Title
The Effects of A Parent-to-Parent Advocacy Program for Low-resourced Minority Parents of Children With Autism Spectrum Disorder (ASD) and Other Disabilities: Empoderando Padres

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Publication Date
2018

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The Effects of A Parent-to-Parent Advocacy Program for Low-resourced Minority Parents of Children With Autism Spectrum Disorder (ASD) and Other Disabilities:

Empoderando Padres

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of Philosophy in Special Education

by

Paul Luelmo

2018
ABSTRACT OF THE DISSERTATION

The Effects of A Parent-to-Parent Advocacy Program for Low-resourced Minority Parents of Children With Autism Spectrum Disorder (ASD) and Other Disabilities:

_Empoderando Padres_

by

Paul Luelmo

Doctor of Philosophy in Special Education

University of California, Los Angeles, 2018

Professor Connie L. Kasari, Chair

This pilot study was designed to rigorously test, using randomization, a parent-to-parent advocacy mentorship program for parents of children with ASD within a low-income, mostly Latino population. The study design includes randomization to a parent IEP advocacy mentorship or to receive the program materials after intervention. Specifically, this dissertation study addresses the following research questions: RQ1: Does a parent-to-parent advocacy
mentorship program for parents of young children with ASD increase their advocacy knowledge (i.e. their rights under IDEA)? RQ2: Does a parent-to-parent advocacy mentorship program for parents of children with ASD increase their family empowerment and family outcomes (i.e. their likelihood to exercise their rights under IDEA)? RQ3: What are the strengths and challenges of implementing a parent-to-parent mentorship program within an urban low-income, mostly Latino context? Therefore, this dissertation study examines the effects of PARENT- a parent-to-parent advocacy mentorship program for parents of children with ASD and other disabilities—on parent empowerment and advocacy knowledge. A total of thirty parent enrolled in the study Parents and were randomly assigned to receive the PARENT intervention or to a CONTROL group. Parents in the PARENT group (n=15) participated in 3 one-on-one meetings (biweekly from January 2018-March 2018) with a community Parent Mentor (PM) at the parent’s home or a public space. RESULTS: There was a statistically significant increase in parents’ IEP advocacy knowledge (i.e. their rights under IDEA) for parents in the PARENT group when compared to the CONTROL group. There were no statistically significant differences between the PARENT group and the CONTROL group for family empowerment or family outcomes. Qualitative interviews were conducted with 9 participants in the PARENT group. These parents reported feeling very grateful for the information they received and found the program to be very effective. Further directions are discussed, such as simplifying the logistics of intervention implementation (e.g., session schedules).
The dissertation of Paul Luelmo is approved.

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2018
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KEY TO ABBREVIATIONS

ASD: Autism Spectrum Disorder
FE: *Fiesta Educativa* - A community-based parent advocacy organization based in Los Angeles.
FES: Family Empowerment scale
FO: Family outcomes measure
IDEA: Individuals with Disabilities Education Act
IEP: Individualized education program
JASPER: Joint Attention, Symbolic Play Engagement & Regulation
PARENT: Parent-to-parent advocacy mentorship program for parents of children with ASD
PM: Parent Mentor
VITA

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2017 Advocacy in Special Education During the School-Years, Community-Partnered Participatory Research Annual Autism Conference, Healthy African American Families & The Center for Autism Research and Treatment at University of California, Los Angeles, March 17th, 2017

2016 Autism and Parent Advocacy in the Special Education System, Fiesta Educativa Annual, Autism Conference, Mexican Consulate General of Los Angeles, October 27th

CONFERENCE ACTIVITY

2017 Multiple Perspectives on how a Change in the Law Affected the Provision of Mental Health Related Services, Council for Exceptional Children Annual Conference, Boston, MA, April 19-22.

2017 “I Thought the Regional Center Was a Deportation Trap” Undocumented Mexican Mothers of Children with Autism and Barriers to ASD Services, Special Education, Disabilities, & Developmental Risk 11th Annual Conference, University of California, Santa Barbara, CA, January 27-28

2017 A Cross-Site Examination of Barriers to Diagnosis and Service Utilization for Autism Spectrum Disorder (ASD) Among Latino Families in California International Meeting for Autism Research San Francisco, CA, May 10-13

2016 Teachers’ Perceptions of Latino Parental Involvement Within an Urban Low-Income Charter School Context Council for Exceptional Children Annual Conference, St. Louis, MO, April 13-16
CHAPTER 1: INTRODUCTION

Maria grew up in a Zapoteco rural community, an indigenous pre-Columbian civilization from Oaxaca, Mexico. In the 1990s, an economic crisis and the North American Free Trade Agreement (NAFTA) decimated agricultural production (Browning, 2013) in her farming community. Millions of Mexicans living in rural communities like hers were forced to migrate to Mexican border cities and the United States in search of work. Maria was one of the many Zapotecas who migrated to Los Angeles, California, where an estimated 51,000 Zapotecas and Mixtecas (a related ethnic group) from Mexico now reside (U.S. Census, 2010). Maria’s first language is Zapoteco; a language spoken by about half a million people in Mexico (Mexico, Census, 2010). While she has very little formal education, she managed to learn Spanish while growing up in Mexico. Her ability to speak and understand Spanish has been useful while living in Los Angeles; she does not speak any English.

Maria has been working in the sewing industry since her arrival in the U.S., earning about $0.25 cents per piece of sewing (about $50 a day & below minimum wage). Maria and her 12-year-old son live together in a studio apartment in a high-crime low-resourced urban neighborhood in L.A. The father’s child, also of Mexican origin, abandoned them both many years ago. Her child, Jose, is now a 7th grade student and was recently identified as being on the autism spectrum and diagnosed as having attention deficit hyperactivity disorder (ADHD). Maria receives frequent calls from the school staff about Jose’s behavior. Jose often runs out of the classroom, interrupts teachers, and uses profanity in and out of class. As a result, Maria was invited to attend an Individualized Education Plan (IEP) meeting for Jose. While her work schedule is not flexible and oftentimes she is disciplined for missed work, she managed to attend the meeting.
The Individuals with Education Act (IDEA)

The IEP meeting is a federally mandated protocol for addressing the needs of children with disabilities ages 3 to 21 in the public school system (Abernathy, 2009). During the IEP meeting, Maria was expected to engage in the discussion and to know her legal rights regarding the IEP. The bilingual (Spanish speaking) special education teacher started the meeting by giving Maria two different booklets in Spanish. One is titled “A Parent’s Guide to Special Education Services (Including Procedural Rights and Safeguards)” and the other “Least Restrictive Environment (LRE).” While these are informative booklets in Spanish, much of the content of these booklets is based on the U.S. federal law called the Individuals with Disabilities Education Act (IDEA), which includes complex legal and educational terminology that can be hard to understand. Since Maria has very little formal education she cannot read nor understand these materials. Additionally, Maria is expected to have a general sense of the Least Restrictive Environment (LRE) for Jose, that is, to the maximum extent appropriate children with disabilities are to be educated with students without disabilities (e.g., special day class vs. inclusion in general education). She is also expected to listen and understand Jose’s academic and behavioral strengths and challenges (e.g. oral reading fluency, grade-level reading comprehension benchmark, etc.). Most importantly, Maria reported feeling intimidated by being surrounded by four different school professionals at the meeting: a special education teacher, a school principal, an English teacher, and the school psychologist. The special education teacher is expected to explain the purpose of the meeting to everyone, have a clear agenda, and recommend appropriate placement and services for Jose. Maria is quiet during the entire duration of the meeting. It is clear that she does not understand her role and thinks the real reason for the meeting is that Jose has been getting in trouble. The English teacher determines that Jose needs
to be removed from a general education class to a self-contained class, where he will be in a small class setting with a special education teacher during the duration of the school day. Maria, not knowing what options she has, agrees to the English teacher’s recommendations and everything else that is discussed in the meeting without ever questioning anyone.

CHAPTER 2: REVIEW OF THE LITERATURE

Current State of Specialized Services in Public Education

While the story of Maria is anecdotal, it is not unique. The student population in the public school system in the United States is becoming increasingly racially, ethnically, and linguistically diverse. In 2011, nearly 24% of school-age children in the United States were the children of immigrants (Migration Policy Institute, 2011), most frequently from Mexico or Central America (Hernandez, Denton, & Macartney, 2008). In addition to the challenges faced by all parents of children with disabilities, immigrant parents, such as Maria, face additional challenges to understanding and navigating the special education system and related legislation. In order to effectively advocate for their children, which can be broadly defined as “the act of speaking and acting on behalf of another person or group of people to address their preferences, strengths, and needs” (Wolfensberger, 1977), parents need to understand complex special education laws and regulations. Due to a multitude of factors, parents of immigrant-origin students, and Latino parents may be at a disadvantage when advocating for services and educational placements for their children. For instance, in Maria’s case, Latino immigrant-origin parents, whose primary language is not English appear to be particularly affected by factors such as difficulty making meeting times during school hours, a perception that schools do not make parents feel welcome, and meetings being conducted only in English (Turney & Kao, 2009). Like Maria, there are many Latino parents who work in low-wage, inflexible jobs that may not
allow them to attend school meetings and events (Ramirez, 2003). Some parents may be undocumented, which can add more barriers. Furthermore, some immigrant-origin parents are intimidated by a complex educational system that may work in different fashion from the systems in their countries of origin (Ramirez, 2003). Low-resourced and ethnic minority families are commonly described as “hard to reach,” and are less likely to participate in the IEP (Munn-Joseph & Gavin-Evans, 2008). While not all immigrant children are under-resourced and not all are disadvantaged, research suggests that immigrant-origin students, Latino students in particular, are more likely to live in poverty and be at higher risk of academic difficulties than White students (U.S. Census, 2010; Carhill, Suárez-Orozco & Páez, 2008).

**Special Education and Minority Status.** IDEA focuses on the public education of K-12 children or children 3-21 of age and also infants and toddlers birth through age 2. Because the earlier a child gets a service, the more likely there are better child outcomes, it becomes critical that parents become knowledgeable about their rights in the early years. In the school year 2013-2014, students with disabilities comprised 13% of the total public school enrollment (National Center for Education Statistics, 2016). Some researchers suggest there is over-representation of minority children in special education (Skiba et al, 2015) while others provide contrasting data suggesting under-representation or representation on par with the overall population (Morgan et al, 2015). The debate seems to hinge on what secondary data sets are analyzed, and the particular analytic methods employed. Recent national data (2013-2014) suggest that some minority groups may be over-represented in special education (17% American Indian/Alaska Native students and 11% Pacific Islander compared to 1% and 5% general education, respectively while others are under-represented, 13% White students in special education versus 50% in general education (NCES, 2016). These national data may not reflect some local districts;
therefore, parents must play an integral role in the eligibility process of their children with respect to special education services and placement. Because low-resourced, minority, and immigrant-origin parents may be most vulnerable to the under or over-representation of their child in the special education system, the proposed study targets low income, minority and immigrant origin parents in a school district that is overwhelmingly Latino and low income. LAUSD serves 14,000 children with ASD, is 75% Latino, and 80% free and reduced lunch eligible.

Background

The last ten years have witnessed an uptick in the numbers of programs developed to address parent advocacy and specifically to help parents navigate the special education system. In response to the authorization of the IDEA in 2004 which mandates parent involvement, many programs emphasize parent participation. Of 265 papers published over the past ten years on parent advocacy, only 15 are peer-reviewed and focused on special education K-12 programs. Important aspects of these papers are highlighted below.

Definitions and models of parent advocacy. A first issue is how studies have defined parent advocacy. A majority (9 of 15) included a definition for special education parental advocacy corresponding to three subthemes: (a) general definition and models of parent advocacy, (b) collaborative parent advocacy, (c) passive parent advocacy, (d) adversarial parent advocacy. Each of these is discussed in greater detail below.

Special education advocacy is defined similarly across studies. One definition illustrates the broad consensus of parent advocacy: "Individuals with knowledge of both special education law and advocacy skills to assist parents in working with the school system” (Burke, 2013, pg. 228). Within this general definition of special education advocacy, different models emerge in
the research literature. I synthesize these models of parent advocacy into three broad categories: collaborative, passive, and adversarial. In the broad “collaborative advocates” model, parents described their relationship with professionals at the school as one established in mutual trust and partnership. Parents in this model formed close relationships with educators and trusted them (Lalvani, 2012; Rehm et al 2013). Collaborative parents were also seen as leader advocates or parents who had strategies in navigating the system (e.g. requesting assessment results before the meeting). Also called “leader advocates,” collaborative parents negotiated for goals and services and were willing to compromise (Rehm et al, 2013). In one study focused on fathers, collaborative fathers are referred as “active IEP team members by partnering up with their children mothers, collaborating with the education team, advocating for their needs, and learning the system” (Mueller & Buckley, 2014, pg. 47).

“Passive parents” were also commonly discussed in the literature. These parents, also called “Grateful-Gratifier parents” “engendered good will by appealing to educators’ desires to make a difference in students’ lives, and by being appreciative of assistance offered” (Rehm, et al 2013, pg. 1383). In other words, passive parents were willing to accept any help offered by school professionals, with little resistance, and were less likely to inquire about educational placement or services.

Adversarial parents or “high profile” parents can be described as a combative category of parent advocacy. In this model, parents see their relationship with professionals as contentious and marked by enduring conflict (Lalvani, 2012; Hess, Molina & Koleski 2006; Nespor & Hicks, 2010). Parents in this category of parental advocacy emphasized extensive services for their children and often hired lawyers to advocate on their behalf (Rehm et al, 2012; Rehm at al, 2013). Parents that needed to monitor or oversee professionals fell into this
category; these parents could be seen as those who used sophisticated knowledge about IDEA and the human and financial capital to more directly advocate on behalf of their children (Lalvani, 2012; Trainor, 2010).

**Barriers and helpers to parent advocacy.** The second theme explicitly defined in 8 of the 15 articles was barriers and supports for parent advocacy in special education. Extant literature is clear in establishing that parent participation in the IEP process is shaped by access to cultural and social capital resources (Trainor, 2010). Social capital refers to the socio-economic status (SES; e.g., parents’ level of education), and parents’ cultural or linguistic background (Ryndak, Orlando, Storch, Denney & Huffman, 2011). More importantly, there is a strong consensus that higher-SES parents are better able to understand and navigate the special education system as compared with lower-SES parents (Lalvani, 2012; Munn-Joseph & Gavin-Evans, 2008). A qualitative study involving 33 parents of children with disabilities from diverse backgrounds found that parents from middle and upper-middle class backgrounds had greater understanding of special education laws and the range of learning environments that can be considered for children with disabilities than did lower-income parents (Lalvani, 2012). On the other hand, parents from lower-SES backgrounds were less familiar with special education laws, and for the most part unaware of the range of educational environments that can be considered for children with disabilities (Lalvani, 2012; Hicks & Nespor, 2010). Likewise, most of the parents in the lower-SES group were unaware of the concept of a least restrictive environment (LRE). As a result, children in the lower-SES group were educated in more restrictive settings (i.e. special education classes) than were children with higher-SES parents (Lalvani, 2012). More importantly, higher SES parents reported that they spent “inordinate amounts of time, effort, and resources in order to effectively negotiate the special education system” (Lalvani, 2012. pg. 479).
For instance, one parent reported hiring a lawyer and getting the school district to pay $100,000 for her son’s tuition and transportation to a private school in a different town (Rehm, et al, 2013). While lower-SES parents also engaged in these efforts, they were more likely to be restricted by work schedules, lack of financial resources, language barriers and lack of understanding about their child’s educational rights (Lalvani, 2012; Burke & Goldman 2015). Also, minority low-income families report not feeling included in the IEP meetings (Hess, Molina, Kozleski, 2006).

Similarly, social capital is also defined as “relationships and social networks among people that afford the interchange of information and cultural goods (i.e. cultural capital) economic capital, and additional social capital” (Rehm, 2013, pg. 37). While some of the reasons behind the discrepancy on parent advocacy by parental SES may be obvious (e.g. more money makes it easier to hire an attorney to advocate for services), other reasons are related to cultural capital. Cultural capital “consists of material items as well as disposition and knowledge that inform the way a person thinks and act” (Rehm, 2013, pg. 36). In one study in California, the authors found that parents with social and cultural capital were able to leverage public education resources and obtain advantageous resources for their children through special education (Ong-Dean, Daly & Park, 2011). Specifically, their social capital allowed them to get reimbursement claims in due process hearings (i.e. they had the financial resources to pay costs upfront). Their cultural capital allowed them to have persuasive parent testimony during hearings (Ong-Dean, Daly & Park, 2011). Together, social and cultural capital allows for advantageous pulling of resources from the public school system for high-income parents. On the other hand, the lack of social and cultural capital can place barriers to advocacy for low-resourced minority parents.

**Strategies for effective parent advocacy.** The third theme identified in 10 of the 15 articles was a description of promising strategies for parent advocacy in special education. This
included model programs for increasing effective parental advocacy, collaboration (i.e., building
trust, mutual respect and cooperation amongst all stakeholders in the IEP meetings) (Mueller &
Buckley, 2014) and inclusion models in special education. Five of the 15 articles mentioned
different examples of model parent advocacy training programs. The Special Education
Advocacy Training (SEAT) is a federally funded program involving 230 hours of coursework for
parents (115 hours of instruction and 115 hours of practicum (Burke et al, 2013). The trainers in
this program were attorneys and advocates. SEAT has been evaluated across three cohorts and
144 participants. The researcher’s objective was to increase participant knowledge of special
education advocacy skills and special education law. However, as the authors noted, some of
main outcomes of the program are still in the analysis phase. Other important limitation of this
program is that the SEAT’s rigor may discourage underrepresented, minority groups from
participating (Burke, 2010). Definitively, more formative and summative assessments are needed
to evaluate its effectiveness (Burke et al, 2013).

The Volunteer Advocacy Project (VAP) is another parent advocacy program. The
purpose of the VAP is to train special education volunteer advocates based on 40 hours of
coursework and one shadowing session. The trainers are diverse speakers (professors,
community members, parents and attorneys); outcomes are measured by linking one volunteer to
four families of students with disabilities (Burke, 2013; Burke, Mellon & Goldman, 2016). In
general, 244 individuals have graduated from the VAP across eight cohorts. Participants showed
increases in special education law and advocacy skills (according to a 40-item pre/post survey).
The VAP was evaluated using quantitative (summative, formative and long-term surveys) and
qualitative (open-ended responses in the summative evaluation sources of data; Burke, Mellon &
Goldman, 2016) methods. According to these measures, VAP was effective in providing
participants with support, recruitment, completion rates, participant satisfaction and sustainability (Burke, Mello & Goldman, 2016). Limitations of this program include a low response rate at a follow up time point. However, the most significant qualifier is that 77% of the participants were White and the majority attended some college or were college graduates. Therefore, this study fails to address the need of increasing special education parental advocacy for low-resourced minority parents.

A third evidence-based model of parent advocacy in special education is the Parent Advocacy Coaching (PAC) program. In this program, the researchers looked at longitudinal change in a children’s intervention program in a sample that was 44% Latino. Results found the program to be effective in increasing services for children. However, the focus of this program was to understand the role of child characteristics, family demographics, and parent cognition in the use of services in autism spectrum disorders, and not to evaluate the advocacy program itself. Furthermore, this study only focused on families impacted by Autism and 45% of the sample had incomes of $75,000 or above (Siller, Reyes, Hotez, Hutman & Sigman, 2014). These are important limitations because this study also fails to address the need of increasing special education parental advocacy for low-income parents and fails to include families affected by other disabilities.

Finally, another model for increasing parental advocacy and leadership is the Parents as Collaborative Leaders (PACL) program. In this program, parents from across the U.S. engaged in an advocacy and leadership internship at the local, state and national level (Sheperd & Kervik, 2016). In this program, a parent was paired with a mentor who helped the parent engage in various advocacy and leadership activities (e.g. one parent created support group for parents focused on supporting children with learning disabilities). Using qualitative methods (i.e.
interviews & document reviews) the authors found their program effective in increasing parental advocacy and leadership in their communities, state, and national level (Sheperd & Kervik, 2016). Mentors of the parents reported that parents made contributions to policy and practice at the local, state and national level. However, this study has important limitations. First, the follow-up response rate was very low (12 out of the initial 33 participants) (Sheperd & Kervik, 2016). The most significant limitation that is not adequately addressed by the study authors is that 76% of the participants were White and SES is not addressed in the study.

**Special education class v. inclusion setting.** Inclusion of students with disabilities in general education settings (i.e., general education classroom) has been shown to have a positive effect on some children with a disability and also on the general education student population (Barclay et al, 2006). Hence, it is very important that inclusion is discussed during the IEP meetings and as part of the federally mandated least restrictive environment (LRE). Nonetheless, the literature shows that school professionals do not usually consider inclusion for students with disabilities, unless parents initiate the conversation (Lalvani, 2012; Ryndak, Orlando, Storch, Denney & Huffman, 2011). This may be particularly important for low-resourced parents who may have less knowledge of different placements for their children. Research shows that parents from higher SES backgrounds often know more about inclusion as a possibility for their children, and as a result are more likely to advocate for inclusion for their children (Ryndak, et al 2011; Nespor and Hicks, 2010; Denney & Huffman, 2011; Lalvani, 2012; Sheperd and Kervick 2016). It is well established that parents from middle- and upper-middle class backgrounds commonly have greater understanding of special education laws and the range of learning environments (i.e., inclusion versus other placement options) that can be considered for children with disabilities (Lalvani, 2012). For example, all the parents from higher-SES backgrounds in
Lalvani’s study (2012) were aware of inclusive education in contrast with parents from lower-SES backgrounds who were less familiar with special education laws. And, a majority of the lower-SES parents were unaware of the least restrictive environment (LRE) concept. Perhaps due to limited knowledge of the LRE concept, children in the low-SES group were educated in more restrictive settings (i.e. special education classes) than the children with high-SES parents (Lalvani, 2012). Importantly, Los Angeles Unified School District, the second largest district in the U.S. has a modified consent decree that expects schools to include more children with disabilities in the general education classroom. This is important, because parents from low-resourced backgrounds need to know the range of educational options available for their children in order to effectively advocate for the most appropriate placement.

Summary

Overall, the literature suggests that there is broad consensus in the definition of parent advocacy in special education. Namely, parent advocacy in special education can be generally defined as “parents with knowledge of both special education law and advocacy skills to assist parents in working with the school system.” (Burke, 2013, pg. 228). If we framed this definition around the case of Maria, two dimensions of parent advocacy emerge. First, Maria needs to have access to information about and understand the special education laws as they relate to her child, Jose, in the United States. The literature shows that special education laws are complex, and parents need specialized training that is easy to understand in order to effectively advocate for their children. Second, Maria needs to have the advocacy skills or attitudes to ask for the appropriate placement and services for Jose. While the school system is hampered in helping Maria to increase her social and cultural capital, it can do more in terms of providing Maria with the advocacy tools she needs. There are three actions that school professionals can do to help
Maria advocate for her child. First, they can host a culturally sensitive program (e.g. with oral instead of written information) for low-resourced racial and ethnic minority parents, such as Maria, focused on special education laws and regulations. Second, they can provide Maria with the explicit training regarding her role and the roles of other professionals during IEP meetings. Third, school professionals can model how to ask the right questions, and more explicitly show Maria the array of educational placement and services available to Jose.

**Gaps in the Research**

Given the increasingly diverse student population in the United States, there is critical need to conduct parent advocacy in special education research that is more inclusive of low-resourced, minority and immigrant-origin communities. Most of the current research in the field is focused on White middle class families. Second, we need to conduct more rigorous research to identify effective advocacy training programs. To this end, it is notable that none of the reviewed parent advocacy programs utilized a rigorous methodology to test the effects of the program. The gold standard for determining efficacy in program development remains the randomized controlled trial (RCT), and these are increasingly being used in school settings (Kasari & Smith, 2013). RCTs protect against bias, and help to move the field towards the inclusion of evidence based practices in schools especially when RCTs are applied to authentic, school programs. While RCTs have not been applied to special education parent advocacy programs, they have been used in other fields. For example, a seminal study of diabetes in children found that parent-to-parent mentoring programs in the context of a clinic-based program showed statistically significant positive gains on measures of coping, attitude, and progress on addressing problems compared to a control group (Singer et al., 1999).

Parent to parent mentoring
Other studies suggest that parent-to-parent interventions may be effective in supporting parents of children with a variety of disabilities (Kerr & McIntosh, 2000). In one study, parent mentors provided social support to parents of children who were ill. Parent mentors in the study provided informational support, such as tips for travel, school, and how to advocate for their child. The parent mentors reported feeling empowered (Sullivan-Boyai & Lee, 2011). Parent mentors may be specially qualified to develop their own curriculum. This approach is based upon a model of empowerment that emphasizes that parents, working together, can affect meaningful change in their lives (Wright & Wooden, 2013). Hence, parent-to-parent mentorship suggests an enhanced vision for parent leadership and engagement (Shepherd & Kervik, 2016).

An important goal for future research is to rigorously test whether parent-to-parent mentorship programs can increase parental advocacy in special education for low-resourced, minority and immigrant-origin families. The proposed study attempts to contribute to the research base by piloting a parent-to-parent advocacy intervention study within a mostly Latino urban low-resourced environment.

CHAPTER 3: CURRENT RESEARCH STUDY

This study is designed to rigorously test, using randomization, PARENT: a parent-to-parent IEP advocacy mentorship program for parents of children with ASD within a low-income mostly Latino population. The comparison is between parents/caregivers randomly assigned to receive the PARENT intervention or not. Specifically, this study answers the following research questions:

RQ1: Does a parent-to-parent advocacy mentorship program for parents of children with ASD increase their IEP advocacy knowledge (i.e. their rights under IDEA)?
RQ2: Does a parent-to-parent advocacy mentorship program for parents of children with ASD increase their family empowerment (i.e. their likelihood to exercise their rights under IDEA)?

RQ3: What are the strengths and challenges of implementing a parent-to-parent mentorship program within an urban low-income minority context?

Hypotheses

RQ1: The parent-to-parent IEP advocacy mentorship program for parents of children with ASD will increase their IEP advocacy knowledge (i.e. their rights under IDEA) when compared to the control group.

RQ2: The parent-to-parent advocacy mentorship program for parents of children with ASD will increase their perceptions of family empowerment when compared to the control group.

Methods

Participants

Parents or caregivers. Parents/caregivers (N=30; 97% female) of a child with an IEP were recruited from parents participating in the JASPER in the classroom study. The JASPER in the classroom study targets urban, low-income schools (as defined by free/reduced lunch), and mostly minority participants. All if the schools in the study are located in East and Central Los Angeles, and all of them are part of Los Angeles Unified School District. Recruitment flow is presented in Figure 1. The inclusion criteria were 1) parent of child with ASD or other disability; 2) child had an active IEP within Los Angeles Unified School District; 3) parent spoke English or Spanish; 4) parent had 4 or less years of experience with the special education system; and 5) household income was considered low-income (250% below federal average income level). Exclusion criteria included 1) parents who had more than 4 years of experience participating in
the IEP process; and 2) parents who spoke a language other than English or Spanish. A total of 4 parents in the PARENT group dropped during the intervention phase. A total of 2 parents in the CONTROL group dropped from the study during the intervention. Hence, this study presents data on 24 parents. Parents randomized to the PARENT group (n=11; 90% female) had a median family household income of $10,000-19,999 and ranged from “Less than $9,999” to “$70,000-79,999.” Parents’ higher level of education completed ranged from “Elementary/Middle School” to “College/Technical School.” On average, parents in the PARENT group, had attended or graduated from High School. Most participants in the PARENT group self-identified as Latino/Hispanic (100%) and a majority spoke Spanish (67%). Parents randomly assigned to the CONTROL group (n=13; 100% female), had a mean family household income of $20,000-29,999, and ranged from “Less than $9,999” to “$50,000-59,999.” Parents’ higher level of education completed in the CONTROL group ranged from “Elementary/Middle School” to “College/Technical school.” On Average, parents in the CONTROL group, had attended or graduated from High School. Most participants in the CONTROL group self-identified as Latino/Hispanic (93%) and a majority spoke Spanish (67%). All of the parents in the study had experienced at least one IEP meeting. Descriptives for the dissertation study sample are presented in Table 1. Household descriptive statistics are presented in Table 2.
Figure 1. Recruitment Flow Diagram

Table 1: Descriptive Statistics (N=24)  
<table>
<thead>
<tr>
<th></th>
<th>PARENT Group (n=11) (Percentage)</th>
<th>CONTROL Group (n=13) (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent’s Gender</td>
<td>Male 1 (9%)</td>
<td>0 (0.0%)</td>
</tr>
<tr>
<td></td>
<td>Female 10 (91%)</td>
<td>13 (100%)</td>
</tr>
<tr>
<td>Parent’s Language</td>
<td>English 3 (27.5%)</td>
<td>4 (30.5%)</td>
</tr>
<tr>
<td></td>
<td>Spanish 8 (72.5%)</td>
<td>9 (69.5%)</td>
</tr>
<tr>
<td>Parent’s Education</td>
<td>Elementary/Middle 3 (27.5%)</td>
<td>2 (15.5%)</td>
</tr>
<tr>
<td></td>
<td>Some High School 1 (9%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td></td>
<td>High School Graduate 3 (27.5%)</td>
<td>6 (46.5%)</td>
</tr>
<tr>
<td></td>
<td>Some College 0 (0.0%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td></td>
<td>College Graduate or Technical</td>
<td></td>
</tr>
<tr>
<td></td>
<td>School 4 (36%)</td>
<td>3 (23.5%)</td>
</tr>
<tr>
<td>Parent’s Race/Ethnicity</td>
<td>Latino 11 (100%)</td>
<td>12 (93%)</td>
</tr>
<tr>
<td></td>
<td>Southeast Asian 0 (0.0%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Parent’s Age Mean</td>
<td>34.4 (SD= 5.5)</td>
<td>34.3 (SD= 7.4)</td>
</tr>
<tr>
<td>(SD)</td>
<td>Range 26-45</td>
<td>Range 23-42</td>
</tr>
</tbody>
</table>
Parent Mentors. Five Parent Mentors (PM) (N=5) were recruited in partnership with *Fiesta Educativa*, the community-based parent advocacy organization. Parent mentors are experienced and involved parents of children with disabilities. Specifically, the inclusion criteria for the Parent Mentors were: 1) bilingual (Spanish/English) parent of at least one child with a disability; 2) at least 3 years of experience with the IEP in the public-school system; 3) highly engaged with the community, as referred by FE parent coordinators (e.g., Volunteering with FE and community-based events). Initially, four parents mentors (n=4) were recruited and trained during the months of August 2016- December 2017. A refresher training took place in October 2017 before the start of the intervention study. However, as the intervention started one of the PMs fell ill, resulting in her withdrawal of the study. As a result, a fifth, PM was recruited and trained separately at the beginning of the intervention phase in early January, 2018.

Procedure
The development of the PARENT intervention employed community-partnered participatory research methods (CPPR). Community-partnered participatory research is a bidirectional approach to conducting research where researchers partner with a community-based organization to design and implement research studies (Wells & Jones, 2009). For this study and other Kasari Lab studies (e.g., Mind the Gap Study), we have partnered with *Fiesta Educativa* (FE). FE was founded in California in 1978 to support and inform Latino families to navigate the special education process effectively and to obtain appropriate services for their children (Fiesta Educativa.org).

**Community Partnered Participatory Research Principles:** This dissertation study followed the principles of community participatory research (Minkler and Wallerstein, 2002). The underlying principles are the following:

1) The project seeks to enhance the community’s welfare through empowering the community to address its own health issues. (Minkler and Wallerstein, 2002). Members of FE have active roles in addressing the autism service gaps that exists in the Latino community. Moreover, they empower Latino parents to advocate for their kids with disabilities through their different programs. For example, the IEP Empowerment Program that the researcher helped develop, focuses on teaching advocacy skills to parents who are unfamiliar with the IEP of their child. As part of this IEP Empowerment program, the researcher of this study, facilitated multiple community-based workshops for parents over the span of 2 years.

2) The project is designed to increase community academic knowledge of the issue (Minkler and Wallerstein, 2002). In keeping with the principles of CPPR, professors, researchers, and post-doctoral trainees have presented at numerous community-based
events in order to increase community academic knowledge of autism and parent advocacy. For example, the researcher of this study, played a key role in planning and organizing as well as inviting academics to present at three different annual Autism Conferences at the Mexican Consulate General of Los Angeles. These conferences were designed to increase academic knowledge of autism, by bringing academics and community together. For example, in one of these conference, a UCLA professor was invited to present the latest research on social communication in children with autism. Likewise, the researcher of this study presented the latest research on service gaps and the importance of parent advocacy at all of the three different conferences.

3) Community and academic participants will be involved in all project phases, including planning, implementation, research and evaluation, analysis, interpretation, and dissemination. (Minkler and Wallerstein, 2002). The researcher of this study formed a workgroup with Fiesta Educativa members. This workgroup was co-led by a the researcher and a parent coordinator at FE. Additionally, interested FE PM formed part of this workgroup. All of Workgroup Committee (WC) were knowledgeable about parent’s rights in the IEP. Also, all of the WC members were committed to the goals of increasing parent advocacy skills in the IEP. The WC was formed by the lead researcher and a FE Lead Parent Coordinator ad well as the Parent Mentors. The workgroup met regularly during August 2016- March 2018. The workgroup committee had an oversight role over the planning, implementation, research and evaluation. For instance, the WC had oversight and made final decisions over the main outcome measure (i.e. IEP Advocacy test) of this study. Likewise, the WC, made final decisions on the materials of the intervention and the intervention protocol
of this study. In keeping with the principles of CPPR, the workgroup committee will continue to be part of the research process by providing input in academic research papers for publication. The Workgroup Committee will also set a policy for authorship of papers from the project. This phase includes the analysis, interpretation, and dissemination of this dissertation study.

4) The project may consider the political, social, and economic determinants of the main issue addressed by the project. This dissertation study considered the current political, social, and economic determinants of the main issue of IEP advocacy addressed by this research. This dissertation study is focused on an understudied population (i.e., racial/ethnic minority, low income parents of children with disabilities). Given that the study took place in a Southern California location with large number of Latino parents, considerations included language and cultural considerations. For example, the IEP Meeting videos created for this intervention were conducted in Spanish, using Latin American cultural expectations. Likewise, given the current strong anti-immigrant rhetoric in the U.S., the Workgroup made the decision to avoid any questions related to immigration status in the study. Also, it was decided that recording of sessions was to be avoided, given the fear experienced by the immigrant community at the moment.

5) Mechanisms to voice and resolve differences of opinion or concerns about fairness of the process will be implemented through the Workgroup, and each participating agency will have one vote. (Minkler and Wallerstein, 2002). The workgroup in this study consisted of two agencies: the University of California, Los Angeles, and Fiesta Educativa. The mechanism to voice and resolve differences of opinion involved the researcher of the
study and the Lead Parent Coordinator at FE, and the Parent Mentors. For example, the
duration of the intervention was discussed during the Workgroup meetings, reaching an
agreement as a group (i.e. Intervention consisted of 3 1-hr sessions).

6) Dissemination of the research results will be the responsibility of all project participants,
and academic and community partners will have opportunities for presentations and
publications, under the governing conditions of the Workgroup. (Minkler and Wallerstein,
2002). The dissemination of this dissertation study’s results were discussed in the
Workgroup. Additionally, future research papers for publication will include FE’s input
as well as authorship of those involve.

The IEP Advocacy Mentorship Program. The PARENT intervention was developed
based on a research of the literature, a review of the IDEA law, and feedback from FE’s
community Parent Mentors. The IEP Advocacy Mentorship Program consisted of three 1-hour
sessions. (Figure 2).

Figure 2: PARENT- IEP Advocacy Mentorship

<table>
<thead>
<tr>
<th>Mentorship Session</th>
<th>Advocacy Activity (IEP Checklist)</th>
<th>Session Routine</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: IEP Basics</td>
<td>Section 1:</td>
<td>1. Check-in (5-10 min)</td>
</tr>
<tr>
<td></td>
<td>a. What is an IEP?</td>
<td>2. Review of IEP checklist and child’s IEP (20 min)</td>
</tr>
<tr>
<td></td>
<td>b. The IEP Meeting</td>
<td>3. Watch IEP Advocacy Module 1 on tablet (7-14 min).</td>
</tr>
<tr>
<td></td>
<td>c. Present Levels of Performance</td>
<td>4. Watch IEP Advocacy mock IEP meeting videos on tablet (3-5 min)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Discuss with parent questions/concerns (10-15 min)</td>
</tr>
<tr>
<td>2. IEP Development</td>
<td>Section 2:</td>
<td>1. Check-in (5-10min)</td>
</tr>
<tr>
<td></td>
<td>a. Eligibility</td>
<td>2. Review of IEP checklist and child’s IEP (20 min)</td>
</tr>
<tr>
<td></td>
<td>b. IEP Goals</td>
<td>3. Watch IEP Advocacy Module 1 on tablet (7-14 min).</td>
</tr>
</tbody>
</table>
| 3. Free and Appropriate Public Education | Section 3:  
   a. Least Restrictive Environment  
   b. Services, accommodations and supports  
   c. Parent consent and procedural safeguards |
|------------------------------------------|--------------------------------------------------|
| 4. Watch IEP Advocacy mock IEP meeting videos on tablet (3-5 min)  
5. Discuss with parent questions/concerns (10-15 min) |

**The IEP Advocacy Mentorship Main Elements.** The guiding element in the PARENT intervention is the interactive IEP checklist (Appendix A). The IEP checklist serves as a point-by-point guide for the PM to cover the different topics of the mentorship. Secondly, the IEP checklist is linked to online modules and videos that cover the different topics in the program.

For example, when the PM went over the Present Levels of Performance (PLPs) in the IEP, the IEP advocacy module 1 explained this concept. Additionally, the IEP meeting mock videos show how the PLPs are discussed during an effective IEP meeting. The PM was responsible for delivering the mentorship materials and to respond to questions and concerns from parents. Additionally, PM provided differentiated instruction depending on parent’s literacy levels.
**Figure 3: IEP Advocacy Mentorship Main Elements**

1. **IEP Checklist**

2. **Online IEP Advocacy**
   - Modules and IEP mock meeting videos

3. **Fiesta Educativa**
   - Community Parent Mentors
The IEP Checklist. The research literature shows that parents consistently express a lack of knowledge and lack of understanding of the special education process as the main barrier to advocacy (Lalvani, 2012). Thus, one of the main advocacy components of the PARENT intervention consists of an IEP interactive checklist developed by the researcher and covering basic principles of advocacy under the IDEA law (i.e. the IEP meeting, present levels of performance, IEP goals, free and appropriate public education, least restrictive environment, due process safeguards, parent and student participation in decision making). The IEP checklist is divided into three sections encompassing basic principles in IDEA. (i.e. IEP Basics, IEP Development, and Free and Appropriate Public Education (FAPE). The outline of the 3 chapters in the checklist is presented in Figure 2. Each of the IEP checklist sections was labeled with a QR code that was linked to three different digital modules. A QR (i.e. quick response) is a type or matrix barcode that can be scanned and linked to specific websites, YouTube videos, etc. Additionally, PM were given tablets preloaded with the videos as part of this intervention. Hence, parent mentors were able to show and access the resources using a tablet as they cover the different modules. For instance, when a PM explained the “Services” section in the IEP, the PM was able to use the tablet to scan the QR code on that page and access a video that explains how services in the IEP are part of a Free and Appropriate Public Education (FAPE). More importantly, as part of the intervention, the participant parent was asked to review their child’s IEP with the parent mentor, comparing what is the child’s IEP to the IEP checklist after reviewing different resources (e.g. videos). This aspect represented an additional layer of individualization for the parents in the intervention.
The IEP Advocacy Modules. The digital modules included informational videos with explanations of concepts (e.g., the PLPs are the child’s current level of academic and behavioral performance in school). The IEP mock meeting videos included examples of ineffective parent participation in the IEP meeting and examples of an effective parent participation in the IEP meeting. The IEP meeting videos were scripted based on IDEA and researcher’s experience attending hundreds of IEP meetings. Additionally, IEP informational modules based on a research of the literature, a review of the IDEA law, and feedback from the community parent mentors. The modules and videos will be freely available online at the end of the intervention phase (May, 2018) on this dissertation study’s website: www.IEPadvocacy.org.

Training of Parent Mentors. Parent Mentor recruitment was initially completed at the end of 2016 with an initial orientation and subsequent trainings. The additional meetings (4 meetings lasting 3-4 hours) with parent mentors focused on covering basic IEP advocacy knowledge (i.e. parents’ rights under IDEA) through the revision and discussion of the mock IEP videos. PMs were active participants in providing directive feedback on the development of the intervention materials (e.g., the items to point out in the IEP checklist) using CPPR methods. PMs also practiced taking the outcome measures to familiarized themselves with the goals of the intervention. A final orientation took place at a public school in October, 2017. This final orientation took place once the intervention materials were finalized and final IRB amendments were approved. Additionally, parent mentors took the IRB-approved CITI training on conducting research with human subjects.

PARENT Intervention Phase

From the pool of eligible participants in the JASPER in the classroom study and community referrals, parents were invited to participate in this study. Then, an individual
meeting was conducted with parents who expressed interested. The researcher then explained the
details of the study and went over the IRB-approved consent. Parents that agreed to participate in
the study during this initial meeting completed entry questionnaires and measures and received a
$5 gift card. Parents were given the option of responding orally or in written form to
accommodate for parents with low literacy levels. A total of 30 families (N=30) consented to
the study and were enrolled on an on-going basis during the months of December, 2017 –
February, 2018. Fourteen families declined participation due to unavailability, uninterested at the
moment, or did not meet eligibility criteria. Parents who enrolled (N=30) were asked to respond
to the “empowerment scale” questionnaire (FES), family outcomes advocacy subscale (FO), and
IEP Advocacy knowledge scale (15 min- 30 min, entry and exit). After consent and baseline data
collection with each participant, parents were assigned a participant number and entered into an
excel randomization table. Parents that were randomly assigned to receive the intervention were
assigned to the mentor that closely matched the parent on three main criteria. First, if the parent
was more comfortable in Spanish, the parent was assigned to a parent mentor more comfortable
speaking Spanish. The two other factors considered in assigning parent mentors was geographic
proximity and schedule (availability). A total of fifteen parents were randomly assigned to the
intervention PARENT group while other fifteen were assigned to the CONTROL group. Parents
in the intervention PARENT group were asked to complete a fidelity checklist over the phone
with a UCLA research assistant at the end of the intervention. Four parents in the PARENT
group dropped from the study, resulting in a total of 11 parents completing the study (n=11).
Two parents in the CONTROL group dropped from the study, resulting in a total of 13 parents
completing the study (n=13). Parents in the CONTROL group were only asked to complete exit
measures (i.e., Family Empowerment, Family Outcomes, and IEP Advocacy Knowledge) 3-6
weeks after initial enrollment. All parents were given an additional $5 gift card for completing the exit measures. Finally, parents in the PARENT group were asked to complete a 5-item interview at the end of the study to explore the strengths and challenges of the intervention (15 min, one time).

Parent mentors received compensation of $12 per each mentorship session, a total of three approximately 1-hour sessions, plus transportation costs. Most families preferred to have the intervention carried out in-home, while a minority preferred to have the intervention in a public place (e.g., library, coffee shop).

**Intervention Fidelity**

Overwhelmingly, parents in the study and PMs did not want the sessions recorded or observed by a researcher. As a result, parents in the intervention group were asked to complete a 10-item researcher-developed checklist over the phone to check intervention fidelity (e.g., Parent mentor reviewed the IEP advocacy modules and videos with me: yes or no) (Appendix F). Their responses in the checklist were used to calculate intervention fidelity in the mentorship protocol. A total of 100% fidelity rate was calculated according to participant’s responses.

**Measures**

*Family Demographics.* Parents completed standard demographic forms about their family and child. These variables are used to describe the sample. This is important because this intervention study targets a very specific parent population (i.e. low-income, racial/ethnic minority, immigrant-origin).

*Family outcome survey-revised.* The family outcome survey-revised (FOS) is a 24-item self-report instrument designed to gather information on a family’s strengths and needs to support early intervention programs for children with disabilities and their families (Bailey,
Hebbeler, Olmstead, Raspa, & Bruder, 2008). The instrument assesses five family outcomes using a 5-point Likert scale ranging from (1) not at all to (5) completely. The FOS was previously translated and used in Spanish. Olmsted and colleagues found two of the subscales to have Cronbach’s alphas ranging between .80 and .63 with a Spanish-speaking sample (Olmsted et al., 2010). The five family outcome subscales (with sample items in parentheses) used in this study included: (a) understanding your child’s strengths, needs, and abilities (e.g., we understand our child’s strengths and abilities); (b) knowing your rights and advocating for your child (e.g., we know our rights related to our child’s special needs); (c) helping your child develop and learn (e.g., we are able to help our child learn new skills); (d) having support systems (e.g., we have friends or family members who listen and care); and (e) accessing the community (e.g., our child’s care needs are met). Cronbach’s alphas for the individual scales for past studies were .63, .82, .84, .88, and .82 respectively; and .94 for all 24 family outcome items (Magana, 2015). Because this is parent advocacy intervention study, the main subscale analyzed in this study is subscale (b) Knowing your rights and advocating for your child).

**IEP Advocacy Knowledge.** A researcher-developed 10-item multiple choice assessment of basic facts about special education parents’ rights was given to all parents. Items assess basic knowledge of the six pillars of special education law: zero reject, least restrictive environment, free and appropriate public education (e.g., The least restrictive environment means: a) always general education b) always self-contained class c) always a resource program d) Placement depends on the needs of the child). The scale range is 1-5 possible answers. Each item in the test had one correct response and was graded as correct or incorrect. Each participant received a cumulative score based on the number of correct answers. Then the cumulative score on the test was classified as a dichotomous variable (i.e. Proficient/ Not proficient). Proficient (i.e. 1)
signifies a score of 100% correct items in the test. Not proficient (i.e. 0) was any score of less than 100% correct items on the test. A reliability analysis yielded a Cronbach’s alpha of 0.82 on the post-test in this study.

**Family Empowerment Scale (FES).** The family empowerment scale, evaluates parents’ perceptions of their agency in the special education laws. The FES was developed by the Research and Training Center, Research Institute for Human Service, Portland State University (1992). The scale includes a total of 34 items evaluating activities that parents may or may not do (e.g. When problems arise with my child, I handle them well: 1= never, 2= seldom, 3= sometimes, 4= often, 5= very often). The scale range is 1-5. The FES is divided into 3 different subscales: about your family, about your child’s services, and about your involvement in the community. A mean score is calculated for each subscale, with higher scores representing higher levels of family empowerment. The FES has shown validity in parents of children with disabilities. A shorter 16-item version has shown a Cronbach’s alpha of .80 and .82. Because this study focuses on parent IEP advocacy, the main subscale analyzed and calculated was “About your child’s services.”

**Parent post-intervention interview.** Parents in the intervention group (n=11) were asked to complete a short 5-item interview regarding the strengths and challenges of the PARENT intervention (e.g. What was helpful/effective in the intervention?) over the phone. A bilingual research assistant called the parents, audio-recorded their responses and transcribed them in Spanish and English.

**Results**

**Research Question 1.** Does a parent-to-parent advocacy mentorship program for parents of young children with ASD increase their IEP advocacy knowledge (i.e. their rights under IDEA)?
Outcomes measures for parents were analyzed across time (baseline/exit). The analysis strategy was based on randomization of parents to the PARENT intervention or the CONTROL group. The primary outcome measure for this dissertation study is IEP advocacy knowledge (i.e. parent’s rights under IDEA). The IEP Advocacy Knowledge or test measure was initially scored as a sum of the number of correct responses in the scale (range 0-10). The mean scores for each group are presented in figure 4 at T1 and T2. The graphs show an increase in the IEP Advocacy test for the PARENT group. Similarly, the mean scores for the CONTROL group are presented in figure 5 at T1 and T2. The graphs show a slight decrease in the IEP Advocacy test for the CONTROL group.

*Figure 4: PARENT group mean scores at T1 and T2*

*Figure 5: CONTROL group mean scores at T1 and T2*
Then, a difference score for each participant was calculated by subtracting the score at exit (T2) minus the score at baseline (T1). These scores were then compared between PARENT and CONTROL using an independent sample t-test. Differences in mean scores were statistically significant (p=.04; t=2.179). On average, the PARENT group mean difference was 8.6 points in the IEP advocacy measure (SD=1.87). The CONTROL group mean difference was -0.08 (SD=1.5). Results from these analyses are presented in Table 3. These analyses show that parents who received the IEP mentorship program, on average, increased their IEP advocacy knowledge 8.6 points (out of a total of 10). A Cohen’s d was calculated to determine effect size (d=5.2). This shows that the intervention had a very large effect size on the IEP advocacy knowledge scale.

Table 3: Independent samples t-test comparing PARENT and CONTROL on IEP Knowledge Score Differences

<table>
<thead>
<tr>
<th></th>
<th>PARENT</th>
<th>CONTROL</th>
<th>95% CI for Mean Difference</th>
<th>t</th>
<th>df</th>
</tr>
</thead>
<tbody>
<tr>
<td>IEP Advocacy Knowledge</td>
<td>8.6</td>
<td>1.87</td>
<td>0.08</td>
<td>7.325, 10.162</td>
<td>2.179, 22</td>
</tr>
</tbody>
</table>

Proficiency Analysis of The IEP Advocacy Scores

The PARENT intervention is focused on teaching parents the essential tools and knowledge they need to be effectively engaged in the IEP process. Hence, the results from the IEP advocacy knowledge scale were further analyzed to look for mastery of parent’s rights in the IEP. Specifically, the sum of the IEP advocacy knowledge scores at T1 and T2 were coded and classified as a dichotomous variable (100% correct= proficient or <100% correct = not proficient). Hence, a proficiency change score was created. Proficiency change is defined as not proficient at entry (T1) AND proficient at exit (T2). A proficiency of 100% is expected because
the IEP Advocacy measures only 10 very basic rights under IDEA. This is considered the most basic knowledge a parent must have to minimally participate in the IEP process. The possible proficiency change conditions are presented in Table 4.

Table 4: Possible Outcome Conditions in the IEP Advocacy Knowledge Scale

<table>
<thead>
<tr>
<th>Entry (T1)</th>
<th>Exit (T2)</th>
<th>Change (T1=0 &amp; T2=1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

A proficient/not proficient score was calculated at T1 and T2 for each participant in each group. Participants who met the proficiency change condition (i.e., not proficient at entry, and proficient at exit) were given as score of 1 in the proficiency change score. In the PARENT group, this resulted in a total of 7 participants out of 10 (for which both T1 and T2 data were available) meeting the proficiency change condition. This signifies that 63% of parents in the intervention group started the intervention as not proficient and exited the intervention as proficient. In the CONTROL group, only 2 out of 13 (for which T1 and T2 data were available) meeting the proficiency change condition. This signifies that only 15% of parents in the CONTROL group started the study as non-proficient and exited the study as proficient. Results from these across time analyses are presented in table 5.
Finally, a z-test for a population proportion was used to test statistically differences between the PARENT and the CONTROL groups. The result was statistically significant (p = 0.0151). The proportion of parents changing from non-proficient to proficient in the PARENT group is 0.60 (60%). The proportion for of parents changing from non-proficient to proficient in the CONTROL group is 0.154 (15%).

Attrition. A total of 4 participants in the PARENT group dropped from the study during the intervention phase. Two of these participants reported to the researcher not having the availability to meet with the PM. The other two participants did not respond to PM requests or researcher requests to follow-up (i.e., phone calls, emails, texts). In the CONTROL group, 2 participants did not respond to several requests to follow-up (i.e., phone calls, emails, texts).

Research Question 2. Does a parent-to-parent advocacy mentorship program for parents of children with ASD increase their family empowerment and family outcomes?

Family Empowerment Scale (FES) and Family Outcomes (FO) were the outcome measures used to answer the above-mentioned research question. These measures were analyzed across time at baseline and exit (i.e., T1, T2). A mean score was calculated for the advocacy subscale of the Family Outcomes (FO) measure at T1 for PARENT (M=3.6; SD=1.19) and the CONTROL (M=3.79; SD=0.74) groups. Similarly, a mean score was calculated for the advocacy
FO at T2 for PARENT (M=4.2; SD= 0.57) and CONTROL (M=3.79; SD= 0.74). A graph comparing the results from these analyses are presented in figure 4. Then, a mean difference score was calculated for each participant by subtracting the exit score (T2) minus the baseline score (T1). Lastly, an independent samples t-test was employed to look for statistical differences between the mean change scores in the PARENT group compared to the CONTROL group. Results show there were no statistically significance differences between the PARENT and the CONTROL groups (p=0.20). Results from the independent samples t-test for the FO measure are presented in Table 7.

![Figure 4: Family Outcomes Advocacy Subscale Scores](image)

In a similar fashion, a mean score was calculated for the Family Empowerment Scale (FES) advocacy subscale at T1 (M=4.5; SD=0.50) and T2 (M=4.28; SD= 0.58). Then, a mean difference score was calculated for each participant by subtracting the exit score (T2) minus the baseline score (T1). Finally, an independent sample t-test was used to look for statistically significant differences between the two groups. Results show that there were not significant differences between the PARENT and the CONTROL groups (p=0.70). Results from the independent samples t-test for the FES are presented in Table 8.
Qualitative Data Analysis

Research Question 3. What are the strengths and challenges of implementing a parent-to-parent mentorship program within an urban low-income minority context?

English and Spanish interview audio recordings were transcribed by the principal investigator and a research assistant. Transcripts were inputted into an excel document which facilitated data management.

Codebook Development. Guided by the study’s research questions (i.e., the effects of a parent-to-parent advocacy intervention), the researcher conducted *apriori* coding of the
transcripts and identified a preliminary list of categories based on the interview questions (e.g., How helpful would you describe the mentorship program you participated in?).

**Coding and Thematic Analysis.** The researchers used line-by-line coding to assign categories to phrases, sentences or paragraphs within the different responses; multiple categories could be assigned simultaneously to accurately capture the overall sentiments of the passage. Information from the category applications and identification of the subcategories guided the development of the final themes. The final themes are explained more in detail below.

**Theme 1: Useful IEP Advocacy Mentorship Program**

Overall, all participants responded very optimistically to the intervention. Participants’ comments suggest the PARENT intervention was effective. Participants showed mastery of basic rights in an IEP meeting. For example, participants consistently expressed how they were not aware that they were encouraged to ask questions during IEP meetings.

“That I get to understand a little bit better what how his IEP works so that I can follow up with his options and know how to learn about my son a little bit better.”

“Yo aprendí en eso que, usualmente cuando yo iba a las juntas, a el IEP usualmente yo no hacía preguntas, nunca, yo pensaba que todo lo ellos decían era lo correcto. En esta vez que yo tuve un meeting para el IEP, fui mas segura y saber que lo que yo iba a preguntar y que eran mis dudas. Porque antes yo solo me quedaba con lo que ellos me decían.” (I learned that when you go to the IEP meetings you can ask questions, before I use to go to the IEP meetings and didn’t ask anything, I thought everything they said was correct. This time, I had this IEP meeting and went in there more confident knowing what I was going to ask and specific questions I had. Because, before, I only took what they told me”
Theme 2: The trustworthiness of having a parent mentor from the community as the interventionist. All participants expressed gratitude and a trustworthy relationship with the parent mentor. Specifically, participants expressed that parent mentors were passionate and the fact that the PM had themselves a child with a disability helped them connect with them.

“I mean she was like a really good person you know. We did understand both of us, since the first time she came to my house, I felt confident talking to her. Even though I didn’t really know her. She gave us the trust when we asked her a lot of stuff and she would answer. She had nice attitude.”

Theme 3: Suggestions for Future Implementation of the Parent-to-Parent Mentorship Program. Most participants expressed that the program is useful as it is. One suggestion that came across was to let more people know about these programs for parents. Participants expressed that other members of their community do not have this information nor are aware of advocacy programs like this one.

“From what, from the experience we had I wouldn’t change anything, it works, it works. It provides parents with information that they didn’t know prior. It helps them in the actual IEP and just brings light to what information we don’t have.”

“I don’t think I would change it. I think it’s fine the way it is, just I guess letting people know more about it when or having more announcements about it like on the internet or on TV or commercials. Where you can put where parents could get help for their special needs children. Like at the tip of a hat, you know. I did not know there was this much help for my son.”

“Pues pienso que en involucrar a mas padres para que puedan orientar a mas padres que no tienen mucha información, que no saben mucho de lo que es el IEP cosas importantes para ellos para con el grupo del IEP. Para tener un progreso positive en sus hijos. (Well, I think that that
you can involve more parents to orient parents that do not have much information, they do not know much about what the IEP is, important things for them as well as for the IEP team. This is so they see a positive progress in their children”)

**Case Profiles.** In addition to the thematic analysis, the researcher created 2 case profiles for two of the participants in order to illustrate the experience of partaking in this IEP Advocacy Mentorship program.

**Participants Case Profiles**

Participant: Fernando

Fernando (not his real name) is a 37 years old Latino male. He is the father of a 3 year old child with autism. Fernando attended vocational school and he is now a traffic officer in the city of Los Angeles. His household annual income is in the range of $70,000-79,999. He speaks English and Spanish fluently. Fernando is married to Sara (not her real name). Sara is an immigrant from Mexico who speaks Spanish only. He and Sara had attended one IEP meeting at the beginning of this dissertation study. Fernando was randomly assigned to receive the IEP Advocacy Mentorship program.

Fernando’s wife, Sara, was present during the consent meeting, and during the 3 IEP advocacy mentorship sessions. However, Fernando was the main participant in the study and data were collected on him only. Fernando scored a 6/10 during baseline on the IEP Advocacy assessment. Some of the items he missed include “By law, the Individuals with disabilities education act (IDEA) provides a way to solve disagreements you (parents) may have with the school through:” His answer to this question was “I do not know.” He also missed items related to the Least restrictive environment, and procedural safeguards regarding the signing (or not) of the IEP.
At exit, Fernando scored a 10/10 on the IEP Advocacy assessment. After the intervention was completed, Fernando explained that the IEP Advocacy Mentorship “was very helpful, informative, there was a lot of information that we were not aware of. It just prepared us to ask more questions. Some of the information was that we didn’t have to sign the IEP right then and there, and that our input was very important in the actual IEP and that the participants that were supposed to, had to be present that were scheduled to be there. I’m glad that you guys are doing this it’s helpful to us. We’re basically left, if we don’t have any information we’re helpless. I would say for those of those that don’t really know where to look for or who to contact. I’m glad that you guys are doing this and it’s good work.” The experience that Fernando expressed is validated by his increased knowledge on the IEP advocacy assessment items related to IEP procedural safeguards. For example, at baseline, Fernando missed the item “By law, I ALWAYS have to sign the IEP document at the end of the IEP meeting.” His initial response was “true” at baseline, while his response at exit was “False.” False was the correct response, as parents are not required to sign the IEP document at the end of the IEP meeting.

Likewise, Fernando expressed that “if any challenges it would be the schedules. But you know our mentor was able to, she was very flexible so it worked. But yeah just the time and the scheduling since we’re both, my wife and I both have schedules that are pretty tough to meet.” Hence, the scheduling and availability of both parents presented a challenge during the intervention. However, this challenge was overcome with the help of the Parent Mentor. This appreciation for the mentor was also expressed by Fernando “You can tell that the mentor was very passionate about what she was doing, what she was saying and that reflected on us being the same, and having the same passion. And us trying to get all the information we can to assist the kids and getting all the help and that they deserve and the information we need to get the
help for them." In general, Fernando had a very positive impression of the IEP advocacy mentorship. He found the information very useful and his feelings were validated by the data.

Participant: Rosa

Rosa (not her real name) is a 26 years old Latina woman. She is the single mother of a 3-year old child with autism. She attended vocational school and she is now a part-time ultrasound technician. Rosa reports that her annual household income is around $9,999. Rosa and her son live in a house that is shared with eight other people. She was randomly assigned to receive the IEP Advocacy Mentorship program.

At baseline, Rosa scored a 2/10 in the IEP Advocacy assessment. Hence, she missed most of the items on the test. Some of the items that she answered incorrectly include “The Individualized Education Program (IEP) for children with disabilities usually include:” Rosa answered “Regional Center Eligibility and insurance information,” while the correct answer was “My child’s strengths and areas of need, goals, and services.” One item that she scored correctly was “The determination that a child has a disability and qualifies for the IEP is made by:” Her correct answer was “The IEP Team.”

At exit, Rosa scored a perfect 10/10. She found the IEP Advocacy Mentorship to be “Very helpful because I had no idea what the IEP was really about. I learned that it was a legal document and that the teacher or the person doing the IEP can specify clearly so that I understand what they are trying to say or what they mean with my son’s IEP. What his goals are and that the administrator, the teacher, and the therapist that is giving him speech language needs to be there, I need to be there. And if they don’t go then I need to or they need to provide a letter written with a reason why.” The sentiment that Rosa expressed is validated by her increased knowledge on the IEP advocacy assessment items. Furthermore, Rosa found the parent
mentor very trustworthy, as she explains “*she is in a similar situation as me with being a single mom with a special needs child with autism that also needs the help so I kind of saw myself in her. And her trying to guide me to get the help that my son needs and she was there in the same situation as me that she didn’t know what there was and what she can do with a child with autism.*” In general, Rosa found the IEP advocacy mentorship useful and her feelings are validated by the results of her IEP advocacy assessment.
CHAPTER 4: GENERAL DISSERTATION DISCUSSION

Key Findings:

- Parents in the intervention PARENT group increased their IEP advocacy knowledge at a higher proportion than those in the CONTROL group.
- There were no differences between the intervention PARENT group and the CONTROL group in the Family Empowerment scale or the Family Outcomes scales.
- Results from qualitative post-intervention interviews suggest the intervention was very helpful and effective in increasing parents’ IEP advocacy skills.

The initial gap identified in the literature was the lack of an advocacy program in special education for low-income, minority families. The current research literature on special education advocacy interventions focus overwhelmingly on White middle-class families. Hence, this dissertation study was designed to test, using randomization, a parent-to-parent advocacy mentorship program for parents of children with ASD within a low-income, mostly Latino population.

The purpose of this study was to close that gap and deliver an advocacy intervention designed for this population. Hence, the participants in this study were low-income, 93% Latino and 50% Spanish speaking. While focusing on an underserved, under-studied population was a strength of the study, it also presented challenges. Below I address the initial challenges of intervention implementation, and conclude with the strengths of the intervention and future directions.

**Challenges of Implementing a Parent-to-Parent IEP Advocacy Mentorship.** Several challenges were particularly salient in recruiting and working with a low-income mostly Latino
population. First, while most of the participants showed great interest in engaging in the intervention, participants found scheduling for the sessions difficult. This resulted in two parent dropping from the study, as we were unable to find matching availability for both the parent mentor and the parent. For example, two participants assigned to the intervention group dropped from the study for this reason. As mentioned in the qualitative results section, this logistical difficulty with schedules was also expressed by some participants.

A second challenge, was addressing a general unfamiliarity from the participants about research studies. Even though I am bicultural and bilingual and with a teaching background, enrolling participants in the study proved difficult. I found that most participants were not very aware of research in general. I addressed this by meeting participants one-on-one and explaining the consent form in detail. Additionally, I scaffolded the different terms and expectations of this study (e.g., the randomization process). Likewise, I addressed common misconceptions one-on-one with participants (e.g., The program is free of cost, not a business). Still several parents declined participation, and several more dropped from the study during the intervention (n=4), or were lost to follow up (n=2). Two parents in the intervention dropped because their schedules did not work with the PM’s schedule.

A third challenge was recruiting participants for an advocacy intervention in a hostile socio-political environment towards immigrants. Currently, the U.S. is experiencing an anti-immigrant rhetoric mainly targeting those from Latino origin. This challenge was exacerbated by the participants’ unfamiliarity with research. For example, the word for “research” in Spanish is “investigación” which sounds as a “law-enforcement investigation.” Latino parents in the study who may have had an irregular immigration status were probably concerned about their data being collected. This is a reasonable and understandable fear. This fear compounded with an
unfamiliarity with scientific research, could be a reason why some families decided not to enroll in the study or dropping shortly after. In one instance, as I was conducting the consent and intake meeting with one parent that I will called “Ana”, she mentioned that “My husband just got deported, I lost my job, and my son has been diagnosed with autism.” Her situation was indeed dire, and understandably so, she was one of the parents that dropped during the intervention. For parents like her in survival mode, an IEP advocacy programs is simply not a priority in her life. In this dissertation study, it is possible that case like “Ana” above, might have not been unique, given the 6 families that dropped from the study. In another instance, a parent I will call “Sandra” was a full-time college student who was also working part time. Sandra dropped from the study, due to not having the availability to meet with a mentor. Understanding the challenges that parents like Ana and Sandra face is a point of future research.

**Strengths of the Parent-to- Parent IEP Advocacy Mentorship.** This dissertation intervention study targets a traditionally “hard to reach” or “hard to engage” parent population (Lalvani, 2012). Nonetheless, with an attrition rate of 20% and given the logistical challenges (i.e., scheduling matching) of the intervention, the study provides valuable information to future efforts in engaging these families in research. While a majority of participants engaged in the study, and had overwhelmingly positive feedback about the intervention, others probably required other engagement strategies to get them to participate.

**Implications**

Maria’s case is not unique. There is a growing number of minority parents with disabilities that need help navigating the complex set of special education processes and laws. Parents like Maria and the participants in the study benefit from explicit instruction on what the expectation of their role is in IEP meetings. This dissertation study suggests that a low-intensity,
low-cost program for minority parents can increase their basic understanding of their role and rights in the IEP process. As a special education teacher working in a low-income, urban, mostly minority context, I witnessed the struggles parents had in navigating the special education system. It was my responsibility to inform parents that they did not have to agree to the IEP, that they could review it before signing it. Likewise, it was my responsibility to let them know that they could ask questions, and add valuable input during the meetings. Most Latino parents I worked with did not know these basic parent’s rights. Accordingly, most of the parents in this study, struggled with the same basic parental rights in the IEP. For example, many parents in the study had the misconception that they had to sign the IEP at the end of the IEP meeting. Many also believed that their role was to listen and not question anything during IEP meetings. In most cases, parents in the study did not know they have legal options if they didn’t agree to their child’s IEP. This dissertation study suggests that a low-intensity and low-cost intervention can help parents learn these basic rights in the IEP process.

Limitations

The study found that parents in the intervention group showed a higher mastery of special education advocacy rights when compared to the control group (60% in PARENT vs. 15% in CONTROL). However, their family empowerment, did not differ between the intervention and the control group. There are at least two possible explanations for this. First, the intervention was tightly focused on increasing parent’s IEP Advocacy knowledge, but did not extent to changing participants self-perceptions of empowerment or attitudes towards exercising advocacy rights. It is also possible that the intervention did have an effect on these measures but, because the sample was so small it was underpowered to draw any statistical inferences, or the measures themselves were not sensitive enough to the specific focus of this study. Nonetheless, the
qualitative results of the participants in the intervention group suggest that the intervention was helpful and increased their feelings of empowerment. For example, one of the goals of the program was to teach parents that they had a voice in the IEP process and that their participation was critical and expected. Specifically, participants consistently expressed how they were not aware that they were allowed to ask questions and provide input during IEP meetings. These findings suggest that this empowering information was lacking with most of the participants before the intervention. Finally, attrition of participants proved challenging. In the PARENT group 26% or 4 out of 15 parents dropped from the study. Two of these parents reported unavailability to meet with PM, but it’s unknown why the other two dropped. In the CONTROL group, 13% or 2 out of 15 participants dropped for the study from unknown reasons. In all instances, I tried contacting participants via phone calls, texts, and emails on multiple occasions. Hence, other methods of engagement need to be considered in future studies trying to reach this specific population.
APPENDIX A

TABLE OF CONTENTS

SECTION 1
What is the IEP?
The IEP Meeting
Present Levels of Performance

SECTION 2
Eligibility
IEP Goals

SECTION 3
Least Restrictive Environment
Services & Supports
Parent Consent / Procedural Safeguards

IEP advocacy mentorship
Luelmo, P., Kasari Lab, University of California, Los Angeles & Fiesta Educativa Inc. (2017)
THE IEP
INTERACTIVE
CHECKLIST

THE IEP TEAM
At each IEP meeting, the following must be present or excused in writing:
the parent or caregiver, special education teacher, general education teacher,
school administrator student (when appropriate)
THE IEP

Individualized Education Program (IEPs) for children with disabilities should always include:

- How is my child doing?
- What is she going to learn/do in one year?
- What services and supports will get her there?
- Do I agree or disagree?

Parent's or caregiver’s

Reviewed once a year

Full evaluation every 3 years

WHAT IS THE IEP?

Check Name
Next IEP
Next Evaluation
Student language
Foster care?

Eligibility
Date of birth
Type of IEP Meeting
WHAT IS THE IEP?

ELL status

ELL level

did your child meet her goals?

PRESENT LEVELS OF PERFORMANCE

How is my child doing in?

What is his/her disability? How does it affect my child?

Am I missing an area of concern? If so, ask for an evaluation?

His/Her Strengths

His/Her Areas of challenge

Are there more evaluations needed?
SECTION 2

Eligibility

IEP Goals

- Autism
- Blindness
- Deafness
- Emotional Disturbance
- Hearing Impairment
- Intellectual Disability
- Multiple Disabilities
- Orthopedic Impairment
- Other Health Impaired
- Specific Learning Disability
- Speech or Language Impairment
- Traumatic Brain Injury
- Visual Impairment

Note: Eligibility is determined during the IEP Meeting with input from all participants including YOU, the parent.
SECTION 3

Least Restrictive Environment
Services, Accommodations/Modifications
Parent Consent/Procedural Safeguards
The diagram illustrates a hierarchy of educational environments, from least restrictive to more restrictive. The categories include:

- **Least Restrictive Environment**
  - Non-Public SPED School
  - Public SPED School
  - Self-Contained Class (SDC)/Autism Class
  - Resource Lab (RSP)
  - In-class support/services
  - General Education

The diagram also includes a reference to a document page labeled "FREE AND APPROPRIATE PUBLIC EDUCATION".
Dispute Resolution & Due Process

If you disagree with the school in the IEP, there are procedural safeguards that you can follow to work out disagreements with the school.

IDEA is based on constitutional premise of due process.

If parent disagrees with decision about child's education, they can challenge the decision. Contact the districts special education complaint response unit to get more information.

Weinberg, L. (2007)


Appendix B
LISTA DEL IEP

EQUIPO IEP

En todas las juntas del IEP, las siguientes personas tienen que estar presentes o ausentes con justificación por escrito.

Uno de los padres o persona responsable del niño, el maestro de educación especial, el maestro de educación general, administrador de la escuela, alumno (cuando sea pertiente)
EL IEP
El programa individualizado de educación (IEP) para niños con impedimentos siempre debe incluir:

- ¿Cómo le va a mi hijo/a?
- ¿Qué va a aprender hacer en un año?
- ¿Qué apoyos y servicios le ayudarán a lograr sus metas?
- Estoy de acuerdo o no

Se revisa una vez al año

Se hace una evaluación general cada 3 años

¿QUÉ ES EL IEP?
SECCIÓN 2
Elegibilidad
Metas del IEP

¿Cuál es la discapacidad que tiene mi hijo/a?
¿Tiene algún otro problema?
Do you suspect a secondary disability?
• Autismo
• Ceguera
• Sordera
• Disturbio emocional
• Discapacidad auditiva
• Discapacidad intelectual
• Discapacidades múltiples
• Impedimento ortopédico
• Otro tipo de impedimento
• Discapacidad de aprendizaje específica
• Impedimento de habla o de lenguaje
• Traumatismo cerebral
• Discapacidad visual

ELEGIBILIDAD

El estudio más de una discapacidad está sentado de mayor impacto

Note: Que discapacidades se discutieron durante la Junta IEP.
SECCIÓN 3
Entorno menos restrictivo
Servicios, acomodaciones/modificaciones
Consentimiento parental/salvaguardas del procedimiento
ENTORNO MENOS
RESTRICTIVO

Escuela de educación especial pública o no pública

Mayor restricción

Menor restricción

Clase de contenido autónomo (SDC/clase para autismo)

Laboratorio de recursos (RSP)
Apoyo o servicios en clases regulares
Educación general

EDUCACIÓN PUBLICA GRATUITA Y APROPIADA

Eduación general
o educación especial

Acompañamientos
específicos o apoyos
SERVICIOS

Los servicios más comunes de un IEP

- **Instrucción Académica Especializada**: Ayuda a los estudiantes con lectura, escritura, matemáticas u otras áreas académicas.
- **Lenguaje o habla**: Ayuda a los estudiantes a comunicarse, en su articulación, lenguaje, fluidez, etc.
- **Educación Física Adaptada**: Ayuda a los estudiantes con sus habilidades motoras, control de objetos (bajar una escalera), aptitudes físicas, etc.
- **Terapia Ocupacional**: Ayuda a los estudiantes con habilidades motoras refinadas (escribir con un lápiz o pluma), percepción visual, integración motora, autocuidada.
- **Consejería**: Ayuda a los estudiantes con habilidades sociales y emocionales (mantener amistades).
Resolución de disputas y procesos
Si no estás de acuerdo con lo escrito con respecto al IEP, existen salvaguardas del procedimiento que puedes seguir para resolver estos desacuerdos.

IDEA está basada en la prensa constitucional del debido proceso.
Si el Padre, Madre o Tutor está en desacuerdo sobre cualquier decisión en la educación, de su hijo(a), pueden apelar dicha decisión.

Contacte a la Unidad de Respuesta de Quejas sobre Educación Especial de su Distrito.

Weinberg, L. (2007)


Appendix C

Scoring directions for the “Family Empowerment Scale”:

Scores for the subscales are simple means. Calculate the mean by adding the scores for the subscale items, and dividing by the number of questions. If there are missing items (up to 3), then add the scores for the subscale items, and divide by the number of answered questions. You can add all subscales for an overall score, but be aware that each of the subscales addresses quite different topics. Many published articles have employed this method (adding for an overall score). Examining each subscale score in relation to other variables of interest is another approach that may give more specific information.
FAMILY EMPOWERMENT SCALE

These questions ask about several areas of your life—your family, your child’s services, and your community. The questions include many different activities that parents may or may not do. For questions that do not apply to you, please answer “Never.” Also, we know that other people may be involved in caring for and making decisions about your child, but please answer the questions by thinking of your own situation. Feel free to write any additional comments at the end.

**ABOUT YOUR FAMILY...**

<table>
<thead>
<tr>
<th>Question</th>
<th>NEVER</th>
<th>Seldom</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When problems arise with my child, I handle them pretty well.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. I feel confident in my ability to help my child grow and develop.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. I know what to do when problems arise with my child.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. I feel my family life is under control.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. I am able to get information to help me better understand my child.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. I believe I can solve problems with my child when they happen.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. When I need help with problems in my family, I am able to ask for help from others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. I make efforts to learn new ways to help my child grow and develop.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. When dealing with my child, I focus on the good things as well as the problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. When faced with a problem involving my child, I decide what to do and then do it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. I have a good understanding of my child’s disorder.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. I feel I am a good parent.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

**ABOUT YOUR CHILD’S SERVICES...**

<table>
<thead>
<tr>
<th>Question</th>
<th>NEVER</th>
<th>Seldom</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. I feel that I have a right to approve all services my child receives.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I know the steps to take when I am concerned my child is receiving poor services.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. I make sure that professionals understand my opinions about what services my child needs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. I am able to make good decisions about what services my child needs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. I am able to work with agencies and professionals to decide what services my child needs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. I make sure I stay in regular contact with professionals who</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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are providing services to my child. | 1 | 2 | 3 | 4 | 5
---|---|---|---|---|---
19. My opinion is just as important as professionals' opinions in deciding what services my child needs. | 1 | 2 | 3 | 4 | 5
20. I tell professionals what I think about services being provided to my child. | 1 | 2 | 3 | 4 | 5
21. I know what services my child needs. | 1 | 2 | 3 | 4 | 5
22. When necessary, I take the initiative in looking for services for my child and family. | 1 | 2 | 3 | 4 | 5
23. I have a good understanding of the service system that my child is involved in. | 1 | 2 | 3 | 4 | 5
24. Professionals should ask me what services I want for my child. | 1 | 2 | 3 | 4 | 5

ABOUT YOUR INVOLVEMENT IN THE COMMUNITY...

| ABOUT YOUR INVOLVEMENT IN THE COMMUNITY... | NEVER | Seldom | Sometimes | Often | Very Often |
---|---|---|---|---|---|
25. I feel I can have a part in improving services for children in my community. | 1 | 2 | 3 | 4 | 5
26. I get in touch with my legislators when important bills or issues concerning children are pending. | 1 | 2 | 3 | 4 | 5
27. I understand how the service system for children is organized. | 1 | 2 | 3 | 4 | 5
28. I have ideas about the ideal service system for children. | 1 | 2 | 3 | 4 | 5
29. I help other families get the services they need. | 1 | 2 | 3 | 4 | 5
30. I believe that other parents and I can have an influence on services for children. | 1 | 2 | 3 | 4 | 5
31. I tell people in agencies and government how services for children can be improved. | 1 | 2 | 3 | 4 | 5
32. I know how to get agency administrators or legislators to listen to me. | 1 | 2 | 3 | 4 | 5
33. I know what the rights of parents and children are under the special education laws. | 1 | 2 | 3 | 4 | 5
34. I feel that my knowledge and experience as a parent can be used to improve services for children and families. | 1 | 2 | 3 | 4 | 5

Comments


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Family Empowerment Scale (FES)


Section I: Studies using the FES


Updated January, 2010


*This article makes reference to several California CMH sites using the FES*
Section II: FES cited


Updated January, 2010


Updated January, 2010
Appendix D

FAMILY OUTCOMES SURVEY
Revised Version
Section A: Family Outcomes

Instructions: Section A of the Family Outcomes Survey focuses on the ways in which you support your child’s needs. For each statement below, please select which option best describes your family right now: not at all, a little, somewhat, almost, or completely.

<table>
<thead>
<tr>
<th>Outcome 1: Understanding your child’s strengths, needs, and abilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. We know the next steps for our child’s growth and learning.</td>
</tr>
<tr>
<td>2. We understand our child’s strengths and abilities.</td>
</tr>
<tr>
<td>3. We understand our child’s delays and/or needs.</td>
</tr>
<tr>
<td>4. We are able to tell when our child is making progress.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome 2: Knowing your rights and advocating for your child</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. We are able to find and use the services and programs available to us.</td>
</tr>
<tr>
<td>6. We know our rights related to our child’s special needs.</td>
</tr>
<tr>
<td>7. We know who to contact and what to do when we have questions or concerns.</td>
</tr>
<tr>
<td>8. We know what options are available when our child leaves the program.</td>
</tr>
<tr>
<td>9. We are comfortable asking for services &amp; supports that our child and family need.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome 3: Helping your child develop and learn</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. We are able to help our child get along with others.</td>
</tr>
<tr>
<td>11. We are able to help our child learn new skills.</td>
</tr>
<tr>
<td>12. We are able to help our child take care of his/her needs.</td>
</tr>
<tr>
<td>13. We are able to work on our child’s goals during everyday routines.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome 4: Having support systems</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. We are comfortable talking to family and friends about our child’s needs.</td>
</tr>
<tr>
<td>15. We have friends or family members who listen and care.</td>
</tr>
<tr>
<td>16. We are able to talk with other families who have a child with similar needs.</td>
</tr>
<tr>
<td>17. We have friends or family members we can rely on when we need help.</td>
</tr>
<tr>
<td>18. I am able to take care of my own needs and do things I enjoy.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome 5: Accessing the community</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. Our child participates in social, recreational, or religious activities that we want.</td>
</tr>
<tr>
<td>20. We are able to do things we enjoy together as a family.</td>
</tr>
<tr>
<td>21. Our medical and dental needs are met.</td>
</tr>
<tr>
<td>22. Our child care needs are met.</td>
</tr>
<tr>
<td>23. Our transportation needs are met.</td>
</tr>
<tr>
<td>24. Our food, clothing, and housing needs are met.</td>
</tr>
</tbody>
</table>

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Appendix E

Participant ID __________________________ Date __________________________

Test of Parent IEP Advocacy

Directions: Read each item below and choose an answer to the best of your knowledge.

1. An Individualized Education Program (IEP) is characterized by:
   A. Supports that school provide to help children when they think is a good idea.
   B. Supports for some students who are behind
   C. An individualized education for children with disabilities as established by federal law
   D. An individualized education for children who had bad teachers in the past
   E. I do not know

2. Individualized Education Program (IEPs) for children with disabilities usually include:
   A. My child strengths and areas of needs, goals, and services
   B. School principal’s information & doctor’s diagnosis
   C. Regional center eligibility & insurance information
   D. Information about other students my child’s class
   E. I do not know

3. The Present Levels of Performance for my child in the IEP usually include:
   A. My child’s strengths, needs and impact of disability
   B. The school performance as compare to the neighboring schools
   C. The school ranking in state performance tests
   D. My child’s IEP performance compared to other kids with IEP
   E. I do not know

4. That determination that a child has a disability and qualifies for the IEP is made by:
   A. The school psychologist
   B. The special education teacher
   C. The principal
   D. The IEP team (including the parent)
   E. I do not know

5. By law, the IEP team must include:
   A. You the parent, special education teacher, general education teacher and administrator
   B. You the parent, special education teacher, and the child’s doctor
   C. The special education teacher and the general education teacher
   D. The school psychologist
   E. I do not know
6. The least restrictive environment (LRE) means:
   A. Your child needs to be educated in a special education classroom with ONLY children with IEP
   B. Your child needs to be educated with his peers in general education to the “maximum extent that is appropriate”
   C. Your child needs to be taking general education classes ONLY
   D. Your child needs to be enrolled in special education classes ONLY
   E. I do not know

7. Who decides what services my child will get in the IEP
   A. The general education teacher
   B. The school psychologist
   C. The special education teacher
   D. The IEP team (including you, the parent)
   E. I do not know

8. By law, the school is required to provide the services for my child as stated in the IEP
   A. Always
   B. Usually
   C. Sometimes
   D. Never
   E. I do not know

9. By law, I ALWAYS have to sign the IEP document at the end of the IEP meeting
   A. True
   B. False
   C. I do not know

10. By law, the Individuals with Disabilities Education Act (IDEA) provides a way to solve disagreements you (parents) may have with the school through:
    A. A due process hearing
    B. A meeting with the school psychologist
    C. A small-claims lawsuit
    D. A class-action lawsuit
    E. I do not know

Luelmo, P. (2017) University of California, Los Angeles
Appendix F

PARENT/PARENT MENTOR
Interview Protocol

Thank you for taking the time to meet with me today. My name is [_____] and I'm a [_______] at UCLA. Today we want to ask you to discuss your views about your participation IEP parent mentorship program.

When we talk today, I want you to think about the parent-to-parent sessions you participated. The goal of this study was to help parents increase their advocacy and engagement in the special education process.

Your answers will not be linked to your name. This questionnaire will be identified by a number not by your name and your identifying information will be destroyed. Your participation is completely voluntary and you are under no obligation to discuss anything that you do not feel comfortable discussing with me. You can leave at any time. All the information that we discuss together will be kept confidential by the research team.

I will be audio taping our conversation. One of our research team members will be transcribing this tape so that we make sure we accurately capture the information you provide. Only a member of the study team will listen to the tape and we will destroy the tapes upon completion of the study. During our conversation, you can use pseudonyms and you can feel free to change the names of anyone you may mention.

Our conversation will last for about 15 minutes, that might be a bit longer or a bit shorter depending on how long we talk about each question and how much you would like to share.

Do you have any questions before we start?

1. How helpful would you describe the mentorship program you participated in?

2. What are the main benefits of your participation in this program?

3. What do you think the challenges or barriers are to participating in this mentorship program?

4. Did you find the mentor/parent relationship trustworthy? Why? Why not?

5. How would you change this program to benefit families of children with ASD in future studies?
Appendix G:

IEP Advocacy Mentorship
Intervention

Intervention Fidelity Checklist

Participant ID______________________ Date________________

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Parent mentor usually arrived on time</td>
</tr>
<tr>
<td>2.</td>
<td>Parent mentor had all the materials needed for the session (tablet, binder, IEP checklist)</td>
</tr>
<tr>
<td>3.</td>
<td>Parent mentor reviewed the IEP advocacy modules and videos with me</td>
</tr>
<tr>
<td>4.</td>
<td>Parent mentor reviewed the concepts from the modules using the IEP checklist</td>
</tr>
<tr>
<td>5.</td>
<td>Parent mentor responded to parent’s questions and concerns</td>
</tr>
<tr>
<td>6.</td>
<td>Parent mentor assessed parent’s learning (checks for understanding)</td>
</tr>
<tr>
<td>7.</td>
<td>Parent mentor used the IEP checklist to locate specific parts in the IEP</td>
</tr>
<tr>
<td>8.</td>
<td>Parent mentor provided additional resources for me</td>
</tr>
<tr>
<td>9.</td>
<td>Parent mentor used supportive language</td>
</tr>
<tr>
<td>10.</td>
<td>Parent mentor was respectful</td>
</tr>
</tbody>
</table>

Fidelity score: _________/ 10= ___________
Appendix H

University of California, Los Angeles

CONSENT TO PARTICIPATE IN RESEARCH

PARENT

IEP Parent Mentorship Program

Dissertation study: Paul Luelmo, UCLA
Dissertation Chair: Connice Kasari, Ph.D., UCLA
310-825-8342

You have been asked to participate in a research study conducted by Paul Luelmo under the supervision of Connice Kasari, Ph.D., from the Education Department at the University of California, Los Angeles. You are invited to this study as you may be a parent of a student with an Individualized Education Plan (IEP).

Your participation is VOLUNTARY. Your decision to participate will not impact your relationship with UCLA or with any school district.

- PURPOSE OF THE STUDY

The proposed study aims to determine the effects of a parent-to-parent advocacy mentorship program for parents of children with ASD and other disabilities within a low-income, minority context on parent’s advocacy skills and empowerment in the IEP process.

- PROCEDURES

Parent who participate in the study will need the following inclusion criteria:

- A parent of at least one child with a disability
- Fluent in English or Spanish
- Have less than 4 years of experience with Individualized Education Plans (IEP) in the public-school system

If you agree to participate in this study: You will have 50/50 chance of getting one of the following:

- IEP district guideline documents.
- OR
- You will be asked to attend 3 individualized IEP advocacy sessions (Approximately 1 hour each) with a mentor from the community. A parent mentor is an experienced parent with a child with the IEP recruited and trained by the research team to deliver the intervention materials.
- The sessions can be at your home or a public place of your choice.
- You will be asked to engage and complete advocacy educational modules.
You will also be asked to complete the following questionnaires at the beginning and at the end of the study:
- Demographics (approximately 5 minutes)
- Family Outcomes (approximately 5 minutes)
- Family Empowerment scale (5-10 Minutes)
- IEP knowledge Scale (5-10 Minutes)

Additionally, you may be asked to complete an optional 15-minutes interview (approximately) at the end of the study. This one-on-one interview will ask you questions about how the strengths and possible ways of improving the advocacy program.

- **POTENTIAL RISKS AND DISCOMFORTS**

No risks are anticipated from this study, although it is possible that some people may be uncomfortable during the course of the study. For example, parent may be uncomfortable sharing their experiences with the parent mentor. Participation in this study is completely voluntary, and if at any time the questions become too uncomfortable, participants do not have to answer or participate.

- **POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

Parents will learn advocacy strategies that they can use in the Individualized Education Program (IEP) meetings to better serve their children with disabilities.

- **PAYMENT FOR PARTICIPATION**

Parent will receive $5 gift card at intake and $5 at the end of the program.

- **CONFIDENTIALITY**

All information you provide will be kept confidential. To protect your confidentiality, we will not link any personal identifiable information (including your name) to your questionnaires. Your answers will be used for research purposes only. No information that you disclose will be shared with anyone outside the research project, except as required by law. No identifying information will appear when we present this study or publish its results. Although the investigators conducting the research will maintain subjects’ confidentiality, it is not possible to guarantee that all subjects participating in the study will maintain participants’ confidentiality. The research team must report to appropriate authorities when, in the course and scope of this study, he or she knows of, or reasonably suspects, that a child, elder or dependent adult has been the victim of abuse or neglect.

As part of the study, you might be audiotaped when mentor is delivering the sessions. This audiotaping is completely optional. You may review these audiotapes at any time. These audiotapes will be used for teaching and/or research purposes only and your identity will not be disclosed. You have the right to refuse to have the tapes used for educational purposes. You have
the right to review, edit, or erase the research tapes of your participation in the research study in whole or in part.

- **Voluntary Nature of the Study**

Your decision whether or not to participate in this research will not affect your relationship with your employer. You can end your participation at any time. All this is completely voluntary. We can stop at any point you feel uncomfortable.

- **IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact:
Paul Luelmo (Dissertation Study investigator) 619-746-2452 or/and Connie Kasari, Ph.D. (Principal Investigator/ Dissertation Chair) at (310) 825-5140 UCLA Semel Institute.

- **RIGHTS OF RESEARCH SUBJECTS**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions about your rights while taking part in this study, or you have concerns or suggestions and you want to talk to someone other than the researchers about the study, you may contact the UCLA OHRPP by phone: (310) 825-7122 or U.S. mail: UCLA Office of the Human Research Protection Program, 11000 Kinross Ave., Suite 102, Box 951694, Los Angeles, CA 90095-1694.

---

**SIGNATURE OF RESEARCH PARTICIPANT**

I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

__________________________
Name of Participant

__________________________  ______________________
Signature of Participant                  Date

**Videotapes for Educational Purposes**

You have the right to refuse to have the audiotapes used for educational purposes.

[ ] I agree to have my audiotapes of my parent sessions used for educational purposes.

[ ] I do not want audiotapes of my parent sessions used for educational purposes

---

Participation in Future Research Studies
Could we contact you in the future to ask you to participate in follow-up or associated research projects by mail or by phone? (Circle your response)

By phone?  YES  NO
By email?  YES  NO
By mail?  YES  NO

SIGNATURE OF INVESTIGATOR

In my judgment the subject is voluntarily and knowingly giving informed consent and possesses the legal capacity to give informed consent to participate in this research study.

Signature of Investigator ___________________________ Date ________________
Appendix I

DEMOGRAPHICS
Parent IEP Mentorship Program
PARENTS/CAREGIVERS

Completed by (please circle one):  Mother  Father  Caregiver (male)  Caregiver (female)  Grandparent
Other (please specify): ________________________________

Date completed: ___ / ___ / ___

First name: ___________________________  Last name: ___________________________

Phone: ___________________________  Email: ___________________________

Preferred method of contact (circle one):  Phone  Email

Address: ________________________________

City: ___________________________  State: ___________________________  Zip: ___________

**Your answers to the questions are confidential. They will NOT be made available to anyone except the people listed in the consent forms. Answers to the below questions are voluntary.**

Section 1: Participating Caregiver’s Personal Information

1. Age: ____________ years  2. Gender: ☐ Female  ☐ Male  ☐ Other

3. Are you Hispanic/Latino? Choose one.
   ☐ Hispanic or Latino
   ☐ Not Hispanic or Latino
   ☐ Prefer not to answer

4. What is your race? Indicate all that apply.
   ☐ African American/Black
   ☐ Caucasian/White
   ☐ Indian/Alaska Native
   ☐ Prefer not to answer
   ☐ Asian American/Pacific Islander
   ☐ Native Hawaiian or Pacific Islander American
   ☐ Multiple
   ☐ Other (please specify): ___________________________

6. ☐ English  ☐ Korean
   ☐ Mandarin  ☐ Spanish
   ☐ Cantonese  ☐ Other (please specify): ___________________________

1/5
7. What is the highest level of education you have completed?

☐ Elementary/Middle School  ☐ Master’s Degree
☐ Some High School  ☐ Doctoral Degree
☐ High School/GED  ☐ Professional Training
☐ Some College  ☐ Vocational/Technical Training
☐ 2-Year College Degree  ☐ Other (please specify): ______________________
☐ 4-Year College Degree

8. What is your current occupation? ________________________________

Section 2: Child’s Information

9. Child’s age: _______ years

19. Child’s gender: ☐ Female  ☐ Male  ☐ Other

10. Child’s Date of Birth: _______/_______/___________

11. Child’s current grade (if applicable): ______________

12. Is your child Hispanic/Latino? Choose

one. ☐ Hispanic or Latino

☐ Not Hispanic or Latino

☐ Prefer not to answer

13. What race is your child? Indicate all that apply.

☐ African American/Black

☐ Caucasian/White

☐ Indian/Alaska Native

☐ Prefer not to answer

☐ Asian American/Pacific Islander

☐ Native Hawaiian or Pacific Islander

☐ Multiple

☐ Other (please specify): _____________________
14. Who does your child live with most of the time?

- Both biological parents
- Biological mother only
- Biological father only
- Biological mother and step father
- Biological father and step mother
- Adoptive parent(s)
- Grandparents
- Grandmother only
- Grandfather only
- Fosterparent(s)
- Other (please specify): ______________________

15. How old was your child when he or she was given an IEP? _______ years, _______ months

Section 3: Household Information

16. Are you currently:

- Married
- Separated
- Divorced
- Widowed
- Living with partner
- Single
- Other (please specify): ______________________

17. How many people live in your house? _________________

18. Number of adults over the age of 21: _________________

19. Do you have other children with disabilities?  
   - [ ] Yes  
   - [ ] No

20. If Yes, how many other children do you have with a disability? _______

30. What is your family's total income per year?

- [ ] $9,999 or less
- [ ] $10,000 – 19,999
- [ ] $20,000 – 29,999
- [ ] $30,000 – 39,999
- [ ] $40,000 - 49,999
- [ ] $50,000 – 59,999
- [ ] $60,000 – 69,999
- [ ] $70,000 – 79,999
- [ ] $80,000 – 89,999
- [ ] $90,000 – 99,999
- [ ] $100,000 or more.
**Appendix J**

**DEMOGRAPHICS**  
**Codebook**

<table>
<thead>
<tr>
<th>Column</th>
<th>Value(s)</th>
<th>Descriptor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant ID (P001)</td>
<td>P001-P030</td>
<td>Researcher assigned participant ID</td>
</tr>
<tr>
<td>Age</td>
<td>18-100</td>
<td>Parent’s age</td>
</tr>
<tr>
<td>Gender</td>
<td>1=Female 0= Male</td>
<td>Parent’s gender</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td>1= Latino 2= Asian 3= African American 4= Native American 5= White</td>
<td>Race/Ethnicity of parent</td>
</tr>
<tr>
<td>Language</td>
<td>0= English 1= Spanish 2= Other</td>
<td>Parent’s language (What language do you speak most at home?)</td>
</tr>
<tr>
<td>Edu</td>
<td>0= Elementary/Middle School 1= Some High School 2= High School/GED 3= Some College 4= 2-year college degree 5= 4-year college degree 6= Master’s 7= Doctorate 8= Professional training 9= Vocational training 10= Other</td>
<td>Parent’s highest level of education</td>
</tr>
<tr>
<td>Parent Occupation</td>
<td>0= Homemaker/caregiver 1= Full time 2= Part time</td>
<td>Parent’s employment</td>
</tr>
<tr>
<td>Child Age</td>
<td>0-15</td>
<td>Child with IEP age</td>
</tr>
<tr>
<td>Child Gender</td>
<td>1= Female 0= Male</td>
<td>Child’s gender</td>
</tr>
<tr>
<td>Child’s grade</td>
<td>1= Pre-k 2= Kinder 3= Elementary 4= Other</td>
<td>Child’s school grade</td>
</tr>
<tr>
<td>Child’s Ethnicity</td>
<td>1= Latino 2= Asian 3= African American 4= Native American</td>
<td>Child’s ethnicity</td>
</tr>
</tbody>
</table>
| **Child’s caregivers** | 1= Both biological parents  
2= Biological mother only  
3= Biological father only  
4= Grandparents | (Who does your child live with most of the time?) |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child’s IEP Age</strong></td>
<td>Numerical age 0-15</td>
<td>(How old was your child when he or she was given an IEP?)</td>
</tr>
</tbody>
</table>
| **Parent’s marriage** | 1= Married  
2= Separated  
3= Divorced  
4= Widowed  
5= Living with partner  
6= Single  
7= Other | Parent’s marriage status |
| **Household**         | 1-10 | How many people live in the house |
| **Household Adults**  | 1-10 | Number of adults living in the household over 21 |
| **Other Disability**  | 0= No  
1= Yes | Do you have other children with disabilities? |
| **Family Income**     | 1= 9,999 or less  
2= 10k-19,999  
3= 20K-29,999  
4= 30K-39,999  
5= 40K-49,999  
6= 50K-59,999  
7= 60K-69,999  
8= 70K-79,999  
9= 80K-89,999  
10= 90K-99,999  
11= 100K or more | Income brackets |
| **Intervention**      | 0= No  
1= Yes | |
Appendix K

Total IEP Advocacy Mentorship Costs

1. Parent mentors training time (12 hours x 5 parent mentors) = $780
2. Parent mentors sessions time ($12 dollars per hour) total hours for 11 participants
   
   33 hours x 12 = $396
3. Amazon Fire Tablets ($40 each x 4) = $120
4. Gift cards for participants: $10 per participant, total of $300
5. Other materials and website: $400

Grand Total: $1996

Funders: Dissertation Year Fellowship (UCLA), Project LEAD (CSULA) and the Goldman Foundation.
References


