An Exploration of How Parents Obtain Information on Special Education Rights and Services: An Insider Looking Out

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EDRS 812

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Introduction

Every summer I find myself at Saturday afternoon barbecues with my wife, talking with friends and enjoying the food. Eventually, I mention that I work in the special education field and sooner or later I find myself entrenched in a conversation with a parent of a child receiving special education services. During the course of the conversation, the parent might reveal a frustration with getting services or say something that I recognize the school should be giving to them. When I hear parents tell their stories about how they could not get services I offer advice on their rights and the obligations of the schools under both state and federal law. If I am not able to give them information in that moment, I spend time researching what will help them. As I engaged in more of these conversations, I began to wonder why these parents did not know the things I was telling them about the special education process. I thought about this issue for about a year before realizing that I was not asking the right question. The real questions were how would they know what their rights and services are? How does the school communicate rights and services? How do parents inform themselves about rights and services? The barbecue conversations became the inspiration for this study. ☺

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The purpose of this study was to explore how parents learned about the special education process and to learn about their perspective on how the school communicates information could be improved. The goal was to study how parents of children receiving special education services accessed information designed to help them learn about their rights and the available services. The types of information includes procedural safeguards and resources provided by the school and independent research that parents do to inform themselves including books, websites, and talking to other parents. Navigating the special education process can be challenging because when the eligibility process starts, parents have 90 days to learn about it before they are making important decisions about their child. A lack of awareness about available services may prevent parents from requesting them. Therefore, it is important that they learn about their rights and the available services so they know the obligations of the school system as provided by federal law.

The experience I have with my topic is grounded in three different roles I have had: personal, professional, and consultative. From a personal perspective, I have been responsible for helping my step-brother receive adult services for his cerebral palsy and severe intellectual disability. When my family first became responsible for him, he was nonverbal and unable to walk. The process of how to request services was never explained and it has taken my family 6-7 years to learn how to access the appropriate services. We did not seek out independent resources and relied solely on his case manager to help us navigate the system. As a result, it has taken many years to get the services he needs to increase his independence. Our diligence with getting him services has allowed him to develop to his current point where he walks, talks, lives in a group home, and participates in sheltered employment.

From a professional perspective, I am a licensed special education teacher and have a master's degree in the field. On many occasions, I have served as the building level administrator in meetings where the central office administrator either denied services or did not heed the requests of parents or teachers. The experience has included seeing parents lose services for their children without them understanding the decision that was being made. In cases where the school I work for was able to provide ample data to support the provision of a service, the school system continued to refuse to agree to the service. The parent did not pursue it any further because they perceived the school system's decision as final. In these cases, the parents did not understand their rights. The school consists primarily of students who come from low socioeconomic backgrounds whose parents typically have minimal education. In these troubling economic times school systems are trying to save money and the perception is that services are denied or terminated because of their cost. Procedural safeguards are written in technical language and may be difficult for parents to understand.

The third experience has been in a consultative role for friends mentioned at the beginning of this paper. I have found myself on several occasions talking to a friend at social gatherings about their experience in learning about special education. As I had these conversations, I pondered, how do parents learn about the special education process, what resources beyond the procedural safeguards do the schools provide, and how do parents identify what other resources may be helpful to them in this process? Very nice introduction.

Conceptual Framework

In the movie The Incredibles the main character works for an insurance company. When faced with a woman who is not able to receive her claim, Bob Parr, the main character tells her what she should do to receive her claim. Bob communicates the procedure to her by speaking in a soft voice and beginning each step of the process with “I’m not supposed to tell you that…” The woman is grateful for the insider information and leaves his office to follow the steps. However, shortly thereafter Bob is chastised by his boss because the customers are able to navigate the system to receive their claims. The boss’s frustration culminates with the statement, “They’re permeating the bureaucracy.” (Bird, 2004)

In looking back on my experiences with special education processes from the aforementioned personal, professional, and consultative perspectives, the scene from The Incredibles represents my beliefs about the special education process. The procedural safeguards provided by the school are about parental rights but are written in technical language. Special educators may provide information about rights and services but it is from their perspective as an insider and they may not be aware of the parent’s background in special education. They may also assume the parent knows more than they actually do. Figure 1 illustrates the connections of my conceptual framework where the sequence is started with the child beginning the eligibility process. Once that process has started, the parents must learn about it in order to make informed decisions about their child and to ensure that the school is able to provide appropriate services. In some cases, information may be intentionally withheld to prevent the parents from gaining services in an attempt to save money or because the school system does not believe the student has a disability. In cases of low incidence disabilities, school administrators may be less aware of services that are available for those children due to a lack of experience in dealing with certain disabilities. Building level administrators may lack awareness of the types of services that are available beyond their building. In order to learn about the special education process, parents need to do independent research beyond the school provided procedural safeguards in order to navigate the process. In order to navigate all of these issues, parents must become educated about the process and their rights in order to “permeate the bureaucracy” to ensure that their child is able to receive the appropriate services for their exceptional learning needs.

The beliefs I have on this topic have caused me to focus solely on the parental perspective of how rights and services are communicated. The school system may believe that they are communicating effectively but the information may not be understood. If the parents are not able to understand or access the information that the school system is trying to convey then the school system needs to communicate rights and services in a manner that parents can understand. An awareness of my assumptions about the schools ineffective communication will also help me frame questions that do not reflect that bias in order to effectively gather data from parents about their experiences. Finally, I must be aware that I am also an insider in the special education world and need to frame my questions in terms of the parents explaining the process to me as opposed to my own assumption of what I believe they should already know. Good point.

Figure 1: Conceptual Framework of my beliefs

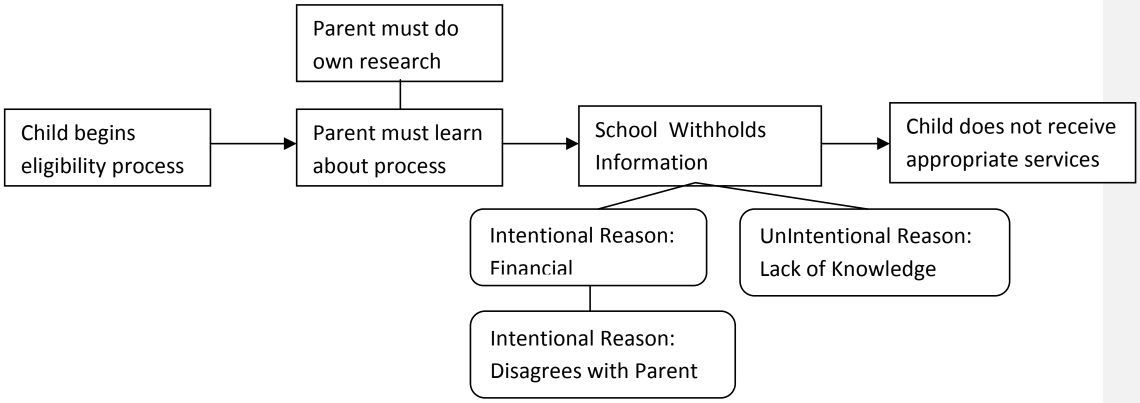

Figure 1. Represents my belief of the flow of how the parent may inform themselves and how and why the school may withhold information which prevents the child from receiving appropriate services.

I couldn't read the concept map

Research Questions

Upon beginning this project, I focused on the assumption that parents were focused on their rights and the services they would receive from the schools when their child was identified as potentially having a disability. This assumption was based on my experiences as a special educator which provided me with an insider perspective. The original research questions to address the goals were:

1. How do schools inform parents of students receiving special education services about their rights and the available services?

2. How do parents of students receiving special education services inform themselves of their rights and the available services?
3. How do parents think the schools can improve their communication of rights of services?

Participants

The original design of the study included interviewing two sets of friends about their experiences with special education. I planned to collect the majority of the data from these two sets of parents and would then recruit a third family for the remainder of the data. I hoped that these families could connect me with the third family and that would provide a sufficient amount of data for the project. However, though they were very interested in participating, one of the sets of parents indicated they would be out of the country for several weeks during the data collection period. When they returned, we were never able to align our schedules to meet. Neither sets of parents were able to connect me with a third family to interview.

When the one family indicated they were going to be traveling, I started recruiting additional participants just in case they would not meet with me. I recruited additional participants for this project by e-mailing a large group of friends and classmates with a brief description of the study. I asked them to have anyone with a child receiving special education services that might be interested in participating to contact me. Three different people responded to the e-mail and I set up interviews with them. One interview took place in the person’s home, two interviews took place in a coffee shop, and one interview took place via Skype, an internet based teleconferencing software.

Ron and Sally (pseudonyms) are the parents of Timmy (pseudonym) who has both a medical diagnosis and an educational identification of Autism. Timmy was identified prior to entering school and has received special education services since the age of two. Ron and Sally have fought very hard to get what they believed to be an appropriate placement for Timmy which is currently a separate private day program.

Tina (pseudonym) is the parent of Oliver (pseudonym) who is a child with a medical diagnosis of high functioning Autism and an educational identification of Emotionally Handicapped (EH). Oliver attends a special program within his high school for students with Autism that supports inclusion in general education while providing supports. Oliver was identified for special education in kindergarten and has been receiving services in the general education setting ever since.

Mary (pseudonym) is the parent of Kim (pseudonym) who h as a medical diagnosis of Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS) and an educational identification of Other Health Impaired (OHI). Kim was initially found eligible for special education in preschool as a child with an Emotional Disturbance (ED). However, due to her progress, services were terminated halfway through the first grade. Towards the end of fourth grade, she began to struggle and her parents pursed services. The school was resistant to finding her eligible and the parents engaged in a contentious struggle with the school until she was found eligible at the end of fifth grade as OHI. Kim attends a middle school in an inclusionary model and receives educational supports during resource periods.

Leslie (pseudonym) is the parent of Billy (pseudonym) who has a medical diagnosis of Fragile X and Autism and an educational identification of Autism. Billy began services prior to entering school and is currently receiving services in a self-contained classroom in a general education school.

All of these children attend different school systems with three of them in the Northern Virginia area and one in the Richmond area. The parents involved in this project include two parents who were employed in instructional design, one of whom had previously been licensed as an elementary school teacher. Another parent had worked for the school system in developing computer software and had served on the school system's Special Education Advisory Committee (SEAC). Good explanation.

Research Relationships

To ease my way into the interview process, I conducted my first interview with a friend. Given our established relationship and that I had been in their home on numerous occasions, I assumed they would be comfortable meeting there. We spent some time reconnecting and talking about events in our lives since we had last seen each other. I transitioned the conversation into the context of the research and gave a brief explanation of the study. Since I had many prior conversations with this friend on this matter, the transition into the topic was very smooth and they were very willing to participate. One of the challenges of this interview was that the power went out just as we were about to get started. After locating candles and flashlights, I offered to reschedule but they insisted on conducting the interview.

For the two people in the area that I did not know, I suggested we meet in a public location near their homes. Since they were willing to give me their time, I wanted the interview to be convenient for them. I offered a public location to avoid any anxiety that may be produced by having a stranger in their home. For both of the coffee shop interviews, I arrived at each interview location early to try to find the quietest spot and offered the interviewee a beverage when they arrived. One of the challenges I faced was how to develop a relationship with a stranger in a short period of time to get them to discuss their experiences with the special education process. For each of these participants, I discussed my background and experience in special education. After I talked with them about who I was, I explained the purpose of the study in detail but did not provide any information on my preconceived beliefs. I explained what would be done with the tapes and the transcriptions and told them who would have access to the information and final report. I offered the opportunity to answer any questions and when it came time for the interview to begin, I opened a new tape in front of them and placed it in the empty cassette player. By engaging in these steps, I was able to establish some rapport before the interview as they identified me as a “friendly expert”. They were very interested in the research project itself and each felt that they had some valuable contributions to make to the study from their experiences.

The last participant recruited lived in the Richmond area and it was impossible to travel to that area for that interview within the timeline I was working. To gain a clear recording of the conversation, I contacted her via Skype and used Pamela, an add-on recording software to record the conversation. We discussed how we each knew the friend who had connected us. Similar to the coffee shop interviews, I then discussed my background and experience in special education and explained the purpose of the study. I offered the opportunity for questions and then proceeded with the interview.

Data Collection

Data was collected through tape-recorded interviews with each of the families. The length of each interview lasted from 45-71 minutes. Initially, I had an interview guide with specific questions to ask. However, I thought reading off a list of questions would interfere with the natural flow of the conversation. Interfering with the flow might prevent the participant from providing as much description and detail in their responses. Locking into a specific set of questions might also prevent me from learning about phenomenon beyond the scope of my conceptual framework. I brought the list of questions with me and occasionally glanced at it to ensure I was capturing the information I was hoping to obtain.

At the beginning of each interview, I assured the participant that I would be the only person listening to the recordings, their names would be changed for purposes of transcription, and that this report could not be published because it had not gone through a formal Human Subjects Review Board (HSRB) review. I let them know they were able to stop the interview at any point and that they could request their data not be used. The questions were primarily open-ended and reflected the experience with special education and how they obtained information about their child's needs. Each interview started with the parent giving an overview of their experience with special education and then specific questions were posed regarding the information they had provided. At the end of every interview, I debriefed with the parent and talked further about some of the issues they mentioned. When I returned to my car, I recorded a brief memo about my impressions of the interview and how the data from that interview might be connected to data from other interviews. Table 1 outlines the date, location, and length of each of the interviews.

Table 1

Interview Detail

Date	Participant	Length	Setting
6/22/2010	Ron and Sally	55 minute	Home
6/30/2010	Tina	48 minutes	Starbuck's
7/3/2010	Mary	56 minutes	Caribou Coffee
7/8/2010	Leslie	71 minutes	Skype

Throughout the course of the study I felt my interviewing skills improve. ☺ During the first interview, I asked an abundance of closed and yes/no questions. I also struggled with asking

Formatted: Font: Times New Roman, 12 pt a series of questions at once. In some cases I asked several questions at once to clarify the original question I posed. As I listened to the transcripts and came to recognize I was doing this I made a conscious effort to let the participants do more of the talking. I tried to avoid closed questions (though I did not escape this entirely) unless I was posing a question for clarification. I also made an effort to ask one question at a time and then wait for the response. Sometimes it was necessary to sit in silence for a moment to allow the person to collect their thoughts. I realized that if the participant needed clarification, they would ask for it. Though I was not able to completely achieve this goal, I did make a lot of improvement in the manner that I posed questions over the course of the project. People were very happy to talk with me and by the last interview it was just a matter of guiding them through the information rather than trying to draw it out of them.

One of the potential issues I anticipated was my propensity to try to propose solutions to issues the parents might be experiencing in gaining access to services. I solved this problem by making a note of the issue when I heard it and then speaking to the parent about it afterwards. The parents were comforted by the advice and I offered to send them additional materials to help explain the solutions I was presenting. Excellent description, good reflections.

Data Analysis

Each of the interview tapes was transcribed and the transcription was broken into two columns. The text of the interview was in the left column and the right column was used to capture any notes from the interview or thoughts as the transcription was being read. I read through each transcription once and the second time through I highlighted different segments of text. I then used the review feature of the word processing software and added comments to each segment of text regarding what the text represented or why I thought it was important. Upon completion of labeling each highlighted section of text for the first transcription, I conducted a thematic analysis by identifying substantive categories that captured the different themes associated with the highlighted text. I created a second document and used each identified theme as a headline. I copied all of the different segments from the transcription to their appropriate place under each theme in the second document. Some of the text segments represented more than one theme and were copied into both of the corresponding areas. After the first transcription, I created a separate file for each identified theme. I repeated the coding process for the rest of the transcriptions and copied the segmented text to the file that represented the appropriate theme. For every interview after the first one, if there was not an appropriate place to put the identified text, then a new file was created to represent that theme. The font from each interview was given its own color to help later identify the source of the text.

After each transcription was sorted into the appropriate files, I reviewed the files to determine if there were any subcategories. I also made personal notes about the different concepts that were being identified and the perspectives of the parents on the special education process. It became challenging for me to focus solely on the original research questions because there were many of questions that could be answered with the data I collected. In focusing on the original motivation for conducting this study, I looked at the emic representation of both the ways that parents learn about the special education process and the parent's perspective of the challenges and difficulties they have with special education. I was able to use the participants' own words to explain the context in which they learned about special education and the barriers they faced in getting services and learning about their rights and available services. As I reviewed each of the parents' words about their experiences with special education within each of the identified themes, I was able to gain a better understanding of their perspectives.

Throughout the project I wrote memos about the purpose, participant relationships, my conceptual framework, date collection, data analysis, and conclusions. ☺ These memos helped me identify my own personal beliefs about the topic. Being aware of these beliefs helped me to see beyond them to understand what the participants were saying. Originally, I had an abundance of data and struggled with making the data fit into my conceptual framework. However, I read back through the idea memo and the research relationship memo and that helped me recognize that I was too focused on my own beliefs and needed to look at the issue from tha participants' perspectives. As I reviewed the themes within each of the categories, I was able to make connections between several of the themes to generate a new theoretical framework. Upon making these connections, I wrote a memo to capture my thoughts.

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To confirm my new theoretical framework, I read back through each of the transcriptions to ensure that there was data from each of the interviews to support this framework. I looked for specific quotes that supported the framework either by directly using the participants' words or making interpretations of the words that represented each of the themes. Small adjustments were made to the new framework after reviewing the data to ensure it supported the theoretical framework.

I realized that parents were less focused on rights and services than they were on learning about the nature of their child's disability and how they could support their child in the home. Parents sought to understand what the disability meant and were more focused on techniques to help their child than they were on the legal obligations of the school. As I realized that parents were more focused on helping their child than they were on getting the school to provide services the research questions changed to:

1. How do these? parents of students receiving special education services inform themselves about their child’s disability?
2. What resources does their school provide for information on special education?
3. What is these parent~~’~~s’ perspective of how the schools communicate information relevant to special education?
4. What solutions to parents propose to improve the interaction between parents and the school?

Findings

The identified themes from the data were Independent Research, School Provided Information, Perspective of School Communication, and Improvement/Solutions. To me, all of these are categories, rather than themes, and all except the first are organizational rather than substantive; only the first identifies something that actually characterizes the parents’ experience or strategies. See my discussion of themes in chapter 5 of my book. Independent research consists of parental behavior to learn about special education and includes books, the internet, consulting with medical professionals, and talking with friends. School provided information is any information that the school either actively or passively provided to the parents. The active provision of information includes providing the procedural safeguards and any other activity where the school reached out to the parent. Passive provision involves information that is made available by the school system that the parent must seek out. This includes websites and resource libraries where the parent must take the initiative to find information in these areas. Perspective of school communication is the parents’ impression of how information is conveyed by the school. Finally, Improvement/Solutions includes ideas and problem solving strategies that either parents have used or are proposing to improve their experience with special education.

Independent Research

When the children in the study were identified as potentially having a disability, the parents conducted research on the challenges their child faced. The primary focus of the research was to learn about how the parent could support the child in the home environment. I would call *this* a theme. The disability manifested itself within the home and the parents were focused on learning how to both help their child and provide a supportive environment. Parents were also focused on finding additional resources to help support their children with disabilities. For example, when Ron and Sally started noticing their child was not developing in a normal fashion, they started doing some reading:

> When he was one and a half to 2 years old, yours truly didn't really know what I was dealing with, I read a book by Stanley Greenspan on the floor time method which obviously is very appealing to parents because it's all about getting kids to do what they want and then kind of engaging them, and I was focused on some of the data, because I was still focused in my own head, and this is probably kind of the, I was focused on really understanding is this kid autistic or not, because the jury was out based on what I was reading in this book this book was really leading me down the path to believing perhaps deniability, that denial, that there's a chance that he wasn't autistic, in fact the data was showing, you could see the scatter diagram that 64% of cases if Timmy did what Timmy did on his second birthday which is to take you to lead you through a complex set of procedures to get something he wanted then the chances were very good that he wasn't autistic, that was actually a problem for me because what that ended up doing was that ended up having focusing on continuing to deny or to continue to think that the issue here is that he's not autistic at all and maybe what he needs is this floor time. (Ron) This quote might have benefited from a little editing. See Weiss.

The reading that each of the parents did was to help them understand the child's disability and how it would impact their lives both in the moment and in the future. Learning about the different disabilities helped the parents identify what they believed their child needed to be successful in both school and the home. Both Tina and Mary did some independent reading on how to support their children with disabilities. They were both interested in what they could do within the home to help their children. Both of them had reached out to individual professionals for advice and services to help support them.

> In sixth grade the psychologist gave me a list of books, she put me on to books about NLD, nonverbal learning disability, and once I started reading that, I was like aha, this is what's going on, so I read quite a bit about that and then once we got the diagnosis of high-functioning autism read quite a bit about that, it's funny because I read a lot of non-fiction but I've also read some fiction that was really helpful in kind of interpreting what goes on inside of someone who's autistic. (Tina)

> At that point it was really just understanding more about her disabilities, and so it was more along the lines of, online bulletin boards and support groups and those kinds of things, not so much what the schools could do but what I could do because you know she was having issues in the school so she was also having issues at home, so it was more informing myself about the home side. (Mary)

Leslie had a brother with Fragile X and when her child was identified, she believed she was prepared based on her experience with her brother. However, she later revealed that her experience with her child was much different than with her brother and she worked with the school system to try to find resources to help support her in the home.

> I had an older brother who was mentally retarded, I thought I had a pretty good understanding of what my life would entail, though now Billy is getting older, he's nine now, I realize that my son will not function at the level of my brother, my brother is articulate, my mother said fairly early on was easy to potty train. (Leslie)

As each of the quotes demonstrates, all of these parents were focused on learning about what life would be like living with a child who had the specific disability. Contrary to the original conceptual framework, these parents did not do any research on their rights or the available services in the schools. As mentioned in these quotes, parents used books, the internet, and life experience to inform themselves about living with a child with a disability. Tina and

Mary identified credible resources by reading materials that were referred to them by medical professionals.

School Provided Information

All of the parents were provided with the special education procedural safeguards but had not had read them. Their initial interactions with the special education process were positive and for some of them, it stayed that way. Many of the parents indicated that they had not read the procedural safeguards because their initial interactions with the special education process were positive. However, one parent did expand on why she had not read them.

> it's verbose, it's big, it's intimidating, (Leslie)

Beyond the procedural safeguards, the parents all of them? If not, how many? felt that additional information was not actively provided and they had to seek out information and resources on the school websites. Several parents reported an awareness of a parent resource library within the school in addition to parent workshops. However, for at least one parent, the workshops were difficult to attend as there was no childcare provided for parents attending these events.

> I know that there is a Parent Resource Center, I've gone to that website on the X County public school site I haven't really found too much there though, (Mary)

> every so often I go to the special ed section of Fairfax County [website] just to see what’s there (Tina)

One parent reported that the school system had a great resource library with a librarian to help them find information. However, despite this great resource, the parent still was required to take the initiative to both know the library was there and to contact them regarding their question.

> they had, they had a library of sorts and if there was a specific line of study, or if there were something that you as a parent really wanted to know about and they

> didn't have that resource that you are looking for they would take the initiative to try to find a resource document or just helpful documents to you as a parent (Leslie).

In all of these situations, the only manner in which the school system actively attempted to provide information was through the procedural safeguards. Which the parents you spoke to hadn’t read. The rest of the information made available by the school was provided passively meaning the parent had to seek it out independently on the school website or in the resource library. This paragraph describes what I would call a second theme.

Perspective of School Communication

Many of the parents felt that the school communicated with them by simply telling them information without any check for comprehension. A third possible theme, but see my comment below. The schools did not elaborate on available services or parental rights in regarding to serving their children. Parents were asked for input about their child’s education but they were not aware of the options in regards to services, modifications, and accommodations. As a result, parents felt bullied and intimidated by the lack of communication resulting in anger and frustration.

> I think that some of the terms that we are so familiar with that we speak every day, a parent might not understand because they’re tossed around like we're using the word blue to describe the sky we don't even perceive that they may not have any clue about what we’re talking about, socialization, inclusion, self-contained, OT, PT (Leslie)
>
> they described it and stuff but it's like I don't think there was much, I don't think there was much check for comprehension, which is kind of shameful in an educational institute, it's like you say something and then you make sure that they understand and I don't think I understood (Tina)
>
> that's another thing that bothers me is that they when they ask us what you want on there, there apparently is this whole book that talks about modifications that parents can't see and I would love to be able see that because then I could say hey yeah this would help my kid (Mary)

> a principal said in front of me, an elementary school principal, that the goal of the pri ncipal in the IEP team meeting is to get the parent in and out of the meeting as quickly as possible and give up as few services as possible (Sally)

Only one of these quotes explicitly supports your "no check for comprehension" statement; one could be seen as implying this, but the other two don't; they raise other possible findings.

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Some parents were able to navigate this issue either by developing relationships with the staff or by consulting with an expert in the special education field to learn about what was available for their child. Through consulting with an expert, they were able to gather insider information that helped them contact the right people and ask the right questions. Parents found that when they were asked what they wanted, they were unable to respond due to a lack of knowledge of their options. Through relationships and insider consultants, some parents were able to better prepare themselves when these questions were posed. Another theme.

> so I've managed to make teachers allies and that's helped a lot, so they tell me stuff, you know the set of teachers in elementary school, you know they knew me they liked me, they'd tell me stuff, same thing with the middle school, and I'm trying to make the same kind of relationships with the people at high school as well (Tina)

> I really think another part is definitely having that face-to-face, trusting relationship with someone, be it your social worker, be it your teacher or someone within your exceptional Ed Department (Leslie)

> I actually have a friend who works in special ed in XX County, she's currently an AP but she used to be what's called a consulting teacher and she worked at alternative schools in XX and all kinds of places so she knows special ed, so I reached out to her (Mary)

Mary is the best example of using the insider consultant. Every time she believed the school failed to meet her child's needs or if she was denied services, she contacted her friend. Her friend would advise her in terms of who she should contact, what she should say, and how she should say it. Mary found this to be extremely helpful in getting services for her child.

Improvements/Solutions

The parents all had solutions about how to improve the flow of information from the school system to help educate parents about the special education process. Parents who had successful experiences in dealing with the school system recognized that they had unique situations and knew other parents who struggled with getting appropriate services for their child. Tina and Leslie both suggested additional workshops for parents to help teach them about their rights, the processes, and available services.

> I understand research I understand education, I educated myself so I understand more or less what's going on with my child, you know I've done that basically by the grace of God, not everyone's that lucky, not everyone can do that, so the thing that we need to do is make sure that everybody can do that, that there is enough, people that speak the language, people that can translate, people that can say wait a minute here is a good idea, here is information for you, let me tell you, so that those people can have a similar experience (Tina)
>
> I feel like there are doing that with the parent resource center but specifically for exceptional ed parents, have an open house, centrally located, XX County is a big county but find a central location are coupled central locations and send out an invitation to your exceptional ed parents, if you want to do it once a year for all parents or if you want to do it for parents entering the system and say that we're having an IEP workshop or were having an explanation of your rights and get someone in there who speaks a layperson's English or who may be able to communicate at an even lower level than that because we have some parents that don't have a higher level of education, they may not hit even have a GED, I think that you need someone to speak to all levels, that can speak to a professor, I can speak to someone who doesn't have that education and talk to them in terms that they can understand and create an open environment that they can ask those questions so that they don't feel stupid (Leslie)

These quotes seem a bit diffuse, and only Leslie explicitly mentions a workshop.

Sally and Mary supported having an independent advocate to help parents navigate the special education process to help them gain access to services. Having an independent and objective expert will help prevent the school system from intentionally withholding information in an effort to deny access to services.

> I think the only thing the school district can do is have an independent counsel, a parental liaison (Sally)

> you know you think about it if you go to a hospital, the Hospital, one of the services they provide is patient advocates, why doesn't the school system have advocates that are available for parents who can help to inform them and attend these meetings with them, I mean I knew a little bit more having been an educator and having my friend but the average person doesn't and so I would love to see that be a service in a school system (Mary)

Sally and Mary came to these conclusions based on their experiences in trying to obtain what they believed to be appropriate services for their children. They both had contentious experiences with accessing services. They believed that an informed objective third party would help parents with contentious experiences by helping them understand the process and speaking the special education language of the school. Some of the quotes in this section could have been tightened up, making clearer just how they support your claim.

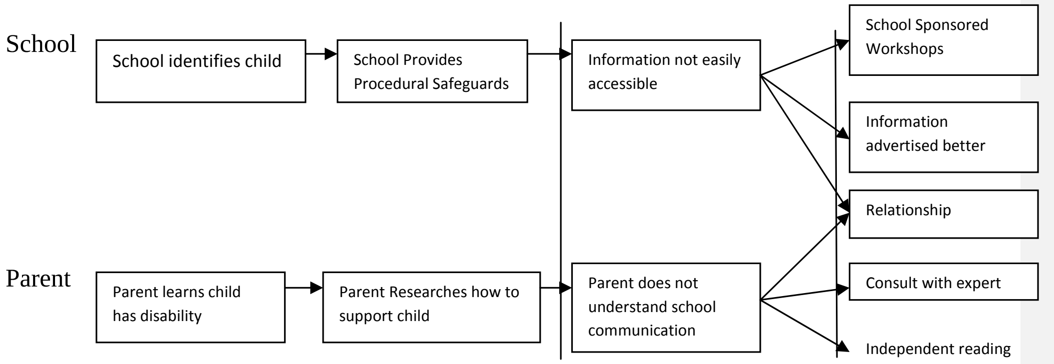
Connections

When parents realize their child has a disability, they are primarily focused on how they can support the child in the home. They will conduct independent research on the disability so that they can help the child within the home environment. The schools provide the procedural safeguards but do not actively provide additional information to the parents about their rights or available services. Parents must actively pursue information on the school website, in resource libraries, or by attending workshops. To me, this is overgeneralizing from your participants.

When information is explained to parents, it is from the perspective of the special educational professional. The professional may use jargon or industry terminology to describe different things that the parent may not understand. Though the school is attempting to communicate information are you sure? Also, schools don't "attempt" things; people do, it is not being received. Some Parents have been overcoming this by developing relationships with school staff and finding experts in the field with whom they can consult to learn about their rights and services. They use these consultants to identify exactly what they should say in order to gain access to services. The system of communication can be improved by having additional workshops for parents on special education that would focus on communicating the process and rights in laymen terms. Having the workshop outside of the context of a meeting will allow the parents to ask questions and understand what is going on outside of a regular meeting when the pressure of making important decisions exists.

A paragraph break here would help. The other way that participants mentioned to improve parents' ability to navigate the special education process is for the school system to hire independent advocates to serve as a liaison between the school and the parents. These liaisons will be experts in special education and can provide the parent with an objective opinion of their rights and the services their children should receive. Figure 2 below outlines these connections through the parents' perspective on the school process, their own experiences, and how the flow of information between parents and schools can be resolved. The figure represents a parallel process where the school is providing information to the parent while the parent is attempting to learn on their own.

Figure 2: Theoretical Framework of Connections



Barriers Solutions

Figure 2. Demonstrates the parallel flow where the school attempts to provide information that is difficult to understand and not particularly visible. Parents focus on other aspects of special education and it is through relationships and working with those knowledgeable in the field that they are able to navigate the process.

The connections and Figure 2 deviate from the initial conceptual framework which assumed both that parents were focused on special education rights and schools were withholding information. The data from all of the interviews supports the framework presented in Figure 2 where parents are more focused on learning about the disability and schools do provide information and resources. Parents are able to access information provided by the schools through websites and resource libraries. However, these resources need to be more visible to help parents take advantage of them. Finally, parents need help from experts to access the proper terminology to find the information they are seeking.

Implications

The participants in this study were all educated individuals who had navigated the special education process. For some of them it was easy while for others it was a constant fight. Each of these parents expressed that somewhere along the process they did not know or still do not know or understand aspects of special education. If these parents are struggling with the process then there is a strong likelihood that many other parents out there are having similar experiences. However, other parents may not have the education or the tenacity to be persistent with obtaining the proper services for their children. As a result, their children may be underserved because they are attending an inappropriate program.

In order to successfully obtain services for their children, parents must be aware of their rights and the process associated with disagreeing with school system decisions. “Must” seems a bit overstated. Simply sliding the procedural safeguards across the table is usually? not enough for communicating rights and services to parents. The information needs to be communicated in a language and medium that all parents can understand. School systems need to make a better effort of communicating special education information in language that parents can understand. Though they do have information available, it needs to be marketed better and more easily accessible for parents.

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The federal legislation that supports special education encourages collaboration between school and parent. Though parents do not share the expertise in special education, it is the school’s responsibility to help them participate in meetings and make informed decisions. When the schools do not explain what is being discussed and try to force a decision on the parent, they are acting in a contrary manner to the spirit of the federal legislation. If this does not improve then parents will continue to be frustrated and angry with the special education process and students with disabilities will continue to be underserved. If children with disabilities are underserved then they face a strong potential of not seeking postsecondary education and being underemployed. Collaborating with parents will help the child reach their full potential. However, it is challenging for the parents to collaborate if they do not understand what the school staff are saying.

From a policy perspective, schools need to adapt their communication style that the parents are able to understand. The procedural safeguards need to be written in language that is easy to read and understand. School staff need to work with parents and make sure they understand the decisions that are being made and what they mean for their child.

Limitations

The first limitation to this project is my own bias and preconception of how parents learn about the special education process. I approached the project through my own lens based on my personal, professional, and consultative experiences. Very early in the interview process, I found myself trying to bend the questions to match the framework. In some cases, I posed leading or closed questions that would fit within my understanding of the phenomenon. However, I recognized I was doing this and adapted my interview style to be open and listen to parents 'experiences in working with the schools. The limitation created by this is that some parents may have been lead to respond in a manner that supports my own beliefs. However, I believe I was able to modify my interviewing style early enough in data collection to focus on what the parents were saying independent of my own beliefs. And for some of your conclusions what the parents said contradicted your prior belief.

The second limitation is that the data from this project could support an alternative conclusion that is consistent with the initial conceptual framework. The alternative conclusion is that schools intentionally withhold information from the parents in an attempt to impose decisions and limit options. The school decides which program or service is most approapariate for the child and forces that decision on the parent. The data supports the belief that the schools will determine the appropriate program or services for a child regardless of the parent's opinion. In some of the cases in this project the services were appropriate and the parent did not have any issues with the school decisions. However, in other cases, the parents believed the school tried to bully or strong-arm them into different programs. Ron expresses this in talking about negotiating placement options:

> What's out there on the books the law is that the schools have too much power to barter or to oversee that exchange and that negotiation (Ron).

Mary expresses a similar belief about how the school system does not share information and a concern that parents will accept the school system's decision as final.

> I don't feel that parents are educated beyond the legalese that's in those documents and not about what it is that the school system can do for your child and I'm worried that people will hear know no? from the school system and take it at face value (Mary). You could have used this quote to support your second theme.

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Both Leslie and Tina also expressed that program options were not presented. However, they were both pleased with the level of services they were receiving. Nonetheless, Leslie reported feeling intimidated at meetings due to the special education language and number of educational professionals in attendance versus only her and her husband to speak on behalf of their child.

Though this alternative interpretation is consistent with part of the initial conceptual framework, all of the parents reported both receiving the procedural safeguards and not reading them. Regardless of whether the information within the procedural safeguards would have been helpful to them, they did not know the information that was contained in the document and therefore did not know if the document was beneficial. The schools actively distributed this information and none of the parents used it as a tool. The second argument to schools intentionally withholding information is that the majority of the parents expressed familiarity with school sponsored special education websites, resource libraries, workshops, and activities, designed to help educate families about special education. Though these resources were not well advertised, their presence demonstrates that the school system does make efforts to provide useful information which is contrary to the belief that they intentionally withhold information. Nonetheless, in some cases the data indicated strong belief by parents that decisions were being forced upon them and they did not have the proper information to debate them.

The generalizability of this project is limited due to the small sample size. ☺ Since the sample size was the parents of four students, it is challenging to make inferences that would apply to all children with disabilities. All of the children were from different jurisdictions resulting in different experiences based on individual jurisdiction policy. However, based on ~~the researchers~~ my prior experiences in observing the behavior of multiple school systems in connection with the data and findings from this project, it can likely be generalized that there is a problem with how the school system communicates information to parents regarding special education services.

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Reflection

This project taught me a great deal about the qualitative process. The most important thing I learned was the importance of analyzing the data as you go and recognizing that my conceptual framework was incorrect. Coming at this problem as a practitioner, I assumed that parents would be focused solely on their rights and the services they could receive. However, as I conducted the interviews, I could not get them to match that information. I found this to be very frustrating and as a result, I started trying to lead the parents in the interviews. By going back to the data I had obtained and beginning the analysis, I realized the reason the data would not fit my framework was because my framework was not accurate. I did not share the experiences of these parents and therefore did not view the issue through the same lens. Once I was able to focus on what the parents were saying, I was willing to let go of the original framework and recognize what the parents were actually saying. I was able to adjust interviews after that and they went much better regarding gathering information.

The second thing I learned from this experience is to stay focused on the original purpose of the study. Though the research questions may change the original purpose of doing the study does not. Initially, I was bogged down in the data and had a difficult time separating what was relevant to the study from what was irrelevant. I walked around for several days distracted by my thoughts of how I was going to make all of the information fit together. I was able to solve this problem by going back to the idea memo and research identity memo to refocus myself. Once I reread those, I was able to tune out the extra data and stay focused on the purpose of the study. However, tuning out the other data was difficult as there was a lot of good information provided by the participants.

The third thing I learned was how to develop relationships with participants. My original design had me collecting data primarily from friends. However, the vast majority of my data came from people I did not know. Engaging in this process helped me learn how to snowball sample and quickly establish rapport to gain meaningful information from people.

I have learned two different things about the topic I studied. The first was that parents will focus on the needs of their child when they recognize there is a disability before they are concerned with special education processes. This is mostly due to a trust in the school system to do the right thing for their child. In some cases, the school system does the right thing while in others, it does not. The second thing I learned was the relevance of this topic in the special education community. Though my own perception was incorrect, I was able to discover a problem with the system. Even the parents who had overall positive experiences had some negative attributes to report. Parents with positive experiences also recognized themselves as lucky and realized there were other parents out there who struggled to understand the process and gain services for their children. The result of this is that children with disabilities become underserved and may not be able to reach their full potential. The policy implications for the results of this study are that policy needs to be modified to facilitate the communication of rights, services, and processes, to parents of children receiving special education services. I believe this topic requires further study and plan to revisit it in the future. Good reflections.

Our view, having gone through this with both our daughters, is that there's a major problem with the IEP process itself. The school's main concern is to determine *eligibility* for services; if the child is eligible, the focus then shifts to what services will be provided. There is very little attention paid to *diagnosis*. It's as if someone took a child to a doctor because he was falling down a lot, and the doctor focused on whether he was eligible for crutches or a wheelchair.

Dave:

This is a good report. Your descriptions of, and reflections on, your process are excellent. I felt that you data analysis would have benefited from more use of substantive categories, and I think that these could made your conclusions a bit more detailed and insightful.

References

Bird, B. (Director). (2004). *The Incredibles* [Motion Picture]. USA: Walt Disney Pictures.