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## Rethinking the Individualized Education Plan process: voices from the other side of the table

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### ABSTRACT

Parent involvement in the process of creating an Individualized Education Plan (IEP) is authorized under the Individuals with Disabilities Education Act, a federal law in the United States that ensures children with disabilities have the opportunity to receive a free appropriate public education alongside their peers without disabilities in the least restrictive environment. Yet much research has shown that parents often feel like outsiders during the process. To understand parent perspectives about how educators might help make the IEP process more collaborative and inclusive, this study collected qualitative data from 35 parents of students with disabilities who have worked to develop an IEP with a school team. Our findings provide insight into parent experiences and evidence that parents have many suggestions for how educators can improve the IEP process. In our discussion section, we provide educators with strategies to address parent suggestions.

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### Points of interest

- This study explored how parents in the United States view the experience of collaborating with educators to support their children with disabilities in general education settings.
- This study used a collaborative research approach, working with two parent participants to co-create the study's research questions and co-write the article.
- Parents shared many concerns about collaborating with educators, such as persistent fears and anxieties due to lack of communication, trust and negative perceptions of disability.
- Findings highlight that positive collaborative experiences were more likely to occur when educators treated parents like partners, focused on the child's

strengths, explained ideas and policies clearly, and were flexible and willing to learn and try new things.

- The discussion section provides educators with specific ideas and strategies to use when collaborating with parents of children with disabilities in order to make the process of creating Individualized Education Plans more inviting and collaborative.

## Introduction

The Individuals with Disabilities Education Act (IDEA) is a United States federal law originally created in 1975 to provide all students with disabilities a free and appropriate public education alongside their non-disabled peers in the least restrictive environment. This appropriate education is implemented through each child's Individualized Education Plan (IEP), the legal document in which parents and school personnel determine specific supports and services the student will need to access general education. This IEP process is one of the most powerful aspects of the student's education and therefore the IDEA mandates that parents are equal members in the creation of the IEP (Yell 2012). Parents are therefore required to be included in the decision of evaluation and eligibility for their child's special education services, placement and the actual writing of the IEP (Federal Register 1999, 12472; Huefner 2000; Drasgow, Yell, and Robinson 2001). The letter and spirit of the IDEA, then, envisions the family and school working together to create and enact shared educational visions and goals for each child.

Educational research evidences that this type of family-school relationship is critical to support higher achievement for diverse student populations and create inclusive school practices (Bouffard and Weiss 2008; Epstein 2001; Pushor and Murphy 2004). Professional literature is therefore understandably filled with book chapters and journal articles dedicated to providing advice for special educators about how to develop effective IEPs in collaboration with families (Council for Exceptional Children 1999; Dabkowski 2004; Drasgow, Yell, and Robinson 2001; Huefner 2000; Mason, McGahee-Kovac, and Johnson 2004; Mueller 2009). Topics generally include but are not limited to how to get parents to the meeting, overcome cultural and linguistic barriers, communicate with all stakeholders – including the general education teacher – and understand and adhere to the law.

Yet parents continue to feel like outsiders during the IEP process despite these legal mandates and all the professional advice for educators (Salembier and Furney 1997; Garriott, Wandry, and Snyder 2001; Hauser-Cram et al. 2001; Ferguson 2002; Mueller 2009; Sauer and Kasa 2013). As Hansuvadha (2009) and Houtenville and Conway (2008) explain, this could be because teachers continue to feel underprepared to understand diversity as it pertains to families with students with disabilities. Other research suggests the IEP process can be difficult and complicated because school staff and families do not always share the same goals

and perspectives about disability and education (Engel 1993; Valle and Aponte 2002) and teacher interaction with families of children with disabilities often uses a paradigm that reflects the dominant narratives of disability as deficit (Ferguson and Ferguson 2006; Zeitlin and Curcic 2014). Research by Valle and Aponte (2002) has even drawn upon the work of Bakhtin to highlight the way professional and authoritative discourse of school professional dominates and devalues the discourse of parents.

### ***Theoretical framework***

To address some of these ideological disconnects, researchers have suggested teachers consider a Disability Studies (DS) framework as they collaborate with families on the IEP process (Ferguson and Ferguson 2006; Lamar-Dukes 2009; Sauer and Kasa 2013). As a field, DS challenges the view that disability is an individual deficit that can be remediated. Instead it seeks to understand disability as a social, political and historical phenomenon, and DS scholars focus on the social valuing and inclusion of persons with disabilities. Scholars approaching DS through an educational lens apply this understanding to the exploration of dis/ability in school contexts (see, for example, Baglieri and Shapiro 2012; Connor et al. 2008; Ferri 2009; Slee 1997).

Using Disability Studies in Education (DSE) as a framework when working with families to create effective inclusive IEPs may help educators begin to think about the nature and meaning of disability as something socially constructed. Because school professionals and parents are navigating the IEP process in a system in which 'disability is constructed within social, cultural, historical, legal, and medical discourses' (Ferri and Connor 2006, 14) by using a DSE lens, educators can begin to interrogate their individually held theories of disability, learning and schools (Slee and Allan 2001). A DSE framework asks educators to embrace an educational philosophy that sees disability as an attribute (Schwarz 2006), not a deficit, and to view human diversity as something natural, expected and valued that contributes positively to classroom climate, learning outcomes and community quality (Brantlinger 1997, 435).

### ***Purpose of study***

In light of the extant research suggesting the use of a DSE lens to approach family-school collaboration, and the need to continue to qualitatively explore the parent perspective in relation to disability and schooling (Bacon and Causton-Theoharis 2013; Hodge and Runswick-Cole 2008; Zeitlin and Curcic 2014), we sought to utilize a DSE framework to explore parent experiences. We believe that this lens may help to counteract the often-negative impact of the positivist paradigm that has long driven the field of traditional special education. In attempts to understand the most effective practices for education, special education researchers and professionals

often imitate the ideology and practices of objectivity assumed to be found in the natural sciences (Ware 2005). However, assumed objectivity has often meant that as researchers and educators we focus on how to 'fix' a student's problems, and as experts we dismiss much of what the student and their family bring to the table. Building upon the work of Bacon and Causton-Theoharis (2013) and Hodge and Runswick-Cole (2008), this study seeks to understand how educators can work with families and loved ones during the critical IEP process to move away from a deficit-driven conversation and instead collaboratively create individualized goals that provide thoughtful accommodations, adaptations and modifications for the student.

We therefore explored the experiences, needs and desires of 35 families of school-aged individuals with disabilities who have worked with school teams to develop appropriate and inclusive IEPs for their children. For the purpose of this article, when we say collaboration during the IEP process we refer to all of the communication surrounding the meeting, the meeting itself, as well as specific strategies that parents and teachers have developed to create effective and inclusive IEPs. Our goal for this research is threefold: to provide the perspective of the parent; to provide educators with specific ideas and strategies for making the IEP process an inviting and collaborative meeting that draws from a DSE framework; and to align these perspectives and strategies with the letter and spirit of the law.

## Method

Our study uses the phenomenological qualitative approach (Creswell 2012; Van Manen 1990) in order to examine the beliefs and perspectives of the families involved in the IEP process but also to 'grasp the very nature' (Van Manen 1990, 81) of the phenomenon of the collaboration process as seen from the parent perspective. In our literature review we found that surveys appeared to be the most prevalent way researchers have examined issues related to the IEP process between schools and families (Mitchel, Morton, and Hornby 2010). Yet while surveys provide a broad understanding of the IEP process, they do not get at the deeper reasoning that have brought participants to particular views (Harry 2008). Also, surveys do not address solutions that participants might believe could alleviate issues with the IEP process. Therefore, we sought to provide our participants with the opportunity to respond to open-ended questions. Our participants were part of an online parent advocacy group in which they frequented an online space daily or weekly to garner support from one another, so we determined that using this familiar supportive space to collect data would be most effective. Additionally, using the online space provided participants with the opportunity to respond to our questions in writing, at their leisure.

While this online open-ended questionnaire method was an important choice, we believe an even more integral feature of our research is our use of Deyhle's (2009) 'mutual collaboration' approach, which allowed us to more fully intertwine

the relationship between researcher and participant (Clandinin and Connelly 1994). Because both the first and second authors consider ourselves scholars in the field of DSE, we seek to decenter the voices of professionals and focus on the voices of those with lived experience of disability, including their closest supporters (i.e. parents and guardians) (Taylor 2006). To decentralize educator and professional voices (including our own), which have often dominated the literature surrounding family–school collaboration (see Engel 1993; Salembier and Furney 1997; Garriott, Wandry, and Snyder 2001; Hauser-Cram et al. 2001; Ferguson 2002; Mueller 2009; Sauer and Kasa 2013), we asked our first two parent participants, Mary and Patrick, to work on this research with us as experts and collaborators.

Mary and Patrick are parents of a young child with Down syndrome. Over the past four years they have collaborated with their son’s elementary school team to fully include him throughout the school day in general education classes. Until his arrival in kindergarten, the school had never educated a student with a significant disability. When we asked Mary and Patrick to participate as collaborators, we explained that this meant they could be involved in the creation of the research questions, collection of data and writing of the article. Deyhle (2009) explains that this type of mutual collaboration helps to provide the fullest possible picture of what an event or experience is like for the participant. This approach is grounded in activist scholarship that aims to represent a plurality of voices and concerns of local communities/participants and is useful for and accessible to the community collaborators (Fine and Vanderslice 1992; Lassiter 2005). They agreed to participate as collaborators and were subsequently involved in the decisions about participant recruitment (i.e. they suggested the Facebook parent advocacy group they belong to) as well as contributed to the questions we might ask participants (i.e. they stressed the importance of asking parents about their beliefs in how to improve the IEP process). For each process in the research, we discussed our collaborative roles, making sure Mary and Patrick had time to reflect on the tasks they wanted to take on. When conducting collaborative studies, there can often be unknown burdens placed on the participants (Lassiter 2005). Scholars have found that sometimes there are times when participants prefer to highlight academic knowledge or process, rather than always rely on co-constructed knowledge (Gubrium and Harper, 2016). This was the case for Mary and Patrick when we discussed data analysis processes: they reflected on their goals and needs for the project and decided that rather than spend many hours coding data, they would rather have us present them with analyzed data. Then we decided that together we would determine how to turn the analyzed data into a co-created narrative that would successfully highlight the parent perspective. Mary and Patrick suggested the italicized vignettes (evidenced throughout the findings section) as a means to introduce each theme from their particular parent perspective.

## ***Participants***

We purposefully recruited Mary and Patrick as participants because we knew that they had had many different experiences collaborating with their school. In our first few conversations about the research project, Mary and Patrick explained that they were members of an online Facebook advocacy group for parents seeking inclusive educational experiences for their children with disabilities. Together we decided we would utilize this Facebook group to recruit more participants. We agreed that it would be a useful purposeful sampling, because we wanted to effectively align this study with the inclusive spirit of IDEA and the IEP process. Therefore, we wanted to hear from parents involved in creating inclusive IEPs for their children. For our study, we refer to inclusion as a schooling experience in which a child with a disability label spends the majority or all of the school day in general education classrooms with their peers without disabilities, and receives the supplemental supports and services needed to access the curriculum.

After approval by the Institutional Review Board, we posted a call for participants on the Facebook advocacy group page. We explained the study and criteria for participating: participant has a school-age child who is identified with one of the 13 federal categories of disability; participant has collaborated with a school team to create an IEP for their child; and participant desires inclusion in the general education setting for their child. Through this post we recruited 33 participants, 35 including Mary and Patrick, who met our criteria and consented to participate. We understand that our participant pool is a small sampling of parents and does not speak for all families of children with special education labels. But they are all interested and active in advocating for inclusive educational experiences for their children and this was critical to our study. The participants also varied by age and gender, represented states across the country and have a great variance in their experiences with IEP meetings. Some parents had older children and consequently had attended more IEP meetings than others, and several parents had moved in the past and had experiences in different districts. With informed consent we created pseudonyms to describe participants named in this article, with the exception of Mary and Patrick, who chose to use their names. Finally, it is important to note that although we use the word 'parent' throughout this study, we have chosen this term to represent an inclusive understanding of guardians who support a child at the IEP meeting (e.g. mom, grandparent, aunt, uncle).

## ***Data collection and analysis***

We collected qualitative data from our participants by posting our research questions as a query onto the Facebook 'wall' of the private parent advocacy group. We grounded our research questions in the extant literature involving parent perspective and in a DSE framework, which intends to privilege the voice of those with lived experience of disability, including close supporters of a child with a

disability. We asked participants who consented to participate to share their experiences collaborating with schools during the IEP process and to provide advice for educators about collaborating with parents who seek inclusive opportunities for their children. Our query was posted from 15 March 2015 to 30 March 2015 and garnered over 50 responses from 35 parents and guardians who were members of the closed Facebook group. Facebook allows posts to include up to 63,206 characters, and the average single response to each question was 5000 characters. However, participants were also able to respond more than once and many of the participants responded multiple times, increasing the average response to 30,245 characters. During the two weeks the questions were posted, whenever a participant posted a response, Kate would read the post and respond with a probe when necessary, such as ‘can you explain what you mean when you say it was helpful when the teacher showed flexibility?’ These probes garnered more responses from participants. After these two weeks, Kate and Julie organized and coded responses using deductive and inductive analyses (Corbin and Strauss 2014). We began deductively coding the text looking for passages and data examples that addressed our main research questions about experience and advice for collaborating during the IEP process. Then we inductively coded line by line to further refine the analysis (Corbin and Strauss 2014).

As major themes emerged we discussed the need to pose more questions related to each theme to achieve greater understanding of participant experience. For example, vulnerability and trust came up in many responses, but more information and detail was needed. In June 2015 we posted a description of each theme and included more specific questions about each, such as ‘can you describe a time in which an educator gained your trust or acknowledged your vulnerability?’ These further questions garnered eight responses from our participants. Kate and Julie then pulled these responses and organized and coded them, again using deductive and inductive analyses (Corbin and Strauss 2014). Finally, after back and forth edits between Kate and Julie, we presented our draft findings to Mary and Patrick. They then created their italicized vignettes to introduce each of the five themes: parents are experts too; acknowledging vulnerability and building trust; seeing the whole child; willingness to learn; and flexibility and creativity in approach. After many edits between the four authors, we posted a draft of this article to the closed Facebook group to provide all participants with a member check, asking each participant to read and provide suggestions or changes to most accurately represent their voices. To date no participants have responded with requests for changes beyond grammatical errors, which have been addressed.

## Findings

### *Parents are experts too*

*Parents know that educators went to school for a long time and consistently try to make professional assessments and judgments grounded in good practice. We know*



*educators have dealt with difficult situations with patience, wisdom and grace. We know educators are passionate about their work and care about our kids. Often, when we suggest they try something different or disagree with an IEP goal, service recommendation or placement for our son, the teacher's first reaction can be to take offense. They believe they are in the best position to see our son objectively and to recommend a program, placement or service. They wonder, who are we to question their judgment or compassion? Worse, they wonder if we do not trust them. But we do not want educators to think like this. We simply want them to know we are experts too. Not unbiased experts, admittedly. But we have spent more time than anyone living with our child. If for no other reason than pure survival, we have found a strange alchemy of patience, firmness and attitude that allows us to make it through the day, most of the time. We practice inclusion every single day – trying to find a way to support our child in the context of our otherwise typical family. We have spent time researching his disability. We have talked with other parents and shared best tips and practices – and horror stories – along the way. We want educators to listen to what we have to say! When we say we see it differently, we are not questioning professional competence or personal compassion. We are just asking educators to think about something in a new or different way. Accept our advice for what it is. Remember our experience and unique perspective. Reconsider assumptions. Ask whether the 'way it's always been done' is still the best way or still the right way. We want educators to always remember that we are experts too.*

Like Mary and Patrick, the parents in this study recognized that educators have extensive knowledge of how to educate children with disabilities and are passionate about their work with students. But largely parents expressed that during IEP meetings educators often downplayed their ideas and advice or caused them to feel marginalized in the care of their own child. One parent, Jennifer, explained that these interactions with professionals led her to feel like an outsider, 'alienated' from the IEP process. She explained: 'When I feel like our teacher isn't listening to me, I feel alienated and alone. I can become defensive: I am his mom! I know him. You don't!' Parents also expressed this alienation could even manifest from the physical positioning at the IEP meeting itself. For example, Kimber explained:

If I am an equal contributing member of the IEP Team, don't make me sit outside while everyone else is in there talking before they let the parents in, don't position my seat at the table in an 'us against them' format (everyone facing toward the parent instead of sitting right by them in more of a circular format).

Another parent, Leila, felt similar pangs of anger and disillusionment with the IEP process when teachers did not appear to listen to her about an activity she knew her son found difficult:

We spent hours at the library, picking out books. I read to him so much and he loved this. When the teachers tell me he is not reading because it is not a 'preferred activity' or writing because it is not a 'preferred activity'. I say 'BS'. It is so difficult for him to do these things. If he could do it as easily as me, he would be a great writer and reader! I see the struggle; they see a 'lazy' person who isn't trying!

A majority of the parents reported similar struggles during the IEP process, specifically related to feelings of anger and defensiveness. They largely reported that they were not a 'valuable' part of the IEP process or felt, like Jennifer, that they saw different sides of the student that the educators did not see. Kimber highlighted that parent knowledge is crucial to understanding how to support children in the general education settings:

I have worked my butt off to understand my child in all settings and what happens at home does translate into the school day. I really *do* want to help you to make your job easier and my child's education more successful for everyone involved.

However, parents also explained that they do not believe this type of marginalization from professionals is intentional. Carla, a parent who is fairly new to the IEP process, explained maybe educators simply 'don't know what we know.' Parents had many recommendations that they thought might resolve this misunderstanding between professional and parent with regards to 'expertise.' A majority of participants explained that arriving to the IEP meeting without any prior discussion about what was going to occur was 'scary' and 'inefficient.' Several parents therefore suggested the importance of having the chance to review and contribute to the IEP in advance of the meeting, particularly so they had time to determine specific language or goals that they would like to see removed, changed or included. Finally, parents wanted to be treated as 'real' team members during the meeting, with time to share their vision, goals and fears.

### **Acknowledging vulnerability and building trust**

*Taking any child to school for the first time is nerve-racking. You are trusting your precious person to the care of strangers – trained, caring strangers to be sure – but strangers nevertheless. As parents of a child with disabilities, the seemingly ordinary fear of the drop-off moment is compounded by extra worries about bullying, behavior, toileting, safety and specialized learning needs. We want to trust our son's teachers. We want to believe they will include, support, understand, be patient and succeed. But we are scared. Basic milestones do not always just 'happen' for us. We worry about things other parents hardly think about. Our son might never read all that well; he might not always be able to express himself in a way others can understand; he might hurt herself or someone else; he might never have a true friend.*

*So whether I have just sent my second e-mail of the week to the school or we arrive at the IEP meeting with a binder full of ideas, remember that we are relying on teachers to support our son effectively, positively and patiently. And this is a scary, vulnerable feeling.*

Many parents in this study echoed Mary and Patrick's words and spoke of 'trust' between educators and families as one of the most crucial elements of building and maintaining positive collaborative relationships. For example, Alice explained:

I am *trusting* educators to include my child in the general education classroom, with all the services and supports that will be needed to make it a success, but I don't know if they see it the same way.

Other parents discussed their vulnerable positions as parents who are required to place great trust in educators who either do not explain special education procedures or do not use parent-friendly language:

What is common sense or standard knowledge to a teacher (especially normal procedures at a school) are not necessarily that of the family. Just letting the family know what could, is, or will be happening will set minds at ease, help parents to prepare the child and avoid frustration. (Victoria)

Similarly, parents discussed that trust was often 'lost' if they felt educators were 'ignoring' them or when they felt educators were being dishonest. Kayla's emotionally charged words in the following highlight how tenuous these collaborations can be and how crucial honesty is when building and keeping the trust of parents:

Do not lie to us! I can handle the truth and I'm pretty good at finding solutions to hiccups in the program! If you're not honest we will never fully serve this child. Once that trust is lost it will be the hardest thing to repair.

While Kayla's understanding of a 'lie' may be perceived differently by families and educators, it is clear that the imbalance of knowledge, power and authority between professional and parent can result in an adversarial, rather than collaborative, IEP process. As Victoria mentioned, 'normal procedures' that educators complete everyday are in fact complex and filled with language that parents may not understand, particularly if they are new to the IEP process. This imbalance of power, when not addressed clearly and effectively by educators, has caused many parents in this study to experience high levels of uncertainty, anxiety and vulnerability.

Yet the parents in this study also believe there are many ways to counteract this seemingly asymmetrical relationship between IEP collaborators. For example, Alex calls for educators to make an effort to remain positive and enthusiastic about the competence of the student, particularly when the student is struggling to provide evidence of success:

Show me how you are raising the bar because you BELIEVE in my child. And not just when she is doing great, but especially those times when she isn't. I need to hear the positive enthusiasm the most during those times. Tell me she failed and then tell me it's ok because you still haven't stopped believing in her! Let me know what the other options are you are thinking of. It lets me know you haven't given up on her.

Like Alex, many parents had ideas about how to establish trust and re-balance power between professionals and families. For example, Kimber wanted educators to help her better understand the special education process, specifically, so that she was aware of her rights as a parent. Victoria similarly wanted unfamiliar special education jargon to be explained in parent-friendly language.

Nearly every parent that responded to our follow-up question about trust explained that maintaining communication was perhaps most effective. Ryan and Tyler both suggested that regular check-ins, both before and after the IEP meeting, would help build trust. But parents like Karrie and Mary who wrote about strong and trusting relationships with teachers explained that they communicated

(however briefly) daily or weekly throughout the year via text message, email or written notes.

Finally, Patrick and Mary explained that if educators would take the time to reflect on why parents feel anxiety and fear, it may be easier to practice patience and compassion and to address the power imbalance.

### ***Seeing the whole child***

*Perhaps our son's teacher has six IEP meetings this week. And there is that project the superintendent's been waiting for. Then she has to pick up her kids. And check in on her mom. And figure out dinner. And the pile of student files on her desk just seems to grow. We can understand why it might be hard for the teacher to give her complete attention and full measure of patience to us, her sixth IEP meeting of the week. We can understand the temptation to move our file into the 'done' pile as quickly as possible so she can get to the next thing. But we want this teacher and all educators to remember that the folder file in her hand concerns our child's education. It is about a person. And that person means the world to us.*

*Please remember that educator decisions are not just paperwork or check-off boxes on the IEP, they shape our child's future, daily experiences and well-being in school. And although that file is about our child; it often does not represent our whole child.*

*We know educators cannot treat every IEP meeting like it is their own child's meeting, but we want them to remember that every IEP meeting is about someone's child. And that child is much more than a disability label or a set of IEP goals about mathematics and reading and speech therapy.*

Here Mary and Patrick have stressed to educators that their child, Mark, is so much more than a 'file,' more than another box to check off on their to-do list, and much, much more than a 'disability label.' Nearly every parent in this study echoed this important sentiment, with response after response addressing the need for educators to 'see the whole child' and focus on their child's strengths and abilities, not on their child's perceived deficits.

Parents explained that effective IEP development relies on educators who see their children in a holistic way, not as a file, or set of goals, or a student who needs to work on mathematics or social skills or reading skills. For example, Kelly, the mom of a second-grader with Down syndrome, explained that she wished her child's school team could understand that 'school is only *one part* of my child's life.' Another parent, Tyler, expanded on this idea:

We would like for future and practicing special education teachers to know that I expect, and need, for them as professionals to take genuine interest in understanding the needs of the students they are teaching and 'learning from' everyday. It isn't enough to have a good grasp on pedagogy ... it is vitally important to see the *whole* child and therefore acknowledge their struggles as a person as well as student.

Tyler's quotation use around the words 'learning from' indicates, to us, her acknowledgment of a disconnect between educator language and action during the IEP

process. For example, if an educator explains to a parent that he is 'learning from' their child, the parent might expect the educator to highlight some of these learnings (i.e. 'Because Danny uses his iPad to communicate other students have come to see diversity of communication' or 'Sabrina has helped me to see that we all need brain breaks!') and incorporate them into the IEP process. However, educators can often leave these 'life' learnings out of the IEP process and instead focus only on the perceived 'deficits' that need to be addressed in the student's goals.

Parents discussed how painful it is to hear their son or daughter talked about as if they were, in fact a 'file' filled with problems and labels. For example, Charlie said: 'I have some terrible stories I could share about how teachers talk about my son. Tears shed over what teachers have said to me.' Similarly, Tanya explained: 'it is so hard to walk into a meeting and immediately hear that my daughter is several standard deviations below the norm.'

Many parents echoed this concern that educators need to look beyond the medicalized remediation model of special education and focus on the child as a whole person:

Don't try to fix or cure my child. Try to facilitate her active participation, respect and acceptance among peers and to support her in reaching her individual potential. (Janet)

Teachers sometimes have trouble looking beyond the issues. So I need to be sure that we talk about his strengths and weaknesses, his interests and extra curricular activities, and my goals for the future, as well as his goals for the future. (Gail)

In contrast to these more painful experiences, several parents explained that educators who focused on their child's strengths were crucial in developing effective inclusive IEPs. For example, Karen, a mother of an adolescent with a label of autism shared the following:

His teacher is not one to talk about what Jamie might have problems with unless it's helpful to get him a better program or service. She'll more or less talk about his strengths and what will help him go further. This is so good to have in the meeting, to have the kind of positive voice – real, but positive, in terms of what will help Jamie. It gets the right information into the IEP that really helps him shine in the classroom.

We understand Karen's use of the word 'real' here with regards to teacher positivity to be a powerful concept. Parents do not want educators to use flowery language simply to make their child or the educator appear to be successful, because this type of hollow language is not helpful for developing effective IEPs. Instead, parents want educators to bring in positive strengths and skills about their children in order to use and integrate them into the individualized goals, plans and daily instruction for their child. For some parents like Kim, this meant relating strengths to how the student learns, as opposed to generic positive attributes: 'my daughter has excellent computer skills not, she is very cute and friendly!'

### **Willingness to learn and adapt**

*No one knows everything. There is no shame in admitting that some additional training or information might be helpful. We realize supporting a student with a disability is not always easy. It can be a challenge to understand a student's behavior, address complex communication needs and find ways to support the student without significantly disrupting the education of her typical peers. However, we still find it difficult to give a school team special education literature, suggest they consider a consultant or propose staff training. However, most form IEPs include a section for 'supports for school personnel.' That's in there for a reason. Even the most dedicated, skilled school team might be able to benefit from a new perspective, especially when that perspective is provided by someone with 'fresh eyes,' specialized knowledge about the particular disability and/or experience supporting similar students. But maybe most important, we want educators to consider that we as family members have ideas and suggestions that might work.*

Across the board, parents explained that including their child in general education had sometimes raised questions and challenges to which neither they nor the schools readily had answers. But it was the school teams open to working with and learning alongside parents that were ultimately able to establish true collaborative relationships that helped to meet the individual needs of the student. The following excerpts for parents that the most effective teams were 'open' and 'willing':

It was their attitude – they were willing to listen. There's so much information out there and they were very willing to look at it with me. Anything I brought in to discuss they would take a look at it, and I mean that was the attitude; it was openness to learn. It was just huge. (Lena)

I pretty much never felt there were two sides of the table for us, like the parent and the educators, it was really a nice cohesive group of people that always seemed to be so open and willing and there for the best thing for my son. (Danielle)

Danielle went so far as to say that in her most collaborative IEP meetings there were never 'two sides of the table.' Clearly parents believe that the most effective IEPs are written when parents feel that educators are working in collaboration with them to figure out what is 'best' for the child. Often this may mean educators are open to learning from parents. For example, Ryan explained: 'educators should be open to the beauty of parent knowledge, vision and undying motivation for their child to be included.' But this openness to learning also includes seeking outside resources and support to better understand and enact inclusive special education services. Parents were strong in their conviction that educators should reach out:

Educators should attend great conferences such as TASH to learn best practices and meet others who have been successful at Inclusion. Surround yourself with positive energy (you'll need it) and strong people, to keep each other going. (Mali)

Our school did not initially provide special education services to students in the general education classroom. The IEP Team said that it was not the District's 'service delivery model' for middle school. They wanted to change my child's class schedule to satisfy

services listed on her IEP. But when an advocate attended the IEP meeting via speaker phone they were knowledgeable and discussed LRE with the Principal and ESE Director. The school has now hired a sped teacher to do push-in services. Many students are benefiting from her support. Sometimes teachers need to be educated on sped law. (Kanisha)

Like Kanisha, other parents felt that education and connection to other knowledgeable parties like advocates was critical for them and the school team. Similarly, parents like Liz discussed how helpful it would have been for team members to read up on current research and articles about enacting inclusive best practices. Several parents even discussed the idea of starting the year out with an article or book discussion, either in person or digitally, to help the team develop a shared vision about the inclusive education of the child.

Parents also had far-reaching recommendations to help their entire school and communities embrace the concept of inclusion. For example, Carly explained that a schoolwide initiative, such as an 'inclusion committee,' would help to 'actively ensure all students are embraced and supported.' She went on to write that an inclusion committee is important because change for her child's experience begins in a deeper place:

It is about building a culture of acceptance and understanding. We are looking for ways to help every student and family feel a sense of belonging, regardless of learning needs, race, religion, socioeconomic status, or any other perceived difference. (Carly)

### ***Flexibility and creativity***

*There is a first time for everything! We understand that educator methods might feel tried and true. However, especially when we are dealing with a challenging or difficult situation, an educator's flexibility and creativity are crucial. Consider the possibilities just as much as the pitfalls. Solicit input. An idea that seems impossible or implausible might not be so after a good brainstorming session.*

Like Mary and Patrick, parents felt that school professionals who demonstrated flexibility in their interactions, procedures and teaching style were most effective in developing relationships, creating inclusive IEPs and ultimately meeting the needs of their children in a general education class. For example, Janet explained that, at the beginning of her child's second grade year, an incident occurred with the teacher after which her child began acting out in class and did not want to go to school. Janet feared the school team would perceive her son and her family negatively and would suggest that he did not belong in the general education class or even at the school. But instead, the teachers and administration showed flexibility and suggested a creative – if not perfect – solution:

We have an unorthodox arrangement now. We ended up moving Jack back to the first grade teacher that he had last year, because she's amazing and she was very happy to take him. She's one of those teachers that, she just kept him working toward his second grade goals even though it was a first grade class. She's just fabulous. (Janet)



Like Janet, a parent named Sonia highlighted the need for educators to be both flexible and creative in developing IEPs and instructional approaches to help effectively include students in the general education classroom. She explained that her hope for educators is to ‘react to problems not with no’s and can’t, but with creativity! It’s a process and a long-term relationship.’

Sonia’s call for ‘creativity’ in individualized education planning is both exciting and necessary if parents and educators are to develop effective inclusive placements for students. The team can and should use flexibility and creativity to provide supports in an environment that the child needs, rather than attempting to fit the student into various programs or structures that, although well intentioned, may not be working.

Another parent, Maria, explained that this type of creativity and flexibility often requires ongoing communication throughout the year. She explained:

If we can work back and forth in a professional manner, I would love that. The IEP is not a one-time meeting, it is a year-long plan, it needs to be adjusted sometimes. I like communication throughout the year, not only when something is wrong. If you don’t understand what is in the IEP, we should meet. If you feel the IEP is not working we should meet. Regular team meetings would make this a great plan. (Maria)

In order to provide this type of ongoing creativity and flexibility and apply individualized student goals and strategies in an integrated way across all settings, it is imperative that the IEP team include many different voices that bring new – and creative – perspectives to the conversation.

One parent, Laura, highlighted the need for a ‘holistic’ team approach rather than splintering staff to deal with specific issues:

If you have staff around you with insight from a new angle, get them involved! It’s not just about delegating work, (having speech deal with speech issues), it’s about a collaborative holistic approach to everything because it’s all connected!

Laura’s suggestion can help teams share what works and what does not, while also planning for goals that are integrated throughout inclusive settings. This means in addition to the special education teacher and general education teacher(s) collaborating on the IEP, the team can include related service personnel, principal or other administrator, custodial staff, physical education teachers, peers and advocates that all can offer new and critical perspectives when creating an educational plan for the student.

## **Implications**

To improve school–family collaboration related to the IEP process, it is imperative for school professionals to understand that parents have great knowledge about their own child and his or her needs, a desire to be seen as equal partners in the process, and persistent fears and anxieties due largely to lack of communication, trust and negative perceptions of disability. Our findings support previous research that found school professionals often reflect a dominant deficit view



of disability (Ferri and Connor 2005; Ferguson and Ferguson 2006; Bacon and Causton-Theoharis 2013; Zeitlin and Curcic 2014) and that in order to improve family–school collaboration there is a great need for school professionals to shift from a deficit perspective to an attribute perspective when working with students with disabilities and their families (Hodge and Runswick-Cole 2008; Sauer and Kasa 2013; Bacon and Causton-Theoharis 2013).

Some parents explained that IEP teams addressed the issue of deficit perspectives about disability by creating a positive student profile. Before the IEP meeting, educators can collect a ‘whole’ picture of the student by sending questionnaires to or talking directly with families, teachers, related service providers, the student’s peers and other staff that may know the child in different capacities. Educators can also include the student in this process by talking about their strengths, talents, dreams and needs, as well as helping the student to plan a comfortable level of involvement in their IEP meeting (i.e. read an opening statement; discuss their strengths, needs and accommodations; create a short video or presentation; or lead the entire meeting.) Studies have shown that when students are heavily involved or lead their own IEP meeting, the conversation is more positively focused on student strengths (not deficits) and team members tend to use language that is more readily understood by everyone present (Kroeger, Leibold, and Ryan 1999; Mason, McGahee-Kovac, and Johnson 2004).

Our findings also confirmed previous research suggesting family–school collaboration can be improved if educator communication styles privileged parent participation (Dabkowski 2004), and minimized dominant (Ferri and Connor 2005) and medicalized discourse (Sleeter 1995) that focuses on disability as deficit. While the IDEA (2004, 34 C.F.R. § 300.503) mandates that parents should be informed of their legal rights and special education processes, this language is often difficult to understand for those unfamiliar with the jargon. We recommend that in order to relieve parents of the anxieties related to professional jargon, educators should explain processes and ideas to parents in advance, in clear language. Parents in the study felt that they built the strongest relationships with educators who clearly communicated ideas, processes and rationales related to student goals, behavioral plans and placement decisions and were open to parent questions and ideas. This type of communication regarding the IEP process complies with the intent of the IDEA regulations (IDEA 2004, 34 C.F.R. § 300.22), which mandates educators should not predetermine IEP decisions or write goals and objectives without family input (Fish 2008).

Parents in this study experienced strong collaborative relationships with educators who showed flexibility and who were willing to learn about and try more inclusive practices, which is consistent with research conducted by Hodge and Runswick-Cole (2008). However, parents also experienced fear and anxiety caused by the perceived need to constantly advocate, and fight, for inclusive services. This confirms research by Bacon and Causton-Theoharis (2013), who recommended that schools receive more training on the legal aspects of inclusion to ensure that

schools are correctly implementing the spirit and law of the IDEA. We expand upon those recommendations by suggesting that educators: seek support from administrators to bring in more professional development; write training directly into the student IEP (IDEA 2004, Section 300.704(b)(4)(i),(b)(40(xi)) provides a space to document the need for professional development); review literature about enacting inclusive best practices with parents; find other schools and educators to observe who practice inclusion or create a community-wide inclusive consortium of teachers and parents to discuss best practices and new ideas for including all students; and, finally, connect with advocates who can offer a wealth of knowledge regarding the law and local organizations that can provide support for students, families and staff.

Finally, it is important to recognize that many of the issues raised by our participants have been raised repeatedly in both national and international contexts (for example, Bacon and Causton-Theoharis 2013; Dale 1996; Hodge and Runswick-Cole 2008; Sauer and Kasa 2013). This persistent power imbalance between parents and school personnel (Hodge and Runswick-Cole 2008), as well as the continued deficit perspective often used to categorize and talk about students with disabilities, continues to create significant barriers in equitable education for students with disabilities.

### **Limitations and future research**

Our use of an open-ended online questionnaire limited the depth of our data. Future studies using semi-structured interviews with parents might provide even richer data about this collaborative process. Additionally, because we used a Facebook group of inclusively minded participants, it is possible that other parents of differing ideologies may have additional insight about the IEP process. Another limitation is the lack of demographic knowledge about our participants. Because of our decision to use a closed Facebook group to collect data, we did not ask participants to post demographic data that would be visible to all participants. Therefore, future research could focus on demographic trends in order to garner deeper understanding about working with culturally, socio-economically and linguistically diverse families.

### **Conclusion**

Family involvement in the IEP is mandated by legislation in the IDEA (2004) and has proven effective to increase achievement for students with and without disabilities (Bouffard and Weiss 2008; Epstein 2001; Pushor and Murphy 2004). But too often parent–school relationships remain strained (Bacon and Causton-Theoharis 2013; Beratan 2006; Hodge and Runswick-Cole 2008; Lamar-Dukes 2009; Sauer and Kasa 2013). This study shared parents' positive and negative experiences surrounding the IEP process and provided many recommendations about how to make the

IEP process more thoughtful, meaningful and accessible. Consistent with existing literature from both the United States and around the world, this study continues to evidence that tensions between parents of disabled children and school professional present barriers to effective and positive educational experiences for children and their families. We therefore believe educational researchers should continue to privilege parent voices in order to document persistent challenges that children, families and schools face. Together, parent voices and legal mandates will hopefully provide educators with a blueprint for more collaborative and productive relationships with families that can lead to the development of IEPs which provide effective and excellent inclusive education for all students.

### Disclosure statement

No potential conflict of interest was reported by the authors.

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