

Copyright

by

Erika Necole Aziegbe

2021

“YOU DIDN’T CALL MY NAME!” BARRIERS THAT PREVENT MARGINALIZED  
BLACK FAMILIES FROM ACCESSING AND UTILIZING EARLY  
CHILDHOOD INTERVENTION SERVICES

by

Erika Necole Aziegbe, MS

DISSERTATION

Presented to the Faculty of  
The University of Houston-Clear Lake

In Partial Fulfillment

Of the Requirements

For the Degree

DOCTOR OF EDUCATION

in Educational Leadership

THE UNIVERSITY OF HOUSTON-CLEAR LAKE

MAY, 2021

“YOU DIDN’T CALL MY NAME!” BARRIERS THAT PREVENT MARGINALIZED  
BLACK FAMILIES FROM ACCESSING AND UTILIZING EARLY  
CHILDHOOD INTERVENTION SERVICES

by

Erika Necole Aziegbe

APPROVED BY

\_\_\_\_\_  
Elizabeth Beavers, Ph.D., Chair

\_\_\_\_\_  
Michelle Peters, Ed.D., Committee Member

\_\_\_\_\_  
Leslie Gauna, Ed.D., Committee Member

\_\_\_\_\_  
Antonio Corrales, Ed.D., Committee Member

RECEIVED/APPROVED BY THE COLLEGE OF EDUCATION:

\_\_\_\_\_  
Felix Simieou, Ph.D., Associate Dean

\_\_\_\_\_  
Joan Y. Pedro, Ph.D., Dean

## **Dedication**

For what the Lord has begun so shall He perfect!

To God, Be All the Glory, In Jesus' Name, Amen.

*Dear My Blessed Children,*

I dedicated this priceless piece of work to your *legacy*. Through your innocence as young blessed children is the way that this dissertation came to be. Your tender voices saying, “Mommy, I understand you are working on my legacy” is the fuel I needed to persevere.

I say thank you.  
Thank you  
*Princeton-Samuel*  
Thank you  
*Elliston-Joshua*  
Thank you  
*Meekness-Faith*

For what the Lord has started so shall it continue.

In closing, my children as a trailblazer for our family- I pass this example to you.

Be Well  
For it is Well  
Be Blessed

For you are equipped to pursue and accomplish.

Love, Mommy—  
Dr. Erika Aziegbe

*Dear My Beloved Husband,*

Through this process you demonstrated the vows that we took. Your encouragement and acts of solidarity of support were priceless. As I grew academically, with your upliftment, so did I spiritually. I say thank you.

*Dear Dad and Mom,*

From this process, I came to appreciate when Dad would engage us in “porch talk” as we listened to stories of the past and how that has shaped our upbringing. Mom, you have always demonstrated the tenacity, grit, and perseverance to see a task complete—I girded this example to cross the finish line. Therefore, the reverberations of “Erika, you will get your education” stands affirmed!

## **Acknowledgments**

*A single tree can never make a forest*

Dr. Beavers! Thank you! From day one you believed in me as I passionately and tearfully shared my research interest - you listened. You allowed me to think outside the box and then go on the journey to make the frame that holds the participants lived experiences. This was an emotional journey from being alongside black families and their introduction to the world of early childhood special education. Thank you, for you too listened to my story. You were the firsthand witness to the degree of perseverance I applied through delays and setbacks. I have a responsibility to bring the families stories across the finish line, so that others can be heard in the field of early childhood special education. Your voice of reasoning was greatly appreciated.

Dr. Peters, I have learned a lot from you, not only about content but how to traverse the world of research. Sincerely, I appreciate you pushing me to be in the field, in order, to learn the intricacies of becoming a researcher. Your sincerity, guidance, encouragement and compassion were tender acts that helped to propel me forward. You are a wonderful cheerleader through this challenging journey. Again, thank you so much!

Dr. Gauna, you saw where the methodology of Narrative Inquiry was fitting for my research. Thank you, for this allowed me to go deeper to capture both the professionals and families deepest thoughts, feelings and experiences. For many of the families viewed this process as a comma and not a period - because their experience continues. Also, as a qualitative methodologist you were open to fusing the arts as a way to render a person's story. I am truly appreciative.

Dr. Corrales, your encouraging words are always well received. Thank you for your authenticity and commitment to seeing students excel.

To all the participants, thank you for allowing me to join alongside as co-creator in the process. Your stories have power and will make an impact for our community.

Rev. Dr. Louise Jones “Arizona Mom”, you have been me with since the beginning as I started my college career as a young, naïve 17-year-old. You always pushed me to not only reach higher but to go higher. I am forever grateful! ~ God Bless

Dr. Chapman, from my days at Johns Hopkins University, as a student in your class has forever changed me. You introduced me to the works of Dewey, Mezirow, Heifetz, Schwab, hooks, Keagan, Merriam, Caffarella and Baumgartner who all realize in some manner the role of an adult and the deliberative process of transformation. Change comes about from the discursive messy process of transformation that is needed to reach our vulnerable communities.

*To my committee, this is only the beginning and I will forever be thankful and greatly appreciative!*

## ABSTRACT

# “YOU DIDN’T CALL MY NAME!” BARRIERS THAT PREVENT MARGINALIZED BLACK FAMILIES FROM ACCESSING AND UTILIZING EARLY CHILDHOOD INTERVENTION SERVICES

Erika Necole Aziegbe  
University of Houston-Clear Lake, 2021

Dissertation Chair: Elizabeth Beavers, PhD

The purpose of this mixed-methods study was to explore the perceived barriers preventing Black families from accessing (completing the intake process) and utilizing (following through with the support) early childhood intervention services. Data was collected from a purposeful sample of Black families who did and did not access Early Intervention Services (ECI) and medical or educational professionals who are Black, Indigenous, and people of color (BIPOC) and primarily serve the same population. Parental, medical, and educational professionals’ perception of the barriers were measured using the *Barriers to Access and Utilize Early Childhood Intervention Services Inventory* (BAUECISI). Survey results were analyzed using frequencies, percentages, independent *t*-tests, Chi-squared test of independence, one-way Analysis of Variance (ANOVA), and logistic regression.

On the quest to understand and inquire into the experience of participants' living story, narrative inquiry through playback was used to capture the embodiment of being *doubly buffooned*—Black and disabled from early childhood. A fusion in qualitative research and the arts was used. Narrative inquiry uniquely situates the relational aspect between the researcher and participants as collaborators in the process where both see themselves in the practice of each living, telling, retelling, and reliving stories. Notably, a narrative inquiry is fixtured in the simultaneous interactions of three commonplaces—temporality (attention to the past, present, and future of the place, things, and events), sociality (interrelatedness of the researcher and participants, and where the condition in which the story unfolds) and place (the physical and topography boundaries) (Clandinin & Huber, in press). Interviews provided data from parental (did and did not access ECI) and professional views to note the diverging and converging perspectives when accessing and utilizing ECI services. Taking caution not to reduce the story to a list of themes, instead metaphors and schematics emerged to reflect the complexity and multifacetedness of *being* a story.

*Stories are medicine . . . they have so much power that they do not require that we act, be, do or act anything—we need only to listen. The remedies for repair . . . are contained in our stories. Paradoxically, stories that rise from deep suffering can provide the most potent remedies for the past, present and even future ills.*  
Dr. Clarissa Pinkola Estes

## TABLE OF CONTENTS

List of Tables .....	xv
List of Figures.....	xvii
CHAPTER I: INTRODUCTION .....	1
Research Problem .....	3
Significance of the Study.....	10
Research Purpose and Questions .....	12
Quantitative .....	12
Mixed-Methods .....	12
Qualitative .....	12
Theoretical Framework.....	13
Transformative Liberation.....	17
Freire.....	18
Mezirow.....	19
Definitions of Key Terms .....	20
Conclusion .....	25
CHAPTER II: REVIEW OF LITERATURE.....	26
Early Childhood Intervention: History and Implications .....	28
First Generation of Individuals with Disabilities Act Part B Section 619 .....	30
Second Generation of IDEA as Part C .....	30
Pillars of IDEA .....	31
Child Find of IDEA .....	33
Child Find Components.....	33
Public Awareness .....	37
Outreach Programs .....	38
Risk Registries.....	43
Tracking Programs .....	45
<i>Program Productivity and Data Analysis</i> .....	45
Partnership and Collaborative Projects.....	49
Application of Child Find Law.....	50
Due Process .....	50
Eligibility and Race .....	52
Empowerment.....	54
Compass of Empowerment.....	55
Empowerment Quantified.....	55
Black Mothers' Voices of Empowerment .....	56
Parental Self-Efficacy and Difference From Empowerment.....	57
Perceived Barriers to Access and Utilization .....	58

Professionals' Perceptions.....	61
Parents' Perceptions .....	62
Other Perceived Barriers .....	65
Enrollment in ECI.....	72
Service Delivery Model.....	75
Part C Utilization .....	75
Children with Special Needs in Texas.....	76
Funding.....	79
Conclusion.....	81
 CHAPTER III: METHODOLOGY.....	 82
Overview of the Research Problem.....	82
Operationalization of Theoretical Constructs.....	83
Research Purpose and Questions.....	83
Quantitative .....	83
Mixed-Methods .....	84
Qualitative .....	84
Research Design .....	84
Population and Sample.....	85
Participant Selection.....	90
Instrumentation.....	92
Perceived Barriers to Access Early Intervention in New Jersey .....	92
Dutch Empowerment Questionnaire .....	94
Data Collection.....	97
Quantitative .....	97
Qualitative .....	98
Purpose of Narrative Inquiry .....	99
Narrative Inquiry .....	105
Autobiography.....	106
Field Text to Interim Research Text.....	106
Conversations .....	107
Interviews .....	108
Data Analysis.....	109
Quantitative .....	109
Mixed-Methods .....	110
Qualitative .....	111
Qualitative Validity .....	112
Privacy and Ethical Considerations.....	112
Research Design Limitations.....	113
Conclusion.....	113
 CHAPTER IV: RESULTS.....	 115
Participant Demographics.....	115

Professional .....	115
Parents .....	118
Child Enrollment Data.....	120
Interviews .....	123
Instrument Reliability .....	125
Research Question One .....	126
Research Question Two.....	129
Employment .....	135
Income .....	135
Notice of Developmental Delay .....	135
Research Question Three.....	136
Medical Professionals.....	137
Nurse Practitioners .....	138
Early Childhood Intervention Director.....	139
Special Education Director.....	140
Research Question Four .....	145
Empowerment.....	152
Professional .....	153
Parent.....	153
Research Question Five.....	154
Dr. Kinder’s Story: From Aging to Babies.....	155
The Imaginary Theatrical Retelling of Dr. Kinder’s Stories as if Conducting a Playback Performance (Gauna, 2014).....	155
One Size Does Not Fit All.....	156
Disconnect Between Systems and Treatment Differences .....	157
How to Change the System for the Future .....	158
Ms. Comfort’s Story: From Majority to Minority .....	159
Restorying of Ms. Comfort: The Imaginary Theatrical Re-telling of Ms. Comfort’s Story as if Conducting a Playback Performance.....	159
Parent Education.....	160
Internal Bias.....	160
Utilization.....	161
Ms. Katarina’s Story: The Oldest to See .....	163
The Imaginary Theatrical Re-telling of Ms. Katarina’s Story as if Conducting a Playback Performance.....	163
Child Find.....	164
Parental Education.....	165
Stigma.....	166
Cultural Tolerance .....	167
Access to Services .....	168
Research Question Six.....	170
Rachel’s Story: Modern Miracle Boy.....	171

The Imaginary Theatrical Re-telling of London’s Story as if

Conducting a Playback Performance.....	172
Implicit Bias .....	173
Label .....	175
Controlled Access.....	176
Utilization.....	176
Joyce: “American” Disability.....	178
Restorying of Joyce’s: The Imaginary Theatrical Re-telling of Joyce’s Story as if Conducting a Playback Performance .....	179
Spirituality .....	180
American Disability.....	180
Low Expectations .....	181
Being Labeled.....	182
Sara: “Baby of a Baby” .....	183
The Imaginary Theatrical Re-telling of Sara’s Story as if Conducting a Playback Performance.....	183
Intergenerational Understanding .....	184
Not Forthcoming .....	184
Research Question Seven .....	185
Not to be Challenged .....	186
Speaking up Cost my Job .....	186
Conclusion.....	187
 CHAPTER V: SUMMARY, IMPLICATIONS, AND RECOMMENDATIONS.....	 188
Summary.....	189
Research Question 1 .....	189
Access.....	190
Utilization.....	191
Research Question 2 .....	193
Barriers .....	195
Research Question 3 .....	196
Research Question 4 .....	201
Research Question 5 .....	203
Research Question 6 .....	205
Research Question 7 .....	206
Implications .....	207
Implications for Medical and Educational Professionals .....	208
State ECI Programs .....	209
Implications for Black Families .....	210
Recommendations for Future Research.....	211
Conclusion.....	212
 REFERENCES.....	 214

APPENDIX A: PERCEIVED BARRIERS TO ACCESS EARLY INTERVENTION IN NEW JERSEY—PARENT .....	247
APPENDIX B: PERCEIVED BARRIERS TO ACCESS EARLY INTERVENTION IN NEW JERSEY—PROFESSIONALS .....	248
APPENDIX C: EMPOWERMENT QUESTIONNAIRE .....	250
APPENDIX D: INFORMED CONSENT TO PARTICIPATE IN RESEARCH .....	251
APPENDIX E: BAUECISI SURVEY INSTRUMENT .....	256
APPENDIX F PROFESSIONALS COVER LETTER .....	271
APPENDIX G PARENT COVER LETTER.....	272
APPENDIX H QUALITATIVE INTERVIEW PROTOCOL PARENT .....	273
APPENDIX I QUALITATIVE INTERVIEW PROTOCOL PROFESSIONAL.....	274

## LIST OF TABLES

Table 2.1 Evidence-Based Practice that Support Components of Child Find (Dunst & Trivette, 2004) .....	35
Table 2.2 Outline of the Purposeful Data Analysis Measures Used to Evaluate a Program’s Effectiveness .....	47
Table 2.3 Taxonomy of Barriers to Early Childhood Intervention Programs for Black Families .....	60
Table 3.1 Birth Rates by Race/Ethnicity .....	85
Table 3.2 Number of Infants and Toddlers Eligible and Enrolled in IDEA Part C.....	86
Table 3.3 Population of Children Enrolled in Preschool Programs for Children with Disabilities in Texas (PPCD) (ages 3-5) .....	88
Table 3.4 States’ Ranking of Children Enrolled in Preschool Program for Children with Disabilities .....	89
Table 3.5 Medical and Educational Professionals in Texas .....	89
Table 3.6 Professional Respondents’ Demographics .....	91
Table 3.7 Parent and/or Primary Caregiver Respondents’ Demographics .....	92
Table 3.8 Description of PBAEINJ Participants Used in the Pilot Study .....	93
Table 3.9 Barrier Instrument Descriptors .....	94
Table 3.10 Description of EMPO Subscales .....	96
Table 3.11 Reliability of the EMPO Scales.....	96
Table 3.12 Permission From Gauna (2014) Sequence of Steps Through the Narrative Inquiry .....	104
Table 4.1 Medical or Educational Professional Survey Participant Demographics .....	117
Table 4.2 Parent or Guardian Survey Demographics .....	119
Table 4.3 Enrollment Data of Families With Children in ECI and/or ECSE .....	121
Table 4.4 Age of Enrollment Into an ECI and/or ECSE Program.....	122
Table 4.5 Interview Participants .....	125
Table 4.6 Parental Perspective of the Barriers to Access or Utilize ECI Services (%) .....	127
Table 4.7 Program Barriers’ Influence on Access of Services .....	129
Table 4.8 Did/Did not Access: Parental Perspective of the Barriers to Access or Utilize ECI Services (%) .....	131

Table 4.9 One-way ANOVA: Professionals’ Perceptions of Program Barriers’ Influence on Access to Services .....	137
Table 4.10 Professionals’ Perceived Parental Barriers to Access or Utilize ECI Services (%).....	142
Table 4.11 Parental Empowerment and Raising a Child with a Disability .....	147
Table 4.12 Collapsed Parental Empowerment and Raising a Child with a Disability .....	150
Table 4.13 Differences in Challenges Between Blacks and Other Ethnicities.....	159
Table 4.14 Rural America Minority Access to Healthcare Services .....	163
Table 4.15 Leadership Accountability.....	170

## LIST OF FIGURES

Figure 3.1. Depiction of the inquiry field.....	100
Figure 3.2. Comparison between playback theatre and narrative inquiry .....	103

## CHAPTER I: INTRODUCTION

There are 6.6 million children with special needs in the US, which equates to 13% of the nation's public-school student enrollment [National Center for Education Statistics (NCES), 2017]. Amongst this data, minority children account for more than the average, with African Americans making up 17% of the total and American Indians representing 14% of those eligible for special education services (NCES, 2017). Specifically, the number of minority children with special needs are on the rise, and attention is being placed on their enrollment in special education programs (NCES, 2017). Notably, the diagnosis of Autism has become a mainstream perspective that is a global issue that transcends racial lines and can be determined as early as 18 months of age (Hyman, Levy, Myers, & AAP Council on Children With Disabilities, 2020). To compound the problems of disproportionality, poverty, implicit and explicit biases, insufficient recourses, high Black infant-mother mortality rates, timing of services, social and cultural contexts, and policy issues all significantly play a role in a child's development and their enrollment prior to kindergarten. Academic readiness for children under the age of 6 has in the literature and documents the benefits when children and families receive necessary supports and services in a timely manner (Black et al., 2017).

Further, Bruder (2010) synthesized the benefits of early intervention for children birth to age 5. From 2003 to 2016, the enrollment of students with special needs in Texas declined by 32,000 [Office of Special Education Projects (OSEP), 2018a]. According to the National State of Preschool Report of 2017, special education preschool classes for 3- and 4-year-olds makes up 3% of the nation's early childhood enrollment, while in Texas, this group accounts for 1.1% of the early childhood special education preschool population (Friedman-Krauss et al., 2018). The overall lower percentage of children

eligible for early childhood special education (ECSE) is attributed to numerous variables. Multiple studies have explained discrepancies in national data that can also be applied to Texas, to include Black males who are nearly three times less likely to be diagnosed at an early age for autism, cultural misunderstandings frequently leading to difficulties for families in locating and accessing needed resources, and various forms of implicit bias including visceral biases impeding interactions during Child Find and referral processes (Black et al., 2017; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Obeid et al., 2021).

Research distinctly establishes the positive outcomes of early intervention for children and their families (Bruder, 2010, Guralnick & Bruder, 2019; U.S. Department of Education, 2019). Moreover, the literature beckons to hear the voices from those behind the numbers to reveal themselves, situationally, to better capture explanations of barriers that impact specific populations of families from accessing and utilizing early intervention services. Presently, there is a significant amount of literature from the mainstream Caucasian perspective related to their early intervention services experiences (Feinberg, Silverstein, Donahue, & Bliss, 2011; Jennings & Hanline, 2013; Morgan et al., 2015). As a result, there is a need to capture an in-depth perspective from marginalized families. The purpose of this study was to explore the perceived barriers preventing Black families from accessing (completing intake process) and utilizing (follow-through with the support) early childhood intervention services. Hence, this study sought to delve more in-depth than the surface level response of best practices and explore the lived experiences, through interviews, of the parents with children who have been failed to be identified for early intervention services, but later in development were determined eligible for a disability which was present in the first 3 years of the child's life. The intent in exploring this phenomenon is to analyze experiences and information to inform enhanced access and equitable services for marginalized Black children and families.

## Research Problem

Black children struggle and fight daily to obtain their academic and societal accomplishments (Pitre, Allen, & Pitre, 2015). There is a reason for those daily obstacles that harken back to the pre-Jim Crow era and its ingrained perceptions of *nigger*, which still resonate in mind and body (Hassan-EL, 2007). In order to keep the power structures in place to prevent an uprising, *miseducation* took place to make Blacks deaf, dumb, and blind by breaking their mental processes (Pitre et al., 2015). This mentality still taunts the Black community with children overrepresented in special education and determined as learning or emotionally disabled [Individuals with Disabilities Education Act (IDEA), 2017; Morgan et al., 2015; Pitre et al., 2015]. Systemic biases that govern the health and educational systems create disparities in access and utilization of services, further widening the achievement gap (Annamma, Connor & Ferri, 2013; Ford, 2012; Ford & Airhihenbuwa, 2010; Ladson-Billings, 1995). Spring (2006) went so far as to say that America is experiencing the second generation of segregation by providing additional programs such as gifted and talented, for which minorities have more significant difficulty qualifying (Pitre et al., 2015).

By 2050 in the US, a new majority comprised of Hispanics, African Americans, Asians, and Native Americans will surpass the White race (Yen, 2009). Currently, these *minoritized* children are falling behind at all levels in the education system prompting educators to view the needs of this changing and ever-increasing majority as a crisis in need of action (Pitre et al., 2015). A *double-buffoonery* exists for Black parents who are cautioned to not enroll in early childhood special education because of the perception that their child is failing at a young age (Annamma, Ferri, & Connor, 2018).

One of the main factors impeding attempts to address this crisis is that although the student landscape is changing, that does not hold true for the educators, the majority

of whom are still European descendants (Ford, 2012; Pitre et al., 2015). For example, in the 2019 Report to Congress, reports children under 5 most prevalent disability category was speech-language impairments, minority children (29.8%) were more likely to have a communication disorder, and that White children (17.6%) were more likely to receive intervention services compared to their counterparts [American Speech-Language-Hearing Association (ASHA), 2015; Texas Health and Human Services, 2018; U.S. Department of Education, 2019]. Representatively, the majority of the master's degreed speech-language pathologists are White, with only a minimal reflection of the ethnic representation of the treatment population (Morgan, Farkas, Hillemeier, Li, et al., 2017). In 2019, the paucity of this was reflected as 150,490 certified speech therapists are White compared to a mere 5,888 of those credentialed as being from the Black race (American Speech and Hearing Association, 2020). The present primary model for early childhood intervention are for therapy services to be provided in-home (89.6%) compared to community based setting (7.6%) or other settings (2.8%) using a coaching model to teach parents to incorporate intervention strategies into the families daily routine (THHSC Rider 98, 2020; U.S. Department of Education, 2019). If the therapists coming into the home are racially and culturally different from the families and children they are working with, this difference can create barriers, however unintentionally, that can negatively impact the services provided (Dunst, Boyd, Trivette, & Hamby, 2002; OSEP, 2018b).

To best serve their target population, current educators and administrators need not limit themselves to become culturally competent but to focus intently on becoming literate in equity, which occurs through understanding and knowing about the lived experiences of marginalized families (Ford; 2012; Gorski, 2016; Vavrus, 2015). This goes beyond reading a high school textbook whose section on Black culture is limited to the story of the Amistad and fails to acknowledge the systemic biases placed on a group

of people who are striving towards the same equitable access to services and education (Stern, 2003; Vavrus, 2015). As involuntary immigrants brought in chains and shackles, the lived experiences of Blacks differ from Hispanics and others who came on their own accord, and this difference is a crucial element of the educational foundation of Black families (Ford, 2012; Ogbu, 2003; Pitre et al., 2015). All too often, people of color feel branded, but a stigma is not limited to the categorizations based on culture, linguistics, and social classifications; it extends into the negative associations and judgments that result in adverse actions (McHatton & Correa, 2005).

Colorblindness is not the solution to cultural incompetence, for that negates the rich culture and languages that others bring to the U.S. (Ford, 2012). In the same way, families who need social services are not best served by applying a monolithic approach (Dunst & Clow, 2007). Negative or culturally incompetent interactions with educators and therapists factor into the parents' reluctance to seek and utilize services.

In the 1980s, Part C Early Intervention of IDEA was established to provide children from ages birth to 3 years support for a developmental delay or disability. In order to make a program available under the local education agency, Section 619 of Part B of IDEA under the Preschool Grants Program was defined as

a federal grant program intended to help states ensure that all preschool-aged children (age 3-5) with disabilities receive special education and related services in their least restrictive environment. The goal of preschool special education services is to enable young children to be active and successful participants in home, school, and community settings resulting in positive outcomes for children and their families. (ECTA, n.d.a)

Nationally, 13% of children are estimated to have a developmental delay or specific disability, which would qualify them for early childhood intervention programs;

still, the number of those who receive services remains steady at around 2.8% (Rosenberg, Zhang, & Robinson, 2008). According to the U.S. Department of Education (2018b), the epidemic of opioid use and abuse by pregnant women has increased the number of children needing early intervention services; birth defects resulting from exposure to Zika and unknown outcomes from the COVID-19 virus have also played a role (Simeone, Shapiro-Mendoza, & Meaney-Delman et al., 2016; Zero to Three, 2020). Furthermore, developmental risk factors can start in-utero because of various conditions that take place prior to, during, and after conception (Guevera et al., 2013). Authors have noted that factors such as prenatal care, premature birth, low birth weight, low maternal education, being a teenage or single mother, and alcohol or drug abuse can increase the prevalence of disabilities such as mental retardation and learning or emotional disabilities (Delgado & Scott, 2006; Rosenberg & Robinson, 2004). Schwarzenberg, Georgieff, and Committee on Nutrition (2018) stated that the first 1000 days of life are crucial to the overall development for both mother and child, and failure to provide adequate nutrition can impact a child's development. A study by Cohen, Onunaku, Clotheir, and Poppe (2005) extended the idea that children who grow up in poverty or high-risk environments and suffered abuse or neglect are at a higher risk of having their developmental capacity negatively impacted. According to the National Survey on Children's Health (Kids Count, 2015) Black parents ranked second to Hispanics in reporting their children's health as being poor to good; substantially, the number of medically eligible children who qualify for ECI services from 2010-2020 has increased by 75% for Autism and 145% for drug-infected infants [Texas Health and Human Services Commission (HHSC), 2020; Kids Count, 2015].

Research showed that certain groups of children, such as those from higher income levels, are more likely to be enrolled in early intervention childhood programs

like Part C (Rosenberg et al., 2008). States have flexibility under IDEA to define eligibility criteria and determine the income sources to fund Part C, which factors into this discrepancy (McManus, Magnusson & Rosenberg, 2014; Rosenberg et al., 2008). Despite the various state interpretations of Child Find, Dunst, Trivette, Appl, and Bagnato (2004) empathetically expressed, “the purpose of Child Find is to locate and identify infants, toddlers, and preschoolers who are or may be eligible for early intervention or preschool special education” (p. 3). As documented, with Blacks identified at lower rates for early intervention services, a racial gap exists in enrollments into district preschool programs (OSEP, 2018a). Through a legislative cycle, a response to a fiscal crisis means the definition could be changed, oftentimes narrowing the criteria for eligibility, changing elements of the programs such as the type of funding sources acquired, or implementation of cost-saving measures (HHSC, 2020; McManus et al., 2014; Rosenberg et al., 2008). Child Find is a variable practice and treated as a budget line item that is usually shifted to save costs and avoid ECI agency loss, resulting in reduced efforts to reach families (HHSC, 2020). Rosenberg et al. (2008) suggest that practices in place for Child Find should be evaluated to determine their effectiveness and keep accountability on the efforts used to reach vulnerable populations.

From the 2004 reauthorization of IDEA, Child Find (CF), Section 300.111 is in place requiring states to have a comprehensive approach that utilizes a multidisciplinary team to locate, identify, and evaluate children from birth who may or are suspected of having a developmental delay or being at-risk (IDEA, 2004; Zirkel, 2017). However, state operating budgets are challenged when fiscal allotments are based on potential monthly enrollment and do not adjust when the number of determined eligible children exceeds the projection (HHSC, 2020). In Texas, from 2010, 58 ECI programs were in

operation and, in 2020, 42 programs remain available to service families. This program reduction resulted in 7,622 children affected by contractor changes (HHSC, 2020).

Intentionally, special education is a field of legality of which both teachers and all parties should be aware (Zirkel, 2015). Child Find (CF) has been deemed faulty because of the flexibility states have in defining the components (Rosenberg et al., 2008). Results from the broad definition of CF has led to and created a litigious platform for school districts (Zirkel, 2015). Recently, in Texas, the defining responsibility fell on the state as the Local Educational Agency (LEA)-Part B of IDEA, and after an audit administered by the Office of Special Programs (OSEP), it was cited for ineffective Child Find practices for children 3-21 years of age (Freed, 2009; OSEP, 2018a; Swaby, 2018). The ideology in special education is derived from the umbrella of cooperative federalism (Freed, 2009). Cooperative federalism was further defined through the pivotal Supreme Court case of *Schaffer v. Weast* that placed the burden of proof on a district or parent, depending on who is seeking the relief (Freed, 2009). Therefore, considering Child Find's legal and ideological aspects, it is imperative states governing organizations utilize multi-responsive efforts to reach vulnerable communities.

In Texas, enrollment during the ages of birth to 3 years, in Part C overseen by the state Health and Human Services Commission (HHSC), Black males account for 64% of the service children in an early intervention program (Texas Health and Human Resources, 2018). According to national data, Black children are only the third most represented group enrolled in Part B, but they are proportionally overrepresented among those identified and placed in special education (Davis, 2003). A long-standing problem with Black males in public education is the increased likelihood of being misdiagnosed compared to mainstream students (Davis, 2003). A possible reason for the misdiagnosis is that many Black males demonstrate excess energy in the classroom by moving around

the room, talking, and/or fidgeting in their seats, all activities that may lead observers to conclude that they have ADHD or associated conditions when, in fact, they are just very energetic (Carter, Hawkins, & Natesan, 2008). Among those who are correctly determined to need special education services, this determination may not occur until middle elementary school (Mandell, 2009). Because early placement is pivotal to provide a strong foundation for students, Black males need to be identified as early as possible in order to offset the disparities of race and gender in special services (Davis, 2003).

For instance, autism diagnoses among children are on the rise, with a diagnosis of autism for 1 in every 59 children residing in the United States [Centers for Disease Control (CDC), 2019]. Dababnah, Shaia, Campion, and Nichols (2018) stated that autism could be diagnosed by the age of two, but in America, children are usually not identified until four years of age. Mandell (2009) found that Blacks and Hispanics are less likely than Whites to be identified with autism, and children of color are usually not identified until around school age (Mandell, 2009).

On the forefront, Black mothers have the greatest number of preterm births and babies with low birth weights (Artiga, Foutz, Comachione, & Garfield, 2016), and Black infants have a mortality rate of 11% compared to 5% for White babies. According to the CDC's (2019) infant mortality data, a societal problem exists to explain why Black babies are dying, untreated, or underserved. Early childhood intervention is a foundational component in the lives of all children and families. It is imperative that minority children are identified as early as possible in order to offset deficiencies resulting from birth-related issues and socioeconomic and cultural challenges that impact their readiness for education.

### **Significance of the Study**

Although minority students make up a majority of those students receiving special education services, they make up a small proportion of those identified early in childhood and receive early intervention services. It is crucial to identify the barriers to both early diagnosis and intervention in order to formulate programs that can ameliorate this groups' failure to achieve at grade level, resulting in a higher dropout rate (Christle, Jolivette, & Nelson, 2007), their proportionally higher representation in the criminal justice system (Dunn, Chambers, & Rabren, 2004), and greater need for social services throughout their life (Dunn et al., 2004).

Previous research has shown myriad factors impacting a minority child's diagnosis and intervention. Children in dual-parent families tend to perform better academically (Parish & Rose, 2010); however, many Black children grow up in single-parent homes or the mother is the primary breadwinner (Black, Dubowitz, & Starr, 1999). Consequently, Black et al. (1999) posit the differentiated roles between the mother and father during early childhood plays a significant part in the child's development, but societal shifts have blurred the lines between Black family's parental functions, as demonstrated when Black mothers have a reluctance to seek help for fear of appearing unfit and losing her children (Copeland & Snyder, 2011). Even if this is not a concern, educational, cultural, and/or language impairments can make it difficult to seek, access, and participate in services for Black families (McHatton & Correa, 2005).

Access to health services is another factor amongst minorities. Artiga et al. (2016) noted that members of all minority groups face increased barriers to accessing and utilizing health care that are not confronted by their majority counterparts. Rather than a child's development being tracked regularly, many minority children received medical care via Medicaid or public health services where they may not see a physician regularly,

or if they do, it often is not the same physician. This results in a child's failure to reach milestones not necessarily being identified early in childhood, screening not being conducted regularly (Dababnah et al., 2018; Guevara, 2013; McManus et al., 2014), or the results of the screening not being correctly interpreted (Mandell et al., 2007). Researchers have argued that there is an underrepresentation of minority children identified as having a developmental delay (Edwards, Gallagher, & Green, 2013; Guevara et al., 2013; Marshal, 2019; McManus et al., 2014), and Black children are five times more likely than White children *not* to receive early intervention services (Feinberg et al., 2011; Morgan et al., 2015).

Personal empowerment is a life-long journey where both intrinsic and extrinsic factors are intertwined and differs from efficacy in that it is a skill (Nachshen, 2005; Nachshen & Minnes, 2005; Zimmerman, 1995). A sense of personal empowerment plays a significant role in a person's health status. If parents feel empowered, they are more confident in their ability to cope with a child who has a disability and to find that child needed services (Nachshen & Minnes, 2005). Personal empowerment can increase the likelihood of an early diagnosis, receipt of intervention and equip minority caregivers to constructively advocate for their child.

This study helps identify factors that both lead parents to and prevent parents from seeking early diagnosis and intervention services for their children. Suggestions for increasing parental access and empowerment, along with existing research, can be useful for health care providers and education professionals. Ultimately, this research should benefit minority children who are being misdiagnosed, under-treated, and disadvantaged in the Health and Human Services oversight of ECI and educational systems.

## **Research Purpose and Questions**

The purpose of this study was to explore the perceived barriers preventing Black families from accessing (completing intake process) and utilizing (follow-through with the support) early childhood intervention services. The study addressed the following questions.

### **Quantitative**

R1: What barriers do Black families encounter that prevent them from accessing early childhood intervention services?

R2: Is there a difference in the perceived barriers encountered by families who did and did not access early childhood intervention services?

R3: What barriers medical and educational professionals perceive impact a family's access and utilization of early childhood intervention programs?

### **Mixed-Methods**

R4: What effect, if any, does parental empowerment have on those families who did and did not access early childhood intervention services?

### **Qualitative**

R5: What are, if any, the discrepancies between the views of parents and professionals regarding the access and utilization of early childhood intervention services?

R6: What are the parents' knowledge, feelings, and thoughts when attempting to access early intervention services?

R7: What evidence of empowerment to advocate in their child's best interest is shared in the respondents' expressions/stories?

## Theoretical Framework

The framework for this study drew from critical race theory, equitable literacy, and transformative learning to guide one's view on external and internal factors that influence the minority access and utilization of educational and healthcare services. One can assume to be critical is to pass judgment or make assumptions based on prior experiences. Therefore, what does it mean to be critical? Works of the *Frankfurt School* during the post-Marx era sought to critique and change society as a whole to liberate those who were oppressed and dominated to seek human emancipation (Horkheimer, 1982). Horkheimer stated critical theory is “emancipation from slavery”, acts as a “liberating . . . influence”, and works “to create a world which satisfies the needs and powers” of human beings (1982, p. 246). Marx believed a capitalist society forms social systems within nations where the dominant groups of prestige and money circumvent the power structures of the haves and have nots (Sowell, 1967). Therefore, a persons' knowledge is not solely obtained systemically, but through subjections of their reality (Chapman, 2007). In addition, Habermas' (1971) development of the *Communicative Action*, which states people have a consensus to uphold the powers that perpetuates the system of those who are able to access supports (Chapman, 2007). By all means through reflection and deliberation, we are made aware the democratic process is not built on a hypothetical-deductive model to prove a point, instead enabling learners to create an understanding of societal influences through dialogue and interpretation (Chapman, 2007; Habermas, 1971). Mezirow, whose work was influenced by the contributions of Habermas (1971), believed that societal change comes through critical reflection and trans formatively being able to identify the levels of hierarchies and positions that subordinates those outside of the hegemonic group (Chapman, 2007; Mezirow, 1991).

Transformation from a personal perspective is the foundation to changing a society and liberating those who are oppressed, in this case, access to services (Chapman, 2007).

In relation to Black families, one must look at the meaning of race to see how the criticality applies to a particular nation of people. Therefore, Du Bois (1897) addressed in a speech what constitutes a group as a *race*.

[I]t is a vast family of human beings, generally of common blood and language, always of common history, traditions and impulses, who are both voluntarily and involuntarily striving together for the accomplishment of certain more or less vividly conceived ideals of life. (p. 53).

Ladson-Billings (1998) cautioned that viewing race as an ideology denies the lived experiences in a racially charged society. Albeit, racism is not gone, reduced, or limited when a person from the norm has a friend from the minority. Even more so, racism is enhanced by those from higher echelons with access and privilege who continue the cycle of inferiority (Delgado & Stefancic, 2011). Along the lines of race, one can ask what does it mean to be critical and aware of race, and furthermore, what is critical race theory?

Critical Race Theory (CRT) is a call to action from the legal scholarship that holds racism is a normal everyday experience and believes the true beneficiaries from the civil rights movement are Whites (Ladson-Billings, 1998). Delgado and Stefancic (2011) defined CRT from the origin of legal studies “as a movement a collection of activities and scholars interested in studying and transforming the relationship among race, racism and power” (p. 3). Whiteness in a racially charged society is classified as the norm (Ladson-Billings, 1998). Therefore, Freeman and Bell, in the 1970s, were appalled at the slow pace of social reform and transformation (Delgado & Stefancic, 2011). Practically, Ladons-Billings (1995) described CRT as a perspective that looks at racism as a normal occurrence, but not an isolated event, and constitutes this as a fixture in the norms of

American life (Pitre et al., 2015). Common pillars amongst scholars of CRT are anchored by (a) racism is ordinary and not acknowledged, (b) White prevails over color, and (c) race is socially constructed to be manipulated and extinguished when convenient (Delgado & Stefancic, 2011). CRT as a tool is aimed to deconstruct oppressive structures, reconstruct human agency, and construct equitable-accessible-justified social structures (Ladson-Billings, 1998). In particular, CRT seeks to bring a voice of the minority into the mainstream conversation derived from historical context and experiences to reconstruct a society (Barnes, 1990; Ladson-Billings, 1998).

Because Pitre et al. (2015) described *diversity* as a tinker within the system to make its outputs slightly less awful; by leaving untouched the fundamental shape, scale, and purpose of the system itself, it extends these inequalities. As an educator, Ladson-Billings (2005) cautioned us that by focusing on race and its impacts on children's educational experiences, we miss the bigger piece, which is the robust contextual aspect of the racial story. Therefore, *multiculturalism* has become a buzzword, neutralizing the racial experience to an input and output system that negates the dichotomies that both educators and students bring into the classroom (Banks & Banks, 2009). Banks and Banks (2009) further added that multiculturalism is a limitation in meeting the needs of ethnic communities because a pretense is created that acceptance and translation meet the need of an integrated culture.

Equitable literacy is a move beyond the generalization of culture to unmask the underpinnings that causes the educational disparities (Gorski, 2020). Drawing from the work of Gorski (2016), accessibility that impacts a person's ability to be responsive because the systems in place have been created around those who have had access. For example, Vavrus (2015) described our society as being wedded to a capitalist economy premised on private accumulation and concentration of wealth, social conservatism, and

liberal multiculturalism offer[ing] no meaningful structural answer to eliminate economically daunting conditions that low-income families and their school-age children face each day.

Consequently, by not doing so, Gorski (2017) highlighted our need to understand the structural barriers that cheat some people out of the opportunities enjoyed by other people. A blind conscience does not serve the purpose either by thinking that we all have access. Gorski prompted individuals and organizations to reflect on their current practices to determine if [opportunities] redistribute access or punish people for their lack of access. In conclusion,

when stereotypes creep into educational practice, policy, and programs, educators and policymakers risk justifying injustice, explaining away failure (including our failure to insist upon equitable educational access) and adopting misguided reform efforts, such as those aimed at redressing inequalities by “fixing” poor people rather than the conditions that disenfranchise them (Gorski, 2012, p. 314), it becomes increasingly difficult for minorities to find and access the services they need.

Graham, Brown-Jeffy & Aronson et al. (2011) explained that racism happens to both a group of people and individuals and is a phenomenon that reaches across paradigms. Critical race theory posits that race is a socially constructed variable (Ford & Airhihenbuwa, 2010). Dababnah et al. (2018) argued the *Public Health Critical Race Framework* (PHRMC) is applicable to families with children who have a disability. The PHRMC was based on the Behavioral Model of Health Services (BMHS), in which Andersen (1995) looked at an equitable access to healthcare model that includes phases that view the external healthcare environment, population characteristics, and behavioral outcomes as variables people experience to obtain health services (Andersen, 1995).

Ford and Airhihenbuwa (2010) expanded on CRT to include a perspective on the public health and behavioral response of patients affected with socially sensitive diseases and their ability to get tested. They built on the model of Andersen (1995) who looked at access to healthcare as a series of phases that include the environment, population characteristics, and behavioral outcomes. Ford and Airhihenbuwa (2010) stated PHRMC is a healthcare model that melds the views from critical race theory and a behavioral model of healthcare utilization, then challenges the notion that race is a predeterminer in the health outcomes of minorities. A study of Blacks with HIV by Ford and Airhihenbuwa examined whether race is a barrier to accessing readily available healthcare for persons with a socially sensitive disease. During the 2-year study, they examined external factors as indicators that influenced people to utilize testing services through the lens of structural racism (Ford & Airhihenbuwa, 2010). Their study controlled for being of the Black race to measure for racialized experiences marginalized people encountered through daily interactions in their neighborhood or individually (Ford & Airhihenbuwa, 2010). Ford and Airhihenbuwa sought to characterize the main themes of the access to care model widely used to examine behaviors in a clinical setting by identifying variables under headings such as external environment, associated with neighborhood, or income (Andersen, 1995). Other enabling factors could be education level, income, or insurance coverage (Dababnah et al., 2018). For change to take place to understand the inhibitions of Blacks' encounter to access to and utilize services, critical reflection of decision makers and deliberation of the policies and paradigms will aid in the reconstruction of education, healthcare, and social systems.

### **Transformative Liberation**

There is still a need to discuss the critical processes of the adult role in shaping the future for early learners. A critical inquiry into the underlying assumptions, beliefs,

and routines that extend beyond the binary inputs and outputs of information can cause a societal shift through a transformation. Mezirow and Associates (1990) emerged from the works of Freire (1970), both of whom sought to create societal change for marginalized communities through critical reflection and discourse.

### **Freire**

Freire believed in educating the poorest of the poor; that liberation comes by educating people at their level. Therefore, to further a person's knowledge, one must not negate the premises of their environment. Freire (1970) described education as the path to permanent liberation as people become aware of their oppression. By doing so, liberation comes from cultural action that facilitates a permanent process (Freire, 1970). He cautioned against "banking education," which resists dialogue as an authoritarian educational system that deposits information and isolates the learner from the content and process of education (Freire, 1970). For example, an assumption is the teacher knows everything; the students know nothing, and therefore the families know nothing. The professionals are the holders of all information as demonstrated by medical and education professionals who narrate, prescribe, and deposit information which the parent then must mechanically receive, memorize, repeat, and apply (Freire, 1970; Merriam, Caffarella, & Baumgartner, 2007). By this process, the transfer of information becomes an emblem and an instrument of oppression that inhibits inquiry, creativity, and dialogue. Freire made it clear that banking education dichotomizes consciousness and the world, thereby controlling reality.

Consequently, as subject teachers, this static and naturalistic conception of consciousness "transforms [families] into receiving objects" causing them to be integrated into the world of the oppressor—a world that is based on the dehumanization of the oppressed" (Merriam & Cafarella, 1999, p. 58). He proposed the notion of

conscientization as a process where the individual increasingly becomes aware of the oppressive conditions that, in return, can motivate them to change (Freire, 2000; Merriam et al., 2007). Dialogue is a start to the liberation of the oppressed from stories of mothers and their children, their definition of a developmental delay, and how they feel when having a pointed discussion with a health professional.

### **Mezirow**

Transformational learning is defined as the change wherein we see ourselves and the world in which we live through meaning and understanding we capture from our surroundings through hues of life (Chapman, 2007; Merriam et al., 2007). A person's level of transformation depends on their quest for change. There are three components to transformational learning: experience, critical reflection, and development (Merriam et al., 2007). Mezirow and Associates (1990) claimed "learning is understood as the process of using prior interpretations to construct a new or revised interpretation of the meaning of one's experience that serves as a guide of future action" (Cafarella, 1999, p. 319). Harken back to the Emancipation Proclamation as document that created freedom. Mezirow et al. stated change is emancipating in that one is freed from previously held beliefs in that as adults we try to define our world and create meaning from our experiences. Instead, not all situations create change, but rather a disorienting dilemma. A dilemma that causes individuals to self-reflect and make critical assessment of their underlying beliefs, values, and assumptions and grapple with the new idea of rejection based on their previous stance (Chapman, 2007). By happenstance, individuals reach a point of facing adversity and bouncing back as they learn what actions are appropriate for a situation to implement change.

Mezirow built on many other theories such as Freire's (1970) because essentially, transformation comes from liberation. Initially, we first identify our thought pattern and

strive to define our world. Merriam and Cafarella (1999) said learning starts with us, and growth depends on our desire to go beyond our present circumstances. Linear, binary reactions limit and negate the rich experiences that various individuals and groups bring to the forefront. When barriers are approached as binaries, a reduction is created as a right-or-wrong or yes-or-no situation for families. Oakeshott (1962) explained a technical approach is formulated into black and white images classified as rules and policy imprinted into a book and used as a manual. In order to initiate change, Chapman (2007) described deliberation as a vehicle to facilitate a meaningful conversation.

Given the study's examination of the relationship between a marginalized population's access to healthcare and educational services, this study's lens was framed around the family-centered model. A family is a social unit embedded within direct and indirect cultural paradigms where the child's behavior is influenced by matters beyond their control and familial interactions (Dunst, 2014). Viewing a family as a unit of cross interactions can facilitate intervention and better meet the needs of the family. Applying this framework should predict that parental access to and utilization of early childhood intervention services are impacted by underlying disparities and assumptions related to their prior experiences with the healthcare systems.

### **Definitions of Key Terms**

*Access* is defined as “actual use of personal health services and everything that facilitates or impedes their “use” and “the link” between health services and people who receive the “right services at the right time to promote health outcomes” (Andersen, Davidson, & Baumeister, 2013, pp. 33-34).

An *Advocate* is described as a parent being a “fighter” to obtain the needed services for their child; a “guardian” as the one to protect and shield their child from unformed, disconnect, and incompetent professionals; and “expert” in knowing their

child and severity of their condition (Lutenbacher, Karp, Ajero, Howe, & Williams, 2005, p. 174).

*Barriers* are the language and cultural differences of a family, lack of understanding of linguistic and cultural diversity by professionals, and lack of support from the systems that influences a family's participation in serviced-based programs (Zhang & Bennett, 2003).

*Child find* is the process used to identify, locate, and evaluate children with disabilities who need special education and related services and the requirement in section 612(a)(1) of the IDEA, to make available free appropriate public education (FAPE) to all eligible children with disabilities residing in Texas (OSEP, 2018, p. 2).

A *Community health worker* "is a lay health educator from the target community who provides health information to others that is a culturally relevant way to reach marginalized communities to disseminate evidence-based information" (Lopez, Magaña, Morales, & Iland, 2019, p. 3).

*Culture humility* is "a process of openness, self-awareness, being egoless, and incorporating self-reflection and critique after willingly interacting with diverse individuals. The results of achieving cultural humility are mutual empowerment, respect, partnerships, optimal care, and lifelong learning" (Foronda, Baptiste, Reinholdt, & Ousman, 2016, p. 213).

A *Developmental delay* means for children under Part C based on quantitative and qualitative measures that are set at the discretion of the state and local education agency criteria, include a child experiencing a developmental delay as measured by appropriate diagnostic instruments resulting in a difference between actual performance and chronological age, or standard deviations below the norm reference in one or more of the following areas: physical development; cognitive development; communication

development; social or emotional development; or adaptive; that places them in need of special education or related services. Qualitative factors are indicated through observed atypical behaviors or development (Shackelford, 2006).

*Early identification* is a broad range of methods, procedures, and practices, such as increased physician referrals and caregiver responses, as measures to initiate a referral for EI services to determine the presence of a condition or identified disability that results in a developmental delay or places a child at risk for a developmental delay or poor outcomes (Dunst & Trivette, 2004, 2009).

*Early intervention* “Part C early intervention is an interagency program for the coordination of efforts within and across community and governmental agencies to address the needs of infants and toddlers with developmental delays and their families. States are given considerable latitude by IDEA in defining a developmental delay for the purpose of defining eligibility for Part C early intervention services” (Rosenberg, Ellison, Fast, Robinson, & Lazar, 2013, p. 384).

*Eligibility* includes the procedures and criteria used to determine if a child meets the definitions for Part C program enrollment that is not limited to quantitative and qualitative measures but also include clinical opinion. Clinical opinion that is derived from standard measures and a consensus formed by a multidisciplinary team with information obtained from the parents and multiple sources (Shackelford, 2006).

*Empowerment* is naming, analyzing, challenging oppression on an individual, collective, and/or structural level that occurs through critical consciousness, is gaining control, exercising choices, and engaging in collective social actions that is transformed from individual strength into collective power (Bernard & Bernard, 1998, p. 46).

A *family-centered model* is a service-oriented model that is based on parental choice that includes various family members input and support that are built on the

family's strengths in collaboration with early childhood service professionals (Corr, Santos, & Fowler, 2016; Dunst, Bruder, Trivette, & Hamby, 2006).

*Health literacy* includes “skills required to derive meaning from written words and numbers” from health-based materials (Hibbard et al., 2008, p. 1443).

*IDEA Part B Section 619* is also known as The Preschool Grants Program, a federal grant program intended to help states ensure that all preschool-aged children (age 3-5) with disabilities receive special education and related services in their least restrictive environment. The goal of preschool special education services is to enable young children to be active and successful participants in home, school, and community settings resulting in positive outcomes for children and their families (ECTA, n.d.b).

*An Infant or toddler with a disability* means children under 3 years of age who are in need of early intervention services due to a delay in one or more of the following areas: cognitive, physical, communication, social or emotional, adaptive development; or who have been diagnosed with a physical or mental condition that has increase chance of resulting in a developmental delay (Individuals with Disabilities Education Act, 2017).

*A Natural learning environment* “natural learning environments are places, settings, and activities where learning opportunities or experiences exist for children from birth to 3 years of age” (Dunst & Bruder, 2002, p. 362).

*Part C of IDEA* “authorizes states to provide early intervention services for infants and toddlers with a developmental delay or diagnosed physical or mental condition associated with developmental delay” (McManus et al., 2014, p. 1031).

*Parental empowerment* is the outcome of the process created that has stimulated their conscious awareness as an internal sense of power in a parent's feelings of their ability to have control in their circumstances. Constructively demonstrated as them using their voice to advocate, take action, and gain access to resources, such as locating and

using external services that could assist when raising a child with a disability (Damen et al., 2016; Dempsey & Dunst, 2004; Kim, 2012) .

*Perceptions* are parents' level of consciousness and awareness to their environment that relates to their needs; their capacity for comprehension to notice judgements from others; and level of satisfaction with the process to obtain ECI services (Merriam-Webster Dictionary, 2019; Scarborough et al., 2004).

A *Professional* "is one who not only possesses and uses special expert knowledge and skill, but who serves the public good", or "professes' a special expertise for the good of society" (Chapman, 2007, p. 328).

*Poverty* is defined as characteristics that include families with lower education attainment, under or lack of employment, and lack of health insurance that results in family's underutilization of social service delivery models (Corr et al., 2016).

*Referrals* are the procedures or steps taken by an individual or group on behalf of an infant, toddler or preschooler to obtain the opinion, supports or services of another individual or group for a child; encompasses a range of activities influencing decision-making processes used by primary referral sources to recommend or suggest provision of early intervention or special education and the decisions made by parents to seek out early childhood intervention program practitioner opinion or advice (Dunst & Trivette, 2004).

A *Screening* is the use of a standardized tool to identify the risk of a developmental delay (Guevara et al., 2013).

*Utilization* is the action of a family qualifying for resources, but not necessarily using the available services (Arcia, Keyes, Gallagher, & Herrick, 1993).

## **Conclusion**

This chapter discussed the need to discover the perceived barriers Black families encounter when accessing and utilizing services aimed at addressing concerns for their children with a developmental delay or disability. In addition, this chapter presented an overview of the research problem and the significance of the study. Chapter II provides an exhaustive review of the literature that considers the external factors that influence minority reactions to accessing and utilizing intervention services.

## CHAPTER II: REVIEW OF LITERATURE

The purpose of this study was to explore the perceived barriers preventing Black families from accessing (completing intake process) and utilizing (follow through with the support) early childhood intervention services. To appropriately address how to increase the participation rate of Black children in early childhood intervention programs, the factors that influence a family's participation need a thorough examination. Significant growth is happening in our nation's cohort of 386,155 infants and toddlers who make up 3% of the child population (Davis, 2020). A troubling picture arises as state funding for Texas ECI programs has been reduced by 11% since 2011, having a disproportionate impact on Black children whose ECI enrollment has declined by 27% (Hornbach & Rubin, 2016). Given this, there is an anticipated need to increase enrollment to provide early supports for the youngest children as the national minority population continues to grow. Blacks, Hispanics, and Asians are on the trajectory to surpass the Caucasian race in the next few decades (Pitre, 2015). There are contradictory theories as to why Black children continue to lag behind their counterparts in receipt of early intervention services. As Feinberg et al. (2011) pointed out, the number of Blacks receiving early intervention services declined from 18% in 1998 to 13% in 2007. Further, data from 2017 revealed Black children represented 12.1% of children eligible for ECI (U.S. Department of Education, 2019). Given this steady decline, evidence supports the need for further inquiry. Additionally, Black infants, once referred, were less likely to be tested for developmental delays until they presented with a recognizable condition; instead, hidden tendencies that require further surveillance were overlooked (Feinberg et al., 2011; Khetani, Richardson, & McManus, 2017; Zuckerman, Mattox, Sinche, Blaschke, & Bethell, 2014). Consequently, Morgan, Farkas, Hillemeier, and Maczuga

(2017) argued that Black children are being enrolled at greater rates in school-age special education programs but remain underrepresented in ECI programs that could help decrease the impact of their developmental delays (Morgan, Farkas, Hillemeier, & Maczuga, 2012). As recently in 2020, Black children, on average, were diagnosed at 64.9 months; roughly 3 years after a parent's first concern was reported to the primary care physicians. This points out the implicit biases and systemic racism that keep them from accessing EI services (Constantino et al., 2020).

Depicting institutional racism through a gardening allegory, Jones (1999) described the *gardener* as the government or institutions that control the resources and responses to disparities between groups (the two planters with different types of soil). Rather than recognizing that the planter with poorer soil will produce weaker plants (the codified practices, laws, norms and criteria that hold minorities back), the gardener, unless recognizing the different resources available between the two planters, blames the plants in poor soil for failing to flourish. This explains the need for children to be serviced at the earliest age possible; it has the potential to reduce the third-grade special education population by 10% (Dodge, Bai, Ladd & Muschkin, 2017).

To contextualize the variables that impact parents' access and utilization of ECI programs, this chapter presents an exhaustive review of the literature. This representative view of the literature discusses the various components that influence a parent's ability to access services, follow through with the referral process, and further explores their sense of empowerment through the cycle of ECI.

To truly understand the interconnectedness of cultural, societal, and historical contexts that impact educational and healthcare disparities, there needs to be acknowledgment and action taken from the lived experiences of Black families (Artiles, Kozleski, Trent, Osher, & Ortiz, 2010; Vavrus, 2015). Morgan, Farkas, Hillemeier, Li et

al. (2017) stated that the monolithic methodologies that mute the risk factors for determining enrollment in special education programs cause a false narrative that should not be oversimplified (Skiba, Artiles, Kozleski, Losen, & Harry, 2015). Depending solely on the binaries of race and enrollment fails to take into account all the factors that result in enrollment disparities for early intervention services for children of color (Ladson-Billings, 1995). After all, as Cornel West (2012) said, you can't really move forward until you look back by placing yourself in a narrative of our history.

This chapter begins with a look at the history of early childhood education and intervention, elements of IDEA and Child Find, and barriers to access and utilization and elements of IDEA. Cultural and familial factors impacting access to and utilization of services are examined, before addressing issues which are reflected by ECI enrollment rates of different racial groups. Because this study focused on services offered through Texas programs falling under the Child Find legislation, elements of this program, its funding, and how it is implemented are also presented.

### **Early Childhood Intervention: History and Implications**

On the back of the civil rights movement fighting for equity and inclusion for Black Americans came the added attention to young children with disabilities. In particular, *Brown vs. the Board of Education* prompted further attention to populations not only limited by race, but by ability (Ramey & Ramey, 1998). Recognizing the value of early childhood intervention (ECI) for children and families from diverse ethnic, cultural, and socioeconomic backgrounds, moves our society beyond the limit of “my” children to celebrates “our” children. A review of the historical implications and social determinates that have shaped the policy and supports for special education for young children is needed (Jones, Jones, Perry, Barclay & Jones, 2009). In 1985, Senate Bill 2294 aimed to create universal access for children with disabilities from birth to age 3

(Florian, 1995). In order to garner bi-partisan support for the bill attention was given to the economic savings accrued through lower special education costs (Florian, 1995; Gomez & Rendon, 2019). Senator Lowell Weicker of Connecticut used his personal experience as a father of a child with Down's Syndrome to garner his colleagues' support for Part H that aimed to provide services to all families from age birth through 2 years, not limited by geography, age, or disability (Florian, 1995). A rationale for early intervention revealed that children most at risk for cognitive disabilities and poor school readiness were from families of lower socioeconomic status and maternal educational attainment of 10th grade or lower. These situations led to the societal defects of increased juvenile delinquency, teen pregnancy, and underemployment (Ramey & Ramey, 1998) and were an outgrowth of the civil rights era and its demands for equality for all (Bartlett & Mickelson, 2019).

Early childhood has been defined as a continuum starting from in-utero rapidly progressing through a predictable cycle of development, displayed by acts of learning to move, speak, and interact with their environment, and, most of all, play (Barger, Rice, Simmons, & Wolf, 2018; Cole, Oser, & Walsh, 2011). Prior to the aforementioned legislation, the attention on early childhood education focused on both typically developing children and children with disabilities. In 1856, the first kindergarten school was founded in the United States (McLean, Sandall & Smith, 2016), inspired by German kindergarten programs that were in place to support the emotional and developmental needs of young children. This model worked well for typically developing children and increased equality in education for women and girls. Parents were encouraged to keep children with disabilities at home or institutions rather than exposing them to mainstream society (McLean et al., 2016). Parental grassroots began in the 1970s when it was observed that 1 million children with disabilities lacked equal access to education or

services. These movements drew attention to the need for equality for all children, leading to the creation of *Headstart* programs used to improve outcomes for children living in poverty. Subsequently, early childhood intervention was begun at birth for those with obvious etiologies such as physical or mental deficits along with hearing loss or Down's syndrome (Rosenberg, Robinson, Shaw, & Ellison, 2013). The field of early childhood special education is still in its infancy, marking 45 years since the passing of the first special educational law, P.L. 99-457, specific to children from birth to 3 years old (McLean et al., 2016).

### **First Generation of Individuals with Disabilities Act Part B Section 619**

Prior to 1988, states were incentivized by grants to serve children aged birth to 3, and Headstart programs for children 3 to 5 years were mandated to have 10% of their enrollment made up of children with disabilities (McLean et al., 2016). The early childhood component, Section 619 of IDEA Part B, was intended to meet the needs of preschool age children (ages 3 to 5) with a disability by providing them with services under the auspices of a Free Appropriate Education (FAPE) to take place in the least restrictive environment (LRE) (ECTA, n.d.a), but the gap remained for children from birth to 3 years before being formally enrolled in a school-based program.

### **Second Generation of IDEA as Part C**

In 1997, the reauthorization of the Education of all Handicap Children's Act was renamed the *Individuals with Disabilities Education Act (IDEA)*, and Part H was changed to Part C (Ramey & Ramey, 1998). As a dedicated portion of legislation for Early Childhood Intervention (ECI), the purpose of Part C is to provide services for children from birth until their 3rd birthday who have or are at risk of a developmental delay and their families, using a family-centered model to assist with school readiness (Bruder, 2010; Feinberg, Silverstein, Donahue, & Bliss, 2011). Under Part C, the change to the

law was reflected in the eligibility, service models, and location for the services (i.e., natural environment) for the impacted children, with a particular emphasis on building family capacity (Bartlett & Mickelson, 2019). Also, the research focus for ECI shifted from whether the intervention works to what works and under what condition. Particularly, researchers seek to account for parental sensitivity and the necessary interventions for sub-groups that ranges from the conceptualization of outreach to dynamic assessments that form a holistic measure (Guralnick, 2011; 2017). Bartlett and Mickelson (2019) contended the influence of power, privilege, and culture places nondominant communities in a deficit position that adds to the one-size-fits-all approach to servicing families.

### **Pillars of IDEA**

The pillars of IDEA span across all categories of Part B and Part C, while there are some notable differences related to infants and toddlers. This section will introduce the pillars as well as discuss the distinctions between Part B and Part C.

IDEA legislation was passed to ensure that no individual, of any age, socioeconomic status, or disability type would fall through the cracks of the educational and treatment systems. There are six “pillars” which highlight critical areas which ensure proper functioning of the IDEA: Individual education plans (IEPs), free appropriate public education (FAPE), least restrictive environment (LRE), appropriate evaluation, parent and teacher participation, and procedural safeguards.

The pillars of Part C that are similar to Part B school-age requirements are focused on ensuring children receive services and are educated in the LRE with a FAPE, zero rejection, engaged in non-discriminatory assessment, adhere to a procedural process, and required parental participation. While Part B requires the development of an Individual Education Program (IEP), Part C, as a family-centered model, requires the

development of an Individual Family Service Plan (IFSP) which seeks to build families' capacity to integrate the supports into daily routines and activities (Bartlett & Mickelson, 2019; Brown, McMullen & File, 2019). An IFSP is a legally binding document created by a multidisciplinary team that captures the strengths and needs of children within their natural environment in order to enhance the ecological capacity to meet the developmental needs of infants and toddlers (Guralnick & Bruder, 2019).

A push in the second generation of EI research is the position that children should have universal access to programs in an inclusive environment to maximize participation in all community or school-based activities (Guralnick & Bruder, 2016). In 2017, 90% of infants and toddlers enrolled in a Part C program were serviced at home compared to 8% in community placements (U.S. Department of Education, 2019). Consumers of EI programs were primarily families living below the poverty line; Corr et al. (2016) pointed out that as many as 49% of infants and toddlers are poor, surpassing the percentage of adults in this category. Based on these conditions, children with disabilities are *doubly* vulnerable to failure to participate in services. A family-centered approach is an umbrella for the natural learning environment modeled where parent choice is honored. This includes cooperation of family members and collaborations with early intervention professionals that takes place in everyday places where learning and opportunities are accessible to the young child. For economically vulnerable children, additional factors should be considered, such as disruption to the family routine and the family's ability to support the demands that comes with participation (Bruder, 2010; Corr et al., 2016). A challenge lies in implementation of the intended law, research, and best practices by service professionals to make the link with families that may reshape the pillars of IDEA to meet the needs for families of young children (Bruder, 2010; Dunst, 2007).

This section sought to identify the primary pillars of IDEA which include the principles of zero reject, free appropriate public education, least restrictive environment, due process, nondiscriminatory assessment, and mandates for parental participation. Also presented were distinctions between aspects of Part B (applicable to preschool aged children) and Part C (involving children birth through age 2). In providing distinctions for service delivery, considerations associated with natural environments versus the least restrictive environment, research was presented to demonstrate infrastructure considerations as well as parental preferences. Given the access to point to services lies within Child Find and the referral process outlined in IDEA, the next section will both describe these elements and offer a synthesis of research which describes practices and considerations.

## **Child Find of IDEA**

### **Child Find Components**

The specific components for CF include public awareness, outreach programs, community-based screening programs, risk registers, tracking programs, and partnerships and collaborative projects that promote referrals to EI or ECSE programs (Dunst & Trivette, 2004). Public practices are ongoing outreach efforts, communicating to the public about available resources and the importance of child development, using the influence of opinion leaders to support and deliver a tailored message to the community. A point of caution for EI programs is not to assume intrareliability with primary professional referral sources and seek to work in conjunction to have a streamlined application. An ongoing practice involves community screenings which are intended to be easily accessible (i.e., child care programs, community fairs) to eligible populations. In addition, risk registries are commonly used to identify the children with predetermined conditions or those at risk (i.e., child protective registries) to track and periodically

monitor a child's progress. Table 2.1 outlines evidence-based practices related to the major categories of CF (Dunst & Trivette, 2004). Dunst and Trivette (2004) encouraged the use of evidence-based methods from both health and educational entities as tools to close the referral gap.

Table 2.1

*Evidence-Based Practice that Support Components of Child Find (Dunst & Trivette, 2004)*

Major Categories of Child Find Practices	
<i>Public awareness</i>	Public communications campaigns Social marketing Public service announcements Printed materials Message Framing
<i>Outreach programs</i>	Outreach to physicians Outreach to hospitals Community outreach Academic detailing Opinion leader practices
<i>Community-based screening programs</i>	Community fairs Child care programs Child development screening days
<i>Risk registries</i>	Birth defects surveillance programs Newborn medical screening programs Newborn hearing screening programs Child protective services registers
<i>Tracking programs</i>	High risk tracking systems “Staying on Track” programs Service coordination
<i>Partnership and collaborative projects</i>	Physician office-based programs Hospital-based programs Health care. Early childhood provider partnerships

Developmental milestones are key component in EI to provide universal understanding of children’s abilities from birth to 5 years. Policies, curricula, programs, and funding all draw from hierarchical set of based norms used portray developmental status of young children (Scarborough, Hebbler, Spiker, & Simeonsson, 2011). Child

growth in EI is measured by attainment of the expected skill and chronological age and success is determined by whether they mastered (survived) or did not master anticipated developmental skills. However, this model fails to account for the complexity of working with young children and families because of the heterogeneity of the population and measuring meaningful outcomes. In Scarborough et al.'s (2011) study they used survival analysis, a common method used in medical and biological sociology to measure time-based events, and suggested use in education provides a measure of change with regard to an event with a specific time point and allows determination of factors that may indicate timing for future events. Data from the National Early Intervention Study (NEILS), looked at 3338 infants and toddlers who received EI services and found the survival function for children with developmental delays in all domains (i.e., cognition, communication, motor, and independence) who entered kindergarten after participating in a Part C program failed to achieve milestones expected for their age. Notably, children who participated in EI and enrolled in kindergarten receiving special education services who failed to master earlier developmental milestones outpaced children with a disability who did not receive services. For example, children's cognitive abilities revealed pronounced disproportions for children who did or did not receive services; 55% of kindergarteners with no disability attained their developmental milestones compared to 16% of these who received special education services and 33% of those with a disability who did not receive special education services (Scarborough et al., 2011). These finds suggest that the variability in the disability characteristics at time of entry into a Part C program strongly impacted their survival function rate.

Contrastively, this section of the literature presents an area for further investigation into how potential factors in Part C implementation may non-favorably affect participants outcomes. Particularly, the perceptions of those from ethnically diverse

backgrounds adds to the need for a deeper analysis. Considering the established norms for child developmental attainment, there is a need to recognize the institutionalized practices that may close off opportunities for children of color while opening the door for others. Professionals should thoughtfully advocate for children and families culturally and linguistically, including languages and dialectical implications on developmental outcomes (Lester & Andres, 2014)

### **Public Awareness**

As a foundational component of IDEA, CF is a mandate for EI programs to close the developmental debt for children who access EI services. The intent of CF is to have a reciprocal relationship between agencies and family, but the burden is on the service organization to identify and locate children and families and to provide an evaluation for any child who is suspected of having a disability, medical condition, or developmental delay from birth onward (IDEA, 2004). The pillars of IDEA are fashioned as a hierarchical classification system, similar to a library catalog structure, made up of practices (i.e., referral, evaluation, and eligibility) that are not mutually exclusive or dichotomous (Dunst & Trivette, 2004). Therefore, states are required to develop a comprehensive Child Find (CF) system that includes:

A public awareness program focusing on early identification of infants and toddlers with disabilities, including the preparation and dissemination by the lead agency . . . to all primary referral sources that include physicians, local education agencies, public health facilities, social service agencies and hospitals and physicians, of information to be given to parents, especially to inform parents with premature infants, or infants with other physical risk factors associated with learning or developmental complications of the availability of early intervention services .....(118 STAT. 2747)

Accountability is placed on states to seek out the children even if they do not have working knowledge or reasonable suspicion of a disability (Raj, 2015). However, demographic shifts in our nation necessitate the lens of cultural perception of a disability on the CF mechanisms to be considered as vital measures needed to effectively reach all children (Stone, 2005).

### **Outreach Programs**

Given the components of CF, Dunst and Clow (2007) examined the implemented efforts made by education agencies in reaching children and families eligible for services. Dunst and Clow looked to ascertain whether public awareness evidence-based measures were effective in promoting and sustaining referrals to EI programs. From the six major categories of CF practices indicated in Table 2.1, public awareness is the more significant form of outreach used by Part C programs. Dunst and Clow organized outreach methods (i.e., information campaigns, referral or practice guidelines, feedback to physicians, outreach to physicians) on a scale of organizational interventions to explore links to primary and secondary providers (Dunst & Clow, 2007).

#### *Minority Outreach*

Parenting practices differ across cultural boundaries. To address the generalizability of cultural adaptations made to evidence-based practices to improve consumer participation, Lau (2006) derived a framework from parental training targeted towards minority families to increase their buy-in for children's mental health services. Lau (2006) explained that cultural and ethnic experiences influence parental receptivity to outreach efforts. Individuals and families in the most need of assistance are likely to experience more significant barriers; therefore, the initial communication should be targeted towards the parent's problem-solving abilities based on the family's condition instead of utilizing a broadly prescribed approach. Detailed attention in how a program

advertises itself as an educational or therapeutic entity makes a difference in the perception to families of color because a deficit takes precedence when presented as therapy or an intervention (Lau, 2006). Within Lau's research, parents noted they are less likely to see the connection between therapeutic activities without a clear link to how these supports reduce behavior problems. Marked improvement to reach Black families is seen with structural changes (i.e., community network recruitment, ethnic provider match, support groups in community or church locations, and addressing basic living needs). In parallel, Mexican American mothers have heightened sensitivity when programs try to change parental corrective behaviors because they already come from a place of guilt, instead respond better when presented in a non-blaming manner. Meanwhile, Black families are more responsive to programs when teaching behavioral strategies with a strong connection to racial socialization that teaches children and families how to navigate their environments. Lau (2006) cautioned that the dimensions of cultural adaption to marketing efforts remain at the surface-level but need systemic-structural changes to show marked improvements that is considerate of the global perspective.

### *Health activation*

CF has an activation component that is assumed to be an obvious feature geared toward children and families. Cultural and racial implications, coupled with social-environmental factors, influence minority self-management of care. In conjunction with Stone's (2005) view of the consumer instead of patient, Hibbard et al. (2008) analyzed consumer activation as a person's willingness and ability to manage his or her health care; in this case, for a child that includes preventative care (i.e., developmental screener) or seeking information such as knowing the different treatment options or available programs.

### *Predictive Child Find Factors*

A primary intention for CF is to provide a referral for evaluation. Tracking referrals is a function of CF; however, programs report lack of staff, funds authorization for reimbursement and coordination between screening programs and agencies are notable barriers (Jennings & Hanline, 2013). Findings suggested minority families with an income below the poverty line and presence of a health or social concern were strong predictors for not completing the referral process. A majority of the completed referrals were characterized by families of White children from a higher SES and were eight times more likely to complete the process. Further, girls, in the same demographic were 12 times more likely to complete the CF process. Referrals are the initial component that creates an opportunity for a child to be screened for further evaluation (Bruder, 2010). If the child is eligible for further testing, holistically, an evaluation is conducted which synthesizes a realm of information to include a developmental profile, and appropriate assessments, relevant medical information collected from a multidisciplinary team of professionals. The evaluation, which includes standardized developmental measures, reports the nature of the child's abilities and delays. (Bruder, 2010). However, the first step in the process involves a formal referral to ensure early identification for children who are at risk of developmental and behavioral delays. Referrals can be received from physicians, educators, social workers, counselors or therapists, individuals connected to a family or family members themselves. The following section addresses considerations and implications addressed in the literature pertaining to referrals made by physicians, childcare educators, and indirect sources.

### *Physician Referrals*

Most commonly, pediatricians are a primary source for referrals of young children to ECI. When pediatricians are the parental first line of inquiry, the research reveals that

responses to parental concerns are inconsistent (Yockelson, Linder, & Asman, 2016). Sand et al. (2005) surveyed a random sample of 1617 members of the American Academy of Pediatrics society whose primary area of practice was general pediatrics and found that physicians tend not to consider risk factors such as parental concerns as a signal to make a referral. Only 23% of these physicians reported that they used any type of standardized screening to assess the need for a referral. Time constraints, trained personnel, and lack of adequate reimbursements as barriers that impeded implementation for a screening program, suggesting parental reports used on a standardized measure could help to offset the demand on office personnel and that system-level policies are needed to make these screenings medically necessary (Sand et al., 2005).

It has been noted that physicians are tasked with the added responsibility of referring children for special education evaluations, advising families about the special education process, and staying abreast of the local school system and children's education rights (Hastings, Lumeng, & Clark, 2014). Once children have aged out of Part C, there is still a need for screening. The authors explained that a developmental screener as a milestone checker used at wellness checks can function as a visual support for parents to facilitate conversations about their child's age-related abilities (Hastings et al., 2014).

#### *Childcare-Based Referrals*

Approximately 65% of Black children 3 to 5 years old are enrolled in full-time center-based early childhood programs (U.S. Department of Education, 2018a). Since more than half of children are enrolled in a form of care outside of their home, there is often a need to obtain referral input from childcare providers. Branson and Bingham (2017) examined the impact on referral rates made by childcare providers from privately owned, for-profit daycare centers that served children from 4 months to 5 years of age. A

set of themes emerged from the data that revealed an inability of childcare providers to recognize a developmental delay and the perceived barriers to making a referral, such as child care providers' resistance to communicating such concerns with parents (Branson & Bingham, 2017). The authors noted that child-care providers have an advantage, unlike physicians, to compare developmental targets within peer groups; however, a barrier the providers encountered was the response from a parent being told there is a concern about their child and not having the training to handle such situations (Branson & Bingham, 2017). Branson and Bingham (2017) further suggested child care personnel need training in recognizing, referring, and supporting parents through the early intervention and early childhood special education processes.

#### *Referrals From Providers Using Media With Minority Families*

Reaching the targeted audience for children of color involves a need to examine the various entry points to meet the needs for families and caregivers. While this section addressed referrals from physicians and childcare educators, anyone, including family members, can make a referral for an evaluation within the parameters of IDEA. However, families are often uninformed of the processes, support, and services their children are entitled to receive (Turnball & Turnball, 2002). Jennings and Hanline (2013) emphasized that considerations about the parental interpretation of the referrals reflected a lack of consideration for cultural implications which actually widened the gap for families accessing services. Child Find and referral processes are critical aspects in ensuring access to needed services for children with special needs, as it is only once a child has been referred, screened, and evaluated that they can then consider actual eligibility. This process warrants further examination especially for minority children.

## **Risk Registries**

Federal guidelines are provided that note a minimum that states must use in determining eligibility under Part B that includes parameters of FAPE; a developmental concern such as intellectual disability, emotional disturbance, specific learning disability, physical need, or autism; and services in the least restrictive environment that is provided by qualified personnel (Marks et al., 2015; ECTA,2014). To be eligible for special services under Part C, a child has to show a disability or developmental delay as defined by the Individuals with Disabilities Education Act (IDEA, 2017). States have some flexibility and, as a result, various criteria that define eligibility for ECI; this is challenging with the growing number of premature births, genetic disorders, autism spectrum disorder (ASD), and language delays (Bruder, 2010). Each state has the flexibility to interpret the law that meets their need to assist children with a disability (Cole, Oser, & Walsh, 2011; McManus et al., 2014). By doing so, states establish the threshold for who qualifies; for instance, in Texas a child has to demonstrate a medical diagnosis, auditory or visual impairment, and developmental delay of at least 25% (Scarborough et al., 2004; Texas Health and Human Services Department, n.d.). As a result, these factors can impact the effectiveness of Child Find and make it imperative individuals understand what conditions constitute the need for a referral for an ECI or even ECSE evaluation.

Section 303.111 of IDEA Part C requires states to provide a rigorous definition of developmental delay that states use to guide their programs and set eligibility criteria for infants and toddlers under Part C (IDEA, 2017). To be eligible for special services under Part C, a child has to show a disability or developmental delay in accordance with the IDEA. A developmental delay is defined as

a child whose has a developmental delay of at least 25 percent in one or more areas of development- social emotional, self-help, communication, motor function or cognitive skills—qualifies for ECI services. If the delay is only expressive language development, there must be a 33 percent delay to qualify. (HHS, 2020)

People with more profound developmental delays have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person’s lifetime (National Center on Birth Defects and Developmental Disabilities, 2020).

Minimum criteria states must include that are derived from research-based practices available to all infants and toddlers are included. States are to consider eligibility for medical conditions that have a high probability of resulting in a developmental delay, ranging from chromosomal abnormalities, severe attachment disorders, exposure to toxic substances, fetal alcohol syndrome, congenital infections, disturbances to the nervous system, to sensory impairments (The National Early Childhood Technical Assistance Center, 2012). As previously stated, each state has the flexibility to interpret the law that meets their need to assist infant and toddlers with a disability, but an issue to consider is if a federally establish minimum threshold for eligibility would increase enrollment (Cole et al., 2011; McManus et al., 2014). Cole et al. (2011) posited that the opposite may take place, resulting in a ceiling that has a greater chance to reduce the number of eligible children. For now, states establish the threshold for who qualifies; for instance, in Texas a child has to demonstrate a medical diagnosis, auditory or visual impairment, or developmental delay of at least 25% (Scarborough et al., 2004; Texas Health and Human Services Department, n.d.).

McManus et al. (2014) analyzed states' utilization rates based on narrower eligibility criteria and concluded families' access to services were significantly impacted in states with thinner criteria. Particularly, states with stricter criteria had an unforeseen impact on the eligibility of children with complex medical issues. Considering they would presumably qualify; it creates a hyperbola. In part, children with more complex needs are more likely to be referred to private therapy services compared to a public system of support. The authors suggested the reason for restriction on enrollment was based on stress placed on the system (i.e., need for skilled practitioners) and also the demand on parents coordinating the efforts from a multidisciplinary team and locating services (McManus et al., 2014). In contrast Elbaum, Celimli-Aksoy, Marshall, and Berkovits (2017) found that some states sought to narrow their criteria as a means of containing the expanding costs for providing children and families with EI support.

### **Tracking Programs**

#### *Program Productivity and Data Analysis*

Liebman (2018) highlighted the need to improve outcomes for the entire population and not limit recourses and supports to those who access the agency. As a goal to reach vulnerable populations a particular type of data analysis makes a difference throughout how the service delivery chain is implemented to in order to reengineer the process for continuous improvement. Commonly organizations are stifled in their reengineered efforts due to stale data and slow transitions that do not keep abreast with the rapidly changing dynamics. Liebman (2018) suggested a means to address the rapidly changing social problems such as (a) help state and local government use data and data analysis more effectively to generate innovation, system reengineering and continuous improvement; (b) breaking away from funding silos utilized to measure population-wide social problems outcomes by launching, restructuring, and funding purposeful data-

driven community level efforts to address accountability; and (c) speaking from a “what-works” perspective incorrectly orients policy makers into the thinking that the program effectiveness is a static process and budget is the primary means to see results. Further analysis is warranted to examine the level of difficulty that belies in working with a vulnerable population to hold agencies accountable and not lose sight of the reengineered processes needed to produce continual performance. Liebman (2018) outlined purposeful data-driven efforts to create the categories that holistically consider to service programs for families and children with special needs (see Table 2.2).

Table 2.2

*Outline of the Purposeful Data Analysis Measures Used to Evaluate a Program's Effectiveness*

Purposeful Data Drive Efforts	
1. Identify target population	Formulate hypotheses for how the intervention policy affects the problem.
2. Refer the right people to the right service	For specific populations (i.e. teen mothers, low term birth weight, etc.). use data on risk levels and interventions for cost effectiveness.
3. Track service receipts in real time	Collaborate with service providers to minimize the impact on targeted populations to reduce the chance of falling through the cracks.
4. Cross compare	Annually states cross compare outcomes for individuals referred for different services to make decisions about allocation of resources and adjustments to the referral protocols

Dunst and Clow (2007) examined the CF activities used by states and coded as type of activity (i.e., electronic, print, web-based), type of intervention (i.e., information campaigns or materials, feedback to referral sources, outreach to referral sources, and collaborations with referral sources), tailoring (i.e., targeted or nontargeted), approach (i.e., passive or active), and emphasis (i.e., degree to which the practice constituted a

main focus of state efforts). In their findings, they reported more than half (53%) of the states relied on distribution of materials (i.e., pamphlets and agency website) and parental screening materials such as checklists for them to monitor their child's development, are classified as the least effective means for reaching families. Materials were 84% non-targeted and 97% of CF efforts were considered passive (i.e., not utilizing the power of a tailored message). Meanwhile, collaborations with primary referral sources evidently were more effective in increasing referrals but used less frequently by state agencies. These findings suggested overall that states relied more heavily on non-evidence-based practices to define the CF programs. The authors suggested states need to take proactive measures to evaluate their CF practices, and that effective measures involve a combination of procedures to focus on using more impactful efforts resulting in a greater return on investment in both resources and personnel (Dunst & Clow, 2007).

In a study analyzing the effect of passive versus active promotional materials to increase health outcomes, Huet, Frail, Lake, and Snyder (2015) examined the impact of passive versus active modes of promotion types to determine a patient's acceptance for medication therapy management (MTM). Patients responded favorably to making an appointment to participate in the MTM programs when an expert opinion shared with a patient was educational and informative. A barrier was presented when the patient felt they knew the information or felt comfortable with their medication management.

Morgan, Farkas, Hillemeier, and Maczuga (2012) posited that underutilization of EI is associated with various factors: (a) cultural and linguistic and racial obstacles; (b) special education emphasis on communication, language and performance disproportionality disfavors children for the interpretations differ across racial/ethnic lines; (c) attitude towards help seeking differs so may rely on social support opposed to professional help; (d) aversion to stigma, and professionally are reluctant to refer in fear

of being perceived as racially biased. These points highlighted the complexity that makes up access and utilization of services. Therefore, we are charged to consider the multifacetedness of serving Black infants, toddlers, and their families.

Emerson, Morrell, and Neece (2016) found that Black children were identified earlier to have a developmental delay yet found their utilization of services to lag behind the mainstream population. What does it mean to underutilize a service? According to Arcia, Keyes, Gallagher, and Herrick (1993), “the utilization of services by people who are eligible for services and do not use the services to their full extent” (p. 283) is the definition. They noted that socioeconomic and cultural beliefs serve as indicators that influence minority parents’ use of early intervention services (Emerson et al., 2016). Yet, Arcia et al. included variables in minority communities that may impact their access and utilization of services such as race and ethnicity, young parental age, educational level, and family composition (Corr et al., 2016).

### **Partnership and Collaborative Projects**

#### *Medical Professionals’ Role in CF*

Physicians, pediatricians, developmental physicians, and nurse practitioners are classified as primary referral sources in the CF process. However, EI organizations are not to assume that physicians participate in CF to the same degree; these professionals require targeted outreach to increase buy-in and assume an active role in reporting reasonable suspicion of developmental delays opposed to facilitating the “wait-and-see” perspective. In a systematic review, Dunst and Gorman (2006) examined interventions that had increased referral patterns rates from medical personnel. Active outreach had the most impact on organizational interventions when primary and secondary providers’ locations were included in the information along with listing the comprehensive services

provided and whether consultative visits with physicians were included in descriptors and guidelines about the referral process (Dunst & Gorman, 2006).

Hibbard and colleagues (2008) suggested that Black populations who received training in asking the right questions and types of mental health services had increased access to care. Lau (2006) cautioned that health activation adaptation measures should not be limited to practitioners' perceptions of an ethnic community's needs but should be based on empirical data.

### **Application of Child Find Law**

Federal requirements systemically and individually place the burden of proof on the State systems to implement mandated CF procedures (118 STAT. 2747). Zirkel (2017) suggested school district personnel need to beware of the legalities associated with CF principles and professionals become more attuned to reasonable suspicion and make all efforts to reach children as lawsuits related to CF increased sevenfold from 2014 to 2017. Reasonable suspicion (consent to evaluate or initiate an evaluation within an equitable time period) utilizes a combination of factors such as academic performance on report cards, standardized assessments, school discipline, observations, teacher input, parent request, and private diagnosis (Zirkel, 2014). Reasonable time is generally considered to be within 60 calendar days, yet some court case rulings have upheld a 4- to 7-week window as a reasonable time period (Zirkel, 2017). However, the transition period for Part C to Part B poses challenges for children being evaluating in a timely manner when there is disconnect between program eligibility.

### **Due Process**

When children age out of a Part C program, prior to their third birthday, they are assessed and redetermined for eligibility under Part B, where services are then transferred to the local education agency or school district. Hebbler, Spiker, and Khan (2012) pointed

out that this process is a burden placed on the infrastructure of the programs as they operate as two distinctly different entities with different eligibility requirements. The hidden message communicated to parents is that if a child is close to 3 years it is better to delay the process due to the potential of a short-lived interaction with the Part C program and differences in eligibility requirements (Hebbler et al., 2012). Hebbler et al. advocated for a program that spans across the years without a disruption in the middle of their EC years. The transition gap presents notable opportunities for children to fall through the cracks.

In the case of *D.L. v District of Columbia* (2011) when the school district failed to identify locate and provide timely initial evaluations to preschool age children, the district argued the following:

[T]he range of days beyond the third birthday for a student to have an IEP developed and implemented is 1-572 days. The reasons for delay include LEAs not having adequate resources (evaluators) to conduct evaluations; a lack of understanding regarding the requirement to conduct evaluations by a child's third birthday rather than applying the State-established timeline for initial evaluations (120 days); difficulty coordinating evaluations and eligibility meetings with parents; and inadequate systems for communication between Part C and Part B (D.D.C.2011, p.8.82.210). (Ennis, Blanton, & Katsiyannis, 2017)

The brief of the case stated that preschool age children suffered substantial harm by being denied vital educational opportunities. Changes were made requiring the district to provide annual and semi-annual reports to ensure 95% of the referred children were evaluated in a timely period and ensured a smooth transition from EI programs. Ennis et al. (2017) suggested that agencies create checklist to promote adherence to timelines for determining eligibility, encourage mindfulness of staff to not negate students' progress,

and not fail to respond to the mental health, social, and behavioral concerns of a child's development. These steps can facilitate a smooth transitions and adherence to the CF polices.

### **Eligibility and Race**

Feinberg et al. (2011) examined the impact of race and participation in an early childhood intervention program serving children from birth to age 3 with developmental delays in a Part C program. Overall, the number of children receiving ECI services showed steady growth; however, the proportion of Black children served in 1998 was 18%, declining to 13% in 2007, raising concern to the disproportionality of received services (Feinberg et al., 2011).

From the Early Child Longitudinal Study, Birth Cohort a sample of infants and toddlers (n=1,000) with not easily recognizable medical conditions or delays was analyzed to identify the number of accepted services noted in an IFSP. For infants at 9 months of age, race did not impact service enrollment. However, at 24 months, a difference was noted between Black and White children wherein Black children who were eligible for services were five times less likely to receive them when based solely on a developmental delay. Feinberg et al. (2011) attributed this to the idea that Black children without an established condition fell under the surveillance category that depended on a cue to the parent and health care providers before a referral was made.

Child Find is a not a linear model for reaching multicultural communities and when service organize apply this perspective by integrating knowledge from an in-depth perspective that reaches beyond the norm (Zirkel, 2015). Therefore, organizations are to be reminded matters affecting Black families, such as the ripple effects of socioeconomic and racial disparities have an overarching impact on identifying children (Dababnah et al., 2018).

## **Empowerment**

Power is a part of the word empowerment. Before looking at the act and feel of being empowered, first the power structures that anchor a familiar term are to be considered. Solomon (1987) described power as an act that is observed as an insidious consequence of membership to a stigmatized group who experience negative valuation and discrimination in its daily transactions with society's major institutions (p. 80). When viewed as an intrapsychic explanation for their problems, this suggests problems are viewed as consequences of their own characteristics (Solomon, 1987). This situates the problem as transactional between a person and society, foregoing the achievement of positive goals and not taking into account the outcomes as a form of oppression and misuse of power. Therefore, stigmatized minoritized groups are challenged to override the powerlessness to direct their lives toward reasonable gratification. Solomon described a power block as any act, event, or condition that disrupts the process whereby individuals develop effective personal and social skills. Power absorbed into Black families' way of being and doing prevents optimum development of personal resources such as self-esteem; second, it limits resources to develop interpersonal and technical skills. Those limited skills reduce the families' effectiveness to perform valuable social roles such as parent or employee (Solomon, 1987). From the tiered level of direct power, minority groups experience blocks, which manifest in families not having access to needed resources in order to develop good health and education. Then they experience limited education and technical abilities, consequently reducing level of advancement professionally and personally. Third, a lack of a valuable social role is seen as not obtaining adequate or advanced employment. Therefore, empowerment means "an acknowledging and enhancing of the strengths that have been the basis for survival of Black families despite tremendous suffering, hardship, and that feelings of

powerlessness, are internalized because of negative valuation by the larger society” (Solomon, 1987, p. 81). From the professional perspective, empowerment is a method used by professionals and institutions as an attempt to deal with the power blocks.

### **Compass of Empowerment**

One’s ability to speak for themselves with authority and conviction is an action of empowerment. Nowadays, caretakers of young children with disabilities are challenged in their daily interactions with society to speak from their truth (Copeland & Snyder, 2011). Therefore, the ability to recognize, analyze, and challenge any form of oppression is demonstrated through empowerment to gain control over one’s best interest (Bernard & Bernard, 1998). Kim (2012) and Rawlett (2014) both highlighted the need for cultural sensitivity of empowerment that accounts for societal experiences that influence a person’s sense of liberation. Empowerment models should encompass a multicultural lens that incorporates language and social supports resulting in increased parent participation (Kim, 2012). Kim further added that empowerment should increase the knowledge of the resources available to parents. As in the previous studies, there was a need for parents of children with a disability to embody the control over their decisions regarding the best interest of their children (Dunst & Trivette, 1987). In addition, Cox (2002) described being aware of oneself and one’s role within the community as an act of liberation leading to a sense of personal power for the betterment of one’s surroundings by operating as a part of the greater society (Vavrus, 2015).

### **Empowerment Quantified**

Damen et al. (2016) set out to quantify a demonstrated characteristic of a parent’s perception of empowerment. They sought to capture an innate response and draw a behavioral perspective from Dutch parents regarding their empowerment when raising children. Parental empowerment (Damen et al., 2016) was defined

as the outcomes of a parental process by which parents are strengthened in raising their child by increasing their feelings of personal control, their critical awareness of handling parenting issues within and in interaction with their environment, and their parental control over the child. (p. 425)

The basis for parental empowerment was derived from the concept of psychological empowerment that included three sub-components: (a) the amount of a person's willpower is their intrapersonal ability, (b) a parent's ability to reason within a task is an interactional ability, and (c) a parent's response to a problem through their actions is a behavioral capacity (Zimmerman & Rappaport, 1988).

### **Black Mothers' Voices of Empowerment**

In a qualitative reflection of a mother and daughter experiences of their role in the institution of a Black family, Bernard and Bernard (1998) have set forth to define their tacit understandings of their multiplexable roles at home and in society. A voice of a Black mother described empowerment as an embodiment of confidence through a critical consciousness to the surrounding environment that allows them to transform their inner strength into a collective power. All too commonly, Black mothers serve as the shoulders of a family to keep the head in place, causing the weight of the world to influence their decisions as they navigate travails as either empowered or disempowered (Bernard & Bernard, 1998). This is compounded when raising a child who is a double minority, being Black and disabled.

#### *Parents' Voice to Barriers*

In a glimpse into another minority group, the Latino perspective of receiving a diagnosis of autism, Zuckerman, Sinche et al. (2014) conducted qualitative interviews with 33 families whose child was an average age of 2.8 years. Parents reported that the limited amount of available information and stigma and lack of empowerment within the

Latino community plagues their willingness to inquire and then access services. In addition, parents felt that their concerns, comments, or inquiries were more likely to be dismissed by health care providers; for example, “Let’s wait until he is 3 years old to see if he will speak because some speak earlier than others, don’t worry” (p. 307).

### **Parental Self-Efficacy and Difference From Empowerment**

From a correlational study of first-time mothers and postnatal depression, Leahy-Warren, McCarthy, and Corcoran (2011) defined parental self-efficacy as a mother’s internal confidence in her parenting ability. In order to explore the distinction between self-efficacy and empowerment, Rawlett (2014), through an empirical review of studies of health disparities among vulnerable populations, found there to be a difference in the concepts. The author utilized the term *vulnerable populations* to designate a group of people with an increased risk or disposition that leads to disparaging health results. In addition, at the individual level, self-efficacy is people’s internal confidence in their ability to carry out an action for their betterment to achieve success (Bandura, 1977; Rawlett, 2014). A stepping-stone to empowerment is one’s self-efficacy, as continual growth and development from completing a task results in a person being empowered. From a study of patients with diabetes, Rawlett (2014) noted empowerment is a continuous skill that people use to act and follow-through with their healthcare needs. *Parents and Disability Empowerment.*

Nachshen and Minnes (2005) worked to quantify the factors associated with parental empowerment of those raising children with a disability. The authors defined empowerment as a purposeful process, in which those without adequate resources gained control and access to the available supports. They described empowerment as an internal belief that helped reduce their stress; by doing so, they were able to be flexible and adaptable to various situations. The results of their study of 100 participants who had

children with and without a development delay indicated that behavioral problems among children with a disability increased parental stress and need for social support, yet decreased well-being for both the parent and child. In addition, they connected the family-centered model created by Dunst and Trivette (1987) which focused on lessening the attention from the cause of the disability to equipping parents with the tools such as problem-solving to assist in goal attainment. By using this model, parents rearing children with disabilities have a reference to see the child first and the disability second (Dunst & Trivette, 1987; Nachshen & Minnes, 2005).

The intent and ability for families to seek help is not an action that may come easily to all individuals or groups. Help seeking is a skill that requires fuel to take a step, access, follow-through, receive and to utilize. Children and families of the earliest population are placed in a susceptible position of navigating the provocation of life and society encompassed with race, gender and disability.

### **Perceived Barriers to Access and Utilization**

Barriers are applied classifications to the taxonomies that impedes marginalized communities' access to care and services (Betancourt, Green, Carillo, & Ananeh-Firempong, 2003). Health disparities, sometimes called health inequities, are classified as any imbalance in health, understood as unjust, unnecessary, and unavoidable, burdening a particular subgroup of the population especially racial/ethnic, gender, and socioeconomically vulnerable populations (Noonan, Velasco-Mondragon, & Wagner, 2016). Minority families tend to be more socioeconomically disadvantaged, attaining lower levels of education, working in low paying, high-risk jobs, classified as essential workers exposed to hazards and pollutants in both their living and work environments (Betancourt et al., 2003). Systemic racism perpetuates a prolonged impact on poor health outcomes and access/utilization of care in part because of the belief that the primary

human traits and capacities produce an inherent superiority of a particular race which is manifested by both distal and proximal factors affecting educational and health outcomes from the cradle to the grave (Betancourt et al., 2003; Noonan et al., 2016). Barriers that influence access to services are categorized as social cultural, organizational, structural, financial, clinical. Table 2.3 lists examples associated with five taxonomies of barriers families encounter when accessing and utilizing early childhood intervention services. For Black families, the barriers represent intermediary factors that may aid in design of local intervention targeting access disparities.

Table 2.3

*Taxonomy of Barriers to Early Childhood Intervention Programs for Black Families*

---

<b>Examples of Organizational</b>
Leadership: minority representation (Betancourt et al., 2003)
Institutional policies
Bureaucratic intake process
Misuse and Accountability (Macy, 2014; Bruder 2010)

---

<b>Examples of Structural</b>
Transdisciplinary model (Albridge, 2015)
Family centered practices (Summer ,2007)
Black Family structure
Family Capacity and efficacy (Swanson, Dunst et al., 2011).
Family interpretation (Zuckerman, 2014)

---

<b>Examples of Financial</b>
Access to insurance (Medicaid, Bruder, 2010)
Maternal work status

---

<b>Examples of Cognitive</b>
Maternal education (Boyle et al., 2011)
Predisposed knowledge of developmental delay (Carrillo, 2011)
Developmental Surveillance (Raspa et al., 2015)
Maternal belief (Zuckerman and Mattox, 2015)
Health Literacy

---

<b>Examples of Clinical</b>
Parent perception (Raspa et al., 2015; Zuckerman, Sinche, et al. 2014)
Patient-provider communication
Racial/ethnic concordance of provider ( <i>Betancourt; Winslow</i> )
Clinical decision making
Culture humility

---

## **Professionals' Perceptions**

In order to assess a primary care physician's knowledge of special education supports available for children outside the window of ECI, specifically children older than 3, Hastings et al. (2014) also solicited the perspective of physicians' understanding, knowledge, attitudes, and practices when making referrals to ECSE. Given physicians are usually regarded as the gatekeepers between parents and special education services, the study sought to determine physicians' perceived barriers keeping families from accessing school-based services for children with developmental delays. The physicians noted families are not yet involved with the public schools and would benefit from knowledge shared by the physicians about the process. They highlighted the distinction for qualifying based on impact to a child's education and stricter guidelines to qualify at the public-school level impacted their confidence and knowledge in being able explain available age-group specific resources to parents (Hastings et al. 2014).

### *Depathologization*

Shields, Bishop, and Mazawi (2005) defined pathologization as [t]he process whereby perceived structural-functional, cultural or epistemological deviation from an assumed normal states is ascribed to another group as a product of power relationships, whereby the less powerful group is deemed to be abnormal in some way. (p. 10)

Although depathologization is the action taken to mitigate the labeling and reinforcing of dominant power structures to compare abled and disabled embodiments, the course of alignment is not leveled to the interpretations parents have regarding the educational system (Heydon & Iannacci, 2009). In ECI, children may be identified with a delay or deemed *at risk*, yet Heydon and Iannacci (2009) highlighted institutions' utilizing the *at-risk* category as a tool to predict and control those who are deemed troublesome.

Intentionally, parents are challenged to “fix” the delay in hopes of the child becoming homogenized (Heydon, 2005). This is further perpetuated for Black families as the research has supported that they are subject to the powers that be in determining the homogeneity of acceptance (Annamma et al., 2013; Pitre et al., 2015; Shields et al., 2005).

Without a level of consciousness of one’s biases it is possible to mentally reduce an individual from whole-normal to tainted-discounted. Goffman (1963) argued that this type of stigma is a deterrent to one’s identity when one deviates from the norms that society has institutionalized upon their race. As a fundamental cause of health inequities, stigma is a social process that requires distinguishing and labeling differences, labeling associated human differences with negative attributions. Separating *us* from *them* creates a status loss, which contributes to the unequal distribution of resources, dependent on the core sociological enterprise of power and ability to stratify resources (Clair, Daniel, & Lamont, 2016; Pescosolido & Martin, 2015). The field of stigma research has a traditional domain within mental illness, but it has expanded to other arenas such as hearing loss (Wallhagen, 2010) and this presents opportunity for more specific conversations in the field of early childhood (Pescosolido & Martin, 2015).

### **Parents’ Perceptions**

Jimenez et al. (2017) studied various types of media used to reach parents at the beginning of referral process to help close the recommendation and access-to-services gap. A majority of the referrals come from pediatricians; however, Jimenez et al. piloted a randomized control study in a major urban hospital to find a way to streamline the referral process for families with children aged 13 to 24 months. Their sample (n=64) consisted of 88% Black families, 61% of whom had a male child referred to early intervention services by their medical provider. The planned intervention consisted of

parents receiving a short video by SMS (text) messaging describing the developmental milestones and certain topics specific to early development with the intent of increasing healthy literacy about developmental delays and EI to increase the number of referrals. In the study's focus group consisting of parents and medical professionals, a parent commented that they prefer direct communication and providers noted it is necessary to be aware of the barrier families encountered. Parents stated barriers such as lack of understanding about a developmental delay, communication between the agency professionals, and logistics with scheduling contribute to lower follow-through with referral rates. In their findings, both the parents and professionals saw the benefit to using a video because it showed empathy toward the family's best interest and the messaging was communicated at the parents' level of understanding. However, due to the sample size and health literacy level of the parents, there was no statistically significant increase in intake and evaluations when using that type media. Jimenez et al. suggested there is more work needed to overcome barriers in the early intervention process and meeting parents at their level.

### *Family Factors*

Historically, Black families are not native to the United States, brought here by force and knowledge of their yesteryears erased, factors that, today, taunt the community. The Black community of today is the most acculturated minority in the US with a more homogenous relationship to their ethnicity, language, and religion (Coles, 2016). Earlier studies of Black populations characterized them as improvised versions of the White middle class but this view negates the cultural remnants of their heritage, shaping a problematic perception of who and how Blacks fit into the larger context of society.

The Black family structure harkens back to slave plantations where small farms resulted in more broken families, children growing up without their biological father and

viewing the master as their caretaker, increasing the number of single-parent households (James, Coard, Fine, & Rudy, 2018). On the other hand, a large estate increased the likelihood of your family staying together to 47% as opposed to that on a small farm of only 18%. Living on a larger plantation provided benefits to Black families in terms of longer marriages and access to a personal home (albeit a windowless shack with dirt floors) that provided stability for the family unit. Once freed, the Black family carried their historical family structure forward with them, a history that impacts them to this day with more than 60% of Black families being headed by a single parent (James et al., 2018; KidsCount, 2018) and two-thirds of Black grandmothers serving as the primary caretakers of school-age children (Clotney, Scott, & Alfonso, 2015).

Society at large has negative connotations regarding Black children (James et al., 2018) and successful child rearing is judged by their level of adaptation to White middle-class standards which tend to overlook what it means to Black parents to speak of their child's disability. Particularly in low-income Black communities, women have the primary responsibility for the meager resources available with added societal pressures from racism, income, and public policies which can influence her perspective regarding the needs of her children (Black et al., 1999). Samuel et al. (2017) revealed that grandchildren raised by a grandparent were more likely to have poor developmental outcomes while Black et al. (1999) noted that mothers who have household help from a father are more sensitive to cues from their children.

Samuel et al. (2017) noted that while roughly 15% of the nation's children have a developmental disability, Black children from socioeconomically disadvantaged backgrounds were represented at proportionally higher rates than children of other races, socioeconomic backgrounds, and health outcomes that were not limited only to developmental disabilities; they also included obesity, allergies, asthma, learning

disabilities, and anger management causing problems at home and at school (Clottey et al., 2015). Dunst, Hamby, Raab, and Bruder (2017) highlighted that families from varied ethnic and cultural backgrounds have different interpretations about the children's behavior and expectations.

Black parents have noted they have little information about access and support services that connect them to care (Samuel, Hobden, LeRoy, & Lacey, 2012; Zuckerman et al., 2018). Samuel and colleagues (2012) extended this idea that low-income families feel the caseload of their caseworkers did not allow for the attention needed to navigate the health system causing the providers to have increased unwillingness to refer. Most ethnic parents stated their access to services was impacted by not being informed of the services, but getting confused when information came from various sources, was incomplete, or was wrong (Cho & Gannotti, 2005; Sontag & Schacht, 1994). Sontag and Schacht (1994) suggested there is an inadvertent information bubble amongst professionals unconsciously or unknowingly limiting information given to parents, which could result from parents not asking eliciting questions. In addition, once minority parents did receive services, they were less likely to pass that information and support along to other parents.

### **Other Perceived Barriers**

In a comparison study of the racial and ethnic disparities of Black and Hispanic children, Magaña, Parish, Rose, Timberlake, and Swaine (2012) examined the obstacles for children with autism and developmental disabilities. Data analyzed from the National Survey of Children with Special Healthcare needs (n=4,414) found that disparities do exist for marginalized groups. Physicians felt inadequately prepared from medical school and residency programs and noted the reduced amount of time to see patients from insurance constraints contributes to the less effective interactions. Consequently, a

shortage of doctors and those willing to take on patients with additional needs created challenges for families that already have limited access to quality care. Furthermore, the authors found that medical professionals, when faced with discussing autism with parents, were more reluctant to provide options for specialty care or have deeper conversations. Results of their study indicated that race is a predominant factor and hindrance to families accessing the health care system for their children with a disability and when they did doctors were 53% more likely to not spend enough time with the patient and show sensitivity to cultural needs or provide enough information.

In the arena of public health, patient activation has become mainstream and policy changes have been enacted to increase a patient's activation through their "increased knowledge, skill and confidence to manage their healthcare needs" (Chen, Mullins, Novak, & Thomas, 2016, p. 26), while patient empowerment focused on their control and ability to make informed decisions regarding their healthcare. Through self-determination, patients are motivated to become active in their care by asking questions, reciprocating conversation with providers, and advocating for their preferences (Chen et al., 2016).

In the context of patient activation, Alegria, Carson, and Flores (2014) highlighted a need to assess a patient's capability to ask direct health questions to health providers. Through training that included direct instruction focused on brainstorming and role playing, they found professionals were open to the idea of patient self-management, yet their responses did not align with their real-life actions where they tended to limit patient-initiated talk. When a questionnaire or checklist was used in an appointment, healthcare providers were more likely to use open-ended questions that could elicit questions from the parents (Raspa et al., 2015). Furthermore, Cox, Huntington, Saada, Epee-Bounya, and Schonwald (2010) found that the well-being checklist often distributed to parents was not

specifically designed to elicit a response from various ethnic groups. They suggested using the form as a framework to guide questioning and that medical practitioners need to further develop questioning skills to meet the needs of their patients' various ethnicities and socioeconomic levels.

The intent and ability for families to seek help is not an action that may come easily to all individuals or groups. Help seeking is a skill that requires fuel to take a step, access, follow-through, receive and to utilize. Children and families of the earliest population are placed in a susceptible position of navigating the provocation of life and society encompassed with race, gender, and disability.

### *Stigma*

The 1950s Civil Rights Movement marked a historical shift in our nation that drew attention to the racialized structures that impacted Black Americans and highlighted how states have marks the interactions between varying ethnic groups (Waters, Kasinita, & Asad, 2014). Foner (2000) noted that Black-White issues becoming the focus of national agenda allowed the marks, beliefs, attitudes, and stereotypes that define a group of people to continue as they are the main character on the stage. Claire et al. (2016) depicted this exploitation of African Americas as stigmatized anti-cladic ideologies that have been with America for a long time. However, these stigmas still plague our society through various venues such as healthcare, education, job security, family structure, and financial access constructively situated as barriers.

Therefore, stigma is commonly referred to as a negative stereotype causing separation amongst groups who are labeled with these differences, limiting access to material, social, and cultural resources for members of a stigmatized group (Clair et al., 2016, p. 1). Derived from the seminal works of Goffman (1963) who looked at the etymology from the Greek who used strong visual aids to refer to bodily signs designed

to expose something unusual and gave a bad about the moral status of the signifier (p. 1). In a move beyond the enactment of the word are the preconceptions of stigma referred to as the way society

establishes the means for categorizing persons and the complement attributes felt to be ordinary and natural for members of each of these categories. The routines of social intercourse in established settings allow us to deal with anticipated others without special attention or thought. When a *stranger* comes into our presence, then, first appearances are likely to enable us to anticipate his category or attributes and his social identity. These anticipations that we have transforming into normative expectations, into rightly presented demands. We do not become aware that have these demands or are until an active question arises . . . it is then likely to realize that all along we had been making assumptions as to what the individual ought to be. (Goffman, 1962, p. 2)

Historically, White society has seen Black fecundity as a method for women to increase their welfare checks in order to make a living. This tactic has been used to justify the unspoken belief that the mother is to blame for high Black infant mortality (Metzi & Roberts, 2014) and results in Black mothers being more likely to be tested and reported for gestational drug use than White mothers. The consequences of this testing perpetuated further structural discrimination in healthcare and reduces a mother's willingness and ability to access health services for her children beyond a basic wellness check. A deep stigma within the community is created based on societal treatment and perceptions; even with surface level improvements the deep generational wounds arise in professional-client interactions.

### *Organizational Barriers*

Bruder (2010) pointed out the field of EI seeks to adopt a step-by-step process to improve organizational structures for diverse populations. Nationally, EI is organized under the Office of Special Education Programs in the U.S. Department of Education. Macy, Marks, and Towle (2014) noted that Part C is fragmented, inefficient, and suboptimally effective due mainly to missed accountability, misused, miscommunication, and mismanagement. While an estimated 15% to 17% of our nation's children have a developmental disability, children are missed due to the variability of activities and strategies, along with lack of accountability in state programs (Macy et al., 2014). Outcomes of eligibility evaluations are rarely collected by states and they are allowed to select and define their own criteria for measurement, meaning the longitudinal data from the initial screening, length of time in IDEA, and school outcomes are limited (Bruder, 2010). Macy et al. (2014) suggested state coordinated plans should provide a streamlined approach; without this system in place families rely on inaccurate information from family and friends. Meanwhile, miscommunication between health, education, and social service professions can occur because of their differing backgrounds. They may communicate differently to families and when families are service by multiple organizations, they may feel overwhelmed or pit organization against each other based on the path of least resistance or which is easiest to understand. Further, Betancourt et al. (2003) noted that the composition of institutional leadership should be representative of the targeted population. Therefore, consideration on the senior leadership roles, structural policies procedures are inappropriately designed to meet the needs of diverse constituents. Barriers are depicted as bureaucratic intake processes, long wait lists, underrepresent of minorities on all levels within the organization creates a disconnect from the minority communities.

### *Financial Barriers*

As a part of the financial barriers for EI, Bruder (2010) pointed out that the financial infrastructure of Part C has never been funded to the extent promised by Congress, placing programs in jeopardy and calling for accountability to meet the law. Increased attention to the importance of EI has led to states competing for funding from Head Start programs and states are challenged to make systemic changes when governed by several various entities. The financial gap could be closed via health insurance reimbursements.

In our nation, children of color make up half of the infant populous who are more susceptible to living in low-income families whose experiences start before birth with limited access to adequate housing, increased hunger, and a 55% likelihood of being born with a low birthweight (Zero to Three, 2020). Black children, in 2016, made up 14% of the nation's population and comprised 20% of Medicaid/Children Health Insurance Program (CHIP) recipients (Wagnerman & Brooks, 2017). Therefore, when states expand their Medicaid/CHIP coverage the number of uninsured children declines, playing a significant role in reducing health disparities. Medicaid for young children can be expanded to cover mothers during their pre-, peri-, and postnatal experiences making it possible for them to access quality health care during childbearing years, reducing avoidable birth and developmental risks (Zero to Three, 2020). Unfortunately, the care accessed by Black mothers is often not comparable in quality to the treatment rendered to White mothers, and minority mothers have often noted they experienced discrimination during a health visit. Coverage for mothers would provide the opportunities for them to stay home longer with their baby; 65% of Black mothers have returned to work by 9 months post-partum (Han, Ruhm, Waldfogel, & Washbrook, 2008) which created

challenges such as inadequate childcare and limited disability-specific support (Parish & Rose, 2010).

### *Mothers' Work Status*

In 2016, 71% Black mothers were likely to be working full-time but remained at a 24% poverty rate when compared to mothers of other races (Artiga et al., 2016). Arcia et al. (1993) mentioned that maternal work status has a significant impact on utilization of services. According to the U.S. Census, 72% of Black mothers with children under the age of 6 are employed full-time and families have a full-time worker in the home yet remain second among family incomes below poverty (Artiga et al., 2016; National Women's Law Center, 2017). Parents caring for a child with a disability noted financial factors influenced their well-being (Resch et al., 2010), including not having money for the additional services and an inability to access services due to financial conditions (Resch et al., 2010).

Contextually, the increased number of working mothers impacts the time available to obtain services, reducing the utilization rate (Arcia et al., 1993). Black mothers expressed the pressure they felt to obtain therapy service for their children due to ultimatums given by the educational systems. This led to economic pressure and fear dominating Black mothers; Copeland and Snyder (2011) described them feeling if they increased their income, they would be close to losing health insurance for themselves and their children, making it difficult for them to access resources. Economic woes have a perpetual effect on child rearing, parenting styles, and parent-child relations. employers are viewed as not understanding the situation, creating conflict between them and the employee (Green, 2007).

Financial burdens are a deterrent when families have to focus on meeting basic needs. Naturally, these barriers impact the utilization of services because families are

facing additional stressors that lead to them being categorized unpredictable and unstable which can increase pressure and disrupt the continuity of services, affecting their level of engagement (Corr et al., 2016).

### **Enrollment in ECI**

The third generation of EI research is situated around the idea of closing the cracks by considering all children who are at risk as eligible candidates for preventive practices. In a study conducted by Morgan, Farkas, Hillemeir, and Maczuga (2009), risk factors associated with eligibility at 24 months were used to analyze the extent to which socioeconomic status, gender, race/ethnicity, and parenting contributed to a child's behavioral problems. The study found that boys were twice as likely as girls to display behavior-related problems. Learning-behavior problems prior to entering school were associated with the mother's level of educational attainment. In addition, children from ethnic backgrounds had an increased chance of a cognitive delay. Relatedly, while 12% of the nation's children are being diagnosed with a developmental delay, only 3% are being enrolled in a ECI program with only six states serving at-risk children (Marks et al., 2015). States with stricter criteria isolate infants and toddlers from low-income families whose mothers may suffer from depression because their children may not show overt signs in the moment but will prior to entering kindergarten (Marks et al., 2015).

Access to services spans across a life span. EI is positioned to strengthen the abilities of children so that they are better equipped to handle the ebbs and flows presented by the educational system. Specifically, Child Find initiatives continue to be a challenge in culturally diverse communities, impacting who receives services. EI is a delicate profession; when a delay is present, they are the first to determine and work with families through the process of being serviced. The prevalence of development disabilities is on the rise (Marks et al., 2015).

Williams et al. (2018) pointed out 9.5% to 14.2% of children from birth to 5 years of age have a social-emotional problem but remain underrepresented among young children being serviced for social-emotional needs. When detected early and intervened, the impact of an emotional or behavioral problem on school function can be lessened with notable progress over a lifetime, while also being a cost-saving measure. Perplexingly, autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) for Black and Latino children are less likely to be diagnosed at a younger age compared to their White counterparts, but these two areas are the most commonly serviced under early childhood developmental conditions (Zuckerman, Mattox et al., 2014). Yet, when professionals rely on a parental response to a behavioral or emotional concern without formally screening a young child, this can lead to limited results (Williams et al., 2018).

As demonstrated infants and toddlers are barely screened or referred for mental health services. Among a sample of low-income, majority Latino families, Williams et al (2018) found both medical providers and parents with children under 3 years were least likely to respond with a behavioral or emotional concern, in part due to failure to recognize, cultural implications, and stigma. They also found less than 50% of children were screened when pediatricians relied on a parental response. Zuckerman, Mattox et al. (2014) suggested Black and Latino parents have differing views on developmental milestones when compared to their White counterparts. They also argued that increasing screenings will not help the minority communities if services, tools, and resources are not culturally sensitive, but would instead further the disparity in access. Instead, Zuckerman and colleagues suggested follow-up on parent concerns and home visits and collaboration from medical providers within the community could help improve the care for young

In a comparison study of the racial and ethnic disparities of Black and Hispanic children, Magaña et al. (2012) examined the obstacles for children with autism and developmental disabilities. Data analyzed from the National Survey of Children with Special Healthcare needs ( $N = 4,414$ ) found that disparities do exist for the marginalized groups. Physicians felt inadequately prepared from medical school and residency programs and noted the reduced amount of time to see patients from insurance constraints contributes to the interactions (Magaña et al., 2012). Consequently, a shortage of doctors and those willing to take on patients with additional needs created challenges for families that already have limited access to quality care (Magaña et al., 2012). Furthermore, the authors found that medical professionals, when faced with discussing autism with parents, were more reluctant to provide options for specialty care or have deeper conversations (Magaña et al., 2012). From their study, results indicated that race is a predominant factor and hindrance to families accessing the health care system for their children with a disability (Magaña et al., 2012). They also noted that a doctor was 53% more likely to not spend enough time with the patient and did not show sensitivity to cultural needs or provide enough information (Magaña et al., 2012).

Dunst and Paget (1991) noted that parents are viewed as subsidiaries in the determination of a health concern; in response, they resort to medical professionals to obtain the most appropriate solution. Therefore, parents may be apprehensive about initiating a dialogue regarding a health concern with their healthcare provider (Dababnah et al., 2018). A qualitative study of 22 urban parents with varied educational backgrounds, Dababnah et al. (2018) noted parental responses on a continuum that ranged from parents with a high school diploma being more comfortable receiving suggestions from a nurse practitioner than a primary care doctor to a degreed parent who took the initiative to find early intervention services.

## **Service Delivery Model**

In conjunction with the service delivery of a home-based model for early intervention implementation, Bowers et al. (2018) sought to determine if utilization rates increased with this type of model. In this study, a comparison of families who did and did not access home-visiting programs were examined. Home-based therapy programs are a common model used by early intervention programs provide support in their natural learning environment, which can narrow the access gap for children identified as needing services (Bowers et al., 2018). They found two key time periods when utilization increased were at birth and between the ages of 2 and 3 years. They also noted that Black children were eight times less likely to access early intervention services. Therefore, the authors suggested targeting high-risk families based on demographics. Corr et al. (2016) noted that families living in poverty may be confused about the service model in a natural environment because of a disruption to their daily routine resulting in a negative response from the parent.

## **Part C Utilization**

Lutenbacher et al. (2005) studied the unmet needs of 37 families raising children with special needs identified between birth and 3 years. Early intervention and school systems emerged as categories that bore watching. Parents noted challenges with coordination of related services, inconsistent delivery, poor communication with parents, and lack of academic programming made the journey difficult to navigate. Although the parents had a positive perception of the early intervention program, they felt the process was exhausting and required a vast amount of time and dedication. In addition, they became frustrated with the disconnect between the identified need and actual delivery of the services. Lutenbacher et al. suggested program implementation should be viewed from the lens of the participants to gain deeper insight from their feedback.

As Waters et al. (2014) pointed out, Blacks remain at the bottom of the racial order with a myriad of continual negative experiences within the school, healthcare, and society as a whole. Therefore, in reviewing the structural competence of Part C, Edwards et al. (2013) highlighted the need in EI to create a diverse “portfolio” in order to meet the needs of families at their level. Further analysis is recommended to address the structural deficits in Part C and tailor the service-delivery models that are reflective of social, economic, and geographic influences families’ utilization of services.

### **Children with Special Needs in Texas**

From 2003 to 2016, the enrollment of students with special needs in the state of Texas declined by 32,000 (OSEP, 2018a). According to the National State of Preschool Report of 2017, special education preschool classes for 3- and 4-year-olds made up 3% of the nation’s early childhood enrollment, while in Texas this group accounted for 1.1% of the early childhood special education preschool population (Friedman-Krauss et al., 2018). The overall lower percentage of children eligible for early childhood special education (ECSE) can be attributed to numerous variables. Multiple studies have explained discrepancies in national data that can also be applied to Texas, to include Black males who are nearly three time less likely to be diagnosed at an early age for autism, cultural misunderstandings frequently leading to difficulties for families in locating and accessing needed resources, and various forms of implicit bias including visceral biases impeding interactions during Child Find and referral processes (Black et al., 2017; Mandell et al., 2007; Obeid et al., 2021).

Texas refers to Part B Section 619 as the Early Childhood Special Education Program (ECSE) which includes school-district based services provided to children 3 to 5 with a disability that impacts their education (THHSC and TEA, 2019). The responsibility for defining eligible children fell on the state as the Local Educational

Agency (LEA)-Part B of IDEA. In Texas, a child has to demonstrate a medical diagnosis, auditory or visual impairment, or a developmental delay of at least 25% for eligibility for ECI (Scarborough et al., 2004; Texas Health and Human Services Department, n.d.). From 2010, 58 Texas ECI programs were in operation and, in 2020, 42 programs remained available to service families. This program reduction resulted in 7,622 children affected by contractor changes (HHSC, 2020).

In Texas, enrollment in Part C during the ages of birth to 3 years is overseen by the State Health and Human Services Commission (HHSC). Black males account for 64% of the service children in an early intervention program (Texas Health and Human Services, 2018). This shows that a higher representation of Black males enrolled continues into Part B as, according to national data, they comprise the largest percentage of those identified and placed in special education supporting the notion of overrepresentation (Davis, 2003). A long-standing problem with Black males in public education is the increased likelihood of being misdiagnosed when compared to mainstream students (Davis, 2003). A possible reason for the misdiagnosis is that many Black males demonstrate excess energy in the classroom by moving around the room, talking, and/or fidgeting in their seats, all activities that may lead observers to conclude that they suffer from ADHD or associated conditions when, in fact, they are just very energetic (Carter et al., 2008). Among those who are correctly determined to need special education services, this determination may not occur until middle elementary school (Mandell et al., 2007). Because early placement is pivotal to provide a strong foundation for students, Black males need to be identified as early as possible in order to offset the disparities of race and gender in special services (Davis, 2003).

Overall, Texas ECI enrollment is categorized at 2.85% percent of the infant and toddler population compared to Massachusetts at 9.05%. According to Rosenberg et al. (2013) this places Texas at the lower end of the spectrum rate for servicing children in Part C; furthermore, they placed below average when compared to other southern states (as cited in Wagner & Wright Burak, 2017). Black infants and toddlers with disabilities account for 9% of the serviced ECI population compared to 54% of Hispanic children. However, among children ages 3-5 with a disability under Part B 619, Black children increase to 10% while Hispanics decline to 50% of those served (AEM Corporation, 2016a). McManus et al. (2014) noted that when states change their criteria it impacts eligibility, as seen in Texas. When eligibility criteria were tightened in 2011 progress was no longer captured by the ratings for those infants and toddlers with more significant developmental needs (AEM Corporation, 2016b). Nationally, Black child enrollment in EI programs increased, but in Texas, enrollment decreased from 40th in 2011 to 45th in 2014, categorizing the services as underperforming for Blacks, while enrollment increased for Hispanic and White infants and toddlers (Wagner & Wright Burak, 2017).

Since 2010, Texas has closed 16 ECI programs and has failed to retain ECI contractors impacting 7,622 children across 83 counties (THHSC, Rider 98, 2020). From 2010 to 2017, the Texas legislature has reduced funding to ECI programs by 11% and placed barriers on the eligibility criteria adding narrow guidelines to qualify, while adding administrative requirements to ECI contractors. Subsequently, in 2015, Black children had the most significant difficulty in accessing services in Texas, as enrollment dropped by 27% for this group compared to a statewide decline of 14%, creating notable community disproportionality for Black families.

## **Funding**

Texas ECI operates under a total budget concept where contractors bill ECI and are reimbursed for their services, as Medicaid is a primary source of revenue that has been cut. At the state level, this type of model is used to ensure compliance and that ECI agencies meet their expenses, closing the year with a surplus. However, there is a disruption between the state and contractors because oversight shows that the majority of programs expend 95% of their budget with little to no surplus; the state interprets this as success but does not account for its effect in impeding enrollment (THHSC Rider 98, 2020; Texas Care for Children, 2016). Recently, Rider 98 (2020) was put in place to offset the financial challenges by having the state explore funding strategies, implement cost saving strategies, and maximize Medicaid funding. Consequently, ECI on the state's agenda is a discretionary program that is subject to political and economic cycles as states are mandated to have a balanced budget. This creates a ripple effect on social programs (Cole et al., 2011) since state funding for Texas ECI programs has been reduced by 11% since 2011, having a disproportionate impact on Black children whose ECI enrollment has declined by 27% (Hornbach & Rubin, 2016).

In 2020, Texas was challenged to maximize funding and cost saving measures to provide rehabilitative services to children and families. Over the years, Texas has seen a 4% growth in the infant and toddler population while the rate of ECI enrollment has substantially dropped (Wagner & Wright Burak, 2017). When state budgets are supplemented by Medicaid dollars, the cuts have a drastic impact on CF abilities. In 2016, 46 ECI providers were active in the state, in 2020 it was reported that 43% of those entities had eliminated their CF position and only 22% of organizations still staffed this as a dedicated position (Texas Care for Children, 2016). Programs noted that lack of cash flow from delayed service reimbursement affects continuation impacting the quality of

service. An ECI letter to Texas Legislators from the Department of Health and Human Services and State ECI contractors proposed, as a means for cost savings, to eliminate or significantly reduce their budgets allotted for CF efforts (THHSC Rider 98, 2020).

### *Medicaid*

Funding for EI programs relies on medical funding and payor as last resort models. In Texas, 66% of the ECI recipients are on Medicaid and children are serviced free of charge; otherwise, family cost share is offered on a sliding scale for services. In 2015, the Medicaid budget was cut by \$350 million dollars creating a downward spiral for programs (Texas Care for Children, 2016). Vail, Lieberman-Betz, and McCorkle (2018) measured states' perception of the impact funding has on state program implementation. Results revealed that states have a dependency on Medicaid funds to cover service coordination of a multi-disciplinary team (i.e., speech-language, physical, and occupational therapies) and reimbursable limits are placed on services outside of the primary service delivery model. Therefore, majority of the states' cost recovery efforts are billed to Medicaid with a match in state funds or private insurance. A compounding factor is related to the family's access to early children intervention services and their ability to obtain private insurance or Medicaid. A cost burden on the family with private insurance usually requires a copayment for each service session; with related services, this could occur 2 to 3 times a week causing a financial burden for families (Vail et al., 2018). Therefore, in North Carolina, a study that examined the funding sources for Part C programs and suggested that an increased investment of \$1,100 per child has significant long-term implications that resulted in 10% reduction of third graders in special education. This demonstrates a benefit to the life cycle with sufficient funding for Part C services (Heckman, 2017; Muschkin, Ladd & Dodge, 2015). Failure to do so is a constraint placed in various ways ranging from the quality of services and personnel.

## **Conclusion**

Although disparities exist in the access and utilization of early intervention services for Black families, there is still a need to discover the barriers that result in Black children being identified at lower rates for disabilities than their White counterparts (Dababnah et al., 2018). This study was an exploration to add to the existing research base, as well as fill in a gap in the literature with regard to early intervention services for Black families in the state of Texas. Variables explored in the study were parent and service providers' perceptions of barriers to accessing early intervention services including attitudes, feelings, and experiences related to their children's disabilities.

## CHAPTER III: METHODOLOGY

The purpose of this study was to explore the perceived barriers preventing Black families from accessing and utilizing early childhood intervention services. As a mixed methods study, data were collected from survey and interviews, from a purposeful sample of Black parents with children enrolled in a preschool special education program who did or did not access an ECI program. In addition, surveys were administered to medical and educational professionals to solicit their perceptions as to the hinderances that obstruct families from enrolling into intervention services. This chapter presents an overview of the research problem, operationalization of theoretical constructs, research purpose and questions, research design, population and sampling selection, instrumentation used, data collection procedures, data analysis, privacy and ethical considerations, and the research design limitations of the study.

### **Overview of the Research Problem**

Black children are five times more likely to not receive early childhood intervention services and increasingly determined as being learning or emotionally disabled (Feinberg et al., 2011; IDEA, 2017; Morgan et al., 2015). As recent as 2019, a U.S. District court ruled in the case of *COPAA vs. DeVos*, noting minorities are still overrepresent in Part B of IDEA, and drew attention to the systemic prejudices and racism that interpret a Black child's behavior as unjustifiable, problematic, or atypical, causing an uptick in special education enrollment (Marshall, 2019; Morgan et al., 2015). Over the years, the federal government has focused on over-representation of minorities in special education, in particular Black children, yet the statistics reflect the opposite as minority children are being underidentified for early childhood intervention programs referred to as Part C of IDEA (Morgan et al., 2015). Therefore, there is a need to explore

the perceived barriers that prevent Black families from accessing and utilizing early intervention services.

### **Operationalization of Theoretical Constructs**

This study examined four constructs: (a) barriers, (b) access to ECI programs, (c) utilization of ECI services, and (d) parental empowerment. Barriers are defined as a parent's knowledge, perceptions, socioeconomic, and work status that impacts their ability to access an ECI program (Giordano, 2008). Access is defined as the parent's level of awareness of their child's developmental needs and need of an assessment to qualify for services (Andersen et al., 2013; Arcia et al., 1993; Giordano, 2008). Utilization is the follow-through with participation in an early childhood intervention program (Andersen et al., 2013; Arcia et al., 1993; Giordano, 2008). Barriers, access, and utilization were measured using the *Perceived Barriers to Access Early Intervention Services in New Jersey* (PBAEINJ) survey. Parental empowerment is defined as their personal control, critical awareness, and ability to respond to parental issues when raising a child with a disability and was measured using *Parental Empowerment: Construct Validity and Reliability of Dutch Empowerment Questionnaire* (EMPO).

### **Research Purpose and Questions**

The purpose of this study was to explore the perceived barriers preventing Black families from accessing (completing intake process) and utilizing (follow-through with the support) early childhood intervention services. The study addressed the following questions:

## **Quantitative**

R1: What barriers do Black families encounter that prevent them from accessing early childhood intervention services?

R2: Is there a difference in the perceived barriers encountered by families who did and did not access early childhood intervention services?

R3: What barriers medical and educational professionals perceive impact a family's access and utilization of early childhood intervention programs?

## **Mixed-Methods**

R4: What effect, if any, does parental empowerment have on those families who did and did not access early childhood intervention services?

## **Qualitative**

R5: What are, if any, the discrepancies between the views of parents and professionals regarding the access and utilization of early childhood intervention services?

R6: What are the parents' knowledge, feelings, and thoughts when attempting to access early intervention services?

R7: What evidence of empowerment to advocate in their child's best interest is shared in the respondents' expressions/stories?

Quantitative data were analyzed using descriptive statistics, a one-way Analysis of Variance (ANOVA), Chi-square test of independence, cross tabulations, and logistical regression. An inductive coding process was used to look for themes that may emerge from the interview responses.

## **Research Design**

An exploratory mixed-methods (QUAL-quan) design was used for this study. The design consisted of two phases: first, a quantitative phase and second, a qualitative phase. The implementation this design allows for a comprehensive viewpoint and in-depth exploration to support the quantitative findings. A purposeful sample of Black families in the Southeast region of Texas who were enrolled in a Preschool Program for Children

with Disabilities (PPCD), who did or did not access an ECI program, were solicited to complete the *Barriers to Access and Utilize Early Childhood Intervention Services Inventory* (BAUECISI). In addition, medical and educational professionals working with children birth to 3 years completed the *Perceived Barriers to Access Early Intervention in New Jersey-Professionals View*, to depict their perception of the barriers families encounter. Semi-structured interviews of both professionals and parents were conducted to provide a holistic view into the barriers that impact marginalized children enrollment into related services.

### **Population and Sample**

The target population of this study consisted of Black families with infants or toddlers living in southeast Texas. In 2017, a national representation of birth rates was comprised of 565,164 children born to Black mothers (CDC, 2019). In Texas, Black infants make up 8% of the national birth rate, comprised of 48,300 minority babies (CDC, 2019). Table 3.1 provides the national birth rate of children across racial/ethnic groups obtained from the 2017 National Vital Statistics Report (CDC, 2019).

Table 3.1

*Birth Rates by Race/Ethnicity*

	<i>Frequency (n)</i>	<i>Percentage (%)</i>
United States	3,855,500	100.0
White	2,014,898	52.2
Black	565,164	14.6
Hispanic	898,764	23.3

The service age of children in an early childhood intervention program are the ages of birth until their 3rd birthday. Nationally, there are 11,957,307 children who are in this age category (OSEP, 2018b). Table 3.2 shows the number of infants and toddlers in 2016 who were served under Part C versus those who were eligible and not serviced, indicated as the risk ratio (OSEP, 2018b).

Table 3.2

*Number of Infants and Toddlers Eligible and Enrolled in IDEA Part C*

	<i>Frequency (n) Total Population</i>	<i>Frequency (n) Enrolled</i>	<i>Percentage (%)</i>	<i>Risk ratio</i>
United States	11,919,290	367,700	-	-
White	5,895,837	192,926	3.3	1.1
Black	1,645,423	44,930	2.7	0.9
Hispanic	3,087,454	95,781	3.1	1.0

According to the America Community Survey Data , there are nearly 10-million Black children in the US accounting for 14.0% of the population (U.S. Census Snapshot, 2019). Of the 6.6 million students identified with a disability under Part B of IDEA, 17% are Black children (NCES, 2016). In particular, children birth to 5 years of age account for 759,801 of the U.S. Special Population; among this group, 10.0% are Black or African American (ECTA, 2016). Texas has the third largest special education population for children 3 to 5 (ECTA, 2016). However, Black children under Part B Section 619 have a risk factor of 1.0, meaning they are less likely to receive services under the preschool special education program (OSEP, 2018b). According to the U.S. Department of Health and Human Services 574,977 children under the age of 6 accounting for 29% of children in Texas were screened for a developmental delay based on a parental concern

Kidscount, 2012). An infant or toddler up to the age of 3 years who is determined as being developmentally delayed or at-risk will, according to individual states' thresholds, qualify for early intervention services (CDC, 2019; OSEP, 2018b).

Meanwhile, the Office of Early Head Start and Head Start programs offers a comprehensive agenda that entails screenings and evaluations for developmental delays starting from infancy through kindergarten (OSEP, 2018b). Families will have to qualify for a Head Start program; factors such as being of low-income, homeless, or in foster care. In addition, these entities offer comprehensive services to their enrolled families through partnerships with various agencies such as ECI. Pairing with ECI, they provide developmental screenings and a baseline of data for entering children to establish their health, social and emotional, behavioral, and developmental abilities at the start of the intervention. Therefore, as children enter into a Head Start program they are screened for a developmental delay and this does not pose a barrier gap because the resources and/or referrals take place within their program for early intervention services (Early Childhood Learning and Knowledge Center, 2020). These reasons excluded early and head start programs from being included in the criteria for this study. Thus, the aim was to capture the voice of parents who did and did not access early intervention services through a prescribed program to identify their perceived idea of the barriers. For that reason, a purposeful sample of parents of children aged 3-5 with a disability enrolled in a school district-based special education program had a greater chance of directly enrolling into the district bypassing any previous resources.

The following tables function as a numerical representation of Black children and early intervention programs in Texas. Table 3.3 provides an overview of the race/ethnicity of students who are enrolled in an early childhood special education preschool program in Texas; the risk factor indicates the likelihood that group will

receive services (ECTA, 2016; OSEP, 2018a). Table 3.4 displays the state rankings for serving children 3 to 5 years of age who are enrolled in a preschool special education program (ECTA, 2016). Table 3.5 shows the number of various medical and educational professionals who have direct experience working with children, infants, and toddlers.

Table 3.3

*Population of Children Enrolled in Preschool Programs for Children with Disabilities in Texas (PPCD) (ages 3-5)*

	<i>Children in Texas (n)</i>	<i>Children in a Texas PPCD program (n)</i>	<i>Texas enrolled in PPCD (%)</i>	<i>Risk ratio for children (3-5)</i>
Total Special Education Population in Texas (ages 3-21)	498,320		9.3%	
Black Population		4,796	10.2	.09
American Indian or Alaska Native		227	.04	.04
Asian		1,890	4.0	.37
Hispanic		23,974	51.3	4.8
Native Hawaiian or Pacific Islander		55	.01	.00
Two or more races		1,191	2.5	.02
White		14,549	31.1	2.9
Total		46,477		

Table 3.4

*States' Ranking of Children Enrolled in Preschool Program for Children with Disabilities*

<i>Total Special Education Population In the United States (ages 3-5)</i>		
		<i>759,801</i>
Ranking		
1	California	80,903
2	New York	66,317
3	Texas	46,652
4	Florida	40,412
5	Illinois	37,253
6	Pennsylvania	34,056

Table 3.5

*Medical and Educational Professionals in Texas*

	<i>Professionals in Texas (n)</i>	<i>Specialty (%)</i>
Pediatricians	4,098	7.0
Family Nurse Practitioners	6,198	54.0
Pediatric Nurse Practitioners	1,153	10.0
ECI Directors (Harris and surrounding counties)	7	-
Special Education Directors (Region 4)	48	-

## **Participant Selection**

In the qualitative portion of the study, a purposive sample of five respondents were chosen for narrative interviews. An advantage to narrative interviews is that it allows the researcher and participant to be interconnected. Using a questionnaire for the qualitative interviews allows a researcher to look further through the lens of an underlying piece of text or dialogue (Hood, 2006). In this study, the respondents were made up of professionals and families. A criterion for inclusion of the professional respondents was direct experience working with families who need ECI services. Therefore, a total of four professionals, a pediatrician, special education and ECI directors, and an interventionist who provides home care to Black families were included. Participants in this study were from the BIPOC community and included professionals who largely serve Black children with special needs. In addition, two Black families who did or did not access ECI were selected for the interviews.

The medical professional is a pediatrician from the United States directly servicing children with disabilities in a minority-rich area in southeast Texas and familiar with the need to refer families for early intervention services. The educational professionals are an early intervention director, a school district special education director, and an interventionist, who all have experience working with Black families. Table 3.6 features the professional respondents' pseudonyms, profession, location, and years of experience.

Table 3.6

*Professional Respondents' Demographics*

		Profession	Location	Years
1	Clyde Palace	Pediatrician	Urban	15
2	Donna Jo	Early childhood intervention program director	Rural	20
3	Karen Likely	Special education director in a school district	Urban	18
4	Tina Thompson	Early interventionist-Physical therapy	Urban	10

Both of the families who participated have a child between the ages of 3 and 5 years old, identified with a disability. One of the surveyed parents received early intervention services when their child was under 3 years of age. The other parent had directly enrolled their child in a PPCD program without having accessed early intervention services when their child was under the age of 3. Table 3.7 features the parent or primary caregiver respondents' pseudonyms, profession, geographic region, and age of child when they received services. All of the respondents who met the criteria for the interview were asked by telephone and email to participate. To ensure their comfort, the purpose of the study, time constraints, potential risks, benefits, and the assurance of confidentiality were included in the initial contact.

Table 3.7

*Parent and/or Primary Caregiver Respondents' Demographics*

		Profession	Geographic Region	Years
1	Linda Smith	Educator	Urban	2
2	Sienna Jackson	Primary caregiver	Rural	4

**Instrumentation**

**Perceived Barriers to Access Early Intervention in New Jersey**

The *Perceived Barriers to Access Early Intervention in New Jersey* (PBAEINJ) survey, as provided in Appendixes A and B, was created by Giordano (2008) to capture the perceived barriers that Caucasian mothers face when trying to access early intervention services in the state of New Jersey along with the perspective from medical and educational professionals. The original survey was piloted with a group of nine people who were parents and professionals. The feedback was used to adjust the survey accordingly. The professional instrument was slightly adapted to solicit their perception of the barriers that families encounter when accessing ECI programs. Items for the survey were derived from the literature that assessed the influential factors that are barriers and examined the respondent's perception of the greatest obstacles encountered (Giodarno, 2008).

The 44-item survey consists of two parts made up of demographics and barriers to accessing early intervention services in the state of New Jersey. The first 19 items are demographic questions that were used because this study is targeted toward a minority population. For the purpose of this study, only the 25-questions from the PBAEINJ

survey related to the barriers were used. The parents responded to identify the barriers using a 3-point Likert-type scale with 3 = Major barrier, 2 = Minimal barrier, and 1 = No barrier. A composite score between 25-75 was used to represent the degree of challenge faced when accessing an ECI program. A higher score alludes to a greater sense of difficulty to obtain the needed services. Table 3.8 shows the sample of the respondents selected for the pilot study. Table 3.9 provides detailed descriptions of the barrier questions asked to the parents and professionals.

Table 3.8

*Description of PBAEINJ Participants Used in the Pilot Study*

	Group	Frequency of Participants ( <i>n</i> )
1	Parents enrolled in a preschool special education program	3
2	Parents who are in enrolled in an early intervention program	3
3	Medical and Educational Professionals	10

Table 3.9

*Barrier Instrument Descriptors*

	Category	Barrier (Giodarno, 2008)	Sample Item
1	Knowledge	A parent’s knowledge for the need of services and how to access	I was told that there are no educational services for children under 3 years.
2	Culture	Cultural implications that influence a parent’s perception	I believe my child’s delay was due to cultural differences.
3	Perception	A parent’s view of the financial costs associated with the program.	I found out that I could not afford EI services.

**Dutch Empowerment Questionnaire**

In order to measure parental empowerment, the *Parental Empowerment: Construct Validity and Reliability of a Dutch Empowerment Questionnaire* (EMPO; see Appendix C) constructed by Damen et al. (2016) was used. Reliability and validity were established through clinical ( $n = 673$ ) and non-clinical ( $n = 1212$ ) trials of Dutch parents raising children with behavioral challenges. The clinical group was referred based on parenting issues such as family climate or childrearing skills. This group received professional support from a government child welfare program.

The survey was derived from psychological empowerment, which focuses on individual level liberation intertwined with three components that include intrapersonal, interactional, and behavioral perspectives. In order to quantify what may be considered elusive, the EMPO instrument sought to capture a parents’ stimulability to solve their problems when rearing a child with disability. Therefore, the authors kept the same

categories from the original survey that was created to measure three domains: (a) intrapersonal, (b) interactional, and (c) behavioral control, tailored to a parental audience.

This version of the EMPO is made up 12 questions and 3 subscales (intrapersonal, interactional, and behavioral) that contain statements descriptive to each category of parental empowerment. Table 3.10 lists the name of each scale and clarifies the meaning of each scale by providing a description and sample item for each category. Participants were asked to respond on a 5-point Likert-type scale (1 = disagree completely, 2 = disagree, 3 = don't disagree/agree, 4 = agree, and 5 = agree completely). Individual scores are reflective of their feelings of empowerment and personal control. Composite scores for each subscale can range from 12-60. The higher score is representative of increased parental empowerment to advocate for their child's best interest.

Table 3.11 details the description for each subscales as follows: (a) the *intrapersonal* component is made up of four questions related to how parents perceived themselves and their ability to control their immediate surroundings, (b) the *interactional* component consists of five questions that looked at the parent's capability to face challenging situations and ability to resolve the problem, and (c) the *behavioral* section is comprised of three questions sought to elicit the parent's interpretation on how they controlled their behavior in raising their children. Also, the behavioral component determined if actions were taken by the parent or primary caregiver when needed to seek services or advocate for their child. In addition, reliability was determined through the use of test-retest reliability and Cronbach's alpha. Lastly, Table 3.13 provides the reliabilities for each of the subscales for both the clinical and non-clinical groups.

Table 3.10

*Description of EMPO Subscales*

	Scale	Frequency of items ( <i>n</i> )	Description (Damen et al., 2016)	Sample Item
1	Intrapersonal	4	A person's feeling of control to approach their personal matters.	I don't easily get stressed.
2	Interactional	5	Alertness, willingness, and resolve of a person to change an undesired situation.	I always fight for things that matter, that are important to me.
3	Behavioral	3	A persons' behavior aimed at solving their problem.	I am very much in control of the raising of my child.

Table 3.11

*Reliability of the EMPO Scales*

Scale	Items	Non-clinical group ( <i>n</i> = 673)		Clinical group ( <i>n</i> = 1,212)	
		A	R	A	R $\alpha$
Intrapersonal	4	0.74	0.83	0.73	0.87
Interactional	5	0.73	0.76	0.87	0.74
Behavioral control	3	0.74	0.82	0.82	0.97

## **Data Collection**

### **Quantitative**

Prior to collecting data, the proper approvals from the Committee for the Protection of Human Subjects (CPHS) at the University of Houston-Clear Lake were obtained (see Appendix D for Human Subjects Application). Once approval was granted, the researcher proceeded to collect data from the respondents. A collection of methods were employed in this study, that included the use of both a paper and an online survey. A purposeful sample of parents enrolled in a PPCD programs were solicited to complete the *Barriers to Access and Utilize Early Childhood Intervention Services Inventory* (BAUECISI) (see Appendix E). A portion of the respondents were obtained through the researcher's personal contacts from families enrolled in a large childcare center as well as from targeted social media groups and paid advertisement, and school districts' push-in text message notifications to parents. In addition, a survey was sent to pediatricians, pediatric nurse practitioners, ECI directors, and special education directors in southeast Texas. Then an email list request was sent to the Texas Pediatric Society and Texas Nurse Practitioners Association to obtain emails for electronic survey distribution. Once initial contact was made, then weekly follow-up emails or boosted social media posts to encourage participation continued for 5 weeks. The email was addressed with a cover letter for each mode of administration. A cover letter included purpose of the study, assurances of confidentiality, reinforcement that participation was voluntary, and instructions to complete the survey by the deadline (see Appendixes F and G). The survey was distributed online through Qualtrics or by in-person administration with responses read aloud to the respondent. Data were collected over a 5-week period.

## **Qualitative**

Parental and professional perceptions of the barriers that Black families encounter when trying to access and utilize early intervention services were examined through narrative inquiry. Schwandt (2000) expounded on the idea gaining an understanding comes by way of looking beyond the instant presence, but through conversation and observing, which is the purpose of qualitative inquiry. After an exhaustive review of the literature, no established interview protocols that included the perspective of the perceived barriers from both educational and medical professionals were found; therefore, their view will be included in the interviews. An advantage to using semi-structured interviews is the baseline of consistency for all respondents; in addition, the structure of the questions allows improvised follow-up to elicit further details (Kallio, Pietilä, Johnson, & Kangasniemi, 2016). The interview protocol was designed with open-ended questions derived from the quantitative data and literature that noted the barriers (see Appendixes H and I). Prior to conducting the interviews, the questions were reviewed for content and alignment to the research questions found in earlier in this chapter. In order to protect the identity of the individuals they were assigned a code.

A purposive group of respondents were chosen for this study who provided varied perspectives for each of the following constructs: (a) perceived barriers to accessing or utilizing ECI, and (b) parental empowerment in raising a child with a disability. Six people were chosen including parent or primary caregiver and medical and educational professionals. The parents included in the study had direct experience with ECI or did not access the services. In addition, the medical professional, specifically, a pediatrician, special education and early intervention program directors, and the early interventionist all have direct experience working with Black marginalized families.

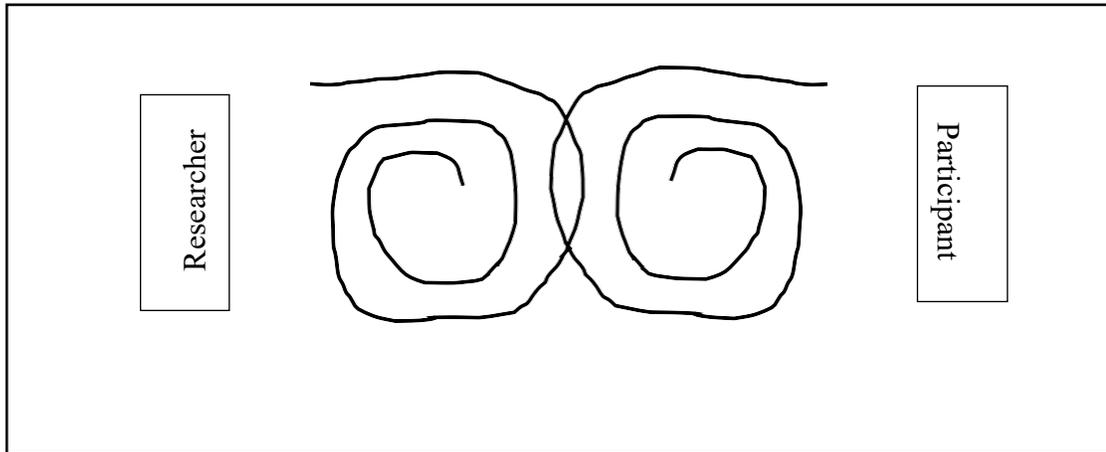
## **Purpose of Narrative Inquiry**

Hymns, code-talking, and fireside stories kept the experiences of Black slaves alive through generations. As an adult, I still hear an inner narration of my father's daily stories on our morning commute. Narratives of our elders cannot be denied, or worse yet, mishandled. In the Black community, there is a responsibility to listen, keep, share, and build upon the stories of those who reared us. An actionable step is through narrative inquiry. As the next generation, we are bequeathed to understand the "I Dun Told Yous."

For the qualitative method, I wanted to extend beyond the art form of storytelling to listening to how others interpreted their story. Storytelling is dispersant of one's self toward others but not a solicitation of feedback about the told story. Gauna (2014) stated narrative inquiries are stories based on one's experience equating to their reality. In order for transformation, liberation, and reorganized power structures within policy and the like to take place, experience is to be seen as an essential piece captured for the intended audience (Merriam, Cafarella, & Baumgartner, 2007). Merriam et al. (2007) stated the direct embodied experience "is an immediate encounter, in the here-and-now, planned or unplanned, involving us physically, emotionally, sensually, mentally, and perhaps spiritually" (p. 144).

An opportunity exists to imagine how a parent's reality is different from the mainstream perspective when contemplating the developmental milestones of their child. Clandinin and Connelly (2000) highlighted narrative inquiry is a means of understanding an experience, which takes place over and through time to capture the essence behind the thoughts, movements, and interpretations of the individual; in this case, the family. Thus, a difference in narrative inquiry is a reciprocal process in which the inquirer and participant are sharing in the course of their stories (Clandinin & Connelley, 2000).

Figure 3.1 displays the interconnectedness between the researcher-participant through their living stories.



*Figure 3.1.* Depiction of the inquiry field.

Naturally, Mezirow and Associates (1990) stated when communicating from experience, a person's consciousness is raised, extending beyond the process of simple reflection, through the retelling or recalling individual experiences such as the feelings of mistreatment, or muted through nonverbal gestures. Commonly, when the consciousness is raised, this is also known as critical self-reflection (Mezirow and Associates, 1990). Narrative inquiry is a tool that allows a participant to recollect their lived experiences and their influence on their daily lives. The researcher and the participant are not in a dominant-subordinate interaction but share parallels in their stories. Connelly and Clandinin (2006) formally defined narrative inquiry as

[a]rguments for the development and use of narrative inquiry come out of a view of human experience, in which humans, individually and socially, lead storied lives. People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful. Viewed this way,

narrative is the phenomenon studied in inquiry. Narrative inquiry, the study of experience as story, then, is first and foremost a way of thinking about experience. Narrative inquiry as a methodology entails a view of the phenomenon. To use narrative inquiry methodology is to adopt a particular narrative view of experience as phenomena under study. (p. 477)

Black families have a story that has subtleties unique to them as a community. Clandinin and Connelly (2000) reminded us that as individuals and society we are indebted to our history. A narrative lens jolts us not to take for granted the places, times, and events that have shaped our forefathers, communities, and selves (Clandinin & Connelly, 2000). Since experience happens naturally, narrative inquiry studies the narrative of that journey.

#### *Narrative Creed*

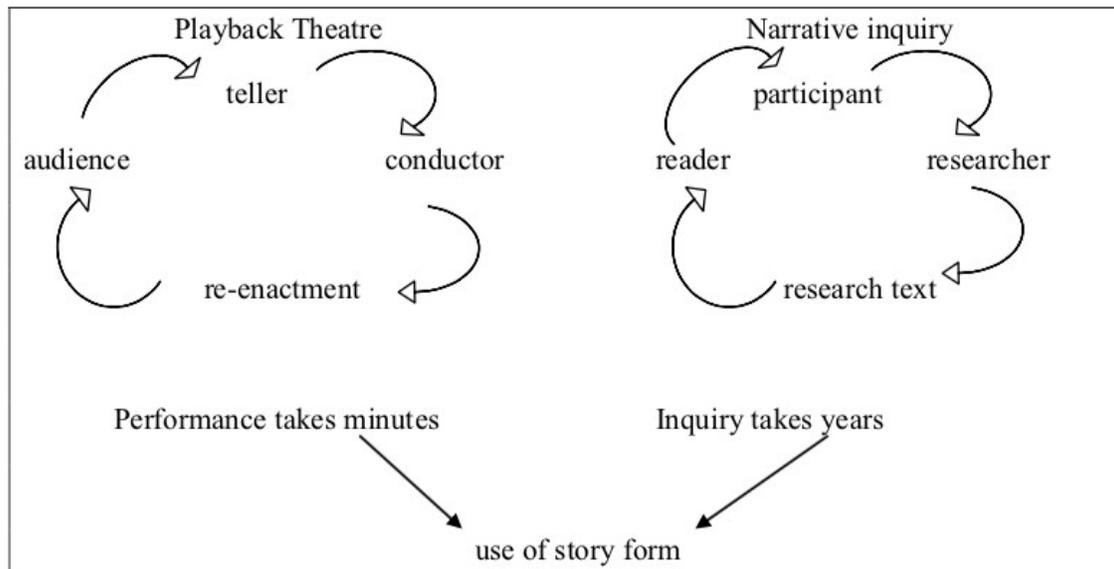
Through the process of narration, the communication can be difficult as Clandinin and Connelly (2000) described the struggle or tensions of temporality, place, and sociality. Temporality is the premise of lost but not forgotten that derives meaning from the influences of the past, present, and future (Clandinin & Connelly, 2000). Sociality occurs as we are adjoined in a milieu that embodies lived stories (Clandinin & Connelly, 2000). During sociality, the inquirer considers the feelings, thoughts, and state of being of the participant that is tied to their environment, surrounding factors, and forces (Clandinin, 2006). Place is important when delving into the temporality of a participant for the location to ascertain positive or negative associations (Clandinin, Pushor & Orr 2007). “Researchers’ principal interest in experience is the growth and transformation in the life story authored by the researcher and participant” (Clandinin & Connelly, 2000, p. 71). Dewey’s notion portrays the “black box” of experience as irreducible, limited to the author, yet we have to answer the “why” for the way things are done through experience

(Clandinin & Connelly, 2000). Embodiment is the expression made tangible for others to see, feel, and experience, similar to the daily interactions of a mother whose interactions are influenced by her personal and social exchanges. Narrative centers the researcher's position as an ongoing process of reflection, particularly "wakefulness," constantly being aware, engaging in consideration, attending with acuity the events around them (Clandinin & Connelly, 2000).

Three dimensions continuously explored by the researcher are comprised of four directions of inquiry: personal and social (interactional), inward and outward (situational), and backward and forward (temporality) (Clandinin & Connelly, 2000, p. 50). Inward and outward comprises the participants' internal conditions; the feelings, hopes, aesthetic reactions, and moral positions. Outward are the extensional environmental factors that influence the thoughts, decisions, and reactions of past, now, and what is to come. Backward and forward relates to a position in time the spatial situation that constitutes the means for doing.

### *Playback*

The cycle of inquiry is reminiscent of the art form that takes place in playback theatre. Playback theatre is a physical representation of one's embodiment as personal recollection is interpreted and displayed through others. A communal art form was created by Fox (1994) to have the common people for the community act out the story of other's daily lives. Playback theatre is an improvisational art form that explores the personal stories of an individual or community where tribal-ritual people whose lives are intertwined come together to elaborate and celebrate their stories through action in a safe and comfortable place to share (Salas, 1993; Salas et al., 2009). Gauna (2014) highlighted parallels between playback theatre and narrative inquiry as depicted in Figure 3.2.



*Figure 3.2.* Comparison between playback theatre and narrative inquiry.

The roles overlap between the researcher and conductor as they determine the entry and exits points to their story in a non-intrusive manner (Gauna, 2014). Cyclically, both roles are set to elicit a response with a conclusion “when well done, offer readers a place to imagine their own uses and application” (Clandinin & Connelly, 2000, p. 42). Gauna (2014) synthesized the process into actionable steps as outlined in Table 3.12.

Table 3.12

*Permission From Gauna (2014) Sequence of Steps Through the Narrative Inquiry*

<b>Attention to the temporal dimension</b>	Begin by thanking the teller and pose very open-ended question such as, “ <i>When</i> does your story begin?”
<b>Attention to place</b>	“ <i>Where</i> does your story begin?”
<b>Attention to the story line</b>	“Then, what happens?”
<b>Attention to people</b>	“Could you describe yourself or (so & so) in this situation?” What did you do or what did you say in this situation?”
<b>Request clarification for meaning and attention to context</b>	With questions such as, “when you say that you were in (Harlem), what does it mean for you?” (attention to context). Avoid commonplace assumptions.
<b>Paraphrase or re-story to check for understanding</b>	“Let me see if I heard you right.” Do not ask about feelings, it brings up red flags as if the participant was in a therapy session without the proper therapist and in public
<b>Explore meaning of the story</b>	“How does the story end? What’s the title of your story?”

*Professional lens of narration*

During his time as a medical resident, Coles (1989), a child psychiatrist, was challenged to identify symptoms and diagnoses, but he was urged to inquire more by listening to the patients and their stories. On the horizon was a subtle revolution of change as he sought to listen holistically to his patients. Dewey (1938) stated there is always a history. He viewed a good listener as a practitioner who

noted the manner of presentation; development of the plot; character; the addition of the new dramatic sequences; the emphasis accorded to one figure or another in

the recital; and the degree of enthusiasm, of coherence, the narrator gives to his or her account. (Clandinin & Connelly, 2000, p. 13)

How could this change the outcome for Black children if the elevated volumes of a mother's voice or fragmented explanations of the Black parents' stories were viewed as a piece of literature?

### *Parents' lens of narration*

An explicit practice from the Division for Early Childhood is “practitioners build[ing] trusting and respectful partnerships with the family through interactions that are sensitive and responsive to cultural, linguistic, and socio-economic diversity” [Division of Early Childhood (DEC) Recommended Practices F1, 2014]. In the wake of upholding the duty of professional practices there is a chance for families to think beyond the surface interaction to ask, *Who am I?, What do I do?, What did I say?*, questions that go beyond careful interactions but provoke practitioners to apply a lens that could change their perspective. Narrative inquiry is a means of listening for the responses that may stretch our limits beyond culturally responsive behaviors and reorganize policy to reflect equity of access.

### **Narrative Inquiry**

Beyond the rote understanding of collecting data through interviews, recordings, and transcriptions, Clandinin and Connelly (2000) stated research carries the idea of an objective representation foregoing the interconnectedness of the experiences that both the participant and researcher contribute to the lived experiences. Attention is called to the “centrality of a researcher's own experience through their own living, telling, retellings and reliving” (Clandinin & Connelly, 2000, p.70). Narrative inquiry has a quest to enhance personal and social growth (Clandinin & Connelly, 2000). Therefore, in continuation of the journey, data were collected through several forms that included an

autobiography, field text, conversations, interviews, family stories, photographs, video, and a memory box.

### **Autobiography**

My story as the researcher is not separate from, but inclusive of, the participants in this study. An initial point was to capture a segment of my recollection of needing help through ECI. Used as a means to frame the context for this study, my story was established as a new mom thrust into the meeting the needs of a dependent.

July 18 was a momentous day as Princeton-Samuel was born; a blessed child who found deep comfort in the nest of his mothers' bosom. He acknowledged the world through rhythmic cries and peeks from behind his newly budding eyelids. On a dew-dressed morning, Dr. Kindle came by for his early rotations before his practice opened for the day. It is commonly understood that doctors are on a limited schedule and maximize their efforts in each slotted window. That day, time appeared with no boundaries and Dr. Kindle was there for an appointed time. Princeton-Samuel was not meeting his newborn milestones and through further inquiry as to my health, this moment took a different direction. I will admit that my stubbornness peaked as I wanted to nurse my child with no introduction to an artificial pacifier or bottle. Compassionately, Dr. Kindle pushed time aside and showed how to nurse my child through a syringe. He saw how restless I was and finished the whole serving. That was a time of rest for me in the hospital. This was the start to the family bond we have established with our pediatrician.

### **Field Text to Interim Research Text**

Field texts are notes such as interviews and conversation transcripts composed with attention to the narrative creed that is cultivated during the inquiry process, which allows the researcher to actively participate rather than being a distant observer

(Clandinin & Huber, in press; Clandinin & Connelly, 2000). Regarded as markers, field texts are created through the tensions of living in the field formed as a note that represents the relational aspect between the researcher and participant (Clandinin & Murphy, 2013). These are not stagnate works instead budding inscriptions to form interim research texts. Interim research texts are partial notes not closed to the action or experience, and is open to further co-compose storied interpretations (Clandinin & Huber, in press). This process brings about points of negotiations from the multiplicity of arrayed meanings from either participant (Clandinin & Huber, in press). By doing so, this collection of notes captures the essence of the scene and daily details that serve as reminders to fill in the memory outline (Clandinin & Connelly, 2000).

### **Conversations**

Face-to-face interactions are a tool that demonstrates the equality between the researcher and participant (Clandinin & Connelly, 2000). Through conversations, a reflection is created that displays mutual trust, listening, and caring about the experience (Clandinin & Connelly, 2000). An excerpt from a conversation with Dr. Kindle on a doctor's visit (November, 2019) is provided below.

Dr. Kindle: "Hey there! It has been a while, how's is everyone doing?"

Me: "We're doing wonderful, the children are excited to come see Dr. Kindle."

Children interject, "Are we getting a shot, today?"

Dr. Kindle: "We'll see bud." He high fived the oldest. "How are you doing? Let's talk about your concerns."

Me: "As you know, I always come with my list. Here goes, starting with the middle and the trial of different medicines and the impact of his diet on his skin."

Dr. Kindle: "Well, do you remember when we first talked about this in the hospital with him [pointing to the oldest]? You as the mom, with your asthma,

we can strongly suspect to see signs in the children. I remember that we were planning since then to be cautious with all the children, hence for why we tested them earlier.”

Me: “Yes, I do remember and used that as a point of reference to my observations and interpretations to their health and development. I also noted on the baby well-check form the need to get her tested for I am seeing some concerns.”

Dr. Kindle: “I do understand and think we need to be on that right away. I will make sure to put the paperwork in place to have that done. Now, tell me more about the continuation of speech.”

Me: “I noticed that the middle child stutters, but talks in long phrases.”

Dr. Kindle: “Again, going back to our initial signals, I think we are on the same page.”

Me: “Great Dr. Kindle. I know that we are a team and appreciate your understanding.”

## **Interviews**

From a narrative lens, we are cautioned to not tangle with a linear interview, in which a dominant relationship establishes another form of inequality (Clandinin & Connelly, 2000). A means to restructure the coined idea of an interview is to ask for a person’s story (Clandinin & Connelly, 2000). Daloz (1986) recognized that transformation and development come from a holistic depiction of a person’s experience (Merriam et al., 2007). An interview creates a dialogue where the inner thoughts becomes less subject to the compulsions, obsessions, and complexities of society (Merriam et al., 2007). When people are asked to share their story, this positions them in the uppermost position and raises their awareness as a start to the conscientization (Clandinin & Connelly, 2000, Freire, 2000; Merriam et al, 2007).

In essence, dual-phase interviews were used to obtain participants' initial response, then coded for emergent themes that were then used to make connections from their past, present and future as a means to capture the complexity of their living story.

Overall, the individual interviews lasted between 30 minutes and 1 hour, depending on the time needed by the respondent. These individuals had a face-to-face or telephone invitation to participate in the interview; followed by a phone call and email to confirm a date, time, and location. Meetings were scheduled at a mutually agreeable time for both the researcher and interviewee. The meetings took place at a public café or the professional's office or by telephone in a quiet place with minimal distractions. At the actual interview, the purpose of the study, confidentiality and anonymity were explained to the respondents. Once a verbal acknowledgment was obtained, the respondents signed a consent to participate in a semi-structured interview. Interviews were recorded to ensure accuracy of the transcription. For all data, additional security measures included a password protected flash drive and folder on the researcher's hard drive. Physical data were locked in a secure cabinet in the researcher's office. As required by CPHS, all data will be kept for 3 years and destruction of the data will occur once the expiration date has been reached. Quantitative data were analyzed using descriptive statistics and a one-way Analysis of Variance (ANOVA), while qualitative data were analyzed using an inductive coding process.

## **Data Analysis**

### **Quantitative**

All collected survey data were entered into SPSS for further analysis. To answer Research Question 1, *What barriers do Black families encounter that prevent them from accessing early childhood intervention services?*, frequencies and percentages were used to determine any formed pattern of occurrences into the barriers families encounter. Coefficient of determination ( $r^2$ ) was used to calculate the effect size and a significance value of .05 was used for this study.

To answer Research Question 2, Is there a statistical difference in the perceived barriers encountered by families who did and did not access early childhood intervention services?, an independent samples t-test, Chi-squared test of independence, and cross tabulations were used to determine if there was a significant mean difference between the two group of parents. The independent variable, family enrollment, was divided into two categories: (a) those who did access early childhood intervention services and (b) those who did not access the ECI program. Effect size was measured using the Eta-squared ( $\eta^2$ ) and a significance value of .05.

To answer Research Question 3, What are the barriers medical and educational professionals perceive impacts a family's access and utilization of early childhood intervention services?, a one-way Analysis of Variance (ANOVA) with common frequencies and percentages was used to determine if there was a significant mean difference between the two group of professionals (medical or educational). The independent variable, profession, was divided into two categories: (a) medical professionals with experience at the point of referral and (b) educational professionals who responded to the referral. Effect size was measured using the Eta-squared ( $\eta^2$ ) and a significance value of .05.

### **Mixed-Methods**

To answer Research Question 4, What effect, if any, does parental empowerment have on those families who did and did not access early childhood interventions services? logistical regression with common frequencies and percentages was used to determine if there was a significant mean difference between the two groups of parents. The independent variable, family enrollment, was divided into two categories: (a) those who did access early childhood intervention services and (b) those who did not access the ECI

program. Effect size was measured using the adjusted  $r^2$  and a significance value of .05. In addition, the qualitative data were analyzed using an inductive coding process.

### **Qualitative**

To answer Research Question 4, What effect, if any, does parental empowerment have on those families who did and did not access early childhood interventions services? an inductive coding process was used to identify emerging themes from parents perception of their own parental empowerment if this impacted them accessing ECI services. Participants were families who either did or did not access supports. Data were collected using a rendering of playback theatre to capture the three-dimensionality of their stories.

To answer Research Question 5, What are, if any, the discrepancies between the views of parents and professionals regarding the access and utilization of early intervention services?; Research Question 6, What are the parent's knowledge, feelings, and thoughts when attempting to access early intervention services?; and Research Question 7, What evidence of empowerment to advocate in their best interest is shared in the respondents' expressions/stories, a set of colors was assigned as codes to highlight the themes and key areas. Data from the semi-structured interviews were explored for a central phenomenon through the use of inductive coding (Creswell & Gutterman, 2019). Due to the sensitivity of the questions, the respondents' exact words were transcribed. A visual model of the codes was used to segment by themes in order to pinpoint overlap and redundancy (Creswell & Gutterman, 2019), then broad codes were used and reduced to identify themes until the point of saturation.

By the use of inductive coding, the researcher applied an innate lens to what the respondents were saying by listening to the prosody in their voice and observing their body language. After reviewing the transcript, the researcher sought to identify an overall

perspective from the emerging themes. In order to establish validity, the emergent themes were cross-referenced with the literature for links in the data. Those themes in the literature about parental barriers were used to determine the relationship, if any. Holistically, the codes from the data were used to expand, transform, and reconceptualize data to make an opening for more diverse analytical possibilities (Coffey & Atkinson, 1996).

### **Qualitative Validity**

Qualitative analysis through triangulation of the data were used from various points, such as from families with children enrolled in an ECSE program and medical and educational professionals' interview responses. In order to determine the interview protocols are reliable and valid, both sets of questions were reviewed by a content expert for feedback regarding alignment of questions to the constructs. The input from the reviewers was used to amend the interview protocol. The interviews were recorded and transcribed verbatim. After the interview, follow-up questions were asked to the respondent to ensure clarity of their responses. Heppner and Heppner (2004) noted this as a process of clarification, which could be helpful when interviewing marginalized populations. Furthermore, the following tools were used to triangulate the data: member checking, peer debriefing, and journal log kept during the interviews process. In order to present the most comprehensive findings, parent and professional interview responses were placed into thematic units and summarized by each group.

### **Privacy and Ethical Considerations**

Prior to the collection of any data, the appropriate approvals from UHCL CPHS and participating school districts were obtained. Given the survey was derived from previous instruments, the researcher asked for written approvals for their use in this study. On the cover letter of the survey, respondents were notified that their participation

was voluntary and confidential. In addition, the use a pseudonym was used to protect the identities of the respondents and locations. Informed consent was included on the electronic survey and as a signature page on the paper format. All of the information was secured with single access and stored in the researcher's office. When the 3-year expiration has passed, according to UHCL CPHS protocol, all of the materials will be destroyed. Data collected were closely examined to remain as objective as possible to lessen the influence of interpretation on the responses.

### **Research Design Limitations**

This study had several limitations. First, the internal validity of the study was weakened due to the respondent's sample narrowed to a particular ethnic group not being a representative sample of the regional population of southeast Texas. Furthermore, this was compounded due to the limited sample size of the participating families. Second, the external validity of this study was weakened due to the specificity of the respondent's demographics, which poses a limitation on the generalizability. Third, a compounding factor in this study was that the researcher had personal experiences such as being a member of the Black community and had experienced the process of accessing ECI services. Additionally, an inherent assumption, considering their identity was anonymous, was made by the researcher in the participants' level of honesty to the survey and interview responses, which may have altered the outcomes of the study. Last, another limitation to the study was the length time allotted for the interviews that was centered around the medical and education professionals' schedules that could have limited the amount of qualitative data obtained to support the survey findings.

### **Conclusion**

The purpose of this study was to explore the perceived barriers that prevent Black families from accessing and utilizing early intervention services. This chapter identified

the need to explore the influence of the constructs on parent's ability to obtain early childhood interventions services. In order to better understand the perspectives from parents and medical and educational professionals, both quantitative and qualitative data were collected. Chapter IV will report the survey findings, as well as interview data.

## CHAPTER IV:

### RESULTS

The purpose of this mixed-methods study was to explore the perceived barriers preventing Black families from accessing (completing the intake process) and utilizing (following through with the support) early childhood intervention services. This chapter provides both quantitative and qualitative results of the data analyzed for this study. Parental, medical, and educational professionals' perception of the barriers were measured using the *Barriers to Access and Utilize Early Childhood Intervention Services Inventory* (BAUECISI). Interviews provided data from parental (did and did not access ECI) and professional views to capture the narrative about their experiences when accessing and utilizing ECI services. Survey results were analyzed using frequencies, percentages, independent *t*-tests, Chi-squared test of independence, one-way Analysis of Variance (ANOVA), and logistic regression. Participants' interviews were analyzed using an inductive thematic coding process to look for emerging themes that arose from their three-dimensional experience—*temporality, sociality, and space*. Data for each of the seven research questions are presented in this chapter followed by a conclusion with a summary of the findings.

#### **Participant Demographics**

##### **Professional**

Pediatricians, nurse practitioners, and early childhood intervention (ECI) and special education program directors (SEPD), located in southeast Texas, were sent an email blast with a flyer outlining the purpose of the research and requesting their participation in the study. Based on their professional roles in the region, of the 68 medical, program administrators, and special education directors, 29 completed the survey with a 42.6% response rate. The survey was submitted either through Qualtrics

(n = 26) or in paper format (n = 3) that was then inputted into the survey system. Paper surveys were administered to professionals with whom the researcher made contact either in person or by telephone. Demographic data reflect a balance of responses from the medical participants (44.8%, n = 13) and program administrators within the educational community (44.8%, n = 13).

Table 4.1 notes the demographics for the medical and educational participants. Of the 29 participants, the majority were White (55.2%, n = 16), with the remainder being African American (24.1%, n = 7), Hispanic (13.8%, n = 4), and Asian (6.9%, n = 2). To guarantee a diverse perspective was attained, professionals from various settings and demographics of their served populations were included in this study. The majority of the participants (39.9%, n = 11) had over 15 years of professional work experience and the remaining had 5 years or fewer (13.8%, n = 4) of involvement in the field. The majority of the participants made five or fewer (27.6%, n = 8) referrals to ECI per year with a few professionals (13.8%, n = 4) who made 21 or more referrals. One medical participant noted they made 200 or more referrals in a calendar year.

Table 4.1

*Medical or Educational Professional Survey Participant Demographics*

Total Professionals	Frequency ( <i>n</i> = 29)	Percentage (%)
Type of Professional		
Medical Professional (Physician)	8	27.6
Nurse Practitioner	5	17.2
Special Education Director	8	27.6
Early Childhood Intervention Director	5	17.2
Early Childhood Interventionist	2	6.9
Other: Coordinator AI/VI	1	3.4
Race/Ethnicity		
Asian	2	6.9
Black or African American	7	24.1
Hispanic	4	13.8
White	16	55.2
Highest level of education		
Graduate degree	27	93.1
4-year college degree	2	6.9
Years of Experience in early childhood education or giving referrals		
0-5 Years	4	13.8
6-10 Years	7	24.1
11-15 Years	7	24.1
More than 15 Years	11	39.9
Number of Referral to ECI per year		
0-5	8	27.6
6-10	6	20.7
11-15	7	24.1
16-20	4	13.8
21 or more	4	13.8

## Parents

Thirty-eight parents or guardians whose children were enrolled in a Texas Early Childhood Special Education (ECSE) program completed the survey. Parental contacts were obtained through personal links, direct outreach by the district social worker to the targeted families, or information blasts and flyers placed in the student's home-folder requesting their participation in the study; in addition, parents invited the researcher to join their online social media group. Of the 60 families contacted, 38 completed and submitted the survey resulting in a 63.3% response rate. The survey was submitted either through Qualtrics (n = 21) or in paper format (n = 17) that was then inputted into the survey system.

The majority of the participants were female (99%, n = 37) and the remaining participant was a male (1%, n = 1). Table 4.2 outlines the parental participants' demographical information. All of the participants were Black or African American (100%, n = 38) who were primarily born in the US (73.6%, n = 28) with a few (13.1%, n = 5) from West African countries (i.e., Nigeria or Togo). The majority of the parents (63.1%, n = 24) lived in the US for more than 10 years with some (13.1%, n = 5) residing here fewer than 5 years. Mainly, the biological parent (84.2%, n = 32) completed the survey, along with 7.8% (n = 3) of grandparents who participated. Most of the participants (55.2%, n = 21) were employed, with the exception of 13.1% (n = 5) who were stay-at-home parents. Roughly reported household income fell between \$20,000 and \$40,000 (24.3%, n = 9) and \$60,000 and \$80,000 (24.3%, n = 9), with 21.6% (n = 8) of the families whose income was below the poverty line (<\$20,000).

Table 4.2

*Parent or Guardian Survey Demographics*

	Frequency ( <i>n</i> )	Percentage (%)
1. Gender		
Female	37	99.0
Male	1	1.0
2. Race/Ethnicity		
Black/African American	38	100.0
3. Parent place of birth		
One of the 50 United States	28	73.6
The District of Columbia	1	2.6
One of the U.S. territories (Puerto Rico, Guam, American Samoa, U.S. Virgin Islands, or Mariana Islands)	4	10.5
Another country, where?	5	13.1 Togo, West Africa, Nigeria
4. How long have they resided in the United States		
Fewer than 5 years	5	13.1
5-10 years	9	23.6
More than 10 years	24	63.1
5. Person completing the survey		
Biological parent	32	84.2
Adoptive parent	1	2.6
Stepparent	2	5.2
Foster parent	0	0.0
Grandparent	3	7.8
6. Primary caregivers' employment status		
Employed for pay or income	21	55.2
Self employed	4	10.5
Unemployed or out of work	2	5.2
Full-time student	2	5.2
Stay at home parents	5	13.1
Retired	1	2.6
Disabled or unable to work	3	7.8

Table 4.2 (continued)

	Frequency ( <i>n</i> )	Percentage (%)
7. Primary caregivers' yearly income		
\$0-\$20,000	8	21.6
\$20,001-\$40,000	9	24.3
\$40,001 - \$60,000	8	21.6
\$60,001 - \$80,000	9	24.3
\$80,001 - \$ 100,000	2	5.5
100,001 or more	1	2.7

### Child Enrollment Data

During the initial phase of accessing ECI, 38 parents took note of their child's health condition when completing the referral intake process and the outcome of their enrollment in ECI and/or ECSE. Table 4.3 highlights family's perception of health status of their child and person's involved in decision making for needed services. A majority of the families (42.1%,  $n = 16$ ) perceived their child's health to be in *good* condition with a few of them (28.9%,  $n = 11$ ) rating *poor* health as their present state. Yet, shortly after birth or within the year, 28.0% ( $n = 11$ ) participants received some form of communication (i.e., phone call, postal letter, or email) about ECI. Parents noted (52.6%,  $n = 20$ ) that they were the first to have a concern about their child's development, then a medical professional (36.8%,  $n = 14$ ) made note of a difference in their child's developmental growth. Once tested to determine eligibility for the ECI or ECSE program, the majority of children were determined, in ranking order, to either have a speech and language impairment (36.2%,  $n = 25$ ), autism (27.5%,  $n = 19$ ), or a developmental delay (23.1%,  $n = 16$ ). Parents responded that household decisions regarding the medical and educational conclusions for their child were mostly made as a married couple (52.6%,  $n = 20$ ).

Table 4.3

*Enrollment Data of Families With Children in ECI and/or ECSE*

	Frequency ( <i>n</i> )	Percentage (%)
1. Last wellness appointment, condition of child's health		
a. Excellent	2	5.2
b. Very good	8	21.0
c. Good	16	42.1
d. Fair	11	28.9
e. Poor	1	2.6
2. During the school year or shortly after birth, has the family received the following? ( <i>n</i> = 11)		
a. Notes and/or emails, about early intervention	7	63.6
b. Notes and/or emails, about school readiness	2	18.1
c. Phone calls, about early intervention	1	9.0
d. Phone calls, about school readiness	1	9.0
3. First person to notice a developmental concern		
a. Parent	20	52.6
b. Caregiver	3	7.8
c. Medical doctor	14	36.8
d. Education professional	1	2.6
4. Determination of disability category		
a. A developmental delay	16	23.1
b. An intellectual delay	0	0.0
c. A speech or language impairment	25	36.2
d. Autism	19	27.5
e. Attention deficit disorder, ADD or ADHD	1	1.4
f. A serious emotional disturbance	0	0.0
g. Deafness or another hearing impairment	1	1.4
h. Blindness or another visual impairment not corrected by glasses	0	0.0
i. An orthopedic impairment	3	4.3
j. Pervasive developmental disorder (PDD)	0	0.0
k. A specific learning disability	1	1.4
l. Traumatic brain injury	1	1.4
m. Another health impairment lasting 6 months or more	2	2.9

Table 4.3 (continued)

	Frequency ( <i>n</i> )	Percentage (%)
5. Medical or education decisions are made as a		
a. Single parent	11	28.9
b. Married couple	20	52.6
c. Foster parent	1	2.6
d. Grandparent	4	10.5
e. Custodial parent	0	0.0
f. Other guardian	2	5.2, father

Table 4.4 shows the age of enrollment at which children participated in ECI/ECSE. From the 38 families, 76.1% ( $n = 29$ ) enrolled in ECI with majority of whom (47.3%,  $n = 18$ ) enrolled at the age of 2 years, while 23.6% ( $n = 9$ ) did not enroll into an ECI program or were not eligible for services. Instead, of those children, 68.2% ( $n = 26$ ) transitioned from ECI to ECSE district program at staggered points, such as at 4 years of age; 23.6% ( $n = 9$ ) of the children entered an ECSE program and 31.5% ( $n = 12$ ) did not enroll.

Table 4.4

*Age of Enrollment Into an ECI and/or ECSE Program*

	Frequency ( <i>n</i> )	Percentage (%)
1. What age did you enroll your child in ECI program?		
a. Birth	2	5.2
b. 1 year	9	23.6
c. 2 years	18	47.3
d. Did not enroll	9	23.6
2. What age did you enroll your child in ECSE program?		
a. 3 years	14	36.8
b. 4 years	9	23.6
c. 5 years	3	7.8
d. Did not enroll	12	31.5

## **Interviews**

During the Spring of 2020, a total of six participants who were personal contacts of medical and educational professionals and parents, were referred to and subsequently interviewed by the researcher. The diversity of the participants, range of served population, and geographic location were suited to provide an in-depth perspective of the real-time experiences of the barriers in place to access and utilize ECI services. Table 4.5 reflects the pseudonym assigned to the professionals to maintain confidentiality and the attributes that qualified participants for the study. Participants who agreed to be interviewed were contacted by phone to confirm the dates and the location. An email was sent that provided the purpose of the study, an explanation of the dual-phase process that required two meetings, and assured confidentiality regarding identity and responses. Participants' roles differed with the commonality that they either make or receive referrals to ECI for children suspected to have a developmental delay. The goal was to have a sample of participants who served predominantly minority communities or were a person of color.

From the medical community, the two participants were a pediatrician and a nurse practitioner. The pediatrician was a male who had practiced medicine for 10 years with the majority of his clientele being minorities of whom 80% were Medicaid or CHIP recipients. The nurse practitioner was a first-generation college educated African American female who had practiced medicine for 10 years with a background in family care for a rural community. The ECI perspective was obtained from the program administrator that serves both suburban and rural counties in southeast Texas. The ECI program administrator was newly appointed to her role as the director but had also worked in ECI as an outreach coordinator and intern. In that capacity, the director also provided translation for Spanish-speaking families who are in need of services. She is a

first-generation Mexican American raised by a father who entered the country in pursuit of a better life. Participants completed a dual-phase interview consisting of an initial response to questions followed by feedback on the analysis of their response related to the temporality (past, present, and future) from their perspective.

Equally, three families were interviewed for this study. Table 4.5 reflects the pseudonym of the parents to maintain confidentiality and the attributes that qualified participants for the study. Two of the families did access ECI, while the other entered the school-based early childhood special education program. The families who accessed ECI did so at different ages and stages. Family #1 entered ECI because their son was born 4.5 months early and determined to be medically fragile. While in the hospital, the child received support but when he was discharged the family was required to independently locate services. In addition, the family was faced with the challenge of living in a rural community and having to air vac into the city for continual medical care. Family #2's members are first-generation immigrants from West Africa, who learned their son is on the ASD spectrum. When the child was 2 years old, the parents approached the school district who then referred them to ECI. Family #3 did not access ECI but instead enrolled in an ECSE at 4.5 years of age. The great-grandmother was the primary guardian who noticed a speech delay but felt insecure about enrolling the child in school. The family believed the child would outgrow the language delay, but his behavior was unbearable. Due to the child's behavior, the great-grandmother approached the school district and he was assessed. In the late spring, the child enrolled closer to his 5th birthday. Each participant was assigned a pseudonym to uphold the confidentiality of their identity and responses.

Table 4.5

*Interview Participants*

Participants	Role	Gender	Race/Ethnicity	Access
Mr. Kinder	Pediatrician	Male	Asian/Indian	N/A
Ms. Comfort	Family Nurse Practitioner	Female	African American	N/A
Ms. Katarina	ECI Program Director	Female	Hispanic	N/A
Family 1: London	Biological Parent	Female	Black American	Did access ECI
Family 2: Joyce	Biological Parent	Female	African American	Did access ECI
Family 3: Sean/Sara	Great grandmother/ primary guardian	Female	Black American	Did not access ECI

**Instrument Reliability**

To determine reliability (internal consistency), Cronbach alpha was utilized for the Barriers to Access and Utilize Early Childhood Intervention Services Inventory (BAUECISI) survey. One subscale from Perceived Barriers to Access Early Intervention in New Jersey (PBAEINJ) and three subscales from the Parental Empowerment: Construct Validity and Reliability of a Dutch Empowerment Questionnaire (EMPO) were chosen for this study. Cronbach's alpha was used to demonstrate instrument reliability. Researchers agree that a reasonable degree of the coefficient is  $\alpha \geq .70$  (Creswell, 2019). The Cronbach's alpha for the professionals' perceptions of barriers families encounter to access or utilize ECI services using a 3-point Likert-type scale yielded a .89 reliability. Meanwhile, the Cronbach's alpha for parental perceptions of the barriers had a .92 reliability. To determine the reliability coefficient for parental empowerment based on the

parent's experience of accessing services for each domain yielded the following alpha coefficients: (a) intrapersonal, .69; (b) interactional, .72; and (c) behavioral, .73.

### **Research Question One**

Research Question One, *What barriers do Black families encounter that prevent them from accessing early childhood intervention services?*, was answered using frequencies and percentages of responses categorized as barriers (Items 1-21), within the *Barriers to Access and Utilize Early Childhood Intervention Services Inventory* (BAUECISI) (see Appendix A). The survey was scored using a 3-point Likert-type scale (1 = Major Barrier, 2 = Minimal Barrier, 3 = No Barrier).

Of the 38 parents and guardians, 81.6% ( $n = 31$ ) identified not knowing who to ask for help and being told to “wait and see,” their child may outgrow the delay as *major barriers* impacting access to ECI services. When accessing ECI, 84.2% ( $n = 32$ ) of the families found the process frustrating and 76.3% ( $n = 29$ ) confusing, followed by 81.5% ( $n = 31$ ) who did not want their child placed in the system and “labeled.” *Minimal barriers* noted were that 52.6% ( $n = 20$ ) of parents did not want a professional in their home, followed by 55.3% ( $n = 21$ ) of parents who did not think their child would benefit from ECI services, and 47.4% ( $n = 18$ ) of parents who did not think their child would be eligible for early intervention services. The only factor seen as *no barrier* at all was that just over half of the parents 52.6% ( $n = 20$ ) had no language barrier that made getting early intervention services difficult. Table 4.6 indicates the frequency and percentages of the perceived barriers from the parental perspective.

Table 4.6

*Parental Perspective of the Barriers to Access or Utilize ECI Services (%)*

Barriers	Major Barrier	Minimal Barrier	No Barrier
1. I was not aware of the early childhood intervention programs	81.6 (n = 31)	13.2 (n = 5)	5.3 (n = 2)
2. I was told that there are no educational services for children under 3 years.	57.9 (n = 22)	34.2 (n = 13)	7.9 (n = 3)
3. Other people do not share my concerns.	65.8 (n = 25)	26.3 (n = 10)	7.9 (n = 3)
4. I was told to “wait and see”; my child may outgrow the delay.	86.8 (n = 33)	5.3 (n = 2)	7.9 (n = 3)
5. I had concerns about my child’s development, but did not know who to ask for help.	86.8 (n = 33)	13.1 (n = 5)	0.0 (n = 0)
6. I did not want my child placed in the system and to be “labeled.”	81.5 (n = 31)	15.7 (n = 6)	2.6 (n = 1)
7. I did not want professional workers in my home.	26.3 (n = 10)	52.6 (n = 20)	21.1 (n = 8)
8. I did not want my whole family involved in my child’s treatment.	23.7 (n = 9)	65.8 (n = 25)	10.5 (n = 4)
9. I tried to access early childhood intervention services, but found the process <i>confusing</i> .	76.3 (n = 29)	18.4 (n = 7)	5.3 (n = 2)
10. I tried access early childhood intervention services, but found the process <i>frustrating</i>	84.2 (n = 32)	7.9 (n = 3)	5.3 (n = 2)

Table 4.6 (continued)

Barriers	Major Barrier	Minimal Barrier	No Barrier
11. I did not think my child would be eligible for early intervention services.	34.2 ( <i>n</i> = 13)	47.4 ( <i>n</i> = 18)	18.4 ( <i>n</i> = 7)
12. My child was evaluated in Texas and was determined to be ineligible for services.	10.5 ( <i>n</i> = 4)	15.8 ( <i>n</i> = 6)	73.7 ( <i>n</i> = 28)
13. There are other events going on within my family that needed attention. (For example, financial concerns, another child with special needs, marital discord, work conflicts, etc.)	47.4 ( <i>n</i> = 18)	44.7 ( <i>n</i> = 17)	7.9 ( <i>n</i> = 3)
14. I found out that I could not afford early childhood intervention.	10.5 ( <i>n</i> = 4)	47.4 ( <i>n</i> = 18)	42.1 ( <i>n</i> = 16)
15. I thought early childhood intervention programs are too expensive.	13.1 ( <i>n</i> = 5)	50.0 ( <i>n</i> = 19)	36.8 ( <i>n</i> = 14)
16. I was told about my child's delay, but did not think it is severe enough to require services.	73.7 ( <i>n</i> = 28)	7.8 ( <i>n</i> = 3)	18.4 ( <i>n</i> = 7)
17. I wanted my child to have time to outgrow the delay.	73.6 ( <i>n</i> = 28)	21.1 ( <i>n</i> = 8)	5.3 ( <i>n</i> = 2)
18. I did not want early intervention services for my child.	7.9 ( <i>n</i> = 3)	68.4 ( <i>n</i> = 26)	23.7 ( <i>n</i> = 9)
19. I did not think my child will benefit from early intervention.	18.4 ( <i>n</i> = 7)	55.3 ( <i>n</i> = 21)	26.3 ( <i>n</i> = 10)
20. I did not have enough information about early intervention to make an informed decision.	57.9 ( <i>n</i> = 22)	36.8 ( <i>n</i> = 14)	5.3 ( <i>n</i> = 2)
21. A language barrier makes getting early intervention services difficult.	7.9 ( <i>n</i> = 3)	39.5 ( <i>n</i> = 15)	52.6 ( <i>n</i> = 20)

## Research Question Two

Research Question Two, Is there a difference in the perceived barriers encountered by families who did and did not access early childhood intervention services?, was analyzed using an independent samples t-test to determine if there was a statistically significant mean difference between the two groups of parents who did or did not access ECI services. The independent variable, family enrollment, was divided into two categories: (a) those who did access (n = 25) early childhood intervention services and (b) those who did not (n = 13) access the ECI program. The results of the independent t-test indicated that a statistically significant mean difference existed in the perceived barriers encountered by families who did and did not access early childhood intervention services,  $t(36) = -2.55$ ,  $p = .015$ ,  $d = 0.83$  (large effect size),  $r^2 = 0.144$ . Families that did not access program supports ( $M = 39.76$ ) perceived they encountered more barriers that impacted their enrollment compared to families who did access ECI services ( $M = 33.36$ ). Approximately 14.4% of the variance in perceived barriers can be attributed to whether one enrolls in an ECI program. Table 4.7 displays the results of the independent t-test.

Table 4.7

### *Program Barriers' Influence on Access of Services*

Participation	N	M	SD	t-value	df	p-value	D	r <sup>2</sup>
1. Did access	25	33.36	6.46	-2.55	36	.015*	0.83	0.144
2. Did not access	13	39.76	8.81					

\*Statistically significant ( $p < .05$ )

Table 4.8 displays a comparison of the parental groups for those who did ( $n = 25$ ) and those who did not ( $n = 13$ ) perception of the encountered barriers to accessing and utilizing ECI services using frequencies and percentages. Those who did not enroll found not knowing who to ask for help (100%,  $n = 13$ ), being told to “wait and see” if their child would outgrow the delay (92.3%,  $n = 12$ ), and a confusing enrollment process (92.3%,  $n = 12$ ) to be the most *major barriers* to enrollment. Similarly, families who did enroll in ECI services found not knowing who to ask for help (92.0%,  $n = 23$ ), being told to wait and see if their child would outgrow the delay (96.0%,  $n = 24$ ), and a frustrating enrollment process (96.0%,  $n = 24$ ) as the most important *major barriers*. It is interesting that families who did not enroll found the enrollment process confusing (which may have contributed to their failure to follow through) whereas the families who did enroll considered the process frustrating, perhaps because they were willing to persist through the confusion. Both groups indicated a fear that their child would be placed in the system and “labeled” was a *major barrier* (enrolled: 92.0%,  $n=23$ ; not enrolled: 84.6%,  $n = 11$ ).

Families who did not enroll (61.5%,  $n = 8$ ) considered having a professional in their home as a *minimal barrier* compared to 44.0% ( $n = 11$ ) of those who accessed services. A similar proportion of families who did not enroll (61.5%,  $n = 8$ ) in comparison to those who did enroll (48.0%,  $n = 12$ ) thought there would be little benefit of ECI services to their child. Just over one-half (53.8%,  $n = 7$ ) of parents who did not access noted that they did not think their child would be eligible for early intervention services as opposed to only just over one-third (36.0%,  $n = 9$ ) of families who did access. Just over one-half of the parents who enrolled in ECI (52.6%,  $n = 20$ ) and slightly under one-half of the families who did not enroll (46.2%,  $n = 6$ ) indicated that language was *no barrier* that made getting ECI services difficult.

Table 4.8

*Did/Did not Access: Parental Perspective of the Barriers to Access or Utilize ECI Services (%)*

Barriers		Major Barrier	Minimal Barrier	No Barrier
1. I was not aware of the early childhood intervention programs	Did Access	88.0 (n = 22)	12.0 (n = 3)	0.0 (n = 0)
	Did not access	84.6 (n = 11)	7.7 (n = 1)	7.7 (n = 1)
2. I was told that there are no educational services for children under 3 years.	Did Access	68.0 (n = 17)	28.0 (n = 7)	4.0 (n = 1)
	Did not access	53.8 (n = 7)	38.5 (n = 5)	7.7 (n = 1)
3. Other people do not share my concerns.	Did Access	72.0 (n = 18)	28.0 (n = 7)	0.0 (n = 0)
	Did not access	69.2 (n = 9)	23.1 (n = 3)	7.7 (n = 1)
4. I was told to “wait and see”; my child may outgrow the delay.	Did Access	96.0 (n = 24)	0.0 (n = 0)	4.0 (n = 1)
	Did not access	84.6 (n = 11)	7.7 (n = 1)	7.7 (n = 1)
5. I had concerns about my child’s development, but do not know who to ask for help.	Did Access	92.0 (n = 23)	8.0 (n = 2)	0.0 (n = 0)
	Did not access	100.0 (n = 13)	0.0 (n = 0)	0.0 (n = 0)

Table 4.8 (continued)

Barriers		Major Barrier	Minimal Barrier	No Barrier
6. I did not want my child placed in the system and to be “labeled”.	Did Access	92.0 ( <i>n</i> = 23)	4.0 ( <i>n</i> = 1)	4.0 ( <i>n</i> = 1)
	Did not access	84.6 ( <i>n</i> = 11)	15.4 ( <i>n</i> = 2)	0.0 ( <i>n</i> = 0)
7. I did not want professional workers in my home.	Did Access	40.0 ( <i>n</i> = 10)	44.0 ( <i>n</i> = 11)	16.0 ( <i>n</i> = 4)
	Did not access	30.8 ( <i>n</i> = 4)	61.5 ( <i>n</i> = 8)	7.7 ( <i>n</i> = 1)
8. I did not want my whole family involved in my child’s treatment.	Did Access	28.0 ( <i>n</i> = 7)	72.0 ( <i>n</i> = 18)	0.0 ( <i>n</i> = 0)
	Did not access	30.8 ( <i>n</i> = 4)	53.8 ( <i>n</i> = 7)	15.4 ( <i>n</i> = 2)
9. I tried to access early childhood intervention services, but find the process <i>confusing</i> .	Did Access	80.0 ( <i>n</i> = 20)	16.0 ( <i>n</i> = 4)	4.0 ( <i>n</i> = 1)
	Did not access	92.3 ( <i>n</i> = 12)	7.7 ( <i>n</i> = 1)	0.0 ( <i>n</i> = 0)
10. I tried access early childhood intervention services, but find the process <i>frustrating</i>	Did Access	96.0 ( <i>n</i> = 24)	4.0 ( <i>n</i> = 1)	0.0 ( <i>n</i> = 0)
	Did not access	84.6 ( <i>n</i> = 11)	15.4 ( <i>n</i> = 2)	0.0 ( <i>n</i> = 0)

Table 4.8 (continued)

Barriers		Major Barrier	Minimal Barrier	No Barrier
11. I did not think my child will be eligible for early intervention services.	Did Access	44.0 ( <i>n</i> = 11)	36.0 ( <i>n</i> = 9)	20.0 ( <i>n</i> = 5)
	Did not access	38.5 ( <i>n</i> = 5)	53.8 ( <i>n</i> = 7)	7.7 ( <i>n</i> = 1)
12. My child was evaluated in Texas and was determined to be ineligible for services.	Did Access	12.0 ( <i>n</i> = 3)	20.0 ( <i>n</i> = 5)	68.0 ( <i>n</i> = 17)
	Did not access	15.4 ( <i>n</i> = 2)	7.7 ( <i>n</i> = 1)	76.9 ( <i>n</i> = 10)
13. There are other events going on within my family that needed attention. (For example, financial concerns, another child with special needs, marital discord, work conflicts, etc.)	Did Access	52.0 ( <i>n</i> = 13)	48.0 ( <i>n</i> = 12)	0.0 ( <i>n</i> = 0)
	Did not access	61.5 ( <i>n</i> = 8)	30.8 ( <i>n</i> = 4)	7.7 ( <i>n</i> = 1)
14. I found out that I could not afford early childhood intervention.	Did Access	12.0 ( <i>n</i> = 3)	44.0 ( <i>n</i> = 11)	44.0 ( <i>n</i> = 11)
	Did not access	23.1 ( <i>n</i> = 3)	61.5 ( <i>n</i> = 8)	15.4 ( <i>n</i> = 2)
15. I thought early childhood intervention programs are too expensive.	Did Access	12.0 ( <i>n</i> = 3)	48.0 ( <i>n</i> = 12)	40.0 ( <i>n</i> = 10)
	Did not access	30.8 ( <i>n</i> = 4)	53.8 ( <i>n</i> = 7)	15.4 ( <i>n</i> = 2)

Table 4.8 (continued)

Barriers		Major Barrier	Minimal Barrier	No Barrier
16. I was told about my child's delay, but did not think it is severe enough to require services.	Did Access	80.0 ( <i>n</i> = 20)	4.0 ( <i>n</i> = 1)	16.0 ( <i>n</i> = 4)
	Did not access	84.6 ( <i>n</i> = 11)	7.7 ( <i>n</i> = 1)	7.7 ( <i>n</i> = 1)
17. I wanted my child to have time to outgrow the delay.	Did Access	80.0 ( <i>n</i> = 20)	20.0 ( <i>n</i> = 5)	0.0 ( <i>n</i> = 0)
	Did not access	84.6 ( <i>n</i> = 11)	7.7 ( <i>n</i> = 1)	7.7 ( <i>n</i> = 1)
18. I did not want early intervention services for my child.	Did Access	12.0 ( <i>n</i> = 3)	76.0 ( <i>n</i> = 19)	12.0 ( <i>n</i> = 3)
	Did not access	15.4 ( <i>n</i> = 2)	53.8 ( <i>n</i> = 7)	30.8 ( <i>n</i> = 4)
19. I did not think my child will benefit from early intervention.	Did Access	12.0 ( <i>n</i> = 3)	48.0 ( <i>n</i> = 12)	40.0 ( <i>n</i> = 10)
	Did not access	15.4 ( <i>n</i> = 2)	61.5 ( <i>n</i> = 8)	23.1 ( <i>n</i> = 3)
20. I did not have enough information about early intervention to make an informed decision.	Did Access	57.9 ( <i>n</i> = 22)	36.8 ( <i>n</i> = 14)	5.3 ( <i>n</i> = 2)
	Did not access	84.6 ( <i>n</i> = 11)	15.4 ( <i>n</i> = 2)	0.0 ( <i>n</i> = 0)
21. A language barrier makes getting early intervention services difficult.	Did Access	7.9 ( <i>n</i> = 3)	39.5 ( <i>n</i> = 15)	52.6 ( <i>n</i> = 20)

## **Employment**

To take a further look into access of ECI services, a Chi-square test of independence was conducted to determine the relationship between participant groups for families that did or did not access ECI services and the employment status of the primary caregiver. The results from the Chi-square test of independence indicated a statistically significant relationship between families who did or did not access ECI services and their employment status,  $\chi^2(1, N = 38) = 6.17, p = .013$ . In other words, the employment status (i.e., full-time for pay, stay at home/unemployed) of the primary caregiver had something to do with accessing ECI services. The results indicated primary caregivers who were employed full-time 52% of those families accessed services, as to 92.3% of caregivers who worked still did not access an ECI program.

## **Income**

When examining the relationship between parental access to ECI and socioeconomic status, a Chi-square test of independence was conducted. The results from Chi-square test of independence indicated no statistically significant relationship existed between families who did or did not access ECI services and their socioeconomic status [i.e., high (\$80,001+), mid (\$40,000-80,001), or low (<\$40,000) income],  $\chi^2(2, N = 38) = .698, p = .705$ . Fifty-two percent of low-income families were more adept at accessing an ECI program compared to 40.0% of middle-income families and 8.0% of high-income families. Low-income families typically qualify for Medicaid services are benefitted with a case manager who assists children from birth who have a health condition to gain access to services (Texas Health and Human Services, n.d.).

## **Notice of Developmental Delay**

When examining the relationship between access to services and the adult taking notice of a developmental delay, a Chi-square test of independence was conducted. The

results from Chi-square test of independence indicated no statistically significant relationship existed between the adult taking notice and access to services,  $\chi^2(2, N = 38) = 1.38, p = .499$ . Sixty-eight percent of parents were the first person to notice a difference in their child's development and access ECI services. Moreover, 16.0% of the time, pediatricians or nurse practitioners noticed or utilized the developmental checklist at the well-baby appointments to make a referral to ECI, and those families were more likely to access ECI services. In addition, when a caregiver took notice of a child's developmental delay, 16.0% of those referrals resulted in families who accessed a program. However, for those families who did not enroll, when a medical professional was the first to notice a concern 30.8% of those families still did not enroll in ECI services.

### **Research Question Three**

Research Question Three, What are the barriers medical and educational professionals perceive impacts a family's access and utilization of early childhood intervention services?, was answered using a one-way Analysis of Variance (ANOVA) along with frequencies and percentages to the responses categorized as barriers (Items 1-23) from the Barriers to Access and Utilize Early Childhood Intervention Services Inventory-Professional (BAUECISI) (see Appendix B). The survey was scored using a 3-point Likert-type scale (1 = Major Barrier, 2 = Minimal Barrier, 3 = No Barrier). The independent variable, profession, was divided into four groups: (a) family doctor or pediatrician (n = 8), (b) family or pediatric nurse practitioner (n = 5), (c) ECI program administrator (n = 5), and (d) special education director (n = 8). Results of the one-way ANOVA indicated that professionals' perceptions of the barriers families encounter when accessing ECI services has an influence on their enrollment and utilization of these supports,  $F(3, 22) = 4.39, p = .014, \omega^2 = 0.28, \eta^2 = 0.37$ . The proportion of variance 28% - 37% was based on the type of professional employment and their realization of the

barrier families experienced in accessing and utilizing services. The results from the Tukey Post Hoc indicated the largest mean differences were between the ECI program administrators and special education directors ( $M_d = 22.500$ ), followed by medical doctors and special education directors ( $M_d = 21.375$ ). Table 4.9 displays the results from the one-way ANOVA.

Table 4.9

*One-way ANOVA: Professionals' Perceptions of Program Barriers' Influence on Access to Services*

Participation	N	M	SD	F-value	df	p-value	$\omega^2$	$\eta^2$
1. Medical Professional (Doctor)	8	43.12	8.09	4.39	25	.014*	0.28	0.37
2. Nurse Practitioner	5	49.40	11.37					
3. ECI Program Administrator	5	42.00	3.74					
4. Special Education Director	8	64.50	20.43					

\*Statistically significant ( $p < .05$ )

### **Medical Professionals**

Family doctors or pediatricians ( $n = 8$ ) who serve the population birth to 5 years of age noted their perception of the barriers encountered by Black families when accessing or utilizing ECI services. *Major barriers* doctors identified that impact access to ECI services is that families found the process confusing and frustrating (87.5%,  $n = 7$ ), followed by those not aware of ECI programs (75.0%,  $n = 6$ ), and parents being told

to “wait and see,” their child may outgrow the delay (87.5%,  $n = 7$ ), along with others who did not share the parent’s concerns (62.5%,  $n = 6$ ). A majority of the physicians (87.5%,  $n = 8$ ) perceived parents did not think their child’s delay was severe enough to require services and 87.5% ( $n = 8$ ) also thought parents wanted time for their child to outgrow the delay. Once children were found eligible 100% ( $n = 8$ ) of the doctors thought parents would indicate they did not want a professional in their home. *Minimal barriers* determined by medical professionals where that the primary parent wanted the child enrolled in ECI services, but other did family members were reluctant (100%,  $n = 8$ ), followed by 75.0% ( $n = 6$ ) who thought families did not think their child would benefit from ECI services, and 50.0% ( $n = 4$ ) who believed children, once referred and evaluated, were determined ineligible for services. The medical professionals designated Black families experiencing some type of barrier either majorly or minimally affecting their access and utilization of services as *no barrier*.

### **Nurse Practitioners**

Family or pediatric nurse practitioners (NP) ( $n = 5$ ) who serve the population birth to 5 years of age noted their perceptions of the barriers Black families face when accessing or utilizing ECI services. *Major barriers* Nurse Practitioners identified that impact access to ECI services are that families found the process confusing and frustrating (60.0%,  $n = 3$ ), followed by those not aware of ECI programs (60.0%,  $n = 3$ ), and parents being told to “wait-and-see,” their child may outgrow the delay (100%,  $n = 5$ ), along with others who did not share the parents’ concerns (80.0%,  $n = 4$ ). A majority of the nurse practitioners (80.0%,  $n = 4$ ) felt parents had a concern about their child’s ability, and parents did not know who to ask for help (60.0%,  $n = 3$ ); however, they also felt that when parents were told about their child’s delay they did not think it was severe enough to require services (60%,  $n = 3$ ) and families did not have enough information to

make an informed decision to enroll in an ECI program (60.0%,  $n = 3$ ). Most nurse practitioners noted that parents wanted time for their child to outgrow the delay (80.0%,  $n = 3$ ). Nurse practitioners also emphasized that Black families had other events that were going on within family that needed attention (100%,  $n = 5$ ), cultural interpretations of a developmental delay impacted their enrollment (60.0%,  $n = 3$ ), and immigrant families feared repercussions about their immigration status (100.0%,  $n = 5$ ). *Minimal barriers* nurse practitioners determined included the primary parents wanting the child enrolled in ECI services, but other family members were reluctant (100%,  $n = 5$ ), followed by 100.0% ( $n = 5$ ) who felt parents did not think their child would qualify or benefit from ECI services, and children, once referred and evaluated, were determined ineligible for services (80%,  $n = 4$ ). They also felt a language barrier made getting services more difficult (60%,  $n = 3$ ). As did doctors, nurse practitioners noted from their perception that Black families experienced some type of barrier when accessing and utilizing ECI services to be *no barrier* in obtaining supports.

### **Early Childhood Intervention Director**

ECI program administrators or directors ( $n = 5$ ) who serve families in southeast Texas highlighted their perceptions of the barriers encountered by Black families when accessing and utilizing ECI services. They perceived as *major barriers* that parents are being told to “wait-and-see,” their child may outgrow the delay (80%,  $n = 4$ ), along with others who did not share the parents’ concern (80.0%,  $n = 4$ ), and parents did not know who to ask for help about their child’s development (80.0%,  $n = 4$ ). Moreover, the program directors noted parents are told about the child’s delay but did not think it is severe enough to require services (80.0%,  $n = 4$ ) or think their child would benefit from early supports (60%,  $n = 3$ ). As did nurse practitioners, ECI program administrators noted the perception that Black families had other events that were going on within family that

needed attention (100%,  $n = 5$ ), cultural interpretations of a developmental delay impacting their enrollment (80.0%,  $n = 4$ ), and immigrant families fearing repercussions about their immigration status (60.0%,  $n = 3$ ). Unlike medical professionals, ECI directors identified as *minimal barriers* that impact access to ECI services families found the process confusing and frustrating (100.0%,  $n = 5$ ), families being told there are no additional services for children under the age of 3 (80%,  $n = 4$ ), and once tested and evaluated, the child was determined ineligible for services (60%,  $n = 3$ ). Since services are delivered in the child's natural environment, 80.0% ( $n = 4$ ) of the NPs felt parents not wanting a professional in their home was also a *minimal barrier*. As with the medical professionals, ECI professionals indicated their perception that families of color experience some type of barrier when accessing and utilizing ECI services to be *no barrier* to these families.

### **Special Education Director**

Educational professionals who lead the school district-based special education programs ( $n = 8$ ), noted their perceptions of the barriers Black families encounter when accessing and utilizing ECI services. *Major barriers* SPED professionals noted are that parents came to the district because they did not know who to ask for help (62.5%,  $n = 5$ ), and parents thought ECI programs are too expensive (75.0%,  $n = 6$ ) or thought they could not afford the services (62.5%,  $n = 5$ ). Once parents did try to seek out services, the procedures to access were confusing (62.5%,  $n = 5$ ), and even if the child was referred and tested for ECI services they were then found to be ineligible (62.5%,  $n = 5$ ). *Minimal barriers* educational professionals determined were families were not aware of ECI programs (62.5%,  $n = 5$ ), or were told that programs are not available for children under the age of 3 (75.0%,  $n = 6$ ); for those who were aware of ECI programs, they still came to the district because they thought their child would not be eligible for services through the

program, but instead qualify from the district services (100%,  $n = 8$ ). They also indicated their perception that parents wanted time for their child to outgrow their delay (62.5%,  $n = 5$ ). SPED professionals also noted that *no barriers* existed for Black families as they encountered obstacles when accessing and utilizing ECI services.

Table 4.10

*Professionals' Perceived Parental Barriers to Access or Utilize ECI Services (%)*

Barriers		Major Barrier (%)	Minimal Barrier (%)	No Barrier (%)
1. Parents are not aware of early childhood intervention programs	D	75.0	25.0	0.0
	NP	60.0	40.0	0.0
	ECI	60.0	40.0	0.0
	SPED	37.5	62.5	0.0
2. Parents are told that there are no additional services for children under 3 years.	D	25.0	75.0	0.0
	NP	40.0	60.0	0.0
	ECI	20.0	80.0	0.0
	SPED	25.0	75.0	0.0
3. Other people do not share the parents' concerns.	D	62.5	37.5	0.0
	NP	80.0	20.0	0.0
	ECI	80.0	20.0	0.0
	SPED	25.0	75.0	0.0
4. Parents are told to "wait and see"; their child may outgrow the delay.	D	87.5	12.5	0.0
	NP	100.0	0.0	0.0
	ECI	80.0	20.0	0.0
	SPED	37.5	62.5	0.0
5. Parents have a concern about their child's development, but do not know who to ask for help.	D	50.0	50.0	0.0
	NP	80.0	20.0	0.0
	ECI	80.0	20.0	0.0
	SPED	62.5	37.5	0.0
6. Parents do not want professionals in their home.	D	100.0	0.0	0.0
	NP	40.0	60.0	0.0
	ECI	20.0	80.0	0.0
	SPED	25.0	75.0	0.0
7. Parents do not want the whole family involved in the child's treatment.	D	37.5	62.5	0.0
	NP	60.0	40.0	0.0
	ECI	80.0	20.0	0.0
	SPED	50.0	50.0	0.0

Table 4.10 (continued)

Barriers		Major Barrier (%)	Minimal Barrier (%)	No Barrier (%)
8. Parents try to access early childhood intervention services, but find the process <i>confusing</i> .	D	87.5	12.5	0.0
	NP	60.0	40.0	0.0
	ECI	0.0	100.0	0.0
	SPED	62.5	37.5	0.0
9. Parents try to access early childhood intervention services, but find the process <i>frustrating</i> .	D	87.5	12.5	0.0
	NP	60.0	40.0	0.0
	ECI	0.0	100.0	0.0
	SPED	25.0	75.0	0.0
10. Parents do not think that the child will be eligible for early intervention services.	D	0.0	100.0	0.0
	NP	20.0	60.0	20.0
	ECI	20.0	80.0	0.0
	SPED	0.0	100.0	0.0
11. The child has been tested outside of Texas and the parent was told the s/he was not eligible.	D	0.0	100.0	0.0
	NP	0.0	100.0	0.0
	ECI	0.0	100.0	0.0
	SPED	0.0	100.0	0.0
12. Once referred and evaluated the child was determined to be ineligible for services.	D	50.0	50.0	0.0
	NP	20.0	80.0	0.0
	ECI	40.0	60.0	0.0
	SPED	62.5	37.5	0.0
13. There are other events going on thin the family that needed attention. (For example, financial concerns, another child with special needs, marital discord, work conflicts, etc.)	D	50.0	50.0	0.0
	NP	100.0	0.0	0.0
	ECI	100.0	0.0	0.0
	SPED	50.0	50.0	0.0
14. Parents think early childhood intervention programs are too expensive.	D	0.0	100.0	0.0
	NP	20.0	80.0	0.0
	ECI	20.0	80.0	0.0
	SPED	75.0	25.0	0.0

Table 4.10 (continued)

Barriers		Major Barrier (%)	Minimal Barrier (%)	No Barrier (%)
15. Parents find out that they cannot afford early childhood intervention.	D	0.0	100.0	0.0
	NP	20.0	80.0	0.0
	ECI	0.0	100.0	0.0
	SPED	62.5	37.5	0.0
16. Parents are told about the child's delay, but do not think it is severe enough to require services.	D	87.5	12.5	0.0
	NP	60.0	40.0	0.0
	ECI	80.0	20.0	0.0
	SPED	75.0	25.0	0.0
17. Parents want the time to outgrow the delay.	D	87.5	12.5	0.0
	NP	80.0	20.0	0.0
	ECI	80.0	20.0	0.0
	SPED	37.5	62.5	0.0
18. Parents want the child to be in early intervention services, but other family members do not.	D	0.0	100.0	0.0
	NP	20.0	80.0	0.0
	ECI	40.0	60.0	0.0
	SPED	25.0	75.0	0.0
19. Parents believe the child's delay is due to cultural differences.	D	25.0	75.0	0.0
	NP	60.0	20.0	20.0
	ECI	80.0	20.0	0.0
	SPED	37.5	62.5	0.0
20. Parents fear repercussions about their immigration status.	D	50.0	50.0	0.0
	NP	100.0	0.0	0.0
	ECI	60.0	40.0	0.0
	SPED	37.5	62.5	0.0
21. Parents do not want early intervention services for their child.	D	0.0	100.0	0.0
	NP	0.0	100.0	0.0
	ECI	80.0	20.0	0.0
	SPED	50.0	50.0	0.0
22. Parents do not think the child will benefit from early intervention.	D	25.0	75.0	0.0
	NP	0.0	100.0	0.0
	ECI	60.0	40.0	0.0
	SPED	50.0	50.0	0.0

Table 4.10 (continued)

Barriers		Major Barrier (%)	Minimal Barrier (%)	No Barrier (%)
23. Parents do not have enough information about early intervention to make an informed decision.	D	75.0	25.0	0.0
	NP	60.0	40.0	0.0
	ECI	60.0	40.0	0.0
	SPED	50.0	50.0	0.0
24. A language barrier makes getting early intervention services difficult.	D	75.0	25.0	0.0
	NP	40.0	60.0	0.0
	ECI	0.0	100.0	0.0
	SPED	37.5	62.5	0.0

*Note: MP = Medical Professionals; NP = Nurse Practitioner; ECI = Program Administrator; SPED = Special Education Director*

#### **Research Question Four**

An answer to Research Question Four, What effect, if any, does parental empowerment have on those families who did and did not access early childhood interventions services?, was obtained through a survey and qualitative interviews. Item 26 (sections 1-12) was measured using the Barriers to Access and Utilize Early Childhood Intervention Services Inventory (BAUECISI). The subscale was categorized as parental empowerment and scored using a 5-point Likert-type scale; 1 = Disagree Completely, 2 = Disagree, 3 = Don't Disagree/Agree, 4 = Agree, and 5 = Agree Completely. Data were analyzed using logistic binary regression to determine if parental empowerment had an influence on whether parents accessed ECI services. The independent variable, parental empowerment, was continuous in measurement, while the dichotomous dependent variable was categorical: (a) parent did access ECI services or (b) parent did not access ECI services. The results of the logistic regression indicated that parental sense of empowerment did not have an influence on whether parents accessed

ECI services,  $\chi^2(1) = .594$ ,  $p = .441$ , adjusted -  $r^2 = 0.021$ . In other words, the logistic regression model was not statistically significant ( $p > .05$ ).

Tables 4.11 and 4.12 display a comparison of the parental groups who did ( $n = 25$ ) and those who did not ( $n = 13$ ) their perceived level of parental empowerment they felt in raising a child with a disability and likelihood to access an ECI program using frequencies and percentages. Those who did not enroll found they possess a higher level of control over themselves as a parent (76.9%,  $n = 10$ ), as well as they believe to have better control over matters in life (53.8%,  $n = 7$ ), such as having more control over the behaviors of their child to be the highest level of agreement when making decisions on behalf of raising a child with a developmental delay. Comparatively to those who did access ECI services found that they stand on the notion to correct their child's behavior when necessary (96.0%,  $n = 24$ ), and will immediately take action when a problem arises (68.0%,  $n = 17$ ), more so they will fight for matters that are most important to them (72.0%,  $n = 18$ ) as their highest level of agreement when accessing an ECI program. Those who did not enroll stated that they believe to be very much in control of the raising of their child, whereas families who did enroll has less control and sought help (did not enroll: 84.6,  $n = 11$ ; did enroll: 76.0,  $n = 11$ ).

When parents factored in how easily they are stressed when addressing matters related to their child, families who did not enroll (61.5%,  $n = 8$ ) compared to those who did (40.0%,  $n = 8$ ) found that they disagree, in that they do get easily stressed. Yet, nearly half of families who did not enroll (46.2%,  $n = 6$ ) in comparison to those who did enroll (12.0%,  $n = 3$ ) neither disagreed/agreed that their child behaves in the way they want them to.

Table 4.11

*Parental Empowerment and Raising a Child with a Disability*

	Access*	Disagree completely	Disagree	Don't disagree/agree	Agree	Agree completely
1. I am in control of myself	Did	8.0 (n = 2)	8.0 (n = 2)	16.0 (n = 4)	64.0 (n = 16)	4.0 (n = 1)
	DN	15.4 (n = 2)	7.7 (n = 1)	7.7 (n = 1)	46.2 (n = 6)	23.1 (n = 3)
2. I am in control of my life	Did	8.0 (n = 2)	20.0 (n = 5)	32.0 (n = 8)	40.0 (n = 10)	0.0 (n = 0)
	DN	15.4 (n = 2)	7.7 (n = 1)	15.4 (n = 2)	53.8 (n = 7)	7.7 (n = 1)
3. I don't easily get stressed	Did	8.0 (n = 2)	32.0 (n = 8)	16.0 (n = 4)	40.0 (n = 10)	4.0 (n = 1)
	DN	0.0 (n = 0)	61.5 (n = 8)	7.7 (n = 1)	30.8 (n = 4)	0.0 (n = 0)
4. I feel confident about the future	Did	0.0 (n = 0)	20.0 (n = 5)	24.0 (n = 6)	48.0 (n = 12)	8.0 (n = 2)
	DN	0.0 (n = 0)	23.1 (n = 3)	23.1 (n = 3)	46.2 (n = 6)	7.7 (n = 1)

Table 4.11 (continued)

	Access	Disagree completely	Disagree	Don't disagree/agree	Agree	Agree completely
5. I make use of advice or support from people around, if necessary	Did	0.0 ( <i>n</i> = 0)	0.0 ( <i>n</i> = 0)	28.0 ( <i>n</i> = 7)	60.0 ( <i>n</i> = 15)	12.0 ( <i>n</i> = 3)
	DN	0.0 ( <i>n</i> = 0)	0.0 ( <i>n</i> = 0)	15.4 ( <i>n</i> = 2)	69.2 ( <i>n</i> = 9)	15.4 ( <i>n</i> = 2)
6. I always fight for matters that are important to me	Did	0.0 ( <i>n</i> = 0)	4.0 ( <i>n</i> = 1)	24.0 ( <i>n</i> = 6)	60.0 ( <i>n</i> = 15)	12.0 ( <i>n</i> = 3)
	DN	0.0 ( <i>n</i> = 0)	15.4 ( <i>n</i> = 2)	15.4 ( <i>n</i> = 2)	38.5 ( <i>n</i> = 5)	30.8 ( <i>n</i> = 4)
7. I correct the behavior of my child when necessary	Did	0.0 ( <i>n</i> = 0)	0.0 ( <i>n</i> = 0)	4.0 ( <i>n</i> = 1)	92.0 ( <i>n</i> = 23)	4.0 ( <i>n</i> = 1)
	DN	0.0 ( <i>n</i> = 0)	7.7 ( <i>n</i> = 1)	15.4 ( <i>n</i> = 2)	53.8 ( <i>n</i> = 7)	23.1 ( <i>n</i> = 3)
8. I immediately act when there are problems with my child	Did	0.0 ( <i>n</i> = 0)	16.0 ( <i>n</i> = 4)	16.0 ( <i>n</i> = 4)	60.0 ( <i>n</i> = 15)	8.0 ( <i>n</i> = 2)
	DN	0.0 ( <i>n</i> = 0)	30.8 ( <i>n</i> = 4)	15.4 ( <i>n</i> = 2)	30.8 ( <i>n</i> = 4)	23.1 ( <i>n</i> = 3)

Table 4.11 (continued)

	Access	Disagree completely	Disagree	Don't disagree/agree	Agree	Agree completely
9. I look for solutions myself when I have a problem with my child	Did	0.0 (n = 0)	24.0 (n = 6)	16.0 (n = 4)	56.0 (n = 14)	4.0 (n = 1)
	DN	7.7 (n = 1)	15.4 (n = 2)	15.4 (n = 2)	38.5 (n = 5)	23.1 (n = 3)
10. I have control over the behavior of my child	Did	4.0 (n = 1)	20.0 (n = 5)	24.0 (n = 6)	48.0 (n = 12)	4.0 (n = 1)
	DN	0.0 (n = 0)	38.5 (n = 5)	15.4 (n = 2)	38.5 (n = 5)	7.7 (n = 1)
11. My child always behaves the way I want him/her to	Did	4.0 (n = 1)	36.0 (n = 9)	12.0 (n = 3)	40.0 (n = 10)	8.0 (n = 2)
	DN	15.4 (n = 2)	23.1 (n = 3)	46.2 (n = 6)	15.4 (n = 2)	0.0 (n = 0)
12. I am very much in control of the raising of my child	Did	0.0 (n = 0)	16.0 (n = 4)	12.0 (n = 3)	68.0 (n = 17)	4.0 (n = 1)
	DN	7.7 (n = 1)	7.7 (n = 1)	0.0 (n = 0)	76.9 (n = 10)	7.7 (n = 1)

Note: *Did* = did access services; *DN* = did not access services

Table 4.12

*Collapsed Parental Empowerment and Raising a Child with a Disability*

	Access*	Disagree	Don't disagree/agree	Agree
1. I am in control of myself	Did	16.0 (n = 4)	16.0 (n = 4)	68.0 (n = 68)
	DN	23.1 (n = 3)	0.0 (n = 0)	76.9 (n = 10)
2. I am in control of my life	Did	24.0 (n = 6)	36.0 (n = 9)	40.0 (n = 10)
	DN	15.4 (n = 2)	30.8 (n = 4)	53.8 (n = 7)
3. I don't easily get stressed	Did	40.0 (n = 10)	16.0 (n = 4)	44.0 (n = 11)
	DN	61.5 (n = 8)	7.7 (n = 1)	30.8 (n = 4)
4. I feel confident about the future	Did	20.0 (n = 5)	24.0 (n = 6)	56.0 (n = 14)
	DN	15.4 (n = 2)	30.8 (n = 4)	53.8 (n = 7)
5. I make use of advice or support from people around, if necessary	Did	0.0 (n = 0)	28.0 (n = 7)	72.0 (n = 18)
	DN	0.0 (n = 0)	15.4 (n = 2)	84.6 (n = 11)
6. I always fight for matters that are important to me	Did	4.0 (n = 1)	24.0 (n = 6)	72.0 (n = 18)
	DN	15.4 (n = 2)	15.4 (n = 2)	69.2 (n = 9)

Table 4.12 (continued)

	Access	Disagree	Don't disagree/agree	Agree
7. I correct the behavior of my child when necessary	Did	0.0 ( <i>n</i> = 0)	4.0 ( <i>n</i> = 1)	96.0 ( <i>n</i> = 24)
	DN	7.7 ( <i>n</i> = 1)	15.4 ( <i>n</i> = 2)	76.9 ( <i>n</i> = 10)
8. I immediately act when there are problems with my child	Did	16.0 ( <i>n</i> = 4)	16.0 ( <i>n</i> = 4)	68.0 ( <i>n</i> = 17)
	DN	30.8 ( <i>n</i> = 4)	15.4 ( <i>n</i> = 2)	53.8 ( <i>n</i> = 7)
9. I look for solutions myself when I have a problem with my child	Did	20.0 ( <i>n</i> = 5)	20.0 ( <i>n</i> = 5)	60.0 ( <i>n</i> = 15)
	DN	23.1 ( <i>n</i> = 3)	15.4 ( <i>n</i> = 2)	61.5 ( <i>n</i> = 8)
10. I have control over the behavior of my child	Did	20.0 ( <i>n</i> = 5)	28.0 ( <i>n</i> = 7)	52.0 ( <i>n</i> = 13)
	DN	38.5 ( <i>n</i> = 5)	15.4 ( <i>n</i> = 2)	46.2 ( <i>n</i> = 6)
11. My child always behaves the way I want him/her to	Did	36.0 ( <i>n</i> = 9)	12.0 ( <i>n</i> = 3)	52.0 ( <i>n</i> = 13)
	DN	38.5 ( <i>n</i> = 5)	46.2 ( <i>n</i> = 6)	15.4 ( <i>n</i> = 2)
12. I am very much in control of the raising of my child	Did	12.0 ( <i>n</i> = 3)	12.0 ( <i>n</i> = 3)	76.0 ( <i>n</i> = 19)
	DN	15.4 ( <i>n</i> = 2)	0.0 ( <i>n</i> = 0)	84.6 ( <i>n</i> = 11)

Qualitatively, the participants' emergent themes revealed a difference in how professionals and parents viewed the parents' level of empowerment to access and utilize services. The three participants (one ECI program administrator, one parent who did, and one parent who did not access ECI services) spoke directly to their feelings and experiences of empowerment when raising a child with a disability. The qualitative input yielded from the professional's families' prior experiences in working with government programs does impact how families respond to receiving services. Early intervention is perceived as a government program similar to social services that families access for support. Families of color who access the ECI program more likely not to ask questions and just receive the information. Meanwhile, a parent expressed that she would question everything due to a lack of trust and personal discernment from the interaction.

### **Empowerment**

In addition, this question was analyzed using qualitative inductive coding process. In an attempt to capture a more in-depth perspective into the parental understanding and translation of their personal sense of empowerment when raising a child with a disability. Interviews from both professionals and parents provide a dichotomous view into how a parent interprets their actions compared to how professionals perceive their ability to address matters regarding the supports for their child. Three Black parents (2 = who did access and 1 = who did not access) were interviewed, along with three professionals (2= medical and 1 program administrator). A deductive coding analysis exposed two themes: (a) asking questions and (b) to whom to ask for help. Participants were a part of a dual-phase interview where their initial responses were coded and reviewed with them to denote alignment with their view. The emergent themes are presented from the professional and parent perspectives.

## **Professional**

**The haves and have nots.** Families who have access to the resources know what to ask for and when. In perilous times, when services are depleted minorities are likely to accept what is given versus asking for what is needed. There is a notion of knowing what and whom to ask.

Minorities families who have limited resources are usually susceptible to what authority tells them to do. They may not know any better, but education levels play a role in meeting the needs of the family. (Ms. Katarina, ECI Program Director)

## **Parent**

**Asking questions.** *Parental empowerment* as “the internal force that increases a parent’s feelings of their ability to have control in their circumstances, such as locating and using external resources that could assist when raising a child with a disability (Damen et al., 2016; Dunst et al., 2004). Situationally, she is charged to be in tuned with her child who’s needs equate to caring for two children, seeks help when and wherever necessary.

I am a realistic person. If I don’t like something, I am pretty good at voicing my opinion about it. If I feel that if someone keeps giving me the run around, I am not going to force myself on them. Because you are showing me that you really don’t care. So, then I am going to go this way. I always believe that if you can’t get something done on the first level or the intermediate then don’t be scared to take it to the top. I am good at going over someone in the entry level and going to the superior level. (Ms. Rachel, Parent who Accessed ECI)

### **Research Question Five**

Research Question Five, What are, if any, the discrepancies between the views of parents and professionals regarding the access and utilization of early childhood intervention services?, was analyzed using NVIVO and inductive coding to address the response of medical professionals, program administrators, and parents who did and did not access ECI services. The interview process used narrative inquiry through a dual-phase interview that consisted of questions that targeted the various constructs of access and utilization to ECI services to determine the convergent and divergent perspectives. Dual-phase interviews obtained participants' initial response, then coded for emergent themes that were then used to make connections from their past, present and future. Emergent themes were determined to present the salient points from each participant that was engaged in this study. The qualitative analysis established four major themes which attributed to the in-depth reality associated with children being serviced: (a) explicit outreach, (b) family structure, (c) formidable experiences, and (d) implicit biases. Additional themes emerged including disconnect in communication, lack of trust, and stigma of the program structure.

Three professionals (one pediatrician, one nurse practitioner, and one ECI program director) were interviewed to delve deeper into their introspection as medical practitioners and education-based program administrators for Black families' reduced access and utilization of ECI services. Each participant was chosen to ensure ethnic representation reflected similar to the families of color. Professionals with direct access to families were chosen to obtain their view of the everyday experiences. A majority of the professional participants (66%, n = 2) had more than 10 years' work experience, while the program administrator had been in a leadership capacity fewer than 5 years. While the interviews were conducted separately, they involved two phases; an initial interview followed up with playback that viewed their response from the positions of past, present, and future. This dual-phase process allowed the interviewees to unearth

insights into the roots of the past that have shaped the access of today. Going forward, the data are presented in story sets that allow the participants to make those connections between their actions and others' interpretations of their actions.

### **Dr. Kinder's Story: From Aging to Babies**

Dr. Kinder is a pediatrician in a densely populated, low-income, minority community. He has been a practicing medicine for 10 years. The researcher came to know Dr. Kinder as a highly regarded pediatrician upon referral from her OBGYN. A familial relationship was developed as he patiently guided my family through the beginnings of life with a newborn; displaying his particular bedside manner by taking time to nurse a newborn from a syringe to honor a mother's desire to exclusively breastfeed and to give a moment of rest. This relationship continued through the wellness appointments and referrals to early childhood intervention (ECI) as he listened and applied professional judgment.

### **The Imaginary Theatrical Retelling of Dr. Kinder's Stories as if Conducting a Playback Performance (Gauna, 2014)<sup>1</sup>**

If I had to conduct Dr. Kinder's story in Playback performance, I would divide it into four scenes. In the first scene, we would see how the maternal pursuit of a better life shaped the future of her son by them both becoming pediatricians. As a son of first-generation immigrants from Southeast Asia, he was reared in the parishes of Louisiana as his mother completed her residency. Growing up as an only child but surrounded by cousins, he reflected on a moment in the single room where the children gathered, played, and slept. This is his recollection of what it meant to belong to a family and community from humble beginnings.

---

<sup>1</sup> *Playback is a type of community-oriented improvement theatre where members from the audience tell a personal event and a crew of actors re-enact the story at the moment. Play back was used as a way to render the information to organize as if using this art form.*

In the second scene, Dr. Kinder's pursuit in medicine was based on influential experience but also passion. He majored in biochemistry and attended medical school to study protein science and its impact on aging. In the lab, Dr. Kinder recreated the fountain of youth through science. As a medical student on a dual track of medicine and research, life made a hit outside of the controlled lab environment. A baby girl was born. Dr. Kinder became a father while in medical school; through the ahs and wonders of being a father, he reshaped his career path.

In scene three, prior to him going to medical school, his mother served as a pediatrician in a very low-income, major urban neighborhood where the majority of the population was low-socioeconomic status immigrants and non-native English speakers. Prostitutes and pimps walked the streets by day and night. While balancing the responsibility of a private practice, she also provided a service to families in the public hospital as the pediatrician to the world's newest babies.

In scene four, he took a stance within himself, by way of personal experience. Dr. Kinder answered his inner call to become a pediatrician. Dually, as an only son and new father, he knew the requisite needed in desolate communities for healthcare that meet their needs. Influenced by his past humble beginnings, he saw first-hand how race, language, economic status, and gender impacted access to quality healthcare for families of color.

### **One Size Does Not Fit All**

The benefits of early childhood intervention have an impact on the whole child. Yet, when conversing with Black parents, they are either defensive or open to making a change more from the position of fear of affliction. Professionally, we cannot judge their response for saying "delay," since it is an inner voice saying, "something is wrong with my child." Therefore, the benefits of early detection fall to the wayside as parents

grapple with trying to fix their child or maintaining a “wait-and-see” stance.

Paradoxically, they have to interact with a formal program that makes them, as a family, vulnerable to the judgements of people in power.

I think we have to remember the Black parent doesn't necessarily share the same historical and cultural perspectives as their Caucasian equivalents. From 200+ years of lack of efficient resources, for many of these families when they do access resources there is some skepticism about the motivations in the methods that might be applied to help their child. [Because] deeply rooted [in the] American Black culture [are] problems that have yet to be addressed. (Dr. Kinder, interview transcript)

### **Disconnect Between Systems and Treatment Differences**

A point not to be ignored is that professionals may apply different judgments toward people of color. Unconscious biases fuel the overt discrepancies and imperils access for families of color. As such, this is heightened when families from various backgrounds have limited understanding of how to access resources. Culturally, medical and educational professionals are regarded with high esteem, yet this subconsciously perpetuates the dominant and subordinate interactions. This response does not always favor the best interest of the participants.

A shared story was how a child from immigrant parents taken into the ER was sent to their primary care physician with labored breathing, when medical clinics have basic materials to address urgent matters. “This is not a single occurrence,” parents do not understand how to speak up and advocate, let alone question a person of authority. Parents of color have regard for medical professionals and take them at their word. For families of illegal immigrants or overstays, patient access widens as they try to stay under the radar. On the surface, from the professional lens, there is a difference in how parents

of color and socioeconomic status are treated in healthcare. Attention was drawn to, for instance, whether the same tests are ordered for patients with mirrored symptoms.

### **How to Change the System for the Future**

In seeking an understanding, the future events to be lived by medical professionals are limited by not meeting patients at their point of need. We cannot expect that all families, because of socioeconomic status, race, and gender, approach healthcare in a uniformed manner.

Give me 15 minutes to visit the major Black churches to start a ripple in the Black community. For further clarification, that means speaking to the Black mothers about the importance of breastfeeding and the impact on their child's development. To fathers about how, even though their day-to-day lives are busy, they need to "be there" for their children and we as men have to reshape our pride. And to both parents, the importance of due diligence, of making scheduled appointments, and communicating their unknowns using the well-being checklist as a tool to prompt further discussion

Medical professionals have a delicate balance to walk when communicating to patients from various ethnicities and backgrounds to ensure they do not treat them all the same. A point to remember is that Black families have different tribulations than the modern-day focus on immigration, as shown in Table 4.13.

Table 4.13

*Differences in Challenges Between Blacks and Other Ethnicities*

---

<i>Temporality</i>	Blacks have a deeper past than other ethnic groups and their past is still present. We as a society owe the duty to treat as the same but listen and meet their needs.
<i>Sociality</i>	Acknowledging healthcare access and treatment is not equal and being open to make a change. Subtle daily procedures provides insight such as driving a car versus taking the bus is not the same to access healthcare.
<i>Hopeful future</i>	A holistic approach to include various stakeholders by engaging in church circuit geared towards strengthening Black families. Provide education and support for breastfeeding and child’s development to become a mainstream conversation.

---

**Ms. Comfort’s Story: From Majority to Minority**

**Restorying of Ms. Comfort: The Imaginary Theatrical Re-telling of Ms. Comfort’s Story as if Conducting a Playback Performance.**

If I had to conduct Ms. Comfort’s story in Playback performance, I would divide it into three scenes. In the first scene, as an early teenager, she was brought to America in hopes of a better future. She immigrated from West Africa where she was privileged with the joys of being outside as a child and personally experienced being in the “village that raises a child.” She, too, realized that growing up in a place where the minority is the majority shielded her from the realities of the “Black American” experience.

Scene two, she was the daughter of highly educated parents who worked at the university and made education the focus of her life. As a student, she was determined to

achieve success that would have a greater impact. Memories of fellow community members motivated her to pursue medicine. She recalls seeing the botched work on patients who placed immoderate trust in medical professionals and thought they deserved better treatment. When she became a nurse, her motivation was to become a practitioner; this allowed her to have more decision-making opportunities to benefit families of color.

Scene three, her journey to become a nurse was perilous, navigating the school system while caring for a family. She would work by day and attend school by night. In case management, she realized the barriers that families from different ethnic and socioeconomic statuses encountered, especially in the rural communities that are bounded by the generational experiences with healthcare.

### **Parent Education**

We take for granted that everyone knows and understands how to ask questions. Communication extends beyond the surface of articulation. In some communities, a medical professional is placed in a dominant position meaning whatever they say is the answer. In other cases, for families of colors this is the response. When speaking to parents, the assumption is the information is understood or said for compliance. Yet, on a deeper level, parents may not understand the nuances of what is being said.

The African Americans I encounter in practice are often apprehensive and distrustful of healthcare professionals, certain services/medications, and can often adhere to generational remedies. Therefore, speaking at a 5th grade level, monitoring body language and facial expressions, then always asking for verbal feedback of the information and allowing time to ask questions is critical.

### **Internal Bias**

With a fiduciary responsibility to the betterment of society, professionals are upheld to a higher standard (Chapman, 2007). Therefore, one has to be reflective to admit

that one's responses differ based on economic status, race, ethnicity, and the like. A barrier is continued when medical professionals apply a homogenous view and response to families of varying abilities, backgrounds, and experiences.

Internal bias is the biggest predisposition, especially when patients do not dress to their income and or we make assumptions that they are able to afford a prescribed treatment plan. There is a tendency among patients to ignore conditions and or not believe the treatment prescribed will work. I take the knowledge of a community's distrust into each encounter and have open and honest conversations regarding everything from lifestyle choices to treatment plans to life struggles. We especially try to meet our patients where they are, financially, physically, emotionally, and socially in that diversity and inclusion are different across all ethnic groups.

### **Utilization**

Families have variables outside of the doctor's visit that influence their utilization of services. Location, family responsibilities, and work are issues associated with barriers to healthcare. Particularly in a rural area where the ECI office is an hour away, parents have to visit the office for an assessment because the area does not offer home-based service. This is especially challenging when the primary caretaker is responsible for the well-being of both a young child and an older parent. The time required to attend appointments and work at a low-paying job with no benefits creates more of a barrier.

Accessing ECI in a rural area poses different challenges for there are several hoops to jump through. For instance, parents have to call several numbers and drive to the location for an assessment.

In our town, they do not provide in-home services and the commute is an hour long. Being working mom coupled with a mom to a child with special needs has

allowed me a window into this particular situation/struggle. For instance, [one of my patients] is a mom with three kids who must work; her partner is disabled and she is the primary caregiver. Additionally, she has the responsibility of caring for frail, elderly parents. Therefore, the issue of her child's development and services tends to take a back burner. Therefore, these factors become barriers and any new conditions or information seems insurmountable to the patient. For instance, with ECI, so much time is asked of the parent and oftentimes there can be work and other obligations that get in the way of the child/parent/family getting the most out of ECI.

As shown in Table 4.14, we are reminded access to healthcare is not equal and just, therefore, we are charged with the responsibility to be advocates and lessen our judgments.

Table 4.14

*Rural America Minority Access to Healthcare Services*

<i>Temporality</i>	Stepping back to view the lens from the patient’s perspective, from a community entrenched with scripted distrust of the healthcare system.
<i>Sociality</i>	Using vernacular that is understood and accepted in the Black community and building trusting relationships and being an active listener
<i>Hopeful future</i>	Being an advocate for universal health screening and accessibly to programs for families in need, regardless of socioeconomic status and location. Educating families from the initial point of contact about the tests, reasons, and solutions to make them better.

**Ms. Katarina’s Story: The Oldest to See**

As a program director for Early Childhood Intervention (ECI), Ms. Katarina is newly appointed as the leader but has served in the capacity of family outreach coordinator. From her time as a college student majoring in early childhood development and interning with ECI, her calling to be an advocate for minority communities continued. Her responsibility is to provide ECI services to families in a majority rural area.

**The Imaginary Theatrical Re-telling of Ms. Katarina’s Story as if Conducting a Playback Performance.**

If I had to present Ms. Katarina’s story in Playback performance, I would divide it into three scenes. In the first scene, a child of seven whose father was an illegal immigrant, she was privileged to be nestled within the strengths of a large Hispanic

family. Growing up in the urban area of southeast Texas, she recalls the feelings of what it is to go from a predominately Black school and feeling a part of the landscape, then rezoned to become a minority.

In scene two, Mexico summers played a pivotal role in shaping her perspective on the freedom of education. Under the wing of her Tia, who served her community as a pediatric nurse, she experienced the ebbs and flows of living for others. As the oldest Mexican sister, she was naturally positioned as a caretaker in her family to younger siblings, which initially fueled her motivation to work with children. Within the compounds of her community, the expectation was to care for and give to others.

In scene three, her journey continues as a freshman in college to become a preschool director. The formability of the education system and a class assignment led her down the path of closing the access gap to early education for minority families. Awakened by a social impact project, she realized that society has taken for granted a probable solution to reaching families of color at the tender ages of birth to 3. Cautiously, she chose to pursue the path of leadership to provide access for a greater number of children.

### **Child Find**

In order to provide services, a building is not in operation without people. In particular, ECI requires the community and family to be aware not just of the services, but the reason for the need. Outreach is holistic through garnering relationships from the community.

Evidentially, families of color are lagging behind in getting help soon as possible. ECI programs are not commonly understood or received within the Black community. The ECI director pointed out that the conversations are different to convey a point to minority families.

Currently, we are reaching less than 10% of children in the county who are in need of the service. My biggest concern in that aspect and especially as director is what have we been doing to make sure that families are aware, especially the families who need the most care. In order to reach the families, we created a relationship with the library system to leave my flyers. A hurdle is to be as proactive as possible and making sure that all families of color are getting basic access to even knowing about the services. Then we are faced with another challenge which is to educate the family and piquing their interest to want to know more and have a conversation with a professional. How does a family know when they need the service? Why are we setup to visit them in their home? We take for granted that families know and know where to go. First, we must gain access to those families.

### **Parental Education**

Parental educational level plays a role in knowing how to start the inquiry process regarding their child's development. When families are left to their interpretations and familial priorities, the age of access increases. Families are least likely to seek service out for themselves. The role of director extends into family support groups, church groups, family education, non-profit agencies, executive leaders, to create connections by seeking to educate families and create a central location for access.

Black and Hispanic families alike are very susceptible to whatever authority tells them if they are not educated. It depends on their education level and that is a common ground amongst Black families and Hispanic families alike is that they don't have the same education or privilege as the White majority to even know what exists, or to ask the right questions, or know to question their child's development. Just knowing [of whom to ask] the question or even knowing that something is wrong, or something is going on with your child.

Technology plays a role [when] used as entertainment [in] masking the developmental milestones. As well, college educated parents are unaware to the impact of technology on their child's growth before the age of 2. Minority families face the challenge to meet their basic such as food, and services are likely not prioritize as a need to survive. For instance, speech therapy is not a basic need to survive, but will become a need when the need arises to communicate for help. Minorities close to the poverty line lack the education to shift their focus to seek for services. Therefore, we often see Black families later, often around the age of 2 years unless born with a disability and medical diagnosis.

### **Stigma**

Children with autism have become a common household event. A national awareness month is used to incorporate developmental delay as a common occurrence. Yet, this is not accepted as a blanket condition within all communities. With all minorities, autism is always a very difficult topic to discuss. For a family to inquire about or suspect their child of having autism and ask for an opinion is not very common among Black families. Autism [being] interpreted in the Black community as a "brat" or "spoiled" "bad kid" or "not paying attention" causes them to come later, closer to the age of 2 or beyond. It is critical for families to be serviced before 3 because otherwise precious time is lost. More often, they are more defensive about receiving or relaying information about their child's abilities. Cultural background has shaped their interpretation and response.

A common negative connotation in Black communities is that ECI is seen as a service to help "little" sick kids as opposed to a tool to help them get to a typical developmental level. Autism is a stigma in the community that something is wrong with the little baby and needs help. Also, differences lie between a mother and fathers'

response. In Black families, the mother is regarded as the primary caretaker and fathers, even when present, step aside from that role. Fathers see success as an output of language but fail to see the need for their child to ask for help. Tolerance of the idea that something is wrong with your child takes precedence in minority communities. A difference exists between African and Black American families when a mom was open to the support, but the dad had differing expectations of his son's ability.

An immigrant mother commented that back in her country children with a "problem" are seen as an embarrassment and you are looked down upon if you have a child with a disability. The father's disappointment in his child's ability is also fueled by being disowned by family in their home country. Tension was created in the family between the mom and dad. On the other hand, Black families tolerate social and individual differences with more openness once they have accepted the disability.

### **Cultural Tolerance**

Service professionals have the ethical responsibility to service all clients and families, but this is not always evident. External factors have shaped the delivery of services especially to families of color. Actions are taken for granted as the ideal model for intervention such as family carryover, but what influences the implementation.

When the provider does not have the cultural tolerance and understanding and working with minority families. For example, making a judgment on a family who may appear to not be present or may not be as susceptible to understanding the strategies being taught. Negative connotations around cultural backgrounds is a possibility and likeliness to impact the interactions between professionals and families. Too often the standard of participation is modeled after white families. Leadership is needed to hold therapist accountable for their interactions. To remain conscious of where they are and doing and not to lose sight of the priority

across all families. Professionally some providers are open to reflection and team decisions and some are not. This is an ongoing deep reaction that is going to take years to change.

### **Access to Services**

The type of communication style that families of color are receptive to has an impact on their how far they go to access the program. The type of vernacular communicated has the potential to break through into reality. Yet, in the professional arena, some things remain the same in how information is relayed to families.

The interaction between parents and educational professionals has changed very little, but there is a need to be a bearer of “bad news” and not blind to the reality. It is not uncommon for information to be withheld from the family because the provider does not want to get a negative reaction or be reported. Relationships with families are important and not sugar coating the information but be realistic. Yet, fear and hesitation on behalf of the professional to bring up certain things is a factor. Families deserve to know the whole picture of the observation and given resources and support on how to navigate the system. The lack of cultural tolerance, for example, a White provider going into a Black household and not having the cultural connection with the family makes a difference. It can be very difficult to have tough conversations with families who you don’t have a similar culture, too. Providers have expressed their level of discomfort and this is an ongoing problem. There is a need to break down communication barriers between families and providers.

ECI is a support service to reach children at the earliest point possible to provide direct services. Parents are challenged to acknowledge a difference within their own child

and navigate a formal system. ECI practices are family-first with the intention of not labeling a child for services, but families have expressed otherwise; they do feel labelled.

There is a delicate balance between parents feeling labeled through early intervention. In an African home, the mother is more likely to be open to a discussion; on the other hand, when parents initiate an inquiry into the child's ability this is helpful for the professionals. A barrier starts at the first meeting with ECI professionals when parents naturally expect an answer from those entering their home to observe. We use this as a time to establish a relationship and do not attach an immediate label to the evaluation. Over time, we seek to develop a relationship and when they are reassured by the visits, then a professional observation is shared but with notion of the ECI professional not being a medical professional. Yes, children do walk away with a label. If they do not exit ECI before the age of 3, they need a label to access services through the local education agency. Children enter our program before the age of 3 or up until they reach developmental deficiency, whichever comes first. Usually the label is obtained before the age of 3 because the services are continuing and, technically, yes, they do have a label because of IDEA requires a label to receive special education services. One of the steps we take as an organization is to prep families from transition meetings, because it is scary to have a label. Commonly, parents of color push back when told their child has an impairment or needs special education services. We try to get parents to see how they received support from ECI and that is the same as having a label with the school. During a conversation with parents, we trying to share the positive perspective that our goal is for him to be the best student and explain what supports are needed to get him to that place.

This requires a lot of talking and coaching of the parents that extend outside of the session times.

As shown in Table 4.15, a newness is needed in leadership to redirect accountability efforts from primarily test scores and receipt of services, but to include professionalism.

Table 4.15

*Leadership Accountability*

---

<i>Temporality</i>	Avoiding being a helicopter leader but seeking to be the one who knows and continues to remain close to the past to reshape the future.
<i>Sociality</i>	Implicit biases are real and warrant deliberative attention. Passivity perpetuates the cycles of who “gets” and “finishes.” Honesty is a dose of reality.
<i>Hopeful future</i>	Meeting families at their point of need. Creating a culture of accountability for both professionals and parents to speak on the implicit/hidden tendencies to situate as a prominent feature in conversation and not reduced experiences to page inscriptions.

---

**Research Question Six**

Research Question Six, *What are the parent’s knowledge, feelings, and thoughts when attempting to access early intervention services?*, was analyzed using NVIVO and inductive coding to address the response of parental barriers encountered for those who did and did not access ECI services. Emergent themes were determined to present the significant points from each participant who participated in this study. The qualitative analysis established five major themes which attributed to the in-depth reality associated with families being serviced: (a) trust, (b) stigma, (c) utilization (d) spirituality and (e)

implicit biases. Additional themes emerged, including a breakdown in communication with professionals and type of access to programs. Three parents (two mother/father family units who did access ECI services, and one great-grandmother with custodial guardianship) were interviewed to capture the unspoken stories of raising a child with a disability and navigating programs for help. Each participant was chosen to ensure ethnic representation reflective of the targeted demographic. A majority of the parent participants (66%, n = 2) had accessed ECI services for their child before the age of 3 and had a determined disability of autistic and medically fragile, while the great-grandmother did not access ECI and her child at 5 years old was determined with autism in the Early Childhood Special Education program. They, too, participated in two-phases with an initial interview following up with playback that viewed their response in the positions of (past, present, and future). These additional steps allowed for a relationship to develop with participants to elicit the hidden reasons and tendencies of their rearing and decisions made today. In continuation, the data are presented in story sets that allow the participants to make those connections from their perspective and how they serviced as a family.

### **Rachel's Story: Modern Miracle Boy**

Rachel, the mother of the “modern miracle boy,” was reared in a country town located in southeast Texas. Raised in a dual-parent home, she valued the partnership of a marriage and raising children. Her mom was a schoolteacher and her father worked in a plant to provide a stable living. Family gatherings are a priority. Through the journey of raising a child with special needs, they felt forgotten and muted by the challenges of navigating the system for support.

## **The Imaginary Theatrical Re-telling of London's Story as if Conducting a Playback Performance.**

If I had to conduct London's story in Playback performance, I would divide it into five scenes. In the first scene, a woman going through life as normal, had a sudden change that would reshape her present and future. Uncommon pain is a warning sign not to be overlooked. Suddenly, on a brisk day, going from wife to mother happened; she was admitted into the hospital for sharp adnominal pains. Unaware of cause of the pain, she was surprised she was pregnant; 4.5 months to be exact. Urgently admitted into the hospital, medicine was used to keep the baby attached to his mother for as long as possible.

In scene two, nature takes control and London is born at 5 months equating to 24.5 weeks. Doctors were familiar with saving a life at 27 weeks, but London was an extreme case. He was born with the need for oxygen, and received tear drop-sized portions of food as his meal. He was fighting for his life, as mom and dad took turns, day and night, by his side. The hospital became their extended residence, as they were known as the "did you hear family," having the youngest born baby at the medical center in the recent history.

In scene three, as other families sought advice from the parents and received discharge papers; Mom and Dad were still holding on to the progress made by their frail baby. For the family's story the media beckoned for their attention, but the they were feeble, holding onto the blessing for each new day. As a family, they prayed, for not each day was not promised. So far, the doctors spoke of how miraculous their son's start to life and the journey he has made. Incubators, medicine, research, and compassion kept the team focused on keeping London alive. Honestly, the medical team agreed that London

would not make it past 5 years of age. *During this time of fighting for life, the family was displaced by Hurricane Ike. Their hope was to bring baby London into a renovated home.*

Scene four, the day has come when he could cross of the threshold of his parents' home. Wait! They don't know how to operate a breathing machine. Solely coming home in his car seat was not the case. He was equipped with a breathing machine for his inability to breathe on his own, a brain shunt to drain fluid, syringes for feeding, and terrified parents. What is d-stat? Questions of uncertainty filled their home through the sleepless nights and fear for a blue baby. Prior to 1 year of age, he had endured five brain surgeries.

In scene five, London continued to beat the odds after 10 brain surgeries. As an active 5 ½ year old, he has taught himself to walk, but lost his speech after the fifth brain surgery. He has enrolled in school and returned home with a backpack. Now breathing on his own, he is still on a pureed diet with increased susceptibility to common germs. Even though he has still not been given a clean bill of health, London continues to defy the odds.

### **Implicit Bias**

"I am a parent who likes to ask questions" (Rachel). She felt that not asking would lead to destruction as professionals are inundated with several patients. Rachel went on to share her communication experiences with medical professionals in a hospital and clinical setting. A moment she described when they were in the hospital and the interactions between seasoned doctors, residents, and nurses is off-putting.

There are some instances when doctors feel that they're superior to nurses. When they are actually the right hand to the doctor, because they are attending to the patient, changing the bed pans, nurses take over with the instructions. *There is no I am better than you!* Some doctors need to realize that we are working as a team

for this patient. Not so much as this is my case and you're the nurse. Doctors seem to miss the whole point of that. I've seen nurses be really irritated with that because a doctor will come to the bedside and think that they are more superior, and they treat us like *peons*. I witnessed a doctor saying, "I don't change diapers, I'll let the nurses do that." It's unimportant to say in front of child and miniscule to bring up. The communication is not always professional, "a messy professional site." Because they lack bedside manners as a medical professional and they lose sight of that, this has led me to the fact to ask questions

Dr. Ching (pseudonym) was the pediatrician to London located in the medical center. For a doctor's visit London is air vac'd from his town into the metropolis for a wellness appointment. Due to the long distance traveled to his appointments, Rachel has a list of questions that were left over from the last appointment but feels that they will remain unanswered because of her position with the doctor. In the case with Dr. Ching, she is not able to obtain that peace of mind because of the interaction with the doctor. For instance, the appointments open with the doctor turning the computer around to face the parents and explains what is on the screen. Parents sit and listen to the information with no opportunity to ask questions. Rachel described feedback given by the pediatrician.

This is what you need to know, my job is to take care of your son and not be your friend and if you don't like how I conduct business with your son then you are free to go look from another doctor.

She described hearing this from the pediatrician was heartbreaking but not surprising. Now, she feels silenced and does not attend the appointments; instead, Dad goes with London to the doctor. Dad added, "You have to be determined to tolerate his mouth."

## **Label**

While, in the hospital Rachel described the key to services was a label. On paper, her infant needed to fit into category in order to have access to programs. With his frail system and dependency on oxygen, there were possibilities that he might not qualify for some of the services.

Believe this, they offer early intervention at Texas Children's hospital and while my son was a patient they won't take my son because they said he was not sick enough. They say it is not for all children with special needs; some instances you have to be sicker than you are. I found that out the hard way. I sat and cried because my son has had several brain surgeries, you are telling me that doesn't qualify him as a sickly child. He has a shunt in his brain and the beginning I just had to say my son was born 4.5 months early that would immediately get him in the door with stuff.

In this instance, when they referred us based on the developmental plan they had at Texas Children's they asked to know all that is all wrong with your son. At the time when he was 8-9 months old, it was not a big deal that he was not talking. The fact that he wasn't walking like a normal child, that was a sign of being extremely delayed, so that was kind of *overlooked*. [Mother asked,] what else needs to be significant about your baby who has a shunt and is on a breathing machine. They said, "Hold on let me check and see," when they returned to the phone. "I don't want to say it like this, but your son *doesn't have enough wrong* with him to qualify for the Texas Children's ECI." Then they gave me a list of the outside Easter Seals and that is how I wound up at the local agency.

## **Controlled Access**

This leads to me to the point that access is not equal. Rachel described her experiences when trying to access ECI as challenging based on her location and type of insurance.

Another problem that we have been running into is that a lot of facilities put us on hold and tell us that they are not networking with our Medicaid insurance. Then, 6 months later they are in network with them. Since 2017, the *dreaded waitlist*, we are still on the waiting with no call-back. As well, if I walked in there as a cash patient, they would see me right away; there is a difference in the type of insurance and that plays a part with you getting you services.

Companies when they find out you are private pay they will get you right in there versus when they hear a plan through Medicaid, *you kind of get pushed to the way side*; it is not all instances, but there a few. Even so, I called them before I came down here and they were willing to see me. When I got down here, and I give them my card, well we are *kind of filled up right now*, and we don't have any room to get him in and we will work with the school with whatever schedule they have to work around it, but now we don't have any open availability. *You just feel like you're kicked in the gut*, you think you just closed the gap to get some relief for you son and then only to find out, hey it is still one part of the "door is shut while the other part is open," when the ***doctors told me this would be a roller coaster with my son, they weren't lying.***

## **Utilization**

Communication barrier that still renders no services happen. Rachel described how she had to conjure the inner strength to make phone calls and interact with medical and health professionals. For this reason, she is compelled to keep documentation of interactions and phone calls.

My son is complacent because we haven't been getting any type of service and we have been waiting and waiting and y'all would like to have me to blame, but you can't!...

[They] make you at fault because they are the professionals they get mad and don't want to believe that I didn't do anything. [They said,] actually you did because we tried to set an appointment and you declined. That is not true and I never decline any type of appointment, so she [related therapy] lashed out at me during the conversation, and said to the parent, "I'm not doing this with you and I didn't call you to do this with you". If you want to do this then you can talk to my supervisor, but this I am not going to do this with you.

I am going to set a tone because these people are coming into my home. And dealing with my son and me and there has to be some type of *respect* going, you can't come into my house bossing me around.

Age and location have an impact on access to services for the youngest babies. The availability of resources in the large city compared to rural area presents challenges in access to care.

ECI is the easiest thing because the babies are between 3 months to 1 year old. It was easy for me because I was in the large city. I have never experienced a problem; it was when I came back home I realized the smaller the city the more *crud* you have to go through to get things accomplished and done.

Overall, access services in a controlled environment such as a hospital was streamlined to get the services needed for the family. There are times when dismay sets in requiring a human recharge. Sleepless nights are burden with "what if's" because sometimes the responses from others seems unreal; for instance, when progress is made to only end up empty handed.

[T]he easiest part is going to the hospital. [The hospital is] where they really don't want you to worry about nothing else but your son being okay, they have social workers that come in to help take the weight off of you. [The social workers] ask what were you in the middle of [terms of services] and they [social workers] are very good at picking from where we left off, while you are there [in the hospital], and in those instances, you find out they can get that done quicker. [One time] when he was sick and getting brain surgery done and they were able to get that done [obtain services] quicker, [for] what was taking me 2-3 weeks to get done. That is not always *pleasant*, it really is not. Most of the time it is very *frustrating*. Surface level interactions with professionals have an impact on the access to services and care. Yet, it takes the ability to center the conversation and prompt all parties to look at the bigger picture.

When you take him to be evaluated and they are looking at his background from birth they will skip along and focus on hydrocephalies. Mom said, "We just don't have hydrocephalies. He has had two revisions, so don't skip past that."

Sometimes I have a knack for making them question themselves. It is just me monitoring my son, because I can let them just skip past all of the stuff that we are seeing because it is *medical jargon*.

### **Joyce: "American" Disability**

An immigrant mother of four children, Joyce arrived in the United States with an 18-month-old toddler boy. She worked in her country as an elementary school teacher. In college, she remembered her studies focused on the theory of education and little on child development. She was confident in her ability to teach reading and math. However, she realized a gap in her training regarding children's developmental milestones. Back home,

disabilities were associated with physical manifestations—“hunchback”, spiritually “possessed,” or deaf and blind.

### **Restorying of Joyce’s: The Imaginary Theatrical Re-telling of Joyce’s Story as if Conducting a Playback Performance.**

If I had to conduct Joyce’s story in Playback performance, I would divide it into four scenes. In the first scene, Joyce and her family come to America. She came from Nigeria and left behind a classroom because she was greeted by the land of opportunity and a new life. She was a general education teacher for 10 years. She made clear that her training back home as a teacher was focused on theory, phonics, and not on varying abilities. Arriving in America with a toddler, adjusting to life here presented new insights.

In scene two, as a stay at home mom, the background noise of cartoons was a normal way of life. On this particular day, Joyce became in tune with the commercials, when tips were given to parents on a child’s development milestones. In particular, the focus was on the number of spoken words she noticed in her own child. Looking for an answer was not limited to the test results. Her motherly instincts took over and she sought far and wide for confirmation of Autism Spectrum Disorder (ASD).

Scene three, she flew across country to have her son tested by a family member who is a medical professional. He too sided with the previous results that her son has a developmental delay. Internally, she was torn to hear a “man’s” interpretation of her son’s ability. They don’t have this in their family. Therefore, she turned to her roots as an “African” mom and prayed. Through this period, she grieved the ideal picture of her child’s ability and blamed herself.

In scene four, strengthened through prayer, Joyce took the step to meet her son’s need. But her challenges lay with the low expectations held by others toward children with disabilities. Hesitantly, as a family, they approached the school district for help.

They were reluctant to be in the “system.” Because of his age, they were introduced to early childhood intervention which they believed to be a “start to no escape.”

### **Spirituality**

Nigerian mothers who believe in prayer garner an internal strength to answer life’s most difficult questions. In Joyce’s case, she still relies on the internal strength from a spiritual answer to her questions.

Back in Nigeria the only thing that I could have done was to pray. Since I had no experience from my own family. I would take him to church and keep praying. So when the doctor said that, in my heart “I was saying that I reject that in Jesus’ Name” even though my brother-in-law was saying that is what he has [autism]. I said *no* in the Name of Jesus. Then when I got home it was a battle for me to accept and even now it is still hard for me to accept. So many emotions and each time I read about ASD, I started to cry—asking what is this, calling on Jesus, and thinking, this can’t be my son. I would wake up in the middle of the night and go dry fasting, as an African mom I know what to do when burdened with heavy challenges.

Upon my return to Texas, I was occupied with the spiritual aspect and called on the Lord to make a change. Hesitantly, I showed my husband the evaluations and results. As a mother, I carry the problem and seek a change. Yet, he, too, was surprised and dismayed.

### **American Disability**

Commonly in west Africa, persons with disabilities are seen to be physically disabled or running mad on the market street. Spiritual possession is often believed to be the reason for the difference. Disabilities are a matter of the heavenlies at war for a person’s soul through their mind which is the symbol of their destiny. Therefore,

regardless of whether the families are pagan, Muslim, or Christian, the saying “the head is not correct” is understood without further explanation. It is believed that in America there is a name and label for everything possible that addresses the problem from the surface but not internally.

They talk at me repeating that the behavior is the problem, and nothing can be done without this remedied. I am considerate as a parent for the teacher and her job, but at the same time I want what is right for my child. I talk to the teacher as much as possible, but I feel that she has a *parrot mouth* with not doing something right. It is not just teaching; what you sow you will reap. [I feel that they believe] I will teach them and then collect my check. You must have a conscious to do what is best for the child. By them just talking to me and missing that I am feeling what is said and having to live with this every day is taxing. In my country we say, *I am not “wood”*. Remember that I am human, a mother who wants others to have his best interest in mind, especially from professionals.

### **Low Expectations**

As a parent she felt on the defensive when interacting with education professionals. She noted there is no point in having an opinion because they will use their tests as the final answer. “It hurts my feelings.”

He benefitted from ECI, because I didn’t know jack about getting into the school district. There are times that you can’t win these people no matter your argument with them. They want to argue and said, “oh he did this”. I found that once your child is in the system that the expectation remains the same for all of your children. When my second child wasn’t talking they bothered me from the school. I said, give him time. Because of my first son, the speech teacher even told me

your **second son is** coming to me. That was wrong for the speech teacher to tell me that.

They use medical and educational jargon to reinforce their dominant position. Using this language leaves a parent unable to see a continuum for achieving the desired goal. In meetings, she felt talked at and not treated as a partner in the journey.

It was just an emotional day when they came in and started asking me all that, I was just crying and crying. I just couldn't pull myself together, being my first child, I found it hard and hearing all this, this is my very first issue, I don't know what you're talking about. So when he had the evaluation and qualified for services, they kept talking and very little checking to see if I understood. I felt like "wood", they kept talking and paid little attention to my *disconnect* in receiving the overwhelming information.

### **Being Labeled**

As a parent, she was reluctant to enroll in services for fear of being placed into a government system. As an immigrant, she sought to keep a low profile and not receive help from the government. Pointedly, she recalled when enrolling for ECI services the last step was to be "labelled" for that is how they got paid. She remembers the ill feeling in her gut of her baby having another name. She strongly believed they make you sign up by saying your child can get out of the program but believes it to be a bait-and-switch to enroll. There is no escape, still today.

The label starts in ECI. ECI is helpful. However, in ECI, your child cannot escape, and this continues into the [Early Childhood Special Education (ECSE) class]. Even if your child has started talking, you will still be in the special needs class. They will tell you that when your child improves we will change to gen-ed class. No, the child keeps going on, even, when they get to high school. They use

that as a bait to get into the program. ECI is very good, but once the child is identified, it is very hard to get out and out of that class. All it takes is for one thing to not be right and the child remains in that class.

**Sara: “Baby of a Baby”**

**The Imaginary Theatrical Re-telling of Sara’s Story as if Conducting a Playback Performance.**

If I had to conduct Sara’s story in Playback performance, I would divide it into four scenes. In the first scene, being pregnant is a family affair. Having a 14-year-old who was stricken with the responsibility of having a baby was their reality. Sara needed the help of the matriarchs in her family. She was still living with her grandmother, while being a senior in middle school. The baby of a baby was due.

In scene two, great grandma keeps the family afloat. Granddaughter has delivered a 5-pound baby. That was not the end, for in the hospital she signed her parental rights over to her grandmother. Now the matriarch, a great-grandmother to the new baby, had the custodial responsibility. Great-grandmother grew up on their rural family acreage passed down through generation where children played at all times of the day.

In scene three, we see life for the new baby as he is reared with both old-school and modern ways of parenting. The matriarch is having to learn how the safety of cribs and installation of car seats have changed. He is the only child in a home of elderly adults. His ability is not compared to age peers and his demands take precedence. Looking from the outside, one may assume that Sean’s behavior takes over his great-grandmother. This fueled the concern of his immediate family members to address his behavior, eczema, and lack of spoken language were concerns. Due to their insecurity with the child not being able to talk, they did not enroll him in school until last few months of preschool.

This takeover, in scene four, has persisted as his home placement has changed due to his lack of control. When others see the Sean, they noticed his skin condition, similar to *elephant* skin. He is not able to speak but instead pitches fits and scratches himself until he bleeds. Teachers and the like have a difficult time with his outbursts and the deliberate action of breaking his skin. Due to his custodial parent's deteriorated health, Sean is now with his grandmother, who has rearranged her work life to meet his needs.

### **Intergenerational Understanding**

When he was born, I brought him home from the hospital. From my upbringing, I believed that children should play outside and be with their cousins. In this case, it was his great-grandparents and a newborn living on family acreage.

He is allowed to play and explore the land around him freely. There is a difference in how we see behaviors from the past to now. They quickly want to say he is problematic, but when growing up, we spoke of them as just kids playing or having a tantrum for not getting their way.

Disconnect in the perception of behaviors is not limited to race but also generations. Experiences from the past influence the interpretation, understanding, and access to care into the future. Lack of knowledge of identifying the signs to seek help or asking the right questions pose challenges for intergenerational families.

### **Not Forthcoming**

In communication with the early childhood special education program (ECSE), the grandmother shared her knowledge of his skin condition, behavioral outbursts, and nonverbal behavior. Yet, she was at a crossroads with the program not meeting his needs. For 70% of the time, because of his behavior, his guardian is called to pick him up from school, which creates a problem with his education.

They should be able to help me with him. I mean guide us in the right direction not dead ends or no information at all. I ask them for help and instead they find fault with him. My frustration is growing because, I need help as well. A suggestion was made at his ARD meeting about using a tablet to communicate. Honestly, I have not heard anything else about it. Square one is my common place. He started school later and still there is not progress for his behavior, learning, or ability to communicate. When I talk to them it is not professional, they blame him by saying he needs to have consequences at home. His great-grandmother and grandmother do not agree with them because they should have more solutions.

#### **Research Question Seven**

Research Question Seven, *What evidence of empowerment to advocate in their child's best interest is shared in the respondents' expressions/stories?*, was analyzed using NVIVO and inductive coding to address the response of parental perception of advocating for their child's needs for those who did and did not access ECI services. Emergent themes were determined to present the significant points from each participant who participated in this study. The qualitative analysis established three major themes which attributed to the in-depth reality associated with families being serviced: (a) confidence, (b) constructive conversations, and (c) work status. Three parents (two mother/father family units who did access ECI services, and one great-grandmother with custodial guardianship) were interviewed to capture the unspoken stories of raising a child with a disability and their sense of *parental* empowerment to access and utilize services. Each participant was chosen to ensure ethnic representation reflective of the targeted demographic.

## **Not to be Challenged**

**“American” Disability.** A mother was prompted to look for help based on a children’s television commercial about developmental milestones. From a sense of worry and concern, a mother looked for answers.

I took on the comparison of my child to what they said on the tv as a challenge to know more. I was not happy with having to make this inquiry about my child but realized the necessity. The first response that I heard that my child has ASD, challenged me to look for more answers. I had to speak with someone who understood my culture and the medical system here in America. I have cried many of tears, but with my husband we look to support him in every way possible. So, I will not just take an answer as the final say but seek to have a confirmation within myself.

## **Speaking up Cost my Job**

**“Modern Miracle Boy”.** A father’s perspective of being head of household and caring for a medically fragile child. He shared an innermost experience from taking your child to the hospital and having job.

Man, excuse me, Ms. Aziegbe, I love my boy, but it is hard! I am used to working and taking care of my family. Honestly when [Modern Miracle Bay] gets sick, to me it feels like a wrap. I must and will always be on his bedside, but inside I am torn. Torn because the “job” doesn’t always understand. When I at the hospital when my attention should solely on the best care for my child, instead my attention is divided. I hate the feeling of returning home feeling victorious for my baby but then defeated by the system, there is not support, what the boss says it what goes. On the other hand, when I do speak up and let them know at the

beginning my child has special needs, I feel that cost me the interview. Honestly, I just want to shut my mouth, but I know that I need to be here for my child.

**What to ask?. “Baby of a Baby”.** A great-grandmother and grandmother reluctantly enroll their grandson in school due to the insecurity of not speaking.

As a parent (guardian), I have my understanding for how he should act. When I come to the doctor they should be able to ask me questions to see if there a problem with his development. There are times that I don’t know what, who, or where to ask. I have the trust in the medical people to lead me in the right direction. If they see something then they should say something and not let it pass by as nothing. Let me not get started with the education side because they are a *mess*, you ask for help and nothing gets done in a timely manner. It is agitating! Like clockwork by 11:00 am, I am called every day to pick him up from school because of his behavior. Let me say, I have spoken up about his behaviors and told the school. It likes what I said is on deaf ears. When I do say something still nothing is getting done.

### **Conclusion**

This chapter presented the analysis of qualitative and quantitative data collected from surveys and interviews, participant demographics, and processes of answering each research question. In the next chapter, findings will be presented to compare what was found through this study with existing literature. Implications of this study in education and future research will be discussed.

## CHAPTER V: SUMMARY, IMPLICATIONS, AND RECOMMENDATIONS

The purpose of this mixed methods study was to explore the perceived barriers preventing Black families from accessing (completing intake process) and utilizing (follow through with the support) early childhood intervention services. Part C of IDEA is a federal grant program that serves a particular purpose to provide families and children with disabilities from birth through 2 years of age with direct intervention supports such as speech, occupational, and physical therapies along with nutritional services. More recently, public awareness about children with autism has become mainstream, in part due to earlier determination of ASD starting as early as 18 months compared to 2 years or more (Hyman et al., 2020). Part C of IDEA's federal requirement requires programs to implement child find practices for vulnerable families and children to access EI services. Family-centered practices are a guiding principle in EI programs, a concept of using a transdisciplinary approach to coach the families in continuing the support throughout their daily activity to reduce educational implications (Division for Early Childhood, 2014). Ultimately, there is a benefit to society in reducing the financial obligations needed to educate children with special needs who qualify for special education and require in-school support (ECTA, 2020). Therefore, this study included an examination of the barriers that hinder parental access to ECI and obstacles in place that inhibit, once qualified, their utilization of services from both parental and professional perspectives.

To quantify the parental perspectives of the barriers to accessing and utilizing ECI services, 38 Black families from Southeast Texas completed the *Barriers to Access and Utilize Early Childhood Intervention Services Inventory* (BAUECISI). Also, quantifiable results from a sample of 26 professionals from various entities who have direct

experience working with families of color; encompassing medical professionals, a program administrator, and a special education director; offered their perspectives of the barriers families encountered when accessing and utilizing ECI services by completing the *Barriers to Access and Utilize Early Childhood Intervention Services Inventory-PR* (BAUECISI-PR). Data were analyzed using one-way ANOVA, independent *t*-test, Chi-squared test of independence, cross-tabulations logistical regression, frequencies, and percentages. Then, a sample of three families, who either did or did not enroll in an ECI program, and three professionals who have direct and continual experiences working with families of color were selected to participate in narrative inquiry. Open-ended questions were framed around the three-dimensional aspects of narrative inquiry informed by *sociality*- the personal and social context, *temporality*-context of past, present, and future, a modus related to playback theatre and *space*- the place where their stories unfold. Qualitative data enhanced the understanding of the barriers Black families encounter when accessing and utilizing services. Within this chapter, the results of this study are contextualized in a broad mass of research literature. Implications for medical practitioners, ECI program administrators, special education directors, and Child Find practices with future research recommendations are included.

## Summary

### Research Question 1

Research Question 1, *What barriers do Black families encounter that prevent them from accessing early childhood intervention services?*, was answered using frequencies and percentages of responses categorized as barriers (items 1-21), within the *Barriers to Access and Utilize Early Childhood Intervention Services Inventory* (BAUECISI). The survey was scored using a 3-point Likert-type scale (1 = Major Barrier, 2 = Minimal Barrier, 3 = No Barrier). Additionally, participants' responses to

open-ended questions were utilized. Overall, parents noted that ongoing systemic experiences associated with being told to “wait-and-see” and time demand to complete services impacted their access to ECI and follow-through with the supports. Reportedly, families felt a disconnect between knowing about the benefits. From the interviews, families expressed they had increased hesitancy to have open conversations with professionals about their child’s development instead sought inside guidance from their networks or grandparents relied on their own experiences of raising their children. These findings support Copeland and Snyder (2011), who drew forth the notion of deep hesitations and insecurities that Black mothers have interacted with government or support programs; in fear, it reflects their parenting that may have substantial implications losing their children. According to Magnusson, Minkovitz, Kuhlthau, Caballero, and Mistry (2017), Black mothers were more likely to rely on their comparisons to a “normal” child and believed that children develop at different rates.

### **Access**

Access is the entrance point for programming supports. In mirroring Twardzik, MacDonald, and Dixon-Ibarra (2017) suggestions regarding the type of governing organization, either medical or educational, entities impact a parents' perception of the kind of programs offered and how to access services (Magnusson et al., 2017; Williams et al., 2018). As parents expressed, the process was confusing and frustrating, as demonstrated by delayed responses from agencies, waitlists for direct services, and the amount of time in the week needed to complete the program. Although EI programs do not have waitlists, parents did experience their children not qualifying for services but still felt the need to remedy their concerns and sought private help. More so, according to the interviews they were told to “wait and see” that their child may outgrow the delayed speech or may mature in their behavioral responses. Worcester, Nesman & Mendez et al.

(2008) pointed out that it is not uncommon for parents of younger children to be encouraged by medical professionals to “wait and see” in hopes that maturity would resolve the problem or, in the case of male children, that boys develop later (Edwards et al., 2013).

Meanwhile, families said they felt their concerns were not addressed or misunderstood with little remediation offered. All too often, professionals had a condescending tone or withheld information that could have benefitted the families. According to Hall et al. (2015), implicit and ethnic biases come forth in nonverbal language and patients' interactions. Therefore, the natural power imbalance between the professional and family perpetuates the cycle of biases demonstrating populations operating in parallel (Hall et al., 2015). Once families became aware of available programs and the need to seek services, they believed their child would benefit from the program. However, they still felt professionalism lacked demonstrated through the appointment cancellation, communication with providers, and follow-through required of parents. These feelings align with Campbell et al. (2012) regarding children of color who participate in ECI have shown to make long-term societal gains related to their academic, social, and cognitive abilities.

### **Utilization**

As a factor that impacts utilization, Seeberger (2019) suggested mindfulness to the current state of Black family structures is needed when rendering services, as mothers are more likely to be the primary breadwinners classified under the working poor, meaning demands for meeting during their work time to be observed in a family environment before qualifying for program support or attending scheduled sessions can be burdensome (Swanson, Raab, & Dunst, 2011). Parental responses from this study noted that children were at home and did not access child care programs as an alternative

to receive ECI supports. Services offered in the home for children who do not attend childcare viewed program commitments as a burden on families' ability to sustain attendance. Corr et al. (2016) noted that low-income families are reluctant to take on the responsibility needed for ECI because of the disruption in their daily routines. Cautiously, Dunst et al. (1991) posit that when services are provided in childcare, the parents become subsidiaries impacting the home environment's follow-through.

Meanwhile, in this study, family participants had children who were either suspected or were determined with ASD. Autism is associated with delayed social communication, repetitive behaviors, and demand for sensory inputs that may result in outbursts or behavioral concerns (CDC, 2021). Hyman et al. (2020) pointed out ASD is identified no earlier than 18 months of age, but parents were more likely to seek or attain help at 24 months or older. In this study, the participants indicated their children were diagnosed with ASD after 26 months when they were at the end term for ECI. Magaña et al. (2012) noted it is not uncommon for medical professionals faced with the topic of ASD to be more reluctant to provide options for specialty care. As Constantino et al. (2020) found, Black children are identified even later, on average at 5.4 years of age, revealing a gap between parental initiation of concern and professional response. Notably, in this study, initial parental concerns about their child's delayed development were related to lack of speech compared to peers or siblings. To support this notion, Boyle et al. (2011) highlighted Black children had a higher prevalence of stuttering or stammering. Families admittedly waited to acknowledge the differences but felt compelled to ask for testing when their child was near school age.

*The plot of my story influences my interactions with you.*

## **Research Question 2**

Research Question 2, Is there a difference in the perceived barriers encountered by families who did and did not access early childhood intervention services?, was analyzed using an independent samples t-test, Chi-squared test of independence, and cross-tabulations to determine if there was a statistically significant mean difference between the two groups of parents who did or did not access ECI services. Findings from this study indicated that based on parental perception of barriers, there is a statistically significant difference between families who accessed ECI services and those who did not. Those families who did not access ECI reported they did not know whom to ask for help regarding their child's development and believed their child would mature. Pediatric developmental appointments well check forms, as recommended by the pediatric society, are to elicit parental input and guide targeted conversations. An assumption made when providers solely rely on a form to determine the need for a referral, Cox et al. (2010) states parents' level of ease varies, and they may not thoroughly respond on paper. This finding unearths the disconnect in communication between the provider and parent, for they felt their concerns went unheard or no further recommendations provided for testing or support programs. According to Hastings et al. (2014) a wellness form that obtains the parent's perspective of their child's developmental abilities is a tool used to facilitate conversations with parents about developmental milestones instead of remaining as a static procedure. Further analysis using cross-tabulations of the barriers revealed a mean difference between families, including employment and economic status, and the first person to have a concern.

Additionally, Hastings et al. (2014) reported that medical professionals considered their knowledge about available services, and the stricter guidelines to qualify for services impact their confidence to hold conversations with parents. Families who did

not access were challenged to understand the information from the providers' perspective. Additional areas presented by Shen et al. (2018) included the ability to ask direct questions, perceive increased negative talk, providers dominated the conversation, or information passively presented at the end of an appointment. Hibbard et al. (2008) drew attention to the importance of equipping parents with knowledge on how to ask questions to increase their access to care and derive meaning from the words and numbers in health-based materials; in this case, notes from wellbeing checks or developmental assessments. Subsequently, parents who did not access stated that they did not believe their child would be eligible for services. Feinberg et al. (2011) refuted this point and found that Black children are five times more likely to qualify for assistance but not receive support; partially this due to cultural interpretations of a child's behaviors and abilities that differ from the mainstream perspective, by which the norm are established.

Once families did access ECI, they feared the long-term societal implications of entering a governmental program that labels the child as disabled. However, ECI does not formally label the children while in the program; families disagree that a label is needed to proceed with services. From a professional standpoint, children must have a label by the time they transition to the district program. Parents were concerned that the label would impact their children and place them in special education with no mechanism to be unlabeled. This corroborates with Dababnah et al. (2018) who noted that parents who have children with autism were cautioned not to follow through with services because of a label. Annamma et al. (2013) highlighted that a label is more profound than the two-dimensional inscription on paper in the Black community, for these children are buffooned from early childhood if they are stigmatized with a label to receive services.

## **Barriers**

### *Employment status*

A majority of the parents in this study were employed full-time for pay. This study shows that the primary caretaker's employment status has a statistical significance on access and services utilization. Employment status can reduce the amount of time available to contribute to utilizing ECI services. Artiga et al. (2016) noted that Black families were more likely to be working poor, meaning employed with low wages, which significantly impacted their utilization of services (Arcia et al., 1993). However, some families make slightly above the qualifications for Medicaid or are privately insured and pay on a sliding scale, which Gerardo et al. (2010) posited makes the co-payments for services, despite a desire to help their children, a financial barrier. Qualitatively, families noted unrealistic expectations are in place to meet the appointments' time constraints when both parents work. Another family commented on how the father had lost many *good* jobs due to time away from attending to their child's medical needs and hospitalizations. This is corroborated with Green's (2007) statement that parents often face the choice between family obligation and employment.

### *Economic status*

Findings from this study show no statistical difference in a family's annual household income and access to ECI programs. Results did reveal that families who accessed ECI were primarily low-income and qualified for Medicaid. Medicaid is a large portion of the program's revenue and states depend on those funds (Vail et al., 2018). Furthermore, these findings agree with Kincaid and Sullivan (2017) who noted that income, race, and parental education level are not a predetermining factor in identifying children with a disability. Cross tabulations revealed families in this study from upper income accessed ECI services the least amount of time. In contrast to Zuckerman, Mattox

et al. (2014) noted that children of higher-income families were less likely to be enrolled in formal special education programs and adept at accessing private services.

### *First Person to Notice*

Findings in the study from a cross-tabulation analysis determined that parents were the first to concern their child's development. Qualitatively, parents noted they had growing concerns about their child's abilities and initiated the process to locate services but found the process emotionally and physically arduous. Black families noted they viewed their child's ability through discussion with immediate family members concurring with Samuel et al. (2012) who expressed that Black families preferred to have a conversation about their child's development instead of responding to a checklist. This supports the notion that lived experiences factored into the holistic approach gathered through stories the participants have embodied (Clandinin & Connelly, 2000; Gauna, 2014; Merriam et al., 2007). Rarely was a referral initiated by a medical professional for the participants in this study. Aligned with Zuckerman, Mattox et al. (2014) who stated that racial and ethnic disparities contribute to Part C enrollment, less than 10% of pediatricians used a screening tool to assess a child's development.

*My eyes speak for me.*

### **Research Question 3**

Research Question 3, What are the barriers medical and educational professionals perceive impacts a family's access and utilization of early childhood intervention services?, was answered using a one-way ANOVA with common frequencies, and the responses were categorized as barriers using frequencies and percentages of responses categorized as barriers (Items 1-23), within the Barriers to Access and Utilize Early Childhood Intervention Services Inventory—Professional (BAUECISI-PR). The survey was scored using a 3-point Likert-type scale (1 = Major Barrier, 2 = Minimal Barrier, 3 =

No Barrier). The independent variable, profession, was divided into four groups: (a) family doctor or pediatrician (n = 8), (b) family or pediatric nurse practitioner (n = 5), (c) ECI program administrator (n = 5), and (d) special education director (n = 8). Additionally, participant responses from open-ended questions were utilized. Findings from this study determined a statistically significant mean difference between the professionals' perceptions of the barriers families encounter when accessing and utilizing ECI services. There was a minimal difference between doctors and ECI program administrators. However, the greatest separation in the perception of the barriers families encountered was from both medical and ECI compared to special education directors (SPED).

Doctors expressed that Black families' experiences when accessing or utilizing ECI services is an arduous process that is confusing and frustrating. The delayed reaction of "wait-and-see" is a typical response because children develop at different rates and that parents may overreact in the earliest years when comparing their child to other children. Applying the delayed response method widens the Child Find gap from both the professional and parental aspects. Barger et al. (2018) noted that this perception perpetuates the divide to accessing services when parents use this perception. Beyond the surface of waiting to seek services, Edwards et al. (2013) pointed out that Black families have a more resounding internal response to acknowledge a deficit in their child's abilities because this signals the start of being placed in the "system" where the government knows everything about you. According to Magnusson et al. (2017), Black mothers, in efforts to avoid trouble or out of fear of judgment, simply comply with receiving services although they feel their voices go unheard. Therefore, Artiles et al. (2010) cautioned that Black families should not be categorized based solely on their

demographic markers because this negates the interconnectedness of the lived experience, causing a generalized response.

On the other hand, parents regarded medical professionals as having the answers; they relied on doctors to notice the delay. Still, parents noted they are more likely to see and have a concern before others do. As Juarez et al. (2006) explained, the position and title of a medical professional create a power differential between themselves and the patient, and in the Black community, doctors are viewed with high regard, causing the parents to be less attentive to the concerns of their child, looking instead to professionals for the solution (Dunst et al., 1991). Solomon's (1987) seminal work particularly described how these deeply absorbed power structures facilitate Blacks' ways of being and doing that prevents optimum development of their well-being and those dependent on them. When parents are the first to notice, they still experience a disconnect initiating the process to ask for help. As a parent said, the doctors tell them what is to be done instead of listening to their views for what is happening. Cultural norms and interpretations skew parents' perceptions of the severity of their child's ability. Black parents believe that a disability is physical such as an "ambulant," uncontrolled aggressive behaviors, or delayed communicative skills compared to other children. This aligns with Magnusson et al. (2017) who explained mothers would call a friend of a "normal" child to contrast the behaviors. Culturally, boys' later development is accepted as the norm, and a participant noted her grandson was raised around adults, so he did not have the chance to develop his language with peers. Therefore, when professionals rely on parents to initiate the concern, valuable is lost because their interpretations are overlaid with societal and cultural implications. Williams and colleagues (2018) found that both parents and doctors were reluctant to make a referral for children under 3 for emotional, behavioral

challenges, and children were under-screened when parents were the sole informant (Zuckerman, Mattox et al., 2014).

Nonetheless, in this study, from the pediatrician or family doctor's perspective, they noted that families were more likely to be on the defense when talking about their child's developmental abilities. Qualitatively, the doctors stated families were guarded in their interactions and feared that this would start a lifetime of trouble and being in the system. According to Hall et al. (2015), these actions are interpreted as the ill effect of implicit biases, which factor into the quality of services and parental conversations. Therefore, careful attention should be paid to the perception doctors of color apply in their practice because their perception provides further insight beyond being "gatekeepers" and the surface activity of their job, instead constitutes the societal, cultural, and spiritual dimensions that take place when making a referral to ECI (Annamma et al., 2013; Cox et al., 2012; Heydon & Iannacci, 2009).

From the findings, the greater mean difference was between nurse practitioners and ECI directors regarding perceived barriers. According to the perception between nurse practitioners (NP) and ECI directors, the intimate relationship between them results in greater insight into the family dynamics that impact their access and utilization of services. NPs and ECI directors were more likely to notice that parents felt uncomfortable accessing services due to their immigration status and cultural beliefs. Qualitatively, the ECI director shared how families will speak to her privately to explain the difference in reactions between the wife and husband. She also noted that men are more reluctant to accept services and more likely to believe that their child will outgrow the delay, yet 52% of the families in this study made decisions as a married couple. Similarly, both the NPs and ECI administrators, when compared to doctors, were significantly more likely to notice the impact of cultural interpretations related to the children's abilities. Attention is

drawn to how families of color respond more in-depth when professionals look like them and that the norms of a disability and development of service models need to expand beyond the normed European lens (Begeer, Boussaid, Terwogt, & Koot, 2009).

Overall, the most significant mean difference between the professional groups were the perceptions between medical professionals, ECI program administrators, and SPED district-based programs regarding the level of clarity on how to access ECI is either confusing or frustrating. Clarity is brought to the mean difference based on the perception from medical and special education professionals, in part due to, regardless of the child's age - parents came to the district with the intent to enroll earlier due to their concern or an identified delay. From the interviews, 66% of the families noted that they first approached the school district because they thought all educational support came from the district, only to be told about ECI for children under 3. According to Williams et al. (2013), program linkage between the servicing entities is needed. Due to increased familiarity with schools, this tends to be the first response, and those access points play a significant role in the likelihood of receiving a referral; however, it is not uncommon for referrals at school districts to result in a dead-end.

Furthermore, families thought of ECI as an expensive program that children with severe physical or mental difficulties qualified for instead of a language delay or behavioral tantrums. This explicitly reflects school districts are not immune to the Child Find efforts for children before school-age. Concentrated attention is needed to bridge the Child Find steps between Part C and Part B 619 since parents often understand public schools as the first line of support. As Poppe (2018) pointed out, TEA stands corrected by the OSEP for their lack of sufficient systems and efforts to bridge the efforts between local education agencies to better the Child Find actions (Ennis et al., 2017; OSEP, 2018b; Swaby, 2018). Therefore, Twardzik et al. (2017) suggested at the state level, both

the Departments of Education and Health need to address the information gap that the community has about where to obtain services.

*Isolated systems cause children to be unfound.*

#### **Research Question 4**

Research Question 4, What effect, if any, does parental empowerment have on those families who did and did not access early childhood interventions services?, was analyzed using logistical regression with common frequencies and percentages from the BAUECISI, and supported with qualitative interviews from an ECI program director, and parents who did and did not access ECI services. Item 26 with a subscale of 1-12 was categorized as parental empowerment and scored using a 5-point Likert-type scale where 1 = disagree completely, 2 = disagree, 3 = don't disagree/agree, 4 = agree, and 5 = agree completely. This study determined that Black parents' sense of parental empowerment does not have statistical significance regarding their accessing services. In other words, the more empowered a parent feels, the greater the likelihood they will access and utilize ECI services for their child with a developmental delay. Nachshen and Minnes (2005) cautioned that empowerment is a "buzzword" and that parents' real action is advocacy; particularly empowered advocacy is a proponent to a parents' response to seek improvement for their child's experience with a disability. Overall, Black parents feel in control of raising their child with a disability and maintaining control over themselves to respond accordingly to meet their needs. Parents exhibited empowerment by being in-tuned with the developmental needs of their children. Reportedly, when it comes to the best interest, Black families will fight for what they believe is rightfully owed to them and take immediate action. Contrastively, Black and Latino families were more likely to feel their views were dismissed (Zuckerman et al., 2014). Instead, professionals misinterpreted parents' actions as defensive when news was contrary to their view about

their child's development. However, families have noted they have involved higher-level professionals and go up the chain of command to get an answer. While Nachshen and Minnes (2005) draw forth the combination of reduced fiscal budgets, increased demand for participation, and decreased availability more than ever, the weight is great for parents to accrue the knowledge necessary to advocate and have those behaviors of empowerment (THHSC Rider 98, 2020). Told by Bernard and Bernard (1998) portrayed the Black mothers' sense of empowerment as an embodiment of their environment's critical consciences, causing the world's weight to influence their response. Even though Black families may seem to fight, there is still a misunderstanding in that they do not always ask the questions that result in an answer that meets their situation. Harkening back to the Black culture undertone where elders and titles create a hierarchy in the community, this leaves those needing the help to take what is given and not question authority. Supporting this idea, Dunst et al. (2017) reminded us diverse families and backgrounds influence their perspective, and Black families feel compelled to raise children according to the White mainstream expectations (James et al., 2018).

In this study, parents spoke about spirituality as a coping mechanism when navigating the travails for ECI and disability. Before entering into a meeting, a mother has to gain control over her emotions, for she prepared internally to wage war and take a stance on the ill words spoken against her child's ability. A participant described the agony, anger, frustration, and dismal experienced towards educational professions when preparing for ECI transition. Brown and Gary (1987) recognized the strong correlation of Black women relying on higher powers to face the obstacles and challenges experienced and believing prayer was a solution. Therefore, Ball (1999) described empowerment as self-confidence built, that personalizing change integrates into one's identity, making it one's own. By doing so, they become "'inside-out people' who draw their strength from

within, from the fundamental knowledge of themselves, from their clarity and purpose, from their values and ideal, and from their deep understandings of [their] life and people” (p. 262).

*An assumption is that they know how to constructively advocate for their child.*

### **Research Question 5**

Research Question 5, What are, if any, the discrepancies between the views of parents and professionals regarding the access and utilization of early childhood intervention services?, was analyzed using NVIVO and inductive coding to address the response of medical professionals, program administrators, and parents who did and did not access ECI services. The interview process used narrative inquiry. Collectively, professionals and parents felt access to and use of ECI services was confusing and frustrating. Admittedly, professionals aligned with parents on “wait-and-see” as a standard response that reduced the number of referrals. Just as parents felt that tone and body language was unfavorable toward them, professionals noted that the way a family carried themselves does influence their perception. The way parents or caregivers carry themselves skews the perception toward them, affecting professional and client interactions. A defining point for the professionals is that they see and believe that Black families are treated differently regarding the information shared about children’s development. Strong vernacular is used to describe the present state of access to services as an “undercover genocide” on all healthcare levels that is quietly extinguishing Black families. The professionals' sincerity and realness fashions the innermost feelings families have when interacting with them. There is a sharp line inexplicably drawn when communicating with Black families because the information about a child's difference most often was not well received. Stone (2005) stated we miss the mark when solely focusing on race and culture and overlooking introducing a disability. For example, a

participant in this study flew to Wisconsin to have a family member who is a pediatrician provide a second opinion.

This highlights, Black families had different interpretations of the developmental milestones and believed that spiritual influences and upbringing contributed to their abilities. A grandparent expressed feeling insecure that her grandson could not speak for himself and “tell what is going on” and required that he speak before enrolling in school. From this perception, the lack of verbal abilities outweighed a reluctance to seek early help. Intergenerational homes where grandparents and elders are raising children with disabilities warrant consideration. Increasingly, grandparents assume the role of primary caretaker for young children, adding a generational, economic, health, and educational divide between understanding and recognizing signs and symptoms of a disability to be screened (Samuel et al., 2017).

In another example, a public service announcement exposed a painful reality for a family, seeing their child's comparison to developmental expectations. Ford (2012) called this “the emotional expressiveness” effect when families of color have a heightened sensitivity to their environment, resulting in a defensive and impulsive stance. Lau (2006) cautioned cultural and ethnic experiences influence parental receptivity and attention to detail in how outreach is done and portrayed messages such as forming a partnership depicted as a partaker or consumer makes a difference in parental behaviors to access services (Stone, 2005). This reaction is off-putting to others and reduced the amount of engagement between themselves and the family. Gutierrez, Goodwin, Kirkins, and Mathis (2014) stated that professionals need to consider the foundational and generational depth that guides families' reactions and suggest that messages tailored to meet varying audiences' needs (Dunst & Clow, 2007).

*Systemic stillness is the curse to generational inflictions.*

## **Research Question 6**

Research Question 6, *What are the parent's knowledge, feelings, and thoughts when attempting to access early intervention services?*, was analyzed using NVIVO and inductive coding to address the response to parental barriers encountered for those who did and did not access ECI services. Narrative inquiry was a dual-phase interview process where the participants' initial reactions were aligned with the past, present, and future. Responses were organized into four major themes: (a) explicit outreach, (b) family structure, (c) formidable experiences, and (d) implicit biases. Overall, participants disclosed they felt their interactions with professionals equated to not being heard, or their concerns were reduced in importance. Participants desired to have more meaningful conversations with those who were holders of information but felt the discussions were limited in guidance. The participants suggested they wanted not to feel judged and have an open dialogue with professionals tailored to them because they thought that their experiences were not the same as hegemonic group (e.g., the simplicity of being talked "at" opposed to "with" as a parent and child). Parents felt that professionals were more likely to show disingenuousness through their body language and vocal tone. Gillespie, Bridges-Bond, Scheft, and Livingston (2019) highlighted that preservice direct service providers' clinical competency is associated with their ability to self-evaluate and critically reflect are predictive of their abilities to meet the needs of diverse families. Parents discussed the need for practitioners to meet them at their level of access, such as conversations about disability not being an isolated event yet having the ability to disrupt a family's life. This response coincides with the research about the disconnect between professionals and Black families (Hall et al., 2012). Implicit biases perpetuate the cycle of marginalization and disparity in access to resources (Begeer et al., 2009; Hall et al.,

2015). A call for action by the Division of Early Childhood (2020) was to overcome the implicit biases that negatively impact children and families' service.

Parents expressed a high level of concern about their child being labeled and stigmatized. Nevertheless, families and professionals attest that children do receive a label to proceed with services. Parents noted this creates a barrier in the marriage because the father is not receptive considering the child's age. This paperwork requirement has caused dissension between parents asking for help and told their child is determined with a disability. Stigma comes when families feel identified as different from their counterparts. When labels are applied monolithically- acceptance and stigma reinforce the mark Black children are second-class citizens (Dunst & Clow, 2007; McHatton & Correa, 2005; Ogbu, 2003; Pitre et al., 2015).

### **Research Question 7**

Research Question 7, *What evidence of empowerment to advocate in their child's best interest is shared in the respondents' expressions/stories?*, was analyzed using NVIVO and inductive coding to address the response of parental perception to advocate for their child's needs from those who did and did not access ECI services. Through narrative inquiry, three themes emerged that included (a) confidence, (b) constructive conversations, and (c) work status. Overall, participants expressed that they recognize the need to speak and stand up for matters regarding their child. Fathers had an additional burden of being head of household and available to support the at-home responsibilities in raising a child with special needs. Concerning fathers, their role can either be supportive or rejective of the burden of raising a child with a disability due to societal factors such as stigma or negative interactions with professionals (Jegatheesan, Miller, & Fowler, 2010; McHatton & Correa, 2005).

From the participants, a family vulnerably shared that they do not always know who, what, or where to seek help and lose confidence in the educational system when there is no follow-through. Nonetheless, loss of employment burdens a parent who may speak up because they worry about the unknowns related to their basic needs and how the diagnosis impacts their family unity. As Corr et al. (2016) expressed, meeting a family's basic needs overshadows their view and ability to advocate. Rawlett (2014) describes the difference between empowerment and self-efficacy, parental efficacy is the internal force, taken action, and preliminary stance that is needed to demonstrate the continuous act of empowerment to obtain the necessary services (Damen et al., 2016; Dunst et al., 2004; Kim, 2012). Therefore, an advocate is viewed as a "fighter" who traverses a system not built for them; by doing so, a learning curve exists. They have to unearth their perceptions and forge an alignment with the mainstream definition to access supports. Paradoxically, Rawlett (2014) explained that as a vulnerable population, Blacks are positioned to not only meet their families' necessities while traversing through a multi-tiered system of interactions to access services, all the while consciously considering the multiplexable roles at home and in society. Contextually, Black families know and want to advocate for their child but recognize that there is a limit in how much authority they have to see results.

### **Implications**

As a result of this study's examination of the barriers Black families perceived to encounter when accessing and utilizing services, implications emerged regarding both professional and families' overall perception to identify the intersection of the obstacles. This study was grounded in the theory of transformative learning, critical race theory, and equitable literacy. As a society, we are charged to uphold an equitable, accessible system for all. Thus, the findings offer clarity on the various aspects of the barriers associated

with Child Find and how the perception positively or negatively influences families to seek assessment for ECI and utilize the supports.

### **Implications for Medical and Educational Professionals**

We know of a leader and professional who is motivated to do the best for their constituents. They set policies to grow the organization and keep all parties' best interests at the center. In ECI, we are aware of the benefits of sooner rather than later, as with autism determined before two years of age (Hyman et al., 2020). Child Find in Part C delineates policies and procedures inscribed to keep states accountable for reaching children in this tender age group. As a society, the picture has shifted in color, resources, and languages as our horizon is broadening. Thus, as leaders, we are challenged to change with the times and tend to the past stories that impact today.

Beyond the minutia of looking holistically at minority populations, Mezirow (2000) and Chapman (2007) prompted us to acknowledge a shift is a transformational force that overpowers the status quo. Therefore, critical self-reflection on organizational decisions preempts leaders, medical and educational professionals, and parents to view the gaping holes in the system outcomes holistically. As demonstrated with ECI budget cuts, Black children are the largest group impacted by Child Find, shown as the largest decline in EI enrollment. Chapman (2007) described transformation from a personal perspective as the foundation to changing society and liberating oppressed people, in this case, having to struggle for access to services. Transformation is a discursive process that is messy and turbulent. Coles (2011) eloquently addressed the medical community by redressing the foundation with what matters and explained that subordinates or parents should be told they matter and acknowledged not as a figurehead but as a valued constituent. Their words, actions, and interpretations are utilized as a requirement to propel forward.

By not doing so, educational and health organizations stunt the access to other ethnic groups when forgoing their experiences. Dewey (1938) claimed experiences beget experiences, and this is not to be forgotten. More so, one's experiences are not isolated events but reoccurrences that are now deemed unequivocally generational in the Black community; therefore, health and educational institutions should consciously approach and reflect on their constituents, not as a deficit but as an enrichment to the holistic picture (Skiba et al., 2016). We should ask pointed questions that challenge assumptions, beliefs, and actions; for example, a professional assumption that a disability has a standard definition may be the case in science but is exhibited differently amongst individuals, families, and societal groups. DEC pointed out that as professionals, we need accountability for our unconscious actions (DEC Priority Issues, 2020).

As leaders, we should be encouraged to move beyond tiptoeing around inclusion and equity as this perpetuates the generational cycle of inferiority. Instead, we should face the masked biases that result in unconscious actions and generate awareness of them through reflective practices. Change comes about through a political process that aims to make a societal shift (Merriam et al., 2007, p. 435). Viewing people as binaries misleads curriculum policy and program development because the narrative influences the response and applicability to the access and utilization of services (Clandinin & Connelly, 2000). Globalization is reshaping our society; therefore, we have to be attuned to body language that fosters a more in-depth understanding of miscues that separate us from each other (Goleman, 2015). Dunst (2007) and Lau (2006) brought awareness to this type of outreach and the ability to make a behavioral change.

### **State ECI Programs**

Texas ranks at the bottom with unidentifiable terms in their outreach efforts to families about ECI services (Kids Count, 2012). In conjunction, this aligns with Black

families who have expressed minimal awareness of the availability and benefits of ECI. Per the federal requirement, states must submit a yearly improvement plan that addresses their current CF practices. Despite the decreased enrollment of Texas children in special education, Child Find efforts are not targeted enough; therefore, it is recommended that outreach plans should be culturally explicit beyond a picture change. However, we need to bring awareness to implicit biases that inhibit Child Find practices and recognize the significant role implicit biases play in skewing population access. According to Chapman (2007), we remain *still* a society to identify hierarchies from those of the homogenic group without critical reflection.

The plain fact is the planet does not need more “successful” people. It desperately needs more peacemakers, healers, restorers, storytellers, and lovers of every shape and form. It needs people who live well in their places. It needs people of moral courage willing to join the fight to make the world habitable and humane [for all]. And these needs have little to do with success as our culture has defined it. (Ball, 1999, p. 253)

Professional development that fosters reflective consciousness and awareness to minimize these behaviors to address the matter. Similarly, as we focus on children's social, emotional components, we must not overlook our ability to be skilled in emotional competencies where we are attuned to others' feelings and handle interjections of discourse to ride the messy wave of change (Goleman, 2015).

### **Implications for Black Families**

Families of children with developmental delays have a unique position of navigating various entities (medical, educational, familial) to meet their basic needs. There is room to grow in our knowledge and reactions as parents and seek to collaborate with “gate-keepers” of the necessary information. To reach this point, we have to

acknowledge how we view the world and walk in the truth for what makes us better. The researcher believes that professional platforms are the gateway to enhancing our communities. There is a responsibility on parents to access and utilize services, yet if they express reasons that stop them, we are charged to listen and respond. Therefore, there is a skill set needed, such as speaking up for oneself and family, asking questions constructively, and having an attitude to work as a team with professionals focused on young Black children's best interest.

### **Recommendations for Future Research**

Concerns with Black children accessing and utilizing ECI is gaining attention in the literature as a precursor to reduce the enrollment in Part B special education (Morgan et al., 2015). The literature documents how children with autism may be determined at 18 months of age. However, Black children are commonly identified closer to 5 years of age. ECI is applauded for helping children and families with in-home support and community resources with minimal opposition in the literature to ECI not being a benefit (Bruder, 2010; Fuchs, Fuchs, & Stecker, 2010). However, this study aligns with previous studies that found systemic deficits and implicit biases mask physical barriers to accessing the benefits of services (Betancourt et al., 2003; Bruder, 2010; McManus et al., 2014; Rosenberg, Robinson & Shaw et al., 2013).

Further, this study reveals the depth needed to humanize both professionals and families' experience to unearth the hidden truths and tendencies not previously identified. Although studies note the discrepancy in received services, literature is scarce among this specific population (Morgan et al., 2009; Morgan, Farkas, Hillemeier, & Maczuga, 2012; Rosenberg, Robinson et al., 2013; Obeid, 2021). A need exists to provoke discourse on the foundational influences that cycle into decisions made on behalf of our children. Therefore, further studies should dig deeper into the intersections of race, gender, and

class attributes associated with Child Find's policies and procedures to initiate systemic reform. An additional extension is needed to address the implicit biases as a contributing factor in the access-utilization gap. Moreover, an in-depth examination should include community awareness and support of childcare centers' role in making referrals to ECI to create a holistic approach to *calling* our youngest Black children's names.

### **Conclusion**

The purpose of this mixed-methods study was to explore the depth of perceived barriers preventing Black families from accessing (completing the intake process) and utilizing (following through with the support) early childhood intervention services. Twenty-nine medical program administrators, direct service providers, and 38 parents and guardians from southeast Texas were administered the *Barriers to Access and Utilize Early Childhood Intervention Services Inventory* (BAUECISI). The BAUECISI measured perception of barriers and parental empowerment to access and utilize ECI services. Survey results were analyzed using descriptive statistics, a one-way ANOVA, Chi-square test of independence, cross-tabulations, and logistical regression of the parental groups, and correlated with transcribed responses of three professionals and three families who participated in narrative inquiry interviews.

The most defining characteristic is that the past societal acts impact access and utilization of services. Reflection is a fact of these matters, of the disparities that Black people face on levels of access to healthcare; therefore, it is also reasonable to assume that the benefits of ECI are generally accepted and utilized by all who need them. By not doing so, this will characterize a fraction of the children, and the question arises, what do these points of convergence and divergence signify concerning Black families and ECI programs? Identifying points of divergence may be relevant to the complexity and diversity of expression from all constituents. The points of convergence may represent

the intersection of race and ability. It may be equally important to take a dimensional approach and examine the intersection points of different processes, that is, to determine the implications of access and utilization. An important conclusion from this study is a consideration of the group and the individuals within a group. As a society overall, groups have a collective voice with shared experiences, and this sole perspective masks the individual differences.

In summary, *wakefulness* is an ongoing reflection of the critiques experienced by ourselves and society to consider the overt actions fueled by our unconscious biases—not to mask the everyday moments that are spirited in the dimensions of time, sociality, and place (Clandinin & Connelly, 2000). Even in mainstream society, this applies to “Black families” not treated as an oddity. Holistically, our system beckons for critical reflection at the societal level of one’s being and its influences made on behalf of all.

Unconsciously, these delineations will persist if we do not address our subconscious biases—better to serve children of color from the womb onward. This study sought to explore and offer a better understanding of the perceptions encountered in accessing ECI from parent and professional perspectives. Ignoring certain aspects of Black families' understandings could trivialize the importance of factoring in the formidable experiences into ECI programs and Child Find policies.

## REFERENCES

- AEM Corporation. (2016a). Texas IDEA Part C Profile-FFy14. Retrieved from <https://osep.grads360.org/services/PDCService.svc/GetPDCDocumentFile?fileId=23058>
- AEM Corporation. (2016b). Texas IDEA Part C SPP/APR-FFy14. Retrieved from <https://osep.grads360.org/services/PDCService.svc/GetPDCDocumentFile?fileId=20938>
- Alegria, M., Carson, N., & Flores, M. (2014). Activation, self-management, engagement, and retention in behavioral health care. *JAMA Psychiatry, 71*(5), 557-565.
- American Speech-Language-Hearing Association. (2020). Profile of ASHA members and affiliates, year-end 2019. Retrieved from [www.asha.org](http://www.asha.org)
- American Speech-Language-Hearing Association, (2015). Almost 8 percent of the U.S. children have a communication or swallowing disorder. *ASHA Leader, 20*(8). <https://doi.org/10.1044/leader.NIB1.20082015.10>
- Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior, 36*(1), 1-10.
- Andersen, R. M, Davidson, P. L., & Baumeister S. E. (2013) Improving access to care. In G. F. Kominski (Ed.), *Changing the U.S. health care system: Key issues in health services policy and management* (pp. 33-64). Hoboken, NJ: John Wiley & Sons.
- Annamma, S. A, Connor, D. J., & Ferri, B. A. (2013). Dis/ability critical race studies (DisCrit): Theorizing at the intersections of race and dis/ability. *Race Ethnicity and Education, 16*(1), 1-31. doi: 10.1080/13613324.2012.730511
- Annamma, S. A., Ferri, B. A., & Connor, D. J. (2018). Disability critical race theory: Exploring the intersectional lineage, emergence, and potential futures of DisCrit in education. *Review of Research in Education, 42*(1), 46-71.

- Arcia, E., Keyes, L., Gallagher, J. J., & Herrick, H. (1993). National portrait of sociodemographic factors associated with underutilization of services: Relevant to early intervention. *Journal of Early Intervention, 17*, 283-297.
- Artiles, A. J., Kozleski, E. B., Trent, S. C., Osher, D., & Ortiz, A. (2010). Justifying and explaining disproportionality, 1968-2008: A critique of underlying views of culture. *Exceptional Children, 76*(3), 279-299.
- Artiga, S., Foutz, J., Cornachione, E., & Garfield, R. (2016). Key facts on health care by race and ethnicity. *Kaiser Family Foundation Report*. <http://files.kff.org/attachment/Chartpack-Key-Facts-on-Health-and-Health-Care-by-Race-and-Ethnicity>
- Ball, G. D. S. (1999). Building a sustainable future through transformation. *Science Direct, 31*, 3-4. [https://doi.org/10.1016/S0016-3287\(98\)000133-5](https://doi.org/10.1016/S0016-3287(98)000133-5)
- Bandura, A. (1977). *Self-efficacy: The exercise of control*. New York: W. H. Freeman
- Banks, J. A., & Banks, C. A. M. (Eds.). (2009). *Multicultural education: Issues and perspectives*. Hoboken, NJ: John Wiley.
- Barger, B., Rice, C., Simmons, C. A. & Wolf, R. (2018). A systematic review of Part C early identification studies. *Topics Early Child Special Education, 38*(1), 4-16.
- Barnes, R. (1990). Race consciousness: The thematic content of racial distinctiveness in critical race scholarship. *Harvard Law Review, 103*, 1864-1871.
- Bartlett, M., & Mickelson, A. (2019). *The changing landscape of education for young children receiving early intervention and early childhood special education*. *The Wiley handbook for early childhood care and education* (1st ed.). Medford, MA: John Wiley & Sons, INC.

- Begeer, S., Bouk, S. E., Boussaid, W., Terwogt, M. M., & Koot, H. M. (2009). Underdiagnosis and referral bias of autism in ethnic minorities. *Journal of Developmental Disorders, 39*, 142-148.
- Bernard, W. T., & Bernard, C. (1998). Passing the torch, a mother and daughter. *Canadian Women Studies, 18*(2&3), 46-51.
- Betancourt, J.R., Green, A., Carillo, L.E., & Ananeh-Firempong, O. (2003). Defining cultural competence: A practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports, 118*, 293-302.
- Black, M.M., Walker, S.P., Fernald, L.C.H., Andersen, C.T., DiGirolma, A.M., Lu, C. . . . Grantham-McGregor, S. (2017). Early child development coming of age: Science through the life course. *The Lancet, 389*(10064), 77-90,
- Black, M. M., Dubowitz, H., & Starr Jr., R.H. (1999). African American fathers in low income, urban families: development, behavior, and home environment of their three-year-old children. *Society for Research in Child Development, 70*(4), 967-978.
- Bowers, K., Folger, A. T., Zhang, N., Sa, T., Ehrhardt, J., Meinzen-Durr, J. . . . Ammerman, R. T. (2018). Participation in home visitation is associated with higher utilization of early intervention. *Maternal and Child Health Journal, 22*, 494. <https://doi-org.ezp.twu.edu/10.1007/s10995-017-2415-8>
- Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., Visser, S., & Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics, 127*(6), 1034-1042. <https://doi.org/10.1542/peds.2010-2989>

- Branson, D., & Bingham, A. (2017). Child care providers' competence and confidence in referring children at risk for developmental delays. *Infants & Young Children, 30*(1), 41-57. doi: 10.1097/IYC.0000000000000079
- Brown, D., & Gary, L. (1987). Stressful life events, social supports networks, and the physical and mental health of urban black adults. *Journal of Human Stress, 4*, 167-174.
- Brown, C. P., McMullen, M. B., & File, N. (2019). *The Wiley handbook of early childhood care and education*. Hoboken, NJ: Wiley-Blackwell.
- Bruder, M. B. (2010). Early childhood intervention: A promise to children and families for the future. *Council for Exceptional Children, 76*(3), 339-355.
- Campbell, F. A., Pungello, E. P., Burchinal, M., Kainz, K., Pan, Y., Wasik, B. H., . . . Ramey, C. T. (2012). Adult outcomes as a function of an early childhood educational program: An Abecedarian Project follow-up. *Developmental Psychology, 48*(4), 1033-1043. doi:10.1037/a0026644
- Carter, N. P., Hawkins, T. N., & Natesan, P. (2008). The relationship between verve and the academic achievement of African American students in reading and mathematics in an urban middle school. *Educational-Foundations, 22*(1), 29-46.
- Clair, M., Daniel, C., & Lamont, M. (2016). Destigmatization and health: Cultural constructions and the long-term reduction of stigma. *Social Science in Medicine, (165)*, 223-232.
- Centers for Disease Control and Prevention. (2019). Infant mortality statistics from the 2017 period linked birth/infant death data set. *National Vital Statistics Reports. Table 2*. [https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68\\_10-508.pdf](https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_10-508.pdf)

- Centers for Disease Control and Prevention. (2021). *National Center on Birth Defects and Developmental Disabilities*. Retrieved from <https://www.cdc.gov/ncbddd/autism/index.html>
- Chapman, S. (2007). *A theory of curriculum development in the professions: An integration of Mezirow's Transformative Learning Theory with Schwab's Deliberative Curriculum Theory*. [Doctoral dissertation, Antioch University.] Retrieved from [antioch1173793131%20.pdf](#)
- Chen, J., Mullins, C. D., Novak, P., & Thomas, S. B. (2016). Personalized strategies to activate and empower patients in health care and reduce health disparities. *Health Education & Behavior, 43*(1), 25-34.
- Cho, S. J., & Gannotti, M. E. (2005). Korean-American mothers' perception of professional support in early intervention and special education programs. *Journal of Policy and Practice in Intellectual Disabilities, 2*(1), 1-9.
- Christle, C. A., Jolivette, K., & Nelson, M. C. (2007). School characteristics related to high school dropout rates. *Remedial and Special Education, 28*(6), 325-339.
- Clandinin, D.J., Pushor, D., & Orr, A.M. (2007). Navigating sites for narrative inquiry. *Journal of Teacher Education, 58*(1), 21-35.
- Clandinin, D.J. (2006). Narrative inquiry: A methodology for studying lived experiences. *Research Studies in Music Education, 27*(44), 44-54.
- Clandinin, D. J., & Connelly, F. M. (2000). Narrative inquiry. Experience and story in qualitative research. San Francisco: Jossey-Bass.
- Clandinin, D. J., & Huber, J. (in press). Narrative inquiry. In B. McGaw, E. Baker, & P. P. Peterson (Eds.), *International encyclopedia of education* (3rd ed.). New York, NY: Elsevier.

- Clair, M., Daniel, C., & Lamont, M. (2016). Destigmatization and health: Cultural constructions and the long-term reduction of stigma. *Social science & medicine* (1982), 165, 223-232. <https://doi.org/10.1016/j.socscimed.2016.03.021>
- Clottey, E. N., Scott, A. J., & Alfonso, M. L. (2015). Grandparent caregiving among rural African Americans in a community in the American south: Challenges to health and wellbeing. *Rural and Remote Health*, 15(3313), 1-11.
- Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: Complementary research strategies*. Thousand Oaks, CA: Sage Publications.
- Cohen, J., Onunaku, N., Clotheir, S., & Poppe, J. (2005). *Helping young children succeed strategies to promote early childhood social and emotional development*. Denver, CO: National Conference of State Legislatures.
- Cole, P., Oser, C., & Walsh, S. (2011). Building on the foundations of Part C legislation: Beginning conversations for reauthorization. *Zero to Three*, 31(4), 52-59.
- Coles, R. (1989). *The call of stories: Teaching and the moral imagination*. Boston: Houghton Mifflin.
- Coles, R. L. (2016). *Race and family: A structural approach*. Lanham, MD: Rowman & Littlefield Publishers.
- Connelly, F. M., & Clandinin, D. J. (2006). Narrative inquiry. In J. L. Green, G. Camilli, & P. Elmore (Eds.), *Handbook of complementary methods in education research* (3rd ed., pp. 477-487). Mahwah, NJ: Lawrence Erlbaum.
- Constantino, J. N., Abbacchi, A. M., Saulnier C., Klaiman, C., Mandell, D. S. . . . Geschwind, D. H. (2020). Timing of the diagnosis of autism in African American children. *Pediatrics*. 146(3), 1-9. doi: 10.1542/peds.2019-3629
- Copeland V. C., & Snyder, K. (2011). Barriers to mental health treatment services for low-income African American women whose children receive behavioral health

- services: An ethnographic investigation. *Social Work in Public Health*, 26(1), 78-95.
- Corr, C., Santos, R. M., & Fowler, S. A. (2016). The components of early intervention services for families living in poverty: A review of the literature. *Topics in Early Childhood Special Education*, 36(1), 55-64. <https://doi.org/10.1177/0271121415595551>
- Cox, C. B. (2002). Empowering African American custodial grandparents. *Social Work*, 47(1), 45-54.
- Cox, J. E., Huntington, N., Saada, A., Epee-Bounya, A., & Schonwald, A. D. (2010). Developmental screening and parents' written comments: An added dimension to the parents' evaluation of developmental status questionnaire. *American Academy of Pediatrics*, 126(170), 170-176.
- Creswell, J. W., & Guetterman, T. C. (2019). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (6th ed.). Princeton, NJ: Pearson.
- Dababnah, S., Shaia, W. E., Champion, K., & Nichols, H. M. (2018). "We had to keep pushing": Caregivers' perspective on autism screening and referral practices of Black children in primary care. *Intellectual and Developmental Disabilities*, 56(5), 321-336.
- D.L. v. District of Columbia*, 845 F.Supp.2d 1, 6 (D.D.C.2011).
- Daloz, L. (1986). *Effective teaching and mentoring: Realizing the transformational power of the adult learning experience*. San Francisco: Jossey-Bass.
- Damen, H., Veerman, J. W., Vermulst, A. A., Nieuwhoff, R., de Meyer, R. E., & Scholte, R. H. J. (2016). Parental empowerment: Construct validity and reliability of a

- Dutch Empowerment Questionnaire (EMPO). *Journal of Child and Family Studies*, 26(2), 424-436. <https://doi.org/10.1007/s10826-016-0568-5>
- Davis, J. E (2003). Early schooling and academic achievement of African American males. *Urban Education*, 38(5), 515-537.
- Davis, R. (2020). *41st Annual report to congress on the implementation of the Individuals with Disabilities Education Act 2019*. Alexandria, VA: U.S. Department of Education. Retrieved from <https://www2.ed.gov/about/reports/annual/osep/2019/parts-b-c/41st-arc-for-idea.pdf>
- Delgado, C.F., & Scott, K.G. (2006). Comparison of referral rates for preschool children at risk for disabilities using information obtained from birth certificate records. *The Journal of Special Education*, 40, 28-35.
- Delgado, R., & Stefanic, K. (2011). *Critical race theory: An introduction* (2nd ed.). New York: New York University Press.
- Dewey, J. (1938). *Experience and education*. New York: Collier Books.
- Division for Early Childhood. (2014). *DEC recommended practices in early intervention/early childhood special education 2014*. <http://www.dec-spced.org/recommendedpractices>
- Division for Early Childhood. (2020). DEC priority issues agenda. Retrieved from <http://www.dec-spced.org/PriorityIssues>
- Dodge, K. A., Bai, Y., Ladd, H. F., & Muschkin, C. G. (2017) Impact on North Carolina's early childhood program and policies on educational outcomes in elementary school. *Child Development*. 88(3), 996-1014.
- Du Bois, W. E. B. (1897). *A program for a sociological society, ca. 1897*. *W. E. B. Du Bois Papers (MS 312)*. Special Collections and University Archives, University of Massachusetts Amherst Libraries.

- Dunn, C., Chambers, D., & Rabren, K. (2004). Variables affecting students' decisions to drop out of school. *Remedial and Special Education, 25*(5), 314-323.
- Dunst, C.J., & Paget, K.D. (1991). Parent-professional partnerships and family empowerment. *Collaboration with Parents of Exceptional Children, 25-44*.
- Dunst, C. J. (2007). Early intervention for infants and toddlers with developmental disabilities. In S. L. Odom, R. H. Horner, M. E. Snell, & J. Blacher (Eds.) *Handbook of developmental disabilities* (pp. 161-180). New York: Guilford Press.
- Dunst, C. J. (2014, March 12). Family systems early intervention, model, paradigms, and practices. Paper presented at the Systems Approach to Families: A Context for Australian Children Seminar. Monash University, Clayton Campus, Australia.
- Dunst, C. J., Boyd, K., Trivette, C. M., & Hamby, D. W. (2002). Family-oriented program models and professional help giving practices. *Family Relations, 51*(3), 221-229.
- Dunst, C. J., & Bruder, M.B. (2002). Valued outcomes of service coordination, early intervention, and natural environments. *Exceptional Children, 68*, 361-375.
- Dunst C. J., Bruder, M. B., Trivette, C. M., & Hamby, D. W. (2006). Everyday activity settings, natural learning environments, and early intervention practices. *Journal of Policy and Practice in Intellectual Disabilities, 3*, 3-10.
- Dunst C. J., & Clow, P. W. (2007). Public awareness and child find activities in Part C early intervention programs. *Cornerstones, 3*(1), 1-7.
- Dunst, C. J., & Gorman, E. (2006). Practices for increasing referrals from primary care physicians. *Cornerstones, 21*(5), 1-5.
- Dunst, C. J., Hamby, D.W., Raab, M., & Bruder, M. B. (2017) Family socioeconomic status and ethnicity, acculturation and enculturation, and parent beliefs and child

- behavior, learning methods, and parent roles. *Journal of Education and Culture Studies*, 1(2), 99-122.
- Dunst, C. J., & Trivette, C. M. (1987). Enabling and empowering families: Conceptual and intervention issues. *School Psychology Review*, 16(4), 443-456.
- Dunst, C. J., & Trivette, C. M. (2009). Using research evidence to inform and evaluate early childhood intervention practices. *Topics in Early Childhood Special Education*, 29(1), 40-52.
- Dunst, C. J., & Trivette, C. M. (2004). Toward a categorization scheme of child find, referral, early identification and eligibility determination practices. *Tracelines*, 1(2), 1-18. Retrieved from [http://www.tracecenter.info/tracelines/tracelines\\_vol1\\_no2.pdf](http://www.tracecenter.info/tracelines/tracelines_vol1_no2.pdf)
- Dunst, C. J., Trivette, C. M., Appl, D. J., & Bagnato, S. J. (2004). Framework for investigating child find, referral, early identification, and eligibility determination practices. *Tracelines*, 1(1), 1-11.
- Early Childhood Learning and Knowledge Center. (2020). Ongoing child assessment: A guide for program leaders. *National Center on Early Childhood Development, Teaching and Learning*. Retrieved from: <https://eclkc.ohs.acf.hhs.gov/sites/default/files/pdf/no-search/ongoing-child-assessment-guide-optimized.pdf>
- Early Childhood Technical Assistance Center. (n.d.a). Part b of section 619 of IDEA. Retrieved from <https://ectacenter.org/sec619/sec619.asp>
- Early Childhood Technical Assistance Center. (n.d.b). Public awareness and developmental monitoring. Retrieved from <https://ectacenter.org/topics/earlyid/pubaware.asp>

- Early Childhood Technical Assistance Center. (2016). Part C infant and toddler program federal appropriations and national child count 1987-2015. Retrieved from <http://ectacenter.org/~pdfs/growthcompPartC.pdf>
- Early Childhood Technical Assistance Center. (2014). Early childhood intervention (eci) system of general supervision/oversight. Retrieved from [https://ectacenter.org/~docs/sysframe/Texas-ECI\\_System\\_of\\_Oversight.docx](https://ectacenter.org/~docs/sysframe/Texas-ECI_System_of_Oversight.docx)
- Education Childhood Technical Assistance Center. (2018). Part C grants to states. Retrieved from <http://ectacenter.org/partc/grants.asp>
- Early Childhood Technical Assistance Center. (2020). Program overview: Part C of idea. Retrieved from <https://ectacenter.org/partc/partc.asp#tools>
- Edwards N. M., Gallagher, P. A., & Green, K. B. (2013). Existing and proposed child find initiatives in one state's part c program. *Rural Special Education Quarterly*, 32(1).
- Elbaum, B., Celimli-Aksoy, S., Marshall, J. T., & Berkovits, M. D. (2017). How does the narrowing of eligibility criteria affect enrollment in part c early intervention? *Infants & Young Children*. 30(1), 28-40.
- Emerson, N. D., Morrell, H., & Neece, C. (2016). Predictors of age of diagnosis for children with autism spectrum disorder: The role of a consistent source of medical care, race, and condition severity. *Journal of Autism and Developmental Disorders*, 46(1), 127-138.
- Ennis, R. P., Blanton, K., & Katsiyannis, A. (2017). Child find activities under the individuals with disabilities education act: Recent case law. *Teaching Exceptional Children*, 49(5), 301-308.
- Estes, C. P.(1993). *The gift of story: A wise tale about what is enough*. Boulder, CO: Ballatine Books.

- Feinberg, E., Silverstein, M., Donahue, S., & Bliss, R. (2011). The impact of race on participation in part c early intervention services. *Journal of Developmental Behavior Pediatrics, 32*(4), 284-291.
- Florian, L. (1995). Part H early intervention program: Legislative history and intent of the law. *Topics in Early Childhood Special Education, 15*(3), 247-262.
- Ford, D. (2012). Culturally different students in special education: Looking backward to move forward. *Council for Exceptional Children, 78*(4), 391-405.
- Ford, C. L., & Airhihenbuwa, C. O. (2010). Critical race theory, race equity, and public health: Toward antiracism praxis. *American Journal of Public Health, 100*(1), S30-S35.
- Foner, N. (2000). *From Ellis Island to JFK: New York's two great waves of immigration*. New Haven, CT: Yale University Press.
- Foronda, C., Baptiste, D-L., Reinholdt, M. M., & Ousiman, K. (2016). Cultural humility: A concept analysis. *Journal of Transcultural Nursing, 27*(2), 210-217. doi: 10.1177/1043659615592677
- Fox, J. (1994). *Acts of service. Spontaneity, commitment, tradition in the nonscripted theatre*. New Paltz, NY: Tusitala Publishing.
- Freed, L. G. (2009). Cooperative federalism post-Schaffer: The burden of proof and preemption in special education. Cornell Law Faculty Publications, Paper 983. Retrieved from <http://scholarship.law.cornell.edu/facpub/983>
- Freire, P. (1970). *Pedagogy of the oppressed*. New York: Continuum.
- Friedman-Krauss, A. H., Barnett, W. S., Weisenfeld, G. G., Kasmin, R., DiRecchio, J., & Horowitz, M. (2018). The state of preschool 2017. *The National Institute for Early Education Research*. <http://nieer.org/wp-content/uploads/2018/04/State-of-Preschool-2017-Full.pdf>

- Fuchs, D., Fuchs, L. S., & Stecker, P. M. (2010). The “blurring” of special education in a new continuum of general education placements and services. *Exceptional Children, 76*(3), 301-323.
- Gauna, L. (2014). *Stories of languages and teaching narratives of first year bilingual Spanish/English teachers*. ProQuest Dissertations, University of Houston.
- Gillespie, R. C., Bridges-Bond, S., Scheft, T. & Livingston, J. (2019). Predicating competency in graduate clinical training. *National Black Association for Speech-Language and Hearing, 14*(1), 62-81.
- Giordano, K. (2008). *Barriers to early intervention services in New Jersey*. Available from ProQuest Dissertations & Theses Global, Fairleigh Dickinson University.
- Goleman, D. (2015). *HBR’s 10 must reads on emotional intelligence*. Boston: Harvard Business Review Press.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Simon & Schuster.
- Gomez, R. E., & Rendon, T. (2019). *Early childhood policy and its impact on the field. The Wiley handbook for early childhood care and education* (1st ed.). Medford, MA: John Wiley & Sons, INC.
- Gorski, P. (2012). Perceiving the problem of poverty and schooling: Deconstructing the class stereotypes that mis-shape education practice and policy. *Equity & Excellence in Education, 45*(2), 302-319.
- Gorski, P. (2017). *Reaching and teaching students in poverty: Strategies for erasing the opportunity gap*, New York, NY: Teachers College Press
- Gorski, P. (2016). Rethinking the role of “culture” in educational equity: From cultural competence to equity literacy. *Multicultural Perspectives, 18*(4), 221-226.

- Gorksi, P. (2020). Equity literacy for educators: Definition and abilities. Retrieved from <http://www.edchange.org/handouts/Equity-Literacy-Introduction.pdf>
- Graham, L., Brown-Jeffy, S., Aronson, R., & Stephens, C. (2011). Critical race theory as a theoretical framework and analysis tool for population health research. *Critical Public Health, 21*(1), 81-93.
- Green, S. E. (2007). “We’re tired, not sad”: Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*(2007), 150-163.
- Guevara, J. P., Gerdes, M., Localio, R., Huang, Y. V., Pinto-Martin, J., . . . Pati, S. (2013). Effectiveness of developmental screening in an urban setting. *Pediatrics, 131*(1), 30-37.
- Guralnick, M. J. (2011). Why early intervention works. *Infants and Young Children, 24*(1), 6-28.
- Guralnick, M. J. (2017). Early intervention for children with intellectual disabilities: An update. *Journal of Applied Research in Intellectual Disabilities, 30*, 211-229.
- Guralnick, M. J., & Bruder, M. B. (2016). Early childhood inclusion in the United States: Goals, current status, and future directions. *Infant & Young Children, 29*(3), 166-177.
- Guralnick, M. J., & Bruder, M. B. (2019). Early intervention. In J. L. Matson (Ed.). *Handbook of intellectual disabilities—integrating theory, research, and practice* (pp. 717-742). New York: Springer Publishing.
- Gutierrez, I. A., Goodwin, L. J., Kirkins, K., & Mattis, J. S. (2014). Religious socialization in African American families: The relative influence of parents, grandparents, and siblings. *Journal of Family Psychology, 28*(6), 779-789.
- Habermas, J. (1971). *Knowledge and human interests*. Boston: Beacon Press

- Hall, W. J., Chapman, M. V., Lee, K. M., Merino, Y. M., Thomas, T. W., . . . Coyne-Beasley, T. (2015). Implicit racial/ethnic bias among health care professionals and its influence on health care outcomes: A systematic review. *American Journal of Public Health, 105*(12), 60-76.
- Han, W., Ruhm, C., Waldfogel, J., & Washbrook, E. (2008). The timing of mothers' employment after childbirth. *Monthly Labor Review, 131*(6), 15-27.
- Hassan-EL, K. (2007). *The Willie Lynch letter and the making of slaves*. Besenville, IL. Lushena Books.
- Hastings, E. A., Lumeng, J. C., & Clark, S. J. (2014). Primary care physicians' knowledge of and confidence in their referrals for special education services in 3- to 5-year-old children. *Clinical Pediatrics, 53*(2), 166-172.
- Hebbeler, K., Spiker, D., & Khan, L. (2012). Individuals with disabilities education act's early childhood programs: Powerful vision and pesky details. *Topics in Early Childhood Special Education, 31*(4), 199-207. doi: 10.1177/02711214114290
- Heckman, J.J. (2017). There's more to gain taking a comprehensive approach to early childhood development. *The Heckman Equation*. Retrieved from: [https://heckmanequation.org/www/assets/2017/01/F\\_Heckman\\_CBAOnePager\\_120516.pdf](https://heckmanequation.org/www/assets/2017/01/F_Heckman_CBAOnePager_120516.pdf)
- Heppner, P. P., & Heppner, M. J. (2004). *Writing and publishing your thesis, dissertation, and research: A guide for students in the helping professions*. Belmont, CA: Thompson Brooks/Cole.
- Heut, A. L., Frail, C. K., Lake, L. M., & Snyder, M. E. (2015). Impact of passive and active promotional strategies on patient acceptance of medication therapy management services. *Journal of the American Pharmacists Association, 55*(2), 178-181.

- Heydon, R. (2005). The de-pathologization of early childhood, disability and aging in an intergenerational art class. *Journal of Early Childhood Research*, 3(3), 243-268.
- Heydon, R., & Iannacci, L. (2009). *Early childhood curricula and the de-pathologizing of childhood*. Toronto: University of Toronto Press.
- Hibbard, J. H., Greene, J., Becker, E. R., Roblin, D., Painter, M. W., . . . Tusler, M. (2008). Racial/ethnic disparities and consumer activation in health. *Health Affairs (Project Hope)*, 27(5), 1442-1453. <https://doi.org/10.1377/hlthaff.27.5.1442>
- Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services Research*, 39(4 Pt 1), 1005-1026.
- Hood, J. C. (2006). Teaching against the text: The case of qualitative methods. *Teaching Sociology* 34, 207-223.
- Horkheimer, M. (1982). *Critical theory*. New York: Seabury Press.
- Hornbach, R., & Rubin, S. (2016). *New report from Texas: Thousands of young kids with disabilities excluded from early intervention amid state cuts*. Georgetown University Health Policy Institute: Center for Children and Families. Retrieved from <https://ccf.georgetown.edu/2016/11/30/new-report-from-texas-thousands-of-young-kids-with-disabilities-excluded-from-early-intervention-amid-state-cuts/>
- Hyman S. L., Levy S. E., Myers S. M., & AAP Council on Children With Disabilities, Section on Developmental and Behavioral Pediatrics. (2020). Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics*, 145(1), e20193447. doi: <https://doi.org/10.1542/peds.2019-3447>
- Individuals with Disabilities Education Act Amendments of 2004. Pub. L. No. 108-446 (2004). Retrieved from <https://ies.ed.gov/ncser/pdf/pl108-446.pdf>

- Individuals with Disabilities Education Act. (2017). Sec 303.21 Infant or toddler with a disability. Statue and Regulations. [https://sites.ed.gov/idea/regs/c/a/303.21#:~:text=\(a\)%20Infant%20or%20toddler%20with,intervention%20services%20because%20the%20individual%E2%80%94](https://sites.ed.gov/idea/regs/c/a/303.21#:~:text=(a)%20Infant%20or%20toddler%20with,intervention%20services%20because%20the%20individual%E2%80%94)
- James, A. G., Coard, S. I., Fine, M., & Rudy, D. (2018). The central toles of race and racism on reframing family systems theory: A consideration of choice and time. *Journal of Family Theory and Review, 10*, 419-433.
- Jegatheesan, B., Miller, P. J., & Fowler, S. A. (2010). Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families. *Focus on Autism and Other Developmental Disabilities, 25*(2), 98-109. <https://doi.org/10.1177/1088357610361344>
- Jennings, D. J., & Hanline, M. F. (2013). Developmental screening referrals: Child and family factors that predict referral completion. *Topics in Early Childhood Special Education, 33*(2), 102-111.
- Jones, C. P. (1999). Levels of racism: A theoretical framework and a gardner's tale. *American Journal of Public Health. 90*(8), 1212-1215.
- Jones, C. P., Jones, C. Y., Perry, G. S., Barclay, G., & Jones, A. C. (2009). Addressing the social determinates of children's health: A cliff analogy. *Journal of Health Care for the Poor and Underserved, 20*, 1-12.
- Jimenez, M. E., DuRivage, N. E., Bezpalko, O., Suh, A., Wade, R., . . . Fiks, A. G. (2017). A pilot randomized trial of a video patient decision aid to facilitate early intervention referrals from primary care. *Clinical Pediatrics, 56*(3), 268-277. <https://doi.org/10.1177/0009922816677038>

- Juarez, J. A., Marvel, K., Brezinski, K., Glanzer, C., Towbin, M., & Lawton, S. (2006). Bridging the gap: A curriculum to teach residents cultural humility. *Residency Education, 38*(2), 97-102.
- Kallio, H., Pietilä, A.-M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: Developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing, 72*(12), 2954-2965. doi: 10.1111/jan.13031
- Khetani, M. A., Richardson, Z., & McManus, B. M. (2017). Social disparities in early intervention service use and provider-reported outcomes. *Journal of Developmental Behavior, 38*(7), 501-509.
- Kids Count. (2015). Children who are not in excellent to very good health by race and ethnicity in the United States. *National Survey on Children's Health*. Retrieved from <https://datacenter.kidscount.org/data/tables/8825-children-who-are-not-in-excellent-or-very-good-health-by-race-and-ethnicity?loc=1&loct=1#detailed/1/any/false/1021,18,14/10,11,9,12,1,185,13/17686,17687>
- Kids Count. (2012). Children under the age of 6 who received a developmental screening in Texas. *National Survey on Children's Health*. Retrieved from <https://datacenter.kidscount.org/data/tables/9815-children-under-age-6-who-received-a-developmental-screening#detailed/2/45/false/1021/any/19105,19104>
- Kim, J. (2012). *Defining and assessing parent empowerment and its relationship to academic achievement using the national household education survey: A focus on marginalized parents*. Available from ProQuest Dissertations & Theses Global, University of Maryland, University Park.

- Kincaid, A. P., & Sullivan, A. L. (2017). Parsing the relations of race and socioeconomic status in special education disproportionality. *Remedial and Special Education, 38*(3), 159-170. <https://doi.org/10.1177/0741932516671199>
- Ladson-Billings, G. (1995). Toward a critical race theory of education. *Teachers College Record, 97*(1), 47-68.
- Ladson-Billings, G. (1998). Just what is critical race theory and what's it doing in a nice field like education? *International Journal of Qualitative Studies in Education, 11*(1), 7-24.
- Ladson-Billings, G. (2005). The evolving role of Critical Race theory in educational scholarship. *Race Ethnicity and Education, 8*, 115-119.
- Lau, A. S. (2006). Making the case for selective and directed cultural adaptations of evidence-based treatments: Examples from parent training. *American Psychological Association, 13*(4), 295-310.
- Leahy-Warren, P., Mccarthy, G., & Corcoran, P. (2011). Postnatal depression in first-time mothers: Prevalence and relationships between functional and structural social support at 6 and 12 weeks postpartum. *Archives of Psychiatric Nursing, 25*(3), 174-184.
- Lester, J. N., & Andres, A. D. (2014). Complicating translation: Children with refugee status and special education testing. *NYS TESOL, 2*(1), 25-38.
- Liebman, J. (2018). Using data to more rapidly address difficult U.S. social problems. *The Annals of the American Academy, 67*, 166-181.
- Lopez, K., Magaña, S., Morales, M., & Iland, E. (2019). Parents taking action: Reducing disparities through a culturally informed intervention for Latinx parents of children with autism. *Journal of Ethnic & Cultural Diversity in Social Work, 28*(2), 1-19. doi: 10.1080/15313204.2019.1570890

- Lutenbacher, M., Karp, S., Ajero, G., Howe, D., & Williams, M. (2005). Crossing community sectors: Challenges faced by families of children with special health care needs. *Journal of Family Nursing, 11*(2), 162-182.
- Macy, M., Marks, K., & Towle, A. (2014). Missed, misused, or mismanaged: Improving early detection systems to optimize child outcomes. *Topics in Early Childhood Special Education, 34*(2), 94-105. <https://doi.org/10.1177/0271121414525997>
- Magaña, S., Parish, S. L., Rose, R. A., Timberlake, M., & Swaine, J. G. (2012). Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellectual Development Disabilities, 50* (4), 287-299.
- Magnusson, D. M., Minkovitz, C. S., Kuhlthau, K. A., Caballero, T. M., & Mistry, K. B. (2017). Beliefs regarding developmental and early intervention along low-income African Americans and Hispanics mothers. *Pediatrics, 140*(5), 2017-2059.
- Mandell, D.S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health. 99*(3), 493-498.
- Mandell, D.S., Ittenbach, R.F., Lecy, S.E., & Pinto-Martin, J.A. (2007). Disparities in diagnosis received prior to a diagnosis of autism spectrum disorder. *Journal of Autism and Developmental Disorder, 37*(9), 1795-1802
- Marks K. P., Griffen, A. K., Herrera, P., Macias, M. M., Rice, C., & Robinson, C. (2015). Systemwide solutions to improve early intervention for developmental-behavioral concerns. *Pediatrics Perspectives, 136*(6), 1492.
- Marshall, D. (2019). COPAA victorious lawsuit against secretary DeVos. *Council of Parent Attorneys and Advocates*. <https://www.copaa.org/news/441156/COPAA-victorious-in-lawsuit-against-Secretary-DeVos-ED.htm>

- Mbwilo, G.S.K., Smide, B., & Aarts, C. Family perceptions in caring for children and adolescents with mental disabilities: A qualitative study from Tanzania. *Tanzania Journal of Health Research*. 12(2), 1-12.
- McHatton, A. P., & Correa, V. (2005). Stigma and discrimination: Perspectives from Mexican and Puerto Rican mothers of children with special needs. *Topics in Early Childhood and Special Education*, 25(3), 131-142.
- McLean, M., Sandall, S. R., & Smith, B. J. (2016) A history of early childhood special education. In B. Reichow, B. Boyd, E. Barton, & S. Odom (Eds.), *Handbook of early childhood special education* (pp. 3-19). New York: Springer. [https://doi.org/10.1007/978-3-319-28492-7\\_1](https://doi.org/10.1007/978-3-319-28492-7_1)
- McManus, B. M., Magnusson, D., & Rosenberg, S. (2014). Restricting state part c eligibility policy is associated with lower early intervention utilization. *Maternal Child Health Journal*, 18, 1031-1037.
- McPhee, C., Jackson, M., Bielick, S., Masterton, M., Battle, D., . . . Medway, R. (2018). *National Household Education Surveys Program of 2016: Data File User's Manual* (NCES 201 -100). Washington, DC: U.S. Department of Education. <https://nces.ed.gov/pubs2018/2018100.pdf>
- Merriam, S. B., & Caffarella, R. S. (1999). *Learning in adulthood: A comprehensive guide*. Hoboken, NJ: John Wiley & Sons.
- Merriam, S. B., Cafarella, R. S., & Baumgartner, L. M. (2007). *Learning in adulthood: A comprehensive guide* (3rd ed.). Hoboken, NJ: John Wiley & Sons
- Merriam-Webster dictionary* (2019). Springfield, MA: Merriam-Webster, Inc.
- Metzi, J. M., & Roberts, D. E. (2014) Structural competency meets structural racism: Race, politics, and the structure of medical knowledge. *AMA Journal of Ethics*, 16(9), 674-690.

- Mezirow, J. (1991). Transformation theory and cultural context: A reply to Clark and Wilson. *Adult Education Quarterly*, 41, 188-192.
- Mezirow, J. (2000). Learning to think like an adult. In J. Mezirow & Associates (Ed.), *Learning as transformation: Critical perspectives on a theory in progress*. San Francisco: Jossey- Bass.
- Mezirow, J., & Associates. (1990). *Fostering critical reflection in adulthood: A guide to transformative and emancipatory learning*. San Francisco: Jossey-Bass.
- Morgan P. L., Farkas, G., Hillemeier, M. M., Li, H., Hung Pun, W., & Cook, M. (2017). Cross-cohort evidence of disparities in service receipt for speech or language impairments. *Exceptional Children*, 84(1), 27-41.
- Morgan P. L., Farkas, G., Hillemeier, M. M., & Maczuga, S. (2009). Risk factors for learning-related behavior problems at 24 months of age: Population-based estimates. *Journal of Abnormal Child Psychology*, 37, 401-413.
- Morgan P. L., Farkas, G., Hillemeier, M. M., & Maczuga, S. (2012). Are minority children disproportionately represented in early intervention and early childhood special education? *Educational Researcher*, 41(9), 339-351.
- Morgan, P. L., Farkas, G., Hillemeier, M. M., & Maczuga, S. (2017). Replicated evidence of racial and ethnic disparities in disability identification in U.S. schools. *Educational Researcher*, 20(10), 1-18.
- Morgan P. L., Farkas, G., Hillemeier, M. M., Mattison, R., Maczuga, S., . . . Cook, M. (2015). Minorities are disproportionately underrepresented in special education: Longitudinal evidence across five disability conditions. *Educational Researcher*, 44, 278-292.

- Muschkin, C.G., Ladd, H.F., & Dodge, K.A. (2015). Impact of north carolina's early childhood initiatives on special education placements in third grade. *Educational Evaluation and Policy Analysis*. 20(10), 1-23.
- Nachshen J. S. (2005) Empowerment and families: building bridges between parents and professionals, theory and research. *Journal on Developmental Disabilities*,2, 67-75.
- Nachshen, J. S. & Minnes, P. (2005) Empowerment in parents of school aged children with and without developmental disabilities. *Journal of Intellectual Disability Research*, 49, 889-904.
- National Center for Education Statistics. (2017). Children and youth with disabilities. *The Condition of Education*. [https://nces.ed.gov/programs/coe/pdf/Indicator\\_CGG/coe\\_cgg\\_2017\\_05.pdf](https://nces.ed.gov/programs/coe/pdf/Indicator_CGG/coe_cgg_2017_05.pdf)
- National Center for Education Statistics. (2016). *National households education surveys program 2016*. U.S. Department of Education. Retrieved from <https://nces.ed.gov/pubs2018/2018100.pdf>
- National Center on Birth Defects and Developmental Disabilities. (2020). *Trends in the prevalence of developmental disabilities in U. S. children, 1997-2008*. Centers for Disease Control and Prevention. Retrieved from: <https://www.cdc.gov/ncbddd/developmentaldisabilities/features/birthdefects-dd-keyfindings.html>
- National Women's Law Center. (2017). A snapshot of working mothers. Fact sheet. Retrieved from <https://nwlc.org/wp-content/uploads/2017/04/A-Snapshot-of-Working-Mothers.pdf>
- Noonan, A. S., Velasco-Mondragon, H. E., & Wagner, F. A. (2016) Improving the health of African Americans in the USA: An overdue opportunity for social justice. *Public Health Review*, 37(12). doi: 10.1186/s40985-016-0025-4

- Oakeshott, M. (1962). *Rationalism in politics*. London: Methuen.
- Obeid, R., Bisson, J.B., Cosenza, A., Harrison, A. J., James, F., . . . Gillespie-Lynch, K. (2021). Do implicit and explicit racial biases influence autism identification and stigma? An implicit association test study. *Journal of Autism and Developmental Disorders*, 51(1), 106-128. <https://doi-org.ezp.twu.edu/10.1007/s10803-020-04507-2>
- Office of Special Education Projects. (2018a). U.S. Department of Education issues findings in Texas Individuals with Disabilities Education Act monitoring. U.S. Department of Education. <https://www.ed.gov/news/press-releases/us-department-education-issues-findings-texas-individuals-disabilities-education-act-monitoring>
- Office of Special Education Projects. (2018b). Part C of individuals with disabilities education act: Final guidelines and nonregulatory guidance. U.S. Department of Education. Retrieved from [https://sites.ed.gov/idea/files/Final\\_Regulations\\_Part\\_C\\_Guidance.pdf](https://sites.ed.gov/idea/files/Final_Regulations_Part_C_Guidance.pdf)
- Ogbu, J. U. (2003). *Black American students in an affluent suburb*. Mahwah, NJ: Lawrence Erlbaum Associates Publisher.
- Parish, S. L., & Rose, R. A. (2010). TANF's impact on low-income mothers raising children with disabilities. *Council for Exceptional Children*, 76(2), 234-253.
- Pescosolido, B. A., & Martin J. K. (2015). The stigma complex. *Annual Review Social*. (41), 87-116.
- Pitre, A., Allen, T., & Pitre, E. (2015). *Multicultural education for educational leaders: Critical race theory and antiracist perspective*. Lanham, MD: Rowman & Littlefield.

- Poppe, R. (2018). Texas Education Agency faces loss of millions in special education funding. Texas Public Radio. <https://www.tpr.org/post/texas-education-agency-faces-loss-millions-special-education-funding>
- Raj, C. (2015). The gap between rights and reality: The intersection of language, disability, and educational opportunity. *Temple Law Review*, 283, 285-336.
- Ramey, C. T., & Ramey, S. L. (1998). Early intervention and early experience. *American Psychologist*, 53(2), 109-120.
- Raspa, M., Levis, D. A., Kish-Doto, J., Wallace, I., Rice, C., . . . Wolf, R. B. (2015). Examining parents' experiences and information needs regarding early identification of developmental delays: Qualitative research to inform a public health campaign. *Journal of Behavioral Pediatrics*, 36(8), 575-585.
- Rawlett, K.E. (2014). Journey from self-efficacy to empowerment. *Health Care*, 2(1), 1-9.
- Resch, J.A., Mireles, G., Benz, M.R., & Grenwelge, C., Peterson, R., & Zhang, D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology*, 55(2), 139-150.
- Rosenberg, S. A., Ellison, M. C., Fast, B., Robinson C. C., & Lazar, R. (2013). Computing theoretical rates of part c eligibility based on developmental delays. *Maternal Child Health Journal*, 17, 384-390.
- Rosenberg, S. & Robinson, C. (2004) Out-of-home placement for young children with developmental and medical conditions. *Children and Youth Services Review*, 26, 711-723.

- Rosenberg, S. A., Robinson, C. C., Shaw, E. F., & Ellison, M. C. (2013). Part C early intervention for infants and toddlers: Percentage eligible versus served. *Pediatrics*, *131*(1), 38-46.
- Rosenberg, S. A., Zhang, D., & Robinson, C. (2008). Prevalence of developmental delays and participation in early intervention services of young children. *American Academy of Pediatrics*, *126*(6), 1503-1509.
- Salas, J. (1993). *Improvising real life*. New Paltz, NY: Tusitala.
- Salas, R., Steele, K., Lin, A., Loe, C., Gauna, L., & Jafar-Nejad, P. (2009). Playback theatre as a tool to enhance communication in medical education. *Medical Education Online*. Retrieved from <http://www.med-ed-online.net>
- Samuel, P. S., Hobden, K. L., LeRoy, B. W., & Lacey, K. K. (2012). Analyzing family service needs of typically underserved families in the USA. *Journal of Intellectual Disability Research*, *56*(1), 111-128.
- Samuel, P. S., Marsack, C. N., Johnson, L. A., LeRoy, B. W., Lysack, C. L., & Lichtenberg, P. A. (2017). Impact of grandchild caregiving on African American grandparents. *Occupational Therapy Health Care*, *31*(1), 1-19.
- Sand, N., Silverstein, M., Glascoe, F. P., Gupta, V. B., Tonniges, T. P. & O'Connor, K. G. (2005). Pediatricians' reported practices regarding developmental screening: Do guidelines work? Do they help? *Pediatrics*, *116*(1), 174-179.
- Scarborough, A., Hebbeler, K., Spiker, D., & Simeonsson, R.J (2011). Using survival analysis to analyze developmental achievements of early intervention recipients at kindergarten. *Infants and Young Children*, *24*(2), 133-152.
- Scarborough, A., Spiker, D., Sangeeta, M., Hebbeler, K., Bailey, D., & Simeonsson, R. J. (2004). A national look at children and families entering early intervention. *Council for Exceptional Children*, *70*(4) 469-483.

- Schwandt, T. (2000). Three epistemological stances for qualitative inquiry: Interpretivism, hermeneutics, and social constructivism. *Handbook of Qualitative Research*, 1(1) 189-214.
- Schwarzenberg, S. J., Georgieff, M. K., & Committee on Nutrition. (2018). Advocacy for improving nutrition in the first 1000 days to support childhood development and adult health. *Pediatrics*, 141(2), e20173716. doi: <https://doi.org/10.1542/peds.2017-3716>
- Seeberger, C. (2019). Nearly two-thirds of mothers continue to be family breadwinners, Black mothers are far more likely to be breadwinners. *Center for American Progress*. Retrieved from: <https://www.americanprogress.org/press/release/2019/05/10/469660/release-nearly-two-thirds-mothers-continue-family-breadwinners-black-mothers-far-likely-breadwinners/>
- Shackelford, J. (2006). State and jurisdictional eligibility definitions for infants and toddlers with disabilities under IDEA. *National Early Childhood TA Center*, 21, 1-16. <https://ectacenter.org/~pdfs/pubs/nnotes21.pdf>
- Shen, M. J., Peterson, E. B., Costas-Muñiz, R., Hernandez, M. H., Jewell, S. T., . . . Bylund, C. L. (2018). The effects of race and racial concordance on patient-physician communication: A systematic review of the literature. *Journal of Racial and Ethnic Health Disparities*, 5(1), 117-140. <https://doi.org/10.1007/s40615-017-0350-4>
- Shields, C., Bishop, R., & Mazawi, A. (2005). *Pathologizing practices: The impact of deficit thinking on education*. New York: P. Lang.
- Simeone, R. M., Shapiro-Mendoza, C. K., Meaney-Delman, D., Petersen, E. E., Galang, R. R., Oduyebo, T., Rivera-Garcia, B., Valencia-Prado, M., Newsome, K. B., Pérez-Padilla, J., Williams, T. R., Biggerstaff, M., Jamieson, D. J., Honein, M. A.

- (2016). Zika and pregnancy working group: Possible zika virus infection among pregnant women - united states and territories. *Morbidity and mortality weekly report*, 65(20), 514–519.
- Skiba, R. J., Artiles, A. J., Kozleski, E. B., Losen, D. J., & Harry, E. G. (2016). Risks and consequences of oversimplifying educational inequities: A response to Morgan et al. (2015). *Educational Researcher*, 45(3), 221-225.
- Sontag, J. C., & Schacht, R. (1994). An ethnic comparison of parent participation and information needs in early intervention. *Exceptional Children*, 60(5), 422-433.
- Solomon, B. B. (1987). Empowerment: Social work in oppressed communities. *Journal Social Work Practice*, 2, 79-91.
- Sowell, T. (1967). Marx's capital after one hundred years. *The Canadian Journal of Economics and Political Science/Revue Canadienne D'Economie et de Science Politique*, 33(1), 50-74. doi:10.2307/139860
- Spring, J. (2006). *American education*. New York: Mc-Graw-Hill.
- Stern, S. M. (2003). *Effective state standards for U.S. history: A 2003 report card*. Thomas B. Fordham Institute. [https://edex.s3-us-west-2.amazonaws.com/publication/pdfs/History\\_Standards2003\\_10.pdf](https://edex.s3-us-west-2.amazonaws.com/publication/pdfs/History_Standards2003_10.pdf)
- Stone, J.H. (2005). *Culture and disability: Providing culturally competent services*. Thousand Oaks, CA: Sage Publications.
- Swaby, A. (2018). Texas may have again illegally reduced special education funding. *The Texas Tribune*. <https://www.texastribune.org/2018/11/08/texas-may-have-again-illegally-reduced-special-education-funding/>
- Swanson, J., Raab, M., & Dunst, C. J. (2011). Strengthening family capacity to provide young children everyday natural learning opportunities. *Journal of Early Childhood Research*, 9(1), 66-80.

- Texas Care for Children and Methodist Healthcare Ministries of South Texas, Inc. (2016). Left out: The impact of state cuts to early childhood intervention (ECI) for young Texas kids with disabilities. *Texas Care for Children*, 1-28.
- Texas Health and Human Resources. (2018). ECI data and reports: ECI consumer profiles. *Texas Health and Human Resources*.
- Texas Health and Human Services Department. (n.d.). Early childhood intervention services. Retrieved from: <https://hhs.texas.gov/services/disability/early-childhood-intervention-services>
- Texas Health and Human Services Rider 98, (2020). Early childhood intervention services implementation plan for maximizing funding progress report. *Health and Human Services Commission*. Retrieved from <https://hhs.texas.gov/reports/2020/03/early-childhood-intervention-services-implementation-plan-maximizing-funding-progress-report>
- Texas Health and Human Services Commission and Texas Education Agency. (2019). Memorandum of understanding. *Texas Education Agency*. Retrieved from [https://tea.texas.gov/sites/default/files/TEA%20%20HHSC%20ECI%20-%20MOU\\_0.pdf](https://tea.texas.gov/sites/default/files/TEA%20%20HHSC%20ECI%20-%20MOU_0.pdf)
- Turnbull, A. P., & Turnbull, H. R. (2002). From the old to the new paradigm of disability and families: Research to enhance family quality of life outcomes. In C. D. Lavelly, A. Cranston-Gringas, & E. L. Taylor (Eds.), *Rethinking professional issues in special education* (pp 83-117). Westport, CT: Ablex.
- Twardzik, E., MacDonald, M. & Dixon-Ibarra, A. (2017). The relationship between state lead agency and enrollment into early intervention services. *Journal of Early Intervention*, 39(3) 253-263.

- United Census Bureau Population Division Snapshot. (2019). Child population by race in the united states. *Kids Count Data Center*. Retrieved <https://datacenter.kidscount.org/data/tables/103-child-population-by-race#detailed/1/any/false/37,871,870,573,869,36,868,867,133,38/68,69,67,12,70,66,71,72/423,424>
- U.S. Department of Education. (2018a). Fiscal years 2019-2021 state tables for the U.S. Department of Education. Retrieved from <https://www2.ed.gov/about/overview/budget/statetables/index.html>
- U.S. Department of Education. (2018b). Early Childhood Program Participation Survey. *National Household Education Surveys Program*. Retrieved from: [https://nces.ed.gov/programs/digest/d18/tables/dt18\\_202.40.asp](https://nces.ed.gov/programs/digest/d18/tables/dt18_202.40.asp)
- U.S. Department of Education. (2019). *41st Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2019*. Washington, DC: Government Printing Office.
- Vail, C. O., Lieberman-Betz, R. G., & McCorkle, L. S. (2018). The impact of funding on Part C systems: Is the tail wagging the dog? *Journal of Early Intervention, 40*(3), 229-245. <https://doi.org/10.1177/1053815118771388>
- Vavrus, M. (2015). *Diversity and education: A critical multicultural approach*. New York: Teachers College Press.
- Wagner, K., & Wright Burak, E. (2017). Further state funding cuts and uncertain federal landscape threaten care for young children in Texas with disabilities and developmental delays. Georgetown University Center for Children and Families. Retrieved from <https://ccf.georgetown.edu>
- Wagerman, K., & Brooks, T. (2017). Medicaid and CHIP help address racial/ethnic disparities in children's health. Georgetown University Health Policy Institute:

- Center for Children and Families. Retrieved from <https://ccf.georgetown.edu/2017/04/26/medicaid-and-chip-help-address-raciaethnic-disparities-in-childrens-health/>
- Wallhagen, M. I. (2010). The stigma of hearing loss. *Gerontologist, (50)*, 66-75.
- Waters, M. C., Kasinita, P., & Asad, A. L. (2014). Immigrants and African Americans. *The Annual Review of Sociology, 40*, 369-390.
- West, C. (2012). *Remaking America: From poverty to prosperity panel discussion*. George Washington University. Panel Discussion. Retrieved from <https://youtube/yZ4A4K18hOk>
- Williams, M. E., Zamora, I, Akinsilo, O., Chen, A. H., & Kanne, M. P. (2018). Broad developmental screening misses young children with social-emotional needs. *Clinical Pediatrics, 57(4)*, 844-849.
- Worcester, J. A., Nesman, T. M., Mendez, L. M. R., & Keller, H. R. (2008). Giving Voice to Parents of Young Children with Challenging Behavior. *Exceptional Children, 74(4)*, 509–525. <https://doi.org/10.1177/001440290807400406>
- Yen, H. (2009, Dec. 16). White Americans' majority to end by mid-century. *The Seattle Times*. Retrieved <https://www.seattletimes.com/seattle-news/politics/white-americans-majority-to-end-by-mid-century/>
- Yockelson, S., Linder, C., & Asman, R. (2016). A collaborative approach to early identification and referral of children who are in family childcare settings, birth to five, born to teenage mothers. *Journal of Intellectual Disability, 3(4)*, 205-212.
- Zero to Three. (2020). How covid-19 is impacting babies and families. *Think Babies*. <file:///Users/erikaaziegbe/Downloads/How%20COVID-19%20Is%20Impacting%20Babies%20and%20Families.pdf>

- Zhang, C., & Bennett, T. (2003). Facilitating the meaningful participation of culturally and linguistically diverse families in the IFSP and IEP process. *Focus on Autism and Other Developmental Disabilities, 18*(1), 51-59.
- Zimmerman, M. A. (1995). Psychological empowerment: Issues and illustrations. *American Journal of Community Psychology, 23*, 581-599.
- Zimmerman, M. A., & Rappaport, J. (1988). Citizen participation, perceived control, and psychological empowerment. *American Journal of Community Psychology, 16*, 725-750. doi:10.1007/ bf00930023.
- Zirkel, P. A. (2014). Legal issues under IDEA. In L. A. Wilkinson (Ed.), *School psychology book series. Autism spectrum disorder in children and adolescents: Evidence-based assessment and intervention in schools* (pp. 243-257). Washington, DC: American Psychological Association.
- Zirkel, P. A. (2015). Special education law: Illustrative basics and nuances of key IDEA components. *Teacher Education and Special Education, 38*(4), 263-275.
- Zirkel, P. A. (2017). Child find under the IDEA: An empirical analysis of the judicial case law. *National Association of School Psychologist, 45*(7), 4-6.
- Zuckerman, K. E., Lindly, O. J., Reyes, N. M., Chavez, A. J., Cobian, M., . . . Smith, K. A. (2018). Parent perceptions of community autism spectrum disorder stigma: Measure validation and associations in a multi-site sample. *Journal of Autism Developmental Disorders, 48*, 3199-3209.
- Zuckerman, K. E., Mattox, K. M., Sinche, B. K., Blaschke, G. S., & Bethell, C. (2014). Racial, ethnic and language disparities in early childhood developmental behavioral evaluations: A narrative review. *Clinical Practices, 53*(7), 619-631.

Zuckerman, K. E., Sinche, B., Mejia, A., Cobian, M., Becker, T., & Nicolaidis, C.  
(2014). Latino parents' perspectives of barriers of autism diagnosis. *Academic  
Pediatrics, 14*(3), 301-308.

APPENDIX A:  
PERCEIVED BARRIERS TO ACCESS EARLY INTERVENTION IN NEW  
JERSEY—PARENT

(Giordiano, 2008)

(Major barrier=3, Minimal barrier= 2, No barrier=1).

1. I was not aware of the early intervention program.
2. I was told there are no educational services for children under 3 years of age.
3. Other people did not share my concern/
4. I was told to “wait and see”; my child may outgrow the delay.
5. I had concerns about my child’s development but did not know how to ask for help.
6. I did not want my child places in the system and to “labeled.”
7. I did not want professional in my home
8. I did not want my whole family involved in my child’s treatment
9. I tried to access early intervention services but found the process confusing.
10. I tried to access early intervention services but found the process frustrating.
11. I did not think my child would be eligible for early intervention services.
12. My child was evaluated in New Jersey and was determined to be ineligible for services.
13. There were other events going on within my family that needed my attention. (for example, financial concerns, another child with needs, marital discord, work conflicts, etc.)
14. I though early intervention would be too expensive.
15. I found out that I could not afford early intervention services.
16. I was told about my child’s delay but did not think it was severe enough to require services.
17. I wanted my child to have time to outgrow the delay.
18. I wanted my child to be in early intervention, but other family members did not agree.
19. I believed my child’s delay was due to cultural differences.
20. I did not want early intervention services for my child.
21. I did not think my child would benefit from early intervention.
22. I did not have enough information about early intervention to make an informed decision.
23. A language barrier made getting early intervention services difficult.

APPENDIX B:  
PERCEIVED BARRIERS TO ACCESS EARLY INTERVENTION IN NEW  
JERSEY—PROFESSIONALS

(Giordiano, 2008)

(Major barrier=3, Minimal barrier= 2, No barrier=1).

1. Parents are not aware of early intervention programs.
2. Parents are told that there are no additional services for children under 3 years.
3. Other people do not share the parent's concerns.
4. Parents are told to "wait and see"; their child may outgrow the delay.
5. Parents have a concern about their child's development, but do not know who to ask for help.
6. Parents do not want the child placed in the system and then "labeled".
7. Parents do not want professionals in their home.
8. Parents do not want the whole family involved in the child's treatment.
9. Parents try to access early intervention services, but find the process confusing.
10. Parents try to access early intervention services but find the process frustrating.
11. Parents do not think the child will be eligible for early intervention services.
12. The child has been tested outside of New Jersey and the parent was told that s/he was not eligible.
13. The child is evaluated in New Jersey and was determined to be ineligible for services.
14. There are other events going on within the family that needed attention. (For examples, financial concerns, another child with special needs, marital discord, work conflicts, etc.)
15. Parents think early intervention will be too expensive.
16. Parents find out that they cannot afford early intervention services.
17. Parents are told about the child's delay, but do not think it is severe enough to require services.
18. Parents want the child to have time to outgrow the delay.
19. Parents want the child to be in early intervention, but other family members do not.
20. Parents believe the child's delay is due to cultural differences.

21. Parents do not want early intervention services for their child.
22. Parents do not think the child will benefit from early intervention.
23. Parents do not have enough information about early intervention to make an informed decision.
24. A language barrier makes getting early intervention services difficult.
25. Do you feel that there are other things that are barriers to families receiving early intervention services for their child? Please list them here:

APPENDIX C:  
EMPOWERMENT QUESTIONNAIRE

Parental Empowerment: Construct Validity and Reliability of a Dutch Empowerment  
Questionnaire (EMPO) (Damen et al., 2016)

(1=disagree completely, 2=disagree, 3=don't disagree/agree, 4= agree, and 5=agree completely)

**Intrapersonal**

- 1) I am in control of myself,
- 2) I am in control of my life,
- 3) I don't easily get stressed,
- 4) I feel confident about the future.

**Interactional**

- 1) I make use of advice or support from people around me, if necessary,
- 2) I always fight for what matters that are important to me,
- 3) I correct the behavior of my child when necessary,
- 4) I immediately act when there are problems with my child,
- 5) I look for solutions myself when I have a problem with my child

**Behavioral**

- 1) I have control over the behavior of my child,
- 2) My child always behaves the way I want him/her to,
- 3) I am very much in control of the raising of my child

APPENDIX D:

INFORMED CONSENT TO PARTICIPATE IN RESEARCH

**Welcome to the “*Barriers to Access and Utilize Early Intervention Services Inventory (BAUEIS)*,” a study that focuses on finding the factors that prevent parents from accessing early intervention services. Please read the consent form carefully and know that your participation is voluntary, and you may refuse to participate, or you may decide to stop your participation at any time. If you understand the statements below and freely consent to participate in this study, please sign/date the form.**

**Title: Barriers that prevent black families from accessing and utilizing early intervention services.**

**Faculty Sponsor: Elizabeth Anne Beavers, Ph.D.**

**Student Investigator(s): Erika Aziegbe**

**PURPOSE OF THE STUDY**

The purpose of this research is to explore the perceived barriers that prevent black families with mixed-immigration statuses from accessing and utilizing early intervention services.

## **PROCEDURES**

The research procedures are as follows: Respondents will be asked to participate in a face-to-face survey. The interviewer will guide the respondents through the survey protocol. The *parental barriers to accessing and utilizing early intervention services* survey will take 30 minutes to complete and will be conducted face-to-face or through a website link with video prompts. Respondents will be able to complete the surveys by their cell phone, face-to-face or online. Questions are closed and open-ended which allows for respondents to provide more elaborate responses on factors they think may be a barrier to accessing and utilizing early intervention services.

## **EXPECTED DURATION**

The total anticipated time commitment will be a total of 20 minutes. The data will be collected over a five-week period.

## **RISKS OF PARTICIPATION**

There are no anticipated risks associated with participation in this project and a respondent will remain anonymous.

## **BENEFITS TO THE SUBJECT**

There is no direct benefit received from your participation in this study, but your participation will help the investigator(s) better understand the barriers that immigrant families face when trying to access and utilize early intervention services. By doing so, the implications from the study could help the greater immigrant community receive services that they are eligible to for to help their child from birth to three years of age.

## **CONFIDENTIALITY OF RECORDS**

Every effort will be made to maintain the confidentiality of your study records. The data collected from the study will be used for educational and publication purposes, however, you will not be identified by name. For federal audit purposes, the participant's documentation for this research project will be maintained and safeguarded by the by the student researcher for a minimum of three years after completion of the study. After that time, the participant's documentation may be destroyed.

## **FINANCIAL COMPENSATION**

There is no financial compensation to be offered for participation in the study.

## **INVESTIGATOR'S RIGHT TO WITHDRAW PARTICIPANT**

The investigator has the right to withdraw you from this study at any time.

## **CONTACT INFORMATION FOR QUESTIONS OR PROBLEMS**

If you have additional questions during the course of this study about the research or any related problem, you may contact the Student Researcher, Erika Aziegbé at phone number 713-321-0166 or by email at [aziegbé5722@uhcl.edu](mailto:aziegbé5722@uhcl.edu).

The Faculty Sponsor Elizabeth Beavers, Ph.D., may be contacted at phone number 281-283-7600 or by email at [beaversea@uhcl.edu](mailto:beaversea@uhcl.edu).

**SIGNATURES:**

Your signature below acknowledges your voluntary participation in this research project. Such participation does not release the investigator(s), institution(s), sponsor(s) or granting agency(ies) from their professional and ethical responsibility to you. By signing the form, you are not waiving any of your legal rights.

The purpose of this study, procedures to be followed, and explanation of risks or benefits have been explained to you. You have been allowed to ask questions and your questions have been answered to your satisfaction. You have been told who to contact if you have additional questions. You have read this consent form and voluntarily agree to participate as a subject in this study. You are free to withdraw your consent at any time by contacting the Principal Investigator or Student Researcher/Faculty Sponsor. You will be given a copy of the consent form you have signed.

Subject's printed name: \_\_\_\_\_

Signature of Subject: \_\_\_\_\_

Date: \_\_\_\_\_

Using language that is understandable and appropriate, I have discussed this project and the items listed above with the subject.

Printed name and title: \_\_\_\_\_

Signature of Person Obtaining Consent: \_\_\_\_\_

Date: \_\_\_\_\_

**THE UNIVERSITY OF HOUSTON-CLEAR LAKE (UHCL) COMMITTEE FOR PROTECTION OF HUMAN SUBJECTS HAS REVIEWED AND APPROVED THIS PROJECT. ANY QUESTIONS REGARDING YOUR RIGHTS AS A RESEARCH SUBJECT MAY BE ADDRESSED TO THE UHCL COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS (281-283-3015). ALL RESEARCH PROJECTS THAT ARE CARRIED OUT BY INVESTIGATORS AT UHCL ARE GOVERNED BY REQUIREMENTS OF THE UNIVERSITY AND THE FEDERAL GOVERNMENT. (FEDERALWIDE ASSURANCE # FWA0000**

APPENDIX E:  
BAUECISI SURVEY INSTRUMENT

UNIVERSITY OF HOUSTON - CLEAR LAKE

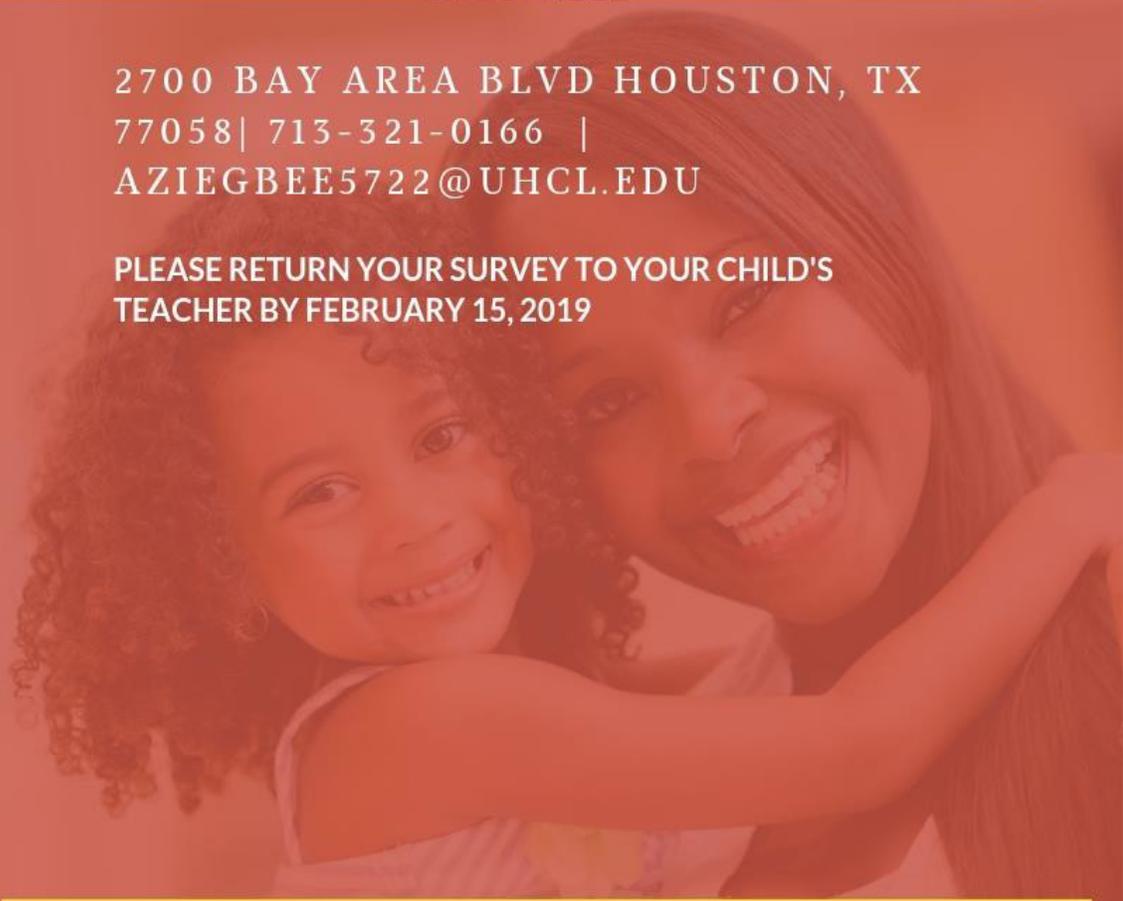
BARRIERS ENCOUNTERED TO ACCESS  
EARLY INTERVENTION SERVICES

SURVEY

LISTENING TO YOU IN ORDER TO MAKE SERVICES  
ACCESSIBLE

2700 BAY AREA BLVD HOUSTON, TX  
77058 | 713-321-0166 |  
AZIEGBEE5722@UHCL.EDU

PLEASE RETURN YOUR SURVEY TO YOUR CHILD'S  
TEACHER BY FEBRUARY 15, 2019



**Directions: The purpose of this survey is to identify the barriers that parents encounter when accessing early intervention services. Please know ALL responses are anonymous and will help to provide insight to better meet your needs.**

**BARRIERS ENCOUNTERED WHEN TRYING TO ACCESS  
EARLY INTERVENTION SERVICES**

**START HERE**

**1) From your child's last wellness appointment at the pediatrician, in general, how would you describe your child's health?**

*Choose one:*

- Excellent
- Very good
- Good
- Fair
- Poor

**2) Tell me about a time when you had a concern about your child and asked for help? *Describe in your own words:***

**3) Has a health or educational professional told you that your child has any of the following conditions?**

*Check all that apply:*

- A developmental delay
- An intellectual disability
- A speech or language impairment
- Autism
- Attention Deficit Disorder, ADD or ADHD
- A serious emotional disturbance

- Deafness or another hearing impairment
- Blindness or another visual impairment not corrected with glasses
- An orthopedic impairment
- Pervasive Developmental Disorder (PDD)
- A specific learning disability
- Traumatic brain injury
- Another health impairment lasting 6 months or more

4) **How do you know when your child may have a developmental delay or disability? Describe in your own words:**

5) **Who was the first to notice a concern with your child?**

*Choose one:*

- Parent
- Caregiver
- Medical doctor
- Education professional

6) **Do you think children can grow out of their developmental delay or disability?**

*Describe in your own words:*

- 7) Write about a time when your child needed additional help at school, daycare, babysitters house, Sunday school, etc. *Describe in your own words:*

- 8) What is your response when the teacher tells you that your child is struggling in school daycare, babysitters house, Sunday school, etc.? *Describe in your own words:*

## Section 2: Identify the Barriers

### START HERE

As a caregiver to a child with a disability think about the time before enrolling into a ECSE program to know if the following are barriers to you accessing early intervention services.

Rate if you experienced any of the following barriers as:

**2= Major Barrier, 1= Minimal Barrier, 0=No Barrier or N/A**

	<b>Major Barrier</b>	<b>Minimal Barrier</b>	<b>No Barrier</b>	<b>N/A</b>
1) I was not aware of the early intervention program.	2	1	0	N/A
2) I was told there are no educational services for children under 3 years of age.	2	1	0	N/A
3) Other people did not share my concern.	2	1	0	N/A
4) I was told to “wait and see”; my child may outgrow the delay.	2	1	0	N/A
5) I had concerns about my child’s development, but did not know how to ask for help.	2	1	0	N/A
6) I did not want my child places in the system and to “labeled.”	2	1	0	N/A

	Major Barrier	Minimal Barrier	No Barrier	N/A
7) I did not want professional in my home.	2	1	0	N/A
8) I did not want my whole family involved in my child's treatment.	2	1	0	N/A
9) I tried to access early intervention services, but found the process confusing.	2	1	0	N/A
10) I tried to access early intervention services, but found the process frustrating.	2	1	0	N/A
11) I did not think my child would be eligible for early intervention services.	2	1	0	N/A
12) My child was evaluated in Texas and was determined to be ineligible for services.	2	1	0	N/A
13) There were other events going on within my family that needed attention (i.e. immigration status, financial concerns, marital discord, work conflicts, etc.).	2	1	0	N/A
14) I found out that I could not afford early intervention services.	2	1	0	N/A
15) I thought early intervention would be too expensive.	2	1	0	N/A
16) I was told about my child's delay, but did not think it was severe enough to require services.	2	1	0	N/A
17) I wanted my child to have time to outgrow the delay.	2	1	0	N/A

---

<b>18) I did not want early intervention services for my child.</b>	2	1	0	N/A
---	---	---	---	-----

---

<b>19) I did not think my child would benefit from early intervention.</b>	2	1	0	N/A
--	---	---	---	-----

---

	Major Barrier	Minimal Barrier	No Barrier	N/A
<b>20) I did not have enough information about early intervention to make an informed decisions.</b>	2	1	0	N/A
<b>21) A language barrier made getting early intervention services difficult.</b>	2	1	0	N/A

**22) During the school year or shortly after birth of your child, has your family received any of the following?**

***Check all that apply:***

- *Notes and/or emails*, about early intervention
- *Notes and/or emails*, about school readiness
- *Phone calls*, about early intervention
- *Phone calls*, about school readiness

**23) Are these services provided by any of the following agencies?**

***Check all that apply:***

- Early intervention provider
- Your local school district (PPCD)
- Early or Head start program
- A doctor, clinic, or other health care provider

**24) At what age did you enroll your child in an early intervention program?**

***Choose one:***

- Birth
- 1
- 2
- 3
- Did not enroll

- 

**25) At what age did you enroll your child in a PPCD program?**

*Choose one:*

- 3
- 4
- 5
- Did not enroll

**Section 3: How empowered do you feel?**

**Directions: Please take a moment and rate your reaction or feeling about responding to challenges encountered with raising a child with a disability.**

**As a parent or guardian raising a child with special needs on any given school day, how would you rate yourself? Using a scale from:**

**1= Disagree completely 2=Disagree 3=Don't Disagree/Agree 4=Agree 5=Agree completely**

*Choose one:*

	Disagree Completely	Disagree	Don't Disagree/Agree	Agree	Agree Completely
1) I am in control of myself	1	2	3	4	5
I am in control of my life	1	2	3	4	5
2)	Disagree Completely	Disagree	Don't Disagree/Agree	Agree	Agree Completely
3) I don't get easily stressed	1	2	3	4	5
4) I feel confident about the future	Disagree Completely	Disagree	Don't Disagree/Agree	Agree	Agree Completely
	1	2	3	4	5

5)	I make use of advice or support from people around, if necessary	Disagree Completely 1	Disagree 2	Don't Disagree/Agree 3	Agree 4	Agree Completely 5
6)	I always fight for matters that are important to me	Disagree Completely 1	Disagree 2	Don't Disagree/Agree 3	Agree 4	Agree Completely 5
7)	I correct the behavior of my child when necessary	Disagree Completely 1	Disagree 2	Don't Disagree/Agree 3	Agree 4	Agree Completely 5
8)	I immediately act when there are problems with my child	Disagree Completely 1	Disagree 2	Don't Disagree/Agree 3	Agree 4	Agree Completely 5
9)	I look for solutions myself when I have a problem with my child	Disagree Completely 1	Disagree 2	Don't Disagree/Agree 3	Agree 4	Agree Completely 5
10)	I have control over the behavior of my child	Disagree Completely 1	Disagree 2	Don't Disagree/Agree 3	Agree 4	Agree Completely 5

	Disagree Completely	Disagree	Don't Disagree/Agree	Agree	Agree Completely
11) My child always behaves the way I want him/her to	1	2	3	4	5
	Disagree Completely	Disagree	Don't Disagree/Agree	Agree	Agree Completely
12) I am very much in control of the raising of my child	1	2	3	4	5

**Section 4: Tell Us About Yourself- All Responses Are *Anonymous***

**START HERE**

**1) Is the parent or guardian the one completing the survey of the child?**

*Choose one:*

- Biological parent
- Adoptive parent
- Stepparent
- Foster parent
- Grandparent
- Other guardian: \_\_\_\_\_

**2) For the mother of the child, what race does the person identify with:**

- Asian
- Black or African American
- Caucasian- white
- Hispanic, Latino or Spanish

**3) For the mother of the child, is the mother a citizen of the United States?**

*Choose one:*

- Yes, born in the United States or
- Yes, in One of the U.S. territories (Puerto Rico, Guam, American Samoa, U.S. Virgin Islands, or Mariana Islands or
- Yes, born abroad to a U.S. citizen parent (s) or
- Yes, citizen by naturalization
- If not, then where: \_\_\_\_\_

**4) For the mother or primary caregiver of the child, which of the following best describes the mother's employment status.**

*Choose one:*

- Employed for pay or income
- Self employed
- Unemployed or out of work
- Full-time student
- Stay at home parent
- Retired
- Disabled or unable to work

5) **For the mother or primary caregiver of the child, what level best describes your income.**

*Choose one:*

\_\_\_\_\$0 - \$20,000

\_\_\_\_\$20,001 - \$40,000

\_\_\_\_\$40,001 - \$60,000

\_\_\_\_\$60,001 - \$80,000

\_\_\_\_\$80,001 - \$100,000

\_\_\_\_\$100,001 +

6) **Do you make health and educational decisions for your child as a:**

*Choose one:*

- Single parent
- Married couple
- Foster parent
- Grandparent
- Custodial guardian
- Other guardian: \_\_\_\_\_

7) **For your child in the PPCD program, did they attend any of the following programs prior to enrollment in the school district:**

*Check all that apply:*

- Early intervention program- home based
- Early intervention program- childcare based
- Early or Head start program
- A doctor, clinic, or other health care provider
- Other, please explain: \_\_\_\_\_

8) **For the person completing this survey, where were you born?**

*Choose one:*

- One of the 50 United States or
- the District of Columbia or
- One of the U.S. territories (Puerto Rico, Guam, American Samoa, U.S. Virgin Islands, or Mariana Islands, or
- Another country, where?: \_\_\_\_\_

**9) Now that you live in the United States, how long have you resided here?**

***Choose one:***

- Less than 5 years
- 5-10 years
- More than 10 years

**10) At some point a person's immigration status could change. What is mother's current immigration status?**

***Choose one:***

- Current (As of date not expired, visitor, student, deferred action or non-status)
- Expired

Thank you for taking the time to complete the survey. Your responses will be helpful in knowing the barriers encountered when trying to access early childhood intervention services.

Erika Aziegbe

[Aziegbee5722@uhcl.edu](mailto:Aziegbee5722@uhcl.edu)

APPENDIX F  
PROFESSIONALS COVER LETTER



University  
of Houston  
Clear Lake

September 2019

Dear Medical Professional:

Greetings! You are being solicited to complete the *Barriers to Access and Utilize Early Childhood Intervention Services* survey. The purpose of this study is to explore the perceived barriers that prevent minority families from accessing and utilizing early intervention services. The data obtained from this study will not only allow UHCL's Education Department to gain further insight into early childhood intervention programs, but also to provide feedback on ways to enhance the child find practices in Texas.

Please try to answer all the questions. Filling out the attached survey is entirely voluntary, but answering each response will make the survey most useful. This survey will take approximately 5-10 minutes to complete and all of your responses will be kept completely confidential. No obvious undue risks will be endured, and you may stop your participation at any time. In addition, you will also not benefit directly from your participation in the study.

Your cooperation is greatly appreciated and your willingness to participate in this study is implied if you proceed with completing the survey. Your completion of the *Barriers to Access and Utilize Early Childhood Intervention Services* survey is not only greatly appreciated, but invaluable. If you have any further questions, please feel free to contact Dr. Elizabeth Ann Beavers ([beaversea@uhcl.edu](mailto:beaversea@uhcl.edu)) or myself ([aziegbee5722@uhcl.edu](mailto:aziegbee5722@uhcl.edu)).

Thank you!

Sincerely,  
Erika Aziegbe  
Doctoral Candidate  
University of Houston Clear Lake  
College of Education  
[aziegbee5722@uhcl.edu](mailto:aziegbee5722@uhcl.edu)

APPENDIX G  
PARENT COVER LETTER



University  
of Houston  
Clear Lake

September 2019

Dear Parent and/or Guardian:

Greetings! You are being solicited to complete the *Barriers to Access and Utilize Early Childhood Intervention Services* survey. The purpose of this study is to explore the perceived barriers that prevent minority families from accessing and utilizing early intervention services. The data obtained from this study will not only allow UHCL's Education Department to gain further insight into early childhood intervention programs, but also to provide feedback on ways to enhance the child find practices in Texas.

Please try to answer all the questions. Filling out the attached survey is entirely voluntary, but answering each response will make the survey most useful. This survey will take approximately 5-10 minutes to complete and all of your responses will be kept completely confidential. No obvious undue risks will be endured, and you may stop your participation at any time. In addition, you will also not benefit directly from your participation in the study.

Your cooperation is greatly appreciated and your willingness to participate in this study is implied if you proceed with completing the survey. Your completion of the *Barriers to Access and Utilize Early Childhood Intervention Services* survey is not only greatly appreciated, but invaluable. If you have any further questions, please feel free to contact Dr. Elizabeth Ann Beavers ([beaversea@uhcl.edu](mailto:beaversea@uhcl.edu)) or myself ([aziegbee5722@uhcl.edu](mailto:aziegbee5722@uhcl.edu)).

Thank you!

Sincerely,

Erika Aziegbe  
Doctoral Candidate  
University of Houston Clear Lake  
College of Education  
[aziegbee5722@uhcl.edu](mailto:aziegbee5722@uhcl.edu)

APPENDIX H  
QUALITATIVE INTERVIEW PROTOCOL  
PARENT

Demographics

1. Please, tell me little about yourself (name, age, number of children, employment)
2. Are you a member of any community organizations, club or church?
3. For your children's primary care, do you have a primary pediatrician or nurse practitioner?
4. How often do you go to the pediatrician?
5. How do you prepare for a doctor's appointment?
6. How do you prepare for when a service provider comes to give intervention services?

Barriers

1. How would you define a developmental delay? Do you think only certain children could have a delay?
2. What is your perception of a child with a developmental delay?
3. Do you think if a child is not speaking according to his developmental age, that you should wait or ask the doctor?
4. If the doctor, tells you to wait and see, what does this mean to you and how would you respond either to the doctor or in your actions?
5. If there is something you do not understand, do you ask questions?
6. What do you do if the pediatrician provides a recommendation that you do not agree with?
7. What are the most enjoyable aspects for you dealing with a medical professional regarding your child Cho and Ganotti, 2005?
8. Are you familiar with the term early childhood intervention services? Have you had any experiences with ECI? If so, describe how you access the services.
9. What obstacles did you encounter in trying to learn about ECI or the preschool program?
10. Once you had your child tested, how did you feel about the services model of coming into the home or if your child attends daycare services provide there?
11. Why, did you choose to have your child serviced outside of the home?

Empowerment

1. Describe a time when you needed help with a matter regarding your child, how did you feel? How did you respond?
2. If the doctor, tells you to wait and see, what does this mean to you and how would you respond either to the doctor or in your actions?

APPENDIX I  
QUALITATIVE INTERVIEW PROTOCOL  
PROFESSIONAL

Demographics

1. Please, tell me a little about yourself (name, age, professions, years of employment)
2. Please describe your background in working with black families with infant and toddlers.
3. What steps does your organization have to place to locate and evaluate children under the Child Find law? Specifically, what is your role?
4. Working with infants and toddlers' medical professionals are regarded as the "gatekeepers", therefore, what is the referral process in your office? On your caseload, how do you keep track of the children receiving early childhood intervention services?

Barriers

1. In self-reflection, do you think your tolerance level working with minorities is the same as compared to white families?
2. What are your joys of working with a black family's population?
3. What frustration do you experience in communicating with black families about their child's development?
4. Do you ever find yourself holding back on information because you are concerned about how it will be perceived? For example, if the child is showing signs related to another health impairment or learning delay?

Empowerment

1. Having difficult conversations about their child's development with black parents, describe your experiences in how receptive they are to the information?
2. As a professional, what is your experience with black families taking initiative for further care and following through?