided with enough time for parents to read through it

thoroughly prior to the meeting." Other participants ($n = 4$) suggested adding external experts

(e.g., social worker, clinician) to IEP teams to provide recommendations or conduct meetings.

One participant suggested, "There should be a system of checks and balances with IEP teams and

a council that includes experts in the field of the child's disability from outside the school

system." Other suggestions included mandating that: the school administrator stays for the entire

IEP meeting, an advocate is at all meetings, paraprofessionals are members of the IEP team, and

facilitated IEP meetings are an option for dispute resolution.

There were two suggestions related to the IEP document. Both emphasized the difficulty

parents face in reading and understanding the IEP. A participant stated, "What I would want to

change, really, is making the IEP simpler so that parents can really understand it. The format is

really complex." The suggestions were to reduce repetition and to add a requirement for an IEP-

at-a-glance document. One participant reported:

> I have been at the IEP process for many years. I have taken the [PTI] volunteer advocacy
>
> course as well so I am fairly well versed in the law and I consider myself a good
>
> advocate. Why is it that with a master's degree in astrophysics I struggle to read my own

child's IEP and fully understand it? While I understand that the IEP is a legal document,

we are freezing parents out of their active role on the team by making it so complex.

What about those parents who are intimidated by such a document and don't read it fully?

Parents really do know their children best and have a self-interest in seeing them well

educated. I want to increase parents' access to and understanding of the IEP process.

These participants identified the complexities of the IEP document itself as a barrier to parental

engagement in the IEP process.

Parent support. Most of the parent support suggestions ($n = 17$) were related to

"expanding" IDEA. Many of the participants ($n = 11$) wanted IDEA to add stipulations related to

ensuring that parents understand their rights and access available resources. Examples included:

mandating parent trainings (e.g., Basic Rights in Special Education), offering low-cost or pro

bono attorneys and advocates, and providing publicly available lists of special education services

and directories of related resources and community agencies. A participant stated, "I believe that

parents should have training about their rights under IDEA and a mandatory non-biased advocate

on every IEP meeting from the beginning to help the parents understand their rights, what is

really going on and what to ask for." These requests reflected the need for parents to be educated

about special education policy and practice, but also a desire for increased partnership with

school professionals. For example, a participant explained, "My hope and dream is that it will

continue as it [IDEA] is being legislated but also expanding to include educational partnerships

where educators as well as parents understand how to respect and recognize one another rather

than parents being especially marginalized so that they can share resources."

Noting a significant barrier to family participation and engagement, several participants

($n = 6$) requested that IDEA guarantee language accessibility with IEPs and related documents

and during IEP meetings. In practice, this means regularly providing translated materials in

parents' preferred language in advance of meetings and scheduling professional interpreters with

knowledge of both languages and special education policy, practice, and terminology. A

participant concisely identified what she wanted changed in the next IDEA reauthorization:

"More outreach to the Latino communities in their language."

School accountability. Most of the School Accountability suggestions ($n = 17$) were in

this Expand IDEA category. Citing instances of schools lacking accountability in service

delivery, participants ($n = 5$) stressed that schools should deliver services as written in the IEP:

"Though it may seem obvious, I would like to see a clear statement within the IDEA that schools

must provide the services as they are written and agreed upon in the student's IEP." Participants

specified that IDEA should add stipulations providing more resources to better support school

personnel to implement the IEP, and also to add penalties for not implementing the IEP. For

example, a participant suggested, "Accountability needs to have clear repercussions for districts

not following regulations such as loss of license, monetary fines, and accreditations of

administrators or teachers that cannot follow the regulations." Other participants ($n = 8$)

requested stipulations regulating monitoring of service delivery to ensure accountability. Specific

requests included: mandating regularly scheduled parent observations of instruction and service

delivery, installing cameras in schools to monitor service delivery, and adding monthly reports of

service delivery with explanations for any deviations to increase transparency. A participant

stated, "I also think that [the] parent participation part of IDEA should be strengthened by

allowing parent weekly visits if they choose to and that the parent can stay the entire day."

Educator training. All of the suggestions ($n = 10$) related to increasing the quantity of

educator training opportunities and the quality of educator training were in this Expand IDEA

category. Participants voiced concerns about educator preparation. A participant stated, "I would also like that the teachers be more prepared. Not only should they rely on a diagnostic result but they should take the time to figure out and engage in extra trainings to be able to work well with the kids." Several participants requested additional funds for professional development. Participants emphasized that paraprofessionals also need additional preparation. A participant stated, "Another one of my concerns is the assistants who assist students with special needs. They should have the ability, the preparation to treat kids with different disabilities." Specifically, participants asked that special education teachers, general education teachers, and paraprofessionals engage in more opportunities to gain knowledge about ADHD, autism, transition services, and evidence-based practices.

Implement: Comply with Existing IDEA Mandates

  Funding of IDEA. The majority of requests related to funding ($n = 28$) were in this Implement IDEA category. Overall, full federal funding of IDEA was the second most frequent descriptive category, but it was also the most frequent single issue suggested by participants for the eventual IDEA reauthorization. Participants were adamant about increased federal funding of IDEA to expand services and improve service delivery. A participant shared a rationale for this suggestion that was representative of other suggestions: "My ask of you would be to support an increase in funding for special education to empower students to have access to additional funds, for adequate staffing to implement a variety of programs, meant to benefit all special education students." Ultimately, participants viewed a direct link between increased funding and improved outcomes for their children. A participant stated, "I want to know that IDEA will be fully funded so that my son can meet his career objectives. I want to see our legislators and voters find money

to make these programs and other programs for people with disabilities so that they can lead inclusive and productive lives."

Special education services. The majority of requests about special education services related to student progress. The requests (*n* = 13) highlighted the need for more appropriate services and service delivery to result in more student progress. A participant stated, "…in that case, that will help timely service to children with special needs, which will increase the possibility for them to contribute to the community in a higher degree, and therefore to the benefit of all people." Another participant emphasized that appropriate services should include functional and other non-academic supports and goals: "And that we look beyond just servicing kids who are struggling with their grades. So, I believe, special ed, my son is somebody who needs those services to be successful beyond the academics."

IEPs. The suggestions related to IEPs were evenly focused on the IEP process (*n* = 4) and the IEP document (*n* = 5). Related to the former, participants requested: early diagnosis, individualized assessment, accommodations in state testing, and considerations of social emotional learning. Related to the IEP document, participants stressed that they needed the IEP and related materials to be translated into their preferred language. For example, a participant stated, "We should be able to receive it [IEP] in our language."

School accountability. The suggestions (*n* = 8) about school accountability emphasized the importance of delivering services as written in the IEP. A participant stated, "The thing I think that should change is when educators are requested to follow the guidelines of the IEP plan, that they should be accountable to implement the services." Generally, the participants (*n* = 6) requested increased transparency in service delivery and compliance with existing IDEA mandates. A participant stated, "Accountability - there are many legal things that are not being

followed and I don't feel the system is there to support children and parents." Several participants highlighted the importance of accountability for all families and protections for all students, suggesting that (as extant research supports) student outcomes and parent satisfaction in special education differ by race, ethnicity, and socioeconomic status. A participant stated, "I would like school districts to be held accountable to the laws put in place to protect all people with disabilities and not just the elite few."

Inclusive education/LRE. Parent suggestions about inclusive education/LRE were only found in the Implement IDEA and Specify/Clarify IDEA categories. In this category, the parent suggestions (n = 7) emphasized non-categorical service delivery in general education classrooms, as well as participation in social interaction opportunities with peers without disabilities during extracurricular activities and non-academic times. Related to the former, a participant explained:

> My main concern throughout all these years of advocacy is around inclusion with proper support. I felt like most of the time, the placement is based on labels - give me a name, and I'll give you a place. It's mostly determined by disability and this is, I think, the major issue that schools have, that they offer partial inclusion versus full inclusion. They don't invest into those kids. They necessarily don't have higher expectations for them, and it's so sad that districts do not thrive on a culture of inclusion.

The participants recognized the presumption of inclusive education in IDEA; they wanted their schools to implement inclusive practices.

Specify/Clarify: Provide Explanation or Guidelines about Existing IDEA Mandates

Special education services. The suggestions (*n* = 7) about special education services in this Specify/Clarify IDEA category focused on guidelines or explanations to strengthen the quality of services. Individual requests included: clearer language in IDEA about what should be

included in transition services (students ages 18-21), specificity about the transition from Part C

to Part B services, and operational definitions of *appropriate* services. Regarding the latter, a

participant stated, "We need clearer language about what is defined now as appropriate

services and placement." A participant also requested that IDEA specify the use of assistive

technology in IEPs.

Inclusive education/LRE. In this category, the suggestions ($n = 7$) emphasized adding

stronger language in IDEA about: inclusive education, the importance of social relationships (as

a reason for inclusive education), and the definition of *appropriate placement*. Related to the

former, a participant specified, "So what I'd like you to do is to help strengthen the language and

the IDEA to better support the inclusion of all students, especially of those with intellectual

disabilities." Several participants requested that IDEA not just strengthen the presumption of

inclusive education in IDEA, but actually include the words "inclusive education" in the law

during the next reauthorization. Related to recognizing the importance of social interactions and

relationships, a participant stated, "I would love to see the language of the law be updated to

reflect the relationship and friendship building as reasons why access to extracurricular activities

for students with disabilities is critical." Lastly, two participants requested clarification of LRE,

and one of them stated, "I would like to see IDEA reauthorize with more clear definition of

what's "appropriate" and what the "least restrictive environment" (LRE) is."

IEPs. The suggestions ($n = 4$) in this category highlighted a need to: simplify the IEP

document, translate the IEP document into families' preferred languages, and provide qualified

professional interpreters during IEP meetings. For example, a participant stated, "Provide

qualified district translators for non-English speaking parents. Qualified district-employed, not a

school employee who happens to be free at the time of the IEP." Thus, participants were

requesting these specifications to improve access to their children's IEPs and IEP meetings.

Demographic Patterns in Requested IDEA Changes

There were patterns with respect to the race/ethnicity of the participants and their

suggestions. While requests for parent support were made across all racial and ethnic

backgrounds, Asian (50%) and Latinx (19.51%) families requested parent support most

frequently, in comparison to White (8.53%) and Black (11.90%) families. Further, in comparison

to White (3.66%) families, Latinx (17.07%) families were more likely to request changes in

regard to the IEP document. Further, Latinx (versus White) families were more likely to request

changes related to educator training (14.63% versus 1.2%, respectively).

With respect to annual household income, there were differences in suggestions among

low and middle-income families (defined as incomes below $69,999) and high-income families

(defined as incomes above $70,000). Specifically, low-income (19.51%, defined as below

$29,999) and middle-income (18.52% defined as between $30,000-$69,999) reported parent

support as their most frequent suggestion. Parent support was only noted among 6.58% of high-

income families. In contrast, high-income families frequently reported accountability (19.74%)

as their most frequent suggestion whereas only 14.63% of low-income and 9.26% of middle-

income families reported accountability in their suggestions.

Looking at the disability diagnoses of the participants' children, there are fewer patterns.

For example, regardless of the type of disability, participants made frequent requests related to

the quality of special education services and school accountability for delivering those services.

Parent support was requested most frequently by parents of children with emotional and

behavioral disorders (20.41%) in comparison to parents of children with ASD (10.84%), learning

disability (7.24%), and speech and language impairment (5.33%).

There were few patterns with respect to state of residence. Notably, there were no

differences in the number of requests to implement or expand IDEA. In comparison to

participants from Massachusetts (10.98%), participants from New Hampshire (29.41%),

Tennessee (25%), and Illinois (24.44%) were most likely to address funding in their suggestions.

In contrast, participants in Massachusetts were more likely to address parent support (18.29%)

and quality of services (18.29%) in their suggestions. Participants in Tennessee also addressed

parent support (16.67%) and quality of services (16.67%) whereas participants in Illinois and

New Hampshire referenced these topics in less than 5% of their suggestions.

Discussion

This study examined individual parent suggestions for the next IDEA reauthorization.

Altogether, this study had three main findings. First, the suggestions reflected an abundance of

requests to expand IDEA. This finding is consistent with previous studies of civic engagement

among parents of children with disabilities (Burke & Sandman, 2014). However, unlike previous

studies, this study expands the literature about civic engagement with respect to the types of

suggested additions to IDEA. In the study by Burke and Sandman (2014), participants frequently

requested that applied behavior analysis and class size be addressed by the next IDEA

reauthorization. However, in this study, requests included: access to timely and appropriate

services, technology use, provision of parent support, changes to IEP processes and documents,

school accountability mechanisms, and educator training. In previous reauthorizations of IDEA,

sweeping expansions have been conducted including, for example, adding autism and traumatic

brain injury as disability categories in 1990 and requiring highly qualified teachers in 2004.

Thus, it is feasible that IDEA may expand in the next reauthorization.

Second, in addition to the requests for expansions, participants also had several requests

for clarity and compliance within the current version of IDEA. These included clear guidance

about appropriate services and the LRE, as well as improvements in delivering services as

written in the IEP and providing families with language access during the IEP process (i.e.,

translated materials and language interpreters). Given that more than half of the states are out of

compliance with IDEA (U.S. Department of Education, 2017), this finding is unsurprising.

However, this finding highlights the importance of the next reauthorization not only expanding

to meet the needs of students with disabilities but also including safeguards and mechanisms to

ensure compliance with the current IDEA requirements.

Third, there were differences with respect to racial and ethnic background, income, and

type of disability. Specifically, there was a pattern regarding parent support with CLD, low and

middle-income families, and families of children with emotional and behavioral disorders

requesting parent support. Notably, parent support groups may be especially helpful among

minority families. In a study comparing parent support group benefits among CLD and White

parents of children with disabilities, Pickett, Cook and Heller (1998) found that CLD (versus

White) families reaped more benefits from parent support. Unfortunately, the majority of

research about parent support reflect White, high-income families (for a review, see Vanegas &

Abdelrahim, 2016). Regarding students with emotional and behavioral disorders, the National

Alliance on Mental Illness (NAMI) is a national agency serving many of these individuals.

While NAMI offers family support to families of adults with emotional and behavioral needs,

they do not offer such support to families of children with such needs. As such, there may be a gap in meeting this need among families.

Limitations

Although an important jumping off point to understanding parent's suggestions for the next IDEA reauthorization, this study had a few limitations. First, one testimonial was conducted with each individual participant after the training. Testimonials prior to the training may have provided richer data about parent suggestions. Specifically, patterns of parents' suggestions could have been compared before and after the training. Also, this study only reflects the perspectives of participants who completed a 6 hr civic engagement training. Thus, although the sample has great diversity, it is not representative of the population of parents of children with disabilities. For example, not all parents of children with disabilities may have time to participate in a six hr civic engagement training; thus, generalizability may be limited. Finally, this study is limited to one time point. Parent suggestions for the next IDEA reauthorization may change over time.

Directions for Future Research

Based on this study, there are several implications for future research. For example, research should be conducted with a larger, more heterogeneous and representative sample of parents of individuals with disabilities, including those who have not participated in the 6 hr civic engagement training. The same parent testimonial procedure could be conducted as a stand-alone procedure outside of the civic engagement training. This study suggests differences in parent perspectives with respect to income, race/ethnicity, and type of disability. Such differences may be due to disparities in accessing services, accountability, and advocacy among, for example, minority (versus White) families (Rossetti et al., 2018). Future research should be

conducted with families who speak other languages to explore their suggestions for the IDEA

reauthorization. To do so, the parent testimonial procedure could be translated into several

languages (e.g., the top three or five languages other than English spoken in the US) and

implemented by multilingual researchers or with interpreters. Further, research should more

closely examine the impact of country of origin and racial background among parent

suggestions. For example, parents from South American countries may have different

suggestions than parents from Mexico given the differences in educational systems and cultural

values (Cohen, 2013). With a larger or focused sample, such comparisons could be made.

Further, research should be conducted with parents of individuals with disabilities across

the United States. Per OSEP's annual report to Congress on the implementation of IDEA

(USDOE, 2018), Illinois is in need of improvement in meeting IDEA requirements whereas

Massachusetts, Tennessee, and New Hampshire are in compliance with IDEA. However, we did

not find clear differences in their suggestions for the next IDEA reauthorization. Future research

should target more states that have been consistently out of compliance with IDEA to determine

if parent suggestions may differ by state. The parent testimonial procedure, with or without the

civic engagement training, could be offered to targeted states.

Implications for Policy

Findings from this study can directly inform policymakers when drafting the next version

of IDEA. Specifically, policymakers may want to collect more data and input regarding the most

frequently discussed suggestions for the next IDEA reauthorization: full federal funding of

IDEA, more appropriate special education services, adding accountability mechanisms, ensuring

linguistic access, extending eligibility for special education services, and simplifying the IEP.

Already, professional organizations have drafted statements regarding their desires for the next

IDEA reauthorization (e.g., School Superintendents Association, 2013). However, there is not one collective, national agency that has put forth suggestions from parents. As such, this study provides a jumping off point for policymakers to consider the experiences and perspectives of parents. Their input can be critical as consumers of special education services.

Further, policymakers may want to replicate the methods used in this study to solicit parent input. Notably, parent participation in previous IDEA reauthorizations was limited (Harr, 2000; York, 2005). In the last IDEA reauthorization, parent input was at its lowest (Turnbull et al., 2011). To this end, the methods from this study may be used as prompts or examples for other parents to provide testimonies about what they want changed in IDEA. Moreover, the study findings may prompt policymakers to examine how they solicit feedback for IDEA reauthorization and possibly expand the options for families such that more parents of individuals with disabilities participate in legislative advocacy. Specifically, policymakers may consider working with PTIs to solicit parent input and/or providing a "hook, line and sinker" format to help parents format their suggestions.

Legislative advocacy is a critical and promising area for family advocacy to affect individual and systemic change. According to IDEA, parents are legally entitled to participate in their children's IEP process. That said, it is imperative that we do more to embed parents into the legislative process that governs their children's education and their participation in educational decision-making. Providing parents with a platform and inviting them to share their recommendations, as this study did, has the potential to enhance the law and its provisions that impact six million children with disabilities, while empowering parents as change agents.

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Table 1.

Participant Demographics

	Total Sample ($n = 127$)	Video sample ($n = 95$)	t/X^2	p
	% or M (SD)	% or M (SD)		
Gender: Female	86.6% (110)	86.3% (82)	.34	.56
Age	46.26 (8.12)	45.71 (7.98)	1.12	.90
Marital Status: Married	66.1% (84)	67.4% (64)	.09	.77
Language: English	89.8% (114)	90.5% (86)	.01	.91
Site attended			6.88	.08
Illinois	29.9% (38)	26.3% (25)		
Tennessee	21.3% (27)	20.0% (19)		
Massachusetts	39.4% (50)	43.2% (41)		
New Hampshire	9.4% (12)	10.5% (10)		
Educational Background			1.67	.80
Some high school	6.3% (8)	6.3% (6)		
High school degree	7.9% (10)	8.4% (8)		
Some college	17.3% (22)	17.9% (17)		
College degree	29.9% (38)	27.4% (26)		
Graduate degree	37.8% (48)	38.9% (37)		
Missing	.8% (1)	1.1% (1)		
Annual income			6.93	.23
Less than $15,000	11.0% (14)	13.7% (13)		

$15-29,999	9.4% (12)	7.4% (7)		
$30-49,999	16.5% (21)	16.8% (16)		
$50-69,999	14.2% (18)	15.8% (15)		
$70-99,999	18.9% (24)_	16.8% (16)		
More than $100,000	22.0% (28)	24.2% (23)		
Missing	7.9% (10)	5.3% (5)		
Race			3.72	.45
Other	7.9% (10)	7.4% (7)		
White	47.2% (60)	44.2% (42)		
Black	19.7% (25)	22.1% (21)		
Latinx	19.7% (25)	18.9% (18)		
Asian American	4.7% (6)	6.3% (6)		
Missing	.8% (1)	1.1% (1)		
Child Gender: Male	63.0% (80)	66.3% (63)_	1.99	.37
Child age	12.17 (5.81)	11.88 (5.28)	1.34	.11
Child's Type of Disability				
Intellectual disability	27.6% (35)	27.4% (26)	.05	.83
Speech impairment	37.0% (47)	37.9% (36)	.04	.84
Autism	48.0% (61)	52.6% (50)	2.59	.11
Learning disability	37.0% (47)	36.8% (35)	.05	.82
Emotional disorder	24.4% (31)	24.2% (23)	.04	.84

Table 2.
Category/Code Frequency and Data Examples

Category/Code	Frequency (*N* = 180)	Example
Expand IDEA services	**47.22% (85)**	
Special Education Services	10.56% (19)	"I would like for services to be extended to the age of 26 in all fifty states."
Parent Support	9.44% (17)	"We need more parent trainings to know the laws and their rights."
IEP	8.89% (16)	"The completed evaluation should be provided with enough time for parents to read through it thoroughly prior to the meeting."
School Accountability	7.22% (13)	"I'm also asking for accountability. Accountability needs to have clear repercussions for districts not following regulations…"
Educator Training	5.56% (10)	"One of my main concerns is that I believe that there should be more education for teachers."
Implement existing IDEA services	**40% (72)**	
Funding of IDEA	15.56% (28)	"I also find it important to meet the initial budget of IDEA of forty percent…"

Special Education Services	8.33% (15)	"My main concerns as a parent and advocate for my daughters are accommodations not being properly implemented…"
IEP	5% (9)	"I definitely want to see that the IEP is being translated and in simple language…"
School Accountability	4.44% (8)	"I would like school districts to be held accountable to the laws put in place…"
Inclusive Education/LRE	3.89% (7)	""Another important aspect is the integration of our children with neurotypical children. It seems to me that we need more inclusion in the classrooms…"
Specify/clarify existing IDEA mandates	**12.78% (23)**	
Special Education Services	3.89% (7)	"…there needs to be even more priority in the law around assistive technology…"
Inclusive Education/LRE	3.89% (7)	"…we need to really take a moment and define what it means per child to be in the least restricted environment."
IEP	3.33% (6)	"Provide qualified district translators for non-English speaking parents. Qualified district employed, not a school employee who happens to be free..."

Note. IDEA = Individuals with Disabilities Education Act; IEP = Individualized Education Program; LRE = Least restrictive environment.

Appendix A
Testimony worksheet

Videotaped Testimony Worksheet

Your name_____

HOOK: Child's name, type of disability, district

_____
_____
_____
_____
_____
_____

LINE: Your main concerns (and a story that illustrates them)

_____
_____
_____
_____
_____
_____

SINKER: What you want changed and how you want it changed

_____
_____
_____
_____
_____
_____