Case Study

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**Abstract**

Both parents and students with disabilities have a vast number of hurdles to jump in life without adding additional mountains to the education process as well. This qualitative case study looks at the further roadblocks that one mom and her son has experienced during his educational journey, and it investigates the two key problems reported by her. Communication and standardized testing are identified as two significant concerns for parents with special needs children. Recommendations for both educators and parents are included and were created directly from statements provided during the interview.

**Introduction**

Over six million children in the United States can be classified in some way as having a disability, and yet these exceptionalities range so drastically one from the other that it becomes difficult for caretakers to connect with other parents due to a number of reasons including the vast differences in these disabilities (Kirk, Gallagher, Coleman, Anastasiow, 2012). Social connections are critical to improvements and growth in our educational system. Parents of children with disabilities in the U.S. may no longer have to fight for the right to an education, but they do still have to fight. The significant problems in education continue to persist and parents’ voices often go unheard. Parents have little opportunity to not only hear from those who have come before but also very rarely get the opportunity to share their own stories for others to reflect. If we learn through our social connections and interactions as Vygotsky theorized (Schunk, 2012), then parental connections are critical to improvements in education as well. Having a child with a disability can completely change your life, and parents need a voice to turn to, someone who understands. The journey for parents can become such a dark and daunting task for even the most educated, but this voyage could be made easier with the social connections, experiences and voices of those who have become proficient experts already. While teachers are the educational experts, parents are the authorities on their individual child. While teachers, administrators and therapists change from year to year, parents are the only member of the Individualized Education Plan (IEP) team who continue to attend year after year and therefore their role in the child’s education cannot be duplicated by any other. It is critical that we not only listen to what they have to say but further explore and use the knowledge that they have to improve the often broken system that we currently have.

This study is built around one parent, Anne Sullivan (name changed for confidentiality), who has fumbled through the education system, grasped for helped, cried with the best of them, and been witness to some of the most cherished occasions in her life. She shares both the good and the bad in hopes that she too might make a difference for not only her son, but for both parents and educators alike. She hopes to help others understand the experiences of parents of students with disabilities. Her work as an advocate not only for her son but as a supporter and friend for many other parents often goes unnoticed, but the researcher, her son’s elementary teacher long ago, has not forgotten her compassion and ever presence in education. Her observations and messages bring a different perspective to educators that could lead to great improvements with the disconnections so often found within the system. As educators, we often forget the “other” educators in our students’ lives. Hopefully Anne’s insights will provide the spectacles needed for all to see.

**Conceptual** **Framework**

The rising recognition of case studies over the last thirty years has grown significantly and created a prominent place in the research process for this exploratory and probing method (Yin, 2013). Case studies share an important voice because “the story of any one of us is in some measure the story of us all” (Beuchner, 1991, p. 6). We are all capable of finding pieces of ourselves and actively living through each story so gracefully written upon the pages. This research puts critical emphasis in the interpretation by the researcher of the participants’ experiences. In order to provide the reader with an in-depth understanding of the participant, the researcher collected a multitude of varying forms of qualitative data (e. g. interviews with both parent and child, observations, and medical and educational documentation). Once the data was collected, in-depth analysis of the data was completed in order to make connections and determine the underlying themes. After analysis, a clear description of all of the findings and any connections made to the research was provided. Finally, from these findings, a set of conclusions are given in order to provide additional meaning to the case (Creswell, 2013). According to Yin (2013), it is critical that the case study researcher use a rigorous methodological approach which includes a thorough literature review, thought provoking research questions and objectives, as well as formal and explicit procedures which protect against threats to validity, maintain a series of evidence, and investigate rival explanations. This case study approach can provide a balance to other quantitative research, and therefore the strengths and limitations of both the qualitative research being written as well as the quantitative research encompassed within in order to effectively build upon it have been included(Yin, 2013). This case study is the mortar between the bricks; it has little use separately, but when mixed together with other research can build a reliable foundation.

**Theoretical Framework**

**Disability Theory**

Disability Theory and all qualitative theories are derived the same way, from human construction with the purpose of telling a person’s story (Denzin & Lincoln, 2011). The problem is that the term “disability” was born from the medical model which, while it provides us with much needed information about specific disabilities, also creates an oppressive, social barrier that many fight daily to overcome (Danford, 2008). The social construct of disabilities itself has created the exact “knowledge” used to define disabilities, and thereby provided us with an unclear definition of these disabilities (Cosier, 2012). The disability theory of today pushes to break this “defective” look at disability and instead reflect on the social construction of these individuals (Creswell, 2013).

Susan Jones (1996, p. 347) writes “Is being handicapped the most salient feature about me?” She reflects in the article how it feels to be “framed primarily by ‘the eyes of others’” (Jones, 1996, p. 347). What is believed to be true about students with disabilities comes directly from the assumptions of those who are not disabled therefore negating the uniqueness that each child brings to the world (Jones, 1996). If these children are thought to be inept and are not given a chance to do what others can do then we have greatly diminished their opportunities to grow. In order to connect and shine, one must create the “self” through social interchanges with others (Dudley-Marling, 2004) and the first voice and closest person to these children are the parents. Parents from a child’s birth become educators, not just to the child, but to those they encounter along this lifelong journey. Humans are constantly growing and changing, and these adjustments are made through the relationships we have with other people including both parents and teachers.

The relationship between teacher and parents is critical to the growth of a student since the parent is the first and most important teacher in a child’s life. Such important knowledge is gained and implemented by the teachers that follow. If the teachers and parents collaborate together, the growth of a child can continue indefinitely. Temple Grandin, a famous scientist who has Autism articulated it most clearly, “I cannot emphasize enough the importance of a good teacher” (Grandin, 1996). Educators are the key to unlocking the door for all students. Educators must observe the “modifiability” of the individual because students continue to grow and change throughout their lifetime and the social constructs of that growth depends on the people surrounding them (Danford, 2008). Students are clearly formed and structured through the social construction of both the school and home setting and therefore both are essential parts of a child’s development.

**Social Constructivism**

Parents of students with disabilities are not automatically provided with a blue print of *How to Best Advocate for your Child with Disabilities* book and yet, they often come to the educational table knowing a vast amount of information. They have not only spent numerous hours researching knowledge about their child, but they have also spent crucial time learning directly from the source, their child. They have built “personal interpretations of the world (their world) based on (their) individual experiences and interactions” with their child (Ertmer & Newby, 1993, p. 63). The knowledge that they gain through these personal experiences are greatly beneficial to all of the educators who will work with these children throughout their educational journey. The teachers’ educational expertise along with the parents’ immense knowledge both bring important information to the table that support the education of each child.

Social Interactions are an essential element of Vygotsky’s theory (Schunk, 2012), and these connections of learning can not only take place in the classroom, but the IEP room as well. Teachers, parents and most importantly, students benefit most when collaboration occurs. Discussion becomes crucial at the collaborative phase (Ertmer & Newby, 1993, p. 66). These discussions with all those involved in the child’s education can take place in many forms (narrative and oral) and provide opportunities for all to build new innumerable and insightful ideas (Ertmer & Newby, 1993). When collaboration occurs, all of those involved learn in and through a scaffolded constructivist approach.

According to Schunk, social constructivism places a critical role in the student’s “cultural-historical” background and its effects on the learner (2012). If we are to learn of the child’s cultural history, teachers need to listen to those who can provide the most insight into this history, the parents. Parental insight into such history is absolutely crucial in the multi-cultured United States of today. If learning takes place when there is a connection made from prior knowledge, the role of culture becomes even more critical (Ertmer & Newby, 1993). Teachers have been provided such an incredible resource when parents are involved, and such involvement is not only required, but one of the best gifts a parent can provide educators.

**Literature Review**

PL-94-142 in 1975, Individuals with Disabilities Act (IDEA), as well as the reauthorization of IDEA 2004 have all brought about significant changes to the educational process in the United States. “Strengthening the role and responsibility of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home”[(IDEA 2004, Finding of Congress, section 601(B)] is a critical component to the most recent law. This important piece to all three of these laws included the mandate for parental participation, but yet, since the laws were put into place, parental participatory roles have changed little (Simpson, 1996). Parents give us great insight into many important key elements to education, and it is with them that we can create a better education for all.

American education revolves around the social expectations of our society and these expectations are even more difficult to achieve for a child with exceptionalities (Kirk, Gallagher, Coleman, & Anastasiow, 2012). Using a constructivist approach, we can conclude that learners “build personal interpretations of the world based on individual experiences and interactions” with others (Ertmer & Newby, 1993, p.. 63). A child learns through authentic experiences with and through others, and these experiences are first created at home. The familial system is one of the most influential elements of a child’s life, and in order to be effective in the education of students with special needs, one must include this critical component not only in the IEP decisions being made, but in the actual educational experience as well (Kirk et al., 2012). The family connection should be looked upon as an important strength for the child with a disability and one in which the special educator should always turn to for further insight into the child’s education.

Previous research on parent involvement completed by Sheehey recognized an important component that resonated with each family and was echoed with Anne’s case study as well. The importance of special educational knowledge sharing by the special education teacher with the parents is critical in drawing parents in as an integral part of the system (2006). Parents have a strong desire to collaborate with the teachers. It is imperative that teachers recognize that the activities and involvements of parents and parent groups (e. g. National Association of Retarded Citizens, ARC; United Cerebral Palsy Association; and Association for Children with Learning Disabilities) were the first advocates for students with special needs and because of their original systemized activism; we have the educational system we have today (Kirk et al., 2012). These parents have worked diligently to be the voice for their children by creating changes to a system that continues to need repairs. If we just listen to each other and work together, we would see that both are searching for the same thing and together the changes we can make are tremendous.

One such movement for change that is currently occurring with parents across this nation is the endorsement of alternatives to standardized testing for students with disabilities. According to No Child Left Behind (NCLB), 2001, students with disabilities are required to take the same standardized tests that all other students take. Unfortunately, the students who fail these tests most often are students who are either poverty stricken, speak English as a second language, or have special learning needs (Nichols & Berliner, 2007). Students with disabilities who already struggle have even more pressure than ever to be “successful”, and their “success” is based solely on such tests.

The effects of increased testing have negatively impacted a number of students with disabilities including those with Autistic Spectrum Disorder (ASD) (Alt & Moreno, 2012. Students with disabilities are either dropping out of school at a significant rate (Allensworth, 2005) or according to Figlio and Getzler (1996) are being reclassified by the schools as disabled in order to exempt them from state standardized testing. Since up to one percent of student body can be labeled as significantly disabled and these students are not required to take standardized testing, the tendency is to have that number maxed out as much as possible. This adjustment is a trend made by schools in an effort to avoid being identified as a failing school (Figlio & Getzler, 1996). Standardized testing for students with disabilities has negatively impacted our school systems in many ways, but the damage has been felt most significantly by specific minority populations which include students with disabilities.

**Bracketing of the Researcher’s Perspective**

The researcher has taught for an elementary school in a large suburban school system in the south for seventeen years. These classes have included self-contained both moderately intellectually disabled (MoID) and mildly intellectually disabled (MiID), as well as pull-out interrelated resource classrooms. The ranges of student communication have varied greatly from each setting and a number of students from each setting lacked “effective” communication skills in order to relay information (orally or written) to parents. While parental communication has always been imperative within the researcher’s classroom, there have been several occasions in which important communication was missed due to the communicative practices within the classroom and these can always be improved upon.

When teaching MiID and MoID, the researcher consistently provided parents with a daily communication notebook which traveled to and from home, but this method has not been required for the resource classroom setting. Instead, if necessary, the school agenda is used to relay information back and forth to parents. In addition to this system, a teacher website is provided and updated daily with information regarding homework assignments and monthly activities. This website is directly connected to the school website and is a great resource for both parents and students. The researcher believes that it is absolutely imperative to keep an open line of communication with parents and from this collaborative communication great changes can be made.

The researcher had the opportunity to teach Thomas for three years (2nd-5th grade) in a MiID classroom and maintained a good relationship with his mom since she was the class’s room mom for all four years as well as the PTA sponsor for all of the special needs at our school. While Thomas was in the classroom, he read approximately 2 grade levels below his reading level and was behind in math as well. During his upper elementary years, his limited social skills began to improve and develop. By the end of his fifth grade year, he was initiating greetings with familiar peer and staff throughout the school. His seizures were observed on multiple occasions in school and directly impacted his educational experience.

**Methodology**

The purpose of the study was to understand communication and testing concerns of one parent in a suburban public school system. At this stage of the research, the communication concerns are generally defined as the triangulated communication between parents, student and teachers. Testing concerns are identified as the parental concerns of required standardized testing on students with special needs.

**Participants**

Participants to this case study included both mom of a student with disabilities, Anne, and her son, Thomas. While working as a room mom in Thomas’s elementary classroom, the researcher had the opportunity to get to know Anne. She was chosen for this study because of her strong support and advocacy for both parents and students with disabilities. Anne is self-described as both a “full-time mom” to two children and a wife. She does not work outside the home and instead spends much of her time advocating and caring for her son as well as providing support to other parents “in similar situations”. She has hosted, supported and currently attends support groups, created and regularly updates an online website for special needs, coordinates special needs classes at church, creates and maintains an incredible website for specific disabilities, and has created a special needs listserv that benefits many in the community. Her website has a plethora of information that is beneficial not only to parents, but medical staff and educators as well.

Thomas on the other hand is described by his mom as an actively engaged teenager who makes automatic decisions just like a “typical” teenager but has the mind of a 6-8 year old. According to psychological testing, his current full-scale IQ is 44 which has significantly decreased since elementary school. He was born 15 years ago and presented as a normal child at birth. It was not until age two that he was diagnosed with Cerebral Palsy (CP). Shortly after this diagnosis at age four, he began exhibiting seizures and then was diagnosed with Pachygyria. He began his public school educational journey in a general education setting with paraprofessional support. During first grade, he moved to a self-contained Significantly Developmental Delayed (SDD) classroom and later in second grade was moved to a self-contained MiID classroom. During seventh grade, the IEP decided to move Thomas to a MoID classroom and that is where he is currently being served today. He enjoys Special Olympics track and basketball, Topsoccer, and aqua therapy. His favorite things are trains, construction vehicles, garbage trucks, playing in the sand, running, exploring, traveling, making puzzles, playing video games and watching YouTube and movies.

**Data Collection**

An interview using an audio recorder for interview data was completed with both the parent and student, and was triangulated with the historical medical and educational records provided by the parent. The questions used for the interview are provided below. The parent interview, completed at the county library, took approximately 2 hours. The participant was given the opportunity to review the written transcript and verify or clarify the statements made during the interview. These notes were added in written form after participant read original transcripts in order to determine any inaccuracies and clarify any confusing statements of recorded and transcribed data. The interview of the student took approximately 30 minutes and was completed at the student’s home after school. Data from the transcripts was read multiple times in order to code and analyze for triangulated themes. The themes identified in this research included a) communication problems, b) and testing concerns. Categorization of the underlying themes were organized and then presented with conclusions which were discovered from the themes.

**Limitations**

A case study is a type of qualitative research design that produces a product directly from inquiry from a real life situation. While this method provides much credible data, there are still multiple limitations to this data. These include the narrow scope of the research since only one student and parent were studied which limits the generalization of this research. Most qualitative research is also restricted to the subjectivity and assertions of the researchers interpretations. While these misinterpretations might still occur, I provided the participant a final opportunity to review over the finished case study to clarify any misunderstandings, misrepresentations, or confusions noted. When completing an interview with a student with intellectual disabilities, you are limited also by his ability to understand your questions as well as his ability to answer your questions completely. While I completed an interview of both parent and child, and an observation of Thomas at home, I was unable to complete a current observation at school and therefore did not get to see him in the educational setting to which the research focusses.

**Interview Questions**

**List of Parent Interview Questions:**

Describe Thomas.

How does he exhibit or what does he present like?

Can you describe the moment or moments when you realized that Thomas was different?

Describe the things about Thomas that you love. Describe the things that have been the most challenging.

As a parent, how did that define you and who you were?

What kind of seizures does Thomas have? What does a typical seizure look like?

And are they typically just at night? Is he tired?

What kind of things does is he doing at school?

Is he swimming?

As a parent of a child with a disability how did you and how do you define you?

Were your plans to go back to work?

What kind of comparisons did you make with other children?

Tell me about your first experience with special education in the school system?

And then how did that go when you moved here?

I know from our experience, tell me about your first experience with Elementary School

If you had to do it again, would you pursue an advocate?

So did the focus of academics changed from the MiID and MoID class?

From that beginning middle school, in the first class to the second class he had. Did you see a difference in him emotionally as how he presented himself or was he the same no matter what class he was in?

And middle to high school transition.

Ok, what kind of curriculum are they doing now?

How many teachers and parapros?

Tell me some of the problems you experienced in elementary school, middle school, and high school?

What was or are your outlets and how did you deal with the ups and downs that you encountered?

Do you feel like that has just become you?

As a strong advocate for your child, what are some of your greatest moments that have made a difference for Thomas?

If you had to do it all again, what are a few of things you would have done differently?

Tell me about a specific time in Thomas’s education that you really felt he was making progress.

What do you consider a success for Thomas? Failure?

What are your greatest fears?

Tell me about your first IEP meeting, and now-a typical IEP meeting?

What would you suggest other parents do to be prepared for the meetings?

When you first started out in the school system, what did you want for Thomas?

How has that changed over the years?

How do you feel about inclusion practices in special education and why?

How have your views changed or adjusted and why?

What do you feel is the most important focus for teachers to consider when teaching a child like Thomas?

The push for all students to participate in academic standardized testing is strong, does Thomas participate in standardized testing?

What are your thoughts and feelings about standardized testing for students like Thomas?

Curriculum pushes have also drastically changed throughout Thomas’s education with a push for all students to participate in the general education curriculum, how do you feel about this push as compared to a more functional curriculum?

What are your thoughts and experiences with community based instruction?

How could teachers make education a better experience for Thomas and for you as a parent?

What could schools do differently?

What have your teachers done well?

What have the schools done well?

What do you feel is the school systems biggest challenge?

What is the teacher’s biggest challenge?

What is a parent’s biggest challenge?

**Student Interview Questions:** (these include additional questions from original list since the interviewer changed and adjusted according to the interviewee’s responses)

I am going to ask you some things about school ok?

Tell me about yourself, what is your name?

What do you like to do? What else, what else do you like to do?

What state is your favorite state?

So what state is that?

Where do you think I live?

Do you remember what grade I taught you?

Can you tell me what school you go to now?

What grade are you in in high school?

What do you like about your friend?

And do you like to play that with him?

So how long have you known your friend?

How long have you been friends, do you know? A year?

Do you have any other friends?

He likes to go to the train shops with you?

Does he really go to the train shop with you Thomas?

I see you grinning, are you telling me a story?

What else do you like to do beside puzzles?

Why do you like them?

So who is your teacher in high school?

What do you like about them? (rephrased) And why do you like them?

What is your favorite class at school?

And what do you like about lunch?

Do you eat hotdogs at school?

Your mom told me that you are doing Special Olympics, is that true?

So do you think the shoes make you fast?

What do you like to do better, basketball or run track?

Are you going to show me how to play *Blokus*?

So, I understand you do some jobs at school, what is your favorite job?

Yeah, that is not a job at school. That I know

Mom interjected with a question: Thomas do you do the board?

What do you do with the board?

Do you like to draw?

What do you like to draw pictures of?

So do you go on community skills?

And where do you go?

Is that your favorite place to go?

You don’t play with the toys when you go to Wal-Mart do you?

Do you get to play with the toys when you go to Wal-Mart?

What do you do when you go to Wal-Mart? Do you work?

Mom interjected another question: What did you buy today?

Honeymaid what?

Did you buy anything else?

Did you buy some peanut butter to go on them?

Did you buy peanut butter today?

You bought beans?

They are called baked beans.

Do you like baked beans?

Do you like hotdogs with ranch and mustard?

How old are you, Thomas? You said you were in second grade, so you must be seven, right? So, how old are you?

Do you get to read Captain Underpants?

**Coding**

The interviews were transcribed and then read numerous times. After reading, the data was coded first by the researcher and then later by an additional special education teacher to provide consistency to coding. The coding was completed in order to determine underlying themes which included the following concerns: a) educational communication deficits b) and standardized testing concerns. Conclusions were made from responses and were verified by participant in order to ensure accuracy of conclusions. All recordings were completed using audio recorder to provide additional reliability to data (Creswell, 2013).

**Results**

Two consistent themes were identified from the parent interview data which were supported by the student interview as well as additional medical and educational paperwork provided by the parent. These two themes can be simplified *as communication problems* with school system and standardized *testing frustrations*.

**Communication problems**

The first problem noted throughout the interview was the necessity for additional communication from the school. Due to Thomas’s expressive and receptive communication deficit noted in both his medical and educational history, Anne struggles to get accurate information from Thomas on a daily basis. These communication deficits, very common in students with disabilities, directly impact his ability to communicate information from teachers and parents alike and were noted consistently throughout the interview. Thomas has impaired verbal output and even though the researcher is familiar with him, it is at times, difficult to understand what he is saying.

During the interview the interviewer had to repeat or reword 22 questions because Thomas did not respond, seven statements were repeated by the student either to help clarify or because of perseveration (this was not clear), and twelve times he responded with an off topic answer. His answers were most commonly one word responses with little elaboration. According to the psychological and speech reports from as far back as preschool, Thomas has displayed speech delays which directly impact his ability to communicate. In addition, his overall psychological assessment places him in the intellectually disabled range cognitively which also impacts his communication deficits. Reports from behavior specialist as early as 2005 report that during observations Thomas did not initiate verbal interactions with peers or teachers, but did respond to interactions initiated by others. This is consistent to what the researcher observed both during the years teaching him as well as during the recent interview. All of this information support mom’s statement that “he doesn’t have a lot of two way communication skills.”

Anne stated her frustration with communication to and from school when she states that “My child is not able to come home and tell me about his day so the teacher has to be his voice and communicate with me every day.” Ann reports that the teachers who have been most effective have been “those that actually communicate with me.” She reports several incidences in which events happened at school and she was never made aware of the events. When a student has limited communication, a parent’s only insight into the day comes directly from the teachers and without this communication, the parent is at a loss. Anne states that “keeping the communication open all year…is important.” If effective communication is not provided, a parent struggles with school to home carryover and much at-home support is lost. When the communication has been lost, Anne has “learned to advocate for Thomas’s needs along the way and be a voice for him.” For the most part, Anne reports great teachers throughout Thomas’s education, but also reports that there have been a few trying times as well. On several occasions she has required additional support from an advocate in IEP meetings. She stated that “if you don’t speak up, they (teachers) won’t speak up for you.”

Parents often have to find ways to be their child’s voice. One way to successfully do this is to communicate with other parents. Anne highly encourages other parents to communicate with those in similar situations. Lack of communication can be overwhelming for a parent. When Anne received the diagnosis for her son, the doctor didn’t say much else. So “you go home and look it up and lose all hope with your child being told they will die by age twenty.” There was limited information provided to parents when she received the diagnosis, but “now a parent can find my site and know they have a chance at a full life.” Her website and LISTSERVE came directly from the need to communicate with other parents so that they would not experience the same feelings that she has experienced. She states “Sometimes I think I should stop sending them out and then a thank you arrives in my email…so I continue sending whatever I can find out to the parents.” She likes to “connect people with other people and can help them and encourage them” and she does a great job with making these connections.

Anne also continues to be buoyed herself by various support groups. These organizations have provided her with “somebody to talk to…anybody who has been through special education.” She states that it is important “to stay connected to the group, not just one person, because everybody has different experiences and ideas to gather information from.” Throughout her parenting practice, she has used multiple avenues to connect with others including Parent to Parent and FOCUS, but in hindsight, she wishes during the moments of tears she had “reached out more and asked because those people are there, and they are helping. They have been down the road before.”

Communication with both teachers and other parents is critical for parents of children with special needs. In order to make education better, Anne states that teachers could “listen to our needs and communicate with us on a timely/daily basis…we want to know what is going on.” When “both parties can work together to make the most out of the goals,” a child can be educated to the fullest potential.

**Testing Frustrations**

The other significant research data reported was her concerns for mandatory, state-wide, standardized testing. She states that “when I have a passion, that’s when I write.” And she did write. She has refused for her son to complete testing since his fifth grade year, but this was not an easy task to overcome. It took multiple letters and phone calls to officials and the board of education alike. She was eventually given the ok to withhold testing through an educational loophole, but most students with disabilities continue to test. Now she is only required to write a letter each year so he doesn’t have to take it.

There are multiple reasons why parents have concerns about standardized testing for students with special needs. First, according to Anne, “they are a waste of time because Thomas is not a standard person. Even the compand that writes the tests stated that the test should not be given to the special needs population as it was not written for them.” Much time is spent teaching students to learn unimportant tasks like bubbling. To Anne, this is a waste of good educational time. “It does not make sense to teach how to bubble in a bubble and spend three hours reading to them for them to answer. It is like a guess answer.” Anne feels that testing shouldn’t replace the more important daily educational activities he needs to do because “whatever he does, he has to do it every day” in order to master the skills. These tests which most often come back as “failure” does little but stress not only the parents and teachers, but most importantly the students. “Taking these tests take away from being educated.”

Anne discussed the widening of the gap that occurs to a child with a disability. This widening does not occur because the child is not being taught, rather the intellectual disability impedes the child from learning at the same rate as typical peers, and therefore the gap expands. “Expecting my child to be at the same level as other fourth graders is a stretch. The teachers modify things the best they can, but some things just aren’t feasible. This is a recipe for failure.” She notes that while he may be recorded as a failure, “he has learned and is still learning so much…this is what he should be tested for.” “If my child cannot even recite his address or phone number, who cares whether or not he can find the Pacific Ocean on a map?” Ever since preschool, “I am constantly reminded how different Thomas is to the other children.” The assessments are already “constant,” and this comparison from one student to another does nothing but leave parents worrying and stressed. “I try not to do it (compare), but every once in a while milestones happen and I think at 15 years old, he should be getting his driver’s license at 16.”

Pointing out the obvious is not the most effective educational tool around and does little for parents. They see it right in front of them. Anne has always been a parent who pushes her son and works to have him reach his potential in all educational aspects, but she recognizes that “in special education, each child is an individual; each child learns differently.” Because of these differences, she feels that educational standardized testing should be reconsidered.

**Tips for Parents**

Since Anne is such an incredible advocate for her son and has had multiple opportunities communicating with other parents as well, it was easy to create a list of parental tips that may be helpful to parents who are new to the educational IEP process or just need some ideas or supports. These parental tips were gathered from the interview and are included below:

1. Make a good, first and continuous impression with the school and teachers with a positive, constructive parent attitude. When expressing concerns, do so in a constructive, solution-based manner. You will be heard and respected with the right attitude.
2. Go to as many IEP “how to” meetings and educational meetings that school systems or other support systems provide. You learn a lot from others who have already experienced it. At these meetings you learn the special needs language, become confident and prepared for discussions about your child. A really good source is [wrightslaw.com](http://www.wrightslaw.com) or parenttoparentofga.org.
3. Know your rights and requirements from your school system before the IEP school meeting. Remember that requests like bringing an advocate or tape recording may require a 10 day prior written notice. Don’t forget to take notes, jot down ideas and questions during the meeting.
4. Ask to have the IEP recorded since you often miss valuable information when you are in the meeting. Everything said is not always written down. This gives you time to process what you have heard and review at a more relaxed time. While this may be interpreted by the school in a negative manner, just reassure them of your reasons for recording.
5. Always take someone with you to the IEP meeting, especially at the beginning. This person needs to be someone who will focus on what is best for the child. An IEP meeting can be like hearing for the first time that you are terminal, once you hear these words; everything else that follows is missed. Bringing another person allows you a second set of ears and provides you with someone to share and discuss issues. The school system will need to be notified of your additional guest if the guest is not a parent.
6. When preparing for the IEP meeting, make a list of questions and don’t be afraid to ask the questions. As always, there are never any dumb questions. Communicate regularly with teachers and stay involved. Let them know that you are a wealth of knowledge by providing all of the previous medical knowledge, prior paperwork, and any additional information you may have to share. Your willingness to share creates openness for all to share.
7. You set the tone of the meeting. Attend with a positive, constructive attitude even if there are challenges. Go in with the attitude of finding a solution and working together for a successful outcome. Some say to visualize in advance a good discussion. If the meeting will be long or stressful bring in a dessert, snacks and/or drinks for everyone. It sets the tone that you appreciate them and that you are working as a team and the team will appreciate you.
8. Collaborate as an active team member. Be prepared. Bring your knowledge, background information and paperwork to the meeting so that you can be an active member of the team. Teachers appreciate your support and knowledge and should build upon it. The better the team works together, the more effective the end product will be for your child.
9. For new introductions at the meeting, you can start the meeting by telling something positive about your child and sharing a picture of him/her outside of school. This can help the team to see your child as a "person" and not another IEP. It can also help the team become familiar with the student from a different perspective other than the school setting.
10. If during the meeting you need to take a break, by all means, do so. Even if the break has nothing to do with the bathroom, you can always take a break just to process the information you have heard.
11. Make sure the IEP contains all the discussed information that needs to be implemented or used for the next year. It is very beneficial to have the IEP projected on the wall for the entire team to continuously view the document as it is being created and saved. It is ok to speak up and have the necessary changes made as you progress through each page. Review the document before signing and do not feel rushed to sign. You can ask to sign it on a later day if you need more time to review it and agree to the IEP. A copy of the draft can be given to you to take home. Once it is signed and finalized, keep all your educational records in a secured location and do not write on originals.

**Tips for Teachers**

A list of ideas for teachers was also derived from the interview and includes the following suggestions:

1. Focus on health needs and concerns first so that students are at their best in order to learn and perform.
2. Understand that students are much more than what they appear on the outside. Search for what is inside and the student’s revelation may surprise you.
3. Provide multiple opportunities and ways to accomplish tasks. Persistence to complete and accomplish goals is critical for success.
4. Never give up on the child. The child wants to be successful more than anyone involved.
5. Be willing to try multiple different teaching methods to reach the student. You never know which one will be a success for that student.
6. Include parents as much as possible in not only the decision making process, but the actual implementation of the educational process as well. Parental involvement helps the carryover of skills so that students can generalizing skills to the home environment.
7. Allow parents to help as much as possible in the classroom. This not only benefits the child, but it provides additional support within the classroom too.
8. Always remember to provide communication daily with parents. Many of our students have limited communication, and that often leaves parents uninformed. Don’t leave your parents questioning what is happening in the classroom. Instead, ensure they always know what is happening which builds trust and security.
9. Recognize parents are a part of the educational team. Working together will provide the best education for the child.
10. Use the parental expertise about the child to its fullest extent. The parent is the expert on the child. Use this knowledge to your advantage.

**Conclusion and Implications**

In order for educators to make the most of a student’s education, it is imperative that we listen to what parents are telling us. Anne echoes repeatedly an increase need for communication with teachers. Vygotsky’s constructivist approach focusses on an important application for teachers and that is peer collaboration. When peers work together collaboratively, these shared interactions work as a tool to effectively attain competence with the goals set forth (Schunk, 2013). Teachers and Parents can and should take the time to learn from each other to better educate the student they are trying to teach, and effective communication is the key to success for our students.

That same social constructivist approach presented by Vygotsky is extremely helpful when teaching students with disabilities. Educators have been using Vygotsky’s methods for many years and this approach while quite effective has become expendable for a more “modern day” approach-behaviorism. The methods in which we use standardized testing does little more than push students to provide the output school systems “think” they need. This current method of measurement does not truly measure what a student with special needs has actually learned. These tests continue to exclude students from education in so many ways and students with special needs is one of its prime targets (Nichols & Berliner, 2007). NCLB unfortunately has left many students behind. Students with special needs have a difficult educational journey ahead of them and “when high-stakes testing is the mechanism chosen to bring about school change, unintended and mostly negative effects for those groups of students still exist” (Nichols & Berliner, 2007). It is these students who end up suffering the most.

**Terms**

Pachygyria (PGY) is a rare developmental disorder resulting from the abnormal migration of neurons in the developing brain and nervous system. Pachygyria is not a specific malformation (like lissencephaly) but rather is used to generally describe physical characteristics of the brain. With pachygyria, the gyri are relatively few and usually broad and flat. In most cases, people with pachygyria have moderate to severe developmental and intellectual delays and epilepsy.  Poor muscle tone (hypotonia), poor muscle control, feeding/swallowing difficulties, and small head size (microcephaly) are also frequently associated with this condition. Retrieved from http://cortfoundation.org/cms/pachygyria/

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