

2015

# Giving a Voice to the Parent/ Guardians/Caregivers of Students with Special Needs: Advocacy for Services

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Giving a Voice to the Parent/Guardians/Caregivers of Students with Special Needs:

Advocacy for Services

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Submitted in Partial Fulfillment of the Requirements for the Degree

Master of Science in Education

School of Education and Counseling Psychology

Dominican University of California

San Rafael, CA

May 2015

Signature Sheet

This thesis, written under the direction of the candidate's thesis advisor and approved by the Chair of the Master's program, has been presented to and accepted by the Faculty of Education in partial fulfillment of the requirements for the degree of Master of Science. The content and research methodologies presented in this work represent the work of the candidate alone.

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## Acknowledgments

The emphasis of this study has been very close to my heart as I move throughout the education system. What I have accomplished during this process would not have been successful without the loving support, and wisdom I have received throughout this journey.

I would like to acknowledge all of the contributions I have received from Madalienne Peters, my mentor throughout this entire process. The idea of writing a critical analysis of a study derived from my own design seemed daunting and impossible, until I began interacting with special education personnel. With their above and beyond assistance, I was able to make this goal a reality. I began this personal endeavor during my first year of teaching. For those of you who are in the education system, within your first year of establishing your own classroom you experience a plethora of challenges. Without the constant stream of encouragement and acknowledgement of both the good and the bad I received from friends and family, this thesis would not have developed beyond a mere idea.

Furthermore, I would not have been provided the opportunity to improve my mind, or teaching philosophy without the financial funds and everlasting love from my family. I appreciate and respect all of the prospects my family has provided me over the years, and hope that one day I can repay each and every one of them for the support you have shown me.

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## Abstract

Parents/Guardians/Caregivers of students with special needs are often at a loss as how to help their child be successful within the public school system. Communication is the key towards developing any form of path to success; however, the PGC of students with special needs are often limited, or at a loss as how to communicate these demands to the teachers and/or the district administration.

The purpose of this study is to enlighten the guardians of the numerous services that are available either at a school or district level within a suburban K-12 education system. Each district varies with the services they provide the guardians and students as a result of their funding limitations. According to scholarly research, despite the lack of federal funds, there are still a plethora of services PGC that can assist PGC's advocacy level, in order to help their child be successful. There are selections of these services that are directly designed to help adults better understand the special education system and the vernacular associated with each service.

Parents/guardians and caregivers, regardless of a student's learning ability, should be aware of the services and options available if it is in the child's best interest within the public education system. Therefore, with the data compiled through this study, the researcher hopes to install a better form of communication between the home and school.



## Chapter 1 Introduction

I sit in a hard, plastic chair observing from afar the interaction that happens within each elementary school classroom. There are the students who embody the leadership role and step up to the plate to guide their group towards their ideal goal, those who just nod their head hoping that their peers would not notice that they really are unclear as to what is expected from them. Additionally, there are a few students who have already given up. It is the last group of students, the individuals who have given up that cause a teacher to lay awake at night. Each student has a role to play within the classroom. Where my story really begins, is with a young boy who among all the chaos caught my attention.

He was not loud and flamboyant, nor was he disinterested and aloof. He appeared to be lost. He sat quietly in his chair as if he were beyond the bustling world around him. There he sat, hood pulled up around his head, and staring into a world beyond what anyone around him could see. The group in which he was paired with seemed to move along without him in a manner that declared no time for the students with no motivation to direct their input into the discussion at hand. Yet, he still sat there perfectly entranced in his own understanding, not bothered by the fact he was not being included among his peers.

I could not look away. How come no one had noticed this young boy? Who was supposed to help him integrate into the group? Does this happen a lot? These were some of the questions that ran through my mind. Screaming in my head for someone to notice, I began to feel the need to make it my duty to find out more about this young boy. I had talked to some educators about the spellbound boy I had observed and inquired as to what they knew about him.

Almost everyone was able to recall right away as to which child I was referring to for he is memorable in his mannerisms and aura. They all had many opinions about the child and how he was progressing throughout his schooling, but it seemed to stop there. No one was willing to raise their voice and actually go beyond making the assumption that he was just one of those kids who was destined to fall through the cracks. This was not sitting well with me. This boy needed someone to step up and help, but who should that responsibility fall to?

Soon, not being able to take sitting by any longer, I introduced myself to him. He was shy and reluctant to talk to me at first. Hiding behind the comfort of his jacket and thrusting his hands deep in his pockets, he would stare fixated at a spot on his desk. Sensing that he would have to open up on his own terms, I began to plant the seed of a comrade and walked away.

Walking away was the hardest part. I felt as if I too was giving him the impression that I did not understand him and was giving up my efforts in correcting that assumption. Now that I have begun to teach a class of my own, I understand how easy it is to walk away from a child like this boy. As educators we rationalize our reasoning by the fact that we have so many other bodies, other minds to fill and engage within the classroom. It is impossible to reach everyone. Yet, when does the rational turn from an excuse into a habit? I could not let myself fall into this habit and have the boy suffer the consequences. So, I began to undertake the challenge of trying various methods to reach out to him and help him in any possible manner. He would be going into the fourth grade the following year and yet, there was still a couple grade level gap within his education. The end of the year was fast approaching. Would he be able to come back from the summer ready to complete work at the same level as his peers? His mom sharing the same fear as myself, sought out my help. This past summer, we began our journey.

We worked together for two days a week. We seemed to slowly progress with each week. His math facts were getting stronger as we bounced a ball back and forth between us. He was trying his best to read different types of text, and various styles of writing. Yet, summer was quickly ending and I could tell that he was getting nervous. Despite our progress throughout the summer, he still was not performing at grade level and I feared he would fall back into a pattern of retreating into his own world. There were moments during our sessions where he would just scream randomly as loud as he could, or pound his hand on the table. If I had experienced these outbursts the first time I met him, I would have been alarmed. However, now that I had spent many months working with him and getting to know his personality better, I could tell this was just his way of expressing his anxiety. I was able to look past this behavior because I was used to it, and I understood that if he behaved as such within a general education classroom he would be sent to the office. He was a boy, often misunderstood by those around him, but in all reality he really was not that different from his peers.

The first week of school came around and I saw him walking in the halls. He was by himself, and seemed to have placed himself farther away from the other students. His anxiety was getting the best of him. I was worried that he was right. He was not ready for the new change, and that he would become blocked and retreat back into his hoodie sweater. I could not help but wonder why he was even in a regular general education class. It was in my opinion in his best interest to be placed in a Special Day Class (SDC). Within this class he would be taught material at a slower pace, and the environment would foster his ability to learn in a different manner. So it left the question. Why was he not in one of these classes?

## Statement of Problem

Where do people go if a child needs extra services? The problem is that within the public education system, PGC (Parents/Guardians/Caregivers) of children with special needs often do not know how to find the necessary services their children qualify for, or even who to ask when they do. As a result of this, we have students in general education classes that are struggling to complete work that is beyond their capacity due to lack of resources. Understanding what services are provided at a school, district level, and beyond can really benefit the parents and the students with special needs.

## Purpose Statement

The purpose of this study is to increase awareness to the PGC, and the students with special needs of the various service options that are available within the public education system in the U.S. The first step towards receiving any service, whether it is from your local school site, or the district, is doing your research. If you think that your child may need some form of service, then they will need to be evaluated in order to determine what form of service is required to help your child. The evaluations range from a test measuring your child's academics, behavior, and social/emotional stability. These assessments provide the school and district with a guide as to what extra accommodations your child may need as they progress throughout their education at a primary level.

## Research Question

Where do parents go to begin or continue to allocate the appropriate services provided by their child's school site or district? Is there a correlation between the specified services and the success of the student with special needs? To whom is the service being provided helping, the parent, the child, or both parties? What legal paths can parents take in order to ensure their children's needs are being met within the school system?

## Theoretical Rationale

*Brown vs. Board of Education*, (Pearson, 2005) launched the campaign for parents, teachers, and administrators to critically analyze the student population that enters our schools. According to the decision made by the Supreme Court, all students should have the right towards an equal education. However, the questions still stands, are all students within an inclusive environment truly receiving an "equal" education?

In order to help protect the needs of these students who may require more guidance, our government has in more recent years pushed through various forms of legislation that require the education systems to take action towards addressing these needs. The legislation passed the Individuals with Disabilities Education Act (IDEA) (federal law) through which the government hoped to articulate the law in a comprehensible manner. These students, regardless of their abilities, have the right to be included within a general education classroom and receive the necessary services for them to be successful within the classroom environment. The act clearly illustrates the various services provided to students at an elementary level. For instance, the services begin through an Early Intervention Program, and progress towards IEPs, and transition

contracts as the students move through the higher-grade levels. These laws bind teams of specialists and students together in order to help put the student on a path towards being able to develop. In theory through these programs, the child, parents, and specialists all should have a working relationship that allows the child the ability to function within a general education classroom. Through this study, the question of what effective practices exist for providing parents a voice for their children within the public education system.

### Assumptions

Using the knowledge I have acquired over the past few years it is apparent that it is safe to assume that I will not be able to find as many service options within my district. The administration does everything they can for the students placed under their care, but with funding cuts, it is hard to offer everything. It has been my experience that the parents within my school district lack the persistent attitude necessary to ask the services provided by the district. There are those executional parents who are more than willing to go stomping through the gates in order to acquire everything their child needs, however, that takes time and a certain level of knowledge of the education system. What happens to those parents who work more than one job or unfortunately does not have the crucial communication rapport with their child to understand what their child needs in order to be successful.

### Background and Need

Services, and the benefits in which children receive from them are dependent upon the administrator, not the legislator. The legislation that has been put in place acts as the base line, or the backbone for all implemented services. If approaching these “guidelines” as curriculum, it

will become apparent that all the different needs that are written into the child's intervention program will not be met.

Czapanskiy, (2014) reported on a group of individuals, examining the perspectives of various programs designed to help students with special needs. The term special needs encompasses a wide range of services, which therefore leaves room for parents to find the flaws or gaps within their ideal perceptions of services their child should be provided. One particular case study focused on the perspective of parental awareness within various programs based on data from two family interviews. Each family had a child with special needs, and were promised some form of service to address their child's needs. The first family, from a high social class, seemed content with the type of service their child was receiving. The parents were involved from the very beginning as to what was happening within therapy lessons, along with their academic work. When requesting to be more involved within their child's education during their first therapy set-up meeting, they were encouraged and welcomed to participate. The educators and specialists who were working with the child were organized and helped the parents learn techniques they could use at home to help strengthen their bond with their child as well as teach them how to handle the more challenging moments within their livelihood. With the support from the specialists, and the encouraging feedback, the perceptions were all positive, and the family felt supported within each step of the process.

On the other hand, the second family was not as fortunate. This family experienced what is most common among the schools that have minimal resources. The specialists who were working with this child made minimum accommodations for the child's needs and refused to have the parents participate beyond the therapy sessions. When the parents requested as their legal right, to be further included in discussions, they were shuffled through a number of

obstacles, which only led to an undesired result (Czapanskiy, 2014). This lack of consideration is what these parents are afraid of when they have their children enter special services within a public school.

It is imperative that the parents understand the legal obligation and privilege they are provided when their child is submitted into a special needs program. By understanding all the regulations, parents can then assert their legal right to be more involved in their child's education.

### Summary

Throughout history educator professionals have made progress towards developing programs that address the learning objectives of those students with special needs. However, parents and students alike, often attest towards the miscommunication between the parents and the school. This divide attributes to large amounts of stress for all parties involved, while additionally stunting the progression of the student. If special needs students are to be successful, there needs to be a system developed or routine that connects their education and their home life. This connection is important in the younger years of a child's life. It is critical to the development of the child to have the same expectations set by the school reinforced within the household. It creates extra practice and more opportunities for these children to develop the new acquired skills. Therefore, by providing this strong connection it will make the transitions among grade levels easier and more advantageous.

Unfortunately, we are finding that this train of communication is often cut short. Parents are not taking advantage of all the possible resources their children can be provided as a result of or lack of communication from the district and the school. There needs to be more than one informative night that the parents are "recommended" to attend. Within this modern world, there



should be a place or website for the parents to go at their leisure to explore and investigate the possible services for their children provided by the district and school site.

## Chapter 2 Review of the Literature

### Introduction

This section examines research literature on PGC legal advocacy for children of special needs, using information gathered from academic library searches through online databases. In order to see the progression within the legal systems and the evolution of the resulting programs, the quantitative data gathered from the research information is organized in the following categories: Historical Context Behind Special Education Programs, Parents' Legal Rights Within These Programs, and The Perceived Development as a Result of These Programs.

### Historical Context Behind Special Education Programs: State and Federal Requirements

The history of special education presumably derives from results ignited by the Civil Rights Movement (Hale, 2011), with individuals banding together toward a common goal for the better development of a culture. Throughout history, educators can track the development of legislation surrounding the special needs community. Educators have passed, revised, and debated many forms of legislation until we have reached our most recent and widely used the "Individuals with Disabilities Education Act" (IDEA Act) (Federal Register, 2013, para. 1). Within this document, the legislation "addresses methods for ensuring services to children with disabilities, including the responsibility of non-educational public agencies to provide or pay for

required special education or related services . . . necessary to ensure the provision of a free appropriate public education (FAPE) to children with disabilities in the State” (Federal Register, 2013, para. 1). These appropriate services, and the requirements associated with them derived from the legislation that evolved and developed with each political discussion. However, administrators, educators, and parents consistently seem to overlook or miscalculate one element within the legislation literature—parent advocacy.

Most PGCs believe the varying levels of parental advocacy for a child with special needs is the crucial element depleting the effectiveness of the IDEA Act. Administrators and specialists alike use the legislation to help develop their school’s curriculum and to ensure a certain level of PCG involvement within the education process. However, this area lacks specificity within the Act’s language. When the IDEA Act was created, the federal administrators specifically addressed the needs not only for students who qualify, but for their parents as well. For instance, Part 300 of the Department of Education 34 CFR states, “Paragraph (A)...describes the specific elements of the written parental consent that a public agency must obtain under FERPA and IDEA before it may release for billing purposes a child’s personally identifiable information to a public benefits or insurance program” (Federal Register, 2013, para. 4). This legislation depicts the parental responsibilities to protect themselves and their children who qualify financially for these programs. However, the text fails to address parental responsibilities beyond being forced to pay any financial burden associated within these grant programs.

Scholars believe that for a child with special needs to be completely successful within a general education classroom or an intervention program, the curriculum design must include a PGC component. “Almost 30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by—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” (Conroy, 2010, p.1). Teachers and specialists can work extensively with these children throughout the day. However, without connecting what goes on within the school environment and the lifestyle at home, these students will never fully develop the skills necessary to interact socially and/or behaviorally at the highest levels.

Acar and Akamoglu’s study on parental participation within various special needs programs address how personnel within the education system define what it means to establish a balanced relationship between the home environment and school. They claim, “. . . , to work collaboratively with families, to strengthen families by helping them secure needed supports and resources, to provide individualized and flexible help, and to capitalize on families’ existing competencies and strengths” is the only manner in which children with special needs can be successful within their educational career (Acar, S., & Akamoglu, Y. 2014. p. 82).

Scholars have analyzed the advocacy level of PGC and their role within legislative measures. Where do we draw the line of PGC involvement, and at which stage within the education development does the line begin to blur? Studies and legislation indicate that children with special needs must undergo a progression of programs throughout their educational careers. “Unlike the classic civil rights laws, however, the IDEA consists of a series of grant programs to get the states and local school districts to provide certain services. States and districts therefore typically approach the IDEA simply as another federal grant program, like the service-oriented grants under No Child Left Behind (which has no private right to action)” (Passachoff, 2014. p. 6). This ideal that these programs are temporary or mediated through each district’s discretion only further emphasizes the lack of support these programs receive from administrators or

district officials. With minimal support on an administration level, PGCs of children within these programs inevitably feel separate from the development of these programs.

Diehm, Brandes, Chesnut and Haring developed a study that focused on the levels of communication between school and parents within IEP meetings across a variety of school settings. Their study went even further by looking at the participation of the child in question, an element that is not often seen within these forms of literature. They state, “Of the 9,628,501 rural students in the U.S., 8.7-17.6% were identified as having Individualized Education Programs (IEPs) during the 2008-09 academic year.” (Williams-Diehm, K., Brandes, J. A., Chesnut, P. W., & Haring, K. A. 2014) Statistically, this means a large number of opportunities to miscommunicate goals and expectations between the school and PGCs.

Studies show that “A total of 70% of parents of children with disabilities believe that their children lose services because parents do not know their rights (Burke, 2013, p. 227). This stems from a poor understanding of the verbal jargon often associated with the legislature and Individualized Education Plan (IEP) meetings. Specialists often view parents as an afterthought when it comes to a child’s development, which only heightens the separation between the child’s school environment and home life. The forms associated with the meetings and registration include a long list of acronyms and terminology that many parents easily misinterpret. Furthermore, educators should keep in mind that not everyone has enjoyed the same academic success as they have.

Scholars have studied how school systems define the role of PGCs for all students within their schools. In a study done by Young, Austin, and Growe, one particular administrator stated “Parental involvement is when the parents starts at home by instilling the value of an education. Then the parent introduces reading and social

behavior at birth to school age and beyond. The parent attends school functions that relate to the child's academic career, communicates with the child's teacher and administrator. In addition, the parent is also aware that policies and procedures are to be adhered. The parent supports and respects the school's policies and procedures." (2015. P.295)

An administrator would claim that parents would be able to accomplish every aspect of this definition. However, parents know that meeting these as well as other school expectations can be overwhelming. Furthermore, this definition of parental participation strictly depends upon the school administrator and the district. All official heads hold their own perspective of their parents and the general community surrounding their school. However, not every parent can meet the administrators' expectations. Still, parents can use this definition as a guideline in order to ensure that their child receives the most benefits.

Understanding that these students need special services, such as working with an Occupational Therapy (OT), speech therapist, and psychologist can help administrators decide where to begin when developing programs that address educational needs. Keeping this in mind, educators should analyze the development of the programs and their qualifications. Similar to legislation surrounding the programs for these students, these services change constantly. Therefore, to keep these programs current and to provide students with recent strategic curriculum developments, each program undergoes a rigorous review period.

Each year, OSEP reviews all of the information it has about each state, whether gleaned through its monitoring visits, through its review of the Annual Performance Reports, or 'any other public information make available,' and puts each state into one of four categories: either it 'meets the requirements and

purposes' of the IDEA, it 'needs assistance,' it 'needs intervention.' Or it 'needs substantial intervention (Pasachoff, 2014, p. 8).

Through the creation of this evaluation process and the combination of the parents' legal advocacy, we have developed and structured these services to provide for and to meet these students' needs.

### Developing Programs

The demand and constant persistence of PGC for services that address their child's needs helped formulate the educator positions and intervention programs in school districts across the United States. Yet PGC have often challenged the distribution and classification of the students admitted within each stage of the programs. Aron and Loprest (2012) found that within these programs a "disproportionate representation . . . has been documented along dimensions such as family income, native language, and gender (boys are more likely to be identified as needing special education than girls)" (p. 8). If this is the case, all personnel involved within the education system should investigate the effectiveness of the offered programs.

The Board of Education currently structures special education curriculum and services in a tiered system that measures students depending on the severity of their academic and/or behavioral demands. (Hallahan, Kauffman, & Pullen, 2012). The first tier specifically targets students who need extra help. These students may be falling behind their grade level, whether academically or developmentally. Administrators and educators monitor Tier One students for a specific time frame and then review the data to determine whether they should continue the intervention or determine whether these students need to move up a tier.

The second tier is more structured and designated for students requiring a more controlled environment than a mainstream classroom. Once students have reached this point, educators hope to see positive results. At this level, administrators and educators structure the program at the teacher's discretion to meet with a small group and a specialist. These sessions address individual academic expectations, but the small group provides the extra help and support these students need. If educators at this level find students still struggling then the struggling students move into the top tier.

The last tier involves not only the child in question, but various specialists and educators as well. Here educators assign students to a special education program (Hallahan, Kauffman, & Pullen, 2012). If a child qualifies for special education, a specialist writes an IEP and establishes all levels of the education hierarchy. The IEP could dictate the environment in which specialist places the student throughout the day, which specialists will be assigned to them, and the other modifications that may need to be set in motion in order for the student to succeed. In this tier, parents must participate. Administrators ask parents to attend these meetings and to engage in the discussions concerning their child's development.

A recent study focuses on quantitative data from a collective student body at a given school that qualified for special needs services. At a glance, the numbers tell an alarming story. These students, regardless of the modifications their teachers made, still missed the necessary curriculum required for their level. PGC and educators alike failed to resolve the concern.

Despite the development of these programs, the community still struggles to help children with special needs. PGC showed enthusiasm for the developing programs, but could not see how to advocate for their children within the new guidelines. According the research, some programs in the past have attempted to set up advocacy workshops or courses for PGC, teachers,



and administrators. These workshops attempted to educate PGC on the vernacular and paperwork associated with advocating for their child. The “SEAT” and the “VAP” programs yielded the best results. (Burke, 2013, p. 229).

The “SEAT” involves a team of advocates including special education attorneys, consumer advocates and paralegals--in other words, people who understand the inner workings of the system. Participants of the workshop meet with these individuals, who guide them through various real-life scenarios and provide them with strategies to advocate for their children. PGC attend the workshop to learn “how to find information, grasping and discriminating between federal and state law, using analytical skills, understanding unauthorized practice of law, negotiating between parties, communicating orally and in writing, identifying issues, addressing parent concerns, and acting in a professional manner” (Burke, 2013, p. 229). Lessons and skills developed throughout these workshops help PGC to represent their child’s needs. These parents no longer feel “voiceless” in IEP meetings once they have developed this understanding. For the past few years California has used the SEAT program model.

The VAP model has also succeeded in other states within the U.S. Like the SEAT program, this model educates PGC on tools they can develop in order to better advocate for their child. This program trains others outside of the immediate family advocate for these children. Program leasers assigned to families who currently have a child enrolled within a special education program. They advise the families for about a year and attend all IEP meetings. These individuals develop their skills through workshops and then use their knowledge of the system with their host families (Burke, 2013).

These two models share similar intentions but employ different styles and approaches. Although great in theory, both programs have their drawbacks. For example, PGC may not have

the time or resources to attend these meetings. These meetings often require an enrollment fee as well as some form of transportation to attend, and they usually require technological devices (computers, tablets, etc.), course materials. As a result, these workshops benefit only the families equipped to attend them. “A review of overall patient retention for the clinic over the past year revealed that 58% of families with children in the 2-to-5- year range who initiate the intake referral fail to make it through the diagnostic interview processes to attend their first treatment session.” (Gross, Belcher, Ofonedu, Breitenstein, Frick, & Chakra 2014). Until districts and schools find a feasible method of training PGC to be better advocates, this conflict will continue.

#### Perceptions of the Effectiveness of These Programs

The development of new programs for the students and PGCs associated with the special education programs offers increased support service opportunities for this population. However, research shows that programs specifically designed to help the adults, PGC and administrative staff often fail. PGC tend to develop their own personal understanding of their role within their child’s education based on their own experiences as children (Fishman, C., & Nickerson, A. 2015). Adults naturally pass on their perceptions and prejudices to their offspring, resulting in a corresponding trend within the education system. Children whose PGC actively participated in their education usually grow up believing that PGCs should actively participate in all aspects of a child’s educational career. Children whose parents either can’t or won’t participate in their education will tend share the same perspective with their own children.

PGCs should understand their own prejudices with these programs as they progress. However, many studies neglect to consider the initial responses PGC experience when they first

hear that their child needs to be put on the special education path. Hanley, Ingalls, and Marin (2013) compare PGC's reaction and rationale to the grieving stages. PGCs typically don't want to admit that their child may need extra support. Our children are a direct reflection of us, which ought to make any parent wonder. PGCs must go through this process in order to feel comfortable and receptive to the services their child may need from that point forward.

Are parents the only ones at fault if they fail to acquire the necessary services for their child? Studies show both parent and educators struggle to collaborate when it comes to the child's needs. This is especially true for young teachers entering the education field. The curriculum within education training programs, teaches strategies and addresses the needs of the students. As this study has shown, these programs only address one element of the equation. What about the needs of the parents? One study showed that "64% of the students from the elementary school teaching program and 79% of the students from the branch teaching programs related that parent involvement subjects had not been covered in any course 'at all.'" (Lindberg, 2014. P. 1356).

Research has shown that in order to convince PGCs that school district administrators are doing what they can to assist these students, educators must go beyond just providing the necessary services. Rodriguez, Blatz, and Elbaum (2014) studied parental perceptions of these programs for students who qualify for special education. One parent stated that "Schools that were successful in promoting collaboration actively solicited parent input, had teachers who were accessible, and communicated frequently with parents through a variety of means" (p. 90). Providing communication through a "variety of means" contributes to the miscommunication between the home and the school environment. Between busy schedules, lack of confidence in

personal abilities, and potential language barriers, no wonder PGCs often feel shut out from their children's IEP program.

At the very beginning of every IEP meeting, administrators, specialists and educators must present PGCs with their legal rights. If PGC are not comfortable with the manner in which the school or district is managing the available programs, then they have the right to establish a hearing or presentation of legal documentation that illustrates a clear record of the student's progression. (Novato Unified School District. 2014.) Regardless of the fact that these regulations are presented within every meeting, there is still room for miscommunication. The documentation contains challenging textual language that presents an obstacle many PGCs. Furthermore; non-native speaking parents might misunderstand their interpreters. If these concerns are not addressed, parents lose their motivation to advocate for their child's benefit.

Is the home element within the foundation of these student populations lacking as a result of parents not understanding what services are available, or is it stemming from them not feeling comfortable or adequate with the curriculum of specialized programs. "In some cases, although the information is being made available, parents are not taking advantage of it because they do not have the time or do not read the information that is sent home." (McClow. Gillespie, 1998. P.133). With this in mind, educators who create any form of documentation that is handed or sent to parents needs to be comprehensible and clearly articulated.

## Summary

Educators and advocacy organizations constantly develop or modify PGC training programs to help family members better understand how to support their children. The problem

is how PGC approach the structure and longevity of these programs, obstructing the child's pathway to success. Without full commitment, resources, and knowledge acquired from these services, PGC continue to feel voiceless. Therefore, in order to make the PGCs feel more confident or sufficient within all legal or procedure demands regarding their child, the first step is to guide PGC to the correct organization.

## Chapter 3 Methodology

### Research Approach

This study is structured to act as a reference to PGCs and spread awareness in regards to educational services within multiple suburban areas within the Bay, specifically support services detailed to students with special needs. A compilation of data was collected about each service and the vast supports they provide the parents who may be looking for these specified services. Using the data derived from this methodology, the information will be used to as a referral guide for PGCs, educators and administrators on how to better approach this concern within the education system.

### Ethical Standards

This paper adheres to ethical guidelines according to the American Physiological Association (2010). Additionally this paper was reviewed by my advisor and accepted.

### Data Gathering Procedures

### Sample Organizations

The organizations' that are listed within the findings are based off of recommendations made by several special education specials. These organizations are the most frequented advocacy agencies used by PGCs during IEP meetings within the Northern Bay area of California. In order to provide PGCs, educators, and administrators with a complete reference list

of resources and services available, the researcher first looked into the organizations within the Bay area. Additionally, in order to expand the reference list, possible National Organizations were researched and reviewed prior to being added to the list.

## Chapter 4 Findings

This section is a compilation of the current advocacy organization/service(s) and resources accessible to PGCs from the Northern California Bay area. Special education specialists and educators have suggested this list to be most beneficial to parents of students with special needs. PGCs must go through a progression of legalities and protocols. This section is designed to help PGCs navigate through these procedures and gather a greater sense of expectations at each step of the progression. The first section focuses on available resources at the school and district level. The second portion of this reference guide consists of advocacy organizations specific to the Northern California Bay area, while the last section comprises of a list of National Organizations that could provide assistance to parents who need help developing their advocacy skills.

### School Level

Special education legislation made available to PGCs within the school sites provide a limited and generic overview of the available services and protocol procedures designated by the district. PGCs are provided documentation that expresses the rights of the parents and the children who enter the special education program. The state requires schools to make the rights, procedures, and request forms readily accessible to all PGCs who inquire.

At this level, an educator or physician can refer the child to be assessed for special services. Specialists then analyze the assessment and deliberate with the PGCs and administrators as how to progress with the child's education. A child who qualifies for special



education will be placed accordingly within available services. These services include speech therapy, resource, or a specified intervention specialist. Depending on the severity of the child's disability, the child may be pulled out of the class or have a specialist push-in as to assist the teacher. Educators make modifications within their classroom in order to meet the needs of all their students. However, children who require more modifications than most will be discussed in an IEP meeting.

Children designated with an IEP will have monthly meetings involving the specialist, educator, PGC, and the school administrator. Together they will develop goals and expectations for the child. Within these meetings, the PGCs are read their rights and handed various literature specific to their child. PGCs are expected to read all forms and store them in an easily accessible location. IEPs tend to run annually; therefore, all the documentation that is passed out at each meeting will continue to be applicable throughout the school year. IEP meetings allow opportunities for all personnel involved in the child's education to collaborate and communicate with one another. This consistency provides a stable foundation of support for the child in question.

However, PGCs who feel that their child's needs are not being met will then move to the next level on the hierarchy, the school district.

#### School District Level

PGCs who feel that their child's needs are not being met through their school site will then contact the district. The district, with more funding than individual schools, can provide PGCs with more readily available services than what is listed within a school site. A PGC who has filed the necessary paperwork and arranged a meeting with the Superintendent of Special

Education can be provided services such as a personal aid, interpreter, physical supports, and enrollment within a Special Day class.

A personal aid means refers to a certified specialist to push-in as an in-class support for academics or behavior. This individual will not be considered the child's educator, but more as a one-on-one tutor for their needs. Depending on the severity of the disability, the certified specialist will only stay with the child within the classroom environment. However, for those children with more severe needs, this specialist will stay with the child throughout the entire school day.

The service of an interpreter is similar to that of the personal aid. Interpreters sit in front of the children with hearing disabilities and sign to them from an easily visible location. The interpreter will stay with the child for the entire period. The confidentiality of an interpreter is unparalleled within the education system. Interpreters must not divulge their school site, let alone the name of students. These measures protect the integrity of the child and the interpreter provides the PGCs with an extra set of eyes and ears for the well-being of the child.

Physical supports refer to wheelchair, and other mobility access across school sites. Students with a physical disability will need to discuss with administrators pathways the child would use in case of an emergency, and whether the school indeed offers easy mobility across its campus.

A Special Day class is a specifically-designated classroom for students with severe cases of autism or social and emotional conditions. Educators and specialists who teach Special Day Classes teach regular curriculum at a slower pace or with differentiated materials. Additionally, the room tends to be highly-equipped with different sensory tools to help calm the child and

provide a positive learning environment. Not every school provides this service to students who qualify. Therefore, PGCs requiring Special Day Classes would have to register for a school that provides them.

Extra supports often take time to set up and put into motion. Once the district has approved these extra supports, it will contact the PGCs and school administrators. A meeting will be put in place to discuss the legalities and protocols for these extenuating circumstances. It is within these meetings that PGCs often find themselves voiceless.

To negotiate and to ensure that the school district and the school administrator are not taking advantage of the lack of background knowledge within these legal procedures, PGCs should bring a legal advocate to support them and their rights. Administrators are recommended to suggest advocacy organizations the parents can contact, however, other options out there that may be better-suited for the PGCs needs.

#### Organizations Specific to the Bay Area

##### *Matrix*

The most popular and prominent organization in the Bay area is Matrix. This organization reaches four different counties across the Bay: Napa, Sonoma, Marin, and Solano. Located in Novato and Fairfield, Matrix has been serving the needs of parents with special needs children from birth to the age of twenty-six since the early 1980s. PGCs from all over the Bay rely on Matrix's great depth of knowledge in addressing the PGCs emotional, physical, and fiscal responsibilities. A large percent of the staff have children with special needs, which comforts most PGCs. This insight allows the staff to connect with parents gives them a sense of security they won't find in the school district.

One of their greatest assets of Matrix is their ability to provide for non-native speakers in the Bay area. Their bilingual staff is one of the strongest advocates for the PGCs within IEP meetings. One staff member described how discouraged some of the parents felt when they arrived at IEP meetings with no adequate translator. Not only are these parents expected to overcome the terminology and jargon of these meetings, but they must also overcome a language barrier. Therefore, a balanced relationship between the PGCs and a member of the Matrix organization is critical to the advocacy progression of these parents.

Matrix also provides many opportunities for the PGCs to attend conferences, trainings, and support sessions throughout the Bay area. In order to inform parents of upcoming opportunities, the Matrix website is easy to navigate. The site provides all information about Matrix's organization, recommended resources, and contact information-- updated on a regular basis. Additionally, the organization does everything within its power to reach the tech-savvy PGCs. They currently have a Facebook page that highlights events, and stories that help inform parents of the successes and benefits Matrix can provide. PGCs have the ability to post their own success stories on the page and network with others who may be experiencing something similar within their own family.

Organizations such as Matrix are extremely important for parents when they are in need for an advocate. However, not only does Matrix provide services for the PGCs who ask for help, but also they hold a positive rapport with professional personnel. Physicians and administrators for schools across the Bay call Matrix with recommendations for PGCs they should seek out and assist with the understanding and implementation of getting what their children need. This relationship between these professional personnel is extremely important during the initial

transition period. The network of communication allows for the PGCs to feel supported and comforted within all aspects of their responsibility as guardians to a child with special needs.

All of these elements are reasons as to why Matrix is one of the most commonly used organizations within the special education department. Over the years, Matrix has defined their networking and advocacy participation for all PGCs that go through the company. For more information on the available services and when they are hosting advocacy events, go to their website <http://www.matrixparents.org>.

### *CASE Alliance*

CASE Alliance is a special education advocacy organization that is stationed within San Francisco. Members from this organization serve diverse locations within the Bay area such as: San Francisco, Fremont, Hayward, and Santa Rosa. This organization has been assisting PGCs since the legislation passed the IDEA Act. The first steps PGCs take when navigating through these channels often begin with a simple phone call. Each 45-minute phone consultation is the initial step within the process towards developing a good advocate.

Once a representative from the organization and the PGCs have consulted over the phone, CASE Alliance coordinators review the case file of the recommended student. If the need is required, an advocate from the organization will meet with the PGCs and attend the child's IEP meeting. Within these meetings the CASE Alliance coordinators can advocate or develop a better understanding as how to help the PGCs proceed towards achieving what the child needs to be successful.

Representatives from the organization plan and structure parent trainings that allow PGCs to experience what legal action they have the right to enforce, or how to navigate through an IEP

meeting. These trainings are beneficial for all PGCs, new or veterans to the structure of the special education program. These trainings are held in 50 Bay area communities in Northern California. One of the most beneficial programs associated with CASE Alliance, is “Special Minds at Work”. This is a free service for indigenous families seeking advocacy help for their children. For more information go to their website <http://www.caseadvocacy.org>.

Local organizations are effective when dealing with legalities that are small enough to be dealt with through confined organizations. However, when qualms become larger than the school site and district, PGCs can contact a variety of National Organizations to assist with any of the necessary concerns.

National Organizations:

Autism Speaks

Autism Speaks is a National agency that specifically addresses the needs of those students with Autism. This National organization works with students within a K-12 Education System and young adults who graduate from the schools. Students who suffer from Autism often struggle with social interactions and basic behaviors that can be experienced within a school environment. PGCs are the main advocates for the needs of their children within an IEP meeting, therefore, when their demands are more than they can handle, guardians search for organizations such as these in order to receive assurance.

Autism Speaks website contains opportunities for the parents to learn more as how to support their children when entering a school setting. Parents are able to help their children integrate within the classroom setting by utilizing the various resources, brochures, hand-outs,

and video clips that are available on their website. Each resource covers sensitive topics such as reducing stress levels, integrating into a general classroom, and how to deal with bully. Although they are a National organization, they do a decent job at providing support and guidance to all PGCs with special needs children.

The power and level of support this organization provides is so vast that they even developed a separate branch called Autism Speaks U. This branch is spreading through college campuses across the Nation. College students volunteer their time in order to spread awareness about the services this organization can provide PGCs with special needs students, as well as volunteer to work with children with special needs. The young adults tutor, provide daycare, and even work with families with paperwork when they are applying for support services. This extension of advocacy allows PGCs to learn more about services and opportunities available to them, as well as train the parents to be stronger advocates. To find more information about how to get your school or child registered for these opportunities go to <http://events.autismspeaks.org>.

Furthermore, the National standing of Autism Speaks allows them to be connected with new legislation that is proposed through by the government. Legislation, as we have discovered, changes and can greatly impact the students who sit within the classrooms. Autism Speaks not only keeps an updated record to new and upcoming legislation, but they also put grant/fellowship opportunities on their website. Therefore, PGCs who may be looking for extra fund to support their child with their educational needs can go to their website and download the necessary forms and contact a staff member associated with Autism Speaks.

With this wide variety of supports, Autism Speaks is one of the leading associations aiding PGCs who have autistic children all over the nation. To find out more information or how

to qualify for the numerous services they provide go to their website  
<https://www.autismspeaks.org>.

### Council of Parent Attorneys and Advocates (COPPA)

Council of Parent Attorneys and Advocates or COPPA is a unique organization that specifically focuses on partnering PGCs with a legal attorney or advocate to represent their child. This organization is a national non-profit company that services many school districts across the nation and is comprised of a multitude of committees or organizations that work together in order to fill any need a PGC may encounter when seeking legal advice. Although this organization does not provide personal or individualized support, it acts as a directory or contact list for PGC who are looking for an advocate or attorney.

One of the main benefits this organization provides PGCs are their trainings and webinars. They work on training the PGC with strategies and developing the necessary background knowledge they may need when in a meeting. Within the trainings they bring in other members of the community who have first hand experience within the legal processes associated with advocating for a child with special needs. This interaction helps solidify and ensure the PGCs the practical application and necessities of utilizing these resources.

The organization holds many conferences and trainings throughout the year. COPPA is one of the few organizations that have successfully implemented the SEAT trainings to PGCs across the nation. Parents during these trainings are a combination of web-based and scenario role-playing activities with legal professionals. The format of training allows PGCs to practice and actively participate within various activities that not only enhance the development of their



background knowledge in regards to legal procedures, but it also develops their own personal confidence as an advocate for their child.

COPPA would be a beneficial resource for PGCs who have already acknowledged that they need to hire an advocate or attorney for their child. The reference list developed by COPPA is easily accessible and can help direct PGCs to the best fit for their needs. For more information contact the staff members through their website <http://www.copaa.org>.

### Through the Looking Glass

Through the Looking Glass is a National non-profit organization that works with the families of children and parents with special needs. It developed in the early 1980's in the streets of Berkley. Through the Looking Glass advocates for children and parents in all manners whether it is academic or personal. The families that go through this organization are often living below or at the poverty line. Therefore, this organization is extremely beneficial for those families who wouldn't normally be able to afford these support services.

Through the Looking Glass provides PGCs with Early Intervention, Advocacy for students and parents living with a disability, and support with social services. Early Intervention programs are established to help children prior the age of three. If a child is showing signs of slow development, these programs work with the infants using various manipulatives and resources. This is the first step PGCs take if they believe their child needs extra supports.

The organization holds trainings for PGCs who need help understanding the vernacular and procedures when requesting or following through legal measures. Representatives provide support in all legal cases: custody, and civil rights. The trainings provide PGCs with basic

knowledge as how to advance into these legal interactions. However, without the help from legal representatives provided by the organization, these PGCs would not be successful within these hearings.

What sets this organization apart from the other advocacy organizations that are available to PGCs is that the founders and coordinators of the organizations are continually keeping up to date on the circumstances associated with these families of poverty. The advances in technology and outside resources allow the staff members of the organization to be equipped and accessible to all of their clients. For more information go to <http://www.lookingglass.org>.

Despite the numerous services these organizations provide PGCs seeking advocacy and legal advice, there are other resources the PGCs can access that are closer to home. For those PGCs who are fortunate to have access to technology can use these resources to their benefit. Technology provides an open door to a number of services students, and parents can access within the comforts of their own home. Listed below are a few examples of the resources available to PGCs.

Technology Resources:

The Resource Room

The Resource Room is a website that provides PGCs and educators with resources and lesson plans that have been modified for students whose learning requires more manipulatives or visuals than the rest of their peers. PGCs can focus on Math or Reading Comprehension or spelling. These resources can help provide the extra support they may need to be successful. It is important for PGCs to understand that this resource is simply a guide. These lesson plans or

recourses should be supplemented simultaneously along with additional supports provided by the school and district. Check out the available resources at <http://www.resourceroom.net>.

## Summary

Research has shown that the advocacy progression for PGCs looking for support services is lengthy and full of many obstacles. However, the path is not impossible. Schools, districts, and outside organizations constantly are working together with PGCs towards providing children with special needs extra supports. Using the resource guide developed through this research, PGCs are easily able to navigate through the legalities and procedural obligations in order to help their child be successful. Understanding the path and the channels that can be used in order to achieve these services is the first step for PGCs getting their voice back.

## Chapter 5 Discussion /Analysis

## Summary of Major Findings

The purpose of this study was to understand what services are available for PGCs looking for services that will assist in their ability to advocate for their child. After weeks of trying to navigate through the same channels as the PGC's, it has become evident as to why many PGCs feel voiceless. The confidentiality and the levels administrators and other educators go through in order to preserve the rights for the school districts and school sites is astounding. Simply gathering information as to what services are available is similar to asking a secret service agent what the president had for breakfast. The language and level of divergent logic is enough to prevent anyone from asking further questions.

However, after digging and pestering administrative personal, they were able to point me in the right direction. For PGCs looking for advocacy for their children, there are any options and resources readily available to them. The first step would be to start at the school site.

Administrators and the special education teacher are the best personnel to ask when inquiring about special support services. They are the individuals who will know what service(s) specific to the area would be best suited for addressing the child's needs. Though if that doesn't seem to suffice for the needs of the individual, they can always go to the district level and ask about the services available. When dealing with the district administrators it is important to have a basic understanding as to what you are specifically asking for, meaning it is a must to have completed some background research about the districts resources before approaching these personnel. If PGCs are still finding a level of resistance or feel unclear as how to progress for the services they

believe their child deserves, then outside organizations are accessible and fully capable of walking PGCs through the rigorous procedures.

PGCs do not have to follow this progression path when seeking stronger advocacy for their children. This path is simply a recommendation as to the best methods towards acquiring these forms of services. Outside services can be contacted at any time during the process, but can sometimes be more time consuming and costly. By navigating through the systems already set in place by the school, the child has a greater chance at receiving the necessary services.

### Comparison of Findings to the Literature

The literature gathered through this study illustrate that PGCs feel frustrated even though they had these services they did not know to navigate through the procedures or how to acquire available resources. Parents always seemed to be looking for someone to help guide them and walk them through the process. Another difficulty parents always had to overcome was the jargon or language used throughout the IEP meeting. The services are available but parents need to know how to ask the right questions to get what they need for their child.

### Limitations/Gaps in the Research

There is a big gap between the school and the district office in communicating available services to parents. They seem to want to provide the necessary resources, but are hesitant in explaining to the parents how to go about getting the resources.

Families of non-English speaking children often encounter miscommunication when they are in contact with school officials. Translators are good, when they are provided. However, there is still a chance for miscommunication to occur.

### Implications for Future Research

School district personal and school site leaders need to be increasingly aware of how to inform families of these services. This could be through creating websites, flyers or literature that is given to families at every IEP meeting.

### Overall Significance of the Study

It is important for parents to know what is available. There is a step they can take rather than relying on school administrators or other personnel. With the right tools, parents have a voice in their child's education.

### About the Author

Sara Cofiell is a credentialed teacher in the State of California. In her experience in working in area schools it became apparent that there was a deficit in parent background knowledge and communication between the school and the home, particularly with students with special needs.

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