

DUST FROM THE MOON: SPECIAL EDUCATION LEADERSHIP JOURNEYS OF
SIX LATINO PARENTS

by

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A Dissertation
Submitted to the
Graduate Faculty
of
George Mason University
in Partial Fulfillment of
The Requirements for the Degree
of
Doctor of Philosophy
Education

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Date: _____ Spring Semester 2016
George Mason University
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Dedication

This dissertation is dedicated to my family – my dear husband, James Scampavia, who believes in me on those days I’m full of doubt; my brilliant daughter, Margaret Rei Scampavia Evangelista, who is pursuing her own dreams of a PhD in Entomology; and most-of-all to my amazing son, Peter Takeshi Scampavia, who was born with Costello syndrome 27 years ago and propelled me on this advocacy journey. He continues to inspire and amaze me.

Acknowledgements

I have great admiration for and deep gratitude to the Latino parent leaders who generously shared their time and recounted their journeys with me to make this study possible.

I would like to thank my committee, **Dr. Eva K. Thorp**, who plucked me out of the local parent leadership community, early on my journey as an advocate, and who has been a long-time co-conspirator and collaborator on initiatives such as the Multicultural Early Childhood Team Training national demonstration project; **Dr. Michael Behrmann**, who is a master at breaking down barriers and demonstrated his long-standing commitment to people with disabilities by establishing the LIFE program that fulfilled my son's dream of going to college at George Mason University; and **Dr. Joseph Maxwell** who has been a strong proponent of the rigor, power, and potential of qualitative research to answer the "why" questions that quantitative research cannot.

Dr. Sylvia Sanchez and **Dr. Thorp** have devoted their careers to embracing the strength and competence of culturally, linguistically, and ability-diverse families. Their *New Leaders Now* PhD fellowship program, funded by the U.S. Department of Education, enabled diverse students, like me, to make our mark in the education world.

I'm continually inspired and energized by the pioneer parent leaders in the special education and disability movement and more recent parent leaders in the Latino advocacy community who continue to break down barriers, creating new narratives and future histories for people with disabilities. I also owe so much to the professionals who encouraged me to be "more than just a parent" and boosted me to new heights.

Finally, I would like to thank my dear friend, **Rosalia Fajardo** who showed me how Latino parent advocacy has the extraordinary power to amplify the voices and positive outcomes for Latino families and their children with disabilities.

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List of Abbreviations

Applied Behavioral Analysis	ABA
Child Protective Services	CPS
Culturally, linguistically, and ability-diverse.....	CLAD
Department of Family Services	DFS
Elementary and Secondary Education Act	ESEA
Individuals with Disabilities Education Act	IDEA
Individual Education Program	IEP
Individualized Family Services Plan	IFSP
Interagency Coordinating Council.....	ICC
Neonatal Intensive Care Unit.....	NICU
Occupational Therapy.....	OT
Parents Supporting Educational Excellence	Parents SEE
Special Education Provisions of IDEA.....	Part B
Early Intervention for Infants and Toddlers with Disabilities of IDEA	Part C
Parent Institute for Quality Education	PIQE
Pre-Kindergarten.....	Pre-K
Parent Training and Information Center	PTI
Title I of ESEA	Title I
United States	U.S.

Abstract

DUST FROM THE MOON: SPECIAL EDUCATION LEADERSHIP JOURNEYS OF SIX LATINO PARENTS

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George Mason University, 2016

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This thesis draws from parent involvement research and subtopics in the areas of parent advocacy in special education, parent leadership in both regular and special education, and models of parent involvement. Much of the existing research is concerned with understanding the problem and importance of Latino parent involvement in education and special education. To date, research has not yet significantly explored the positive contributions of immigrant Latino parent leaders and how these parents have become leaders, particularly in areas related to special education. The purpose of this qualitative study was to understand the lived experiences of Latino immigrant parents of students with disabilities who are special education advocacy leaders in their communities and the meaning they made from their experiences. Through this narrative inquiry, I hoped to understand how Latino parents rise to leadership positions and support others on their own journeys as special education advocates for their children with disabilities. The findings of the study include obstacles to Latino parent engagement from

the perspectives of these six leaders; what spurred them to become advocates and leaders; who helped them; and how they overcame the conflicts they encountered. The leaders also shared their insights into the meaning and purpose of their leadership journeys. The study concludes with a proposed model for fostering parent leadership.

Chapter One: Introduction

Even if I have to go to the moon and get the dust from the moon because that's what will save the child, I'm going to do it. (Graciela)

Background

Though a strong foundation of research endorses the powerful effect of parent involvement on student outcomes, few studies have focused on effective practices for Latino parent involvement. Even less is known about the involvement of parents of Latino students in special education. Finally, there is a dearth of research on Latino parent leadership in regular or special education. I believe that Latino parents of children with disabilities who have become special education advocates have the potential to become change agents for how Latino parents engage with their children's special education. By helping other Latino parents understand special education and the importance of advocating for positive outcomes for their children in school and in life, Latino parent leaders have the potential to change the parent involvement equation. This qualitative study is intended to shed light on the leadership process by asking Latino immigrant parents of students with disabilities to share their journeys and perspectives as special education advocacy leaders in their communities.

It is important to focus on Latino parents because Latinos are the fastest growing population in the U.S. and, as of 2011, represent over 25% of the student population in

the public schools (Fry & Lopez, 2012). Yet, according to the National Center for Education Statistics (2012), they also have the highest dropout rates (15.01%) compared to African American students (8.0%) and Caucasian students (5.1%). In 2011, Latino students represented 22.41% of the total students in special education (U.S. Department of Education, 2012). About one-half of Latino students in special education who exited high school received a regular diploma (55.1%) compared to 18.1% who received a certificate and 24.7% who dropped out (U.S. Department of Education, 2012).

This study draws from general parent involvement research and subtopics in the areas of parent advocacy in special education, parent leadership in both regular and special education, and models of parent involvement. Much of the existing research is concerned with understanding the problem and importance of Latino parent involvement in education and special education. To date, research has not yet significantly explored the positive contributions of Latino parent leaders and how these parents have become leaders, particularly in areas related to special education.

Parent involvement research. A large body of evidence indicates that students are more successful in school when their parents are engaged (Ferguson, Ramos, Rudo & Woods, 2008; Henderson, 2010; Henderson & Mapp, 2002). Though there is some evidence that Latino parent involvement may differ from that of mainstream parents, there is much evidence that Latino parents care deeply, about how well their children are doing (Auerbach, 2007; Blue-Banning, Turnbull, & Pereira, 2002; Lian & Fontanez-Phelan, 2001; Mueller, Milian & Lopez, 2009; Olivos, 2006; Villalba, Brunelli, Lewis, & Orfanedes, 2007). Further, a reason that Latino parents may seem to be less involved may

be a result of school rebuff, rather than lack of desire to be involved. (Auerbach, 2007; Drummond & Stipek, 2004; Olivos, 2006; Villalba, et al.).

Parent advocacy in special education. Even parents with privilege have difficulties and experience rebuff when it comes to special education (Valle, 2009). For Latino parents, especially immigrants not familiar with American school systems and with the language, the special education system can be even more confounding. They may not understand their children's rights to special education and may feel powerless when it comes to advocating for their children. (Kalyanpur & Harry, 1999, 2012; Ong-Dean, 2009; Turnbull et al., 2011). Parents of children with disabilities, who enjoy the privilege that comes from a dominant culture orientation - through social capital, access to information, or from socio-economic advantages - are more likely to question school authority and practices than culturally, linguistically, and ability-diverse (CLAD) families (Harry & Klingner, 2006; Lareau, 2000; Marsh & Turner-Vorbeck, 2010; Ong-Dean, 2009; Tutwiler, 2005). Immigrant Latino families of children with disabilities do not have the connections, knowledge about how schools work, and confidence to be able to challenge school decisions – including decisions about special education services. (Barrera, Corso, & Macpherson, 2003; Kalyanpur & Harry, 1999; Lareau, 2000; Olivos, 2006; Ong-Dean, 2009; Turnbull, et al., 2011; Tutwiler, 2005). As a result, IEP meetings can result in feelings of frustration and helplessness. Indeed, many immigrant families are reported to be mystified by the process (Barrera et al., 2003; Kalyanpur & Harry, 1999; Ong-Dean, 2009; Turnbull et al., 2011).

Parent leadership. Researchers are increasingly interested in models that transcend parent involvement and have been exploring the concepts of parent leadership (Han 2012, Henderson, 2010; Kugler, 2012,). Head Start and Title I of the Elementary and Secondary Education Act require meaningful parent decision-making. However, audits of these programs have consistently identified parent governance and leadership as an area of improvement at the local and state level. Often parent teacher organizations are the entre to parent leadership within the school. While organizations such as the National PTA recognize the importance of recruiting more Latino families, a 2003 article (Stewart) cited a PTA survey that found only 3 percent of its membership were Hispanic.

Parent leadership in special education. Head Start and Title I require parent involvement at the programmatic/policy level. The Individuals with Disabilities Education Act (IDEA) offers considerable decision-making power to parents at the individual level when it comes to their own children with special needs. Congress enacted laws guaranteeing the right of children with disabilities access to education based largely on the leadership and advocacy of parents. Even so, minority parents traditionally have been underrepresented when it comes to leadership and advocacy (Ong-Dean, 2009; Valle, 2009).

In summary, a robust body of research demonstrates that children are more successful in school and in life, when parents are involved in their education. However, prevailing parent involvement models do not apply well to Latino families and discount the strengths and assets that they can bring to the school. When a child has a disability and requires special education, many Latino families, already feeling marginalized by the

school, can feel overwhelmed, helpless, and hopeless about special education being able to help their children. Latino students make up about one-fourth of the public school population and have the lowest school completion rates. If parents are key to improving student outcomes, we need to find ways help Latino parents understand and utilize the power of their advocacy.

I began this study with a preliminary theory of systems change: When Latino parents understand and use the power conveyed to their children through special education, they will be able to create more responsive special education services. In turn, their children with disabilities may be more likely to receive the education and services they need to be more successful in school and in life. A better understanding of the journey to leadership for Latino special education advocacy leaders may lead to a conceptual framework for promoting Latino parent leadership so that special education can be more responsive to Latino students with disabilities.

Purpose

The purpose of this qualitative study was to understand the lived experiences of Latino immigrant parents of students with disabilities who are special education advocacy leaders in their communities and the meaning they made from their experiences. Through this narrative inquiry, I hoped to understand how Latino parents rise to leadership positions and support others on their own journeys as special education advocates for their children with disabilities.

Research Questions

- What can be learned from the stories of these Latino parents of children with disabilities?
- How do these parents understand their journeys to special education advocacy leadership?
- How do they describe their conflicts and resolutions?
- How do they describe what they have learned from their journeys?
- What do they believe to be the impact of their leadership on other families and in the special education system?
- What do the stories of these parents tell me about the development of advocacy and leadership of Latino immigrant parents of children with disabilities?

Researcher Identity

Before my son, Peter, was born, I had considerable experience with policy analysis, systems change, and grass roots advocacy. After attaining a master's degree in public administration, I worked in policy and evaluation at the federal and local levels. I became adept at learning how the system operated so that I could become an internal advocate for children in foster care, low-income families, people with disabilities and immigrants. I crafted policy papers and studies that supported the need for changes to make systems more responsive to the needs of its citizens. I felt powerful working in positions where I could identify issues and influence policy and programs. Then I lost my

sense of power, when my son, Peter, was born with complex health care issues and developmental disabilities.

Despite my advocacy in the medical world, we could not find the cause or cure for my son's complex health care issues. He had *failure-to-thrive* because he had feeding difficulties and had trouble keeping down what little nourishment he took in. He had neuro-muscular issues with constant muscle spasms that made it difficult for him to calm down or learn how to use his body and hands to move. His speech and development were slow. We enrolled him in the early intervention system for infants and toddlers with disabilities. Despite all of our efforts, he continued to have significant developmental delays.

My first experience as an emerging parent advocate and leader was both humbling and humiliating. The director asked if I could speak at a public budget hearing because they were planning on raising fees for services. My testimony was not a rational policy argument. It revealed how those increases would affect our family and my son's access to needed services. When I got up to speak, I lost my voice. While I had always been relatively confident at speaking, in this situation as a client rather than a policy analyst, I descended into a tearful and blubbery mess. Somehow, I managed to get through my three-minute speech.

They did not raise the fees that year, and I found that my tears – typically a sign of weakness, signaled power stemming from my love and fears. With commitment and fortitude, I began to power my way to make the system work for families like ours. Soon, I was a parent representative on the local Interagency Coordinating Council (ICC) for

infants and toddlers with disabilities. Through my position as a program analyst at a human services agency in a neighboring jurisdiction, I also served on their ICC as a professional. My struggles, nightmares, and hopes as a parent, merged with my understanding of policy and how systems work, and led to a career in parent advocacy for children with disabilities.

As the leader of a state parent training and information (PTI) center for almost 20 years, I witnessed pervasive parent frustration and desperation when the special education system was not responsive. The special education law requires that each child receive the services and supports needed to be successful in school and in life. Yet, confident and knowledgeable parents, who understood how to negotiate that system, were the only ones who seemed to have any chance of getting the services their children needed. So educated parents, with confidence and privilege, had the agency and social capital to utilize effective advocacy skills to work the system and get the schools to acquiesce to their requests. On the other hand, the parents of the children who I cared most about, were those who weren't even aware that they and their children had special education rights or that they had any rights or obligations to advocate for better lives for their children.

I hired bilingual parent advocates to help families who called us, asking for help in Spanish. In an effort to demystify special education, we translated a basic workshop, *Understanding Special Education* into Spanish. The Spanish version was called *Entendiendo Educación Especial*. The workshop is activity-based with brief, ten-minute mini-lectures followed by an activity to help the participant apply the information to his or her situation. I observed at the pilot and subsequent workshops that instruction needed

to be different for Spanish-speaking families. As the presenter delivered information, she would elaborate about how she used the information for her own child. Then someone might raise a hand or just speak up about an issue of injustice. The group would join in with similar stories and think of ways such an injustice might be addressed. Someone would raise their hand to testify about how they used that information to win services for their child or to confront the school. I was in awe of how the formidable energy and power in that room cracked open possibilities and changed lives. As more families found out about us and about their children's rights to services, they told others. Soon we were receiving many calls from Spanish-speaking families.

But it wasn't until Rosalia Fajardo came to work for us, that I began to understand the importance of leadership. Fajardo approached her work with a passionate and evangelistic zeal. She didn't stay by the phone, waiting for families to call, she reached out to organizations who served Latino families and started offering workshops in their communities. She reached many families who, for the first time, believed that their children with disabilities had possible and promising opportunities in U.S. schools. She was soon busy gathering in families, inspiring them by speaking to them about their rights. A natural leader, she was gifted in bringing in families, but perhaps too engaged to step back and truly understand how to make the special education law work for families. So her parents understood a bit more about special education rights, but did not understand the intricacies of how to make the law work for their individual situations. Soon Fajardo left our organization to work in the compliance and monitoring division for special education at the U.S. Department of Education.

However, missing her direct contact with families, Fajardo chafed at the constraints to her natural advocacy passions. She soon returned to our organization, with a much deeper understanding of the law and how it could work for families. Soon she had hundreds of families coming to our organization for help. Many of those families became successful advocates for their children. Their successes brought an even louder clamoring for services until it was apparent that Latino families had become our largest clientele. Though she exhibited boundless energy, she could not meet the demand. So our next strategy was to bring some of the successful families into a core leadership group.

The leadership group met, dreamed, prioritized, plotted, and planned how they were going to help more and more families. While many families needed to understand that their children with disabilities have a chance for success in the U.S. school system, they needed more detailed information about their rights. To move forward as advocates they needed practice and support. Soon these leaders were preparing presentations on how they received the Medicaid waiver, what they knew about autism, and how to help their children learn. I thought that our model was new and unique. If we could replicate it elsewhere, we might launch an even more powerful movement of Latino parents of children with disabilities who could help other families understand and receive better services for their children.

I explored the process of how Latino immigrant parents of children with disabilities become advocates. In my search, I encountered a few other programs serving Latino parents who also had overwhelming success in reaching large numbers of families and helping them become advocates. These programs also operated differently than the

programs for mainstream families. Fajardo, my outreach director, was a part of an informal network of Latino parent leaders who would speak among themselves about how they needed to work differently with Latino families. She introduced me to some of the parents and shared with me their experiences.

I decided that I wanted to know more about their stories and paths to leadership. These parent leaders, some operating under the radar of the leadership at the state PTIs, were creating new and exciting ways for Latino immigrant parents to become effective advocates for their children. Perhaps, by listening closely to their stories of leadership and success in their communities, I might discover potential paths for other families to take to help parent exercise their children's rights to special education.

Chapter Two: Literature Review

Early childhood programs and schools cannot reach their full potential in preparing children for school success without partnering with families. (Draft Policy Statement on Family Engagement, U.S. Department of Health and Human Services & U.S. Department of Education, 2015)

Substantial research supports the important relationship between family engagement in education and outcomes for students in school and in life. Based on this research, federal education policy promotes and encourages active family engagement. But engagement may be different for Latino families. Likewise, models for parent involvement may not be relevant for Latino families and are not available in many schools and communities. In this chapter I will describe federal policies that support family engagement, review the most relevant research about Latino family engagement, and identify some existing models of parent involvement.

Federal Policies and Latino Families

Policies for these programs encourage culturally responsive services and require that, to the extent feasible, families who speak languages other than English receive information in the language spoken at home. Many programs provide information for Spanish-speaking families, yet the concept of parent engagement and the structure of

parent engagement activities may not be relevant for Latino immigrant families (Han, 2012).

Head Start. From its beginning in 1965, the Head Start program has included families in program governance. The Head Start requirement to include parents on the advisory council has been a powerful avenue for parent leadership development. The Head Start program includes home visit, parent training, and family social work services. Head Start provides extensive technical assistance and training for staff to promote meaningful engagement of families in a culturally-competent manner. Head Start is not universally available and not necessarily equipped to serve children who might otherwise be in a preschool special education program.

Elementary and Secondary Education Act (ESEA). ESEA requires that schools receiving funding under its Title I program have written policies for meaningful family engagement. They also must involve families in developing those plans and implement family engagement activities. Title VII provides for bilingual education and requires information to families in their home language. The parent involvement provisions of ESEA are complicated and difficult for families unfamiliar with the school system to understand. For instance, many school choice programs that are alternatives for “failing schools” require that parents understand the application process and deadlines. The requirement for parent involvement in planning relies on the schools to issue the invitation. Olivos (2006) describes how Latino families are often excluded from school governance and do not have the ability to meaningfully utilize many of their children’s educational rights.

The recently-enacted *Every Child Succeeds Act of 2015* continues a 50-year recognition of the importance of family engagement for student success and directs schools to engage the families of students who are English learners, minorities, students with disabilities, homeless, in foster care and migrant students. A new Part E creates family engagement centers that support parent engagement and systemic initiatives to remove barriers to family engagement in education and support school reform efforts. Since the population of Latino immigrant parents of children with disabilities fit into the first three target populations, it will be interesting to see how these new centers effectively reach and serve these families.

Individuals with Disabilities Education Act (IDEA). The early intervention program (Part C) provides early intervention services for infants and toddlers with disabilities from birth to three years of age. Each child has an Individualized Family Services Plan (IFSP) that is intended to directly respond to families' resources and priorities to meet their children's developmental and learning needs. Part B of IDEA covers special education for children from preschool through adulthood, and requires that parents participate in the development of an annual Individual Development Program (IEP) that cannot take effect without their signed consent. In addition, IDEA contains a provision for at least one parent training and information (PTI) center in each state to help families actively participate in their children's special education. Even though IDEA has strong provisions for parent rights, Ong-Dean (2009) considers the law to be primarily responsive to privileged families with the information and social capital to

exercise their rights under this complicated law. He argues that the law leaves minority and immigrant families behind.

Latino Family Engagement Research

Recent studies that primarily focus on differences in engagement for culturally linguistically and ability diverse (CLAD) families of color and middle class families in the general education population may also be relevant for understanding Latino parents of students in special education. Latino families may be motivated to become involved by their need to help their children navigate barriers or their perception that their involvement may help their children and family become more upwardly mobile (Auerbach, 2007; Lian & Fontanez-Phelan, 2001; Olivos, 2006; Valdez, 1996; Villalba, et al., 2007). So when a child is having difficulties in school, a parent might accept it as the child's or family's fault. On the other hand, if a parent finds out that, in order for their child to do well in school, they will have to become involved in ways such as going to IEP meetings and speaking up for their child or needed services, that parent may be more apt to become involved. In special education, children and parents have individualized rights to programs and services. So although most of the research on parent involvement is not specifically related to special education, I will briefly describe key research about parent involvement related to Latino parents.

Research has clearly established a relationship between parental involvement and children's success in school and in life. However, Latino parent involvement may look different from mainstream families. Latino parents care deeply about their children and want them to do well in school (Auerbach, 2007; Blue-Banning et al., 2000; Lian, 2001;

Mueller et al., 2009; Olivos, 2006; Villalba, et al., 2007). Yet, these parental aspirations and high expectations may not be voiced in a way that the school can hear (Auerbach, 2007; Blue-Banning et al.; Mueller et al.; Olivos, 2006; Villalba, et al, 2007) and may not be the determining factor in how well their children do in school (Lopez & Stoelting, 2010). That is because teacher perceptions and actions matter, when it comes to welcoming (or discouraging) parental involvement (Auerbach, 2007; Blue-Banning et al., 2000; Harry & Klingner, 2006; Marsh & Turner-Vorbeck, 2010; Mueller et al., 2009; Olivos, 2006; Villalba, et al, 2007). A reason that Latino parents may seem to not be involved may be less a matter of desire for parents to be involved than a result of school rebuff (Auerbach, 2007; Drummond & Stipek, 2004; Olivos, 2006; Villalba, et al.). Families have valuable information that would make education of their children more effective, if teachers would be more open to this information (Auerbach, 2007; Blue-Banning et al.; Drummond & Stipek, 2004; Olivos, 2006; Villalba, et al.). Teachers often do not do as much as they should to welcome parents, but it is not necessarily a matter of ill intent. Other factors might include poor facilities and lack of educational materials, high turnover of staff and students and school violence (Olivos 2004, 2006), or lack of time or threat of due process (Blue-Banning et al.).

Parent Involvement Models

Almost all parent involvement models are *school-centric*. That is, they are structured to educate parents about what the school or education system views as important. In most parent-involvement interactions, the teacher or school is in a “power-

over” relationship, instead of a “shared-power” relationship (Harry & Klingner, 2006; Turnbull, et al., 2011).

Joyce Epstein’s model of parent involvement, one of the most widely-utilized models for parent involvement, exemplifies this “power-over” relationship. Her typology for parent involvement defines levels of activities that schools can offer that will foster the types of parent involvement that meets the school’s needs:

- **Type 1 Parenting.** Helping families create a home environment supporting children as students
- **Type 2 Communicating.** Communicating between school and home about school programs and school progress.
- **Type 3 Volunteering:** Encouraging parents to become involved in supporting the school.
- **Type 4. Learning at Home.** Helping families understand how to support their children with homework and other activities linked to the curriculum.
- **Type 5 Decision-making.** Developing parent leadership and decision-making.
- **Type 6 Collaborating with the Community.** Bringing in community resources that will strengthen families, school programs, and student learning and development.

The Center on School, Family, and Community Partnerships lead by Epstein (2005) cites numerous studies to support work based on this model and conducted by their National Network of Partnership Schools. However, a closer examination reveals that the partnership is pretty one-sided. Lopez and Stoelting (2010) elaborate further,

concluding that this model detracts responsibility for student success from the schools and blames parents for their children's failure. At face value, *Type 5: Decision-making* sounds like a way to bring parent leadership into the inner sanctum of school leadership. After all, parents on advisory committees are a requirement of Title I of ESEA. However, school administrators can avoid discord and easily select parents who don't question the hegemony, to be leaders and maintain the status quo.

Henderson (2010) conducted a national scan of exemplars for parent leadership in education. She identified one program geared specifically for immigrant Latino parents: Parent Institute for Quality Education (PIQE). Though PIQE claims that the curriculum was developed with parent input, interpretation and perspective does matter. Their curriculum covers the following:

- creating a positive home learning environment;
- understanding the K–12 school system and expectations for parent involvement;
- supporting the child's academic, social, and emotional development;
- communicating with teachers and initiating meetings to track child's progress;
- preventing gang affiliation and drug use; and
- preparing, in advance, for college, monitoring courses children take, and financial aid.

Similar to Epstein's model, the focus is on teaching parents to value the same things that schools value. It is also interesting to note that, though the study is related to

parent leadership, these subjects are not necessarily related to parent leadership. Parents take courses that parallel the school system's desire to value what they value.

Two other models of leadership that Henderson describes seem to nurture parent-directed initiatives (2010): The *Commonwealth Institute for Parent Leadership* in Kentucky is the only model based outside the school system. This program also offers parents information about school systems. Yet the focus is different. Parents identify their school improvement projects and reach out to other parents – particularly under-served parents, to advocate for needed changes. Another program, *Parents Supporting Educational Excellence* (Parents SEE), is funded through foundation support, but meets in school buildings. The curriculum supports parents as activists for school improvement. Though these programs seem to encourage participation by all families, they are not specifically designed for Latino communities, nor will they necessarily meet a priority for parents of students with disabilities to receive responsive special education services.

Olivos (2006) critiques schools for their lack of respect and responsiveness to the needs of Latino families and introduces a model for potentially transforming schools through parent organization and action research. Ochoa, Olivos & Jimenez-Castellanos (2011) elaborate further on the levels of transformative parent engagement which are radically different from other models.

- **Level 1: Connectedness.** to help link what parents do to their understanding of schools and the core curriculum and ultimately, their children's success.

This level goes further to help parents become socio-politically active in

school community decisions, share ideas and concerns, and take action to improve the school.

- **Level 2: Inclusion and Belongingness.** to demystify schools, democratize them, and make home-school-community social engagement a part of the curriculum.
- **Level 3: Decision Making.** to help parents understand power relations in the school system, and engage all parents in school decision-making.
- **Level 4: Participatory Action Research.** to mobilize the parent community voice and action for problem-posing questions and critical thinking that will lead to more democratic school practices.
- **Level 5: Macro Civic Engagement.** becoming socio-politically active and inclusive on a broader level outside the school environment.

This is a dynamic and exciting model. In the right environment and with the right supports, I could envision drastically different schools and communities. A major limitation to this model of leadership, as it relates to Latino parents of children with disabilities, is that systems change at this level of intensity would be time-intensive and dependent on administrators and teachers agreeing to share their power with parents. There are still innovative and effective ways to combat the often-disempowering ways that Latino families have been traditionally treated. González, Moll and Amanti (2005), Cowhey (2005) and others have highlighted ways of inviting families and the richness they have to offer, to the classroom. Each incorporates a critical framework bringing family insights, perspectives, and opportunities for learning to classroom practices. While

effective ways to encourage broad and meaningful family participation, these practices are not widespread and require an invitation by the teacher to work.

Han (2012) developed a leadership model for immigrant parents reflective of the hardships her own parents faced in realizing their dreams for their four children to be successful in school. While she did not visit Han's school when she was growing up, her mother supported education in her own way. Han has studied immigrant parents and school involvement and worked with thousands of immigrant parents. Based on her work she views immigrant parents as fitting into four stages (see Figure 1 below.)

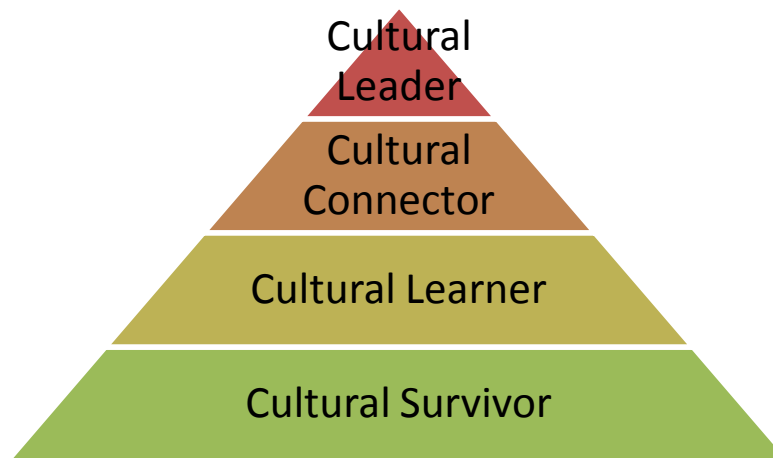


Figure 1. Han's Stages of Parent Involvement

- **Stage 1: Cultural Survivor.** parents are focused on meeting the basic survival needs of the family. They may be recent immigrants who don't know

English and may be illiterate in their native language. They are working, often absent from the home, and do not know how to navigate the school system.

Yet are committed to the idea that education has power in this country.

- **Stage 2: Cultural Learner.** Interpreters or bilingual liaisons help parents to understand how school works and to participate, when invited, to school events in their home language. They begin to understand how to navigate the school system.
- **Stage 3: Cultural Connector.** parents become familiar with the school system, educational terminologies, policies, and procedures. They regularly attend school events in their language and in English-only programs (with help of an interpreter). They become a voice for Cultural Survivors and Cultural Learners and encourage them to become more active in their children's education.
- **Stage 4: Cultural Leader.** after attending leadership programs, they assume leadership positions in school and district advisory councils or PTA. They communicate the needs of immigrant families to school staff, school district, community members and agencies/organizations.

Han suggests ways for schools to tailor their strategies for parent engagement, based on the parent's level. Han's model of parent involvement offers a more relevant framework for structuring services to immigrant families. She suggests that different parent engagement strategies should be used for the different levels. Han also notes that while a person might be a cultural leader, when it comes to one area of how schools work

(such as the English Language Learner program or PTA), they may be a cultural survivor in an area, such as special education.

Discussion

All of these models require some level of invitation. Whether it is acquiescing to parent requests for shared power or welcoming parents as true collaborators and partners, these models help parents emerge as leaders to the extent that schools are willing to listen to them and work with them. When it comes to becoming leaders and effective advocates, immigrant Latino families of children with disabilities may have the connections, knowledge about how schools work, and confidence to be able to challenge school decisions – including decisions about special education services, but this may not be enough to effect change (Barrera et al., 2003; Kalyanpur & Harry, 1999; Ong-Dean, 2009). Ramirez (2008) discusses the importance of perspectives when thinking about Latino families. For instance, he describes a "Catch 22" dichotomy. Latino parents who are active in their children's educations are ostracized and looked upon with suspicion. On the other hand, if they are not involved, they are labeled as "uncaring".

Most of the models fall into three categories: school-centric, parent-centric and community-centric. Traditional parent involvement and leadership models tend to be more school-centric. For instance, Epstein's model promotes parent involvement that is focused on helping with homework and supporting what happens at school. Parents encounter a curriculum containing parent activities supporting what schools believe to be most important. There are no meaningful opportunities to question whether the school system is fair and democratic, truly offering the same opportunities for every child to be

successful. At the other end of the continuum, the transformative parent model promises the most radical changes, while the Commonwealth Institute and Parents SEE might produce more incremental change focused on more narrowly-defined issues that have been identified by parents. These models lean more toward the community and community-identified needs and priorities. They might not be generalizable to parents of children with disabilities and it is difficult to implement and sustain these systems change processes without efforts specifically for parents of children with disabilities.

The parent-centric models begin with an implicit understanding that parents have the will, power, and strength to improve the lives of their own children as well as others. The Funds of Knowledge (González et al., 2005) and Stages of Immigrant Parent Involvement (Han, 2012) models recognize the importance of inviting parents into the school community and establishing reciprocal relationships. With Funds of Knowledge, the teacher might invite the parent into the classroom to share stories, experience, skills, and wisdom initially to inform the curriculum and make it more culturally meaningful for the class. In turn, the parent realizes he or she has agency and a contribution to make; begins to understand how the school system works; and can become a source of information about the school – people who you can trust, programs in place, and other “insider knowledge” not known to most members of the community. Even a teacher, without power to effect what is going on in the rest of the school, can initiate a Funds of Knowledge activity on his or her own.

Han (2012) describes a number of existing programs that provide services and supports that can help parents move from cultural survivors to cultural leaders. The key

to success in many programs is a parent liaison, described by Han as a *cultural leader*. Some schools and systems have well-established parent-involvement programs coordinated by parent liaisons with similar cultural and linguistic backgrounds as the families. Han's model stresses how important it is for schools to consider how to increase parent involvement – especially for parents who do not appear to be involved. Schools also might ally with cultural connectors who can reach out to other parents and acculturate immigrant parents to how schools work and school expectations. A limitation is that implementation depends on school administrative and financial support, understanding, and willingness to adapt to the needs of families. Fewer schools are interested in encouraging parents to become leaders and decision makers. Sharing power with parents can be messy.

None of these models of parent leadership directly apply to the group that interests me: Latino immigrant parents of children with disabilities who become special education advocates and cultural leaders to other parents. These models are not relevant for the following reasons:

- Most prevailing parent involvement models utilized by school systems are based on Epstein's model of parent involvement which, in essence, serves to acculturate families to the school's ways of thinking and acting.
- These models are more suited for mainstream families. Even when program organizers explicitly adapt or design what they are doing for families that have traditionally had no power or voice over their children's education, they

concentrate more on diverse cultural and linguistic groups, than on a narrower group of families that include a child with a disability.

- School-centric models will not work in schools not welcoming to Latino parents and/or Latino parents of children with disabilities. In addition, in schools where the culture is not welcoming of families, school personnel may be intimidated or ostracized for welcoming families.
- None of the models explicitly address individual rights that special education accords to parent and students. I believe that exercising these rights might be a potential source of power that can propel parents into leadership positions.
- All existing models are dependent on individuals in positions of power inviting parents to the leadership table. I anticipate that the parent leaders I will hear from did not rise to a leadership role through support from the school. Some may have received their first invitation from an existing community-based organization. However, it is likely that these parents rose to their leadership roles in much the same way as many of the pioneers in the special education parent movement, with a will to change the status quo for children with disabilities.
- The transformative model described by Olivos, et al. (2011) is very much a family-centered and community-centric empowerment model. A limitation of this model is that it relies on active involvement by facilitators who provide structure and support to parents in the community-based group.

- Parent-centric models such as the Stages of Immigrant Parent Involvement (Han, 2012) are helpful in tailoring school involvement efforts to the different levels of immigrant parent needs. This model also stresses leadership and the contributions that immigrant parents can make. However, most school involvement efforts do not have the intensity and level of effort suggested by Han's model. The model also would not work in schools that are not welcoming to Latino parents and/or Latino parents of children with disabilities such as the communities as described by these parents in my study. Similarly, the Funds of Knowledge approach (González, et al., 2005) also require an invitation from school personnel that might not happen due to school culture or teacher intimidation.

In brief, the prevailing models of parent engagement and parent leadership may not be translatable or relevant to Latino immigrant parents of children with disabilities. Such programs are dependent on invitations from the schools or the availability of an outside community program. In the meantime, the majority of Latino children with disabilities who are not invited or encouraged by mainstream programs are not likely to benefit from current involvement or leadership programs or models.

Chapter Three: Methods

Purpose

The purpose of this qualitative study was to understand the lived experiences of Latino immigrant parents of students with disabilities who are special education advocacy leaders in their communities and the meaning they make from their experiences. Through this narrative inquiry, I hoped to understand how Latino parents rise to leadership positions and support others on their own journeys as special education advocates for their children with disabilities.

Research Questions

- What can be learned from the stories of these Latino parents of children with disabilities?
- How do these parents understand their journeys to special education advocacy leadership?
- How do they describe their conflicts and resolutions?
- How do they describe what they have learned from their journeys?
- What do they believe to be the impact of their leadership on other families and in the special education system?

- What do the stories of these parents tell me about the development of advocacy and leadership of Latino immigrant parents of children with disabilities?

Setting

The study occurred in three communities within an industrial, urban metropolitan area in a northeastern state of the United States. According to the Pew Research Center Hispanic Trends, the 2011 percentages of Latinos, in the three counties the participants resided, ranged from 21- 40%. The Pew site also indicates that Latinos born outside the U.S. constitute 43% of the population in that state, but that the median age of U.S. born Latinos in that state is 19 years old. That 82% of Latino households speak a language other than English may suggest that the majority of Latinos in the state include immigrant parents who may not be acquainted with American schools or special education. The interviews took place at the PTI offices, over lunch at a neighboring diner, a preschool where two participants work, and at a library selected by the sixth participant.

Participants

The project officer for the PTI centers funded by the U.S. Education Department Office of Special Education recommended three states she considers to have exemplary Latino outreach efforts. I interviewed the executive co-director for family and health support at one of the recommended PTIs to learn about the PTI's extensive and impressive outreach and leadership efforts. She suggested that I ask the bilingual parent-to-parent coordinator to be my key informant. I sent an email with the IRB proposal describing the study and how I was referred to that PTI. I asked her if she would be

willing to identify special education advocates and leaders who are Latino immigrant parents of students with disabilities. I asked her to suggest parents who might be able to help me understand how Latino parents rise to leadership positions and support others on their own journeys as special education advocates for their children with disabilities. We arranged a telephone meeting for her to suggest potential participants and their characteristics as leaders. She recommended several Latino leaders with children of varying disabilities and age ranges that met the following criteria:

- Identification as a Latino or Hispanic;
- Parent of a child with disabilities;
- Identified as a special education advocacy leader by the key informant and also in the Latino community; and
- Comfortable with conversational English

She shared with me a little bit about each parent including the ages of their children and disabilities, and why she considered them a leader. I asked her to make the initial inquiries to see if the suggested parents might be willing to be interviewed. After that, the key informant sent me their names, phone numbers, and email contact information. I followed up with an email briefly introducing myself as a doctoral student, describing the study, and identifying myself as a parent of a child with disabilities who formerly directed a PTI with a large Latino outreach effort. I provided my contact information and let them know that I would call to follow up.

When I contacted the potential participant, I verbally described the study to verify that the participant was interested in participating. If the participant was interested, I sent

an email copy of the IRB informed consent form and offered to explain it further or answer questions.

According to Maxwell (2005, p. 89) the qualitative researcher selects participants through a purposeful sample for one or more of four main reasons:

- Achieving representativeness or typicality of the settings, individuals, or activities selected.
- Representing the range of variation: that is, selecting individuals who represent important variations;
- Deliberately examining cases critical to the theory; and.
- Establishing particular comparisons to illuminate the reasons for the differences between settings or individuals.

I selected purposeful sampling primarily to find participants who represented important variations in leadership experiences, including participants with varying educational and socioeconomic levels as well as those who were advocacy leaders in funded or non-funded capacities. Their variety of voices allowed me to examine similarities and differences in their stories. Some participants had extensive experience in special education advocacy and others were relatively new to the experience. I worked with my cultural informant to recruit a pool of participants with diverse characteristics such as:

- Age of child and nature of disability
- Length of time as a leader
- Level of education

- Immigration status
- Ways that they demonstrated their leadership

Because the study was intended to help me to understand parent narratives and I am not fluent in Spanish, I asked selected participants if they were comfortable enough in English to share their stories in that language. I understand this may have somewhat limited the applicability of this study for populations of Latino parents who do not speak English, however, one participant recruited another participant to serve as a back-up interpreter. Though the majority of the interview was in English, she asked him to be there in case I didn't understand what she wanted to say or to be able to articulate her story more fluently in Spanish.

All seven parents suggested by my cultural informant agreed to participate in the study, however one participant had to cancel an hour before our scheduled interview. I interviewed the parent leaders over a three-day period in July 2014. For this study I have changed their names. The following is a brief description of each parent leader:

- **Isabella** and her husband came to the U.S. from Colombia 20 years ago, when Isabella was 22 years old. They have a 19-year-old son, Carlos. Their 13-year-old daughter, Selena, has Down syndrome. Isabella is most comfortable speaking Spanish and arranged for one of the other advocates, Oscar, to interpret for her during the interview. Isabella spoke mostly in English, but asked Oscar to interpret when she wanted to elaborate.
- **Oscar** came to the U.S. when he was three years old. His wife came as a teenager. They are both from the Dominican Republic. Their youngest son is

four and their eldest is eight and has autism. Oscar claims to be more fluent in English as he came to this country as a young child. Oscar grew up with caring adults who prevented him from getting in trouble when he was younger, so he volunteered to work with inner city “kids with issues” and was trained to mentor and advocate. Since his second son was born, he has no longer been able to volunteer, but he uses the advocacy skills he learned as a volunteer.

- **Silvia** came to the U.S. from the Dominican Republic about 20 years ago on a visitor’s visa when she was 21. Her husband is from Honduras. She intended to go to school, and had to legalize her situation when her visa expired. She has a very large, close, and supportive extended family as her mother has 22 brothers and sisters with only 5 of them remaining in the Dominican Republic. Silvia and her husband have two sons. The younger is 14 years old and categorized as gifted. Her eldest son, Andre, is 15 and was diagnosed with autism when he was two-and-a-half years old.
- **Graciela** is originally from Cuba and came to the U.S. over 12 years ago after winning the U.S. immigration lottery when she was 21. When she was able, she sponsored her mother. Then her stepfather won the immigration lottery too and brought her brother to Florida. While her mother and the rest of her family stays mostly in Florida, periodically, her mother has come to help care for her son. Graciela’s ex-husband is from Puerto Rico. He and Graciela were

together for 12 years, married in 2008, and separated last year. Their son, was born in 2008 and diagnosed with autism when he was 18 months old.

- **Magdalena** was adopted when she was six months old by relatives of her biological mother. She always knew she was adopted and has positive relationships with both her biological mother and adoptive parents. She moved to the U.S. from the Dominican Republic when she was nine years old. Most of her biological and adoptive family live in the same state. Magdalena's husband is of Italian descent, and his 85-year-old mother lives downstairs from them. Magdalena is very close to her husband's family. His brother and sister live nearby and are very supportive. His mother loves spending time with their daughter and welcomed Magdalena into the family by passing down instruction on how to cook for their large Italian family dinners. Their 10-year-old daughter, Carmelita, has a rare genetic syndrome, deletion of chromosome 9q.
- **Carmen** came to the U.S., seven years ago to work as a nannie when she was 20 to go to college and be closer to her boyfriend. They are both from Peru and met as teens. He is now her husband, His mother lives with them and sometimes helps care for their three children. Her eldest son is four and has autism. She has two younger children ages two and nine months who receive early intervention services because they have autistic-like characteristics.

The table on the following page summarizes the characteristics of parents who shared their stories for this study:

Table 1

Characteristics of Participants

Participant	Child's School Level	# of Years as Leader	# of Years in U.S.	Age at Entry to U.S.	Country of Origin	Nature of Child's Disability
Isabella	Middle/High	8+	20	20+	Colombia	Down syndrome
Silvia	Middle/High	8+	20+	21	Dominican Republic	Autism
Oscar	Elementary	4-7	30+	3	Dominican Republic	Autism
Magdalena	Elementary	4-7	30+	9	Dominican Republic	Del. of Chromosome 9q
Graciela	Elementary	1-3	12+	21	Cuba	Autism
Carmen	Preschool	1-3	7	20+	Peru	Autism

Research Relationships

I directed a state-level PTI for almost 20 years and have extensive relationships in the national special education advocacy arena, so had preexisting credibility with contacts who could identify key informants and potential participants relevant to the study. As a fellow parent of a child with disabilities, with personal experience in special education advocacy at local and national levels, I have a long-standing relationship with the U.S. Department of Education project officers responsible for the federally-funded special

education parent information projects and they were able to identify the PTIs that, in their opinion, had the most active and successful programs

Because Latino parent leadership has been an area of interest of mine for several years, I have been fortunate to meet a number of Latino leaders who pride themselves in their work and feel under-recognized by the larger parent movement. Before conducting the study, I consulted with these friends and asked them to help me to anticipate potential pitfalls or learn about potential improvements to the interview process. I believe that my interest in Latino parent advocacy and the fact that I am also the parent of a child with disabilities helped the participants more readily share their stories and experiences with me.

Research relationships are not a nicety, they were critical to my being able to understand and make meaning from the stories shared by participants (Connelly & Clandinin, 1990). Understanding the importance of respect and appreciation of their contributions and stories I tried to remain mindful of the generosity and trust of parents who agreed to share their stories and perspective. I was careful to check for my understanding of their stories during interviews, and if there was something unclear to me from interview recordings or transcripts. Central to my relationship with each family was my own experience as a parent and parent leader. I am not fluent in Spanish although I am conversational. Therefore, I selected participants who were comfortable speaking English so that my research relationship with families would not be distanced by an intervening dialogue through an interpreter. One participant asked another participant to remain with her and help with interpretation.

Data Collection

This qualitative study relied on interviews with six Latino parent leaders. I also used observations of the participants and the settings for the interviews and ancillary conversations including descriptions shared by the cultural informant about the parents she suggested. I also did not record conversations with Carmen as we walked to the library and back, but relied on my notes from that visit. Primary data collection occurred through interviews adapted from the narrative inquiry process (Seidman, 2006). After brief introductions and describing the study, each participant provided informed consent.

The purpose of the interviews was to understand the context of the parent's journey as a special education advocacy leader. An interview guide (Appendix C) and prompts helped to organize the interviews and make sure that I asked each parent consistent questions, but I tried to keep the interviews relaxed and conversational. I asked each participant to tell me as much as possible about how he or she came to become a special education advocacy leader. As the interview progressed, I added additional open-ended questions to help clarify my understanding of the participant's journey to leadership. Once the participant shared his or her journey, I briefly summarized the chronological events in this parent's journey to leadership in order to check for understanding. I then asked the participant to fill in gaps that might help me better understand his or her story or add details. I asked participants to elaborate about events, people, challenges, triumphs, or other details to gain a clearer picture of the participant's story of leadership and the relationship of those events to their emergence as a special education advocacy leader. I also inquired about perceived differences as a Latino

immigrant parent as well as perceptions about other Latino families. Once the participant shared his or her story, I asked the participant to reflect on the meaning of his or her experience as a special education advocacy leader. I also asked about the meaning the participant makes of his or her story in relationship to the future.

The interviews took 1.5-2.5 hours. Consistent with previous experiences with Latino parents, their stories did not necessarily follow a linear and organized process. During introductions, a parent might have begun telling his or her story, so during the formal recorded interview I asked to repeat that story. I sometimes asked the participant to elaborate on a topic, and sometimes went back to what was said earlier to see if the participant perceived a connection. When the story the participant shared seemed to be complete, I went back to the interview guide to see if there were questions I needed to ask, but the interviews seemed comprehensive, frank, comfortable and relaxed. After I collected the information from the interview guide I asked if there was anything else the parent wanted to share.

Data Analysis

After completing the interviews, I had them transcribed. When the transcriptions were returned, I listened to the interviews and corrected any errors in the transcriptions. I also began to analyze what I learned from participants. Data analysis took two forms: construction of narrative profiles and coding for themes.

Narrative profile. After transcribing the interviews, I constructed a narrative, using the participant's own words as much as possible. Such a profile can most accurately describe the context, clarify the participant's intentions, and convey a sense of

process and time (Seidman, 2006). I analyzed the transcripts to identify key elements in the stories. I highlighted key passages and phrases, particularly those that described sequence, relationships, conflict, resolution and the meaning the participants made of their experiences. I analyzed the transcript and pieced together extracted phrases to convey the participant's story that described the process, conflicts/struggles, and resolutions for each participant. I then remapped the story in chronological sequence (Creswell, 2008, p. 523-526). To enrich the narrative, I included phrases that described the meaning, perspective, assumptions the participant made of his or her story based on the interview transcripts. This strategy also assisted with using connecting analytic strategies through the development of profiles that shared a parallel sequence and order (Maxwell & Miller, 2008)

Seidman (2006) suggests that not all interviews will lend themselves to a complete profile. I initially planned to construct three narrative profiles that represented the participants, but had difficulties letting go of the compelling stories that each parent shared. So I wrote six draft narratives, then incorporated the draft narratives into three more complete narratives by combining narratives as follows: The three advocates who worked for the PTI; the teacher and family outreach worker who worked for the preschool; and the parent who was working on her own. I used the narratives to identify themes, and to develop an emerging theory of parent leadership across all participants. Then after deeply considering all the stories I selected three participants to write narrative profiles for the writing of the dissertation.

Identifying themes. I identified themes after constructing the narrative profiles that contained order, sequence, characters, settings, and the meaning that each of the six participants made from their experience. By comparing narrative profiles, I identified common connecting strategies that emerged from the narratives within their context (Maxwell & Miller, 2008) and sorted them into general etic categories (Maxwell, 2005) within the narratives, and themes that supported these categories. Then I returned to the full narrative transcripts from all the participants to analyze how data from each interview might support or refute the codes and major themes identified through narrative analysis. As I analyzed the narratives, I considered convergent or divergent themes and the meanings the participants have made from their lived experiences.

Validity

The purpose of this study was primarily to learn from the stated experiences of a group of Latino special education advocacy leaders who are parents of children with disabilities. The group is not representative of all Latino parents: however, I was interested in understanding how their experiences might shed light on a community-centered path to parent advocacy and leadership.

Researcher bias. It was important to note my own story as a non-Latino parent special education advocacy leader and an educator who has studied parent involvement, engagement and leadership throughout my professional career. My experience and knowledge was a valuable tool or lens through which I interpreted the data. While this was an asset to my analysis and interpretation, I worked to remain vigilant to my goal of understanding the meaning that this group of Latino parents made of their special

education leadership journeys. I remained mindful of the advice from Harry, Kalyanpur and Day (1999) to understand how my own experiences and cultures (as an Asian American, a parent of a child with disabilities, an advocate, and a special education expert) could influence my interpretation of the stories and experiences of the families. I have my own story as the leader of an organization that nurtured and supported what I consider to be an exemplar of Latino parent engagement and advocacy. I worked to remain vigilant of potential research bias as I analyzed and interpreted the stories of these families and potentially different definitions of advocacy and leadership relayed through their experiences of advocacy and leadership. I was also careful to check for understanding during the interviews, and minimized the sharing of my own story. In reviewing the transcripts, it was evident that the level of my personal sharing was minimal – sufficient to build trust - After the interview was over, I responded to participant questions about my experiences and family. Through my analysis I was able to identify a number of new ideas shared by these parents. Chapters Five and Six discuss this in more detail.

Reactivity threat. There is a possibility that participants may have said things that they believed that I wanted to hear, instead of what they really thought or felt, because of my history of parent advocacy and their understanding that the topic of the study is about their identities as parent leaders. I worked with my dissertation committee to make sure that the questions were open-ended and asked each participant to share their story. I asked them to elaborate on their stories and continued to press for what meaning

they made of their experiences. During the interview, it was clear that the participant was telling an authentic story, adding details and feelings associated with their story.

Triangulation. I compared the parent narratives with each other to identify consistencies and exceptions for categories and themes. This helped me to see if there was adequate evidence in the raw data to demonstrate connections in the findings. (Marshall & Rossman, 1995). To support that evidence, I developed a table of identified themes and codes and indicated which of the leaders discussed a given element. In the discussion I also added instances where a parent's stated experience did not support that finding (See Appendix D). I also compared what parents shared with existing research and models (see discussion in Chapter Six).

Member check. Member check is a way to confirm the accuracy and credibility of the findings by sharing my interpretations and written narratives with participants. During the interviews I checked for understanding and summarized my understanding of what I had heard. In some cases, the participant elaborated on a story as my summary brought additional recollections to mind. After constructing the narratives, I sent copies to each participant, asking each to let me know if there was anything inaccurate or unfair in my portrayal of the findings. The narratives were primarily verbatim from what each participant had shared and there were no requests for corrections or to omit information.

Generalizability

Cultural variations in the Latino experience are diverse and cannot be reduced to a generalization. Micro-cultural variation includes such characteristics as degree of acculturation, education, country-of-origin, religion, economic status, and a number of

other mixes of influences and circumstances (Kalyanpur & Harry, 2012; Turnbull et al., 2011). I attempted to account for a variation in characteristics through a purposeful selection of identified leader-participants, that included a variety of countries of origin, family structure, experiences and education levels. As a non-Latino I understand that there exists a broad diversity within the Latino community, and I realize that the experience of these parents are not necessarily the experiences of all Latino parent leaders or Latino parents. The parents in this study were comfortable speaking English. Two had come as children and had been in the country over 30 years. The others came as adults and had been in the country for 7-20 plus years. So the findings might not apply to more recent immigrants who are not fluent in English.

Chapter Four: Selected Participant Profiles

I just want to make sure that I leave a fingerprint or some kind of evidence that our kids count, and they should have the same right as everybody else does. (Oscar)

This chapter presents three profiles representative of the journeys of the parents interviewed for this study. I selected these participants to profile because they represent a range of characteristics of the parent leaders and offer the richest examples of the themes that will be presented in Chapter Five.

- **Isabella**, who has been a parent leader for 11 years, started her own group for Latino parents of children with disabilities. She came to the U.S. from Colombia when she was 20 years old about 20 years ago. Of the parents interviewed, she was the least fluent in English. Her daughter, who has Down syndrome, is 13 years old.
- **Oscar** joined Isabella's group when he became unemployed about 5 years ago. Then he started working for the state PTI about 4 ½ years ago. He came to the U.S. from the Dominican Republic as a child, so is fluent in English. His son is 8 years old and has autism.
- **Carmen** is operating primarily on her own as a parent leader. She came to the U.S. from Peru seven years ago when she was 20 years old. She has three

children ages four, two, and nine months. Her eldest was diagnosed with autism, and her other two children receive early intervention services because they show signs of autism.

Isabella

Isabella called me on my cell, the evening before an interview planned at the PTI. She was on vacation, but decided to come in to work anyway, so she could share her story. She arrived the next day with one of the other parents I interviewed, Silvia, and brought along her 13-year-old daughter, Selena. Although Isabella's English seemed pretty fluent, she had pre-arranged for Oscar, one of the other parent advocates I interviewed, to serve as interpreter. So between my basic level of Spanish, Isabella's more advanced level of English, and Oscar's fluent bilingual skills, Isabella shared her story.

Isabella's story as an advocate began before her daughter, Selena, was born. When she was four months pregnant, Isabella had a stroke. She also found out that she would have a daughter with Down syndrome. Her doctor advised Isabella to get an abortion.

They gave me a book with pictures of the children (with Down syndrome) "You want to get the baby?" I am, "Don't worry. I want to get the baby. No, no worry, because I am Christian and I believe in my God," You know what I mean? Because they insisted that I abort the baby. They said "Why? Your child will have a lot of problems. Your child will be a vegetable."

Selena was born with problems. She spent the first two months of her life in the Neonatal Intensive Care Unit (NICU) and stopped breathing, turning purple at times. Two months after Selena left the NICU, Isabella took her to therapy, rain or shine. To learn more about how to help Selena, Isabella attended a parent education group conducted in English, even though she was not fluent in English. Coincidentally, she met Silvia, another parent leader interviewed for this study. They were the only two parents who spoke Spanish and both described that they learned a lot in those classes. The hospital sent her to Social Security and she was able to get information about SSI and Medicaid. She found other Spanish-speaking mothers there. By then, Selena was doing well and was healthy. To give thanks to God, she decided to form a support group. So 11 years ago, she started an organization to help families.

Oh my goodness! I wanted to create the group. It began in my basement of my house. When I begin the parents to talk about the problems with the children, how to get social security and how to get services in the hospitals.

She began with four mothers. Soon there were 25 parents and she needed to find another place to meet. So she asked her city's mayor to let them use a community room for her meetings. They met for about a year sharing information they gleaned elsewhere with each other. Then Isabella found a flyer about the PTI in a library in another town. She called and asked them to send any available information and started to attend their workshops, returning to her group to share the information. After about a year of going to workshops she spoke to the executive director of the PTI who asked Isabella to help them reach other Latino families. The PTI became her "school" and taught her how to run a

group and develop workshops. She invited someone at the PTI who spoke Spanish to explain the resources that were available, to her group. About a year later, when Selena was three years old, Isabella started working at the PTI on a per diem basis. She also introduced her friend, Silvia to the PTI director at a conference for Latino families. Soon after that, Silvia began working as an interpreter for the PTI on a per diem basis. Isabella became a regular employee in 2007.

Isabella continues to lead the group she began 11 years ago. She has recruited parents who are bilingual, like Oscar and Silvia to bridge information gaps for families when the information they need, or the meetings they go to, are only in English. She engages the community in helping the families of children with disabilities by wrangling funds, donations, and transportation services so that her group can host family trips to museums, professional baseball games, and other recreational activities. According to Oscar, these serve as “mini-vacations” for the families. Now there are about 100 parents in the group. The week before the interview, 38 parents attended her workshop.

Isabella energetically responds to calls from families at all hours of the day, even nights and weekends when she isn't working. Her husband tries to discourage her from dropping everything to respond to their constant calls for help. She said that the parents call her every time she is out with her husband. His reaction is to plead, “No more. No, no more!” She responds, “Papi, I need to help!” He says, “No more!” I had the feeling from the way she relayed the story that her husband is generally supportive, but she can't help herself from helping others. However, there may be some cause for concerns about how her constant focus on families affects Isabella's health. In 2012, Isabella had a

tumor due to a blood clot and needed surgery to have it removed. Oscar explained that this was associated with the stroke she had when she was pregnant with Selena. Her doctors warned her that she needed to cut back on her work.

The last time I was in appointment with my doctor. I open my agenda. The doctor said, “Isabella, everything is an appointment?” “Yeah, everything with the kids.” He said, “Wow! Isabella, you have to....” But I said, “I want to continue to help.” And the neurologist say, “Isabella, all that passion! You stay home and don’t continue to work. Don’t continue to help the parents.”

That’s when Oscar stepped in to help her run her group. Because Isabella was not there to lead, he said that it empowered the rest of the families to step up as leaders too. Oscar explained.

So now there are a few more who are always helping, and the rest of the families started getting more involved. As a result, the parents are more engaged and learning better. The PTI supported Isabella as her group was getting started and helped develop workshops. They learned about the law and how to support parents.

Isabella says the reason she does so much for families is to give thanks to her God. Her faith that Selena would be okay was confirmed by the same doctor who tried to convince Isabella to abort the baby. Isabella’s doctor was on maternity leave when Selena was born. So she was surprised the next time she saw Isabella and met Selena, who was healthy and doing well in early intervention. Isabella recalled their encounter with both amusement and pride at the doctor’s exclamation when she saw her beautiful daughter.

“Mrs. Ortega, you kept the baby? You kept the baby?” Isabella replied, “Yes, I kept the baby. This is Selena.” Isabella recounted that the doctor didn’t believe her because Selena looked so healthy. The doctor may have been joking with Isabella. In any case, every time that same doctor continues to see Selena, she calls her a miracle.

Today Selena is 13 years old and beloved by others at the PTI. She is interested in being a beautician and likes to fix her hair and dress fashionably. She is bilingual in English and Spanish. Isabella described her as “very talented” and she is a success according to a Down specialist who sees Selena. According to Isabella, the school considers Selena to be “high functioning” so they do not want to help her more in school, even though she is not reading. But Isabella considers it important to make sure that Selena can learn to read and learn math, even if the school is not willing to provide those services to her satisfaction. So she pays a teacher \$50 a week to come to the home to help Selena with math. She considers it a worthwhile investment. Recently, when Isabella saw Selena begin to use the calculator, she started crying.

Isabella’s relationship with the school has been difficult. She cannot recall any school professionals who have been helpful or encouraging. In fact, Isabella was reported to child protective services three times – all unfounded. Isabella believes that the school reports were a means of intimidation in retaliation for her advocacy. The first time they reported that she sent Selena to school with old food and torn clothes. The second time, after Selena tried to pluck her eyebrows with tweezers to practice her interest in beauty, they reported that Selena had a razor. The third time they said that Isabella was neglecting her son because she took Selena to therapy all the time. When Isabella refused

to be cowed and asked the director of student services to stop allowing them to keep accusing her of being a bad mother, the director acknowledged that Isabella is a good mother. Oscar explained.

When the school gets a rash of parents, they blame her because they know that she's giving them the information. The school will send people to go to checkout – to sit at the group meetings.

Isabella added, “Don't worry. I explain la derecho (the law) and the correct information.”

One thing that motivates Isabella is her worry about the families who don't know their rights and how to advocate for their children. She wants to make sure that families get services. It bothers her to hear parents say, “If I had just known you earlier, my child could speak.” Oscar interpreted, in English, what Isabella said in Spanish.

She sees a lot of families. She's happy that a lot of families are advancing. She's happy with the progress with the families, the majority of them. She also wants to see the children smile. To see the children change. To see the children's behavior change. They start to speak. To pass those barriers. And for her, it gives her more power to do what she does when she sees the families involved. They are involved together to work for their children.

Oscar

Since Oscar came to the U.S. as a young child, he is fluent in English. In fact, his Spanish has recently become more fluent because he feels responsible for explaining information only available in English to families who speak Spanish. Oscar was not as

involved with his son at the beginning. He said that his wife did everything. Oscar described how his “whole world slipped open” when his wife was unable to get clear information from the doctor who diagnosed their son with autism at 13 months old.

When my son was about 8 months old, I starting seeing things that was not typical. I grew up around a lot of family members who were educators. They would, like, give me hints and flash cards and all those little toys. I started seeing he wasn't grasping. He wasn't having eye contact. So at the age of 13 months, I took him to get an eval. That's when my world slipped open. I didn't even know what I was dealing with. That was the first time in my life and in my family's life.

The whole thing started in the sense that I was working so I didn't have time to take my son to the doctor and stuff, so my wife would go. I didn't like the way they were trying to inform her. They would not give her no information enough so she could understand. I was going to her like, “What did they say?” and she couldn't explain it to me. So that's why I started stepping in to do something, to at least understand what's going on.

So I went back and got the results. My wife was working. The doctor was uncomfortable, because he rarely dealt with dads. And I was, like, I thought he was looking at a dinosaur, because of his facial reaction. He didn't know how to react. He said what he had to say and I was asking questions. And that's when he got upset. Because he was, like, “Why you questioning me?” “I'm not questioning. I just want you to clearly explain to me what you're talking about.” Because I was asking him questions that I felt I needed to know. 'Cause I wanted

to let my wife know. Because when she went she told me things that she couldn't explain. That's why I was asking questions. He didn't ever tell her anything enough so that we could understand it.

Oscar described additional complexities faced by Latino families unfamiliar with the way disability is defined and treated in the U.S.

That was the first time in my life and in my family life. Nobody in my family ever been diagnosed with any kind of condition. And on top of that I had to deal with the cultural part of it, because my father, my mother didn't understand what was going on. I had to explain to them and I had to explain to several family members, because coming from a different country they don't see this. And if they do see somebody like this they put in the closet because nobody wants to know about it. Nobody wants you to tell you about them. So it was difficult for me. I grew up here. I came here as little but I grew up here.

That's when I saw the language barrier was a factor and that's when I started my journey and learning how to advocate for myself. So that's how I really started basically just trying to understand what was going on with my son. Then I saw the things they were doing. The doctor would just tell my wife, "We're the professionals. Just listen to what we trying to say." And that hurts me 'cause that's my son. That's our kid. We should know what's going on and we were not provided that opportunity. So, that's what's the challenge.

His sister prodded him to get early intervention services for his son. His experience might shed light on why some parents don't go through evaluation to get initial services. Fortunately, Oscar's sister was persistent.

The early intervention program started. It wasn't because of me but because of my sister. My sister is an educator. She's a professor at a community college. She's actually dean of academic affairs. At that time, she was like, "Listen. You need to get him evaluated. Here's the phone number. Call." I procrastinated. I wasn't afraid. I was afraid of knowing the truth. I was fearing something worse. I didn't know. I didn't know what I was getting into. So she asked me a couple days later, "Did you call?" I said, "No." She made the initial call to get the process started. They evaluated my son. They came back said, "Yeah he has a lot of needs. We have to give him support," at that time what they considered good support.

Oscar found that he needed to be more involved as he met other families and learned more about the process.

As time went by, I started speaking to other families and started seeing they were getting more services than my son. And my son had a more serious condition than their kids did. So that's when I started fighting to get him more services through early intervention through mediations and stuff. When they gave us the paperwork, I read about mediation. So I went online to figure out what was mediation and typed in "early intervention mediation" and it explained to me what it is. So then I just started going with the flow. I didn't really know how to write a letter appropriately but I just sat down and I'm going to find way to fix this. And

that's how I did it. Basically, I learned to navigate the system on my own to try to find ways to help my kid.

Oscar's employer, a medical implant manufacturer, was not understanding or supportive of his need to care for his son. Even the counselors at work told him to "Get over it and go back to work." He used up all of his vacation and holidays to try to go to things to help his son. Oscar said that it got to the point when he was fired from his job for trying to be a responsible father to his son. He was out of work for a year, doing temporary jobs.

As Oscar learned more about special education and the system, he found Isabella's group. Since he spoke English, Isabella asked him to accompany parents to meetings because he was unemployed and lived near Isabella's parent meetings. At first he just went to observe, but when he heard what was being said and that there was no one helping the families, he started going to meetings to help the families.

It was just a parent support meeting. And she invited me to come over. I sat there and listened to everything. I already had knowledge of the basic law because I did all the research myself. But then as I started seeing it, I needed more. So I started getting more involved with her group and learning. Every time they had speakers come in I would just listen to them gather the information and just go home and go on the computer and look it up. And that's how I self-taught myself most of my skills in the sense that I knew where to get it because I had been looking everywhere. Once I was working more in depth with <the PTI>, I started to get training and I went to every workshop that was out there.

In addition to attending Isabella's meetings and accompanying families to meetings, Oscar was hungry to learn everything he could.

I went to English only (workshops) because I'm fluent in English. So I went to the English ones. Spanish...I tried to get my wife to go. Unfortunately, it's not meant. If there is, a lot of the time it's the transportation to get to those places and the schedule. My wife was with the kids, so she was unable when the kids were in school. At that timeframe there were not many workshops. If there were, it was one a month. Stuff like that. Me and my wife kind of when we first started I told her, "Listen. Since I know the English language a little better than you do, let me be the lawyer and you be the teacher." So we become a double team in the sense that I went out and looked for all the information I could find...all the websites...every disability organization website... and just gathered the information.

I didn't know how to really navigate like what's what. Now I do. But when I first began I didn't know anything. It was a challenge for me because I had to learn it and analyze it and then try to translate it to my wife. Because some words I couldn't explain to her. At times it was helpful because I actually developed my Spanish better. I had to find a way to help her understand what we were dealing with. That's how I really got more into the advocacy. And then once I started learning, I utilized what I learned. And, if I ran into somebody: a friend, family member or somebody we knew, and they needed help in any way, I would give them my advice. And that's how I really got into this. And then in

time as I started going to more and more training I was given the opportunity to come here to <PTI> and provide information to Hispanic families.

After attending the first IEP meeting with Isabella and seeing the situations parents faced, Oscar began volunteering more to help Isabella's parents after seeing how other Latino families were being treated.

She just asked me since I was unemployed and I lived nearby. I lived a couple of miles away from where Isabella met with the parents. I would just say, "I'll go just to see what being said," because I felt it was not right. But there was nobody there to help them so I wasn't really doing anything. I was just like, "Let me go and help." The main thing is I didn't get that help. If I would have had someone that sat with me and walked me through that process. Even though (the PTI) was here, I didn't know about it. I didn't really look for them. But I felt that the school taking advantage. So I just tried to find whatever I could find for myself. But families don't have that option because they can't read that information because 90% of the stuff is in English.

As I started learning a little bit more and as I learned both languages, I was helping families out. So I started like the moment I started working with Isabella. The first month I was working with her I was helping her with families. I would go to IEP meetings. Just a support person to make sure the language was being provided appropriately. And looking back at it a lot of times I was seeing things I didn't want to say in front the child study team so I would tell the parent after the

fact. That way I didn't interfere with the process. I was like, "Look this is what was said and this is what was stated."

With my case since I spoke English they would try little things but I would catch them 90% of the time. But when I started seeing with the families who didn't speak the language and they were just saying things in front of them. I was like, "This is not appropriate." One time, "Does she look like she washed her hair?" I was fortunate. I grew up here and I knew both languages. So I was able to understand most of the stuff. I mean I didn't understand the legal component. At least the basics I understood so I knew that they couldn't do certain things. But I was hearing stuff for families that were incredible. I was shocked.

It's just a nightmare. Every time I walked into those meetings I was like, "Wow I thought I had it bad." And one of the things that upset me a lot is once the parent did learn a little bit about what they were doing, they'd use child protective services on the parent to scare them off.

Like Isabella, Oscar was also reported to child protective services. Oscar observed "Once they learn that you have a fight, I had them called on me three times." The first time, it was the daycare provider. His wife marked the diaper to see if the daycare provider was changing it. When his son returned home with the same diaper he had worn all day, Oscar's wife went to the daycare and complained. The provider got upset and the next day they got a visit from the Department of Family Services (DFS).

The second time was in retaliation because of Oscar's continued advocacy. The preschool accused Oscar of mistreating his son because his son had bumps on his head.

Oscar explained that they always put him next to the window on the bus and his son started bumping his head against the glass. When DFS came to do the investigation, it shook Oscar up. He backed off his advocacy because he was intimidated.

I got scared. The first two times I got scared. I stopped. Because I didn't know what I was dealing with. And then as time went by as I went to <the PTI> trainings and one of the presenters actually said, "This may happen or may not happen to you, but this what happened to several families." When he said that I was like [inaudible]. Then I approached him and they were like, "Yeah, you're right. This is what you need to do. Call this office and they'll record it. And if they do it again it will show a pattern of that." (He called the office of advocacy) They oversee DFS or DCPD any complaints or issues to make sure they are following the rules. It stopped. It stopped. Yeah. Primarily the school stopped. But it tried again after that. But then since they've seen the history, the case worker sees the history of it and they close it right away.

Now I talk about it (being reported for abuse) because I don't try to hide anything. Now that I'm working at the parent center. I let them know I been there. So I try to open up the gate so they will have a comfort level with me where I can help better.

Oscar views his work as continuing the advocacy movement.

We need to make sure that the people who did that years ago. For example, the Americans with Disabilities Act. The way it was written was because many people who were in wheelchairs crawled up the steps (of the U.S. Capitol) in the

1970's, 80's roughly. I looked at that and it broke my heart. Because now you have people who have ramps and different types of things that were done because of the Americans with Disabilities Act. That's opened up so many doors for so many people. I've seen kids who were never able to go outside, able to go outside and get in their wheelchair and get some fresh air. That's because those people did what they had to do.

And I want to make sure that, I may not be around, but at least I taught two or three people to remember what happened then, so it will never happen again. Because my son right now has a disability. I don't have one, but eventually I may have one. So I just want to make sure that I leave a fingerprint or some kind of evidence that that our kids count, and they should have the same right as everybody else does. I try to teach whoever I'm working with. I understand parents sometimes just work for their own kids. And that's fine. But the important thing is for them to know their rights and protect their children. Are they going to find many people like me? Of course, there are other people out there. It is like anything. I'm here, it took me time, but I'm here. I look at back at where I came from and I'm always looking for new ways fight better. Because if I learn it, I'm gonna teach it to somebody else.

Carmen

Carmen was a most tenacious example of a parent leader who was determined to do everything she could to challenge the system in order to ensure that her son received the best services possible, regardless of her family's means to fund those services.

Carmen's first request for a referral was when Roberto was seven months old. He was only sleeping four-to-five hours a day. The doctors kept making recommendations that didn't work. Determined to get a referral, Carmen changed pediatricians six times until she finally convinced a pediatrician to refer her when Roberto was 18 months old. By that time, she had already made an appointment in hopes that she would get the referral. No one told Carmen about the availability of free/low cost early intervention services for infants and toddlers with disabilities. She found out about it on the Internet, but it wasn't clear what it was or how much it cost. So she was desperate to get the referral. After her son was diagnosed, she didn't get emotional when she told her husband and mother-in-law. They didn't really understand or accept that Roberto had a problem. Even her husband, who is a nurse said, "Yeah, the doctor wasn't so sure." Carmen felt like she couldn't really talk to them because they wouldn't understand. Later she went to the library to make copies of the report and the lady who printed them said, "Oh, autism?" Carmen recalled the story.

I said, "Yeah, my son has autism." That's when I broke down. It is like I kept it for so long then I started crying, which I never did before ever in my life. And you know also um, how can I say this? I myself was diagnosed with Asperger's syndrome.

That brought back memories of her own diagnosis of a "more mild" form autism when she was a child. Initially she was distraught when she imagined how his life was going to be. After the initial tears, she started thinking about what she needed to do. She had learned how to live with her autism and she was determined that Roberto would too.

Roberto qualified for early intervention services and Carmen recalled that they were fine and really nice to her. She did not seem to hold it against them that the first three interventionists told her that there wasn't anything they could do for her son, because he did not respond to their attempts to teach him. The fourth interventionist knew how to reach Roberto. Carmen could see his behavior and eye contact improve tremendously. Since Carmen never really learned how to play as a child, the interventionist encouraged her to watch and learn how to play with her son. Roberto did so well in early intervention that when it was time to go to preschool, he was not found eligible for special education. It was during the transition to special education preschool that Carmen learned that she couldn't trust every professional.

One of the things with me is that everything like everyone is so nice to you and everyone does the thing and does things in the best of your interest. Like you tell me something is blue I would never doubt that it is blue. I would think it's true. And then I found that that was not the case. I had the IEP meeting with the child study team and they told me that my son is fine that I should feel happy, feel relieved. At times, doctors tend to over-diagnose. The kid was very smart and I said, "Yes, he's very smart" because when he was almost three he could count in the hand up to 99.

He was not talking, but he could point, you know, and then shapes, colors. Like not it is just blue, it is more like navy blue like a shapes or color, you know, and I said like, you know, "I'm sure he's very smart in everything, but he has social blindness. This kid does not have any idea of how to do things and his

theory of mind is really immature and he needs some help.” So they just said like “No, just give him some time. Why do you want to see him classified?” as if that this is a bad thing. I’ve met some parents along the way that also are told the same thing. You see the kid and you don’t need to be an expert. That kid has an issue and needs some help. And they (other parents) feel happy and relieved that the child study told them that. So they felt relief and they don’t get the help. And that’s when I started trying to advocate for myself

Carmen tried to get a pro bono lawyer to appeal the decision and couldn’t get one. Then she researched which private schools might be able to help Roberto. She found one, but could not afford tuition. She didn’t let that stop her.

I went to a school, a private school, every day to get the scholarship for my son, and the dean said like, “Okay, fine. We will give it to him.” Honestly and I felt so bad that I had to do it. I never did it before. But you know, my son was in the limbo. He was three years old. He did not have any kind of schooling and he desperately needed the help.

(The school) was a parent-based program. Yeah. I mean like everyone had a baby sitter. I was the only parent there and they were pretty surprised that we hadn’t a baby sitter because that’s kind of like a wealthy area and you know, they can afford as well because it’s private and I couldn’t. I mean like we had some a little bit of a hard time with the parents because, you know like, they kind of looked us down. But I didn’t care. You know, I didn’t care and I kept bringing him there. My husband was a little bit uncomfortable and he was like, “Oh, you

know, we should maybe stop at this point. You know like if they didn't want to give us a help, it is maybe because he doesn't really need the help." He needs the help and you know, that was also so tense time for us as a couple with my husband because, you know like, he kept saying that I was really, like too pushy like I was demanding too much.

The private school was not going to be a long-term solution, so Carmen decided that she needed to get legal help so that Roberto could receive special education services. The private school director gave Carmen the name of the person that he considered to be the best special education lawyer in the area. After the initial free consultation, they would have to pay for her services. Carmen couldn't afford the fees, but was determined to convince the lawyer to take their case, pro bono.

She talked her husband into driving her to the lawyer's office every day until they could convince the lawyer to take their case. She was pregnant with her third child and they needed to bring Roberto and his sister with them because there was no one else to care for them. But that didn't stop Carmen from doing what she thought she needed to do.

It's an hour and a half from my house. Actually, my husband was giving me a hard time because he was like, "Why are you like going there? She is never going to change her mind." You know I mean like, "Why don't you just go to another lawyer?" And I told him, you know, like "They told me she is the best in the area." (My daughter) went in the car with my husband and I went inside the room with my son and then some hours my husband went in and I stayed with him (Roberto). My husband kept saying like, "You're crazy, you're crazy!"

They made a daily three-hour round trip to the lawyer's office for about two weeks until the lawyer finally relented saying, "Don't come anymore. I don't want to see you anymore." Carmen, smiled triumphantly. "She took the case and we won."

The attorney represented Carmen at the child study meeting. The school district explained that Roberto did not need special education and that Carmen was not acting in the best interest of her child. By that time Roberto was verbal and was able to learn new things quickly. They accused the attorney of not really knowing Roberto or his capabilities. The attorney responded:

You know what? I actually know her son. She goes to my office every day. He says the most incredible things, but the kid has poor eye contact. He has definitely sensory issues. I'm not a doctor. I'm a lawyer, but I can see that he has a need.

She presented Roberto's reports and the Child Study team didn't agree, so they went to mediation. The district ultimately agreed to provide Roberto with services similar to what he had received in the private school.

After they won in mediation and Roberto started preschool, the fight wasn't over. Carmen wanted to confirm that Roberto was receiving comparable services to the private school. She found that she couldn't trust the teachers or the district.

When he was in the private school, he was fine. You know, like he got speech. He got OT. He got PT. He got all the services he needed. They also have like a special play therapy. And he got that. He got swimming classes. He got sensory classes. I mean it was really good for him. Because the school, it's like \$60,000 a

year, but it's only for 2 and a half hours. It's really expensive and that's what I said, I could have never afforded it. Not even half.

And then when he went back to district, they told us – and that was under the IEP that my son would have similar services that he would get it three times a week. He would get OT twice a week. He would get music therapy as all the things he got. Art therapy, you know. In the end, because I'm really – maybe my husband is angry that I'm always on top of him. And then I went to school and I like, I want to see the music therapy class, like, “Ah, the teacher is sick today.” Okay, when is she going to be in again?” “Well she comes once a month.” “My son used to have it two times a week in the other school and you say once a month?” They said like, “Yes it's under the IEP.”

That's when I started like paid more attention to how you really develop an IEP. I kept requesting to see the OT and they would never give it to me. Then I just called the same lawyer that I called before.” I'm not going to ask you to come here with me, but I just want to ask you. What should I do? How can I really request to see them?” She (the lawyer) said that “They should have given OT already. You have a right as a mother to see how your son is doing. So, I will just call them.” She called them and they called me back and they gave me an appointment for the next day, and they told me that he was not getting OT yet, but he would soon. So, and I said like, “But the teacher,” she's main teacher, “she told me that he's having OT, so how come you said that he's not getting OT?” She says, “He's having OT.” She even described some of the things that had happened

during the session.” It’s like, I’m upset that she lied to me. And they told me that there was nothing written saying that backed me up. That’s what the district told me that there was nothing written and that actually I could be the one making it up.

Then the speech, it was supposed to be 3 times a week. And they were giving it to him twice a week and the only way I found out is because I made an appointment. They showed me the speech station. But what happened was that one of them – He has 2 speech pathologists, one of them was on maternity leave and so he was actually having just twice a week for his speech.

There were other incidents in which she had to figure out what was going on, then was discounted when she reported it.

That day he came back from the school like this and he was like, “Roberto had a good day at school.” (slow monotone) I was terrified because usually, he, “Hi mommy! I love you so much! I had -” (lively sing-song voice) It was not like my son – he smelled funny. So it was like – I thought it was like cologne like a perfume or something. But, you know it was like, “Mom yes I did have perfume,” but he didn’t have perfume in his things, you know, it was really bad. So, he had a bad day. He cried. I made him took a bath and the odor persisted, and then the next day I took him and they told me, “Oh yeah, yesterday he poured Lysol on top of him”

I said like, “How come he poured Lysol top of him?” and they said like, “Oh, he doesn’t like to be seen when he goes to the bathroom so we just let him

go to the bathroom by himself.” “Okay I can understand that and why didn’t you just stay at the door?” “Yeah, we were at the door, but he was so quick” and I told them like, “But what was doing Lysol there?” and said “Ah, we had another kid that threw up in the classroom.” They had just used Lysol and they forgot to put it back. It was just there. And they told me that I should feel lucky that he didn’t drink it. And I said like, “Is that the best you can tell me?” And they told me, “Yeah because if he had done that he would have been vomiting more, but he’s fine.” And it was like, I couldn’t believe it, you know? I just couldn’t believe it! And I made a letter for complaint that I just wanted them to be responsible with my son, you know, and they replied back to me that they had no idea what I was talking about. But if anything they always keep an eye on him. But it was really like unbelievable, unbelievable.

Carmen tried to warn the other parents about what was happening.

Then I’m speaking with other moms you know because I always tried to make them aware that you know, this is happening in the classroom. It’s only six kids. It’s the teacher with two aides and this is happening. “Be careful so it doesn’t happen you too.” I don’t mean to really, you know like, say something bad about the district or something like that. What I do is I try to make them really aware that they should be on top of their kids too, so they don’t go through what I did and you won’t believe that five parents I spoke to said like, “You know, this will happen anyway. What can we do? There is nothing that we could change about it.” That’s what they said,

Since there weren't many activities in her community for young children with special needs, Carmen started a music program with activities and songs at the library. The program was not well attended because it wasn't on the calendar. So she tried it in a local community room.

So, I just played the guitar for them, then after that I met up with some moms and I tried educate them about their rights. I mean like, I never tell them go and fight the district, you know I just tell them, "This is an IEP. This is how you make an IEP, the process that we have to follow. If they don't listen to you or you are not content with what you think your son needs, go find and get an evaluation." I gave them the steps to do.

The parent group meets 1-2 times a week. It depends on their need. About 10-15 people come. When it's twice a week it would be four people one day, four people the other day. The thing is that when they need support, we gather and I try to tell them like this works for me for example and what do you think? Then I try to encourage parents to talk because sometimes they said like, "I don't know anything about it." you know like, "I don't know anything," But they do because they do know the kid and I tried to tell them like, "Speak up!" you know, "I could learn from you." And the misconception is like, "No what are you going to learn from me?" It's not. I mean actually I learned from them too.

She bases the workshops on things the parents are interested and calls from a list of about 30 people. They attend based on their interest. Often those phone calls lead to longer conversations.

So, I try (to call the families to let them know about the class). But whenever I do there is someone who has to talk. Because sometimes you just need to talk and talk and talk

Carmen began helping families with their IEPs after she saw what was going on with families.

If a parent needs to go an IEP meeting and they don't have anyone to advocate with them. I'll just go with them and try to put a voice for them. I tried to call also a translator because sometimes parents they don't speak English. And, you know, it's funny because one of their rights is that they can have a translator. And there was this time when this mom, she had a translator and she just told me to go with her just to give her support so I went with her. What the translator was saying, it was like really opposite for what he should have translated.

So from that day on I told every parent, you know like, "If you need a translator, call me. I will translate for you" At no charge at all. I never charged anything at all for anything, and you know, that's basically what I try to do. I try to educate people, you know like, I never stopped requesting what my kid needed and I also never stop trying to encourage other parents to do the same and to go with them.

I also translate for the parents. The first mistake they do is that they go to IEP, they sign the paper and then they said like, "If you don't sign IEP, the service will not start for your son, but later on we can implement." They just go ahead and sign it. So, I said to never sign, send it to me or send to someone else,

that can give it a double check, you know, and I double check it. I translate IEPs into Spanish so they can read it and then I tell them that “This is what they’re saying. Do you agree? Yes, or no? If you agree, you can go tomorrow and sign IEP, if you don’t agree then I will try to find you another lawyer.”

Despite caring for three children, Carmen finds the time to work with children whose parents can’t afford private OT.

I never tell them, “No.” I always try to make some time and schedule. I think that whenever you want to do something there is nothing, nothing that can prevent you to do it, nothing that can prevent. You’ll find the time like, my son is in school right now. Because it’s summer time they only go from Monday to Thursday. I have another daughter (9 months old). I have her in early intervention. I come here to the library. She has the session with the EI where I can see her. Because at this point, they want to make her like, to interact with other person besides me. So, and I have the other kids and the other moms here at the same time. Or, you know what, let’s go all together to the park. What I do is I don’t just let them play. I never do that. I always tried to target it from an OT point of view. Even though I am not an expert, I do have some techniques that I can. I think I can help the kids with. So that’s what I do, you know like, I just tried to find a time and I do it.

While Carmen’s husband has acquiesced to her desire to pursue quality services for her children, he and his mother are not supportive of Carmen’s advocacy for others.

They actually told me to stop. Because they said that I’m not getting paid for it and that I should be working, that I could be working a full time job at this trade,

and I'm neglecting my children. I told them, "I'm not neglecting them. I take them with me or I do it while they are doing something else." Yeah. But they are like, "You should charge at least a dollar per meeting." and I say, "Are you kidding me?" They are really not supportive at all. They didn't really say it because they wanted me to charge. It's because they wanted me to feel offended so that I stop. And I come from the culture where like, if you get something you will give something back. But I'm not like that. So, I come from that type of culture, you know what I mean?

But I am not stopping, just because they don't understand that. Because I think that I'm helping people and I want to do it because there was at one point when no one told me what to do, no one helped me. I didn't know what – I was new in this country. I didn't know where to go. I didn't even know that the school district was going give me the hard time. I believed in them and you know, I've met wonderful people along the way. I made my own research, but I also met a lot of people that pointed me in right direction in a right track, and I want to be able to provide that to people. I mean it is really – especially with Hispanic population. They don't know that they can get free occupational therapy at the hospital through insurance and it's free. They just don't know.

Carmen's son and his success brings meaning to her desire to help other parents understand how they can make a difference.

I am telling you he's come a long way and that's what I call for every kid to come a long way. That's what I want for every single kid that I see. Because I not only

see the moms. I see the kids. So, that's what I come for and I really want them to go the longest way possible and to be able to express themselves as best as they can. And I always tell parents, "Never stop trying, you know, improve your child's quality of life and never stop educating yourself and never say your child cannot do it."

Carmen believes it helps parents to know that she has Asperger's because they are afraid that if their child is diagnosed, there is only so much he or she will progress.

I want them to understand that the more involved they are, the more the kids are going to progress and more kids are going to advance. The goal is not to have a typical kid - a neurotypical kid. The goal is to have a kid that develops all that he or she can develop. The goal is to have the kid that can live in a society as far in the society not just a person that can hide his behavior.

Chapter Five: Cross-Case Findings

Of course I'm not gonna tell you that I didn't cry because I will lie to you. But I said, "Okay. There's something that we have to do to help him. There has to be something out there" (Silvia)

This chapter presents common elements of the parents' leadership journeys: fervent hope and determination to do whatever it took to change the trajectory of their child's life; their identified allies and antagonists; and their insights about the meaning and purpose of their leadership journeys. To convey how their perceptions about advocacy and their trajectory to leadership differs from that of the immigrant Latino parents they serve, this chapter begins with their perceptions of the obstacles Latino families face.

Obstacles for Latino Families

These leaders observed that the main obstacles for Latino families were a lack of information and limited English fluency. They also perceived that parents lack hope and have no confidence that they can do anything to change their child's fate. Three parents shared tales of discrimination and threats against Latino families as well as a fear of deportation for parents without legal documentation.

Helplessness and hopelessness. At some point, these parent leaders decided that they were going to do everything in their power to change the outcomes projected for

their children. In contrast, they observed that most of the families they encounter do not have the same confidence or hope. For instance, when Carmen tried to warn the other parents in her son's class to remain watchful of what was going on in the classroom, they responded with resignation that there was nothing they could do or nothing they could change if something wrong happened.

Magdalena's perception is that families do not have her same sense of hope or agency that they have power over their children's school or outcome. By sharing how her life experience has been positive, despite her daughter's extensive disabilities, she hopes families can envision a more positive future for their own children.

I walk in a different, you know, in a worst direction in a sense that my daughter, you know, they should be. What I try to encourage them when I say something, that in the future is gonna help your child.

Isabella explained that the reason she works so hard to help families is so that they can begin to hope for a better life for their children and how important they are to their children's futures.

Information. Graciela observed that a big obstacle to families not advocating for their children is not having the information families need to help their children.

Latinos need extra help when it comes to special needs. You know, like gathering information, knowing where to go, knowing who to speak to if the child has any problem. Because they don't have, they don't have the information. They don't even know that, you know, your child is entitled to certain things. As simple as a bus to, you know, to move from one, from your place to the school. They don't know, they just don't know. So I see

a lot of, you know, Latino parents with kids with a special needs and they're struggling and they don't even know the help is there, you know.

It is not only the families that these leaders helped that needed access to helpful information. Carmen and Oscar said that at first, they didn't know anything or what to do. They considered themselves lucky because of their English fluency, they could find information in English on the Internet. Early on Graciela, Carmen, and Oscar embarked on an internet search for any information that might offer hope. Although she knew about organizations that might be able to help early on, Graciela felt that she needed to do her own research.

I went to the computer and I looked everything that have to do with autism. I read like, I don't even know how many articles. I cried like never in my life and I said "I don't know if it's meant to be that way, but all the things that I've read about autism were bad things. The kids are not going to be able to talk. Everything was negative, and I said, "Well, you know what? If I find a parent here in the computer who has recovered a case from autism, my son is going to be one of those."

She went to the library and checked out every book she could find. She ignored anything she read that did not point to possible solutions. She learned about Applied Behavioral Analysis (ABA), special diets, and social skills therapy. Then she pressed hard to get those services for her son, supplementing them, with her own money, if the publicly-funded services were not enough.

Oscar, who learned about special education and how to advocate for more appropriate services for his son by searching the internet, questioned how parents who

don't know English or have the cultural understanding of special education services are supposed to get this information. Oscar also helps unaccompanied children. In some cases, the schools don't want to provide services. But because Oscar knows the law he has been able to help others. Oscar explained.

I've gotten the kids their services because I say I know about this case and you need to do something about it. But there's also a bunch of them out there that I don't know about. And that's one of the things that's concerning because I know. For example, there are a lot of kids that are coming here who do have disabilities and some of them don't. But the ones of them who do have issues are not being addressed. And it bothers me that that's something that's being pushed aside like it's nothing. That could have been me, because my parents came here undocumented. I was fortunate that my parents got documents legally. It's concerning because it's kids out there who are basically sitting at home doing nothing. Nobody is paying attention to that.

Isabella and Silvia's first access to information was in an English-language class for families in early intervention services. Isabella wanted more than what the class had to offer, so she established her own group. Oscar found this group helpful, but he also went to classes being offered in English so that he could bring this information to Spanish-speakers.

Language. An obvious barrier for Latino families, whose home language is not English, is lack of information in Spanish. Isabella tries to counter that assumption because language should not be a barrier. She says, "No. You come. Tu puedes (you can). You come!" She also finds English classes for the parents and goes, herself. Isabella

perceives that it is easier for parents who speak English to get more services than non-English-speaking parents.

Oscar's leadership journey began because his wife did not understand what the doctor was saying about their son. Oscar was able to find information written in English that could help him. However, Oscar observed that other families don't have that option and schools take advantage of families who don't have access to information because "90% of the stuff is in English." When he began attending meetings as an observer he was outraged at some of the inappropriate things they say in English because they think that he doesn't understand. Oscar also realizes the advantages he has because he knows English and can navigate the system.

I see it because when I help a family they don't know anything about the process. They feel so lost. When I finally have some communication with them, I feel for them in a sense. I was just like them. I didn't know nothing. I was fortunate to be able to learn the English language and learn to navigate the system a little better just because I knew the English language. And also had the opportunity to get educated because I deal with a lot of families who are not educated because they come from different parts of the world. And the education they didn't go far.

According to Silvia, things are more difficult for Spanish-speaking families, so she feels a responsibility to help.

In terms of the families that don't speak English, I feel like I am their voice. It is very different. Like I said before, a lot of them don't feel like they have any rights; because they don't speak the language; because they don't understand the law. They

don't know that they have rights. And when you start explaining to them, they feel like, actually, they have power. And they know they can do something about it. That's why they rely on us a lot.

Even though special education requires interpreters and translation of IEPs, where feasible, Carmen said that after she attended a couple of meetings with families, she felt compelled to go to as many meetings as she could, because families were not being fairly, or respectfully treated. She observed translators who told the parents the opposite of what was being said. She also observed that the IEPs are not provided in Spanish so she will translate the IEP in order to help parents decide whether or not to sign it.

Fear and intimidation. Magdalena indicated that being undocumented and without knowledge of how the system works, prevents parents from becoming involved.

A lot of them too, they're immigrants without papers... so a lot of these parents don't realize that if your child is a citizen, the child has the right to get all these services whether the parent is a citizen or not or resident. (Are parents threatened?) Not only threatened, and I just feel that, yeah, they are threatened. They feel that if they do more or if they try to do more, they may be either deported or it's just fear of getting.... It's just fear of not knowing what to do.

Oscar and Isabella try to make sure that no one tries to intimidate them, but some parents are afraid. Isabella saw through their threats and marched over to the school to confront them when they tried to intimidate her by filing abuse charges. These accusations of abuse were effective in silencing Oscar until he found out, at a workshop in English, that some schools may try to do this and how to get help when that happens.

Oscar and Isabella continue to warn families to not be intimidated, but they acknowledged that not having legal status, like they do, can be even more intimidating. Oscar gave a couple of examples. A staff member might say something to the parent outside the hallway with no one around. In another instance, a person went to the homes of three of the parents he was helping and told them, “You know you can get deported if you keep doing this.” When they tried to report it, they were told that since it happened outside the school grounds, there was nothing the school administrator could do.

In another situation, a DFS worker told the parents, “You don’t have documents and you need to calm down.” That freaks the parent out. Sometimes a couple of months go by, the parents don’t call us, don’t speak to us. And then they call us and tell us, “Well the reason we didn’t call you was because we got scared because this person told me this.” I said, “You should have said something to me because I would have made sure it won’t happen again.” But it’s fear factor. They get pushed back.

Oscar also told the story about a young father who was deported because he had an out-of-state driver’s license. He was away from his family for almost a year. Oscar explained the difficulties faced by the family.

It became a struggle for the family because he had an autistic son. Fortunately, the family kind of like supported that mom and them living in some place, so she had to move in with the siblings until he came back. But it affected the lifestyle. It affected a lot of stuff. The tension. And the mom couldn’t advocate for the kids,

Oscar couldn’t help either because the mother didn’t want to do anything.

Foundations of Their Leadership Journeys

As opposed to the feelings of hopelessness and helplessness that characterize the situation for other Latino families, clearly their child's diagnosis, and the difficulties associated with their child's disability, somehow changed the trajectory of these parents' lives and launched their leadership journeys. These parents refused to give up hope and access the dire prognoses for their children. They were determined to fight their way to a more promising future for their children. Most of the parents recollected stories of conflicts with the doctor and recalled an intense hope that their child would defy such negative expectations. Spirituality and faith in God fueled three of the parents. In order to advocate for services, they had to learn about how the system worked. Then they had to use that knowledge to either maneuver the system so their children would receive services, or actively fight and win in their struggle against the school. They articulated a sense of pride in how they were able to understand such a complicated system and how well their children were doing because of their efforts.

Defying expectations. Clearly, the devastating news and negative prognoses associated with their children's diagnoses, propelled each parent to devote their energies to making sure their children would not realize such negative expectations. After initial despair, each parent shared accounts of their determination and resolve to make sure that their children would transcend the dire prognosis predicted by the doctor. All but one of the parents shared their dismay at the lack of helpful or hopeful expectations from the doctors as they learned of their children's disabilities. Graciela recalled how the

prevailing expectations about her son's prognosis drove her on her quest for a different outcome.

The most, and I'll probably cry for this, but the most painful thing that happened when my son got diagnosed was that I read, that he wasn't going to be able to say "mom". So that was the saddest thing, actually the thing that made me start this journey. Because I just couldn't have a child who couldn't say "mom".

Isabella's journey as an advocate began when the doctor tried to convince her to get an abortion because her daughter was diagnosed, *in utero*, with Down syndrome. Carmen, worried that her son's autism was much more serious than her own mild form of autism, kept battling over and through any obstacle to the services she sought that would make a difference for her son.

Magdalena attributed her experience, and the progress she's seen her daughter make as two things that keep her going as an advocate.

I always said I was very spiritual. I have my own ways of having faith but I just feel that a parent's perseverance can do anything. You have to be the voice for your child because she has no voice. So you fight and if I don't do it my husband is also gonna do it for her. So she is my drive, she is our drive. She drives us to do what's best for her and for all the families too.

Spirituality. Spirituality and strong faith were mentioned by three of the parents as helping them to overcome difficult times. Isabella said that she refused to abort the baby because of her belief in God. That her daughter is doing so well now is an affirmation of that early decision she made. She boasted that even the doctor who gave

her daughter, Selena, such a dire prognosis considers Selena a miracle because she is doing so well. When the doctor predicted that she would not learn to walk until she was six, Selena began walking at two years.

Graciela recounted her encounter with God she had in a dream:

God was telling me, “Your son is okay. The only reason why he got a diagnosis is because that's the only way for his father to get his papers.” And guess what? That was the only way for his father to get his papers. He recently got his papers last year and the only thing, the only reason why he got those papers? Because my son has a diagnosis and all the expenses that we had.

Even when she and her husband separated, she told her husband that he would have to stay in the house to pay the bills so that she could spend all of her earnings on therapies and treatments for her son. Her faith was affirmed last year, after her husband decided to move out.

At first I don't know what to do and I can't pay for that anymore. But then, I realized that my son didn't need it. He didn't need speech anymore and he didn't need ABA anymore. So he gave me the support. God showed me the way to do it until he needed it. Now he doesn't need it anymore. I don't have the money. I don't have the money because he doesn't need it.

Triumph and pride in child's accomplishments. The parents conveyed a sense of success in their advocacy for their children and others. They also were pleased by what their children have been able to accomplish through their efforts. For instance, Graciela is full of pride when describing the progress her son has made.

He's a different child. He is talking like a parrot. He never stops. He understands everything very clever. Really, really smart. He's always alert of everything that is happening around him. Whereas before, even the dog was at home when he was little and he never noticed the dog around him. Now, he's very much aware of his environment. He's very social. Sometimes I wonder if the social skill was good for him because he's too social now. And he goes out, he says "Hi" to the other kids and they don't even look at him. But because, you know, kids sometimes are not that social. But because he was taught to be social, he's extremely social. I would say that he has recovered from autism. I wouldn't say that he's cured from autism but I'm waiting for him to turn five so I could take him for another evaluation. In the meantime, he's going to be receiving those services that he's still is entitled to 'cause as long as he has a diagnosis, he's entitled to the services.

Even though Magdalena's daughter Carmelita has significant delays, she is nonetheless pleased with the progress Carmelita has made since being in the new placement that they advocated for her to attend. The school can address Carmelita's speech delays. "She is finally learning to put little words like two to three words together. She is running, which is something they thought she will never do."

Carmen marvels at how much her son has progressed.

Everyone told me, "Your son will never speak." That's what I got from the doctor when he was there. Then they told me, "He will never be able to express himself. The most we can get are the phrases, 'I'm hungry and thirsty.'"

Now her son is articulate about his feelings. For example, when he recently said, “Mommy, my teacher said that to me and it hurt my feelings.” Carmen felt bad that the teacher said that to her son, but was happy that he was able to share those feelings with her.

Carmen has also learned to appreciate Roberto’s autistic behaviors and his coping strategies. For example, when she asks him what time it is and he answers, “It’s 4 pm with 26 minutes and 35 seconds.” Carmen demonstrated how she learned to handle her own “stimming” by twirling her hand in small graceful circles. When Roberto feels like he needs to throw his body around, he prepares in advance by putting a mat on the floor saying something like, “Mommy, I’m going to throw because I need it.” Or “Mommy, I’m going to throw. I will be back in one minute. Don’t worry Mommy I’ll be nearby.”

Silvia sees promise that her son will lead a normal life. Oscar didn’t know he was going to a special school and was in special education, because his younger brother goes to a special gifted education school. Now in high school, Oscar takes public transportation to school because he doesn’t want to be viewed as a special education student and take the special bus. He also had his first job over the summer, and Silvia’s eyes sparkled with pride as she described how promising her son’s future is now.

He likes expensive clothes. He says, “Mom I don’t want you to spend too much money. I want to have a job and buy my own stuff.” I asked my aunt and uncle if they could allow him to stay with them for the summer and work with them. And of course they said, “Yes.” They are thrilled. That’s their adopted son right now. And he’s doing really good. He’s following the rules. He’s waking up before my uncle. Actually, he’s

ready to work before he is. And he's very happy. Because he has money and he's planning on what to spend the money on.

(He) carries merchandise when they go shopping. Cleaning up. He paints when painting is needed. My uncle knows. I explained to him that it is better when he explains to him one job at a time. "Do not tell him, you do this and that; then do this and that." He gives him a chore. Then he tells him, "When you finish come to me and I'll tell you what to do next." So that's how he's working.

He's one of the best workers he's ever had. I was very proud. In the beginning I thought he was telling me that to make me feel good but he said, "No. You can ask the other workers. He is always busy. He is always asking for help. He wants to learn. He wants to work."

Allies

All of the parent leaders could easily name others who helped them on their leadership journeys. Isabella is clearly an inspiration and leader who enthusiastically engages anyone and everyone in her cause of helping families. Early on she asked the mayor of her town to provide meeting space when her group became too large to meet at her house. She asked Silvia to interpret for guest speakers who did not speak Spanish, but who had important information for her families. Next she introduced Silvia to the PTI. Soon Silvia was also working for the PTI on a per diem basis, as an interpreter. Isabella even engages families who do not speak English to accompany each other to IEP meetings for moral support. After she sent Oscar to a couple of meetings, he felt that he had no choice but to become an advocate. When Isabella had to cut back her efforts because of a medical issue, Oscar and the other parents returned the favor and stepped up to help. In this section I will discuss who parent leaders identified as allies and how they helped.

Early intervention program. Unlike special education that is mostly concerned with the academic and developmental needs of children, the Early Intervention Program for Infants and Toddlers with Disabilities and their Families (Part C of IDEA) is intended to base services on the needs and priorities of families. The early intervention program was consistently viewed as an important early ally in most of the parents' journey. Even though Carmen's first three early interventionists were unable to help her son, they kept sending new interventionists until the fourth one was finally able to break through Roberto's unresponsiveness. That same interventionist helped Carmen with her own

autism so that she could play with Roberto. This interventionist continues to be a source of trusted support, providing intervention services for her younger children, both identified with autistic tendencies.

Magdalena and Graciela credit the early intervention program as making a difference in the early development of their children and easing the transition to special education services. Both Magdalena and Graciela have maintained relationships with the folks at their early intervention services program. At this point, the early intervention providers continue to refer other families who need help and both parents continue to help new families.

When Silvia learned that her son had autism, she enrolled him in early intervention. Silvia was pleasantly surprised that the early interventionist came to her home. When the therapist brought a toy one week, she went to Marshalls to buy the toy and was working with her son the next week when the therapist came again. The therapist suggested that she become a volunteer at his developmental preschool. Before she knew it, Silvia was a floater substitute teacher, a teacher's aide, then a teacher. The early intervention program also had a parent group. When Silvia started going to the groups, she said she learned more than she had in the previous six months. It was at this group that she met Isabella one of the other parent leaders interviewed for this study.

Parent Training and Information (PTI) Center. No entity was consistently mentioned as an ally more than the state parent training and information center (PTI). Graciela and Magdalena learned about the PTI from their early intervention providers. Magdalena and Graciela's relied on the PTI as a source of information about how the

system worked and how to negotiate with the schools for services. Although Graciela knew about organizations like the PTI early on, she felt that she needed to do her own research.

I decided that I wasn't ready to be in a place where other parents were discussing their kid's situation because I always have in mind that my kid is going to be okay. I didn't want to hear what other parents have to say about their kids, about their situation. Not that I didn't want to help. It's just that I didn't want to-- it was too overwhelming for me at that time. I just wanted to understand how to help my son first.

Yet the PTI was instrumental in help Graciela get services for her son. She also recalled that invoking the name of the PTI as the entity that gave her information seemed to carry weight with the school.

I got all the information that I needed to know in order to get the best program for him. So they told me, (the PTI) told me that, he was entitled to a full day program and according to his needs, you know whether it's speech, OT, ABA. So with that in mind, I went back to the school and I told them. I wrote a letter stating that I was not satisfied with, you know, whatever they have offered me. And then I had to bring, at the time, a diagnosis in order for him to get... 'Cause otherwise they were not going to give me a full day. They didn't have any diagnosis. So when I brought the diagnosis and I told them that I had the help from (the PTI), then we came to an agreement on the best program for him. I got a full day program, full day-- half day in the self-contained class, and the other half day he was in an inclusive Pre-K.

The PTI told Magdalena about the services her daughter could receive if they moved to a different county. At this point, their relationship with the PTI seems to be reciprocal as Magdalena and Graciela are willing to help any families the PTI refers to them.

The parent leaders who are now employed by the PTI, see the organization as a source for information, but also one of encouragement and support. Isabella was the first to encounter the PTI about a year after she had started her own parent group of Latino parents. When she found out about the PTI, she began going to their workshops and inviting speakers to present to her parents. Isabella brought Silvia and Oscar into her leadership circle. Isabella is not as comfortable communicating in English as Silvia and Oscar. But it was clear to me that they consider her to be the lead of a group of Latino parents in their community. Isabella also introduced Silvia and Oscar to others in that PTI, and the three now work there.

Families. Not surprisingly, families and extended families were important supports for most of the leaders. Oscar described the difficulty of explaining his son's disability to the family, though his sister is the one who nudged him to get his son evaluated for early intervention. Magdalena's mother-in-law lives in an apartment upstairs from her family and loves spending time with her daughter. Silvia's large extended family live close by and are supportive. Her uncle gave her son a job last summer. Oscar's brother gave him temporary work when he was unemployed. Graciela's mother came from Florida to take care of her son, allowing her to retain her job as a preschool teacher.

Oscar and Magdalena both characterized their spouse's role as a partnership in caring for and advocating for their children. Oscar initially took on a more active role because his wife is not fluent in English and could not communicate well with providers. However, as she learned more, his desire to communicate with her about what he was learning propelled him to learn more Spanish, specific to special education and disability. Magdalena's husband is of Italian descent, and she observed that being an "interracial couple" is not accepted, but exclaimed, "I have to tell you, my husband is amazing. He is involved in every aspect of my daughter's progress and education."

Other allies. Magdalena and Graciela work at the same preschool and said that their director encourages them to advocate for their own children and the families of children who attend the preschool. In fact, the director suggested that Magdalena move from an office manager position to that of family worker so that she could help other families. The director is knowledgeable about special education and serves on a national early childhood board. She encourages her staff to be advocates for all the children.

Carmen and Oscar mentioned staff members from other agencies as advocates who can help families fight the system. In Oscar's case, teachers have become secret allies. They confide in him about things that are going on, but ask him not to tell anyone because they fear retaliation.

Conflicts and Resolutions

The first, and perhaps most meaningful, conflict seemed to be early encounters with doctors. All but one of the parents described conflicts with the school system. Oscar illustrates how his advocacy and leadership was honed by his determined advocacy in the

face of adversity. Carmen, Oscar, and Isabella detailed several stories of how they had to fight the system to get needed services. All the leaders shared how they help families understand and fight the system for their children's rights. This section will describe conflicts these parent leaders faced on their advocacy journeys.

Medical community. In the previous chapter, I discussed how Isabella refused to get an abortion against what she considered to be the strong advice of her doctors. Oscar began his advocacy because he did not believe that his wife was getting all the information from their son's doctor, and that he didn't think that either of them had been treated with respect. Graciela recalled her saddest moment to be when the doctor said that her son might never be able to say "mom". Silvia began her story of her journey as an advocate in defiance against the doctor's prognosis for her son.

Well the doctor was basically telling us the limitations he would have growing up. That he was not going to be able to ride a bike because his eye/hand coordination was not going to allow him to do that. He was probably not going to have enough language skills to communicate. He was not going to be able to function like any other regular kid. And I basically said that was not going to happen to my son because I was going to do everything in my power to help him develop as a regular child - knowing that he had a disability - but I was not gonna limit him in any way, shape or form.

Since the doctor said that her son would never ride a bike, the first thing she and her husband did when her son was diagnosed at two and a half years old, was to buy him a bike. Even though he was seven before he mastered riding a bike, Silvia proudly recollected his triumph.

On the day he learned to use the bike without the wheels, because he didn't want help, me and my husband was trying to help him...hold him one hand in the front one hand in the back and he was like, "No, I got it. I got it!" I was so scared. He was seven already and he was on a tiny little bike with two wheels. So he even felt that he was too big for the bike. So he wanted to get rid of the wheels. So he kept telling us, "Don't help. Don't help. I got it! Stay there. Stay there!"

And I was afraid because I knew he was gonna fall. And actually that's what he did. But he got up. He cleaned himself and started again. At one point, because he had fallen like four times, I told him to stop because I didn't want for him to get hurt. He said "No I gotta do it. I'm gonna do it!" And then he got up and he went all the way to the end! And then when he made it, he threw the bike on the floor and "I did it! I did it! I did it!" And then after that, no more training wheels. And then we got him a bigger bike because he was ready. So now he has the giant size mountain bike that he rides everywhere.

Because I dreamed of that day for so long. And for somebody to tell me that my son was not gonna be able to do that. And that's what I really tried to teach the parents at daycare. Because they would come to me with the same story "Oh the doctor said he not gonna do that. The doctor said..." And I used to look at them in the eye and, "I tell you. He's going to be able to do whatever you want him to do because it's up to you. You're the one that's gonna put everything on the table for him. How do you know he's not going to be able to do that if you don't try? If you don't try that means he will never. But

if you try at least you know that you tried. And then you move on for something else. You're not gonna get stuck." You have to help them be as independent as possible.

Like, I didn't even know the help was there until I really feel that I need to find somebody. There must be a way to get my son what he needs, what I think is the best one, but I just feel like for me the motivation like I told you, was you know my son, not been able to say "mom". And that was what helped me overcome anything that was in my way. The language, not knowing what to do. I had a motivation and I had a goal in mind and that was what really helped me.

School system. Four of the six parents had been in some dispute with the school system, and a fifth, Magdalena, moved to another community so that her daughter would be able to attend a different school with superior services and she could avoid a fight with the school system. After she won her dispute over placement for her son, Graciela said that the team at his first school was "amazing". Even though his next placement was not as optimal, she was happy with the teacher he had.

Carmen's son is only four years old, but she has had numerous disputes with the school, as noted in the previous chapter. She doggedly convinced an attorney who was considered to be the best, to accept their case *pro bono*. The first time was because the school system found her son to be ineligible for special education preschool services. Then when Carmen found out that the school was not implementing the IEP, she had the attorney call the school again. Because the teachers betrayed her trust, Carmen has been diligent about making sure that her son is receiving needed services. Even though she

complained to the administrator after the teacher admitted wrongdoing to her, the administrator said that it would be Carmen's word against the teachers.

Shortly after Oscar began working at the PTI, he noticed the ways that schools attempt to intimidate parents and realized he had power because he knew his rights.

I walked in there and they had a lawyer. And I never considered myself that knowledgeable in terms of the law. But I walked in there and they were so unaware and so afraid of making a mistake that they had their lawyer there. I already knew that he shouldn't have been there, so I mentioned it. You're here to do what? He says I'm an observer. Okay you're an observer then I'm going to record this. And that's when he got upset and walked out the room. Apparently, he was going to confront me but now that I was recording it he couldn't say nothing. So that's when I seen I had a little bit of power.

Even staff assumed to be allies are not necessarily helpful. Carmen and Oscar mentioned how the translators do not give accurate information. Oscar discounted the helpfulness of parent liaisons hired by the schools. It would seem that these parent liaisons could be natural allies for families. However, that is not Oscar's perspective. Oscar said that the parent liaisons go to training, but they don't utilize what they know to help the families.

I know they know the rules, and know they can do more than what they can do. A lot of parent liaisons is just today be like, help the principal when he has to meet with the families. But instead of giving the parent the information they need to get for the children, and they don't get that.

I know one that was very good. She was ...over one year, and the following time they have to renew the contracts. She's released because they said that the parent complained. But the parent never actually complained. They made it up. So she was released basically just because she was helping families. And she was really good at this. She got fired. So there's parent liaisons but do not be utilized, or do not allowed to use the skills of the training. Some of them are not trained, no most of them are not trained

When I asked Isabella if in the 11 years her daughter has been in school, there was anyone who was helpful or encouraging, she said that there was no one. She considered the worst to be the case manager who spoke Spanish. Because Selena was not making progress, Isabella began to send Selena to a teacher the next town over that she pays for privately.

Silvia was the only parent who could not recall a disagreement with her son's teachers. In fact, they have suggested the best programs available for her son, and she cited an instance in which her son could have been suspended or expelled, and they listened to and acquiesced with her request to make her son do extra work at school instead of rewarding his behavior by allowing him to stay home.

Threats and intimidation. I was surprised to hear that both Oscar and Isabella had been reported to child protective services multiple times. They said that it is a way that schools try to intimidate and silence parents. Their situations are described in the previous chapter. Carmen also alluded to some of the ways people tried to intimidate her, but she was so focused on her son getting the services he needed that these threats did not stop her.

Meaning/Purpose of Leadership Journeys

When asked the meaning of their leadership journeys, they all pointed to how they were driven by their own experiences and successes to make a difference in the lives of children. They understood that they had privilege because of information and knowledge of how to be successful in a system in which they perceived that the special educators and administrators had most of the power. With this privilege came the obligation to use it to help others. The parent leaders reflected on the meaning they make of their leadership journeys and their purpose for continuing to help other families. This section describes how parents explained what drives their leadership and advocacy.

Help families understand they have agency. The leaders learned, struggled, and persevered over conflict, but felt that their children were better off because of their struggles. As they were able to overcome obstacles, they wanted to make a difference in the lives of other children too. Silvia summed it up when asked about what meaning she makes of her journey to leadership.

I would have never guessed in my whole life this was gonna be my career. But I think this was my calling actually. It's like if you put all the lines together, it makes sense. This was gonna be my future actually. It was like preparing my own experience to help other families with what they're going through right now.

When asked to speculate about what else she would be doing if she wasn't an advocate, she scoffed.

It wouldn't matter because my life changed with my son's disability. It wasn't about me anymore. It was about him, and that's the line I have been following ever since.

In the beginning, Graciela wanted to do her own research and learn about her son's diagnosis and possible treatments without much help from others. Her son is doing fine now. So she sees the importance of the time she spent on her research, to her current role in helping and encouraging families.

Now I kind of like understand a little why I needed to go through all this. I think that this is like the right place for me right now because when I see parents who have kids with problems, especially autism. I always tell them everything that I went through. That it's really up to the parents whether they want do it or not, or whether they want to follow what I did or, you know, which is read something so you could have your own idea. But I feel like this is a right place for me to help parents, also I help parents.

I always tell them, "This is what I learned from reading all these books from people who have recovered their kids. It doesn't work for everybody. You have to try it. You would not know if it works for the child if you don't try it. Maybe what works for my son is not going to work for yours. But it doesn't mean that there's not out there something that is going to help the child. You just need to get more information. The main key here is get educated and gather all the information that you can to help your child. There is so much information out there.

With great privilege comes responsibility. Magdalena also spoke to the different treatment that she may receive because of her knowledge, social capital, and position. Magdalena is known as a person who knows how the system works and advocates for a number of families. She believes she is able to get the school system to

respond to her requests more readily than other Latina families and is emboldened even more when her non-Latino husband teams up with her.

They still look at you as though you're not...you know second class citizens. But I have to stand my ground. So I think that's why and even now, it's sad to say. I don't know if it is good to say, when they hear my name at the board they react. I get a response quicker.

Oscar also sees it as an obligation to help families who don't speak English.

One of the things that, how can I explain it? I don't get paid to do this. In a sense what pays me is seeing the family smile to finally be able to understand what they need to do. That kind of pays me because I see the challenges. I see the injustice in the way they navigate the system. They don't have that window or don't have that opportunity to learn, because they don't have that information. Like the other day I had a parent here who is French. There's nothing out there in special education in French. I looked it up everywhere on the Internet. There is nothing out there. You can Google it, but Google translation stinks. But I'd rather use it because having something is better than nothing.

I just wish they made it easier for everybody. What I mean by everybody I mean anybody that has a language barrier. But they make it so hard. That's why so many parents get discouraged and don't say nothing. So many years go by and these kids could have gotten help earlier on and you lose a generation.

Carmen was trained as an OT in her country and has learned much from the therapists who have worked with her children and what she has learned from her allies.

Despite being responsible for caring for three children, she finds the time to work with children whose parents can't afford private OT.

Making a difference/legacy. Perhaps the most powerful purpose of all for these parents was to make a difference. Oscar summed up the meaning he gives to his work as an advocate and leader:

To make a difference. To try to make a difference. One of the things that I do now is look back at the history of what were disability rights and I've seen the injustices that were done. I don't want that to be repeated again. I want whoever I work with. I try to convert myself now as a teacher. I think it's important now that I develop the future leaders. Whatever way I could. Like I say, the resources are limited. If I had more leaders out there, that looked like me, or resembled me, or they speak a different language, we can make a big difference. Because there is a lot of stuff that should have been done years ago and still are not done.

Graciela has her sights on potential ways to make a lasting difference.

I need to be a part of some organization or someplace where I could help more people or either go back to school and get a masters on special needs. So I could, you know, have more information. I have a little bit of conflict with the school. That's why I think I haven't been able to go back. Because the school -- the books they see autism from certain point of view and I -- based on my experience which I feel to supplement on different perspective. But I do want to go back to school and get a masters. I feel like God wants me to share what I have -- elevate the experience I have and all the knowledge I have with all of the parents. They need help here and all the parents that need help from

an intervention and more. They just don't know where have to go. You know, like I've been trying to get in touch with person from (the PTI) and see if there is any way that I can get involved. I know I can just give an extra hour just voluntarily. I know that I need to do more. I just don't know where to go.

Sometimes I feel like I need to write a book. I need to write book, but there are so many books. But you know there's always going to be that one that is going to be-- that's going to apply to your child, you know. So you need to do your homework, you need to read. This is what worked for my son, I did this, I did that, I went to this place, you know, I tried this therapy, I tried this other one, it's really up to you to try or not. You know, it's a commitment, you have to make a hundred percent. I didn't have a life until recently. But now I see my son and we could have a conversation all the time.

Carmen got a scholarship to the Son-Rise Program in Massachusetts that teaches parents how to be therapists for their children. When she returned, she turned her house into a small gym with a ball, mats, and bean bags. This program helps parents learn how to mimic what their children are doing, in contrast to another autism treatment, applied behavioral analysis which reinforces appropriate behavior for children with autism.

According to Carmen, it is pretty intensive and based on acceptance and love. She would like to create a similar program for her parents. The program would cover special training for parents to learn, then go back home and apply it with their children.

Now, my next step is to try to educate parents on how to – I wouldn't call it therapy, but how to play in a more meaningful way with your kids. Let's say like, um, they play with their kids and they interact with their kids but just doing it a different way.

Not just say like, “What is it?” You know, ‘that this is a crayon. This is a brown crayon’ like to have more expression like, “This is a brown crayon. bruh-bruh brown. It sounds so silly, but just to teach them that, “What do you use crayon for? You use it to color.” You know like trying to expand that, and it sounds really silly but I helped my son. So, maybe I can help any other person.

Isabella worries about the families who don’t know their rights and how to advocate for their children. She wants to make sure that families get services. It bothers her to hear parents say, “If I had just known you earlier my child could speak.” The parents call me every time when I go with my husband. He wants to say, “No more. No, no more!” I say, “Papi, I need to help!” He says, “No more!”

Chapter Six: Discussion and Implications

Insofar as I am a conscious presence in the world, I cannot hope to escape my ethical responsibility for my action in the world. If I am a pure product of genetic, cultural, or class determination, I have no responsibility for my action in the world and, therefore, it is not possible for me to speak of ethics. Of course, this assumption of responsibility does not mean that we are not conditioned genetically, culturally, and socially. It means that we know ourselves to be conditioned but not determined. It means recognizing that History is time filled with possibility and not inexorably determined – that the future is problematic and not already decided, fatalistically. (Freire, 2001, p. 26)

The purpose of this qualitative study was to understand the lived experiences of Latino immigrant parents of students with disabilities as special education advocacy leaders in their communities. I wanted to learn about their journeys, allies, conflicts and resolutions. I was interested in what they believed to be the impact of their leadership on other families and in the special education system. I hoped that the stories of their experiences would help me better understand advocacy and leadership for other Latino immigrant parents of children with disabilities. Chapter Four contained narrative profiles of three of the parent leaders to describe their journeys, how they resolved challenges, and the meaning they make of their leadership. Chapter Five described the perceptions these leaders had about obstacles that Latino families face including as sense of helplessness and hopelessness, lack of information, language barriers, as well as fear and

intimidation. The chapter identified elements of their leadership journeys including defying expectations; spirituality; and triumph and pride in their children's accomplishments. Predominant allies were the early intervention program staff, the PTI, and their families. Common antagonists included the medical community and school system. When asked about the meaning and purpose of their leadership journey, the leaders understood the responsibility that comes with their privilege; they want to help families understand that they have agency; and they want to make a difference in the children's and families' lives. This chapter will discuss the findings and present implications for research and practice.

Discussion

In the opening quote for this chapter, Freire refers to the ethical obligations of teachers to not be constrained by hegemonic ideas. The same concept applies to these Latino immigrant leaders as they embrace the idea of changing the portent of "history" for their own children, and other children with disabilities. In other words, they consider it as their responsibility to transform the limiting situation associated with disability to one of promise and humanization rather than despair. Unlike some professionals who claim that parents who refuse to acknowledge that their child's disability will severely limit their ability to live a 'normal' life, these parents were well aware of the prevailing understanding of their children's disabilities. Freire (2007, p. 85) posited that *conscientization*, or deepened consciousness of a situation as an historical reality susceptible of transformation, begins with questioning or challenging the situation and that compels action to change the reality.

Individual advocates. Their early realization that they were destined to become advocates began with their own children. Once they heard the dire prognosis for their children, they realized that they needed to create a new prognosis: develop a counter-narrative based on what they dreamed of for their children. Even Magdalena, whose child has a genetic condition that usually manifests as a severe disability, did not resign herself to that prevailing narrative. Instead she made sure that her daughter was able to go to a therapy-rich school. She was proud that her 10-year-old daughter can now put two-three words together to communicate and that her daughter can run, which children

Silvia did not want her son's diagnosis of autism to define him. So, even though he has always gone to special education schools, he did not know he was in special education until tenth grade. When the doctor said he wouldn't ride a bike, the first thing she did was get him a bike. When he wanted to work and couldn't get into the youth jobs program, she used her family network to find him a job. It isn't the case that she is in denial about her son's autism. Instead, because she is well aware of his diagnosis, she just makes sure that he has every opportunity to not let his diagnosis define or limit what he is able to accomplish. So in her mind, every milestone he's working on is achievable, and every limit he surpasses is a victory.

Community advocates. These parents were all knowledgeable and strong advocates for their own children. They could have gotten the services and supports their children needed, and continued on with other pursuits. At this point, Graciela, Carmen and Silvia expect their children to lead fairly normal lives. What distinguishes these parents as leaders is their strong commitments to changing the situation for other children

with disabilities and their families. While being an advocate for a child with disabilities can be overwhelming, these advocates also recognized how socio-political and cultural pressures make it even more difficult for Latino families. Oscar said that once he saw what was going on for other families, he didn't have any other choice but to become an advocate. Silvia could not envision any other life than that of an advocate. According to her, the decision was made for her once her son was born with a disability.

Most of the parent advocates perceived that Caucasian families were treated with respect by the medical and educational community and could more readily receive the services their children need. These leaders perceived Latino families to be more oppressed because they were treated disrespectfully, did not have information about their rights and were coerced into silence and signing their children's IEPs because they didn't have the perceived agency to exercise those rights. These leaders recognized that although they, too, are Latino, they enjoyed the privilege of understanding the English language and the special education laws. While feeling fortunate about their privilege, they also recognized that with a different twist of fate, they could be in the same shoes as the families they feel compelled to help.

Oscar, Isabella, Carmen and Magdalena articulated how school personnel try to oppress and intimidate Latino families. Oscar and Isabella share their own stories of intimidation and unfounded CPS reports so that parents may become less cowed when school personnel try to threaten families with child protective services or immigration. Carmen and Oscar spoke of personnel who seemingly should be allies – or at least not oppressors- such as translators or school-based parent liaisons. After observing

translators providing incorrect and misleading information, they decided to attend as many IEP meetings as possible to make sure that families were not compromised. School personnel who wanted to be allies were also perceived by a few of the leaders as being oppressed and intimidated from allying with families. To get around this, they would discreetly share information with the advocates, in hopes that the advocates could help families.

Writing a new history. A young lady, with Down syndrome, coined a term that I loved the first time I heard it. Her mother relayed her daughter's response when she was admonished for some long-forgotten wrong-doing. She said, "But Mom, I'm writing a new history!". Indeed, what these parents are doing as leaders is revolutionary. They are writing a new history that is not limited to Latino children with disabilities. Oscar tied what they are doing as activists to what has been done in the history of disability advocacy. In fact, the special education laws were enacted due to the efforts of parents in the 60's and 70's who demanded that the over million children with disabilities who were barred from attending public schools, have the same right to education (Ong-Dean, 2009; Turnbull, et al., 2011). Historically, children with disabilities were placed, at birth, in institutions. According to Turnbull, et al., family members of individuals with disabilities, fighting to provide access to public education for their children, formed a collective identity to advocate for the initial special education laws and later reauthorizations, challenging general and special educators, Congress, state officials, and agencies to secure rights for their children without the benefit of established institutions. In doing so, they challenged cultural beliefs and practices that excluded their children,

acted individually and collectively, and formed coalitions to advocate for the rights of students with disabilities.

These leaders are following in the footsteps of these pioneer special education parent advocates, Isabella started a small group of Spanish-speaking parents in her home, and that group now numbers in the hundreds, meeting regularly to learn more about special education, disability, and advocacy as well as to enjoy recreational activities as families. Graciela considered furthering her education as a special educator, but wondered if she might have a larger impact for writing a book that rewrites much of what she read about children with autism. Carmen started a group that meets in the library and dreams of establishing a training program for families to help their children learn and develop. These parents continue to pursue alternatives to the current situation because they see special education as being nonresponsive to the needs of children with disabilities. The hegemony of limited expectations for students with disabilities is something they want parents to question and to demand much higher expectations.

Quite thrilling to me was Carmen sharing how she manages a desire to stim, related to her autism, by slightly twirling her hand. Equally revolutionary was how her four-year-old son manages his need to “throw himself”. He is self-aware of a need to throw himself and communicates with her not to worry because he will return in a minute. Then he goes to his room and arranges a mat so that he can safely (and appropriately) throw himself on the floor. Both Carmen and her son have the potential to establish new ways for others to better understand autism better, and for people with autism to live more functional lives.

These parent leaders seemed to regard the early intervention staff as helpful early allies. However, they cited numerous examples of violations of the special education law. Three parents shared stories in which an administrator told them some variation of “It is your word against ours”, even when a teacher or other staff admitted wrongdoing. What surprised me was how successfully these parents learned to navigate the system and use the law to advocate for their rights. When he found out that his son was receiving less intensive services than other children who were less seriously involved, he advocated for his son by using mediation, even though he said that he didn’t know what he was doing. Magdalena figured out how to get the best services for her daughter by moving to a different community. As they learned about their rights and shared the information with others, other Latino families in their communities began advocating for their rights also.

Alinsky (2010, p. 151) identified a tactic for “have nots” to reach their aims by pushing those in power to abide by their own regulations, as winning by “their own petard.” The fact that that their advocacy was related to special education rights may have strengthened these parents’ ability to advocate on their children’s behalf. In his study of parent involvement and rebuff, Olivos (2006) mentioned that one of the few Latino parents who effectively advocated on her child’s behalf was the parent of a child in special education. Though it may be more difficult for Latino immigrant parents to win a conflict with the school (Ong-Dean, 2009), Oscar, Graciela and Carmen mentioned utilizing their due process rights to gain services for their children.

Understanding their children’s legal rights and finding legal support, as Carmen did to win her case, has potential for an even greater ripple effect in services for students

with disabilities. In *Sacramento City Unified School District Board of Education v. Rachel H* (1994), the parents of a child with Down syndrome demanded inclusive placement and services. Winning this case provided a legal precedent and support for children with disabilities in California and elsewhere in the U.S. to be included in schools. *Florence County School District IV v. Shannon Carter* (1994) upped the expectations for schools to teach children to read. Perhaps in the future, one of these leaders might also prevail in a case that opens up services for students in special education.

As stated in Chapter Two, research suggests that parental aspirations and high expectations may not be voiced in a way that the school can hear (Auerbach, 2007; Blue-Banning, et al., 2000; Mueller et al., 2009; Olivos, 2006; Villalba, et al., 2007) and may not be the determining factor in how well their children do in school (Lopez & Stoelting, 2010). These leaders are changing that narrative. By encouraging parents to have high aspirations for their children with disabilities and supporting their advocacy efforts, more Latino parents are able to effectively advocate for services that will help their children reach their potentials. School rebuff may be a factor that keeps parents from being more involved in some cases (Auerbach, 2007; Drummond & Stipek, 2004; Olivos, 2006; Villalba, et al, 2007) yet, these parents have come to expect that rebuff, and are not deterred in their efforts. This study did not uncover ways to help teachers become more receptive to Latino parents. Although, a threat of due process cited by Blue-Banning, et al. may have been a factor, in the stories shared by Oscar and Isabella, when school personnel came to Isabella's workshops to check on what she was saying; and stories of

retaliation after the school personnel perceived that Isabella and Oscar were behind more complaints by families.

Silvia and Isabella both mentioned a parent class offered by the early intervention program that helped them understand how to support their children's learning and opened their eyes to how they could help their children. Silvia went out and bought all the toys so her son was adept at the new skill the following week. Carmen mentioned how helpful it was for her son's early interventionist to show her how she could support her son's development through play. So there may be a place for school-centric parent involvement models such as those developed by Epstein (2005) and PIQE (Henderson, 2010). However, these models can also be poorly implemented. For instance, these parent leaders said that in some schools, teachers who wished to be allies with parents needed to communicate in secret with the parent leaders. Oscar also commented that the parent liaisons, employed by the schools to help parents were really there to serve the principal and not allowed to share what they know with parents. In fact, he relayed that one parent liaison who was fired for being too good at helping families. Whether these programs are in place or not, this study opens new possibilities for models focused on community leadership development and advocacy.

Implications

This section contains a conceptual framework for both child and systems advocacy that builds upon the power that parents have to change the trajectory of their children's lives. As parents are successful in confronting barriers to the success they dream of for their own children, they are also able to build upon their advocacy successes

to join with other families and allies and make more systemic changes. This study also leads to questions for further research. Finally, the stories of these parents lead to implications for actions that can tap the formidable power of Latino parents and others to change more histories for children with disabilities and their families.

Conceptual framework for child and systems advocacy. As previously mentioned, this study evolved from my experience as a special education advocate and director of a PTI that actively promoted Latino Parent Advocacy. Before this study, I thought that our program was doing such a wonderful and miraculous job and the success of the program relied on Fajardo, my Outreach Director. Each workshop or event she planned became a celebration of possibility for the thousands of families she reached. She became a rock star in the Latino community, with outreach to the embassies, television, radio, news, churches, community agencies and businesses. We actively sought more families to become leaders and found that, in the process of becoming leaders, the families were even more successful in their confidence and advocacy. When I contacted the PTI recommended by the project officer at the U.S. Department of Education, I had my doubts that anyone could replicate success such as ours. I was intrigued to learn about how this particular PTI promoted advocacy and leadership. I was particularly impressed when the director of advocacy told me that they even had an undocumented Latino father register to speak to the general assembly. I was utterly amazed and delighted to meet and hear from this group of Latino immigrant parents, who demonstrated their leadership in different ways, but who shared themes familiar to me in the history of special education parent advocacy, and in our own work with Latino families.

Like the special education pioneers, these parents wanted a different life for their children than the prevailing narrative. Early special education pioneers were primarily Caucasian, well-educated mothers, with the determination and social capital to convince the Congress to enact a special education law strongly influenced by parental rights (Ong-Dean, 2009). It was always clear that their dreams for their children were the main driving force for these parents. However, these parents could only be effective in changing the narrative for students with disabilities when they linked with similarly-minded parents as a social movement (Turnbull et al., 2011). It is truly revolutionary what they did to set the bar for success to the extent that the expectation in for students in special education is that they graduate from high school, and move on to postsecondary education, gainful employment, and a fully inclusive life in the community.

That this group of Latino parent leaders have been so successful in reaching out to other families and helping them become effective advocates despite fear and oppression is also revolutionary. Isabella went even further when she started her own group and recruited others like Oscar and Silvia to become leaders too. Isabella and Oscar observed that they become stronger and more effective leaders to the extent that they can nurture more parent leaders.

What emerges from this study is a conceptual framework that incorporates the importance of a parent's child with disabilities as the center and grounding force for individual advocacy efforts. A similar framework can be applied when a parent assumes a leadership role and presses for broader systems advocacy that will benefit other children

and families. At this level, leaders join with families to dream and act on different futures for their children. (See figure 2.)



Figure 2. Framework for Child and Systems Advocacy

Child-based individual advocacy. The leadership journey begins with parents advocating for their own child.

- **Dream.** Beginning at the child-based individual advocacy level, it is important for a parent to fixate on his or her dream for a different possibility and potential for a child that transcends the prevailing wisdom about children with the child’s particular condition or disability. *Examples:* Silvia dreamed that her son would ride a bike: Graciela could not imagine a future where her

son would not be able to call her “Mom”; and Isabella wanted her daughter to not be a like the deformed vegetable the doctors predicted she would be.

- **Discover.** The next step is for the parent to discover what he or she needs to know and where to get the information. After identifying what they need to know, they can find answers by searching the internet or asking knowledgeable people. *Examples:* Magdalena needed to know where she could get the best services for her daughter; Graciela needed to know if there were any successes for children with autism, and how those successes came about; and Carmen needed to find the best special education attorney
- **Connect.** Effective advocacy is strengthened when there are allies to support the parent’s dream. *Examples:* These advocates identified their allies as family, overt or covert supporters at the school or early intervention programs, advocacy organizations like the PTI, friends, fellow advocates, and others they convinced to take his or her side as an ally. They are ready allies for other families who may need assistance or support in their quest for a better life for their children.
- **Act.** The parent and connected allies can figure out what needs to be done and support each other as they act. Information gathered during the *Discover* step can also guide a parent’s thinking. *Examples:* Oscar learned about mediation and tried out the process to get services for his son; and Carmen figured out what she needed to do and boldly stayed with her plan until she was successful in finding a pro bono lawyer.

- **Grow.** With each success parents become emboldened to advocate even more. Each success spurs parents to dream and continue the cycle of advocacy. Once parents conquer one challenge or obstacle, they continue to set new dreams and expectations. And the cycle for individual advocacy continues with the parent becoming stronger and more confident with every victory. *Examples:* Isabella's decision to not have an abortion and keep her daughter Selena was a defining moment in Isabella's life. This was a story she repeated two or three times and she returns to this decision and victory, each time she pursues a new dream.

Community-based leadership systems advocacy. Becoming an effective advocate for one's child is an achievement in and of itself. After achieving a few successes with child-based advocacy, a few parents may realize that they have the confidence, skills, knowledge and agency to help others. The journey to leadership can follow a similar cycle. The conceptual framework works in a similar way for parent leaders. Again, a leader's own child or other children he or she encounters are at the center of the process – the reason they do what they do.

- **Dream.** These advocates articulated how they dreamed of helping other families and clearly want to see children with disabilities be successful and have better lives. *Examples:* Oscar is determined that others, less fortunate, are not oppressed by the special education system. Initially Carmen wanted other parents to have a place to get together and learn from each other. Now she dreams of creating a parent institute where parents come to learn how to

help their children develop and overcome conditions of their disabilities.

Isabella wants to see the children of the families she serves learn, grow and develop. She lives to see the smiles on the children's faces.

- **Discover.** These leaders continue to build on their knowledge about how systems work to think of new ways for families to get services for their children. They actively search the internet, go to workshops and network with others. *Examples:* Oscar continues to learn more about how to navigate the special education system and delves deeper into the knowledge he needs to help families. Carmen had to find a location for her families to meet. She needs to know what the families want and how to help them get what they want or learn what they want to learn. Isabella needs to figure out how to continue to help all the families who need help while protecting her family life and health.
- **Connect.** All of the parent leaders were able to identify allies they could connect with to get the help their families need. Carmen and Oscar mentioned free legal services. Parent leaders also talked about the PTI being a wealth of information and support. Oscar is comfortable joining with mainstream (nonLatino) allies so that he can bring information back to the Latino communities. Most interesting is the way that these leaders, particularly Isabella and Oscar are embracing and adept at bringing other parents on as leaders.

- **Act.** Isabella dreamed of starting a parent group to help other Latino families. When the group outgrew her home, she enlisted the help of the mayor of her town in locating free meeting space and helping to secure transportation for family outings. The PTI helped her learn how to do workshops for other families and became her employer, giving her programmatic and financial support to follow her dream. Carmen dreams of developing a program to train parents on how to teach their children. By attending training, organizing the parent education group, and seeing other children developing beyond their parents' expectations, Carmen is on her way to achieving that dream.
- **Grow.** The advocates employed by the PTI clearly revel in every victory. As their efforts gain momentum, they continue to dream of what else they can do to grow the family network and see Latino families as a force that can no longer be ignored.

The following table provides key questions for every step in this framework at the individual child-based individual advocacy level and the community-based leadership systems advocacy level.

Table 2

Child and Systems Advocacy: Key Questions for Every Step

Framework Step	Child-Based Individual Advocacy	Community-Based Leadership Systems Advocacy
Dream	What is the future you want for your child?	What is the future you want for (Latino) children with disabilities and their families?
Discover	What do you need to know to be able to create that future?	What do you need to know to be able to create that future?
	Where can you find that information?	Where can you find that information?
Connect	Who are the allies who can support this dream?	Who else supports the same or similar dream?
		Who are potential allies who might support this dream?
Act	What do you and your allies need to do to achieve your dream?	What needs to happen to achieve your collective dream?
	How do you respond to setbacks?	How do you adapt to new opportunities or obstacles?
Grow	Each obstacle you overcome and every victory makes you stronger	Each obstacle your group overcomes and every victory makes you stronger.

Implications for research. Most research on parent engagement is school-based.

However, after almost 50 years of federal policy and mandates for parent engagement

and parent leadership, school based programs are only as successful as those who administer and support these programs. While some schools and communities enjoy the benefits that active parent engagement has on student outcomes, communities like those that this group of parents live in continue to rebuff and oppress Latino parents and continue the hegemonic narrative that children with disabilities and Latino children are “at risk” of failure. This study opens up a number of possibilities for future research.

How Latino parent advocacy and leadership, that emerges in communities where schools are resistant to family involvement, can inform alternative ways to nurture and encourage such systems.

- How parent advocacy and leadership emerges in other traditionally marginalized groups such as African American, low socioeconomic, and/or other immigrant families.
- Comparisons of student outcomes in demographically-matched communities where there is strong Latino parent advocacy vs. weak parent advocacy.
- What Latino families wished schools would understand, and how they want schools to respect and support their dreams.
- How teachers and/or community-based programs can support the development of Latino advocacy and leadership.
- The effects of silencing teachers and other school personnel who wish to ally with families.
- The experience of more recent immigrants.

Implications for action. Understanding this largely untapped power of Latino parent advocacy offers a number of implications for action.

- Community-based organizations like the PTIs, the new state family centers authorized by the *Every Child Succeeds Act of 2015* and family support organizations need to work intentionally to strengthen Latino parent special education advocacy. These parents show that it can be done.
- There is a need to nurture more Latino parent leaders. They have more credibility with Latino families and can be more effective in helping families dream and act for their children with disabilities.
- Some early intervention programs already are already doing a great job in helping Latino families understand how the system works and where to go to get help. Such support needs to be intentional and purposeful. Encouraging and supporting Latino families early can have lasting effects throughout their child's life.
- Whether schools continue to rebuff and resist Latino parent advocacy, there will be families that can see and understand the potential power of their own actions and advocacy. So schools need to embrace this largely untapped energy, and examine what they can learn from Latino families and how they can partner for the mutual goal of successful outcomes for children with disabilities.

Conclusion

I return to something that Fajardo taught me about the power of Latino parent advocacy. She said that the main revelation for her families was simply, “Yes. We have chances!” That there were possibilities for their children with disabilities to have a chance at success was enough to bring in thousands of Latino families to learn about their rights in special education and other possibilities for a successful life for their children with disabilities. I witnessed a whole cultural shift in the communities where Fajardo worked as families understood that the prevailing wisdom, that children with disabilities cannot learn and have no future, was a lie. Once they understood that their children’s chances at a better life depended on their efforts and actions, there were no barriers or obstacles that could stop these parents. The parent leaders in this study had similarly compelling experiences and successes. And they are writing new histories for Latino children with disabilities and their families. They demonstrate how leadership that builds upon dreams and small victories can arise even in oppressive environments. Isn’t it about time the education field joins them in dreaming for a new history full of possibilities for all children with disabilities?

Appendix A

IRB Exemption Letter



Office of Research Integrity and Assurance

Research Hall, 4400 University Drive, MS 6D5, Fairfax, Virginia 22030
Phone: 703-993-5445; Fax: 703-993-9590

DATE: January 2, 2014

TO: Eva Thorp, EdD
FROM: George Mason University IRB

Project Title: [500422-1] Latino Parents as Special Education Advocates: A Narrative Inquiry of Their Leadership Journeys

SUBMISSION TYPE: New Project

ACTION: DETERMINATION OF EXEMPT STATUS
DECISION DATE: January 2, 2014

REVIEW CATEGORY: Exemption category #2

Thank you for your submission of New Project materials for this project. The Office of Research Integrity & Assurance (ORIA) has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations.

Please remember that all research must be conducted as described in the submitted materials.

Please note that any revision to previously approved materials must be submitted to the ORIA prior to initiation. Please use the appropriate revision forms for this procedure.

If you have any questions, please contact Karen Motsinger at 703-993-4208 or kmotsing@gmu.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within George Mason University IRB's records.

Appendix B

Informed Consent Form

Save as **Consent**

Latino Parents as Special Education Advocates: A Narrative Inquiry of Their Leadership Journeys

INFORMED CONSENT FORM

RESEARCH PROCEDURES

I want to understand the stories of Latino immigrant parents of children with disabilities who have become leaders and advocates in special education. I hope to understand how Latino parents rise to leadership positions and support others on their own journeys as special education advocates for their children with disabilities. If you agree to participate in this research, and sign this consent form, I will interview you in person and audio record the interview so that I can create an accurate written transcription of our interview. I will summarize my understanding of your story and I will check back with you about its accuracy so that I can understand how you came to become a special education advocate and what you have learned in the process. I anticipate that the initial interview may take approximately 2-2½ hours. After the first interview, I may need to ask you additional questions so that I have a better understanding of your story. If this is the case, the interview will take place in-person or over the telephone; depending on your comfort level. I anticipate that additional interviews would last between 1-1½ hours. There is a remote possibility that I may request an additional interview of between 1-1½ hours so that I'm sure that I understand your story. However, you are not obligated to commit to additional interviews. If at any time you decide not to continue an interview, you will have the option of allowing me to use the information that you have shared with me, or asking me not to use the information. If you decide to withdraw your consent, all records will be destroyed and none of the information you have shared with me will be used in this study in any way.

RISKS

There are no foreseeable risks for participating in this research.

BENEFITS

There are no benefits to you as a participant other than to further understanding about leadership of Latino parents of children with disabilities.

CONFIDENTIALITY

If you agree to be interviewed, all of the information you provide will remain confidential. Your name and contact information will be given a code during transcription and on any written documents or presentations so that your identity will remain anonymous. Only the researchers will have access to your identifying information. Data collected will be stored on password-protected computers. Once stored information is no longer needed for this study, it will be destroyed.

Appendix C

Interview Guide

I may not ask all of these questions, but may bring them up to help stimulate memories or bring fuller detail to the parent's story. As I fill in details of the parent's narrative, I may have follow-up questions for a later interview.

Introductory questions

1. Please tell me a little about yourself and your family.
2. How did you first find out that your child had a disability?
 - Is this something that you knew or did someone tell you?
 - Do you remember where you were? What did you think/feel?
 - What do you remember about where you lived?
 - What was it like? (describe)
 - Who lived with you? (describe relationships)
 - Who were the important people in your support network? Why?
 - What brought you through this period of your life (resilient factors, sources of support, beliefs)

Experiences with special education

1. What were your first experiences with special education?

2. How did you become an advocate for your child?
3. Was there a time when you felt discouraged or disempowered?
4. Was there a time you felt your power as a parent?
5. What kept you motivated, gave you confidence or restored your confidence?
(beliefs, friends, conviction, encouraging professional

Journey to Leadership

1. Tell me as much as possible about how you came to become a special education advocacy leader?
2. What events were important? (triumphs/setbacks)
3. Who helped?
4. Who presented challenges to your leadership?
5. What meaning do you make of your journey to leadership?

Experiences as a Latino/a Immigrant

1. Did you have any experiences in which you felt being Latino helped you as a parent or advocate?
2. Did you have any experiences where you felt as a disadvantage because you are Latino/a?
3. How do you think your experiences may be different because you are a Latino/a immigrant?

Appendix D

Themes

Theme	I	O	S	M	G	C
Changed whole life/purpose/direction for child						
Will defy low expectations	x	x		x	x	x
Hope/Determination vs. Despair	x	x	x	x	x	x
Spirituality	x			x	x	
Pride in child's accomplishments/triumph	x	x		x	x	x
Allies						
Family		x	x		x	
Parent Training Information Center	x	x	x		x	
Early Intervention		x		x	x	x
Teachers/Professionals		x	x		x	
Employer (non PTI employer)				x	x	
Other	x					x
Antagonists						
Medical community	x	x	x		x	x
Family						x
early intervention			x			
teachers/professionals	x		x		x	x
employer			x			
CPS	x		x			
Obstacles for Families						
Information	x	x	x	x	x	x
Language	x	x	x	x	x	x
Fear and intimidation	x		x	x		
Helplessness and hopelessness	x	x	x	x		x
Meaning/Purpose of Leadership						
Obligation – justice/injustice	x	x	x			
making a difference/change lives for children/legacy	x	x	x	x	x	x
Because of own experiences/successes	x	x	x	x	x	x
So that families see they have agency	x	x	x	x	x	x
Privilege – education/language/knowledge of system		x	x	x	x	x

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Biography

Cheryl Rei Takemoto (BA, Psychology/Sociology, University of California, Santa Cruz; MPA, San Jose State University). has over 20 years of experience managing disability advocacy and information resource programs. Projects funded by the U.S. Department of Education include personnel preparation, model demonstration projects, RSA-funded parent training information, state parent information and resource center (NCLB), and Steppingstones to Technology. Much of Takemoto's work has focused on building partnerships that increase understanding of the myriad of problems families of children with disabilities face – especially those without the knowledge or resources it often takes to build a successful life for their children – the most vulnerable children of all.

Takemoto served on the President's Commission on Excellence in Special Education, assuming a role as a reality check that bridging research, expert testimony and ideals to what really happens families and children. She served on a number of national and state advisory boards related to special education. She has strived to create new ways to address old problems and complaints while fully embracing her charge to improve results for students with disabilities. She is co-author on the 4th Edition of *Negotiating the Special Education Maze*.

Currently, Takemoto works at New Editions Consulting where she directs contracts to support to the Interagency Committee on Disability Research (ICDR) and the National Clearinghouse on Rehabilitation Training Materials (NCRTM). She is also a subject-matter expert on reentry for people with disabilities who have been involved in the criminal justice system on a subcontract. She continues to help families advocate for their children and is the current president of the Costello Syndrome Family Network.