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# A Phenomenological Study on Parents' Advocacy Experiences for The Inclusion of Children Experiencing Disability in The General Education Setting

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A PHENOMENOLOGICAL STUDY ON PARENTS' ADVOCACY EXPERIENCES FOR  
THE INCLUSION OF CHILDREN EXPERIENCING DISABILITY IN THE GENERAL  
EDUCATION SETTING

By

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Presented to the College of Education  
George Fox University  
in partial fulfillment of the requirements  
for the degree of  
Doctor of Education

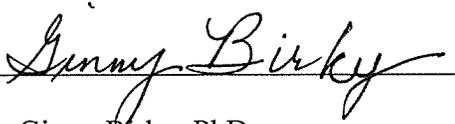
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“A PHENOMENOLOGICAL STUDY ON PARENTS' ADVOCACY EXPERIENCES FOR THE INCLUSION OF CHILDREN EXPERIENCING DISABILITY IN THE GENERAL EDUCATION SETTING,” a Doctoral research project prepared by ELAINE FOX in partial fulfillment of the requirements for the Doctor of Education degree in the Educational Foundations and Leadership Department.

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## ABSTRACT

Recent changes to the Individuals with Disabilities Education Improvement Act (IDEIA) position parents as a mandatory participant in the special education process. Additionally, these revisions to laws mandating increased student access to general education environment have served to increase interest on the topic of inclusion. Despite this legislation, the field of special education continues to be ripe with controversy about parent advocacy. Especially contentious is parental advocacy for inclusive placements for their children. The purpose of this phenomenological study was to learn about the lived experience of five parents advocating for inclusion of their children who experience disability within a large suburban school district in Oregon. Despite over 40 years of legislation and judicial action designed to support their children's access to quality instruction, this study illuminates the advocacy challenges that still remain for parents. The data analysis revealed seven salient themes as key areas on which professionals need to provide continued focus and progress. As a result of the findings, this dissertation addresses important implications and prescribe specific recommendations.

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## CHAPTER 1

### INTRODUCTION

My palms were sweating as the lawyer laid out her case for the family at my first ever legal Individual Education Plan (IEP) meeting. The district did not have an attorney present, so I was it. My boss told me I was good enough to do it alone, with the help of the vice principal and teacher. The student, a 15-year-old-girl was beautiful, precocious, outgoing and opinionated, as a lot of girls her age. She was also diagnosed with Down Syndrome. Her parents, a teacher and mail carrier, were greatly frustrated. Their daughter had passed her standardized 9<sup>th</sup> grade assessments but still would not be assigned in a general 9<sup>th</sup> grade algebra class. They had hired a lawyer to help them navigate the “overwhelming” special education system. My job was to facilitate the meeting, keep costs down, and avoid litigation. After hearing the parent’s requests, the vice principal told the lawyer, “It will never work, we’ve already done the schedules. The class is full.” The words flowed from the 15-year veteran administrator who managed the 400 9<sup>th</sup> graders in an Oregon comprehensive high school.

The school suffered from common ailments of poverty, large class sizes, and a wide horizon of socioeconomic and academic needs. I emphatically explained from a logical and legal standpoint why the vice principal had a point and argued in my new role, famously modeling my behavior from meetings I’d observed. I could do this well because I was pretty good and knew my stuff. In fact, better than most; my own boss had told me so.

The next hour consisted of the lawyer carefully laying out the parent’s vision for their daughter to have as “typical” an experience as possible during high school. Requests included general education classes by day, lunch with a group of typical peers, every imaginable service

to help her be successful, along with individualized supports in each class. They wanted a lot. The lawyer followed with legal arguments for the student to participate. The jargon started, acronyms bounced around the table like ping pong balls. “Least Restrictive Environment,” “Inclusion,” “IDEA,” “OT,” “PT,” “Specially Designed Instruction.”

Parents sat with jaws and fists clenched as the lawyer’s words reverberated in the air. Wasn’t it logical, they said, that their daughter be given a chance? She could connect socially, they said. She wanted to be part of her class. Hadn’t she passed the standardized test? Weren’t there kids without Down Syndrome that failed? What did they do with them? I anticipated these issues and was ready. Her IQ was 65, I argued, there was no way. She couldn’t keep up; an assistant would stigmatize her; the pace was too fast; the law said the district decided where she received services, not the parents. The power was ours. Parents looked straight at me and said, “You are like all the rest of them. They all think she can’t do it. We were hoping you’d be different.”

I remembered my former university professor’s warning not to set up “us” and “them” situations in meetings, yet I had never felt more like one of the “them” and wondered if parents felt at all like the “us.” I knew IEP meetings were supposed to be collaborative. Yet in this meeting we seemed to have a chasm between us filled with alphabet soup, frustration, discrepant interpretations, and beliefs. The family wanted an “inclusive placement.” I had no experience with inclusion. Besides, how would I convince the vice principal to agree to such a thing? The teachers? My boss? Our district and this school were not set up for this. We were not ready to support such “out of the box” thinking financially or academically, and we certainly weren’t going to be pressured by a lawyer. We were the *experts* after all! I reassured myself I was supporting the district and conflict was normal. Compartmentalizing the whispered voice of my

conscience, I defended my point. Gradually, the whisper crescendoed. What if this beautiful girl could do it? What if that's what was right? What did the parents know that we didn't? Why did *they* think she could do it? What if the district was wrong? What if really in my heart of hearts I was in the "us" camp and not on the "them" team? None of it mattered though, because my main job was to be a "them" and to be one that didn't get sued to boot.

The lawyer finished, and as the team struggled out of the alphabet chasm it was finally agreed the student would spend an hour a day in the algebra class. The class was three hours in length. Parents and lawyer agreed to a check-in meeting after two months. Parents left with a silent, unreadable expression on their face. The student seemed confused (but really weren't students with IEP's always that way?) and asking if she "got it" shuffled out with her parents. Got what, I wondered? I didn't bother to ask. The lawyer simply said she'd be back. The vice principal and teacher were furious I supported the "one hour" decision and asked me if I planned on coming in and personally teaching the student in class. They were going to call my boss, complain, request another district office facilitator.

I got in my car, took a full breath and wondered if I had done right or wrong. What did I do? What should I have done? Was this about student rights, teacher rights, or parent rights? They all had a point. But if I did what I was supposed to do, why was I so stressed? Doubts edged closer and closer to my conscience, transforming to tears that dribbled down the steering wheel. Were the parents and lawyer right? What if they were? What if *that girl* could have made friends, become part of a classroom community and teach her peers more about the world than they could ever teach her. What if she could have done it? What if she was more capable than I thought? What if our district gave her a chance? What if my boss was wrong? What if as professionals we *didn't know*?

Three more years of similar experiences and reflection propelled me to a place where I could finally judge that first meeting. Clearly, it was an epic failure. “The district” (i.e., *me*) had used their power to exclude, rather than include. Truthfully, the meeting was a violation of her dignity, access to a quality education, a denial of her civil rights. I often wonder what happened to her. Little did I know then, as a doctoral student twenty years later I would again deeply consider my experience as an educator, a parent, and a school district executive. Hoping to finally be an “us,” it was impossible to predict writing a dissertation about *that meeting*, all the others, and why parents must be heard about the imperative and perilous topic of *inclusion*.

As special education laws, philosophy and research have evolved over time, the contemporary ideology in special education has become one of educating students with disabilities in inclusive settings alongside their non-disabled peers (Winzer, 2006). This process is known as *inclusion*. However, the parent voice for advocating for an inclusive placement is often muted by professionals (Bacon & Causton-Theoharis, 2013).

Despite the proven value of inclusionary practices, there remains a conspicuous gap in qualitative research voicing the experience of parents as they engage with the school and advocate for their child to be educated among nondisabled peers in a general education setting. This study will examine the experience of four such parents.

### **Problem Statement**

The purpose of this qualitative study was to learn more about the experience parents have advocating for inclusion of their children who experience a disability. I used personal interviews with a small sample of parents of children experiencing disabilities in order to explore their perceptions and experiences with advocating for inclusion services. Until we understand human stories related to parent advocacy for inclusion, we are limited to quantitative data results that are

unable to inform us of essential challenges and victories in their efforts. Thus, this study provides valuable textured insight.

### **Research Questions**

I used general research questions while anticipating greater levels of specificity to emerge. The following research questions were examined:

#### *Research question 1*

How do parents define or conceptualize inclusion?

#### *Research question 2*

In what kinds of activities/experiences have parents engaged to advocate for their student?

#### *Research question 3*

When advocating for their student, what kinds of barriers have parents faced in obtaining an inclusive placement?

#### *Research question 4*

What do parents perceive as the school district response to advocating for an inclusive setting for their student?

#### *Research question 5*

Were advocacy efforts successful in the estimation of the parents?

### **Key Terms**

One of the consistent problems in the research related to inclusion of students with disabilities in the general education setting is the terminology and definition of *inclusion*. Terms such as *full inclusion*, *mainstreaming*, and *integration* have been used interchangeably in much of the research. A common definition is needed in order to create precise understanding. For the

purposes of this study I choose to use the term of inclusion to mean both a placement *and* a process (Forbes, 2007). The following terms and definitions were used throughout this study:

*Advocacy*: The process of arguing, pleading for, or supporting a specific cause or policy (Merriam-Webster, 2015).

*Disability*: For purposes of this study, a student with a disability is a child evaluated in accordance with Sec. 300.304 through 300.311 of the 2004 Individuals with Disabilities Education Improvement Act (IDEIA) as having mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to in this part as "emotional disturbance"), an orthopedic impairment, autism, traumatic brain injury, a health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services (Individuals with Disabilities Education Improvement Act, 2004).

*Disability Rights Oregon (DRO)*: A tax-exempt 501(c)(3) organization that is dedicated to “promoting and defending the rights of individuals with disabilities.” The organization functions on a sliding scale (Disability Rights Oregon, n.d.).

*Families and Communities together (FACT)*: Oregon’s Parent Training and Information Center (PTI) that is mandated by IDEIA (Parent Technical Assistant Centers, n.d.).

*Individuals with Disabilities Education Act/Individuals with Disabilities Education Improvement Act (IDEA/IDEIA)*: IDEIA is cornerstone legislation in the field of special education. It is the fourth revision of the Education for All Handicapped Children’s Act first passed in 1975. It was amended in 1986, and then was reauthorized as the Individuals with Disabilities Education Act (IDEA) in 1990. It then was reauthorized in 1997. The most recent

reauthorization mandating parent engagement occurred in 2004. The 2004 iteration is called the Individuals with Disabilities Education *Improvement Act* (IDEIA). I use IDEA and IDEIA interchangeably depending on the referenced timeframe; however both terms essentially refer to the same basic set of legislative actions.

*Inclusive environment:* Disability expert Norman Kunc defines an inclusive environment as an environment that values “diversity within the human community. When inclusive education is fully embraced, we abandon the idea that children have to become ‘normal’ in order to contribute to the world...and in doing so, begin to realize the achievable goal of providing all children with an authentic sense of belonging” (Kunc, 1992, p. 38-39).

*Inclusion:* “The process of educating children with disabilities in the regular education classrooms of their neighborhood schools – the school they would attend if they did not have a disability – and providing the necessary services and supports” (Rafferty, Boettcher & Griffin, 2001, p. 266).

*Individualized education plan (IEP):* A specific student plan mandated by law that guides the implementation of specially designed instruction and necessary related services (such as occupational therapy, counseling or physical therapy) a student needs in order to access their education (McLeskey, Rosenberg, & Westling, 2013).

*Integration:* Any degree to which students with disabilities collaborate, interact, sit near, or do similar kinds of activities in the same environment as students who are non-disabled.

*Least restrictive environment (LRE):* This mandate is embedded in the revision of the Individuals with Disabilities Education Improvement Act (IDEIA) enacted in 2004. It requires children with disabilities are educated with non-disabled children “to the maximum extent appropriate” (Individuals with Disabilities Education Improvement Act, 2004).

*Mainstreaming:* The process of including children identified as having a disability in activities with their typically developing peers during activities such as lunch, recess, physical education, music or art classes (Posney, 2013).

*Parent:* Parent refers to an adult or set of adults parenting either a biological or adopted child. Parents also form the basic unit of analysis for this study. In that regard, the parent can either be one or both adults who are the basic guardian of the child either through biological or adoptive parenting.

*Parent engagement:* An umbrella term for parent activities characterized by varying levels of frequency, response effort, and types of settings in which they occur. Educational engagement can occur in a variety of school-related contexts such as attending a meeting with the teacher or helping with homework (Sawyer, 2014).

*Universal Design for Learning (UDL):* Universal Design of curriculum and instruction offers learning alternatives to students with and without disabilities and provides a framework to both create and implement lessons that value flexible goals, methods and assessments (Universal Design for Learning, n.d.).

### **Limitations and Delimitations**

This study involved personal interviews with parents who have advocated for their student experiencing disability, within the K-12 school system. While the detailed information derived from those interviews provide a significant amount of information regarding parent experiences advocating for their children, it is recognized that a limitation of the study is the inability to generalize the findings to the larger parent group in Oregon and the United States. Specifically, because I used a non-probability sampling strategy to recruit participants, I cannot

make any claims to generalizability to the larger population of parents who advocate for their disabled children.

Though the small sample size can clearly be viewed as a limitation because it lacks generalizability, that limitation must be balanced against the advantage of transferability. Namely, this study provides a detailed and thorough look at the advocacy experiences of the parents interviewed. These insights will reasonably inform scholars and practitioners on the needs, desires, and perspectives of parents. It should be noted that these details would likely not be possible using a quantitative survey or other method of gathering information.

While limitations are primarily related to the lack of this study's generalizability due to the limited sample size, there are important delimitations to consider as well. The focus of this study restricted the definition of "parents" as it may traditionally be defined in a broader social context. That is, this study was limited to parents who are related to their children through birth or adoption. Selecting such participants eliminated other factors that could potentially impact the parental perspectives. These factors include but are not limited to the temporary nature of foster parenting, limited history with a student, and partial knowledge of the child's overall experience in school. This delimitation impacted the recruitment and sampling process. Additionally, all parents interviewed were from one school district in Oregon.

### **Bracketing**

It is important to acknowledge the current position in which I serve and the potential for prior relationships with the parents who might have been interviewed. I currently serve in the role of Executive Director of Student Services at a large district in Oregon. Meeting with parents in multiple contexts is a routine part of my job, and has been for the previous eight years. Therefore, the potential for participants chosen to interview to have a prior relationship with me

was a real possibility. I regarded any such relationship as hopefully serving to elicit a deep level of information and feedback.

I chose to research this topic in order to contribute to my personal and professional knowledge base. This study was completed in accordance with the Doctor of Education requirements at George Fox University. Professionally, I have practiced in the field of special education for 23 years in the K-12 public school system in Oregon as a classroom assistant, teacher, meeting facilitator and an administrator. During that time, I have met with hundreds of families who have shared their challenging and rewarding advocacy experiences as they fought for their student experiencing disability to be in a more inclusive placement. As the volume of research increases revealing the academic and social benefits of inclusive placements for students, my experience as a special education director is that parents are becoming stronger and better advocates. Yet, their stories are not well represented in the research. It is critical this perspective is documented and heard to improve the educational experiences for students, parents, and practitioners. It is my desire that this study will contribute to the knowledge in the field for all three of these important groups of people and become part of the larger body of research looking at multiple perspectives of inclusion.

## CHAPTER 2

### REVIEW OF THE LITERATURE

#### **Introduction**

Despite decades of special education law and practice, the social and legal evolution of educating students experiencing disability has placed parents as a key player in designing service delivery in the American school system (Bacon & Causton-Theoharis, 2013; Rodriguez, Blatz & Elbaum 2014; Winzer, 2006). Nevertheless, parents and educators continue to struggle with successful service delivery models for students with disabilities. The Individuals with Disabilities Education Act (IDEA) has provided strong mandates related to parent involvement in the special education process. Parents of disabled students currently have critical, specific responsibilities and roles at various points when interacting with their child's Individual Education Plan (IEP) team. Often times, this parental role becomes one of advocating for their child to be educated alongside their non-disabled peers. As special education laws, philosophy and research have changed over time, the prominent ideology has emerged in special education of educating students with disabilities in inclusive settings alongside their non-disabled peers (Winzer, 2006). This concept is known as *inclusion* and is reflected in current educational law.

There has been a sizable body of research generated about the effectiveness of inclusionary practices (Bailey, 2004; Causton-Theoharis & Kasa, n.d.; Forbes, 2007; Roach & Salisbury, 2006). Despite the preponderance of evidence supporting inclusive settings, the concept of inclusion often remains supported more in research than practice (Winzer, 2006). As a result, parents who advocate for their student to be in an inclusive setting often face resistance from educators (Bacon & Causton-Theoharis, 2013).

While multiple definitions of inclusion exist, for purposes of this paper the word *inclusion* is defined as the process of educating children experiencing disabilities in the general education classrooms of their neighborhood schools – the school they would attend if they did not experience disability – and providing them necessary services and supports (Rafferty et al., 2001). Even recently, this concept if imagined, was rarely put into practice.

This review of the literature will focus on several important aspects of parent advocacy within the special education process. Specifically, I will explore the relevant literature related to five general areas. First, I offer a survey of the social history of inclusion. Second, I will review the legal history of inclusion. Third, I will examine the legal role of the parent. Fourth, I will outline the benefits associated with parental involvement in the inclusion process. And finally, I will present the literature surrounding the nature of the advocacy experience for parents.

### **Social History of Inclusion**

In order to assess the current practice of inclusion advocacy in context, it is helpful to review the way those experiencing disability were treated historically. This difficult history contributes directly to the way individuals and families experiencing disability are perceived in the school setting today. Knowledge often brought forth by parents is related to “a pathological understanding, where families and students with disabilities are assumed to have deficits...” (Bacon & Causton-Theoharis, 2013, p. 684). The ideology of special education in our public school system has been the subject of controversy for several decades and is based on a deficit model (Fitch, 2003). It is within this context of “supposed inferiority” within the hierarchy of the American public education system that parents must bravely approach their advocacy efforts (Bacon & Causton-Theoharis, 2013).

Given the rutted social and political evolution of service to students experiencing disabilities, the perception of historical inferiority is easily understood. In the American public school system, different ideologies regarding their *inclusion* in the general education environment are reflected at various points in history (Winzer, 2006).

The early history of educating individuals who experience disability in our public school system can be traced back to the days when the socially deviant term *idiot* was used to describe disabled people who were subsequently denied educational rights and social privileges. They were, in fact, labeled as social and economic problems (Winzer, 2006). *Idiots* in the early eighteenth century were outcasts of society who rarely, if ever, were educated (Winzer, 2006). The current ideology has evolved to reflect one of increased academic and social inclusion for the development of cognitive and social growth (Alkin & Freeman, 2000).

The word "*idiot*" comes from the Greek ιδιώτης, *idiōtēs* ("person lacking professional skill", "a private citizen", "individual"), and from ἴδιος, *idios* ("private", "one's own"). The word *idiota* ("ordinary person, layman") means "uneducated or ignorant person" ("Idiot," n.d.): This mid-eighteenth century "perceptual norm" evolved over time into a softer view that was informed by the influence of the European Enlightenment. The Enlightenment was helpful to the disabled since it promoted a humanitarian ethic that emphasized equality of all people (Winzer, 2006). In the post Enlightenment period, social philosophers such as John Locke contributed greatly to the empirical thinking that ultimately influenced the education of deaf individuals, especially among the French (Gutek, 2004; Winzer, 2006).

By the mid-nineteenth century, the French beliefs regarding education of the disabled reached America and basic institutions began to be established across the United States. This institutionalization had a dual effect. One effect was acknowledging and offering educational

opportunity to a socially “shut out” group of people and the other was taking an already socially marginalized group of people and further limiting their opportunities by institutionalizing them and not allowing them to become part of mainstream society (Winzer, 2006). Packed between the two words *idiot* and *inclusion* stands one of the most difficult practical, ethical and legal challenges parents and educators face – whether or not (and when) students experiencing disability should be educated alongside their non-disabled peers in the general education classroom.

This fundamental ethical debate between the exclusion of the disabled through segregation, and inclusion of the disabled into the American fabric of education has sparked a debate that continues today.

### **Legal History of Inclusion**

The year 2015 marked the 44th anniversary of a landmark inclusion judicial decision on students with disabilities in the United States. In 1971 a US federal court ruled in favor of students diagnosed with mental retardation in the case of *Pennsylvania v. Pennsylvania Association of Retarded Citizens* (Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania, 1971). The decision in this case was the first of its kind and mandated Pennsylvania students with mental retardation receive a free and appropriate education. It also emphasized the notion that students experiencing disability should be educated in general education classroom alongside their non-disabled peers whenever possible.

Following the Pennsylvania decision in 1971 was another important decision in 1972. In the case of *Mills v. Board of Education of District of Columbia*, the court cast a wider net than the Pennsylvania mandate to include students with cognitive disabilities in general education

settings, and in their ruling, included *all* children experiencing disability (*Mills v. Board of Education of the District of Columbia*, 1972).

Since that time, a series of connected legislation has passed that promoted both parent involvement in the special education process and inclusive practices. In 1975 Congress passed Public Law 94-142, also known as the Education for all Handicapped Children's Act (Public Law 94-142, 1975). This law guaranteed students with disabilities would receive a free and appropriate public education (FAPE). PL 94-142 also used language that has become the cornerstone to inclusion advocates and guarantees students experiencing disability will be educated in the Least Restrictive Environment (LRE). The language in this section generally is interpreted to mean that students experiencing disability will be educated alongside non-disabled peers in general education settings to the maximum extent to which they can still make academic progress. This law has been reauthorized four separate times, most recently in 2004. The Individuals with Disabilities Education Improvement Act (IDEIA 2004) and the Elementary and Secondary Education Act, known as No Child Left Behind Act of 2001 (NCLB) both strongly support parent involvement in the special education process, and support students experiencing disability greater access to the general curriculum. The 1997 reauthorization of IDEA was the first time that access to the general curriculum was mandated for all students. At that time, there was a tremendous lack of curriculum alignment for students experiencing disability (IDEA 2004: Law and Regulations - Wrightslaw, n.d.).

The National Center for Accessible Instructional Materials newsletter writes, "The 1997 reauthorization of IDEA (IDEA '97) attempted to address many... problems, introducing important changes in the provision of educational services for students with disabilities. One of the most significant changes was the new requirement that students with disabilities have access

to the general curriculum – i.e., the same curriculum as that provided to students without disabilities” (Access to the General Curriculum for Students with Disabilities, 2003). Expanding upon the earlier concepts of Free Appropriate Public Education (FAPE) and LRE, the goal of IDEA 1997 was to raise expectations for the educational performance of students with disabilities and to improve their educational results. Four years later, Congress passed the No Child Left Behind Act of 2001 (NCLB), the purpose of which was to promote equal opportunity for all children to receive a high-quality education and attain proficiency, at a minimum, on challenging state achievement standards and state assessments (Access to the General Curriculum for Students with Disabilities, 2003). NCLB included several requirements that have implications for the participation of parents and students with disabilities in the general curriculum.

The IDEIA also provides a continuum of services to all students with disabilities consistent with the spirit of NCLB. This continuum spans from the least restrictive to most restrictive placements and includes the following mandates:

- early supports and intervention to help all students succeed;
- a decision making process that *incorporates parents and family members*;
- the same learning standards as students without disabilities;
- provisions for students with disabilities to be educated in the LRE;
- teachers who are skilled enough to work with any child on making progress in the general education curriculum;
- differentiated instruction designed to meet all student’s learning styles; and
- programming to support transition age students from ages 15-21 who need to learn practical life skills to be productive citizens (Posney, 2013).

Despite nearly forty years of continued legal progress, educators and parents continue to struggle with issues of service delivery models to student with disabilities due to lack of professional know-how, lack of personal motivation, and systemic barriers to support the process (Roach & Salisbury, 2006).

The current state of special education is based upon legislation that has occurred in the last 60 years. Key legislation supporting current practice is summarized in Table 1:

*Table 1. Key Legislation on Current Inclusion Practices*

<b>YEAR</b>	<b>HISTORICAL EVENT</b>	<b>IMPACT ON PUBLIC SPECIAL EDUCATION/GENERAL EDUCATION</b>
<b>1965</b>	Congress adds Title VI to the Elementary and Secondary Education Act of 1965 creating a Bureau of Education for the Handicapped (this bureau today is called the Office of Special Education Programs or OSEP).	Educating students with disabilities is still NOT mandated by federal or state law. However, creation of the Bureau signified that a change was on the horizon.
<b>1972</b>	Two significant supreme court decisions [PARC v. Pennsylvania (1972) and Mills v. D.C. Board of Education (1972)] apply the equal protection argument to students with disabilities.	The courts take the position that children with disabilities have an equal right to access education as their non-disabled peers. Although there is no existing federal law that mandates this stance, some students begin going to school as a result of these court decisions.
<b>1973</b>	Section 504 of the Rehabilitation Act of 1973 is enacted into statute. This national law protects qualified individuals from discrimination based on their disability. It is originally a labor law but ultimately is applied to educational environments.	This national law was enacted with little fanfare. Most educators were not aware that this applied to public schools.
<b>1974</b>	The Family Educational Rights and Privacy Act (FERPA) is enacted.	Parents are allowed to have access to all personally identifiable information collected, maintained, or used by a school district regarding their child.
<b>1975</b>	The Education for All Handicapped Children Act (EAHCA) is enacted. This act is also known as P.L. 94-142. Today we know this law as the Individuals with Disabilities Education Act (IDEA).	Before 1975, children with disabilities were mostly denied an education solely on the basis of their disabilities. EAHCA, along with some key supreme court cases, mandated all school districts to educate students with disabilities. The Individual Education Plan (IEP) is born!
<b>1977</b>	The final federal regulations of EAHCA are released.	The final federal regulations are enacted at the start of the 1977-1978 school year and provide a set of rules in which school districts must adhere to when providing an education to students with disabilities.

<b>1986</b>	The EAHCA is amended with the addition of the Handicapped Children's Protection Act.	This amendment makes clear that students and parents have rights under EAHCA (now IDEA) and Section 504.
<b>1990</b>	The Americans with Disabilities Act (ADA) is enacted.	ADA adopts the Section 504 regulations as part of the ADA statute. In turn, numerous "504 Plans" for individual students start to become more common place in school districts.
<b>1990</b>	The EAHCA is amended and is now called the Individuals with Disabilities Education Act (IDEA).	IDEA is born. One of the biggest changes from the EAHCA was the addition of transition services for students with disabilities. School Districts were mandated to look at outcomes and assisting students with disabilities in transitioning from high school to postsecondary life (18-21 yrs.)
<b>1997</b>	IDEA reauthorized	This amendment calls for students with disabilities to be included in on state and district-wide assessments, <b>and have an access to the general curriculum considered</b> . Also, Regular Education Teachers are now required to be a member of the IEP team.
<b>2001</b>	No Child Left Behind is enacted.	This law calls for all students, including students with disabilities, to be proficient in math and reading by the year 2014.
<b>2004</b>	IDEIA reauthorized (Individuals with Disabilities Education Improvement Act)	There are several changes from the 1997 reauthorization. The biggest changes call for more parent engagement, accountability at the state and local levels, as more data on outcomes is required. <b>An important change involves school districts providing adequate instruction and intervention for ALL students and mandating they progress in the general education curriculum.</b>

(Adapted from Petersen, 2007; McLaughlin, 2004)

Although the political, social and historical backdrop of educating people who experience disability is intertwined and controversial, each phase of history and each piece of legislation defining and protecting their rights have allowed them more opportunity socially and educationally. As legal mandates evolve, scholars have become more interested in studying the true benefits and potential drawbacks of inclusionary practices, along with the moral and ethical implications that go along with them.

### **Legal Role of the Parent**

The term *parent involvement* appears 1,299 times in the IDEIA (2004) and contains a section requiring states to report how parents feel about the district facilitating their involvement

(Frew, Zhou, Duran, Kwok, & Benz, 2012). It also requires states to report the percentage of parents who regard the district supported parent engagement (Frew et al., 2012). Given such a prominent legal place, and such clear research on parent involvement in general education, there is surprisingly little research on parent engagement in the special education process, particularly with respect to advocating for inclusive placements in the IEP meeting.

Along with mandatory access to core curriculum, an essential principle carefully laid out in the IDEIA 2004 is the mandate to increase meaningful parent involvement. It was developed so that schools and parents will share responsibility in ensuring students who are receiving special education services have equitable access to educational opportunities (Fish, 2008). Indeed, parent participation is woven throughout the entire IDEA/IDEIA and includes family engagement in informal and formal settings with school staff mandates (Trainor, 2010). Parent responsibilities include being a member of the IEP team and attending one or more formal IEP meetings each year, making a good faith attempt to understanding the complicated special education process, understanding and providing permission for unbiased and fair evaluations, and ensuring their student's IEP is actually being implemented and followed in the classroom (Trainor, 2010). Thus, parental involvement is considered in the legislation to be vital, intensive, and enduring.

### **Benefits of Parental Involvement**

Research findings documenting a link between parents' involvement in their child's education and improved educational outcomes are clear and consistent. In their extensive research on the impact of parenting on education and parent engagement, Desforges and Abouchaar (2003) point out that it is widely recognized that if students are to maximize their educational experience, they will need the full support of their parents. Moreover, established

benefits of parent involvement include improved social emotional outcomes for students, greater academic achievement gains (including improved literacy), and less negative behavior issues with students (Egbert & Salsbury, 2009; Jeynes, 2007; Rodriguez et al., 2014). In the context of parent engagement positively impacting student outcomes, an argument can be made that it may be especially important for parents of students experiencing disability to engage in their child's education and advocate for their student to receive an education in an inclusive setting (Frew et al., 2012). When such a process occurs and IEPs are crafted with parents as partners, academic achievement for students is shown to improve (DeFur, 2012).

Current research suggests that approximately 90% of parents of students experiencing disability are involved in the IEP process through their student's K-12 school experience (Blackorby, J., Knokey, A., Wagner, M., Levine, P., Schiller, E., & Sumi, C., 2007; Frew et al., 2012; Newman, 2005). Existing research on general education and parent participation yields similar parent involvement results (Frew et al., 2012). Families who have students experiencing disability participate at about 77% (vs. 70% of general education families) in school meetings, 62% in classroom events (vs. 59% of general education families) and 24% of volunteer opportunities (vs. 26% of general education families) (Frew et al. 2012; Newman, 2005).

### **Parent Advocacy**

Parents engage with their students' education in multiple ways and through several activities. Clearly in the special education system, the IEP process in particular touches upon themes of parenting, communicating and decision making. For instance, Joyce Epstein's research has identified six main types of parent engagement: parenting, communicating, volunteering, learning at home, decision-making, and collaborating with the community (Epstein, 2010). Ashford University Special Education Professor Laurie Wellner (2012)

discusses the trust that is necessary for both parent and professional when collaborating during the special education process and elements of Epstein's six categories. She notes that trust must build with time and happens when there is a constant, sustained positive effort on the part of both parent and professional to work toward a common goal for a student. Much of what Wellner and Epstein both describe is the work of parent advocacy. Advocacy is a key tool parents need to use throughout the involvement process since it is critical they be heard (Bacon & Causton-Theoharis, 2013).

Community meetings and/or groups is another way parents engage with their student's experiencing disability. Successful support of students "will likely require educators and service providers to cultivate new partnerships and natural supports within the broader community" (Carter, Swedeen, Cooney & Moss, 2012, p. 16). Working with the school district alone often does not produce the results parents need. Community groups provide support, information as well as local and legal advocacy for parents (Carter et al., 2012).

Although there are many ways to categorize the different reasons parents engage with their child's education, Rodriguez et al. (2014) point out three primary reasons in which the subject of parent and school involvement are important to consider. First, parent involvement legal mandates have significantly evolved (Individuals with Disabilities Education Improvement Act, 2004; No Child Left Behind, 2001). Second, there is substantial evidence that parent involvement improves student achievement and overall success of a child (Desforges & Abouchar, 2003). Third, there is an ethical and moral component that advances the need to engage parents as "the right thing to do" (Auerbach, 2012. p. 10).

As parents advocate for more inclusive placements for their students, they have significant inclusion research to help strengthen their case. Indeed, the value of inclusion has

been well studied. Inclusive practices have been shown to raise the achievement of disabled and non-disabled students in the classroom (Causton-Theoharis & Kasa, n.d.; Hanushek, Kain & Rivkin, 2002; Rodriguez et al., 2014). Additionally, inclusive practices have been shown to improve the social skill abilities, and academic achievement of all students (Causton-Theoharis & Kasa, n.d.; Posny, 2013; Waldron & McLeskey, 1998). Furthermore, the rate of student learning increases when inclusion of students with disabilities is practiced. Research has also demonstrated when students experiencing disability are included, teachers work harder to teach, provide more technology access, and teach with greater levels of differentiation (Causton-Theoharis & Kasa, n.d.; Kasa-Hendrickson & Ashby, 2009). One parent who participated in a study looking at the benefits of inclusion noted, “Typical kids are learning from the experience tolerance, responsibility, perspective, social responsibility. There are not as many prejudices” (Carter et al., 2012, p. 10).

There is mounting evidence that the more we include students experiencing disabilities in our general education classrooms, they construct a sense of themselves that is significantly more positive than students who have been in more segregated settings (Fitch, 2003). In their research on the efficacy of special education programs practicing inclusion to raise student achievement, Hanushek et al. (2002) found inclusion improves the achievement of both special education and general education students. They report:

Special education programs on average boost the achievement of students provided this special treatment...More surprisingly, achievement gains for students who do not receive special education are positively related to the percentage of students classified as special education, and there is little or no evidence that mainstreaming systematically harms non special-education students. (p. 585)

When McLeskey et al. (2013) using the lens of practicing educators interviewed teachers from three elementary schools in a qualitative study on inclusion, the participants pointed out many benefits of inclusion. They noted that when students with disabilities enter their classroom, it caused them to set higher expectations and ultimately they discovered many students had skills that they originally thought they didn't have. They also reported students experiencing disability learned good coping mechanisms that benefitted them long term through high school. Acquired coping skills included how to deal with workload, and how to seek help on work when the teacher is unavailable. One teacher commented that a supportive, inclusive environment helped students feel safe. She noted, "I think [inclusion] presents an opportunity for them to learn without being judged. It's a non-stigmatizing environment for them. Everyone sees them as students, not based on their labels" (McLeskey et al., 2013, p. 54).

Causton-Theoharis and Kasa (n.d.) point out that a benefit of inclusive classrooms is they create a strong sense of belonging. The concept and importance of belonging is further defined by McLeskey et al. (2013) as being part of a community in which members care for and respect its members whomever they are, taking into account any strengths and shortcomings. They also define community as a place that brings "satisfaction and comfort, and knowing that they can depend on others for support when it is needed" (McLeskey et al., p. 4).

Interestingly, there is little research evidence to suggest that inclusionary practices are *harmful* to students. Parental and educator concerns around the practical aspects of implementing an inclusion model are well documented, however there are virtually no empirical findings that non-disabled students suffer adverse effects from learning alongside their disabled peers.

Although there has been some research on parent's overall perception of their engagement in the IEP process, very little of this research pertains directly to parent advocacy for inclusive placements. Parent perceptions of school meetings vary fairly significantly. In a 2008 study, researcher Wade Fish (2008) surveyed 51 parents about their experiences in their child's IEP meeting. Although the 63% of parents reported that their experience was positive, some barriers and concerns were noted including relationships with special education staff, knowledge of the special education process and understanding of a specific disability. Fish also notes the key importance of educators creating positive relationships with parents, allowing parents to equally share their viewpoint at the IEP meeting, and valuing parents as equal partners. Fish's results are consistent with those of Rodriguez et al. (2014) who note that a parents' view of their own self efficacy in the IEP process will impact the extent to which they become involved. Additionally, there is some research suggesting that another motivator for parent involvement occurs when school personnel are perceived as not reaching out to students. That is, some parents tend to be frustrated and are motivated to engage the school as a means of understanding what is going on for their student (Rodriguez et al., 2014).

Counter to the research conducted by Fish (2008), Stoner et al. (2005) studied the perceptions of families with young students experiencing autism spectrum disorder. Her conclusion is that parent's perception of their initial IEP meeting had been "traumatic, confusing, and complicated, and that their perception led to dissatisfaction with the special education system" (Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, E. P., 2005, p. 43).

Despite consistent research, findings on the value of inclusionary practices, parents often encounter a series of barriers when they advocate for their student to be in an inclusive setting

and can find themselves advocating for a system that is poorly understood and implemented (Causton-Theoharis & Kasa, n.d.). Part of this lack of understanding could be that schools continue to organize in traditional patterns of segregated settings. In his book, *The School Leaders our Children Deserve: Seven Keys to Equality, Justice and School Reform*, prominent inclusion researcher George Theoharis (2009) points out school leaders need to “see inclusion in the broader context of social justice, not only as a placement or type of programming for students with disabilities” (p. 27).

Theoharis (2009) asserts that raising academic and social skills for all students is just the tip of the iceberg when it comes to inclusionary practices. He believes inclusion is a civil and humanitarian right all students deserve and to which they are legally entitled. He also argues for a wider view of inclusion to encompass more than students experiencing disability, “The overlap of race, class, language, and disability has aided in preventing inclusive services for all students as schools have created a proliferation of programs aimed at students who struggle” (Theoharis, 2009, p. 28). He contends a successful system cannot exclude one group and include another. For example, students who are English language learners (ELL’s) cannot be integrated and included in general education settings and students experiencing disability left out of the inclusion equation. From a social justice perspective, Theoharis would say that the choice to “exclude and include” is inherently excluding. The challenge educators have is to balance their inclusive focus for *all* students, including those experiencing disability.

Additionally, Fishman and Nickerson (2014) assert that parents of students experiencing disability face greater barriers to engagement than students who do not experience disability. Although parents often are recognized as stakeholders in public school district reform, their “...active involvement, expertise, connections and especially, leadership, may not frequently be

drawn upon within inclusive initiatives” (Carter, et al., 2012, p. 9). In other words, parents do not necessarily feel they are an important part of the inclusionary placement process for their children. Because inclusive programming efforts require many resources (time, money, expertise) there is often a difference in power between school staff and parents. Often times the party in power gets what they need, and others don’t (Trainor, 2010). Researcher William Fish (2006) notes that “Despite federal law (IDEA), many parents feel alienated because educators continue to dominate the decision-making process” (p. 60).

In a 2014 study that looked at 96 parents’ views of schools’ involvement efforts to include them across 18 schools, several prominent and noteworthy themes emerged (Rodriquez et al., 2014). They included variance in parent and school collaboration, parent involvement in the academic progress of their child, parent initiative taken in their involvement, a wide variance in communication needs, academic work and transition stress and varying levels of parent trust with the school. Studies such as this one help clarify the multiple forms of parent engagement and the issues that can be challenging as parents assume the role of advocate and educational partner for and with their child. In other words, parent engagement is not a one-size-fits-all proposition. It needs to take into account the individual needs of families, their students and their beliefs about education (Wellner, 2012).

Embedded within varied family values and beliefs related to inclusion is a notion held by some that non-disabled students in general education classrooms will be harmed by students experiencing disability. However, there is a growing body of evidence supporting the assertion that non-disabled students are not just unharmed, but likely to benefit when participating in an inclusive environment in which students experiencing disability are present (Peck, Staub, Gallucci & Schwartz, 2004).

Carter et al. (2012) analyzed the benefits of inclusion for non-disabled students and concluded "...at least some nondisabled children experienced their opportunities to have relationships with peers who have severe disabilities to be highly rewarding" (p. 9). In another study, Giangreco (1993) et al. surveyed 81 parents who enrolled their non-disabled child in an elementary classroom with at least one child who had a severe disability. Eighty-one percent of parents believed the experience with inclusion had improved their child's social and emotional growth and 90% acknowledged their non-disabled child had a positive experience in a classroom in which students with severe disabilities were present. Their study also revealed that the emotional climate of the classroom improved when children highly impacted by disability were included.

Additional procedural and technical barriers exist. Research suggests many parents lack knowledge regarding special education jargon, acronyms and terminology (Fish, 2006). Indeed the field of special education is ripe with specialized jargon and acronyms. Examples of such acronyms include "IEP," "IDEA," "ASD," (autism spectrum disorder) "OT," (occupational therapy) "PT," (physical therapy) and "SDI" (specially designed instruction) (Fish, 2006). Fish (2006) notes that parents also are at a disadvantage because they lack the professional expertise of the professionals they are team members with at the table. As a result, parents feeling this way easily allow professionals to make important decisions.

Due to the political, social and cultural implications of the special education process, there is often a power dynamic present in meetings between school staff and parents. Ware (1994) describes the bureaucracy of the educational institution undermining parent and professional collaboration and relationships. She asserts that the contextual views of the parent are often discounted (i.e. "you are not a professional") and instead the medical and psychological

knowledge of professionals is deemed as more important. This dynamic immediately establishes a social hierarchy in which the parent is not on top (Bacon & Causton-Theoharis, 2013; Ware, 1994).

In his 2008 study of 51 parents' perceptions of the IEP process, Fish (2008) notes that IEP meetings are often more heavily influenced by the expertise of professional educators than by parents' anecdotal knowledge. As a result, parents are often the recipients, rather than sharers, of important information about their child. He ultimately concludes by noting that "positive and equal partnerships" between parents and school personnel are critical in order to increase the effectiveness of IEP meetings (Fish, 2008, p. 12)

Research has also documented important cultural barriers to parent's abilities to advocate within the context of the school structure. The special education system in the United States is dominated by cultural assumptions from the prevailing Caucasian culture (Woo Jung, 2011). Several factors have been identified as inhibiting parent involvement with the IEP process for culturally and linguistically diverse families. They include: a family's acculturation level, limited English proficiency, the difference in values and attitudes toward disability, a communication style different from mainstream American culture, and minimal knowledge about the IEP process and school organization (Harry, 1992). Parent engagement systems often also assume parents will want to engage in English and are not prepared for alternate languages to be used. Kalyanpur and Harry (1999) assert that this belief is based in a United States culture that values traits such as individualism, equality and "the need to exercise one's rights" (p. 122). Although the benefits to parent engagement are well known, these values are not always shared in families with diverse cultural and ethnic backgrounds who are often excluded from opportunities (Lo, 2012; Salas, 2004).

Currently, Latinos are the largest minority group in the country (U.S. Census Bureau, 2015). Many Spanish speaking families report that language and cultural barriers exclude them almost completely from engaging in the IEP process (Mueller, Milian, & Lopez, 2009). As a result, cultural and language barriers set up an imbalance of power between parent and professionals (Harry, 2002; Kalyanpur, Harry, & Skrtic, 2000; Mueller et al., 2010). Research suggests there are two main forms of discrimination culturally diverse parents endure, including discrimination based on culture (which encompasses ethnicity, language custom and appearance), and discrimination based on disability (making judgments about why a child has a disability, such as discrimination based upon, i.e. “She must be retarded because you did drugs”) (McHatton & Correa, 2005).

Research has also yielded similar results with African American students and families. Brandon and Brown (2009) noted that when an achievement lens is pointed at African American students, data reveal that they as a group do not do as well academically, socially, or behaviorally as compared with their white peers who are non-Hispanic. It also has been widely noted that these students are overrepresented in special education programs since the passing of IDEA.

Kalyanpur and Harry (1999) argue that professionals must refrain from interpreting their communications with culturally and linguistically diverse families through the context of their own lens. They suggest that school professionals work toward understanding the family’s beliefs, compare them to their own and then engage parents from that point forward. It is suggested that school personnel must reach out to families and that parents want to be involved but “...do not know where to begin” to engage with their child’s school system (Brandon & Brown, 2009, p. 87).

Many principal and teacher training programs do not adequately prepare educators with the personal knowledge and leadership skills necessary to implement a successful inclusion program (Barnett & Monda-Amaya, 1998; Lazaridou, 2009; Roach & Salisbury, 2006). Consequently, parents are often faced with the prospect that their child's school personnel are not knowledgeable of inclusive practices. As a result, principals may have a difficult time responding positively to parents and implementing a successful inclusion model (Roach & Salisbury, 2006).

Historically, much of the principal role did not require knowledge of special education or students with disabilities. As recently as 1985 the Commission on Special Education identified crucial gaps present in special education training for school administrators:

The present special education structure gives community superintendents and principals no formal responsibility or authority for the hiring, training or supervision of special education teachers or support staff, the curriculum for special education programs, the allocation and assignment of special education guidance counselors...or the supplies for special education classrooms. They also have no formal authority over the referral, assessment, and decertification process or the decision to mainstream a special education student from a self-contained classroom into a regular classroom for part of the school day...Once students are placed in special education, regular education administrators usually relinquish any responsibility for these students' education, and there is virtually no dialogue or interaction between the two systems. (p. 117-118)

Since 1985, the limited literature on principal preparation programs suggests progress has been minimal. Valesky and Hirth (1992) investigated multiple states in an effort to measure principal preparation requirements in the specific area of special education. A similar survey

was conducted in 1998 by Bateman. Although the design and questions posed in each study are different, the results are similar. In their 1992 study, Valesky and Hirth found that of the 47 states responding to their research, only 21 states had a special education training component. A generalized introductory course was required in 16 of the states, however the content of these courses were unknown. The four states remaining required that principals have “general knowledge” of special education, however a course was not specifically mandated in the subject. Six years later, Bateman (1998) reported similar results; 48 states responded to the survey and of those respondents, 23 different states reported that no special education coursework was required for principals to obtain an administrative license. The other eight states did require a general special education introductory class for administrative licensure. The content of the courses again was unspecified.

More recently Payne (2005) suggests teachers are often ill equipped to carry about all the responsibilities special educators face in the field. Preparation programs for special education teachers are also another factor in looking at retention and attrition. He notes, “Researchers have found many special education teachers to be unprepared for all the responsibilities that the job encompasses” (Payne, 2005, p. 89).

The results of this gap in educator preparation programs have led to significant skill deficits in multiple areas of the principalship and teacher preparation, as related to special education programs. Principals often do not have enough basic curriculum and instruction knowledge for special education to be effective program leaders (Roach & Salisbury, 2006). These findings were corroborated by Lazaridou (2009) who noted that many current principal training programs place a strong emphasis on managerial and instructional leadership, however not with respect to specialized populations. Additionally, creating an inclusion based setting

often requires making changes to more traditional segregated teaching models. However, despite the fact that principals are in a powerful position to facilitate this change, they often do not have the skills to do it (Bailey, 2004). Shifting to an inclusion based model often requires a principals' ability to carefully navigate the transition from a more restrictive to less restrictive program. Many principals do not possess the skills necessary to effectively manage this change process within their building. Effectively managing change requires principals to provide professional development, incorporate all stakeholders and creating communication feedback loops to enhance and support the communication process (Poon-Mcbrayer & Wong, 2013; Salisbury, 2006).

As budgets cinch down in the public education system and more demands are placed upon schools, time and resources can be challenging. One principal shared that timing is often a huge barrier to planning, "We meet, we meet, we meet because you cannot coordinate all these people and services without meeting..." (Salisbury, 2006, p. 77). Causton-Theoharis and Kasa (n.d.) note that classrooms need to be physically set up for space as well. Using models such as a Universal Design for Learning (UDL) for a classroom ensures that all students have access to learning. UDL classroom models include setting up areas where students in wheel chairs and ambulatory students can work collaboratively on projects and both have access to adequate space, along with other concepts such as multiple means of knowledge expression. With increased numbers of students in many districts, and budget restrictions, the inclusion mentality can take some re-thinking of traditional spaces.

## **Conclusion**

Over time, it is clear the social and legal evolution of educating individuals experiencing disability has placed parents as a key player in designing educational services for their child in

the American school system (Bacon & Causton-Theoharis, 2013; Winzer, 2006; Rodriguez et al., 2014). Increased research on the benefits of inclusion and parent involvement have intertwined to create renewed hope of finding effective service delivery models for students experiencing disability (Bailey, 2004; Causton-Theoharis & Kasa, n.d.; Forbes, 2007; Roach & Salisbury, 2006). Parents are now involved on multiple levels of their child's education and research shows it is crucial they do so to ensure their success. Yet, despite the advantages inclusive placements offer, parents still face barriers to achieving such an education for their child (Bacon & Causton-Theoharis, 2013). Due to social, cultural and professional issues related to disability, parents still often find themselves struggling to understand and be understood.

## **CHAPTER 3**

### **METHODS**

#### **Introduction**

The purpose of this study was to examine the experiences of five parents who have a student experiencing disability for whom they have advocated to be educated in an inclusive setting. More specifically, I used personal interviews to understand their perception of opportunities to advocate (in both formal and informal structures), advocacy activities in which they have engaged, their perception of school district personnel, and their students' responses to their advocacy. An objective of this investigation was to better understand positive and negative perceptions articulated by these parents. This chapter identifies the setting for the research, a brief discussion on the logic and methods of phenomenology as a research approach, the procedures used to collect and analyze the data, the critical ethical considerations, and the potential contributions of the study.

#### **Setting**

All participants came from a large suburban and rural district serving K-12 students in Oregon. Thirty percent of students are identified as English Language Learners and approximately 2,800 students are eligible for special education services. Specifically, the district has 49% of students living in poverty and eligible for the free and reduced lunch program.

#### **Sampling Strategy, Participants, and Research Design**

I employed a purposive sampling strategy involving five parents who have a biologically related or adopted student with an IEP currently in an Oregon, K-12 public school. Purposive sampling is appropriate for this study because I had a specific type of family in mind. The

research parameters required the parents be related to children by birth or adoption. The parameter avoids introducing factors that may interfere with the participants being able to provide in-depth answers. For example, a foster parent may not have knowledge of the history of the student's education or what the student's experience has been. Thus, participants were deliberately recruited based on my assessment that the participants had met the key criteria necessary to answer the research questions. These criteria included families who currently have or historically have had children attend school in the district. These families also needed to have a willingness to share their stories.

A qualitative research approach within a phenomenological framework using personal interviews was the design of this study. The personal interviews averaged approximately 90 minutes each. A series of five guide questions were asked to each participant with subsequent follow up questions as necessary (see Appendix A). Interviews were recorded and later transcribed in order to analyze and code the collected data. An interview-based, qualitative approach for this research is appropriate because it was my desire to dive deeply into the lived experiences of the participants. The goal was to understand deeply both perceptions and experiences of those whom give their time and energy to be interviewed. Thus, this research involved a phenomenological approach.

### **Phenomenology**

A phenomenological approach is appropriate to frame this qualitative study because, as mentioned, my intent was to explore the lived experiences of parents advocating for their child experiencing disability to be educated in an inclusive setting. I selected this specific qualitative tradition because I was interested in capturing the perceptions of parents through their personal lens of experience. The current literature reflects a large gap in qualitative studies with respect

to parents' advocacy experiences for their children who experience disability. Without understanding the phenomenon of parents' advocacy experiences, we cannot understand the nature of the inclusion for which they are advocating and cannot ultimately be better prepared as professionals to address the challenges and victories inherent in working with parents in the context of inclusive settings. Parent voice is a critical factor in understanding the experience and impact of inclusive settings, as well as implications for professional development and practice.

A phenomenological approach "...aims at gaining a deeper understanding of the nature or meaning of our everyday experiences (Van Manen, 1990, p. 9). Jon Creswell (2007) asserts that phenomenological research is well suited in situations where the goal is to understand people's "common or shared" experiences. He also points out that the analysis of experiences is important to understanding "practices or policies or to develop deeper features of the phenomenon" (Creswell, 2007 p. 60). Van Manen explains, "Phenomenology asks for the very nature of a phenomenon, for that which makes a some-'thing' what it is – and without which it could not be what it is" (Van Manen, 1990, p. 10). Therefore, in order to discover what the experience is of parents who are advocating for their children who experience disability, it is necessary to understand the multifaceted nature of their conscious experience when doing so.

Phenomenology is a form of interpretive research rooted in the philosophical traditions of Kant, Hegel and Mach (Gay, Mills & Airasian, 2009, p. 12; Creswell, 2007, p. 7). However, German philosopher Edmund H. Husserl is credited as the founder of phenomenology (Patton, 2002, p. 105). His basic philosophical assumption was that a human being is limited by the experience received through their senses (Patton, 2002). He asserted that all the conscious data people receive through their senses then must be "described, explicated and interpreted" (Patton, 2002, p. 105). Ultimately he developed the view that phenomenology consists of how people put

together the various phenomena we experience and ultimately form a world view (Patton, 2002). Van Manen calls this form of study, "...study of the lifeworld" and explains its opposing form of research is a study of the natural world" (Van Manen, 1990, p. 9). The job of the phenomenologist is to deeply explain and interpret a phenomenon so the reader can understand the "lived quality and significance of the experience in a fuller or deeper manner" (Van Manen, 1990, p. 10).

Phenomenology also is appropriately used to address experiences that may not have an absolute "right" or "wrong" answer, and that may have a moral piece embedded within them. Phenomenology by nature is not boiled down to specific data or a concrete conclusion. It is rather about the journey through an experience. Van Manen (1990) compares this idea to written poetry, in which each word is explicitly chosen to create a rhythm or flow. To dissect the poem and expect a conclusion, would ruin the essence of the poem itself (Van Manen, 1990). Much like poetry, a parent's advocacy experience cannot be divided into little pieces to understand the total experience. It must be taken as a whole and looked at in a complete way to understand its essence. Phenomenology also takes this experiential essence and carries with it a "moral force" that may influence others' actions and choices (Van Manen, 1990).

My ultimate desire is that by understanding parents' advocacy experiences for their child experiencing disability through phenomenological study, professionals will be better equipped to ultimately create more supports for the students, parents, and professionals involved in the education process.

### **Data Collection and Analytical Procedures**

Data were collected from personal interviews with each one or both parents in four families. It is important to note that "parents" is the unit of analysis, and thus, it is consistent that

the interview involved either one or both parents at the convenience of the participants.

Additionally, consistent with phenomenological interviews, I used “grand tour” questions (that is, general questions) in order to allow the participants to frame their own lived experiences (Appendix A).

I used digital recordings that were later professionally transcribed. Additionally, I also used field notes to supplement transcriptions. Field notes contained observations not captured in spoken words as well as potential emerging themes observed. Data were derived from primarily the transcribed personal interviews and secondarily from the field notes. Data were coded into themes that emerged from interviews. The salient themes were then used to examine and provide answers to the research questions used to structure the investigation. As my objective was to understand the lived experience of the participants, I used a great deal of excerpts derived from the interviews as a way to document those lived experiences. Phenomenologists refer to this analytical technique as “chucking” the data in order to extract meaning from the participants’ point of view and personal experience (Moustakas, 1994).

### **Research Ethics**

Informed consent was obtained via a letter of consent given to each prospective participant (see Appendix B). Those agreeing to participate in the study signed the letter of consent, as did I as the researcher. Data derived from the interviews were analyzed and are presented in an anonymous fashion in which no individual is personally identified. All personal information and identities are confidential, thus ensuring anonymity and confidentiality among participants.

In order to mitigate any risk to participants, all research materials (i.e., audio recordings, transcriptions and signed consent forms) will be locked in a separate, secure location for a period

of three years. I am personally responsible for them and am the only individual who will have access to these materials. After a period of three years I will personally destroy all relevant materials and delete the audio recordings. Permission for this research was obtained from the Institutional Review Board (IRB) through George Fox University and through the school district in which the interviews were being conducted.

### **Potential Contributions of the Research**

Understanding the lived experience of parents advocating for inclusive placements for their children is critical to both professionals and families in order to continue improving the education of students experiencing disability. If professionals are unable to understand the experience of parents who feel strongly about inclusion, they are simply unable to effectively collaborate and create agreed upon goals, practices and behaviors with those parents. The small body of qualitative literature on parent advocacy related to inclusion clearly documents that parents feel overwhelmed, misunderstood, and confused about the complicated special education process and related laws. This study and others like it are valuable to the field to inform professionals of the likely position from which parents come from when they advocate for their children. A greater appreciation of common parent challenges and likely requests will also allow professionals to effectively problem solve and create strategies in advance of any conflict to promote positive and productive family-school partnerships, which in turn translate to improved student experiences.

This research has implications for specific and practical changes for professionals to consider. A major contribution is to underscore the importance of districts reviewing and developing more collaborative and inclusive IEP meeting practices. If districts can more accurately understand the parent perspective they can build stronger parent partnership programs

at the building and district level, and be able to serve students more effectively. The research also suggests districts would benefit from willingness to understand and promote an inclusive climate and culture in buildings through professional development. Such increased understanding and communication would also likely lead to less conflict, improved authentic relationships with parents and less litigation for districts. Qualitative research has the unique ability to tap into our affective thinking, and therefore impacts our emotional response. This response is critical to understand since part of our “lived experience” is related to how we feel as human beings, and it drives much of what we do. This study has the potential to help us understand why parents advocate for inclusive settings, and in doing so understand why it is crucial professionals partner, problem solve and remove barriers for parents and students so students can ultimately meet their full potential.

## CHAPTER 4

### FINDINGS

#### Introduction

Van Manen contends that the ultimate goal of qualitative research is to create a form of phenomenological text (Van Manen, 1990). According to Patton (2002), the phenomenological text involves how an individual experiences a particular phenomenon. While this study sought to explain the experiences of five parents who have students experiencing disability, it is important to keep in mind that the nature of phenomenology itself mandates the researcher “meditates between different meanings of the lived experience” (Van Manen, 1990, p. 26). The investigative requirement generally is what is meant by hermeneutical social reference or hermeneutical phenomenology (Finlay, 2009; Heidegger, 1976; Kafle, 2011; Lavery, 2003).

Kafle (2011) identifies three types of phenomenology: transcendental phenomenology, existential phenomenology, and hermeneutic phenomenology. While transcendental phenomenology is the branch of philosophy concerned with an “adherence to the notion that experience is to be transcended to discover reality” (Kafle, 2011, p. 186) and existential phenomenology is the branch of philosophy that “share the view that philosophy should not be conducted from a detached, objective, disinterested, disengaged standpoint. This is because, they contend, certain phenomena only show themselves to one who is engaged with the world in the right kind of way” (Kafle, 2011, p. 201), it is hermeneutical phenomenology that has largely become the domain of social scientists. Kafle explains:

Hermeneutic phenomenology is focused on subjective experiences of individuals and groups. It is an attempt to unveil the world as experienced by the subject through their

life world stories. This school believes that interpretations are all we have and description itself is an interpretive process. To generate the best ever interpretation of a phenomenon it proposes to use the hermeneutic cycle. (2011, p. 187)

Van Manen (1990) argues that hermeneutical phenomenology requires dynamic interplay between the researcher and her participants. Therefore, the reflected textual process needs to be understood as a dynamic interplay and inherently includes the history, experiences, interpretations, feelings and interactions of both researcher and participant.

This chapter presents a hermeneutical use of phenomenology. Namely, I will first describe the participants in order to establish some contextual background. Next, I will identify and articulate the major themes, that is “lived experiences” present within the personal interviews. The field notes also provide much needed information, especially regarding the background, contextual material. As a result, the field notes helped to achieve what Van Manen and other phenomenological thinkers identify as the “interplay” necessary for hermeneutical social research.

### **Description of the Participants**

Three mothers, and one mother and father couple were interviewed for an average of 90 minutes each. I sent the participants questions in advance in order to increase the quality of the interview by allowing for reflective preparation. All participants currently have students receiving special education services in the same large Oregon suburban school district. I hold a current executive administrative position in this district as well and was cognizant of this limitation noted in the discussion on bracketing presented in chapter 1.

*Participant A* is a 46 year old married mother with four biological children. She is a homemaker and active in her Latino community. She is of Hispanic origin and although she is

bilingual, she was more comfortable expressing herself in Spanish. An interpreter was used during the interview to ensure accurate understanding both for interviewer and interviewee. Two of her children experience profound disability. One child currently is enrolled in the district 18-21 year old transition program and the other is currently in his junior year in his neighborhood high school and accesses a “life-skills program” as needed.

*Participant B* is the 47 year old married mother of a son she and her husband adopted from China when he was an infant. She is Caucasian and her primary language is English. Her son currently attends school in a 3<sup>rd</sup> grade “life-skills program” that is not his neighborhood elementary school, but rather in another elementary school in the district. She has a professional career as a research librarian for a major local company and does not have other children.

*Participant C* is a 49 year old married mother of biological twin boys. One of her twins experiences multiple profound disabilities. Her sons are now 18 and her son who experiences disability is involved in the district’s 18-21 year old transition program. She is Caucasian and her primary language is English. Participant C currently works as a resource teacher and case manager in the same school district and credits her sons for motivating her to complete her teaching licensure degree.

*Participants D and E* are husband and wife, respectively. Participant D, the husband, is 45 years old; participant E, the wife, is 44 years old. They were interviewed together and both actively participated in the interview process. They are the parents of two biological sons. Their older son experiences moderate autism and participates fully as a 6<sup>th</sup> grader included in his neighborhood elementary school. Both parents are Caucasian and speak English. Participant D has met with the researcher on multiple occasions to build a relationship with administrators who

work in the district office and both parents are very active in their children's education and their community.

### **Data Analysis and Identification of Themes**

I identified seven multidimensional themes during the data analysis process. Specifically, I followed a three stage data analysis process common among qualitative researchers (Kleiman, 2004; Patton, 2002). These stages included initial coding, focused coding, and thematic coding.

I first identified all individual experiences discussed by the participants. This part of the data analysis process resulted in the identification of 325 individual phrases representing the experiences of the participants. These initial coding themes were collected in a database in order to organize them for refinement during the focused coding process. Using the technique of repetition, essentially the frequency to which an experience or perception is cited by participants (Creswell, 2007), I was able to collapse the 135 initial coding themes down to seven prominent themes shared by the participants. Essentially, these seven focused coding themes represent the "lived experiences" common to the participants of this study. During the thematic coding process, I examined the totality of the interviews and lived experiences for important patterns and insights. The thematic coding allowed me to critically address and provide answers to the five research questions guiding this phenomenological investigation (see chapter 1).

This chapter presents the findings resulting from the focused coding by identifying the seven "lived experiences" common to the participants. Chapter 5 presents the findings emerging from the thematic coding through a discussion of the research questions. The seven lived experiences themes are:

1. Definitions of inclusion

2. Advocacy: A mixed experience
3. Advocacy is an emotional journey for parents
4. Sources of support for parents
5. We want to be a team!
6. Communication
7. Professional development needs of staff

### **Definition of Inclusion**

Each parent I spoke with had a similar but varied definition of inclusion and inclusive practices. The research is very clear that a common challenge of dealing with inclusionary practices is the lack of a single, accepted definition. Runswick-Cole's research with parents suggests that parents hold "complex and conflicting views about the policy and practice of inclusion" (2008, p. 176). She further points out that while the professional literature discusses inclusion in a socio-political context, parents also often associate inclusion with the location in which their child attends school. In many respects, that is the case for the participants in this study. For instance, Participant A related:

Inclusion...is for children to be treated the same as any other student. For them to get the same opportunities as all other students. To get the respect and to get, obviously, the accommodations and modifications to the opportunities all other students get, they need to be available to students with disabilities as well. Inclusion is when children are looked at for their ability and not their disability. In inclusion, the children need to be looked at for all their abilities they do have. Staff needs to remember that all children regardless of their disability, have the same feelings as a regular child. I walked into my son's regular

classroom one time and he was just sitting in the corner by himself with his assistant. For me, that's not inclusion.

Regarding the notion of inclusion, Participant B reflected:

It's interesting because I think the concept of inclusion in my mind it gets confused with the idea of mainstreaming. I think my personal concept of inclusion with [her child's name] is that he is included in the school with his peers as much as possible within the framework of what his needs are. I don't look at it as- I look at it more as a continuum, and that changes depending on where he's at and has changed throughout the course of time at [his school]. Actually my concept of inclusion changes depending on what I see going on with him in class.

Participant B also commented on the concept of inclusion related to school culture and community:

I think more than just be included with his peers is that the idea of inclusion in the school is that kids are included or thought of as the greater community without separating them into a separate group. And that the teachers and the staff think of all of their students, even if they are in a self-contained classroom part of the time, they're still included.

They are not thought of as the special ed. kids...I think that's my idea of inclusion is that there's this idea of including all kids as our students. They're all our students.

Participant C also viewed inclusion in terms of both the culture and climate of a school.

She stated:

To me inclusionary practices is how a child is treated when they're in their school as a valuable member of that community. So that you look at the school culture and climate and you say, "Do we look at all of our students as important members?" "Do we give

those opportunities to be included all over and in different an unusual ways?” You know because you have to think a little outside the box. You’re looking at a student with a certain skill set and skill deficit. You may have to find interesting ways to make them part of the class.

She also spoke about what inclusion was not. She related, “We have a lot of work today, because just dropping a child in who can’t access what’s going on and just is looking like a learner is not inclusion. Some people think it is.”

Participant D characterized inclusion in terms of adult attitudes and beliefs. For him it is important to keep a larger social, personal, and even professional perspective:

In terms of inclusion, how it looks, I guess I’m looking at more of the big picture with it – is that all kids have access. So when you go into the room, that the community is the community. We all need to “assume competence” with kids. Don’t assume incompetence. Assume they can do something, and then work from there. I think, also, that helps cultivate a strong environment for including practices, is that it is strengths-based in how it’s implemented, not necessarily deficit based.

His wife, Participant E, added:

I’d say the maximum amount of time in the general education classroom, with support. [Son’s name], especially has always wanted that anonymity. He wants to do what everyone else is doing. He doesn’t wanna be pulled out and like he’s having to be separated, he’s having to do everything else. He doesn’t want to think he’s missing anything that’s happening in that Gen Ed classroom. So as much as he can be integrated within that, it is best for him.

### **Advocacy: A Mixed Experience**

There are little data on parent advocacy experiences with respect to specific advocacy for inclusive placements for students experiencing disability. However, the data that do exist are varied. Researchers report a tremendously negative experience among some parents, while other parents feel their experience is relatively positive (Bacon & Causton-Theoharis, 2013). The findings derived from the interviews included as part of this study indicate that same diverse mixture. However it is critical to note that although all of the participants had some positive experiences, the majority of the lived experiences shared among the participants were negative. Notably, the positive experiences often occurred with some advocacy support. The advocacy experiences occurred primarily in the school setting, although parents also utilized community, medical, other professional and parent-to-parent support to successfully advocate for their child.

Simply at times, the school district's response was positive and at times, negative.

Reflecting this varied experience, Participant A recalled:

I remember a meeting with the Special Education Director at the time. This was with my older son when he was in elementary school. In the meeting, he held up two drawings for me. One drawing was of a self-contained classroom, which for me is a classroom that is segregated, and the other picture was of [her son's name] in a general education classroom but the rest of the day in the segregated classrooms. So, with those two drawings, those were the only options that my son was given. I remember telling the Director at the time "You forgot the picture with the normal students and [her son's name] in that. You forgot the full inclusion picture." I was requesting for my child to have the right of what he can do. And they didn't respect his right to be there. So I had

to take many steps - many – and go through many people in the special education department - to give my son the rights of being in a general education classroom.

Yet, despite some negative experiences, participant A also had some positive experiences. She also related:

I had taken many steps within the district to try and get inclusion and I was not successful. So I recruited some organizations in the community that help families with disabled children to get the rights and inclusion that I wanted for my kids. I specifically used Disability Rights Oregon. It was then I got the help and support with inclusion and then my children started to get the support they needed in inclusion.

Participant B also related examples of positive and negative experiences advocating for her son. She was successful at times and frustrated and unsuccessful in other attempts. Her negative experiences pertained to the climate and culture of her neighborhood elementary school. A positive experience she shared pertained to her emailing the then Director of special education advocating for her son to be in a full time kindergarten placement. At the time in Oregon, full day kindergarten was not mandated. She explained:

Our neighborhood school (named school) had barriers to inclusion. I liked the teachers there but I didn't really feel like it was necessarily called an inclusive environment, because it wasn't set up that way. Basically the idea was "[Her son's name] isn't going to fit in here. We don't have the resources for him here at this school." As a result, he moved to another school in the district that had a special program for him.

She continued by saying:

One of the good examples I have of advocacy – you've probably forgotten about this – ...was an email...I basically asked you whether [her son's name] could be a full day

kindergarten student in the life skills class. Basically it was a K-2 class, and even though he was getting two-and-a-half hours, all the students in there were going full time. So my rationale for advocating for him to go as a full-day student was that he's not really a kindergarten student, he's more in the K-2 environment. What I really appreciated was the fact that because I advocated for this, you would respond and said "I don't see why not." That actually surprised me a little bit because I figured that there would be some kind of push back. So I was happily surprised that by my just thinking outside the box and advocating for that placement that it worked.

Participant C had mixed experiences as well. Among her negative experiences involved the occasional confrontational nature of her son's IEP meetings. However, she also discussed how the confrontational approach could be effective. She related about how she felt her son was systemically penalized for his time away from school due to medical issues:

Well, when I was in earlier years it was a lot of very confrontational meetings where I remember my first IEP meeting I was on one side actually everyone else was lined up on the other side. You know there was a good nine people because my son is very complicated so everyone is there. So that confrontation model is how I advocated early on...Here is an example of when advocacy worked, even though it was confrontational. Teachers were accepting far below what my son could deliver. I said, "Well I've heard of inclusion and I have done my homework. I have gone and talked to people. I have relatives who have done the full inclusion model. This is what I think would suit my son. Full inclusion I think is a brilliant idea. The team told me "No" and that my son didn't participate in class enough so that – I said, "You mean times he was out for surgeries? My son has had about 20 major surgeries and probably as many minors....She explained

the gap was too great, that he wouldn't really be able to participate. I said, "Nonsense. If you can't do it I would like for the district to pay to have him sent to [a neighboring district] so we can go to a school who's committed to inclusion. At that point, they made a spot for him and said, "We can do full inclusion. We can do mainstreaming."

Participant D talked about his advocacy for more inclusion in the district and noted the negative reaction and sense of risk he felt when he advocated for a superintendent meeting for parents during a time when the district was dealing with massive budget cuts. He related:

During the period in the economy...where the perception of resources wasn't there....I remember going to superintendent meetings my first year and sitting with another dad who was in a similar situation as us. And we are hearing other departments are not being cut. At the point that push was for more support for English learners. And SPED was getting cut in the double digits. And we were raising our hands, and we were not popular people that night.

Participant E injected:

Yeah, from an Individual Family Service plan to IEP, that kindergarten transition IEP was hard. It was a smaller room, and it was a lot of people around a little table, and we didn't know any of 'em. So it was kind of us versus them, is what it felt like it was going to be.

It was at that time, Participant D and E figured out they needed a strategy and recalled their next successful move. Participant E continued:

We heard, you know, from early intervention, we needed to be really, really careful when we went in for a transition to school because "they will try to put him in an autism box." So I thought, I have all these pictures of all these things I know [her son's name] can do,

that he won't necessarily do when somebody asks....So, we got pictures of him writing his name in the sand, and playing with his brother, and doing all these things that we knew might be kind of points in question. And so, we made up a booklet of all these pictures and statements of saying, "[Son's name] likes this, and this is what he loves to do...it kind of answered their questions right off the bat. We thought "Oh that worked really, really well. So that was kind of our first real thing."

### **Advocacy is an Emotional Journey**

It was very clear from listening to all five parents interviewed that their inclusion advocacy efforts have been an intensely personal and emotional experience. Each participant recounted feelings of anxiety, stress and intense emotion during different aspects of their advocacy process. Three of the five parents became tearful when recounting their experiences advocating for their children. Participant A described the constant anxiety she felt as she advocated for her son, whose future is uncertain, "When I was reading the questions for this interview, I was reminded of my frustrations, my anxious times and my sleepless nights."

She went further to describe the feelings of marginalization and judgment she felt as she attended one of her son's IEP meetings. She recounted:

I know there is a part of the team that wanted to help my son. But, I would like staff members not to look at me like, "Oh, here comes the mom again. What does she want? I wanted them to look at me like, "Oh, this is the mom. I wonder what kind of input she is here to bring us." I did not feel like they thought I had anything valuable to say.

Participant B discussed her anxiety over not initially understanding how the special education process works and feeling confused about understanding if a program is not in a neighborhood school, where other options exist and why. She related:

....We were just realizing the team told us [her son's name] couldn't stay at his neighborhood school if the neighborhood school can't meet his needs. I don't think I understood that in the beginning. I thought he could stay there. We didn't really know what "special programs" were like. I'm reliving the anxiety of the parents and families and early on they need to understand some of these things."

She also recounted the frustration and pain she felt when her son became suspended from school due to behavior related to his disability.

I think it bothered me that [her son's name] was suspended. ...I was just trying to figure out the policy of why he would be suspended. I've read a lot of stuff about kids who were suspended in kindergarten and it obviously was because of his disability. I mean, with the issue of disability, would that really be a suspension for a kindergartner? Could they do it another way? Could it be called something else? I don't know. I'm getting a little emotional at this point. Sorry.

As a current special education teacher, Participant C addressed the grief and acceptance process parents go through as they accept their child's and their own experience of disability, and how staff giving of their time is critically important. She also talked about the significance of always maintaining a sense of hope:

I remember sitting with (her son's teacher) for three hours one day. She dismissed everybody else and then she and I just chatted for an extra hour talking about hopes and dreams. I mean so I really felt heard as a parent...I think that parents operate from a position of fear a lot. And they want their child to be successful in life...So a lot of times if you are compassionate with parents, you'll get a lot farther and identify kind of where they are in their journey. We are all on a journey. We need to respect parents enough to

understand what's going on even if they're unhappy and then we support them as they go through that grief and their unhappiness.

Nevertheless, she also conveyed her hope and excitement about the districts' transition to inclusive practices. She explained, "...I see where we're going for inclusive practices and the potential is so phenomenal that once we have developed there is no reason to pull out kids any more. So I'm excited and I'm looking forward to taking part of that transition in part of that movement to really shore up what's happening in the classroom."

Participant D also talked about he and his wife's emotional experience describing his son to the IEP team he and his wife were working with at the beginning of his school career. He stated, "Yeah, we didn't know what we were doing at that point. 'Cause at that point, it's like, okay, I know how to sell my company, myself, my services, but now I'm selling my kid. And that was a very emotional process for me and for Lisa, too. It's like, 'We're doing this'."

He then went on to describe the added anxiety and challenge parents face when they try to balance their child's need to be independent and learn from their own mistakes in inclusive settings with their own protective sense, by using a poignant example from a well-known children's movie. His analogy would likely apply to most parents, however when a child's disability increases the actual or perceived risk of them becoming more independent, he says it's clear parents are challenged:

Have you seen the movie *Finding Nemo*? You know that scene where it was just Dory and Marlin, the dad, and they were looking for Nemo, and he says to Dory, "I promised Nemo I would never let anything happen to him!" And she replies with, "Well, if you don't let anything happen to him, nothing ever will"...Because, I mean, when you have a child that experiences disability, we tend to be a little more on top of 'em, protecting

them at all times, because that's what we've had to do. But the part where, if we want them to engage in the community, you gotta let 'em fall. And not let that be an excuse, right?

Participant D and E also talked about the emotions of hope and shame they have learned is a component in the community of parents who have children experiencing disability.

Participant E related:

I think overall it takes a lot of time and it takes hope. I think a lot of parents...face a challenge and don't necessarily have hope or know where to go, and so maybe they just don't do anything...Nobody talks about it, yeah, because there's this perceived – you know, veil of shame...you know, something that the parents did or that there is a sense of blame.

### **Sources of Support**

Given the intensely emotional nature of the advocacy in which parents engage for their children experiencing disability, it's no surprise that they often require and reach out for support. Within the personal interviews, the participants identified over 20 specific supports they either had or are currently utilizing. Supports included parents supporting other parents, parents hiring attorneys to advocate with them through an organization called *Disability Rights Oregon (DRO)*, parents reaching out to the school and medical community for support, parent conferences on disability, and school district and community workshops. All parents interviewed reached out to Families and Communities Together (FACT), Oregon's federally mandated parent training initiative group (formerly called *Oregon First*). FACT is funded by the US Department of Education, Office of Special Education Programs (OSEP) under IDEIA (*FACT PTI*, FACT Oregon, n.d.).

Recalling her sources of support, Participant A related:

[DRO] was helpful because they know the rights. And they know, like, what inclusion specifically is and what the school can and cannot do. They came and stepped in and that's when the school noticed that what I wanted was inclusion and what my vision of inclusion was. It helped. I saw a lot more modifications and communication with the assistant and teacher.

Participant B explained that her frustration in understanding laws associated with her situation led to seeking greater support:

I was trying to understand. I reached out to Disability Rights Oregon to get some more understanding of the definition and what the law would say...so I did reach out to try to get some more advocacy. That helped me. Just having an understanding that it's not black and white, and getting an understanding of the definitions and of the law, so that was helpful.

Participant C discussed community supports in which she engaged to advocate for her son. For this participant connecting with professional groups was crucial:

I used to go to the Oregon Mega-conference years ago. Every conference that I could get to because I figured I was the advocate for my son, I was the one who knew him best and I was the one who's always going to be with him. Teachers would come and go and I would be there, so I better be well informed...I much preferred FACT. I was involved in Sibshop which is for siblings with children with disabilities. I went to every conference I could. I would jump in so I could attend [district psychologist] trainings and I also became heavily involved with the DAN! Movement, the Defeat Autism Now!, which is the biomedical intervention. So I spent a lot of time and a lot of our family's resources

trying to educate myself. I also had a social worker that would help, and would send me information, anything that was being presented so I could go to it.

Participant D discussed his engagement in an Oregon program called Partners in Policymaking (PIP), a leadership program for adults and children with developmental disabilities and for parents of children with developmental disabilities. It exists in 46 states and has been present in Oregon since 1994. It is run by the Oregon Council on Developmental Disabilities. The program's goal is to provide people with the knowledge and advocacy skills to influence the issues, agencies and people affecting their lives (Oregon Council on Developmental Disabilities, n.d.). Regarding PIP he stated:

Partners in Policymaking...was an eye opening experience...I think it helped broaden my understanding of disability – what it is, where it's been, where it is now, and what it should look like. Also, understanding, too, what parents before us had to go through, and what they did to help with that.

Another strong component of parent support was parents supporting each other.

Participant D talked about he and his wife's engagement with other families who have a child experiencing disability. In particular, he discussed his concern for fathers who he feels need some special support in order to remain supported and engaged in the advocacy process:

In terms of how we've gone forward. [Wife's name] has been this way with moms at our school – whether it be coffee or go for walks – and with moms that aren't sure what they need to be doing or where they are with things. And sharing our story and what we did, and getting names and phone numbers and where to go, and that kind of thing. So the path is less confusing, that they don't have to do a whole lot of machete cutting to make their pathway through this. The biggest thing that I've asked for...is that the dad be a

part of the process. And then we've done a couple of meetings in dad groups. I think both parents have to be on board, for this advocacy to be successful. This can't be one. And the dads, as a whole – not saying all – but a lot of them, tend to check out, or they are kinda only half way in. I think some of it is that dads, they, you know, in these situations, we tend to be the, you know, we've got the fulltime job and what we are doing. But your bandwidth does have to expand a little bit more, to help support your kid.

### **We want to be a Team!**

Despite the perception among some educators in the special education community that adversarial parents want to litigate and fight the school district in which they attend (Bacon & Causton-Theoharis, 2013; Mlawer, 1993; Wright & Taylor, 2014), all the participants expressed the desire to team and partner with school district personnel. Along with this cooperation, all parents acknowledged difficulty partnering with the school. Especially frustrating to them was that because they were trying to learn and understand the special education system, they did not comprehend the rules fully. They often began their process with full trust. However, as concerns emerged they began learning they needed to constantly be in advocacy mode and alert for important but easily missed issues. Trust was especially difficult for the participants. Yet, despite the difficulties, the participants discussed their fundamental need to be an integral and significant member of the IEP team. Participant A explained her experience by saying, “I want to know I'm part of a team that will help my children. My number two thing is the district needs to be willing to work as a team.”

Participant B discussed her perception of the IEP team and expressed her appreciation of times when the district and parents collaborate:

I think just...trying to determine what's best for my son as a parent and then being a partner with the teachers. Because I've always felt that the people I've worked with have been advocates for [son's name], and so I feel like we are partners in advocacy....I don't come into it as a confrontational, we must have this thing, because I like to think of it as partnership and realized that there's reasons why things can happen and reasons why things can't...I just think we need to try and be supportive, if the teachers are supportive of us and we're supportive of the teachers, then it's such a nice dynamic.

Participant B also discussed feeling empathetic toward teachers. Despite her own parenting challenges, she related an understanding that they have a difficult role in the district:

It's really hard being a parent and having to understand the teachers and the staff dealing with it [the special education system], so it's certainly understandable when this happens...I have always, when we hear about things happening, we want to thank the teachers. We understand how hard this is. "You've got a hard job. We understand. We're the parents. We're learning like you are."

Participant C talked about her process of learning to become part of the IEP team. While earlier in the interview she talked about her initial, very emotional and confrontational meetings, she moved on to share how she learned to work with the IEP team:

So that confrontation model is what I did early. Then I learned to work with the system a little bit more. I really learned to work with the teachers so that became part of my strategy was to really share my son's story with teachers and talk to them about what I could do as a parent so it was more of a team collaboration. So much of that parental input is so important because you just know your child so well and especially a new

teacher or a new to that student teacher just doesn't have that history and the knowledge of those nuances. And that's how an IEP meeting if done correctly, can be powerful.

Participant D described his and his wife's strong desire to partner with the district and be a team. "We always wanna be, you know, We're a team. How can we work on this together? And give as much information as we can, so that they can do their best job. And so I think that's what really worked out well...we came away feeling really good about the whole situation."

Participant D also discussed the critical and fragile role of trust in the IEP process. He identified a negative IEP experience and that lack of trust that has permanently stayed with his family since that event.

I was thinking everyone was doing what they should be doing....and they weren't. So, it was a lesson for us. It's the phrase, "It's not that I just don't trust you, I just don't trust anybody." And it's just, it's a lesson of not to get too cozy. Don't get me wrong, we love our team here. But it's one of those things where you need to stay on your toes, stay sharp, but you can't stop advocating.

Participants E and D also discussed the fact that parents need to learn the system in which they are working. To them, parents typically face a steep learning curve in order to become an effective IEP team member. The district currently has several "parent partnership meetings" in which parents can attend and learn about special education processes and other various issues. Participant D talked about the importance of sharing information so parents are able to be strong team members:

I know you are doing the parent partnership-type meetings – it's important to have resources that help parents know what they can ask for. 'Cause I'll admit, that's the one thing that we spent two or three years figuring out, what can we ask for? We don't know.

Participant E and D both shared their philosophy when they help other parents navigate the IEP team process. They encourage parents to learn and own their place on the IEP team and come to meetings prepared with helpful information:

How do you get that ownership? How do you get those people on the IEP team to really put in that effort? I mean, I think we've helped with that, that we come in and we're all part of a team to do this. When advising parents, you go into these meetings, don't look to be confrontational. Look to prepare. Say, "We're willing to do what needs to be done, to help on our end." I think that gets a sense of relief, from the teacher, you know, they aren't gonna have to take it all on, in addition to 35 other students, and Common Core, and all the other stuff going on.

### **Communication**

Another prevalent theme that was repeated throughout the interviews was the need for communication. Certainly this theme is related to the desire for teamwork. However, I treat communication as a separate theme in this analysis. All participants cited communication as a key to a successful partnership with the school district. They considered communication as the fundamental factor that could "make or break" both their and their child's experience moving through the special education system. Thus, for them, communication is critical to the success of a team. They also named communication as vital in order for them to learn the special education system. The participants felt that communication was occasionally successful. However, they were equally candid that at times the communication they experienced was not. Indeed, Participant A, whose first language is Spanish, said communication was her biggest barrier to overcome:

Communication is the number one thing I need. First, language is a huge barrier for me and my son. My first language is Spanish. When I have a document in my native language...it works for me to reference back and read through it and support the goals that are written on it. [Communication] from the school was only given to me in English. It was also a struggle to communicate with [son's name]. He had an assistant. The assistant only spoke English. I wanted the assistant to speak both English and Spanish...it didn't happen because he never had a bilingual assistant. Everything was in English.

Participant A also discussed the difficulty she had communicating positively with the team, "So a lot of the time, I didn't know if it was the district, the staff, or teacher, or just the – everybody – in the building, I feel like they didn't understand when I talked with them. I was just there to try and help everyone with my child."

Participant B talked about her struggle to understand and learn the special education system and the lack of communication from the district that made that process challenging:

Creating parent understanding by communicating is very important. Parents need to ask, "How do things work?" – it's very difficult to communicate when you don't understand what you are working with. Understanding is important....staff need to explain things like "Here you are right now. Based on what we think [child's name] needs are at this point...these would be options. There are the options." If that's the case, then school people need to have all of that understood. I think that would be good. Communication is important so everyone is working with the same understanding.

Participant B also discussed how the root of much of the conflict between parents and the IEP team relates to communication. She was specifically concerned about parents operating without a full understanding of how the special education system works. She explained:

Except for the bumps, that I think has really much more to do with lack of communication and lack of understanding really than anything else. I don't really feel like I've gotten any pushback on problems. It's really, like I say, more of lack of communication and understanding the processes and that kind of thing.

Participant C discussed the role of communication in building relationships with the IEP team members and district staff:

[Her son's name] has had some really phenomenal teachers along the way. One teacher I met with inspired me to go back to school and become a teacher. She would let me in the class and we would talk for an hour sometime. She would conference with me an hour every week and just, "What can I do? 'How can I help him at home?'" I would say, "What should I do?" and she would show me her data. I thought it was so effective and so wonderful for parents to see.

She also related that there is a sense among parents that the IEP process is a mystery and that there can be a sense of the school and district holding back information through the use of esoteric jargon. Because she works in the special education system, Participant C feels she has a certain advantage:

I think even now it always feels like there's a secret handshake. Like if you use certain jargon things could be done. If you don't have that jargon then it won't happen. So that was probably the biggest lesson that I learned when dealing with the school district if you

have the correct jargon in place and say things like “I don’t think that is the least restrictive environment” things happen.

Participant C continued to explain that up front communication is important for parents to understand all the information, particularly during the early processes of identifying a disability, even if it’s difficult for them. She referenced a case she saw where a case manager label a student with an inappropriate code (such as Learning Disabled) when a more appropriate code would have been “Intellectual Disability” because the case manager was worried the parent couldn’t handle the most appropriate code:

[I asked] So why did they get this code? The case manager said, “Well, parents would have been upset if we would have done another.” I thought well, that’s part of the process that happens sometimes...but for case managers to say “I’m going to protect you because I don’t think you can handle it” is extremely disrespectful. So I think a true identification of kids and respecting parents enough to let them understand what’s going on even if they’re unhappy and then we support them as they go through that grief and their unhappiness. We can’t be afraid of that kind of communication...I think that’s really important for parents to understand...and to actually be given the respect to be told the whole story.

Participant D talked about the importance of accurate written communication in the form of notes during IEP meetings and referenced a negative experience he and his wife had with a case manager:

Yeah, we had no idea what was going on...I just remember we came to a follow up meeting, and we see the notes and the history was re-written by [the case manager]. I said, “I need you to put this back in the history, because these other statement don’t make

any sense because they wouldn't have been said. You said I've gotta advocate for my son, and I'm going against you now. We're rewriting history, here, and if we ever have to come back and refer to this, this needs to be accurate."

Participant E discussed how the role of communication is foundational to a successful student and parent experience during the IEP process. Indeed her emphasis on the need for positive communication was pervasive in the interview:

I think we've always based everything on communication – we just wanna have really good communication. Communication is one of the number one thing. When we've had a problem, it's related to that. Conflict we've seen others have is related to communication – when people are not feeling heard, or like anything can be done...Like one example in particular that I'm thinking of, [a mom] was told by a teacher "No, that just can't be done. No I can't do that" and this goes down to a basic communication. What she wanted was reasonable, like a weekly communication, and they said, "No, we can't do that."

Participant E also described a number of communication strategies she and her husband have learned through their experiences. She related that these strategies are useful in becoming effective IEP team members and advocating for their son:

I think it's helpful for parents, in a way, that, if you do prepare, that you take inventory of where you are, but really that's something you should be doing anyway...That's generally why we do, like, a check-in meeting at the beginning of the year. "How's it going so far? Do we need to change anything?" And then maybe follow up again, 'cause we have that mid-year IEP. You know, what do we need to be doing, maybe, over the summer? What can we do a little differently?

### **Professional Development Needs of Staff**

A prominent theme running through the interviews with all the participants was the lack of knowledge over how to implement inclusion and inclusive practices. This theme encompasses multiple barriers for students to participate in inclusive placements. All the parents want inclusive placements but continuously found that the lack of skill and knowledge on the school district's part was their biggest barrier. Subthemes included teachers having chronically low expectations of students with IEP's, the profound impact an inclusive culture has on a student's school trajectory, and the notion that teachers often wanted to help and genuinely cared about students, but they do not have the personal knowledge or leadership in their building to implement inclusive practices.

Participant A articulated the importance of teachers looking at student abilities rather than deficits and how that relates to an overall culture of inclusion:

I wish that all teachers would look at all the children with disabilities not with – not by their disabilities, but all the abilities they do have. When they [school staff] would look at [her child's name] they would see his disability and they would kind of seem like they didn't have the knowledge or the capacity to work with a child that was that-that severely disabled. A lot of training is needed for staff on how to work with children who have disabilities and how to include them in the classroom. In the IEP meetings, the district wanted to help but didn't know how so they couldn't.

In similar fashion, Participant B related:

The teacher said to me during the meeting, "He's a lovely boy. He's great but I don't – first of all, he wouldn't be able to have an aide since the district won't give me one, so

there is just no way that he can be here.” Even though I liked the teachers there, I didn’t really feel like it was an inclusive environment.

She also discussed how frequently the district system is set up to mandate difficult transitions for students in the midst of their elementary school career. The system in the district currently includes “program classrooms” designed to segregate students with special needs so they can skill build and receive specially designed instruction. However, the programs not only segregate children experiencing disability from their typical peers, but are divided by grade level (K-2, 3-4, 5-6) and often require elementary students to transfer to up to three schools before reaching 7<sup>th</sup> grade, effectively requiring the most transition in the district for the students who are most negatively impacted by them. She continued by explaining:

[Son’s name] was in a K-2 program at his school. We were lucky and [teacher’s name] advocated for him to stay another year for 3<sup>rd</sup> grade. He had friends, he was included more in the school community, so we were working together saying, “It is in [son’s name] best interest to transfer him to another school right now when he’s got a stable inclusive environment?” Everyone likes him, but he’s got this really challenging aspect of what happens when he gets escalated. And is it in his best interest to change schools even though that’s what the policy would normally be?

Participant C also discussed the need to have a vision and professional development plan for teachers in order to successfully include students.

Professional development, the time and the resources to do that well is needed. And I think a lot of it has to be school-wide or building wide...So I think bringing in people so we can affect the culture of our school and say, “Everyone is in this boat and how are we

going to get through it together?” is important...I can see how that could transform into inclusion instruction.

Participants D and E discussed the common but faulty assumption that students on IEP's (*i.e.* “*those kids*”) cannot learn or that they are not smart. In short, teachers can fall into the trap of assuming a student is incompetent and therefore justify not providing daily access to learning opportunities. Participant E asserted:

Well, there's also a perception that, I know my kid's in speech, but he's not one of *those kids*. And really – yes – he is one of *those kids*. You know, there's varying degrees, absolutely, and different kids have different challenges or different needs, and you do what you can to meet those needs. Teachers need training in all that. But as we always say, “assume competence.”

Participant D related:

Yes, don't assume incompetence. Assume that they can do something, and then work from there. I think, also, that helps cultivate a strong environment for including practices, is it is strength-based in how it's implemented, not necessarily deficit based.

Participant D continued to explain that teachers need to be trained and the paraprofessionals they work with need training as well. He also empathized with the staggering workload of teachers:

A lot of these teachers don't really know or are overwhelmed because they have larger class sizes. Or testing, or whatever the situation that's being thrown at them. They have so much coming at them, right now, that do they have the time to differentiate and figure out that [inclusion] situation? So I think a lot of it is the support, and whether it's training on just what differentiation is, versus time to do it. It has to be supported, or else

it's gonna be worse. Also, how much training do the assistants have? And how are they prepared to do that? Can they take on a lesson like [the teacher's name] can take on a lesson....She can't be in all the rooms at once.

Participant D related the importance of being able to connect with parents and understand why they are asking for an inclusive environment. He recalled a frustrating stage in his son's education in which the teacher either would not or could not teach inclusively:

And the challenge with that year, we had someone, I think, that was – we were asking a turkey to fly. I think she's used to an environment where the parents don't really ask anything, they just hand their kids over. And, unfortunately – I mean, I'm sure you see this, here, but – there's a lot of parents that just do that. And, we're not them.

## **Conclusion**

The purpose of this phenomenological study was to explore the lived experiences of parents' advocacy experiences for the inclusion of their children experiencing disability in the general education setting. A total of six individuals were interviewed using a series of five research questions designed to help the researcher understand this subject. Seven multidimensional themes emerged from the interview and research process including: Definitions of inclusion; Advocacy: A mixed experience; Advocacy is an emotional journey for parents; Sources of Support for Parents; We want to be a team!; Communication; and Professional development needs of staff.

Each of these seven themes are interrelated and helped to shape my understanding of the lived experience of parents advocating for inclusive placements for their students experiencing disability. It is through these themes that a series of five research questions were answered,

providing new insight into the world of parents, advocacy and inclusion. The next chapter examines more closely those five research questions.

## **CHAPTER 5**

### **DISCUSSION**

#### **Introduction**

This chapter provides an examination of the five research questions used to structure this study along with general conclusions derived from the findings. I also attempt to examine the lived experiences themes against existing literature on inclusive practices in special education in order to better ascertain implications and general conclusions (Bailey, 2004; Causton-Theoharis & Kasa, n.d.; Egbert & Salisbury, 2009; Forbes, 2007; Frew, et al., 2012; Jeynes, 2007; Posny, 2013; Roach & Salisbury, 2006; Rodriguez et al., 2014; Waldron & McLeskey, 1998).

In the previous chapter, I identified seven lived experience themes emerging from the interviews with the participants. Five individuals shared their specific experiences, feelings and views regarding their personal journey advocating for their child within the context of the special education system of a school district in Oregon. This chapter begins with a summary of the purpose and design of this phenomenological study, and continues with a review of research question responses related to the literature. It also includes a brief discussion of the felt needs of all participants. All participants had clear recommendations for that I consider to be crucial information gleaned from this process. The discussion then progresses to the practitioner-related, scholarly and policy related implications of this research. Finally, the chapter closes with professional and personal reflections.

#### **Summary of the Phenomenological Study**

This study sought to explore parent's experiences as they advocate for their student who experiences a disability to be included in a general education setting. Over a series of two

months a series of four semi-structured interviews were conducted with five participants. The participants were all parents in the district in which I am currently employed as the Executive Director of special education. All parents were either related to their children biologically or through adoption. I audio recorded the personal interviews using two digital recorders. After conducting four, 60-90 minute interviews at a location of the participant's choice, the interviews were professionally transcribed. I then engaged in a coding process that involved three general analytical steps: initial coding, focused coding and thematic coding. Ultimately, seven salient themes emerged. They include:

1. Definition of inclusion
2. Advocacy: A mixed experience
3. Advocacy is an emotional journey for parents
4. Sources of support for parents
5. We want to be a team!
6. Communication
7. Professional development needs of staff

### **Research Questions**

There were five original research questions asked to all the participants. These questions were designed to address a number of areas of inclusion. Before addressing each of the research questions, I present a summary discussion on the general nature of the research findings as a means to provide greater context to the research questions. Throughout the interviews, contrary to much of the literature on parent's perception of inclusion as a place, parents defined and characterized inclusion by focusing on the affective aspects of it, such as a culture of acceptance, an environment where all students are accepted and where every student is valued in the

community.

Parents engaged in a wide array of experiences advocating for their students. While all parents advocated with the school district, they often engaged in community learning events such as conferences or parent support groups. All of the participants actively sought out support and knowledge, and all expressed a desire to share with other parents the knowledge they had learned through their advocacy experiences. Collectively, parents referenced over 20 support organizations they either currently are involved or have been involved in the past.

Parents very openly and emphatically discussed multiple barriers that must be overcome to successfully advocate for an inclusive placement for their child. They identified struggling with their own lack of knowledge about the complex and confusing special education system, school personnel's lack of knowledge regarding inclusive attitudes or placements, and they discussed their constant battle to be heard among groups of professionals who often thought they knew more about their child than they as parents did. They also talked about the extremely difficult emotional nature of both parenting and advocating for a child experiencing disability.

All the participants felt strongly about partnering with their children's educators and all encountered situations where the partnership was tested. At times they received favorable responses from the district, and at times they did not. However all of them emphasized the importance of maintaining hope and believing that better things were ahead for their children. Finally, all parents agreed that some of their advocacy experiences were positive with productive outcomes, and, unfortunately other experiences were not so productive. They each acknowledged that the path to inclusion has been one of learning and adjusting for themselves as much as it has been for their child. All parents currently had students in the system at different levels and all of them enthusiastically shared their experiences and expressed a strong need for

continued education and support both for themselves and for school district personnel.

Additionally, all parents openly and honestly talked about the intense emotion that is associated with advocating for their children. It is clear from listening to them, that this emotion and passion runs deep, providing the fuel they need to continue their advocacy efforts.

### **Research question 1: How do parents define or conceptualize inclusion?**

The definitions all five parents provided were consistent with the general variability of inclusion definitions represented in the literature (Ainscow, 2007; Forbes, 2007; Gee, 2004; Lewis & Doorlag, 2006; Runswick-Cole, 2008; Turnbull, Turnbull, Erwin & Soodak, 2006). Disability researcher Phil Smith (2010) comments, “Arriving at a single, unifying, clear, useful and practical definition of inclusion for students with disabilities, intellectual or otherwise...is no small task, for there is no clear consensus about what, in fact, inclusion is...definitions are all over the place, representing diverse perspectives and ideologies” (p. 39).

Interestingly, all parents interviewed defined inclusion in terms of staff responsibilities. Participant A commented, “Staff needs to remember that all children regardless of their disability, have the same feelings as a regular child. Participant B explained, “...teachers and staff need to think of all their students.” Participant C defined inclusion through her lens as a special education professional, but included herself and her colleagues when describing inclusion. She remarked, “Do we look at all students as important members?” Both Participant D and Participant E discussed the idea of “all means all” stating inclusion happens when “the teachers and the staff think of all of their students, staff and others.” Participant D in particular discussed all adults “assuming competence” with kids instead of starting with a presumption of incompetence. His thinking aligns closely with inclusion researcher Cheryl Jorgensen’s theory that we all must approach the concept of disability and students with the “least dangerous

assumption” in which we must initially assume a student is competent, rather than incompetent (Causton & Tracy-Bronson, 2015; Jorgensen, Schuch & Nisbet, 2006).

All the participants also provided value based definitions or concepts of inclusion that were related to equity concepts such as access and opportunity. These ideas were generally expressed in terms of students needing to be valued by the community. Participant A stated, “Inclusion is for them to get the same opportunities as all other students,” while Participant B included in her definition, “I think more than just be included with his peers is that the idea of inclusion in the school is that kids are included or thought of as the greater community without separating them into a separate group.” Participant C shared her concept of inclusion as “...how a child is treated when they’re in their school as a valuable member of that community.” Participant D echoed similar values in his thoughts, “I guess I’m looking at more of the big picture with it – is that all kids have access. So when you go into the room; that the community is the community.” This “community view” of inclusion is supported by disability expert Norman Kunc (1992) who emphasizes inclusion from a diversity and acceptance standpoint.

Despite similarities in definitions, there were differences expressed as well. Participants A and E discussed inclusion in terms of equitable treatment and access to opportunities that are not different from typical students. The main difference between their definitions and the others was these two individuals included an affective student perspective. For instance, Participant A commented, “...all students, regardless of their disability, have the same feelings as any other child...” Participant E echoed her thoughts although in a slightly different way, “He has always wanted that anonymity [of the general education classroom]...He doesn’t want to think he’s missing anything in the Gen. Ed. classroom.”

Participant B discussed inclusion as a continuum and not as a fixed concept. To her,

inclusion is fluid with flexible alignment according to student needs. Referring to her son's needs, she commented "I look at it more as a continuum, and that changes depending on where he's at and has changed throughout the course of time at [his school]."

Contrary to both policy and literature on parent definitions of inclusion (Rafferty, Boettcher & Griffin, 2001; Runswick-Cole, 2008) none of the parents interviewed described inclusion as a place (Kluth, Villa, & Thousand, 2002; Smith, 2010). The participants largely viewed inclusion through a set of values and practices, rather than location. What is especially noteworthy about this view of inclusion is that it encompasses both values and practice.

**Research question 2: In what kinds of activities/experiences have parents engaged to advocate for their student?**

This question elicited some of the most interesting responses due to the sheer volume of activities and supports in which the parents engaged to advocate for and support their child. Between the five participants, 24 support activities were identified as having been used in the past or were currently being used to support families in their advocacy efforts. These supports included everything from medical personnel to parent volunteer support. The 24 supports documented in Appendix C are most certainly not an exhaustive list. Many, if not all, families likely engaged in several additional activities that were not mentioned in the context of their specific interview. Nevertheless, all supports were cited by parents as critical for the success of their advocacy.

The conclusion drawn from even this small sampling of parents, along with my 23 years of professional experience and observation is that parents need and want to engage in multiple activities on several fronts (medical, educational, psychological) in order to have the knowledge necessary to advocate successfully for their children in the context of their meeting with the

educational experts on the IEP team. Their need for a high level of engagement in activities is well founded, given the challenges in communication often occurring with their district. Inclusion expert Paula Kluth (2010) notes that when parents advocate, they are often seen as “difficult” when they ask multiple questions, visit the school frequently and ask specific questions about their child’s educational program (Kluth, 2010). Sadly, families often have the feeling they are “unwanted” or have too many questions and as a result, have had a poor experience with their child’s school. Furthermore, Harry (1992) pointed out, “Many parents become ‘difficult’ because their views are dismissed and their membership in the educational partnership is threatened” (Harry, 1992, p. 54). As a result, many parents come armed with knowledge and requests with an advocate or attorney to ensure legal backing.

Two primary areas of support parents cited worthy of special mention were Families and Communities together (FACT) and Disability Rights Oregon (DRO). Both of these organizations are different yet both serve a crucial role in supporting families through their navigation of the special education system in our district.

IDEIA mandates the United States Department of Education (USDE) and the Office for Special Education Programs (OSEP) to create national structures designed to support parents of student’s experiencing disability (Commission on Special Education, 1985). This mandate includes each state organizing a functional Parent Training and Information Center (PTI). Oregon’s PTI is FACT. Additionally, six Regional Parent Technical Assistance Centers (known as “PTAC’s”) around the US exist to support state PTI’s. These PTAC’s provide a variety of support to the PTI’s and “help the Parent Centers [PTI’s] in their regions build capacity to provide information and training to families of children with disabilities and to manage the administrative challenges of running a Parent Center” (Parent Technical Assistant Centers, n.d.).

There are also three National PTAC's as well that support all PTI's, not just PTI's in their region. These national centers have a more specific focus that include a resource and information center for parents, a military support branch, and a Native American assistance branch (Parent Technical Assistant Centers, n.d.). As the Executive Director of the district's Student Services program, I encourage all families to connect with FACT and we as a district regularly invite FACT members to our Parent Partnership evenings to present important information to parents.

Disability Rights Oregon (DRO) is a tax-exempt 501(c)(3) organization that is dedicated to "promoting and defending the rights of individuals with disabilities" (Disability Rights Oregon, n.d.). Their vision focuses on "...a society in which persons with disabilities have equality of opportunity, full participation and the ability to exercise meaningful choice" (Disability Rights Oregon, n.d.). I personally have attended many meetings with families who have been represented by DRO and have found their work to be collaborative and student focused. DRO employees include attorneys, professional advocates, and other support staff.

DRO was established in 1977 and is designated by the Governor as Oregon's Protection and Advocacy (P&A) system for individuals with disabilities. In 1975 the media exposed a series of egregious abuse cases occurring in New York facilities for developmentally disabled individuals. As a result, New York Senator Jacob Javitts led Congress to mandate each state receive funding under the Developmental Disabilities Assistance and Bill of Rights Act of 1975. This Bill established a P&A system in each state to protect the rights of people experiencing disability. DRO is Oregon's P&A system. They provide an array of advocacy and support services on a sliding scale so no family is excluded from receiving necessary support (Disability Rights Oregon, n.d.). Both FACT and DRO have helped thousands of parents across Oregon advocate and access support for their child experiencing disability.

**Research question 3: When advocating for their student, what kinds of barriers have parents faced in obtaining an inclusive placement?**

All parents interviewed readily cited many barriers they encountered while advocating for inclusive placements for their children. However, they identified three specific barriers most frequently. They include the district student staff's poor assumptions and attitudes toward the concept of disability and therefore students experiencing disability, the district's inability to communicate with them effectively, and lack of district personnel training as especially troublesome. While all three issues are related, participants provided specific examples of how these barriers looked in the schools their children attended.

Each parent discussed the negative and inaccurate assumptions and attitudes about disability they encountered both in the school culture and specific staff. Additionally, all the parents offered an alternative, more positive lens, through which staff could view their child. Participant A recounted an experience where staff was looking at her son in a wheel chair as she advocated for him to be served in a general education classroom and “didn’t respect his right to be there... They have so much negativity... They look at him and see his disability, not what he can do.” She also said that her son was often taunted and students said things like “Oh look, here comes the little dummy. He sits in here but can’t do much.” These attitudes are in stark contrast to Participant A’s own description of her child, “He worries about everyone else and has a great sense of humor, he’s very funny...” and of her other son she shared, “[Son’s name] is very intelligent. He has a wonderful memory. He can remember dates, events and is smart even though people can see his disability.”

Participants B, C, D and E all spoke of situations where they felt the climate and culture

of a building did not support inclusion. Participant B recounted how a teacher directly told her at her neighborhood school, “We’re not going to be able to have him here...” After further insistence for inclusion, she was told again, “There is just no way he can be here...he would not be able to have an aide.” This attitude was surprising to her as a new mom learning the special education system and once again, contrasted sharply with her understanding of her son. She related, “He’s a really wonderful kid. He’s a very outgoing, social boy, really happy most of the time. I could talk a lot about him!”

Participant C had a similar experience and estimation of her son. She explained, “He is a tenacious little boy. I mean what he went through was incredible. What my family went through was incredible to support him.” Despite her efforts she still finds the culture of inclusion in buildings needing to be constructed. “I think we need to bring in people who can affect the culture of our school and say ‘Everyone is in this boat. How are we going to get through it together’ because the road to inclusion should not have to be so difficult.”

Participant D and Participant E both commented on the “old school” mentality they encountered when working with a veteran case manager. “...we had an old-school SPED teacher that wanted her little gated community.” Speaking more generally about attitudes of staff, they said, “Assuming competence... it really helps to cultivate a strong environment for how kids are included...is that it is strengths-based in how it’s implemented, not necessarily deficit based.” They also view their son as smart and very capable. “We figured out he was a really good speller. In fact we figured out lots of things about him and what an amazing kid he is. We need for other people to see that same amazing kid.”

The need to change the culture and climate of a school building in order to create a sense of value of students with disabilities is well documented. Cheryl Jorgensen and her colleagues

write, “Changing people’s core values and beliefs about inclusion is essential, as a teacher’s self-knowledge of what he or she stands for is the most important gyroscope a professional educator has to maintain a steady course through the bumpy shoals of life in school” (Jorgensen, Schuh & Nisbet, 2006, p. 65). Inclusive schooling only becomes a reality when the school culture values all its’ members. Research shows inclusive schooling generally should stress interdependence and independence, view all students as capable and complex, and value a sense of community (Doyle, 2003). Kluth (2010) noted, “Families should be able to expect that teachers will value their child and see him or her as an individual and as an important person. One of the most significant messages that can be communicated to a family is, ‘We feel your child has something important to contribute to the life of the school’” (p. 63).

Communication proved to be another significant barrier for parents as they moved through the advocacy process. Although communication is a primary theme in this research, it is important to note across the board, all participants referenced communication as an element that is critical to remove barriers. Many communication examples are shared in chapter four, however some additional comments bring even more clarity to this issue.

Participant A discussed how her repeated efforts to communicate her son’s needs were unsuccessful and ultimately pushed her to work with an attorney from DRO. “I took many steps within the district to try and get inclusion and I was not successful. I recruited some organizations in the community that help families with disabled children to get the rights and the inclusion I wanted for my kids.” She also recounted her frustration with not having material or communication in Spanish. “Communication was hard...My first language is Spanish....After working with DRO I got more communication from the assistant and the teacher. Communication is the main barrier I had to inclusion.”

Participant B had similar concerns, “I think to ease transitions there needs to be as much communication as possible.” She also pointed out in parent partnership meetings a lot of special education jargon is used. She said of a recent presentation, “I kind of was thinking to myself, looking at it from the perspective of people who might not be well versed in this language. I thought it was a good presentation, but I was getting the impression it just might not be very understandable to some people.” We can also be reminded of Participant D and Participant E’s previous communication comments, “...And I think we’ve always based everything on communication – we just want to have really good communication...”

Evidence of the importance of communication in building a school-family partnership is abundant. Researchers Harry (1992) and Kluth (2010) both suggest teachers must constantly check for assumptions that professional efforts constitute the only legitimate source of opinion, and that the role of the parents is to give permission for professional activities and automatic approval for professional decisions. Communication is also imperative to effectively build relationships while respecting social, racial, and cultural differences among students and staff. “Every student in today’s schools – including Caucasian students – would benefit from having more teachers of color. Caucasian teachers can be effective, but they must be committed to seeing and valuing the cultural, linguistic, and ethnic differences students and their families bring to the classroom” (Howard, 2007, p. 19). Obviously much more can be written on the topic of cultural and ethnic diversity in schools, however it is important to note that when education processes and communications are not interpreted and translated – including documents such as IEP’s, behavior plans, and 504 plans, into a parent’s native language, we effectively exclude the parent from participating in the process of their child’s special education program, which in turn effectively violates the legal and civil rights of students.

Harry (1992) points out that in a district's view, the "difficult" parents are often difficult because they have not felt heard or had their communication needs met. She contends conflict arises often because parents' views are dismissed and their membership in the educational partnership is threatened. In such situations, her research corroborates the idea represented in all of the interviews that it is when parents have no way of expressing their views, the only way for them to be heard is to "be difficult."

The third most significant barrier to inclusion advocacy in this study's findings, is the barrier of teacher and staff training. While this issue is closely related to attitudes and beliefs (i.e. why would a principal or district train teachers in a subject they don't believe in?), clearly it was very frustrating for the participants to see teachers who generally believed in the idea of inclusion but did not possess the skill set to implement inclusive practices. All but one parent interviewed in this study cited at least one example of a lack of skill being a barrier to their acquisition of an inclusive placement for their child. Participant A commented, "Staff need training for children with disabilities....especially in modifications, but most of all of how to include them in the classroom...If we talk about special education staff, they probably know...but for the general education staff, do they?"

Likewise, Participant C recounted an experience where she was told, "The gap is too great, he really can't participate." She continued to say, "First of all, we need better quality teachers...We need good quality teachers on providing services to all kids and there is this huge range of children out there that need to be served and every model needs to be different...because there is no one size fits all."

Participant D commented on his disappointment when he discovered his child was being pulled out and his IEP had not been read. "They were pulling him out and doing things....and

she had no idea. And she said, “Oh, I haven’t even read his IEP, yet.”

Researcher Phil Smith has written extensively on the problems with teacher preparation programs in relation to the field of special education. He points out multiple issues with current programs, such as the continuation of educating special education teachers in education programs separately from their peers experiencing a general education program. He also notes that of his university, “The...kinds of things we do on a daily basis come nowhere close to modeling the way that special educators, general educators, educational leaders and school counselors should be working together to include students with disabilities...in general education classrooms” (Smith, 2010, p. 201).

Unfortunately, our teacher preparation programs often continue the segregation of teachers much the way we do with students. We segregate teachers of those experiencing disability and teach them “different” skills. Such practices never allow these teachers to experience general education teacher preparation, thus making it impossible for them to serve as inclusion facilitators effectively collaborating with their general education counterparts. Special education researcher Wade Fish (2008) notes the end result for students of poor teacher training. He argues, “Adversarial IEP experiences that parents encountered were primarily due to the lack of educators’ understanding towards student disabilities and improper IEP implementation” (Fish, 2008, p. 62).

I have seen a similar trend in school districts attempts to hire quality special education teachers. Hiring new teachers with skills in Universal Design for Learning, collaborative and co-teaching, ability to differentiate instruction and the ability to communicate well with parents is almost impossible. My team and I have noticed a slight improvement in our candidates over the last year and have seen more of these skills sets within our applicants, however the applicants are

few and far between. For one special education teaching job posted during the school year, the average number of remotely qualified applicants for the last five years in a row has been three per position, and sometimes it's even less. In my own administrative licensure training, I received a total of one class in "administration of specialized programs" that was in no way integrated with other administrative courses. One of the ways in which our district has chosen to manage this deficit, is to begin our own special educator licensure program in our district in conjunction with a local university.

Given the significant use of paraprofessionals in the field of special education, their preparation is important as well. Inclusion experts Causton and Tracy-Bronson (2015) assert, "The more that paraprofessionals understand about teaching and learning, the goals of inclusive education, and their role, the more effectively they will be able to support students with disabilities in...classes" (p. 169). In his book *Visible Learning: A synthesis of over 800 meta-analyses relating to achievement*, John Hattie (2009) references researcher Mary Kennedy's research on the need for educator preparation programs to change their teacher candidates preconceived notions about teaching, learning and students when they are learning to become a teacher. She writes:

The unusual nature of teaching learning is such that students entering teacher education already "know" a great deal about their chosen field. Moreover, they will use what they already know to interpret any new skills or new theories they acquire during the formal study of teaching. This fact means that the simple acquisition of new skills or theories is not adequate to alter teaching practices. Therefore, the central task of teacher learning must be to change these conceptions (p. 13).

Given the marginalization of individuals experiencing disability, it is alarming to think of

what teacher candidates think they know coming into the field. Teacher preparation programs then are tasked with the difficult job of transforming student beliefs and values.

**Research question 4: What do parents perceive as the school district's response to advocating for an inclusive setting for their student?**

Generally the parents had a mixed perception of districts' response to their advocacy efforts. All had both positive and negative experiences as noted in Chapter 4. The unexpected insight into this question proved to be the amount of positive experiences that were mixed with the negative ones. Yet previous research has primarily focused on negative experiences. Bacon and Causton-Theoharis (2013) write, "...research documents parents' difficult position within the special educational system . . . Positive relationships between parents and schools have not been legally forged" (p. 683). Given the challenging dynamics in between parents and school district personnel, the positive experiences documented were largely unexpected and add an important understanding to the advocacy experiences of parents.

Participant A did feel her advocacy efforts were responded to positively by the district and that her success felt short lived. She related, "I feel like [advocacy efforts] it worked at the moment, but in the long run it did not work because the follow up I wanted wasn't there."

Participant B discussed the message she gives other parents about support and advocacy for their child in the district parent partnership meetings:

...if a parent thinks that somehow the district isn't helping them I think it's great to see that [the district name] is providing information about it and not just giving you a pamphlet. There's an opportunity for you to come and to meet these FACT people. I think it's great, because I think it would show parents the district is wanting to be more of a partner and to provide these resources.

Participant C discussed one of her positive experiences when full inclusion wasn't working for her son and she advocated for him to do some skill-building in a specialized program. She recalled, "I said, 'I want to go back to a self-contained classroom with opportunities to mainstream.' They [the district] did and he went. He blossomed."

Participant D and Participant E recounted an advocacy experience for staff training in which they successfully persuaded the principal to provide a training on executive function. Participant A explained, "The concept of executive function came up in one of our meetings. I said, 'This is great stuff.'" And [autism specialist's name] said, 'Yeah, we do trainings for this, for staff.' I said, 'Great...when can we get this for the whole staff?' And within a week, they had [autism specialists name] out there doing trainings."

Despite the fact that the parents in this study had at least some positive perceptions about the district's response to their advocacy efforts, this research, consistent with the existing literature, indicates that is not generally the case. In a study that examined parent perceptions of the IEP process for their student's experiencing autism, researcher Wade Fish (2006) noted, "All of the participants indicated that their overall initial IEP experiences had been negative. Parents were surprised to discover that the views of educators were often not consistent with the implementation of ideas that parents believed to be the best approach for serving their children" (p. 60).

All six participants in this study related times in which the school district responded negatively to them and/or identified a lack of teacher understanding and training as serious issues. These results are further corroborated with the research of Rodriguez, Blatz and Elbaum in a 2014 study of parents' views of schools' involvement efforts. They report, "Parents who spoke unfavorably mentioned that the school was out of compliance with legal mandates, such as

not informing them of their procedural safeguards, or not involving them in decisions that affected a student's educational placement" (Rodriguez, Blatz & Elbaum, 2014, p. 89).

Although parent perceptions of district responses to their advocacy efforts varied and included both positive and negative experiences, my study clearly reveals that the participants often feel their advocacy is a challenging and emotional experience requiring high levels of systemic knowledge and support. Overall, parents appreciated the positive experiences, but all spoke about them with a degree of reserve that likely resulted from the fact that as put by Participant D, "Sometimes things go well and sometimes they don't." With such insight in mind, districts need to look for all avenues to positively engage with families during the special education advocacy process and aggressively pursue them.

**Research question 5: Were advocacy efforts successful in the estimation of the parents?**

This question likely elicited the most surprising responses during the investigation. Participants shared that throughout their overall experiences, their advocacy efforts for inclusive placements were successful. All five participants acknowledged that their advocacy journey at various stages has been an arduous one. However, participants who had children graduate or whom were near graduation all characterized their advocacy efforts as successful. Participant A noted, "So, even though it's been tough throughout all these years, and it's been hard, I see success in my kids." She further related, "...with inclusion, [son's name] is willing to go on the Tri-Met by himself to go to work...and he's had a lot of experiences thanks to all the opportunities that were given here of inclusion...I am really happy for what my boys have accomplished." She discussed her son's graduation with great pride, "When he graduated from

high school, it was a standing ovation ‘cause all the students at [name of High School] knew him.”

Participant C, whose son is in his final year of the district’s transition program referred to her advocacy efforts as “very successful.” She recalled, “I think it was very successful and even the times where I don’t think he was being served correctly, he educated me and really let me think about what was happening with him. Then I could take that to an organization like FACT.”

Those participants whose children were still deep in the district system with years to go also spoke positively, albeit with caution. Participant B who has a young child reiterated her mixed experience. She said, “This is a whole lot of stuff and it’s not just a simple black and white, I’m going to say, in terms of advocacy...I have good examples and frustrating examples.”

Participants D and E also spoke from the perspective of a mixed experience. They reflected, “I think we’ve always spoken really well of our district, and we’ve always been really happy, in the most part...The bumps we’ve had were very specific bumps. But I think the one thing is just, anything we can do to have all of these high ideals that we have as a district, and how can we best implement them and get the rubber on the ground.”

Although there is extremely limited research on the perception of parents advocating for inclusive placements for their children, leaders in this field such as Bacon and Causton-Theoharis, sum up the role of parents in the special education system. They write:

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

bureaucratic processes have on students with disabilities (Bacon & Causton-Theoharis, 2014, p. 696).

### **Felt Needs of the Participants**

When looking at the lived experience of the participants who engaged in this study and the existing literature on this topic, it is clear that there is much work to be done. Participants voiced value-based definitions of inclusion that included their child's school environment embracing values of acceptance and a sense of community for all. All the participants expressed a strong need to engage in supportive activities both within and outside the school district, and at times felt they needed legal expertise to understand the best way to advocate for their student. Furthermore, they sought legal support and practical systemic knowledge in order to combat common barriers they faced. All five participants accessed regularly and relied heavily on Oregon's PTI, called *FACT*, highlighting the importance of parent support structures on both the state and local level. Each of them discussed the deep personal pain and frustration they felt when they perceived district staff holding on to misconceptions or displaying a poor attitude about working with students experiencing disability. Their stories illuminated the critical importance of clear, consistent and respectful communication to be a normative *modus operandi* among district staff. Perhaps the biggest perception noted among the participants was the need for district personnel to be trained and skilled enough to understand inclusionary instructional and other practices.

Overall, parents reported mixed positive and negative experiences when the district responded to their advocating efforts. In fact, two of the participants whose children either completed or almost completed the system characterized their experiences as extremely stressful and emotional although their efforts were ultimately successful. Although these findings

represent the lived experience of the five participants in their specific district, the findings of this study largely reflect the findings reported in the limited body of literature on parents and inclusion advocacy. These findings are also consistent with the much larger body of special education research.

During the research process, a final question naturally arose at the end of each interview. I concluded the interviews by asking, *“If you were standing in front of a group of school staff and were asked to give them advice about how to improve district practices educating our students experiencing disability, what would you tell them?”* I found their responses to be intelligent, perceptive, and consistent with the aforementioned literature results.

I found this part of the interviews to be incredibly powerful. Many of the participants reiterated concerns and issues they had identified earlier in the interviews. However, they also discussed a number of purely personal, inherently human attributes they needed from otherwise professional individuals (see Appendix D). These “softer” skills are different than technical skills on which professionals often focus. In my own professional experience, these “soft skills” relate directly to the way a parent feels about their experience advocating for their students. If their perception is that barriers are placed in the path of success, conflict, likelihood of attorney involvement and eroded trust in the relationship occurs. If we as professionals can foster a true sense of collaboration and communicate our sense of value for both family and student interaction in the context of the special education process, outcomes are significantly improved for the student, family and the district.

### **The Surprising Role of Hope**

So much of the work we do as educators is and must be affective. As professionals we tend to focus on the professional, pedagogical skillset teachers need to implement effective

teaching practices in the professional development we provide. These skills are critical to develop, as all the parents I interviewed pointed out. However, often too little attention is paid to the way our students and families *feel* about coming to school. Perhaps it is important to ask ourselves such questions as, “What was this family’s experience at their IEP meeting today?” “What is this student’s experience in their classroom each day?” All five participants emphasized the value of professionals providing a sense of hope. The importance of fostering a sense of *hope* for families is an unexpected outcome of this final research question, but revealed itself to be one of the most profound.

Each participant interviewed talked, either directly or indirectly, about how critical it is to provide a sense of hope to families who are struggling with a child experiencing disability. Their comments were deeply layered, reflecting the exhaustion of their own personal struggles parenting a child who experiences disability, their deep passion and belief their child be seen as a valuable member of the school community, and their unwavering advocacy support of and commitment to their child’s education and success. There is certainly good empirical reason to be concerned about optimism and hope. Researcher Shane Lopez (2013) found that, in addition to being happier and healthier, students with hope improve their school outcomes by up to 12%.

Participant A discussed hope in the context of her family’s need for professionals to “...not give up on a child. Ever.” Participant B described hope in this way, “We’re not pushing him out. We’re still working on this. This is a process we have to work on.” Participant C talked about her own life experience having the unexpected challenge of a student experiencing disability in the context of her professional practice. She related, “So yes surprise. You have more abilities than you thought. Which is perfect for inclusion, because that truly is what we’re trying to say, ‘You may have abilities we have yet to uncover’ and so we look for opportunities

to uncover...and develop those abilities...”

Participant B also commented on her own professional sense of hope and excitement about more inclusive practices, “And you can see that so many more kids would benefit about with this promise that’s coming. This perspective and this model that’s coming I think is going to be incredible...I’m excited about moving that in.” Participant E reflected, “Overall, it takes time and it takes hope...A lot of parents...don’t maybe necessarily have hope or know where to go, and so maybe they just don’t do anything.” Participant D added to his wife’s sentiments with examples of hopefulness. “What’s hopeful? [Son’s name] just got 19 out of 20 on his spelling test. We can say to him, ‘Look, you can do this!’ And that’s not just spelling, that’s the sentences, how that word is used in a sentence...so that’s what makes us hopeful is that, you know...you just see the little progress along the way.”

The current research identifies hope along with positive, realistic messages as an important aspect of appropriate communication with families at the time of their child’s diagnosis with disabilities (Harnett, Tierney, & Guerin, 2009; Lopez, 2013). In his article *Making Hope Happen in the Classroom*, Shane Lopez (2013) explains that hopeful thinking combines future thinking with a sense of agency or efficacy. Moreover, he cites that over 50 studies have examined the role of hope in predicting the performance of elementary, middle school, high school, and college students. In each, hope predicted test scores and GPA’s. In fact, in several of the studies, hope was a significant predictor of student success, even when controlling for previous grades, intelligence, and other psychological variables such as engagement, optimism, and self-efficacy. Given such data, the importance of providing a sense of hope cannot be ignored by educational professionals. This is a realization already possessed by the participants of this study.

## **Applied Implications of the Research**

The specific issues of concern shared by parents during the interviews illuminate many opportunities for practitioners to transform the experiences of families in the special education system as they advocate for inclusive placements for their children. The importance of parents feeling that they need to become skilled advocates for their children to receive the best education possible cannot be underestimated. Administrators and teachers alike would benefit by approaching and responding to parent advocacy communication with a supportive, team-driven approach that focuses on equalizing a parent's sense of partnership and value within the IEP process. Districts could support this process by providing parent workshops on positive advocacy, communication, available community supports and training on standards-based IEP processes.

The focus in district special education departments is typically compliance based. This focus likely results from the extensive state and federal requirements for special education data collection and submission. Unfortunately, this focus also has resulted in traditionally trained special teachers becoming extremely proficient in the compliance aspects of their work related to student data tracking, IEP writing and timeline compliance, and being far less skilled in effective inclusive instructional practices. The data gathered from this study highlight the importance of district leaders developing an additional focus for professional training in the areas of instruction and communication and collaboration to promote inclusive practices (Bacon & Causton-Theoharis, 2013; Kluth, 2010; Payne, 2005; Smith, 2010). Parent's perceptions of the district's ability to implement inclusive practices on an individual staff level were poor. They all asserted that a significant amount of "heart work" must be done to switch to a more inclusive system and that school personnel and "head work" must be done to teach staff the technical and pedagogical

skills they need in order to successfully include students experiencing disability in the general education setting.

The insight that staff must learn to place greater emphasis on compassionate communication is significant. The data gleaned from this study suggests that parents affective experience in IEP and other school meetings is one of the most, if not the most, impactful factor in their experiences advocating for their children's inclusive education. In my professional experience, a family's ability to engage and partner with the district often depends upon the "softer elements" of the special education process. That is, the affective and communication perceptions of families directly impact outcomes for both the child and the district. Families often come to districts in despair, frustrated and without feeling a coherent direction. If school staff members are able to provide a sense of hope and optimism in their communication efforts, families may have the motivation to engage and participate. This sense of hope can be built by providing professional development to all staff on their critical responsibility to provide a sense of hope for the families with whom they work through careful, genuine listening. School personnel would also benefit from training that teaches them to process parent questions and frustrations as an emotional response resulting from pain and fear rather than interpreting a parent's angry response as making a confrontational, adversarial attempt to "get" something to which they may or may not be entitled. A sense of trust can be built and collaborative plans can be built together (Bacon & Causton-Theoharis, 2013; Kluth, 2010; Lopez, 2013).

Another important professional implication of the study points to the need for professionals to place a greater premium on the simple act of listening. Each participant in this study shared specific situations in which they did not feel heard or feel like their opinion was valued. They expressed a strong feeling of gratitude toward specific teachers who had taken the

time with them to understand them and their child was profound. Students and districts alike would benefit from creating structures specifically designed to listen to parents' stories and experiences. School personnel also need to understand that "disability" is a socially constructed label and that each student and family has multiple other identities critical to understand if effective collaboration occurs (Bacon & Causton-Theoharis, 2013). Creating multiple feedback loops that take into consideration accessible locations, native language, comfortable environments and childcare needs with families is crucial for district professionals to continuously hear feedback about the parent and student experiences. These loops could take place in the form of district parent nights, individual parent meetings, coffee chats, home visits, etc. It is in these spaces that potential issues can be proactively dealt with by both family and districts.

Inclusive thinking ultimately requires professional educators, community agency personnel and support staff to rethink their current roles and take a hard and honest look at their systems and the ways they do and do not impact students and their families (Smith, 2010).

### **Scholarly Implications of the Research**

There is much research still to be done on the topic of parent's experiences in advocating for inclusive placements who have a child experiencing disability. Simply, there is little research on the parental experience as individuals navigate through the special education system. Studying this experience further will allow professionals who are charged with designing the systems to create more humane and almost certainly more efficient processes. The result will benefit all by reducing tension, frustration, and conflict by increasing positive communication and understanding within the field of special education.

There has also been little research on specific experiences of students as they progress

through the special education system. By listening to and understanding student experiences, we will ultimately be able to improve the system to educate our students experiencing disability. Many of the policies and practices in special education are designed by legislators and political leaders who are far removed from the student experience in the classroom. By understanding directly what the student and parent lived experiences are, all parties involved can design better service delivery models. Creating student and parent advisory teams in which students and parents can safely share their concerns and ideas is one possible step districts can take to support effective communication between families and district personnel.

Further analysis and study on teacher preparation programs is critical in order to transform the field of special education. Furthermore, teacher and educator preparation programs should work to seamlessly combine general and special educator training to de-segregate the current perception there are “teachers of the disabled” and “teachers of normal students.” Universities need to understand that until their own professional program design reflects an “all means all” mentality with general and special education teachers alike, they will not model inclusive outcomes. Without such further investigation and growing awareness, segregation is not only likely, but guaranteed to continue. General and special education staff need to have a thorough understanding of each other’s work in order for inclusion to become a reality. All staff need training in areas of Universal Design for Learning, differentiated instruction, co and collaborative teaching models and administrators need to have the knowledge to hold their staff accountable for setting these practices as building and district cultural norms for students with disabilities and those who are intellectually, linguistically, culturally and racially different. Preparation programs and districts would benefit from focusing training on

building diverse communities, and developing a climate and culture in which everybody is valued (Smith, 2010).

### **Policy Implications of the Research**

This research has multiple implications on policies and laws in place for both families and professionals. An interesting fact about IDEIA is that although it contains many provisions for increased access for students to general education curriculum, it never has included a definition of inclusion. In fact, the words *inclusion* or *inclusive practices* are not mentioned throughout the entire law. The legal history of special education, dating back to the original PL 94-142 Education for All Handicapped Children's Act, and the creators of IDEIA have framed special education as a *place* that is less or more restrictive, rather than a set of services and a process. Unfortunately, this iteration of special education as a *place*, not a *set of services* that can be provided in the general education setting, completely undermines the concept of true inclusion for students (Smith, 2010).

The special education system is saturated with extensive amounts of paperwork, "red tape," compliance rules and regulations and technicalities. Oregon's current IEP form has 46 standards on which districts are required to report. Each IEP a teacher writes then has additional bullet points of compliance with which special education teachers must comply (Oregon Department of Education, n.d.). If compliance is not achieved, districts risk a series of state and legal complaints that are extremely time consuming and expensive. As a result of these extensive compliance policies, teachers often focus almost exclusively on compliance and not instruction. If we are to change the special education system and implement inclusive practices, more of an emphasis on instructional practices is necessary. Furthermore, teachers need to be given the time and a reasonable number of students to case manage, to complete the compliance

*and* instructional components of their job.

Additionally, it is crucial teachers are given time to meet with families and provide the critical communication so well represented by parents in this study. Indeed, the desire for greater soft, affective, people skills was pervasive among the participants. With such a large list of demands and high numbers of students, special education teachers and case managers often face conditions that do not set them up for success (Karten, 2009).

The issue of school funding is critical when considering special education research and implications for policy changes. Inclusive models such as collaborative and co-teaching require resources, as, it might be added, do adequate support structures. Reduction of case management loads requires additional funding. While there have been significant increases to special education funding at the federal level, funding levels continue to be inadequate relative to district's needs. When Congress enacted special education legislation in the 1970's it promised to fund up to 40% of the "excess cost" of special education. To date, it has provided less than 19%, not even reaching half the excess cost (Smith, 2010). For example, in the 2005 fiscal year the federal government appropriated 10.6 billion dollars for IDEA Part B. This appropriation left a remaining balance of excess cost for students with disabilities of 46.2 billion dollars (Apling, 2005). This remaining balance is typically shouldered by school districts already overwhelmed by budgeting inadequacies (Kusler, 2003).

The challenge for school districts is that despite the funding deficits, legal compliance requirements remain. As a result, school districts are often forced to make impossible decisions. Too often school officials feel compelled to "rob Peter to pay Paul" by transferring resources from one initiative to another instead of designing sustainable, research-based and effective solutions. Furthermore, districts are not able to design programs and services based upon best

practice models such as inclusive practices and Universal Design, but are forced to develop and implement models based upon affordability. This expense burden adds insult to injury for districts when as a result of poorly designed policies and practices, conflict and litigation result.

The issue of assessing the performance of students with disabilities and accountability is a challenging topic that has been highlighted by the advent of NCLB and the new Every Student Succeeds Act (ESSA). The concept of assessing students through Universal Design and other alternative methods could be further researched to allow equitable access to facilitate multiple means of expression of knowledge (Bacon & Causton-Theoharis, 2013). Additionally, the impact of blanket “one size fits all” policies on students experiencing disability should be examined (IDEA, 2004; NCLB, 2002). In the upcoming weeks and months, the impact of the newly minted ESSA needs to be closely monitored at the state and district level to determine its’ impact on students experiencing disability.

As detailed in Chapter 3, despite nearly forty years of judicial and legislative progress, educators and parents continue to struggle with issues of service delivery models to students experiencing disabilities due to lack of professional know-how, lack of personal motivation, and systemic barriers to support the process (Roach & Salisbury, 2006). It is critical that we continue to look for ways to effectively support and communicate with families so we can understand their experience advocating for their children under current policies and laws. It is only through this process of listening and learning that we will ultimately close the gap between policy and actual experience and begin to value all our students as important members of the school and greater world community.

### **Professional Reflections of the Researcher**

As a professional educator for 23 years, at the start of this investigation I wondered what

I would learn from the families about their experience advocating for their students experiencing disability to be in an inclusive educational placement. As it turns out, I learned a lot. The process has been infinitely valuable in helping me understand in an uninterrupted way, what the families with whom my colleagues and I work, experience in our district.

I have learned that sitting down and listening to parents is something we need to do more often. We currently have district structures set up where parents can come and learn from organizations such as FACT, ODE, and local experts about aspects of the school system. Recent topics have included standards based IEP's, the new state testing systems and requirements and behavior management from a local psychologist. However, I have not created as intentional a 1:1 listening structure where parents are telling *us* about our system's impact upon them and their child. Listening for 90 minute blocks to parents turned out to give me many of the "keys" I have felt were missing in our process. As a result, my administrative staff and I are going to regularly, intentionally ask parents if they will come in to spend some time with us simply telling their story. An example of using this information is a recent change we are initiating based upon parent feedback on their extreme anxiety over transitions. We currently have a system in which students have up to three moves during their elementary years. After hearing about the impact of these transitions from parents, we have already started to work on aligning our specialized supports K-6 in our elementary schools. These kinds of actions reflect progress toward more inclusive practices.

I was profoundly struck that parents see our responsibility as professionals is to foster a sense of hope in the families with whom we work. This idea will change the focus of some of our professional development work to include more skills about the importance of positive communication, listening, and helping families understand that they, not only we, hold many of

the keys we need to supportively educate their child. The commonly heard saying, “They don’t care what you know, until they know that you care” comes to mind. We can’t reach our families if they don’t feel we care. Period. This important finding gives me a deep sense of purpose in my work. Candidates are not lining up at the door to be Special Education Director’s these days. Primarily this is due to the field’s reputation as being ripe with conflict, litigation, long hours and endless paperwork. Many of our special education teachers feel the same way. While there is definitely truth to these concerns, if we can shift their focus to find a sense of purpose and meaning and reward their inclusive and connective practices with students and their families, staff retention and consistency for students may improve and our young teachers would find a sense of purpose in sustainable, satisfying careers in the field of special education.

As parents became tearful or passionate during their interview, I was also struck by a profound sense of responsibility. As educators sensitive to the notion of disability, and with recent state and federal legislative changes pushing districts into inclusive practices as a norm, we have an unprecedented opportunity to change the way we practice our craft. This responsibility must be taken seriously, and in fact may be the hope a student or parent needs to make it through the days, weeks and months ahead. We as educators must resist the temptation to blame our systemic and adult issues on students, pretending that they are the problem when in fact, it is we adults who often are the problem. As system creators we must take the responsibility to model and lead the work of social justice and equity for the disabled.

The feelings parents shared of marginalization and struggle to participate in IEP processes with a sense of equity and value were hard to hear, especially since significant resources have been allocated toward professional development “equity work” in our district. I also would like to think we are just doing a better job. We have a ways to go. This equity work

has been enlightening and powerful, but sadly has not included our students experiencing disability as much as it has those with cultural and linguistic differences. Much needs to be done in this arena and it needs to be done in collaboration with general education teachers and administrators. We are fortunate to have a Superintendent who is supportive of this notion, however we all have a lot to learn together. This year, he was able to present on inclusive practices within our district with myself and an elementary principal at our state special education conference. The response was extremely positive. I know people look to our district for leadership in practices, and we'd like to be able to deliver on what we set out to do. As a next step, we need to present on this issue at a state general education conference and impact a broader audience. There are often times in my role as a Student Services Director that I feel like I need a degree in marketing instead of educational leadership.

Finally, this research has reinforced for me the degree to which our student services department must take the responsibility to build the demand for change and show students and staff "the way" toward inclusive practices. There is a famous quote by Rumi that roughly translates "When you start to walk on the way, the way appears." I am certainly no Rumi, but I don't see him sitting around our school district either. Therefore, the job falls to me, to us, as district and educational leaders to take collective ownership and responsibility to step out on the way, and learn as we go. We need to "market" the idea that students with disabilities matter. That they have value. That they are community contributors, that they are happy, sad, curious, bored, funny, hard workers, and learners, and have things to teach us all. We need to understand that our students, in whatever shape they come to us, are someone's son, daughter, and are deeply loved by them. And that someone needs to be empowered by us as professionals to collaborate, so together we can unearth the power and potential of our students experiencing

disability together. This role of the teacher and educator as a social change agent needs to continue to be looked at and developed.

The next final step is to harness enough buy-in and support from federal, state, district and school leaders to make inclusion a reality for all students. This process needs to happen through district work with a clear vision and values stated from the top down. Directors need to lobby their local legislators, testify at legislative hearings and design district systems and practices that demand social justice and equitable instructional practices become a reality. We need to power through the doubt, shame, labels and structural barriers teachers and parents of those who experience disability constantly face and replace these negative social constructions and emotions with creative, innovative solutions for funding and service delivery. It will take all of us working together to invent these solutions. Solutions will need to be complex, dynamic, relational and intellectual. They need to involve multiple agencies collaborating together and needs to involve lots of learning on everyone's part, because schools cannot do it alone. We must breakdown the professional structured silos we have spent so long creating in order to serve all our children in the equitable way they deserve.

### **Personal Reflections of the Researcher**

Personally, I feel a sense of deep respect, gratitude, and compassion toward the parents that gave me the opportunity to hear their stories. As I reflect upon my experience 23 years ago, trying to figure out how to navigate that first request I received for an inclusive placement, I am amazed at what has transpired in my life. Since that time I have married, and have been blessed with a beautiful family. My husband and I have middle school age boy/girl twins, one of whom struggles with ADHD. When our son was seven years old, we knew something wasn't right when he couldn't read. I remember walking into his private school after a particularly difficult

morning with him, unable to hold back my tears of frustration that he was just not making progress, feeling like I had completely failed as a parent. The principal promptly came up to me, and asked me if she could help. After I explained my distraught state, she patted me on the shoulder and said, “Don’t worry honey. He will get it when he’s ready. I promise. We are going to keep trying until he does. We just need to keep trying and figure out what works. He is a very smart boy.” I could have hugged her. That ten second interaction was exactly what I needed to hear. It was like being fantastically thirsty and being provided with a clear, tall glass of water to gulp down. I felt reassured, validated, not quite so crazy, and tremendously relieved. She had extended me the lifeline I needed to regroup for the day. She had extended me a sense of hope.

As most parents do, we have been learning from the beginning through trial and error and continue to learn about what our son needs and what we need in order to be the best parents possible to his sister and to him. I am continually struck by the difficulty of the daily challenges of parenting in general, much less for a child who struggles. I also know from my work that on the continuum of disabilities our son’s challenges are relatively minor, and we are very lucky. We know our struggles pale in comparison to what other parents’ experience. Yet, there are some days when we can’t imagine how he, or we, will get from point A to point B. I just can’t help but think if I am feeling the stress of parenting, knowing what I know professionally about the field of special education and as a middle class, white female equipped with advanced degrees, blessed with adequate resources to supply him with private school, tutors, and medical interventions, and fully able to understand the support systems we need to navigate, what are other parents going through who don’t have those advantages? I have spent more than one meeting in tears with my son’s teachers trying to problem solve specific issues. It is just *so unbelievably hard*, even with all available resources in play.

It's difficult and overwhelming to believe there are about 3,000 variations of parents who have children labeled with special needs in our district whom are looking to us for guidance, hope and support. Since I've become a parent, there is no question I've become a better professional. I am not saying people without children can't do effective work with families, because I know some tremendously talented individuals who do. For me however, understanding the deep connection between parents and their children has allowed me to see other's struggles through a greater lens of compassion and respect. In the hundreds of families I have worked with I have often heard parents say when things are not going well with their children, their world cannot be balanced. I completely concur. I have found our most challenging parents to simply be afraid and concerned. I understand that on a new level. I now understand if we can provide parents with the combination of skill and hope they and their children need we have done our jobs, they often are able to refocus and problem solve. Somehow, we need to do better at showing them the way, and I'm convinced we can. We must. The research is clear. We know what works. Now we need to find the courage and the will to simply step out and do it.

## REFERENCES

- Access to the General Curriculum for Students with Disabilities. (2003). Retrieved March 5, 2013, from [http://opi.mt.gov/PDF/Assessment/MCPresents/IEPs/curriculum\\_access\\_legal.pdf](http://opi.mt.gov/PDF/Assessment/MCPresents/IEPs/curriculum_access_legal.pdf)
- Ainscow, M. (2007). Taking an inclusive turn. *Journal of Research in Special Education Needs*, 7, 3-7.
- Alkin, M., & Freeman, S. (2000). Academic and social attainments of children with mental retardation in general education and special education settings. *Remedial and Special Education*, 21(1), 3-18.
- Apling, R. (2005). *Individuals with Disabilities Education Act (IDEA): Current funding trends*. Washington D.C.; Congressional Research Service, The Library of Congress.
- Auerbach, S. (2012). *School leadership for authentic family and community partnerships: Research perspectives for transforming practice*. New York, NY: Routledge.
- Bacon, J. K., & Causton-Theoharis, J. (2013). 'It should be teamwork': A critical investigation of school practices and parent advocacy in special education. *International Journal of Inclusive Education*, 17(7), 682-699. doi:10.1080/13603116.2012.708060
- Bailey, J. (2004). The validation of a scale to measure school principals' attitudes toward the inclusion of students with disabilities in regular schools. *Australian Psychologist*, 39(1), 76-87.
- Barnett, C., & Monda-Amaya, L. E. (1998). Principals' knowledge of and attitudes toward inclusion. *Remedial and Special Education*, 19(3), 181-192.

- Bateman, D. (1998). *A national survey of state requirements relating to special education for prospective principals*. Lecture presented at the meeting of the Eastern Education Research Association, Tampa, Florida.
- Blackorby, J., Knokey, A., Wagner, M., Levine, P., Schiller, E., & Sumi, C. (2007). Info & Reports. Retrieved July 21, 2015, from [http://www.seels.net/seels\\_textonly/info\\_reports/what\\_makes\\_difference\\_txt.htm](http://www.seels.net/seels_textonly/info_reports/what_makes_difference_txt.htm)
- Brandon, R. R., & Brown, M. R. (2009). African American families in the special education process: Increasing their level of involvement. *Intervention in School and Clinic, 45*(2), 85-90. doi:10.1177/1053451209340218
- Carter, E., Swedeen, B., Walter, M. C., & Moss, C. K. (2012). I don't have to do this by myself? Parent-led community conversations to promote inclusion. *Research and Practice for Persons with Severe Disabilities, 37*(1), 9-23. doi:10.2511/027494812800903184
- Causton, J., & Tracy-Bronson, C. (2015). *The Educator's Handbook for Inclusive School Practices*. Newburyport: Brookes Publishing.
- Causton-Theoharis, J. & Kasa, C. (n.d.). *Achieving inclusion: What every parent should know when advocating for their child*. Pittsburgh, PA: The Peal Center.
- Causton-Theoharis & Kasa, C. (n.d.). *Strategies for success: Achieving inclusive classrooms that work*. Pittsburgh, PA: The Peal Center.
- Center for Parent Information and Resources. (n.d.). Retrieved from <http://www.parentcenterhub.org/>
- Commission on Special Education (1985). *Special education: A call for quality*. New York: Author. (ERIC Document Reproduction Service No. ED 386 439).

- Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- DeFur, S. (2012). Parents as collaborators: Building partnerships with school and community based providers. *Teaching Exceptional Children*, 44 (4), 58-67.
- Desforges, C. & Abouchaar, A. (2003). *The impact of parental involvement, parental support and family education on pupil achievements and adjustment: A literature review* (Research Report 433). Department for Education and Skills, Nottingham, UK.
- Disability rights Oregon – Opportunity. Access. Choice. (n.d.). Retrieved on January 2, 2016 from <https://droregon.org/>
- Doyle, L. (2003). *Inclusion. The unifying thread for fragmented metaphors*. Annual Meeting of the American Association of Educational Research, Chicago, Illinois.
- Egbert, J., & Salsbury, T. (2009). Out of complacency and into action: An exploration of professional development experiences in school/home literacy engagement. *Teaching Education*, 20 (4), 375-393.
- Epstein, J. L. (2010). School/family/community partnerships: Caring for the children we share. *Phi Delta Kappan*, 92(3), 81-96. doi:10.1177/003172171009200326
- FACT PTI - FACT Oregon (n.d.). Retrieved December 22, 2015, from <http://factoregon.org/parent-training-iep-education/>
- Finlay, L. (2009). Debating phenomenological research. *Phenomenology & Practice*, 3(1), 6-25.
- Fish, W. (2006). Perceptions of parents of students with autism toward the IEP meeting: A case study of one family support group chapter. *Education*, 127 (1), 56-68.

- Fish, W. (2008). The IEP meeting: Perceptions of parents of students who receive special education services. *Preventing School Failure: Alternative Education for Children and Youth*, 53(1), 8-14.
- Fishman, C. E., & Nickerson, A. B. (2014). Motivations for involvement: A preliminary investigation of parents of students with disabilities. *Journal of Child and Family Studies*, 24(2), 523-535. doi:10.1007/s10826-013-9865-4
- Fitch, F. (2003). Inclusion, exclusion, and ideology: Special education student's changing sense of self. *The Urban Review*, 35(3), 233-252.
- Forbes, F. (2007). Towards inclusion: An Australian perspective. *Support for Learning*, 22(2), 66-71. doi:10.1111/j.1467-9604.2007.00449.x
- Frew, L. A., Zhou, Q., Duran, J., Kwok, O., & Benz, M. R. (2012). Effect of school-initiated parent outreach activities on parent involvement in school events. *Journal of Disability Policy Studies*, 24(1), 27-35. doi:10.1177/1044207311427163
- Gay, L. R., Mills, G. E., Airasian, P. (2009). *Educational research: Competencies for analysis and applications* (9th ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.
- Gee, K. (2004). Developing curriculum and instruction. In F. Orelove, D. Sobsey, & R. Silberman (Eds.) *Educating children with multiple disabilities: A collaborative approach* (4<sup>th</sup> edition) (p. 67-114). Baltimore, MD: Paul H. Brookes Publishing Co.
- Giangreco, M. F. (1993). Using creative problem-solving methods to include students with severe disabilities in general education classroom activities. *Journal of Educational and Psychological Consultation*, 4(2), 113-135. doi:10.1207/s1532768xjepc0402\_1
- Gutek, G. L. (2004). *Philosophical and ideological voices in education*. Boston, MA: Allyn and Bacon.

- Hanushek, E. A., Kain, J. F., & Rivkin, S. G. (2002). Inferring program effects for special populations: Does special education raise achievement for students with disabilities? *Review of Economics and Statistics*, 84(4), 584-599. doi:10.1162/003465302760556431
- Harnett, A., Tierney, E., & Guerin, S. (2009). Convention of hope – communicating positive, realistic messages to families at the time of a child’s diagnosis with disabilities. *British Journal of Learning Disabilities*. Dec 2009; (37) (4) 257-264. DOI: 10.1111/j.1468-3156.2009.00580.x.
- Harry, B. (1992). *Cultural diversity, families, and the special education system: Communication and empowerment*. New York: Teachers College Press.
- Harry, B. (2002). Trends and issues in serving culturally diverse families of children with disabilities. *The Journal of Special Education*, 36(3), 132-140.  
doi:10.1177/00224669020360030301
- Hattie, J. (2009). *Visible learning: A synthesis of over 800 meta-analyses relating to achievement*. London: Routledge.
- Howard, G. (2007). As diversity grows, so must we. *Educational Leadership*, 64(6), 16-22.
- Heidegger, M. (1976). *Being and Time*. New York: Harper and Row.
- Individuals With Disabilities Education Improvement Act, 20 U.S.C. § 1400 (2004).
- IDEA 2004: Law and Regulations - Wrightslaw. (n.d.). Retrieved April 1, 2013,  
from <http://www.wrightslaw.com/idea/law.html>
- Idiot. (n.d.). In *Dictionary. Com*. Retrieved July 24, 2015, from  
<http://dictionary.reference.com/browse/idiot?s=t>

- Jeynes, W. H. (2007). The relationship between parental involvement and urban secondary school student academic achievement: A meta-analysis. *Urban Education, 42*(1), 82-110. doi:10.1177/0042085906293818
- Jorgensen, C.M., Schuh, M.C., & Nisbet, J. (2006). *The inclusion facilitator's guide*. Baltimore, MD; Paul H. Brookes Pub. Co.
- Kafle, N. P. (2011). Hermeneutic phenomenological research method simplified. *Bodhi: An Interdisciplinary Journal, 5*(1), 181-200.
- Kalyanpur, M., & Harry, B. (1999). *Culture in special education: Building reciprocal family-professional relationships*. Baltimore, MD: P.H. Brookes Publishers.
- Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and advocacy expectations of culturally diverse families' participation in special education. *International Journal of Disability, Development and Education, 47*(2), 119-136. doi:10.1080/713671106
- Karten, T. J. (2009). *Inclusion strategies that work for adolescent learners!* Thousand Oaks, CA: Corwin Press.
- Kasa-Hendrickson, C., & Ashby, C. (2009). *Strength based classroom: How the presence of students with disabilities enhances the general education classroom*. Lecture presented at Ninth Annual Second City Conference on Disability Studies in Education, Syracuse, New York.
- Kasa, C. & Causton-Theoharis, J. (n.d.). *Strategies for success: Creating inclusive classrooms that work*. Pittsburgh, PA: The Peal Center.
- Kleiman, S. (2004). Phenomenology: to wonder and search for meanings. *Nurse Researcher, 11*(4), 7-19.

- Kluth, P. (2010). *"You're going to love this kid": Teaching students with autism in the inclusive classroom* (2<sup>nd</sup> edition). Baltimore, MD: P.H. Brookes Pub. Co.
- Kluth, P., Villa, R., & Thousand, J. (2002). "Our school doesn't offer inclusion" and other legal blunders. *Educational Leadership*, 59(4), 24-27.
- Kunc, N. (1992). The need to belong: Rediscovering Maslow's hierarchy of needs. Originally published in: Villa, R., Thousand, J., Stainback, W. & Stainback, S. *Restructuring for Caring & Effective Education*. Baltimore: Paul Brookes.
- Kusler, M. (2003). The imperative of fully funding IDEA. *School Administrator*, 60(3), 47.
- Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, 2(3), 21-35.
- Law, P. (1975). Law 94-142. *Education for all handicapped children act, 20*, 1401-1461.
- Lazaridou, A. (2009). The kinds of knowledge principals use: Implications for training. *International Journal of Education Policy and Leadership*, 4(10), 1-15.
- Lewis, R., & Doorlag, D. (2006). *Teaching special students in general education classrooms* (7<sup>th</sup> ed.). Upper Saddle River, NJ: Pearson Prentice Hall.
- Lo, L. (2012). Demystifying the IEP process for diverse parents of children with disabilities. *Teaching Exceptional Children*, Jan/Feb, 14-20.
- Lopez, S. J. (2013). How can schools foster hope?: Making hope happen in the classroom. *Phi Delta Kappan*, 95(2), 19-22. doi:10.1177/003172171309500205
- Mchatton, P. A., & Correa, V. (2005). Stigma and discrimination: Perspectives from Mexican and Puerto Rican mothers of children with special needs. *Topics in Early Childhood Special Education*, 25(3), 131-142. doi:10.1177/02711214050250030101

- McLaughlin, M. J. (2004). *What every principal needs to know about special education* (2nd ed.). Thousand Oaks, CA: Corwin Press.
- McLeskey, J., Rosenberg, M. S., & Westling, D. L. (2013). *Inclusion: Effective practices for all students* (2nd ed.). Boston: Pearson.
- Merriam-Webster (n.d.). *Merriam-Webster*. Retrieved September 26, 2015, from <http://www.merriam-webster.com/dictionary/advocacy>
- Mills v. Board of Education of the District of Columbia. (1972). Retrieved October 30, 2014, from <http://educational-law.org/438-mills-v-board-of-education-of-the-district-of-columbia.html>
- Mlawer, M. A. (1993). Who should fight?: Parents and the advocacy expectation. *Journal of Disability Policy Studies, 4*, 105–116.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Mueller, T. G., Milian, M., & Lopez, M. I. (2009). Latina Mothers' Views of a Parent-to-Parent Support Group in the Special Education System. *Research and Practice for Persons with Severe Disabilities, 34*(3), 113-122. doi:10.2511/rpsd.34.3-4.113
- Newman, L. (2005). Family involvement in the educational development of youth with disabilities: A special topic report of findings from the National Longitudinal Transition Study-2 (NLTS2). *SRI International*. Retrieved July 21, 2015, from <http://files.eric.ed.gov/fulltext/ED489979.pdf>
- No Child Left Behind Act of 2001, P.L. 107-110, 20 U.S.C. § 6319 (2002)
- Oregon Council on Developmental Disabilities (n.d.). Retrieved December 5, 2015 from <http://ocdd.org/index.php/ocdd/trainings/130/>
- Oregon Department of Education. (n.d.). Retrieved January 2, 2016, from

- <http://www.ode.state.or.us/schoolimprovement/accountability/monitoring/prcformsa.doc>  
Parent Technical Assistance Centers | Center for Parent Information and Resources. (n.d.).  
Retrieved January 2, 2016 from <http://www.parentcenterhub.org/ptacs/>
- Patton, Q.P. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Payne, R. (2005). Special education teacher shortages: Barriers or lack of preparation? *International Journal of Special Education*, 20(1), 88-91.
- Peck, C. A., Staub, D., Gallucci, C., & Schwartz, I. (2004). Parent perception of the impacts of inclusion on their nondisabled child. *Research and Practice for Persons with Severe Disabilities*, 29(2), 135-143. doi:10.2511/rpsd.29.2.135
- Pennsylvania Association for Retarded Citizens (PARC) v. Commonwealth of Pennsylvania. (n.d.). Retrieved October 30, 2013, from <http://www.pilcop.org/pennsylvania-association-for-retarded-citizens-parc-v-commonwealth-of-pennsylvania/>
- Petersen, J. (2007). A timeline of special education history. Retrieved October 27, 2013, from [http://admin.foreschools.org/PupilServices/StaffInfo/A timeline of special education history.html](http://admin.foreschools.org/PupilServices/StaffInfo/A%20timeline%20of%20special%20education%20history.html)
- Poon-McBrayer, K., & Wong, P. (2013). Inclusive education services for children and youth with disabilities: Values, roles and challenges of school leaders. *Children and Youth Services Review*, 35, 1520-1525.
- Posney, A. (2013). NASBE - NASBE's State Education Standard Looks at the Importance of Social Inclusion in Schools. Retrieved October 30, 2013, from <http://www.nasbe.org/downloads/nasbes-state-education-standard-looks-at-the-importance-of-social-inclusion-in-schools/>

- Rafferty, Y., Boettcher, C., & Griffin, K. W. (2001). Benefits and risks of reverse inclusion for preschoolers with and without disabilities: Parents' perspectives. *Journal of Early Intervention, 24*(4), 266-286. doi:10.1177/105381510102400403
- Roach, V., & Salisbury, C. (2006). Promoting systemic, statewide inclusion from the bottom up. *Theory Into Practice, 45*(3), 279-286.
- Rodriguez, R. J., Blatz, E. T., & Elbaum, B. (2014). Parents' views of schools' involvement efforts. *Exceptional Children, 81*(1), 79-95. doi:10.1177/0014402914532232
- Runswick-Cole, K. (2008). Between a rock and a hard place: Parents' attitudes to the inclusion of children with special educational needs in mainstream and special schools. *British Journal of Special Education, 35*(3), 173-180.
- Salas, L. (2004). Individualized educational plan (IEP) meetings and Mexican American parents: Let's talk about it. *Journal of Latinos and Education, 3*(3), 181-192.  
doi:10.1207/s1532771xjle0303\_4
- Salisbury, C. L. (2006). Principals' perspectives on inclusive elementary schools. *Research and Practice for Persons with Severe Disabilities, 31*(1), 70-82.
- Sawyer, M. (2014). BRIDGES: Connecting with families to facilitate and enhance involvement. *Teaching Exceptional Children, 47*(3), 172-179. doi:10.1177/0040059914558946
- Smith, P. (2010). *Whatever happened to inclusion?: The place of students with intellectual disabilities in education*. New York: Peter Lang.
- Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, E. P. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals. *Focus on Autism and Other Developmental Disabilities, 20*(1), 39-51.

- Theoharis, G. (2009). *The school leaders our children deserve: Seven keys to equity, social justice, and school reform*. New York: Teachers College Press.
- Trainor, A. (2010). Reexamining the promise of parent participation in special education: An analysis of cultural and social capital. *Anthropology & Education Quarterly*, 41(3), 245-263. doi:10.1111/j.1548-1492.2010.01086.x
- Turnbull, A., Turnbull, R., Erwin, E. & Soodak, L. (2006). *Families, professionals and exceptionality: Positive outcomes through partnerships and trust*. Upper Saddle River, NJ: Person Prentice Hall.
- United States Census Bureau. (n.d.). Retrieved July 22, 2015, from <https://www.census.gov/popest/data/>
- Universal Design for Learning (n.d.). Retrieved September 8, 2015 from <https://www.cast.org>
- Valesky, T., & Hirth, M. (1992). Survey of the states: Special education knowledge requirements for school administrators. *Exceptional Children*, 58(5), 399-406.
- Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: State University of New York Press.
- Waldron, N., & McLeskey, J. (1998). The effects of an inclusive school program on students with mild and severe learning disabilities. *Exceptional Children*, 64(2), 395-405.
- Ware, L. P. (1994). Contextual barriers to collaboration. *Journal of Educational and Psychological Consultation*, 5(4), 339-357. doi:10.1207/s1532768xjepc0504\_4
- Wellner, L. (2012). Building parent trust in the special education setting: Educators and parents of students with special needs must work together to change school culture and move from conflict to collaboration. *Leadership*, 41(4), 16-19.

- Winzer, M. (2006). Confronting difference: An excursion through the history of special education. In L. Florian (Ed.), *The SAGE handbook of special education* (pp. 22-35). London: SAGE Publications Ltd. doi:<http://dx.doi.org/10.4135/9781848607989.n3>
- Woo Jung, A. (2011). Individualized education programs (IEP's) and barriers for parents from culturally and linguistically diverse backgrounds. *Diversity and Special Education, 19*(3), 21-25.
- Wright, A. C., & Taylor S. (2014). Advocacy by Parents of Young Children with Special Needs: Activities, Processes, and Perceived Effectiveness. *Journal of Social Service Research, 40*(5), 591-605.

**APPENDIX A**  
**RESEARCH QUESTIONS AND**  
**PERSONAL INTERVIEW GUIDE QUESTIONS**

**Parents' Advocacy Experiences for the Inclusion of Children**  
**Experiencing Disability in the General Education Setting**

Research Question #1. How do you define or conceptualize inclusion?

*What form of inclusion do you see as desirable for your child?*

*Do you see inclusion as a continuum or as an absolute?*

Research Question #2. In what kinds of activities/experiences have you engaged to advocate for your student?

*What is your experience with advocacy opportunities either provided or not provided by the school?*

*What have been your most effective advocacy experiences?*

*Why?*

*How do you feel about traditional "pull out" services?*

Research Question #3. When advocating for your student, what kinds of barriers have you faced to obtaining an inclusive placement for your child?

*Were these barriers with people or processes, or both?*

*Can you talk a little about that experience?*

Research Question #4. What is your perception of the school district response to advocating for an inclusive setting for your child?

*How did you feel about the district response?*

*Was any one particular process or person helpful?*

*Is there anything your feel anyone involved should have done and didn't?*

Research Question #5. Did you feel your advocacy efforts were successful?

*Why or why not?*

*Did you have support from others when you advocated?*

*What was the outcome?*

*Were there, if any, compromises you felt you made in the process of coming to an agreement with the district?*

*Is there anything else you'd like to add?*

**APPENDIX B**  
**LETTER OF CONSENT**

Dear Oregon School Parent,

My name is Elaine Fox and I am a doctoral student in Educational Leadership at George Fox University. I am conducting research on parent's advocacy experiences for the inclusion of students eligible for special education services in a public k-12 setting. You are invited to engage in a 60 minute-long personal interview regarding your experiences advocating for your son/daughter to participate in an inclusive setting during their experience in grades K-12.

The questions relate to your personal experience with any advocacy activities such as IEP meetings, community meetings, etc. My hope is that listening to your experience will provide insight and further understanding into our special education system and related interactions with parents. I am hopeful our system will be improved for students, staff and parents as a result of your anonymous participation.

The risks associated with this research are minimal. The personal interview questions are non- invasive and are intended to offer you the opportunity to reflect upon, and share, your experiences and perceptions. Please be aware that your participation is completely voluntary and you may decline to continue at anytime or decline to answer any question(s) at your discretion.

The results of this study will only be used for research purposes, primarily, for the dissertation required for the completion of my doctoral program. Information will be analyzed and presented in an anonymous fashion and no individual will be personally identified. All personal information and identities will be kept confidential.

All research materials (i.e., audio recordings, transcriptions, and signed consent forms) will be locked in separate, secure locations for a period of three years. I will be the only individual who will have access to these materials and after three years, I will personally destroy all relevant materials and delete the audio recordings.

Thank you for considering participation in this study. If you have any questions regarding this research, please contact me at (503) XXX.XXXX. If you have any additional questions you may contact my committee chair, Dr. Terry Huffman at (503) XXX-XXXX.

If you understand the use of this research and agree to participate, please sign below.

Participant signature \_\_\_\_\_

Researcher signature \_\_\_\_\_

## APPENDIX C

### PARENT ADVOCACY AND SUPPORT ACTIVITIES

Activity/Support	Participants				
	A	B	C	D	E
All Born (In) (Community Advocacy Group)	x		x		
Association for Retarded Citizens (ARC)			x		
Dad's support group (started in district)				x	
Defeat Autism Now (DAN!) (biomedical intervention)			x		
Disability Rights Oregon (DRO)	x	x	x	x	x
District Parent Partnership Meetings	x	x	x	x	x
District Clinical Psychologist					
Early Intervention Program	x	x	x	x	x
Families and Community Together (FACT)	x	x	x	x	x
Greenspan Training			x		
IEP Meetings	x	x	x	x	x
Individual "check in meetings" outside of IEP's	x	x	x	x	x
Intensive reading/personal learning/research	x	x	x	x	x
Oregon Megaconference			X		
Parent to parent informal conversations	x	x	x	x	x
Partners in Policy Program	x		x	x	x
Physician Support	x	x	x	x	x
Private Speech Therapist				x	x
Private Tutor				x	x
Private Kindergarten		x			
Separate Meetings with District Administrators	x	x	x	x	
Sib Shop (Community Support for Siblings)			x		
Specialized Child Care		x			
Superintendent's Coffee Chats				x	x

## APPENDIX D

### FELT NEEDS OF THE PARTICIPANTS

Felt Needs of Participants	Participants				
	A	B	C	D	E
Staff Training is needed	x	x	x	x	x
Provide families with a sense of HOPE	x	x	x	x	x
Communicate to parents in their native language	x	x			
Treat parents as a valuable member of the IEP team	x		x	x	x
Value each child as a true part of the school community	x	x	x	x	x
Help parents learn and understand the SPED system	x	x	x	x	x
Assume competence first for students with IEP' s			x	x	x
Provide parents as many resources for support as possible	x	x	x	x	x
Practice your craft with more compassion and less judgment	x	x			
Learn about different disabilities	x		x	x	x
See what children CAN do, not what they CAN' T do	x	x	x	x	x
Learn from students with IEP' s-they have a lot to teach us	x	x	x		
Understand how hard it is to have a student who struggles	x	x	x	x	x
Communicate regularly and be honest with parents	x	x	x	x	x