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Parents' experiences in education decision-making for children and youth with disabilities

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Abstract

Families should be an active part of educational decision-making for their children and can be particularly influential in advocating for inclusion for students with intellectual and developmental disabilities. Yet, significant research has shown that parents do not feel schools effectively collaborate with them. We interviewed 19 parents of children with disabilities to investigate the ways they were included and excluded from educational decision-making, and how they decided on their children's placement and services. Five themes emerged: parents' exclusion from decision-making, parents' independent efforts to shape their children's educational services, parents' decisions as a result of school and district factors, parents' role changes to direct their children's education, and discrepancies between beliefs and experiences of inclusion. Parents' responses indicate that specific school structures and institutionalized procedures may regularly exclude parents from decision-making. Results have implications for parent-professional partnership during decision-making for students with disabilities and personnel preparation.

Key Words: decision-making, parent-professional partnership, collaboration

Parents' Experiences in Education Decision-Making for Children and Youth with Disabilities

Parent participation in special education decision-making is a core principle of the Individuals with Disabilities Education Act (IDEA; Turnbull, Stowe, & Huerta, 2006). Parent input during decision-making is considered essential for the implementation of effective, equitable instruction and services for all children (Elbaum, Blatz, & Rodriguez, 2016; LaRocque, Kleiman, & Darling, 2011). Yet, parents' involvement in education decision-making is highly variable. Parents of children with intellectual and developmental disabilities, specifically, generally report challenges communicating with school personnel and that schools are not open to their input or requests (Elbaum et al., 2016; Mueller & Buckley, 2014; Ruppert & Gaffney, 2011). Parents from culturally and linguistically diverse backgrounds face additional barriers to their participation that include access to adequate translation services (Laskey & Karge, 2011), school personnel's use of deficit perspectives towards diverse families (Lalvani, 2012; McHatton & Correa, 2005), and a general lack of cultural responsiveness (Harry, 2008). Parent involvement in decision-making is particularly important for students to have access to an inclusive education as parents are still viewed as the primary advocates for their children to be included and, often, still face challenges to ensuring their child an inclusive education (Lalvani & Hale, 2015; Wang, Mannan, Poston, Turnbull, & Summers, 2004).

Parents' Involvement in Educational Decision-Making

Parents view the opportunity to be involved in educational decision-making as important, but acknowledge it can cause significant stress due to bureaucracy and tensions with schools (Tissot, 2011). Researchers have often found that parents do not think schools communicate with them enough during educational planning and service implementation for students with disabilities (Fish, 2006; Leyser & Kirk, 2011; Mueller & Buckley, 2014; Whitaker, 2007).

Beyond communication, parents generally do not feel they are respected as equal team members, a key indicator of true parent-professional collaboration (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). Researchers have highlighted examples of school personnel making decisions about placements, services, and accommodations for students with intellectual and developmental disabilities without parent input (Elbaum et al., 2016; Fish, 2006). While ample literature indicates parents are not satisfied with schools' communication and collaboration, less is known about the specific processes and practices schools engage in that act to exclude parents from education decision-making. Parents of students with disabilities may have difficulty contributing to education decisions because of both structural and individual barriers. For example, the legalistic procedures that direct Individualized Education Plans (IEP) development can lead to a systematic focus on procedural fidelity and efficiency rather than parent voice (Bray & Russell, 2016). At the individual level, access to special education information can vary significantly based on parents' literacy levels (Mandic, Rudd, Hehir, & Acevedo-Garcia, 2012) and social supports (Fish, 2008).

However, the literature does not uniformly illustrate negative experiences for parents of students with disabilities, as some research has indicated that parents experience positive relationships with teachers and are satisfied with their ability to communicate with school personnel (Fish, 2008; Spann, Kohler, & Soenksen, 2003). Still, most research has found that even when expressing satisfaction, parents continue to emphasize the need for more opportunities to influence IEP decision-making and have lamented that they are largely responsible for educating themselves about special education law and the IEP process in order to participate (Fish, 2008). More recent research has investigated the ways parents can be successful in advocating for their children. Trainor (2010a) theorized that parents' ability to

influence decision-making largely depends on their socioeconomic status as well as their access to cultural and social capital. This finding was relevant to parents of students with a broad variety of disabilities. In the case of parent-professional collaboration, cultural capital is parents' access to specialized knowledge and experiences (e.g. in-depth knowledge of IDEA) while social capital is access to relationships with key individuals and networks (e.g. positive relationships with teachers and administrators; Lareau, 2001; Trainor, 2010a). Lalvani and Hale (2015) expanded on this by noting that parents' access to cultural capital and economic resources can significantly impact their ability to advocate for inclusive education. While the current literature continually points to the resources parents need access to and efforts they must engage in to influence decision-making, less is known about what schools are doing to facilitate parents' inclusion in decision-making.

Factors Shaping Parents' Decision-Making

When parents are able to be involved in education decision-making, there is little information about the factors that actually shape parents' decisions for their children. Of course, their children's characteristics and needs are important, but this may not be the only variable (Elbaum et al, 2016; Patton et al., 2012). Parents of students with various disabilities may be particularly conflicted regarding educational placement decisions because they typically hold positive beliefs about inclusion, but are concerned about school resources and educators' knowledge and skills within inclusive settings (Leyser & Kirk, 2011; Tissot, 2011). Parents' own experiences and attributes may also shape their decisions. In interviews with parents of young children with autism spectrum disorders, Hebert (2014) found that parents' experiences with other people with disabilities, beliefs about autism, parenting style, perceptions of how children learn, and views about their role shaped their intervention choices. Understanding more

about how parents make decisions can help educators know how to better facilitate collaboration during decision-making.

Purpose of Study

Significant evidence indicates parents of children with disabilities are not included in education decision-making to a satisfactory extent. Parents of children with intellectual and developmental disabilities, specifically, have expressed challenges being involved in decisions about educational placement, IEP content, and related services provision (e.g., Elbaum et al., 2016; Fish, 2006; Mueller & Buckley, 2014; Ruppert & Gaffney, 2011). Further, their involvement is often dependent on their own access to resources in the absence of true collaboration with school personnel (Lalvani & Hale, 2015; Trainor, 2010a). However, despite knowing parents are dissatisfied with their ability to be involved in decision-making, little is known about the specific processes through which schools include or exclude parents and what factors shape parents' choices when they are able to help direct their children's education. The latter can inform school processes intended to support parent involvement in decision-making. Therefore, the aim of this study was to understand the school processes that include and exclude parents from decision-making about educational placement and services for their children. This study adds to the extant literature by attempting to shift the focus away from what parents need to do or know to be involved in decision-making in order to highlight the impact of specific school actions on parent involvement in educational decision-making. Further, it investigates parents' decision-making processes to inform how schools can better collaborate with parents. Two research questions guided the investigation:

1. In what ways are parents of students with disabilities included and excluded during the education decision-making process?

2. When parents are included in decision-making, what factors shape parents' decisions about educational placement and the implementation of special education services?

Method

Participants

Nineteen parents and guardians of students receiving special education services participated in focus groups and interviews. Seventeen participants were biological mothers, one was a foster mother, and one was a biological father. Their children with disabilities were ages two through 20 (mean: 12.26 years). The parent of a two-year-old child was included in the study because the child received special education services through IDEA Part C, or early intervention. Students' primary diagnosis included intellectual disability ($n = 9$), autism spectrum disorder ($n = 8$), and learning disability ($n = 1$). Seventeen of the parents identified as White, one identified as Asian, and one identified as being of mixed races (White and Latina). Families lived in two Midwestern states. Because all participants in the present study were biological parents or legal guardians, they will herein be referred to as "parents."

Parents were recruited through emails and fliers to support groups for parents of children with intellectual and developmental disabilities, including local chapters of the Down Syndrome Guild, the Down Syndrome Society, and the Autism Society of America. Parents were also recruited through word-of-mouth using a snowballing method (Miles, Huberman, & Saldaña, 2014). While parents involved in support groups may not be representative of all parents, they generally represent a population who actively attempt to influence their children's education and thus are particularly relevant to the present study's research questions. Such purposeful sampling has been used in previous research intended to understand parents' roles and relationships with school personnel (e.g. Stoner et al., 2005). Parents of students with autism and

Down Syndrome, in particular, provide important perspectives on the experiences of parents of children with intellectual and developmental disabilities because these students are typically identified for special education services early in their education. This early identification means parents have experiences with education decision-making for a longer period of time, increasing the amount of experiences parents draw from in their descriptions and allowing researchers to capture variation across time. Additionally, previous research has paired the two populations to understand similarities and differences in parents' experiences based on disability etiology (e.g., Kasari et al., 1999; Ogston, Mackintosh, & Myers, 2011).

Procedures

Data Collection. Focus groups and individual interviews took place both in-person and over the phone. Focus groups were arranged based on time availability which resulted in all groups having two or three participants. Three parents were interviewed individually because no other participants were available during their preferred times. Previous research has similarly used both focus groups and individual interviews when participant grouping was not possible (Elbaum et al., 2016). However, the use of both methods is recognized as a limitation. Both focus groups and interviews were audio recorded. Each session was facilitated by two to three researchers.

The interview question protocol included open-ended questions in a semi-structured, "tree-and-branch" structure (Rubin & Rubin, 2005, p. 145). Such a structure includes pre-determined main questions while allowing flexibility in follow-up and probing questions. The protocol had four general lines of questioning. Each session started with participants describing their child and where they lived. Parents were then asked to describe their views of special education and their personal experiences deciding on and obtaining special education services for

their child. Next, parents were asked about the school, teacher, and environmental characteristics or qualities they felt were important for their child and whether the identified characteristics were present in their child's current and previous placements and services. In a third line of questions, researchers asked parents to specifically share their experiences with placement decisions, including any perspectives or experiences with inclusive education. Finally, parents were asked about any activities that their children participated in outside of school and post-school goals for their child. All interviews and focus groups were professionally transcribed.

Recognizing the importance of positionality in qualitative research (Trainor & Graue, 2014), researchers acknowledged their role as researchers and teacher educators interested in improving practice during discussions with parents. The researchers are all women who have worked in the special education field in various roles, including serving as paraprofessionals, teachers, and inclusion facilitators. Three of the researchers involved in the study are White, matching the race of most of the participants, while the remaining researcher is African-American. Throughout focus groups and interviews, the researchers shared their experiences with parents, when appropriate, to support researcher-participant reciprocity, which can increase the validity of qualitative research (Trainor & Bouchard, 2102; Trainor & Graue, 2014).

Data Analysis. The research team conducted an initial thematic analysis of the transcripts by closely reading a subset of transcripts and discussing recurring responses and experiences, reflecting a general inductive approach (Thomas, 2006). While a general inductive approach is similar to grounded theory, data analysis is more heavily guided by the specific research questions or project objectives and leads to categories and themes relevant to the research questions rather than new theory (Thomas, 2006). Preliminary analysis resulted in team

agreement on three major code categories addressing the first research question about parents' inclusion and exclusion in education decision-making: school offerings as they compared to what parents preferred, parents' initiations and actions to direct education decision-making, and parent reactions or responses to school offerings. Researchers also agreed on three categories that address the second research question regarding factors that shape parents' decisions. The first two categories were child or family factors, and district or systemic factors. The third category identified the presence of school decisions outside of parent interactions or input.

After the first author read all of the transcripts, she used axial coding to disaggregate the above categories into more refined codes to address the research questions (Saldaña, 2016). For example, the second research question code category of district or systemic factors was divided into four codes: *economics*, *philosophical*, *personnel preparation*, and *legal*. The first author developed a codebook for each research question that defined codes with keywords, example quotes, and non-example quotes (Thomas, 2006). The research team met weekly throughout analysis to discuss any issues and provide feedback. Once the codebook was developed, the first author entered the codes into Dedoose Version 7.0.23 (2016), an online mixed methods data analysis program. Using Dedoose, she applied the codes to all transcripts in a separate, additional reading to once again check understanding and interpretation.

The second author then independently applied the codes to text excerpts within Dedoose. For intercoder reliability, the second author independently coded text excerpts using the codebook established by the first author in order to check for code clarity (Campbell, Quincy, Osserman, & Pedersen, 2013; Thomas, 2006). The second author obtained a kappa score of .83 for the first research question codes and .94 for the second research question codes, indicating high agreement. The second author then applied the codes to five complete transcripts (45%)

that reflected nine participants (47%). Next, the first and second author met to discuss any disagreement on these five transcripts and come to consensus, supporting intercoder agreement (Campbell et al., 2013). The first and second author reached 100% consensus on the five transcripts. Final data themes were formed by the researchers identifying patterns across codes and cases through group discussion, paying particular attention to patterns that are relevant to the research questions (Miles et al., 2014; Thomas, 2006). Using group discussion to build consensus can be an effective way to increase reliability (Paulus, Woodside, & Ziegler, 2008).

Trustworthiness and Credibility. Several steps were taken to address quality standards for qualitative research. Researchers engaged in reflexive practices throughout data collection and analysis, including taking notes during focus groups and interviews, and meeting regularly. Researcher notes during data collection helped highlight responses relevant to the research questions, initial impressions, and pertinent context. Meetings following interviews and focus groups allowed researchers to discuss emerging questions and interpretations. Researchers also took notes during meetings to support interpretive transparency (Trainor & Graue, 2014). Such reflexivity is necessary to monitor researcher bias and impressions while implementing qualitative research (Brantlinger Jimenez, Klinger, Pugach, & Richardson, 2005; Trainor & Graue, 2014).

After the interviews were transcribed, researchers sent electronic copies of the transcripts to parents and invited them to review and make changes to their comments in the transcripts. This member check before initial analysis served to improve credibility (Brantlinger et al., 2005). Parents' changes included taking out previous comments, clarifying responses, and adding updated information. The participant-edited transcripts were used for data analysis. During all analysis, triangulation was supported through the use of multiple transcripts and multiple

investigators to support code development, code application, and theme development (Brantlinger et al., 2005). In addition to meeting following each interview and focus group session, researchers met weekly during data analysis for code or theme discussion and feedback. Collaborative work contributes to credibility (Brantlinger et al., 2005). Finally, codes were always discussed with the codebook quotes to ensure the analysis maintained closeness to the participants' words and codes were sufficiently justified (Brantlinger et al., 2005).

Findings

Codes were analyzed and clustered to form five themes that addressed the two research questions: (a) *In what ways are parents included and excluded during the education decision-making process?* and (b) *What factors shape parents' actions and decisions regarding educational placement and the implementation of special education services?* Two themes emerged addressing the first research question: parents' exclusion from decision-making processes and parents' independent efforts to shape their children's educational services outside of typical decision-making processes. Three themes emerged regarding the second research question: parents' decisions as a result of school and district factors, parents' role changes to direct their children's education, and discrepancies between beliefs and experiences of inclusion.

Parents' Exclusion from Education Decision-Making

Parents were excluded from educational decision-making due to school expectations that they accept whatever was offered, schools' monetary and personnel constraints, and certain school structures.

“You're just supposed to lie down and take what you get.” Parents generally felt that schools did not collaborate with them. Parents described diagnosis, placement, and service decisions that were made without their knowledge or input. One parent obtained an autism

diagnosis for her son through a hospital clinic. When she approached the school, she was told to “just send him to school” and they would decide what his diagnosis and needs were. Regarding placement in particular, parents often had few options and two parents specifically said they had “no choice.” When asked how the decision about her child’s initial early childhood placement was made, a parent expressed that nothing was offered, but rather “it was just that this is where your child is going to go and it wasn't her home school.” Parents were not just excluded from initial placement decisions. When one parent wanted to change her son’s placement, she was told she was not allowed to visit other district schools because the child’s current school had already decided he would stay there. In contrast, schools sometimes initiated placement changes without consulting with parents. One parent described that she and her husband attended what they believed to be a typical IEP meeting. Instead, they found out that school personnel “had totally planned on the transition.” Without either parent’s knowledge, the school had initiated a transition for the student to be moved from his inclusive classroom to a segregated program at a different school. In an update note following another parent’s focus group, she said that she and her husband signed their child’s IEP despite being dissatisfied with the services it included because they “fear[ed] an unauthorized transfer w/o[sic] parent consent” should there be continued conflict with the school. Thus, placement decisions without parents’ input was a reoccurring concern and influenced how parents worked with schools.

“Their budgets keep getting cut.” Parents’ descriptions of what factors shaped schools’ decisions further indicated parent exclusion from educational planning. Parents described schools as being primarily driven by money concerns and personnel constraints. One parent said that schools could not be the ones to inform parents about possible accommodations because reduced school budgets meant “they have to fight and scrape for every dollar.” Another parent

felt that schools purposefully kept some information from parents to avoid having to pay for certain services. She felt that school personnel “won’t even suggest what therapies are the best...because then they have to put it into [her son’s] IEP.” School budgets were frequently cited as a reason students did or did not receive services in line with parent requests or input. This factor was particularly evident among parents whose districts contracted special education cooperatives that provided special education services to multiple schools or towns. Such cooperatives were present in rural communities.

Parents also cited teachers’ education and the lack of preparation to work with children with certain needs as factors that limited their ability to impact education decisions. One parent felt that she was limited to segregated placements for her child because “[t]here is no training for any general education teachers. There is nothing...It’s ridiculous.” Another parent felt that even special service teams within her district were ill-prepared and described an instance when her child’s IEP team could not implement a particular therapy she requested despite previously attending a training. When asked for recommendations to improve special education services for their child, parents overwhelmingly cited better teacher education as a high priority. Although previous research has found teacher education is a particular concern for parents of children with autism (e.g. Kasari et al., 1999), this finding was seen across parents of children with different disability etiologies and was also driven by students’ unlabeled needs, such as mental health challenges. Thus, constraints placed on the schools (i.e. finances, teacher preparation) became barriers to parents being included in decision-making because they limited the placements and services schools could effectively provide.

“You know you’re not part of the IEP team.” Parents named specific ways schools made decisions through institutionalized procedures and hierarchies that excluded parents from

decision-making. School procedures often limited parents' access to the processes and people most influential to educational decisions. One parent said she was told that school personnel make decisions outside of IEP meetings because that was "how [they] always do it." Pre-IEP staff meetings were mentioned by several parents, including a parent who was also a teacher. She reflected,

[I]t's kind of weird being on the inside, knowing that the pre-meetings that I had always been a part of as an educator...they're having their pre-meetings about my child now, so they decide what they're going to suggest as a united front.

She went on to say that decisions were "made before anybody walks in that door for the actual IEP meeting." While typical school procedures, like a pre-IEP staff meeting, made sense to her as a teacher (it allowed staff to make decisions more efficiently), she understood the negative consequences as a parent who felt disempowered. These pre-IEP staff meetings resulted in the IEP meeting being relegated to the position of a "legal obligation", as another parent called it. She described IEP meetings as school personnel simply reading from their reports. Meetings ended with the expectation that parents sign the IEP regardless of any suggestions they had.

School hierarchies were also a clear barrier for parents' involvement in decision-making as teachers and service providers were hesitant to agree with parents and themselves had reduced decision-making power. The parent who was also a teacher said that teachers "learn very quickly you're not allowed to speak up and go against this crowd in [IEP] meetings." Other parents described schools as hierarchical organizations in which only certain people, typically administrators, made decisions. Parents even sympathized with teachers, saying that teachers "really want to help" and do not "lie to parents or intentionally mislead." Rather, administrators tell teachers the school's policy or stance and teachers are obligated to follow. Multiple parents

characterized teachers as encouraging outside of official meetings but more hesitant during meetings that included administrators. One parent expressed that she had learned to bypass teachers and even principals if she wanted something for her child because “you need somebody who’s an actual decision-maker.” These hierarchies negatively impacted parents’ ability to have input because the school personnel that parents had the most access to themselves had reduced decision-making power and were not able to act as effective allies to parents.

By extension, school hierarchies relegated parents to a subordinate position. There were many times when a single person was identified as the sole decision-maker and that person was never the parent, reflecting their position in a decision-making hierarchy. One parent described a district consultant as a barrier to parents’ ability to have input because “she’s the school expert ... and if she doesn’t see it, then she’s the final word.” The most influential decision-maker for placement decisions, in particular, was often a principal or district administrator. For example, one parent said they moved schools solely because “the other principal wanted [her son] out of the school.” This was not always the case. In one instance, a parent described the school’s gifted teacher as being the determining voice in whether a child was placed in her class. Thus, institutionalized practices as well as hierarchical personnel structures excluded parents from accessing the spaces and roles that most influenced education decisions.

Parents’ Independent Efforts to Shape Children’s Services

In light of their exclusion from typical decision-making processes, parents engaged in efforts outside of typical decision-making processes to influence their children’s education. While parents were generally not involved in decision-making within the procedures stipulated by law (e.g., IEP development) or institutionalized school practices (e.g., pre-IEP staff meetings), they pursued other methods to attain appropriate services or supports for their

children. These independent efforts allowed parents to have some agency in education decisions. Parents' efforts included developing relationships with teachers, directly working with teachers to shape their children's class work, and interrupting exclusionary institutionalized practices.

“It's relationship that drives services.” Many parents mentioned relationship-building and making contributions to the school as necessary for them to obtain the services they wanted for their child. They described walking a fine line between contributing time or money to schools and asking for services or particular placements. One parent identified herself as “the best [Parent-Teacher Organization] mom you've ever seen” because that was a primary way she felt she was able to develop the necessary relationships with school personnel that resulted in better services for her son. She advised other parents that they had to be continually positive, regardless of circumstances, and volunteer their time in order to obtain the services they desired. Other parents wrote frequent notes to teachers or even bought them small gifts. Several parents said they had positive experiences with school personnel and were able to improve their child's educational supports through such relationships and other contributions to the school. However, these efforts were taxing. One parent lamented that constantly working to get her child the services and supports he needed was like taking part in “the parental Olympics” while another parent described it as “a second full-time job.” Parents' actions often took an exorbitant amount of time as parents tried to constantly be available to either help the school in general or provide support to specific teachers.

“One educator at a time.” In addition to developing relationships with teachers, parents also influenced educational services by directly supporting teachers' in-service professional development and classroom practices. At least six parents had privately paid for outside professionals or researchers to train school personnel or consult their child's teachers. One

parent described multiple times she and her husband paid speakers' mileage and lodging "to come out and help...teachers." Some parents also took active teacher support roles, bypassing IEP content, to directly help their child's teachers determine what their children would learn and the supports that would be necessary. Parents who trained or worked directly with teachers expressed that it was time consuming, but that they were happy the teachers accepted their help. One parent happily described that the school "let [her] train [her son's] whole staff...it was wonderful." Thus, although parents were not satisfied with their ability to be involved in formal decision-making processes, they were happy to be able to directly shape teacher classroom practices as a way of having input.

"They would never beat me up when she is there." Finally, parents were able to influence their children's educational services when they were able to interrupt the aforementioned institutionalized procedures and exclusionary processes. Several parents mentioned bringing outside professionals to IEP meetings and even paying private service providers to attend meetings as an attempt to change the power dynamics of the IEP meeting. One parent described this tactic, saying that schools "keep stacking the table with more and more people against me... so I did the same thing." Parents also used knowledge about their rights to disrupt exclusionary school practices, including making multiple requests to see draft IEPs before IEP team meetings and refusing to sign IEPs until their requests were taken into account. One parent knew she had a right to request IEP meetings and described a veritable filibuster in which she demanded multiple hours of IEP meetings over two weeks until the school agreed to paraprofessional support. Only one parent gained such knowledge through a school-sponsored event or resource. Thus, when parents were not able to be involved in decision-making as a part

of the typical procedures outlined by law, they impacted decisions by enacting their rights and disrupting exclusionary practices.

Factors That Shape Parents' Decisions

Parents largely made decisions based on discrepancies between their beliefs about inclusion and experiences of inclusion, feelings that the schools were not able to meet their children's support needs, and the perceived need to change their role from that of 'parent'.

"I think [inclusion] is important and that's my struggle." Parents' decisions about placements often reflected an inner conflict between positive beliefs about inclusion and the realities of teacher preparation and service provision. Several parents felt that schools did not understand what inclusion means or did not prioritize it. Parents themselves struggled because they felt schools ineffectively included students with disabilities. A parent described removing her daughter from an inclusive classroom because the lack of teacher knowledge and classroom structure "set [her daughter] up to fail." Despite it having been a challenging experience, she still questioned her decision, reflecting, "did I make the right choice? I don't know. I may never know...I wish it could have been successful." Another parent described moving her child to a segregated classroom as a decision she still "really struggle[s] with." Most of the parents who had moved residences or schools did so because of educational placement concerns, a sign of both its contentiousness and importance.

Interestingly, several parents felt that schools made segregated settings more alluring by restricting certain services to segregated programs and only allowing smaller class sizes in segregated classrooms. When one parent told school personnel she was looking into private therapies to supplement her son's services, they responded that it was unfortunate her son wasn't in the district's segregated program because it offered additional specialized therapies. She

questioned, “Why is it that segregated programs are being sold as having the better services?” Her experience is an example of schools pairing services with placements rather than independently assessing children’s service needs. When another parent’s daughter was placed in a segregated preschool, she tried to change the placement, but resigned that the segregated placement was beneficial because it was a full-day program compared to the inclusive half-day classroom, which was difficult for her as a working mom. Throughout focus groups and interviews, parents verbally weighed the benefits and challenges of inclusion. One parent, in particular, articulated that the “downside” to the segregated program her son attended at a different campus from his same-age peers was that he did not see any typically-developing peer models. However, she loved that “when something happens, they stop, and they deal with it.” The mother felt she had to choose appropriate instructional and behavioral supports for her son over an inclusive educational experience. Segregated placements were not characterized as a choice, but rather a necessity when schools would not respond to parent input or provide certain services. One parent described the difficult series of events that resulted in her son being moved to a segregated program. She recounted that she worked with a teacher who tried “really hard to get the school to follow the IEP...[but] they just wouldn’t.” Eventually, she consented to her son being moved to a segregated school program. This parents’ experience also illustrates the limited influence teachers sometimes have in the face of administrative directives, as discussed earlier. In sum, parents’ placement decisions were significantly shaped by the realities of what schools provided and the regular need to choose between access to inclusive opportunities and effective services.

It should be noted that parents’ experiences with inclusive classrooms were, by no means, uniformly negative. Several parents described social, academic, and behavioral benefits their

children had experienced in inclusive placements that furthered their commitment to inclusion. For example, one parent said that “the best thing [for her son] has been for him to be included.” Another parent specified that her child’s high school inclusion had been “very helpful with social development,” and provided “an opportunity for further learning” compared to self-contained classrooms. These experiences encouraged parents to continue to fight for their child to be included. Parents’ placement decisions subsequently influenced many of their other actions, including modifying their children’s materials themselves, paying for private services, and being more intentional about their children’s out-of-school social experiences.

“Anything they have said ‘no’ [to], we have just gone outside of school.” Parents’ own decisions were most often in response to school or district factors and actions. The school and district factor codes were used considerably more than the child factors code when analyzing data. Furthermore, in light of not being included in schools’ decisions, parents’ decision-making sometimes centered around a desire to wholly remove their child from the influence of a school or district. Five parents decided to move to change the school or program their child attended. One parent expressly said that they “sold [their] house and bought a new house...specifically to access [a] behavior disorder program.” Another parent noted the financial burden moving placed on her family as they sold their house at “quite a loss” to be able to change their child’s school. Several parents had actually been through multiple residence moves or school changes throughout their child’s education due to their efforts to secure the best education for their child.

Disagreements with schools about service provision led many parents to decide to pay for private services or supports. Parents described paying for private tutoring, physical therapy, occupational therapy, applied behavior analysis (ABA) services, and speech therapy. Paying for private services was sometimes at great personal cost financially and in terms of time as parents

in more rural areas had to drive long distances for specialized services. One parent said they “refinanced [their] house...so that [their child] could get therapy” after the school offered virtually none. Schools sometimes benefited from parents’ expenditures. After a school refused to do a functional behavioral assessment on her child, one parent paid to have a private agency complete one, which the school then used. Rather than helping direct decisions, parents’ actions were largely driven by a need to respond to school decisions.

“It’s my job as a parent to have to come up with what are the accommodations.”

Parents felt personally responsible for their child’s education in the absence of collaboration with schools. Accordingly, parents changed their role to ones that allowed them to more directly shape the services and teaching practices their children had access to. One way parents did this was by helping children’s teachers, as previously discussed. However, expanding on that, parents sometimes took over tasks mandated by IEPs that are typically required of the teacher. One parent expressed that because her son was in an inclusive classroom, “making up the lessons, and making up the tests did fall on [her].” As the parent described, school personnel were not adequately responding to her requests so, in the absence of collaboration, the parent took over some of the teacher’s responsibilities. This allowed her to have greater input in her son’s education. When a school refused another parent’s continual requests for assistive technology, she began acting as her son’s scribe. Further, at least three parents homeschooled their child at some point in their child’s education because they felt the school was not providing an appropriate education and was not responsive to their multiple attempts to influence educational decisions. One parent expressed frustration about changes she saw in her son that eventually led her to homeschool him. In the absence of appropriate behavioral supports, she described that her son was “becoming a kid who he isn’t. He was becoming a hurting kid and a

behavior kid and so I pulled him home.” Thus, parents’ decisions were often driven by a need to take on roles other than ‘parent’ in order to be included in decisions about their child’s education and to fill perceived gaps in what schools offered.

Discussion

In this study, 19 parents and legal guardians of children with primarily intellectual and developmental disabilities were interviewed to understand their experiences trying to be a part of education decision-making for their children. Results revealed that schools often excluded parents from decision-making through the use of pre-IEP staff meetings, school policies, unofficial institutionalized processes, and school hierarchies. Parents were able to have some input in decision-making by building relationships with teachers, directly working with teachers to determine their children’s work and classroom supports, and interrupting the institutionalized practices that excluded them. Parents often felt inner conflict around educational placement decisions. They generally favored inclusive placements, but were concerned about school personnel preparation and school structures that made segregated programs seem like more accessible options for families. Parents’ own decisions were often in response to school or district factors as they privately supplemented therapies and personally provided educational supports. Rather than proactively helping plan appropriate services and supports for their children as equal team members, as IDEA arguably stipulates, parents were often retroactively responding to school decisions. While a significant amount of research has generally found that parents of students with intellectual and developmental disabilities are dissatisfied with schools’ collaboration (e.g. Elbaum et al., 2016; Fish, 2006; Mueller & Buckley, 2014; Whitaker, 2007), these results add to the literature by pointing to specific school structures and practices that

prevent parents from being a part of education decision-making and illustrate how parents responded.

Similar to the current study, existing research has described pre-IEP staff meetings as a common practice that relegates the IEP meeting with families to a procedural step required for completing paperwork (Bray & Russell, 2016; Ruppard & Gaffney, 2011). As articulated by parents in this study, pre-IEP meetings excluded parents from the spaces in which their children's educational placement and services were largely determined. In addition to limiting parents' ability to direct their child's placement and services, such meetings denied them access to the cultural capital (e.g., valuable skills, knowledge, and experiences) necessary to assert effective advocacy strategies in the future (Grenfell & James, 1998; Trainor, 2010a). Parents' responses indicate that pre-IEP meetings are an exclusionary practice that should be replaced with more collaborative decision-making that includes parents during every step of the decision-making process. Spann and colleagues (2003) suggest that parents' ability to brainstorm and problem-solve with school personnel using shared information about students' progress is an important component of satisfactory parent involvement in decision-making. This would mean ensuring parents have access to the same information school personnel base their decisions on before the IEP meeting. Indeed, Rodriguez and Lessard (2017) specify that school personnel should communicate with families regularly in laymen's terms, focusing on students' progress and not just challenges or issues that arise. No parents mentioned access to such information unless they requested it, which often further decreased their ability to influence subsequent decisions. Other research has similarly found that parents of students with disabilities are typically the ones to initiate communication and collaboration (Rodriguez and Lessard, 2017), indicating an opportunity and need for more proactive practices.

Although pre-IEP meetings were damaging to parent involvement in decision-making on their own, they also contributed to a power imbalance that only increased during the IEP meeting. Parents named several strategies they used to interrupt this imbalance (e.g., inviting private service providers or friends), but their responses show that school personnel should do more to facilitate shared decision-making both before and during the IEP meeting. Mueller (2009) suggests the presence of a neutral facilitator to address power imbalances between families and school personnel. This would be particularly beneficial given the school pressures parents believed shaped school personnel's decisions (e.g., monetary constraints). However, a neutral facilitator may not be practical in all contexts. In such cases, the tasks completed by a neutral facilitator could be implemented by a school staff person who is not directly implicated in IEP team decisions. For example, Mueller (2009) suggests having all members of the IEP team contribute meeting goals before the IEP meeting that the neutral facilitator posts and addresses during the meeting. She also recommends monitoring participation to encourage equal speaking time during the meeting (e.g., through the use of open-ended questions). The IEP meeting should be an opportunity to thoroughly understand a student's needs rather than a time to report a completed IEP draft or school personnel decisions (Mueller, 2009). Using such strategies before and during the IEP meeting could address some of the concerns parents voiced in the present study. Importantly, parent involvement in educational decision-making for students with disabilities cannot start or end with the IEP meeting.

The hierarchical staff structure of schools also impacted parent's ability to provide input and largely excluded them from decision-making. Though parents had the most interactions with teachers, school and district administrators were more likely to be described as primary decision-makers. Thus, in addition to being excluded from the spaces when decisions are made, parents

reported having little interaction with the people who held the most decision-making power. In addition to being an exclusionary mechanism, this can be thought of as limiting parents' social capital (e.g., relationships and social networks that support their knowledge and involvement; Lareau, 2001; Trainor, 2010b). IDEA requires the presence of a local education agency (LEA) representative who provides or supervises special education services (20 U.S.C. § 1414(d)(1)(B)). This person is often a school or district administrator. However, based on parents' descriptions, that person was often *the* decision-maker, rather than an equal member of the IEP team. Further, parents reported having few interactions with designated district representatives or administrators. The practical implementation of this IDEA requirement suggests an area for clarification in future policies or regulations.

A shared leadership model, as suggested by Gordon and Louis (2009), may address the barriers to parent involvement in decision-making caused by school hierarchies. Within a shared leadership model, principals and other school leaders empower teachers and parents to influence school decisions. Principals support teachers' leadership skills and establish a collaborative school culture in which shared decision-making is institutionalized, regardless of formal roles or the characteristics of families. Shared leadership directly challenges traditional school hierarchies in order to increase collaboration with families and communities (Gordon & Louis, 2009). Such a model could address the negative impact of school hierarchies seen in the present study and facilitate parents' collaboration with all IEP team members, including administrators and related service providers, with whom parents currently have the least contact. Further, it could be particularly beneficial for parents of children with intellectual and developmental disabilities because these students are often served by a wide variety of professionals. However, shared leadership has only been discussed as a way to broadly increase collaboration between

schools and communities. Moving forward, researchers and practitioners should consider how this model may be uniquely applied to parent-professional collaboration within special education decision-making. Parents' responses argue for the need to change how both decision-making power and parent collaboration responsibilities are distributed amongst IEP team members.

This study indicates, once again, the importance of improved teacher preparation around educating students with diverse needs, particularly for general education teachers. As teacher educators, this was of particular interest for the researchers when speaking with families. Parents in the present study specifically noted a need for greater teacher preparation around working with students who did not fit expectations according to disability labels, students with behavioral challenges, and students with mental health concerns. Their responses suggest the possible need to move away from an overreliance on disability labels when educating future teachers, particularly general education teachers. Similarly, researchers have argued for the need to focus on the dynamic support needs of children and youth, rather than a static label, to facilitate educational and life planning (Thompson, Wehmeyer, Hughes, Shogren, Palmer, & Seo, 2014). Disability labels are necessary for the receipt of services under IDEA and do provide some information about a student's needs. Parents did not dismiss the use of disability labels as they sometimes argued for the need to increase some label-specific services (e.g., applied behavior analysis therapy for students with autism). However, eschewing parent input and individualized student needs in favor of label-based placements and pre-determined supports, as illustrated by parent responses in the present study, can be detrimental. Decreasing the focus on disability labels within teacher preparation and support decisions could create more space for parent voice.

Promoting Inclusive Education

Because parents of students with disabilities are still the primary advocates for inclusive education for their children (Lalvani & Hale, 2015), their exclusion from educational decision-making must be addressed to continue to advance inclusion. Parent responses both illustrate and complicate Tissot's (2011) findings that parents of students with autism typically obtained their desired educational placement, but experienced the process as time-consuming and stressful. While parents in the current study were generally satisfied with their children's most recent placements, they experienced significant internal conflict about what placement was best. Additionally, they sometimes had to resort to actions outside of the typical decision-making process to gain their preferred placement (e.g., moving residences and/or schools). Further, the time-consuming and stressful nature of educational placement decisions did not end when a decision was made, even when it was a preferred placement. Parents described continuing to advocate for specific services, guarding against undesired placement changes, and personally providing supplemental supports and experiences.

There were certain school structures and practices that impeded parents' ability to specifically be involved in educational placement decision-making. First, as previously discussed, schools regularly made decisions before meeting with parents and decisions were directed by school personnel with whom parents had little contact. Further, parents' influence was greatest after placement decisions were made as they typically had the greatest impact on their child's education when directly working with teachers. Parents should be actively involved in formative conversations about placements and have access to any potential placement options. Schools could leverage the relationships parents have with teachers to provide them with an avenue to give input throughout placement decision-making and IEP development. This did not happen for many parents in the present study and it limited their ability to understand their

options and to advocate for the most inclusive placements. Finally, the previously discussed shared leadership model would empower teachers, service providers, and families to advocate for inclusion as well as the necessary professional development and school supports required for high-quality inclusive education. Parents favored inclusive education, but recognized several factors that limited schools' ability to provide high-quality inclusive experiences.

Finally, future policy regulations should continue to clarify the relationship between placement and services, and school personnel should actively work to avoid conflating the two. In the present study, multiple parents resorted to a more segregated placement in order to increase the likelihood of their child receiving necessary services and supports. Placement and services were routinely and inextricably linked and it typically led to segregated placements. Yet, IDEA suggests that placement and service decisions should be made independently of each other and research indicates that even students with more extensive needs can be effectively served in inclusive general education classrooms (e.g., Ryndak, Jackson, & White, 2013). Choosing between inclusive opportunities and adequate supports drove many of the parents' decisions. Further, how much they could personally spend on services and supports in both time and money was often a determining factor. More work is needed to ensure parents are not forced to choose between inclusive experiences and adequate services for their child.

Limitations

Several limitations should be acknowledged in the present study. First, this study largely included parents who were White, middle- to upper-middle class, and a part of parent support groups. Given the diverse nature of families and who may be involved in decisions for children, only including parents in the study is limiting. Further, their experiences may not reflect those of parents who do not have these identity markers and/or who are not a part of parent support

networks. These parents' positionality allowed us to understand how parents make decisions and the many ways they respond to or resist exclusion from decision-making. However, many of the actions the parents took in response to school decisions may not be accessible to all parents. These included paying for private services, moving, and independently educating themselves on special education law and practice. Significant research has already illustrated the additional barriers parents face when they are also from a cultural- and linguistic-minority group (e.g. Harry, 2008) or have a lower socioeconomic status (e.g. Hyman, Rivkin, & Rosenbaum, 2011). These qualities particularly limit parents' ability to successfully advocate for inclusive education (Lalvani & Hale, 2015). Future research should more explicitly investigate the factors that shape minority and low-income families' decisions and the specific school structures and practices that impact their ability to be involved in education decision-making for their children. Also regarding participants' demographics, the present study only included one father. The lack of fathers within research looking at the experiences of parents of children with disabilities is a trend that should be better addressed in the future (Mueller & Buckley, 2014). Finally, scheduling challenges resulted in the use of both focus groups and interviews. While this has been done in previous research (Elbaum et al., 2016), it is a limitation as the dynamics of these two procedures may differ in ways that impact parents' responses.

While parents were asked several questions about their children's diagnosis process, educational placements, classroom supports received, and related services, researchers did not systematically collect information about children's abilities and needs. Thus, the results do not account for how children's abilities and needs may have originally caused schools to take certain positions. Future research may supplement parent interviews with more systematic data about their children and also concurrently collect school personnel perspectives.

Conclusion

This study provides some information about how parents navigate education decision-making for their children. While it confirms that parents are often excluded from typical educational decision-making, it reveals specific processes through which exclusion occurs, the ways parents still influence their children's education, and the factors that shape parents' decisions about placement and services. Future research can continue to investigate how parents resist efforts to minimize their involvement, the factors that shape parents' decisions about placements and services, and how school personnel can better include families in decision-making processes.

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