

## **‘It should be teamwork’: a critical investigation of school practices and parent advocacy in special education**

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The Individuals with Disabilities Education Improvement Act (IDEIA) suggests that parents are critical members of the special education system. Through conducting interviews with parents, observing individualised education plan (IEP) meetings, and analysing the discourse between the parent and the professional, this critical qualitative research investigates the parent–school relationship when parents are fighting for more inclusive placements for their children. This study uncovers the bureaucratic processes schools utilise, which do not allow for equitable parent participation in IEP processes including: medical and deficit discourse, professionalised discourse, policy interpretations, and meeting practices. We then describe strategies that parent-advocates use in order to obtain adequate services for their children including: networking, bringing an advocate, and education. We conclude with recommendations for schools and parents which promote enhanced parent–school collaboration throughout IEP planning, with an end goal towards improving educational opportunities for students with disabilities.

**Keywords:** parent advocacy; inclusion; disability studies

Many parents who have children with disabilities find themselves in precarious situations as they enter the world of special education. In order to receive adequate services, parents often face bureaucratic educational structures and must become strong advocates. Through interviews with parents and observations of individualised education plan (IEP) meetings, this study investigates the processes of parent advocacy and how parents are positioned within the US special education system. We begin by situating the relevant critical literature on school systems and parent participation.

A goal of the Individuals with Disabilities Education Improvement Act (IDEIA 2004) is to enhance parent and student participation. Legally, parents are considered a part of the IEP team and the team must consider the concerns of the parent in IEP decision-making. Parents must be informed of their rights and are granted due process intended to protect their interests (IDEIA 2004). Beyond the legal requirements, the literature suggests that parents should operate as partners throughout

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special education processes (Dabkowski 2004; Friend and Bursuck 2009; Spann, Kohler, and Soenksen 2003).

Other research documents parents' difficult position within the special educational system. Researchers have noted that positive relationships between parents and schools have not been adequately forged (Lovitt and Cushing 1999; Turnbull and Turnbull 1997; Vaughn et al. 1988). Various studies have found that communication between schools and parents is dissatisfying (Harniss et al. 2001; Kohler 1999; Munk et al. 2001) and centred on conflict (Spann, Kohler, and Soenksen 2003). Other findings indicate that even when meetings are attended, parents have little influence in actual decision-making (Able-Boone et al. 1992; Goldstein et al. 1980). Lake and Billingsley (2000) analyse factors that contribute to parent–school conflict in special education including: discrepant views of the child, service delivery, devaluing by schools, communication, and level of trust. Trust is also a concern for parents who have children diagnosed with autism spectrum disorder (Stoner et al. 2005).

Because of these difficulties, advocacy is an important tool parents utilise so their voices are heard throughout special education processes. Many parents accept their role as an advocate for their children, and utilise necessary tactics even if it hinders their relationship with educators (Hess, Molina, and Kozleski 2006). Many parents often find themselves advocating for their children as a result of their dissatisfaction with schools (Soodak 1998). Also, access to social and cultural capital is often necessary for parents to become advocates, thus there are inequities in the ability for all parents to act as advocates (Trainor 2010).

This study seeks to understand the processes of special education beyond the competing findings about whether parents are adequate partners in special education processes. This research makes it apparent that both parents and school professionals are embedded in a system where 'disability is constructed within social, cultural, historical, legal, and medical discourses' (Ferri and Connor 2006, 14). Parents and school professionals have different experiences with youth with disabilities, and thus have different frames of reference for understanding the needs of the child. The goal of this study is to neither fault parents nor educators, but to understand more deeply the structures which perpetuate disconnections between parents and educators within special education. The disability studies literature, which describes schools as bureaucratic structures helps to illuminate the ways in which these problems have persisted for decades.

### **Schools as bureaucracy**

School systems operate as bureaucracies and much of special education is bureaucratic in nature. Skrtic (1991) describes how schools maintain their status as bureaucracies over time, even if an illusion of change and progress exist. The knowledge base for the educational bureaucracy is founded on the notion of scientific management which, views organisations and the knowledge they produce as rational-technical. In these bureaucracies, the emphasis is on the standardisation of practice and on hierarchical and specialised professional roles. Schools often screen out students with disabilities because in

public bureaucracies charged with serving all students, special education emerges as a legitimating device, an institutional practice that, in effect, shifts the blame for school failure to students through medicalizing and objectifying discourses, while reducing the

uncertainty of student diversity by containing it through exclusionary practices. (Skrtic 1991, 149)

Educational bureaucracies offer little opportunity for true movement towards democratic goals of education (Gallagher 2004).

The bureaucratic structures of schools impact the IEP process and special education law does little to force schools to make decisions that are best for parents and students (Skrtic, Sailor, and Gee 1996). Ware (1994) describes how educational bureaucratic processes undermine parent–school cooperation. She states that competing discourses between parents and professionals hinder meaningful collaboration, and the contextual view of the parent is often discounted. Instead, medical and psychological knowledge are deemed the most legitimate. Within this traditional and hierarchical bureaucracy, equity of participation becomes difficult.

This concept is again reasserted in Kalynpur, Harry, and Skrtic's (2000) article, which describes how traditional IEP practices prohibit the equal participation of culturally diverse families. The authors claim that equal collaboration is impossible because 'the expectation of equity directly contradicts the hierarchic structure of knowledge and status imbedded in the positivist paradigm of professionalism' (120). The knowledge offered by parents is often considered subjective and not worthy of expert consideration by the IEP team. The supposed inferiority of family and student knowledge contributes to a pathological understanding, where families and students with disabilities are assumed to have deficits, especially those from culturally diverse backgrounds.

Other, more recent literature asserts how dominant educational discourses effect and undermine equitable parent participation. Valle and Aponte (2002) draw upon the work of Bakhtin, illuminating how professional and authoritative discourses dominate the everyday, informal discourses used by parents. These authors call for an opening of dialogic communication, where meaning is generated between participants instead of relying on the transmission of the dominant discourse to be accepted by the parent. Cole (2007) describes the ways that the term 'parent' is gendered, and the experiences of mothers are often presented in contrast to the dominant knowledge of the educational system.

Although the literature has clearly documented the difficult position of parents in special education, little research has relied on both interviews and observations to examine these issues. Furthermore, existing research has not used qualitative data to gain insight into the operations of bureaucratic structures that have been described in depth theoretically (Skrtic 1991; Ware 1994). Our hope is that this research offers insight for both parents and educators regarding the practices of special education so that a deeper understanding will create improved relationships; ultimately benefiting students with disabilities.

## **Method**

We utilised qualitative methodology in order to collect and analyse data. All parents who participated in this study were connected through a parent advocacy centre, which operates in the central New York region. Most parents involved in this study sought out advocacy support so their children could have more inclusive educational opportunities. All participants volunteered willingly and offered consent. In exchange for parent participation, we shared resources and provided consultations regarding their special education needs after interviews and observations.

A total of 17 families participated in this study. The criteria for parents to be eligible for this study were that they (1) be the parent or guardian of a child with a disability, (2) have a school-aged child and, (3) are enrolled in a public school. Representative families are diverse in terms of child's age, gender, disability label, socioeconomic status, and race/ethnicity. Most of the children's disability labels include low-incidence disabilities. Table 1 indicates the demographic information for participants.

In-depth, open-ended interviews were conducted ranging from 90 to 120 min in length. The interviews took place in locales of the parents choosing. All parent interviewees happened to be mothers, and although this was not intentionally sought, it aligns with research documenting the role of mothers as the primary advocates for their children (Cole 2007). During interviews, parents were asked about their experiences with special education and IEP planning. They were also asked about how they become parent-advocates and what tactics they use as advocates.

Following the completion of the interview process, we observed IEP meetings. In only two cases did students attend their own meeting, suggesting a trend in the engagement of students with disabilities in IEP planning (Test et al. 2004). During meetings, we were silent observers and not participants. Student IEP's, psychologists reports, work samples, and parent testimonies were also coded and analysed. All specific details and names of people, schools, and districts, are kept confidential. An inductive approach to qualitative analysis is used (Bogdan and Biklen 2006). All data are analysed together and themes are identified which appear multiple times throughout the data.

This study has various limitations, which affect its generalisability across larger groups of parents. Since these participants came from a parent advocacy organisation, they were either interested in learning about advocacy, or saw advocacy as important. The participants in this study are disproportionately Caucasian and are not a racially representative sample of the residents of central New York.

## **Findings**

The themes in this study offer further insight into the literature, and demonstrate the ways that parents advocate for their children in an attempt to mitigate the effects of the bureaucratic processes they encounter. We begin this study by explaining the focus on more inclusive educational placements that parents in this study actively sought. Following this framing section, we discuss school practices, which do not allow for equitable parent participation in IEP processes including: medical and deficit discourse, professionalised discourse, policy interpretations, and meeting practices. We then describe strategies that parent-advocates use in order to assert their knowledge of the needs of their children including: networking, bringing an advocate, and education.

### ***Least restrictive environment***

This study included many parents who sought out opportunities for advocacy, often so that they could obtain more inclusive placements for their children. Therefore, many parents in this study described that the legal component of the law they addressed most frequently was that of the least restrictive environment (LRE). Also, parents whose children were being pulled out from regular classrooms frequently fought for more related services to be delivered within the general education classroom.

According to LRE, a student who has a disability should be educated together with non-disabled peers, to the 'maximum extent appropriate' (Weber, Mawdsley, and Redfield

Table 1. Demographic information of participants.

Participant	Parent/status	Race	Child's age	Child's gender	Disability label
<i>Interviews</i>					
June	Single mother	Caucasian	21	Male	Autism
2 Tara	Married mother	Caucasian	7, 10	Male	Autism, mental illness
3 Tanya	Married mother	African American	4	Male	Down syndrome
4 Sara	Married mother	Immigrated from India	15	Male	Autism
5 Linda	Married mother	Caucasian	7	Male	Hearing impaired/autism
6 Angela	Single mother	Caucasian	Twins 10	Females	Down syndrome, mental illness
7 Julie	Married mother	Caucasian	11	Male	Learning disabilities/attention deficit and hyperactivity disorder (ADHD)
<i>Observations</i>					
Sarah Lynn Elementary	Mother married	Caucasian	5	Male	Autism
West Elementary	Aunt/adoptive guardian	Undisclosed	7	Male	Global developmental disorder
Riverpond Elementary	Mother, father stepmother	Caucasian	8	Male	Pervasive developmental disorder not otherwise specified, ADHD, anxiety disorder
Daleville High	Guardians (child own legal guardian)	Caucasian	18	Female	Developmental disorder
Donald Elementary	Mother and father present	Caucasian	9	Female	Other health impairment, ADHD
North Erie Middle	Mother and father present	Caucasian	15	Male	Multiple disabilities
Carry May Elementary	Mother and father	Caucasian	8	Male	Developmental coordination disorder
Avondale Nursery	Mother and father	Caucasian	4	Male	Preschooler with a disability
Avon Park High	Father	Caucasian	15	Male	Other health impairment
Bended River Middle	Mother	Caucasian	14	Male	Autism

2004). Kluth, Villa, and Thousand (2002), state that ‘more than 25 years after the law came into effect, many educators and administrators still do not understand the law or how to implement it’ (25). In particular, these authors discuss ways that LRE expectations have been ignored by school districts, and school districts continue to make claims such as ‘our school doesn’t offer inclusion’ (24), or that a certain student is ‘too disabled’ to be included. Skrtic (1995) notes that LRE has not been successful in changing the ways which schools operate, because schools conceptualise students as disabled because of their inability to conform to traditional schooling practices, and thus segregate these students, leading to a more efficient bureaucracy. Thus, schools remain largely segregated, particularly for students with cognitive disabilities (Smith 2010).

Parents in this study spend a great deal of time learning about how to secure LRE for their children, and deem it important for both social and academic reasons. One mother claims that one of her biggest complaints is that: ‘instead of “how to”, it’s always “where to”. They want to move him, instead of thinking about how to include him’. Another parent stated:

Every meeting, what I recite is ‘least restrictive environment’, so I guess that’s my favorite part of the law, because it’s the part that they’re not following, but at least I’m able to say that. You know, at least that law exists and I can at least stand on that platform so, whether or not it matter’s, that’s what I stand on.

Many parents also fight for inclusive related services so that their children spend more time in the regular education classroom. We observed six parental requests for related services to be delivered in the general education classroom, and of these, five IEP teams responded that they could not deliver the services in the general education setting because it did not fit into the schedule of the professional providing the service. Thus, the placement changes thus were not made on the IEP. This goes against the statement that the Office of the Special Education Program set forth which states ‘The lack of adequate personnel or resources cannot be used as an excuse by the district to relieve them of their obligations to make FAPE [Free Appropriate Public Education] available to disabled students in the LRE’ (Huemann and Hehir 1994). During one of the observations, when the parent requested that speech services be delivered in the regular classroom, the speech therapist replied: ‘I want him to work on social skills and that is hard to do in the regular classroom’ (North Erie Middle). This exemplary response seems counterintuitive, as learning social skills is much easier when surrounded by other children, rather than learning the skill in isolation.

For many of the participants involved in this study, more inclusive placements were the primary source of contention that arose. The remainder of this study exemplifies the practices that schools and parents use during IEP processes. The school practices overwhelmingly work against full inclusion, in attempts to maintain traditional and bureaucratic special education programmes. Parents enter with more complex and nuanced understandings of their children and use tactics, which help them to obtain more inclusive placements for their children.

### ***School practices***

Schools undertake a variety of practices, which undermine equity of participation between parents and schools. The practices that are discussed here include the discourse and language used by schools, the use of policy by schools, and the bureaucratic structures of meetings.

*Medical and deficit discourse*

Throughout the observations and interviews, the medical deficits of children saturated conversations, and drove major decisions made about students. To understand the critique of the medical model, it helps to draw from the tradition of disability studies. In this field, disability is viewed as a complex category, where traditional assumptions that ‘ability is innate, biologically predicated, and normally distributed’ (Gallagher 2006, 63) are rejected. This medicalised understanding of disability has a stronghold over traditional special education, and seeks to define the disabled student as inherently medically deficient, and in need of being fixed, often through the use of therapies, interventions, or medicines. The idea of the rational-bureaucratic education system thus can only be legitimised through its reliance on the medicalisation of its students that do not fit into structural norms (Sleeter 1995). This research finds the stronghold of the medical model of disability to be prevalent in the discourse and practice involving the participants.

Unfortunately, many school practices focus on addressing students by their deficits and many schools are hyper-focused on relating all attributes of the child back to the diagnostic characteristics of their disability. For example, one parent describes:

In my situation, we have a log, but the log ends up being a log of dirty deeds: ‘this is what he did wrong today’, you know? Then meetings end up being, ‘we only have this much time to talk, so let’s only focus on the bad stuff because we need to figure out the bad stuff’.

Another parent describes the speech teacher’s perception of her child, which was purely based on the medical label of the student. The parents brought this issue to the attention of the school when they realised that their son had only been receiving speech services 17% of the scheduled time. The parent notes:

We met with the speech teacher, and she indicated that he was not of normal intelligence, so there was only so much she could do with him . . . And his IQ test actually came up normal. But, that makes me question the profession. I mean if this individual already has this idea that he isn’t of normal intelligence then she has already decided by herself that, you know . . . what can she really do for him?

Observational notes show how deficits dominate the discussion of the present levels of educational performance. For instance, during one observation, it is noted that the classroom teacher states the following:

his DRA [reading program] was a level 2 and now higher, better since he has been on meds. It is hard for him to focus. Many of skills are closer to the mean, had a hard time sitting, focusing, and he avoided challenges so we recommended therapy one time per week (River Pond Elementary).

We can see how the problems with the child’s learning are attributed to the medical manifestations of the disability, and the solutions come from medical remedies, such as taking medicines and prescribing therapy.

In our study, the medical model discourse prevailed more often from related service providers, than from classroom teachers. Classroom teachers were more likely to balance discussions, including both strengths and deficits of the students. For instance, a speech therapist describes the performance of an 8th grade male

student and recommends he continue segregated speech services when he transitions into high school:

Speech teacher: 'He needs help in social language and to work on social skills. He is still learning boundaries, like not long ago, he asked another boy; do you think I'm handsome? and this freaked the other student out'. She then turns to dad and says; 'guys don't ask each other that stuff, right dad?' Dad shrugs his shoulders and doesn't verbally respond. She continues; 'Then he asked me the same question, so he really just wanted to know, but he really needs a social component of therapy because he does things that aren't appropriate. I mean I don't think it was anything with the boy, he just wanted to know, and it's not his fault, but when you have a little guy moving to high school, it's hard'. (North Erie Middle)

This therapist's recommendation was to continue the segregated related services so he can work on his social skills. Not only was medicalised discourse prevalent in this statement, but the transgression of hetero-normative social norms becomes a manifestation of the student's disability. Thus, the proposed solution for these 'deficits' becomes remediation through isolated skill building, maintaining the normed educational bureaucracy.

### *Professionalised discourse*

The professionalisation of language is well documented as a barrier between equitable parent-school participation in special education (Cole 2007; Harry 1992; Lytle and Bordin 2001; Valle and Aponte 2002). In order to maintain a rational bureaucracy, both knowledge and skills must be professionalised (Skrtric 1995) and this is often displayed through the language and discourse of the profession (Mehan 1993; Ware 1994).

During IEP meetings, clear trends emerged regarding how school personnel described students. When school personnel described a child, they often discussed the deficits of the child and then juxtaposed the response with an unrelated sentiment about the child's temperament. The negative comments seemed to be the main idea of the statements, where the positive comment had nothing substantial to do with the child. By more closely analysing the discourse of the educators that occurred during IEP meetings, we reveal that each segment of the teachers utterance have a discursive function, which reveals more information about how teachers understand and communicate about the students (Table 2).

The comments may appear to be positive at face value, but when understood more deeply, these comments seem to act as a buffer to the deficit discourse. These 'positive' sentiments seem global and act as a way to sugar coat the true deficit conceptions of the student that prevail. Instead making space for equitable dialogic space between professional and parent (Valle and Aponte 2002), the dominant discourse remains intact. The professional appears to be appreciative of the child and on the side of the parent, but the professional is still upheld as the dominant knowledge-bearer.

Also, school personnel use professionalised language that is not easily understood by parents who are not adept in the lingo of the occupation. For instance, one parent said:

I was after the schools' people to get it done faster for accessing the services. So we had this IEP meeting also, I just went there, I didn't know anything. I didn't know any things



Table 2. Analysis of teacher utterance.

Speech part and interpretation	Speech part and interpretation	Speech part and interpretation	Speech part and interpretation	Personal observation
Even though he is a pain	He is also very sweet	He is just troubled		West Elementary
Negative about personality	Positive temperament	Negative inherent problem		
He loses things all the time	He is always borrowing my pencils	But he plugs along	And is a sweet boy	North Erie Elementary
Negative characteristic	Example	Positive buffer	Unrelated positive temperament	
Her talking is excessive	Redirection is big	And she does not listen	But she is a nice girl	Donald Elementary
Negative characteristic	Need to remediate	Negative characteristic	Unrelated positive temperament	
He's likable	But we are still working on hitting			Avondale Nursery
Positive temperament	Negative behavioural			

that were being said there, I wasn't asked also. It was just the people that were sitting their discussing among themselves.

Also, confusing language and complicated legal terms are often used as reasons to reject service requests, even if legally the child has the right to services. Parents report feeling they have unequal footing in meetings, and thus parents must find and use various tactics to mitigate these linguistic power disadvantages. Parents come into meetings having varying cultural and economic resources and understandings (Harry, Allen, and McLaughlin 1995). This became evident in one meeting when the teachers discussed the reasons to discontinue physical therapy services:

His DRA was a level 2 and now is a level 6, since he's been on meds. His WS is up 50 and was reevaluated. Many of his skills are close to the mean. Before he had a hard time focusing, and was following a top-bottom orientation. I'm pleased with how's he's moved along, he likes the ball, but so do 80% of kids. It won't help academically, and would stigmatize him. Things can change, but it's not sensory based now. It's because of the meds, they have really helped. (Avon Park High)

In another meeting, the speech pathologist describes why the school will not accept the family psychologist's analysis to be a legitimate diagnosis:

'This is something the speech path does with a different evaluation. Scores were commensurate with IQ, and the data you gave us was questionable. Most kids have problems with M's and articulation, and throughout his phonological articulation has remained the

same.’ She then goes through the percentile scores on an articulation test. (Riverpond Elementary)

In this example, it can be seen how complex tests and formulas are spouted out at parents in confusing and complicated ways. Subsequently, the inability of parents to adequately understand the discourse becomes a legitimising tool for schools to make decisions about children without taking into account parental knowledge.

### *Policy interpretations*

Skrtic (2005) describes how the IEP is supposed to consider individual needs of students and emphasise collaboration with families; however, this is often contradictory to the logic of the educational bureaucracy. Special education is known as a system where implementation of the law into practice is often questioned (Smith 1990). The goal of educational bureaucracies is often to maintain the overall school structure (Skrtic 2005). Therefore, it is interesting to understand the discrepancy between the way that the law is written, and the way it is put into practice. During interviews, parents noted things such as:

It’s hard to enforce the law . . . Because, I think the problem is, is it comes from the federal government, then each state interprets them in their own way, and then each county . . . district, and each school. It’s very muddy . . . And then, like, in the due process, we went to a hearing officer, and the hearing officer agreed with the school . . . but when we brought it to the state, the state said ‘absolutely not’.

And, another parent states:

And you know, X county, is a very rough county to be a part of. So I would call Y county, and would tell them what I was looking for, and I would ask them would you provide for this for someone in your county, and they would say yes, yes, yes. I would call Z, and they would provide it. And then I would go back to X and I would say this person from Z county, and this person from Y county all say yes to these services, but because I live in X county, my experience was no. So I would have to go through the fight.

Therefore, it becomes clear parents understand that based on geographical locale, they may need to alter their advocacy practices. Or if a family moves to a different district, they might have extremely different experiences.

The murkiness of the way the law is interpreted is corroborated during meeting observations. During IEP meetings, a new ‘policy change’ from New York State about IEP goal writing is a hot topic. It becomes clear that each team and district interprets this differently. In 7 out of 10 meetings that were observed, goal writing came up. In five of those meetings, the new policy was brought into the discussion as justification for not writing goals the way the parent requested. This issue is illuminated when a parent asks for her child’s goals to be measurable:

Occupational Therapist: the goals are written as we were directed to.

Speech Therapist: you can find averages on website to see measurements.

Mom: You cannot compare my son with the average first grader, that is why he has an IEP. Looking at the website will not help.

CSE chair: Part of the problem is the way that NYS [New York State] wants goals written. So what are the skills that constitute a first grader? There was an error in the not so far past, when goals were very specific. Now they want three or four goals more generically. . .

Mom: Well goals 2 and 3 are well-written, I'd like to see them all like that . . . will the goals be rewritten.

CSE chair: No this is how the state wants them.

Parent Advocate: Is there a written policy on that?

CSE Chair: I don't know, it came from a training, but I'll look into it. (Riverpond Elementary)

In another meeting after a parent asked about goals, the IEP team responded that 'this is a new way of doing it compared to other counties' (Bended River Middle). In this case, the IEP team does not rewrite the goals as requested by the parents. In yet another case, the following occurred:

Mom: these goals are not measurable to me

Chair: We have to use something for the whole year. They have moved to a more global idea of writing goals.

Mom: this is still not giving me a measurement.

Chair: it is the way the state breaks it down. The state wants us to say something globally happens in one year. We used to use short-term goals, now we need to show long term, so that's how they have to be written, and these are specific to her. (Donald Elementary).

It is, thus, evident that the 'mandate' coming from the state is interpreted and implemented differently across locales. These examples illustrate how 'muddy' the implementation of IDEIA is between law and practice and how schools alter interpretations in order to assert their position as the dominate authority over the law, while maintaining traditional bureaucratic practice.

### *Meeting practices*

Several practices were continuously put into play throughout the meetings, which sought to increase the efficiency of the special education processes, but in the end only perpetuated the inequities students and families faced. These included use of electronic IEP writing programmes, and tightly scheduled meetings.

*Use of electronic IEP writing programmes.* In many of the meetings, electronic IEP writing programmes were used. Although these may make the writing of the IEP more efficient for teachers, various problems occur for families. Many times, certain requests of parents were not met because there was no choice in the 'drop down menu'. As students with disabilities are already positioned in terms of labels and boxes, these programmes exacerbate IEP decision-making as out of context from the real needs of the student, and IEP choices are not made based on the individualised needs of the student, but on the pre-scripted available choices. For instance, in one meeting, the following conversation occurred:

Mom: his academic needs should be highlighted and explicit with a breakdown of instruction into smaller parts . . . adding to supplementary aids and services, we could put in that we want a written schedule and we want timed prompting for transition times.

Chair: Well, it's a menu; let's see if we can find anything. We are limited here. There is visualization of things written on the board. . .

Mom: No that is not what I mean.

Chair: study guide, written materials, well I guess that is not a choice in the drop down menu. (Sarah Lynn Elementary)

And, during another meeting, the parent asks about voice recognition software as a program accommodation, and the meeting chair responds: 'We can explore that, but the drop-down gives us word processing only' (North Erie Middle). Thus, the choice for adding some necessary supports became limited, not representing the true individual needs of the student.

*Tightly scheduled meetings.* Almost all meetings were rushed after a certain amount of time had elapsed. Repetitively, we would hear school personnel say things such as: 'we are twenty minutes over for the next meeting, and we have to end' (Riverpond Elementary), 'we have another meeting shortly' (Sarah Lynn Elementary), and '[her] parents are waiting' (North Erie Middle). It was evident that most meetings were scheduled back to back, and some were offered as little time as 20 min for a meeting. This way of scheduling meetings offered little time or flexibility for parents to advocate for their children adequately, and fits into the bureaucratic conception of 'efficiency' that schools operate under. Many parents noted that the speed of meetings caused them to be flustered, rushed, and consequently they did not get a chance to bring up certain issues.

### ***Parent advocacy***

Parents utilise a variety of effective tactics, which help them advocate for their children. Parents often feel they must become advocates for their children in order to adequately obtain services, and an 'advocacy expectation' exists for parents who have children with disabilities. Parents of non-disabled children do not have such similar expectations, and parents who do not act as strong advocates for their children are often viewed by school districts as unconcerned or uninvolved (Mlawer 1993). This study also finds that parents use advocacy as a tactic to assert their knowledge against the knowledge of the professional.

### ***Becoming an advocate***

Parents who have children with disabilities do not necessarily start out as advocates for their children. Many parents described a 'breaking point' when they had to become fierce advocates for their children. They describe advocacy as synonymous with battling and fighting: 'it was like a war, and nobody wants a war, we just want services for our children'. Many parents go to extreme lengths to get what is best for their children. One parent who has moved from India to the USA for her child's schooling experience describes her situation:

I have been too patient I think. Or maybe they think 'she is from a different country, she doesn't know the things here', I mean they are underestimating me, so I have been very patient because it is something cultural. It doesn't mean I am scared of them, maybe they are getting the impression I am nervous and scared of the system, it's not like that at all. But this is the end of my patience, we have been through too much and my child has suffered a lot. He too has been patient . . . I have traveled to the other side of the globe for a better future for my child, for that I wouldn't have come here, I wouldn't have left my job and my family, and my daughter, to come to a new place. I am reaching the end of my patience because I can't take it very long.

In this case, there is a real cost to becoming a strong advocate and many parents state that they have no other choice. One parent noted the different perceptions she had before and after she experienced having a child with a disability:

Before I had my son, when I was working at my old school, there was a boy with a cochlear implant and he was coming into our 5<sup>th</sup> grade. I remember meeting with the parent in the summer. And I just remember thinking, wow! She really knows all her stuff, and she's really pushing to get this and that, you know at the time I just thought wow! Ease up a little! Then you become the parent of a child that has a disability, and you realize nobody is going to give you the service without a fight.

### *Strategies of parent advocacy*

A variety of strategies were utilised by parents to most effectively advocate for their children. These included bringing an advocate, networking, and educating themselves.

*Bringing an advocate.* Many parents found ways to bring in other advocates with them to the IEP meetings, although they often rejected the school-appointed advocate. For instance, one parent stated: 'we just really felt like the parent advocate was really in the pocket of the IEP director, and so we asked that she not be a part of our meetings'. Instead, they sought advocates from outside places such as local agencies, universities, or service coordination centres. Parents felt that having an advocate with them helped mitigate power imbalances between parents and schools, and the perception that the advocate would exert knowledge was often threatening to school personnel. It was evident through observations that when parent-advocates were present, the IEP team often directed comments and questions to the advocate instead of to parents. Parents also described having an outside parent-advocate in meetings:

It's amazing you bring in this new expert, and . . . when I was sitting here showing them all the documents for it, but I'm just the mom. It needs to come from the professional, you know. Even when the documents come from the professional they have to be presented by the professional. Not just the mom.

Here, the advocate is more likely to be viewed as having professionalised knowledge, which is upheld as legitimate by the school personnel.

*Networking.* Another effective tactic that parents use to advocate for their children is to create relationships with people who hold high positions in the school district. Many of the parents informed IEP teams that they were already told by a principal or superintendent that they would get what they were asking for, even if the IEP team refused the request during the meeting. One parent successfully requested the presence of the school superintendent, who confronted the IEP team for unfair practices throughout the meeting. During this meeting field notes state:

Superintendent says to IEP team: I want you to find a device to use to make this easier for parents to understand, you should be giving them the story behind the story. That would be more helpful than just this generic IEP you have been giving. Say exactly what he will be performing and how you will evaluate it . . . The data should be available and understandable to parents . . . The IEP has a nebulous effect, but the parent wants to know about day-to-day progress, and how they are going to get there. (Riverpond Elementary)

When parents made successful connections with powerful school district people, they were more likely to obtain some requests. However, in some schools, there was still a good deal of battling, even when parents had the support of an administrator. In one meeting, the superintendent arrived and he made multiple strong requests to the IEP team in favour of the parent. Unfortunately, he left early and few of the changes that he suggested ended up in the IEP.

*Education.* Another tactic used by parents is self-education. During observations, it was common for parents to describe that they have been learning about legal issues, and even would mention outside degrees or experience that they had within the field of education. For instance, 'I have meet with Riverpond administration, I have been taking Parent University classes, and I have learned about appropriate goals' (Riverpond Elementary). When parents spoke frequently through meetings and had information about the law, power imbalances appeared to lessen because they were able to speak the professionalised discourse. Parents also spent a great deal of time preparing for meetings, and were knowledgeable about changes they wanted on IEP's or aspects of the law that pertained to their requests. One parent stated:

When she was born, from that day I have been educating myself regarding disability, and all different regulations and different programs. I go to get information, be at websites or I am going to different trainings, special ed. trainings, asking my question to the knowledgeable people putting on the training, and you gotta go to more than just one training, and go over and over and over again, because there are going to be more questions as things come up.

Thus, parental knowledge is not enough to be counted by the school as legitimate; parents must learn to embed themselves in the dominant discourse of the school to effectively advocate for their children.

### **Implications**

It is important for schools to understand that parents feel that they must become advocates for their children in order for them to receive the best education possible. Their desires are not inherently adversarial and many parents would prefer collaboration. It is also important for parents to understand the employees of schools often do have the best interest of their children in mind. Unfortunately, too often policies, and constraints that schools face make the need for efficiency a priority over true collaboration. Thus, specific steps can be taken to open up space for a transmission of knowledge that lessens the dominance of professionalised (Valle and Aponte 2002) and medicalised (Sleeter 1995) discourse.

Schools should be thoroughly educated on legal aspects of how to successfully place students into more inclusive environments. Trainings and information about how to successfully integrate inclusive-related services into regular education classrooms should be provided to school personnel. Furthermore, teacher and administrator preparation programmes should educate all teachers on the needs of diverse learners, so that a dual special education/regular education system is no longer necessary. These preparation programmes should also address how to effectively work and collaborate with diverse families.

Schools must understand that students with disabilities are very complex individuals, and disability is only one component of their identity. Enhanced education on

fully inclusive education practices, on disability studies in education, the person's first language, and on the disability rights movement for all education personnel, parents, and policy-makers is necessary. If all parties learn to view disability as a positive identity category, medicalising, dehumanising, and deficit-oriented discourse and practices are unlikely to prevail. For instance, one parent recommends the school educate themselves and students about the positive aspects of autism: 'I think it would be good if everyone knows more about autism so they can know more about this part of him'.

During IEP meetings, a variety of recommendations for schools and parents must be considered. By changing the way disability is viewed in general, and appreciating the equal collaboration of families, the ways that language is used to distance parents would change. More information needs to be disseminated from the government to school personnel to streamline the various ways policies are interpreted, and policies need to be written more clearly and accessibly for both schools and parents. More training, and checks and balances should be put into place to ensure that schools are correctly implementing the policy. It should not fall on the backs of parents to raise awareness about discrepancies between the law and implementation. Finally, schools should evaluate whether practices which may be viewed as increasing efficiency (electronic IEP programmes and tightly scheduled meetings), are in fact detrimental to the overall needs of parents and students.

Parents should continue to advocate for their children. Finding allies through networking should continue. More opportunity needs to be afforded to parents by schools and their local communities so that they can easily access information. It is also important for parents to understand the constraints that schools operate under, so that they can help bridge the gaps in understanding.

Overall, this research seeks to shed light on the experiences of parents through the IEP process and offer suggestions to improve the collaborative process. Schools continue to function as bureaucracies, which hinder equal collaboration with families. Comer and Haynes (1991) offer recommendations as to how schools can integrate parent participation in order to fundamentally change the bureaucratic nature of schools. It is evident through this research that we must continue to prioritise the importance of true parent-school collaboration, as little has changed over time.

Ultimately, this work seeks to enhance educational practices and policies for children with special education labels. Self-advocacy for students with disabilities, along with parent advocacy is a worthy goal, and one that has not fully been investigated. Continued research on this subject is recommended, particularly research that focuses on the perceptions of the student. Also, more research focused on improving and identifying positive school practices would be useful for proactive change.

## **Conclusion**

Parent advocacy within special education in the USA has become necessary for many children to receive adequate services. Although a variety of themes reveal how parents are undermined as equal contributors, various promising practices and ancillary recommendations have also been identified. Parents and schools must work together to mitigate the detrimental effects that bureaucratic processes have on students with disabilities.

After a long road advocating for her child, one mother describes the eventual victory in getting her child finally placed in an inclusive placement, as 'it's where he belongs. It's amazing what a sense of belonging does to his self-esteem and academic

progress . . . He's proud of himself, as we are with him'. It is the hope of this research that it may in the future become less time-consuming and arduous for parents to see their children achieve a place of such belonging, and that parents will meet the extended hand of collaboration in order to make their dreams for their children a reality.

### Notes on contributors

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