College of Professional Studies

An Examination of the Relationship Between Referral Sources and the Reasons for Discharge for Those Enrolled in an Early Intervention Agency

By:

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Dedication

I would like first to dedicate this dissertation to my parents. Your love, sacrifice, and care for me have been the driving force behind my entire academic journey. This accomplishment belongs to both of you as much if not more than it does me.

To those who have supported and encouraged me throughout my academic pursuits; from the halls of Saint Clement, the campus of Assumption, the commute to Springfield, and to this final chapter in Scranton; I thank you for standing behind me, beside me, and at times in front of me when I needed to be pulled along. For each of you I am forever grateful.

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Committee Members: Dr. Michael Accordino and Dr. Yerodin Lucas

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Abstract

Background: Early Intervention, part C of the Individuals With Disabilities Education Act was created in order to provide for support for children and their families when there was the presence of a developmental disability or delay. In order to be successful in providing support, along with early detection, Early Intervention must be utilized. Unfortunately, despite being eligible for services, there are many families choosing not to utilize these supports. A families first introduction to these supports is through the referral process, which is why this study set out to gain understanding on whether or not the referral source has an impact on or is related to what leads to a child's discharge from Early Intervention Services. Children can be discharged due to ineligibility, or while still eligible for services if the family is choosing to not utilize supports.

Method: A retrospective quantitative comparative research design was used in this secondary analysis study. The study utilized a sample from an Early Intervention agency located in Boston Massachusetts. Each child represented in the study was eligible for Early Intervention Services and had an Individualized Family Service Plan, and was closed in 2019.

Results: A chi square test of independence was calculated comparing the referral sources (Parent, Primary Care Physician/Pediatrician, Hospital/NICU, Department of Child and Family Services, Child Care Center, Community Agency, Early Intervention Agency, and Other) and the reasons for discharge (no/lost contact, parent refusal, turned three years old, no longer living in service catchment area, no longer presenting with a developmental delay). A significant relationship was found and referrals made by the parents were 53.8% more likely to have a child discharge from services due to being ineligible as opposed to the family denying or refusing services at 28.2%.

Conclusion: There are many families who are ending services despite still being eligible to receive them. Unfortunately, there is an overall lack of understanding of Early Intervention and the services available, specifically by referral sources. However there are options available to improve these outcomes.

Key Words: Early Intervention, Referral Sources, Discharge, Individuals With Disabilities Education Act Part C

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Chapter One

The Problem and its Setting

Introduction

Children are the cornerstone of any and every society. They provide hope for the future and a sense of carefree joy. They are truly a gift. One of the main purposes of modern day society is to support, protect, and foster the development of society's children. In fact, one of the oldest debates is on what exactly is the driving force behind the development of children, nature vs. nurture. Many have and continue to ask, how does a child develop into the person that they become? Are these characteristics that they were born with, or did their upbringing primarily dictate their development into the individuals that we see? General society is willing to accept that this is truly a combined effort where both nature and nurture work in conjunction with one another in the shaping of small bodies and young minds. (Lewkowicz, 2011)

The nature paradigm refers to the biology of the child. Being born with a developmental disability, or possibly a chronic illness certainly plays a crucial role during a child's formative years and many times will have a lasting impact on their development and growth in the future? Nurture suggests the things outside of biology may also impact a child as they grow and develop such as their parental influences, their home environment, their community, and influences such as media. Unfortunately biology and environment can act as roadblocks to a child's

development, standing in the way of positive growth and healthy maturation. This can be a very difficult experience for the child as well as their family (Lewkowicz, 2011).

There is no life free of encumbrance. However, there are ways in which these roadblocks (poverty, illness, stress, and more) can be addressed. When thinking of children and their families there is opportunity to combat these roadblocks. This can be achieved by providing children and their families with the appropriate support and tools for success. Specifically, the Individuals with Disabilities Education Act (IDEA) has provided guidelines for these necessary resources and opportunities to address these barriers through support for the children and their families at a multitude of stages. It is important to note that this has not always been the case and previously families would often turn to abandonment and institutionalization in order to evade shame, scrutiny, financial burden and generally difficult times. This was often viewed as the best, or most adequate solution for children who presented with developmental delays, disabilities, chronic illness, or any unknown or minimally understood ailments. By similar token, families would also turn to institutionalization when difficulties were present in the home or when the families felt ill equipped to provide the necessary support for their children. The impacts of institutionalization cannot be ignored. Maclean (2003) identified consistent negative impacts associated with institutionalization of children evident in physical, social-emotional, and intellectual development. Children were often physically smaller, described as being shorter and weighing less. These children had greater difficulty with their attention span and had increased behavioral problems. Children who have been institutionalized tend to have insecure attachments and could be indiscriminately friendly which is concerning when it comes to maintaining overall safety and wellbeing (Maclean, 2003).

In order to move forward successfully, it is important to spend time looking back and studying the history of how things once were, and the ways in which they came to be. In doing so we are able to gain a better understanding of the mistakes that were made, and how to avoid them as we progress. Prior to being known as IDEA the Individuals with Disabilities Education Act, it was named the Education for All Handicapped Children Act (EAHCA). This original act was fought for by the parents of children with disabilities. After many years of advocating for such legislation EAHCA came to pass in 1975 (Strassfeld, 2017). The most powerful piece of this act was the guarantee to a free, appropriate, and public education also known as FAPE. This also included additional parental safeguards (Strassfeld, 2017). It was in 1990 that the Education for All Handicapped Children Act was renamed to the Individuals with Disabilities Education Act (IDEA) that we are more familiar with today. According to the US Department of Education those between birth and three years old with a disability along with their families will receive Early Intervention Services under Part C of IDEA (2022).

Early Intervention was created through Part C of the Individuals with Disabilities Education Act (IDEA) in order to provide services and assistance to children between birth and three years of age who are presenting with developmental delays or who have been identified as being at a greater risk of developing developmental delays or disabilities. The US Department of Education reports that between 2020 and 2021 that there were more than 363,000 infants and toddlers, along with their families receiving Early Intervention Services (2022).Early Intervention aims to provide services and support for the child and their family with the hopes that this will help to diminish the need for services in the future through the educational system and Part B of IDEA. It is also hoped that through these supports families will be less inclined to turn to or be forced into utilizing institutionalization for assistance and relief. Universal

accessibility and broad eligibility is the goal of Part C of IDEA (Dragoo & Library of Congress, 2018).

Families and children do not work alone, in order to enroll in Early Intervention Services a referral must be made on their behalf. When a child appears to be presenting with either a developmental delay/disability or familial/environmental risk factors a pediatrician, the parent/caregiver or the department of child and family service, or a separate source must make a referral. Once a referral has been made the agency then moves forward to establish contact with the family and set up an intake appointment. Once the intake is completed the agency conducts a developmental assessment in order to determine eligibility for Early Intervention Services (Dragoo & Library of Congress, 2018). Once an agency begins to provide services, there are several different outcomes, some more preferable than others. The first preferred outcome is that after receiving services a child is no longer eligible due to no longer presenting with a developmental delay/disability and former risk factors are no longer present. However, this is not always the case so another preferred outcome is setting up special education services to assist in the child's transition to the special education system upon turning three years old. It is often impossible to avoid certain life situations such as moving, and in cases like that the ideal outcome is to transfer Early Intervention Services to an agency at the family's new location. These outcomes are all equally beneficial and supportive to the child and their family. The only unfortunate outcomes are the ones when a child is eligible for services and the family refuses to utilize services or is no longer responsive to agency outreach.

Many efforts have been made to research Early Intervention, the benefits of services and possible roadblocks such as perceptions of caregivers, universal access, role of healthcare workers, along with racial and socioeconomic disparities. For this reason some of the necessary

work that needs to be done in order to improve support is clear. However, there is still more to learn. This study hopes to shed light on the possible relationship between Early Intervention referral sources and Early Intervention outcomes. Better understanding of this relationship allows for greater efforts to be made in order to provide timely and most importantly tailored services, hopefully limiting these unfortunate outcomes where families are not utilizing the services available to them.

Theoretical Framework

Maslow's Hierarchy of Needs

There are two theories that guide this research, the first being Maslow's Hierarchy of Needs. This motivational theory was developed by Maslow in 1943 (Maslow, 1943). Maslow stated "people are motivated to achieve certain needs and that some needs take precedence over others"(McLeod, 2018 p.3). This is the driving force behind child development, as well as Early Intervention Services. At its core, Maslow's theory was that humans do what they can and what they are capable of in order to reach internal fulfillment; an indication that they have achieved their goals and desires, the same can be said for families. The role of Early Intervention is to support children and families in their quest for seeking this fulfillment of physiological, safety, belonging, esteem, and cognitive needs. Goals are created and described in the Individualized Family Service Plan, outlining services and steps in order to support the fulfillment of these goals in Maslow's motivation model (McLeod, 2018).

Maslow's theory has been adopted and utilized in the classroom setting, this study will be focused in the home setting, which it aptly applies as well. It is understood that in order for a child to be a successful learner certain things must be in place, and certain needs must first be met. For example, a child cannot be expected to focus on learning when they are tired or hungry.

In order to fully focus on learning to the best of their ability they would need to have received adequate rest and proper nourishment. Children are their most successful when they are able to feel safe physically and emotionally (McLeod, 2018).

The purpose of Early Intervention Is evident in the name - to intervene as soon as possible. Prince and Howard (2002) take a closer look at obstacles due to poverty and a lack of fulfillment of children's basic needs, specifically in children who are born into poverty. Maslow's first need is physiological needs refer to those necessary in order to sustain life. These include food, shelter, and clothing. Without these basic needs being met survival becomes improbable. Children who live in poverty tend to experience hunger daily. Unfortunately, not receiving the proper nourishment necessary for growth and health takes an even greater toll on children who are younger than three years old (Prince & Howard, 2002). Inescapably, a cycle begins where, because these needs are not being met, the child begins to develop illness and the need for healthcare that due to socioeconomic stresses can be difficult to access, which leaves illness untreated maximizing their impact therefore perpetuating the cycle. The results of this cycle can impact the life and development of these children far into their future. Services are provided to children between birth and 3 years old in an attempt to provide support and address these needs early enough to prevent the possible long-term consequences.

According to Maslow, if children experience proper nourishment, the next need is safety. For adults this may look like security, employment, resources, and property. When looking at the caretakers of children, this is extraordinarily important. However, children have their own safety needs, which look slightly different compared to that of their caretakers. Children need a place where they feel safe and are able to explore, consistency and appropriate boundaries are also important. Though differences exist the importance for safety is still evident and paramount at

the children's level. When it comes to impoverished homes and property, many children living in these conditions are exposed to many health concerns such as lead, that have lasting negative effects. Consequently, the younger a child is the greater the chances that they would be the victim of abuse and or neglect. The impact is just as damaging and lasting for those children who observe violence and experience these stressful and emotionally taxing situations in the home. Their overall development is unfortunately altered by these experiences and this absence of safety (Prince & Howard, 2002).

Love and belonging is not always easy or natural though we often hope and expect it to be. In fact, many caregivers who are experiencing difficulties, hardships, and poverty struggle with finding, receiving, and expressing love and belonging. The reality is that as these caregivers struggle they become inconsistent with the care that they are able to provide and may become more absent or less nurturing in regards to the child. Regrettably, this leads to children struggling to feel a consistent sense of love and belonging (Prince & Howard, 2002).

Removing the barriers that stand in the way of a child and their caretakers from having their physiological needs and safety needs met allows for a better chance at fostering love and belonging in the home. When these foundational needs are met, esteem and self actualization become real possibilities for the future. Early Intervention works to remove these barriers, and provide support in order to secure these foundational level needs for these children and their families. In order to receive services the child must present with a developmental delay or disability. Risk factors are also considered when looking at eligibility, poverty and the impacts of poverty are identified as risk factors. As we see here, poverty provides many barriers to meeting the basic needs as outlined by Maslow and his hierarchy of needs (Prince & Howard, 2002).

This is directly pertinent to Early Intervention. The first priority of Early Intervention is to ensure the health and well being of the child. It is difficult to work on other needs and aspects of development if a child is struggling with food insecurity, or if a family does not have secure housing in place. Attempting to meet these needs may also impact the referral process as well as the different possible outcomes of Early Intervention services.

Figure 1. Maslow's Hierarchy of Needs.

Parent Involvement Theory

McCurdy and Daro (2001) created their conceptual model of parent involvement that is depicted below. This conceptual theory was created when parent involvement was investigated in family support programs. Their research found that despite expressed parental interest in programs that offer assistance in child rearing, similarly to Early Intervention services, there was a lack of utilization of these programs. While creating this parental involvement theory it was discovered that this was an integrated theory consisting of four major influences on parental

involvement: individual characteristics, provider attributes, program characteristics, and neighborhood context. Each of these influences impact the parents intent to enroll, the actual enrollment, and lastly retention. The goal of this theory, for both McCurdy and Daro, as well as for utilization in this study, is to gain better insight into parent involvement in order to work towards increasing as well as maintaining parental involvement in voluntary family support programs. These programs and initiatives want to increase their outreach, and continue to provide useful services (Mccurdy & Daro, 2001).

Early Intervention is a volunteer familial support program. The goal of Early Intervention is to provide services to children and their families. However, in order to be successful within an Early Intervention agency there needs to be parental/caregiver involvement. The unsuccessful outcomes of Early Intervention services outlined in this study are described as parental/caregiver refusal of services, or a lack of response to outreach making this theory ideal in better understanding one of the more popular referral sources (parents), and how that impacts different possible outcomes. The parent involvement theory has framed this study and propelled it forward by examining all referral sources and the relationship between the referral sources and service outcomes. The utilization of this information will allow Early Intervention agencies to better understand the outcome possibilities upon referral, prior to providing services. Insight gained here will potentially open the door to greater and more appropriate services for children and their families from the very beginning, saving time, and minimizing the possibility of successful outcomes.

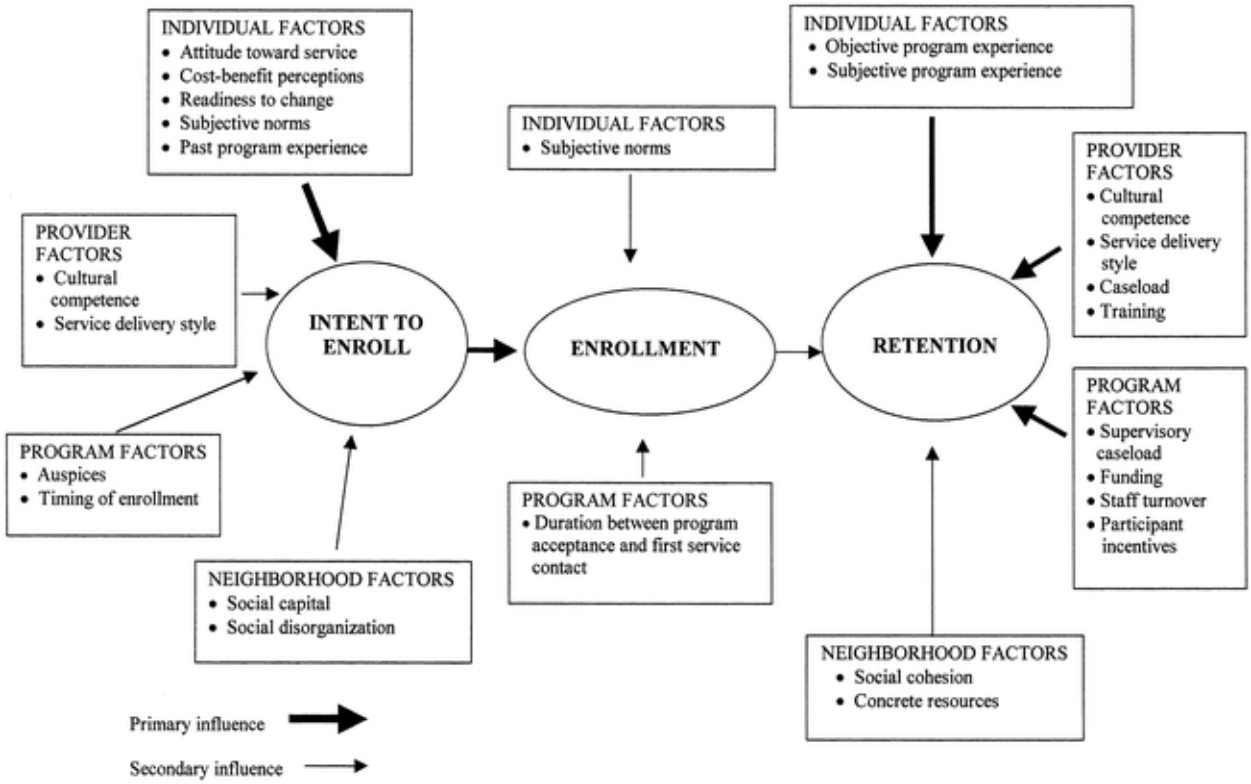

Figure 2. McCurdy and Daro's Parent Involvement Theory.

Conceptual Framework

Accessing and utilizing Early Intervention Services is a linear process. There are very specific steps that must occur in order to access services, additionally these steps must be done in the specific order soon to be outlined. The first step in this process is the referral. A referral for Early Intervention services must be made on behalf of the child in order to begin the process of accessing services. It is possible for anyone to refer a child for Early Intervention services. However, the referral sources that are most common are from the: pediatrician, parent, the department of child and family services, or the primary caregiver. Once the referral has been made it is determined whether or not the child is eligible for services. Eligibility can be granted for several reasons. For example, a child is presenting with a developmental delay determined by the developmental screening tool utilized by that agency they would be considered eligible for

services. In addition a child has received a medical diagnosis, this may also lead to service eligibility. Several risk factors can lead to eligibility of Early Intervention services. If a child is considered ineligible for services at the time a new referral can be placed on their behalf at a later time. Once eligibility is determined the child may then enroll in the Early Intervention agency and begin utilizing services. Services can include home visits from a developmental specialist, along with other specialists as needed such as: physical therapist, occupational therapist, speech and language pathologist, and many more. Services also open the doors for things such as playgroups and other beneficial opportunities. After receiving services a child may exit the agency due to being ineligible. A child is no longer eligible for services when they are no longer presenting with a developmental delay, disability, or no longer have the listed potential risk factors. Turning three years old is also a reason a child can become ineligible for services. Early Intervention services are limited to children between birth and three years old. Children older than three years old are not eligible for Early Intervention services. However, if a child turns three years old and is still presenting with a developmental delay or disability the family has the choice to move forward with a referral into the special education system. Eligibility is not the only factor that may impact a family's choice to utilize services. A child and their family may still exit services despite still being eligible. The reasons behind these exits vary, the first being a lack of response to agency reachout is another reason behind leaving services. It is also possible for families to simply refuse to continue participation in an Early Intervention agency. Different things play into a family's desire to continue, or pursue services. Families may not trust their Early Intervention team, or public support. Work schedules, and outside responsibilities can also factor into this decision. The list for why a family may choose not to utilize Early Intervention services is extensive. Families may in fact be interested in utilizing services but must move out

of their agency's catchment area. A catchment area is the cities and towns that a particular Early Intervention Agency is able to service. Moving out of this area would require the family to secure services from a different agency, doing so may present its own set of challenges.

This study will further investigate what impact the very beginning of this linear process plays on the very end. In other words how the varying referral sources may impact the exit of services. The conceptual framework below outlines the linear process just described. This framework flows from the beginning: referral sources to the end of the process, the exit of services while also identifying possible influential relationships and describing both positive and negative outcomes.

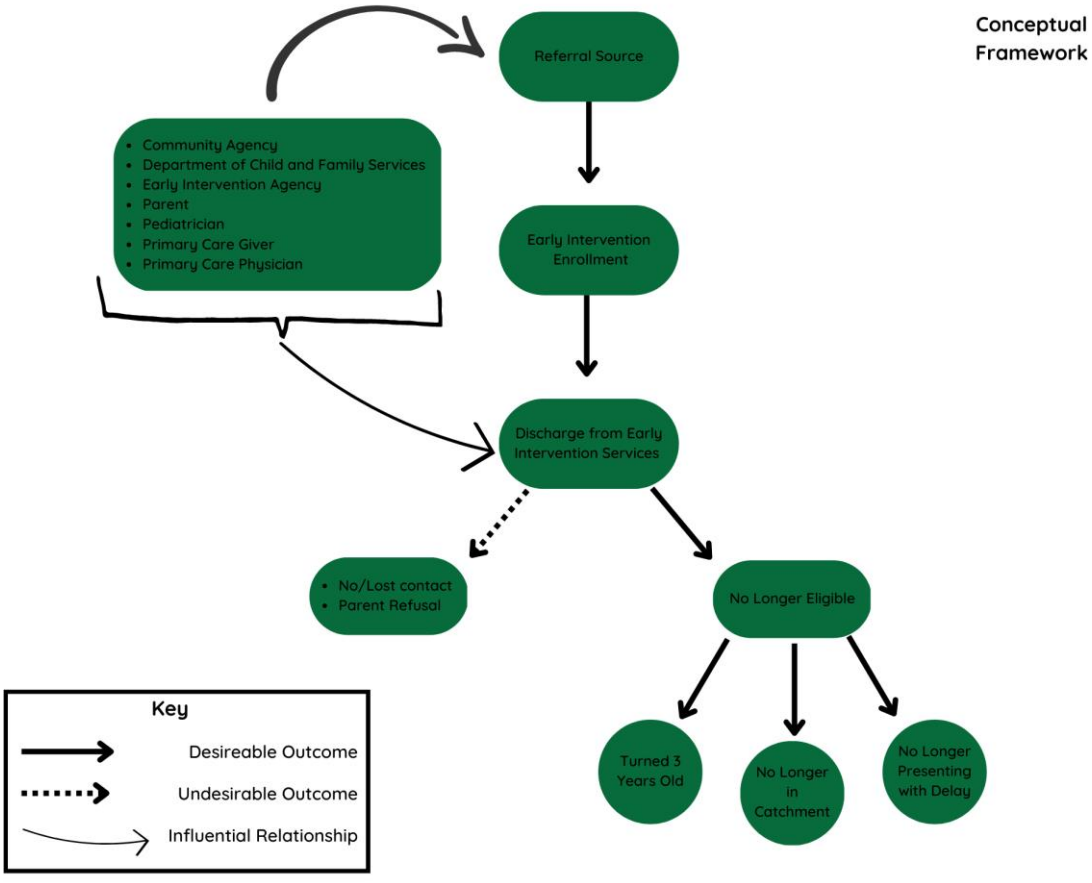

Figure 3. Conceptual Framework.

Purpose Statement

The purpose of this quantitative research study is to gain understanding on whether or not the referral source has an impact on or is related to what leads to a child's discharge from Early Intervention services provided by an agency in Boston, Massachusetts. For this study, possible referral sources are identified as pediatricians, parents, the department of child and family services, primary caregivers, and others. At this stage in the research, a desirable outcome will be defined as the discharge from Early Intervention services due to the child no longer being eligible for services, while an undesirable outcome is a child's exit from services despite still being eligible to receive services.

Research Questions

Is there a relationship between the different referral sources i.e., parent, guardian, primary caregiver, Department of Child and Family Services, pediatrician, or other referral source, and the reasons for discharge from early intervention services i.e., no.lost contact, parent refusal to engage in services, the child has turned three, they are no longer living in the appropriate catchment area, they are no longer presenting with a delay, for children enrolled in an early intervention program in Massachusetts?

Subproblems

1. What are the outcomes of referrals made by the parent for a child enrolled in an Early Intervention agency?
2. What are the outcomes of referrals made by the primary care physician for a child enrolled in an Early Intervention agency?
3. What are the outcomes of referrals made by the hospital/NICU for a child enrolled in an Early Intervention agency?
4. What are the outcomes of referrals made by the department of child and family services for a child enrolled in an Early Intervention agency?
5. What are the outcomes of referrals made by a child care center for a child enrolled in an Early Intervention agency?
6. What are the outcomes of referrals made by a community agency for a child enrolled in an Early Intervention agency?
7. What are the outcomes of referrals made by an Early Intervention agency for a child enrolled in an Early Intervention agency?
8. What are the outcomes of referrals made by “other” for a child enrolled in an Early Intervention agency?
9. What is the relationship between the different referral sources i.e, parent, primary care, hospital/NICU, all outside agencies, and the discharge reasons for children enrolled in an Early Intervention agency?

Hypothesis

Null Hypothesis

There is no relationship between the different referral sources and the reasons for discharge for a child enrolled in an Early Intervention Agency.

Alternative Hypothesis

There is a relationship between the different referral sources and the reasons for discharge for a child enrolled in an Early Intervention Agency.

Definitions

Early Intervention Services

Early Intervention Services refers to a statewide, integrated, developmental service available to families of eligible children from birth to three years of age. (Early Intervention Division, n.d.) For the purpose of this study, the term “Early Intervention Services” will refer to those services provided in Massachusetts.

Children

Children are defined as an infant and/or toddler under the age of three (Early Intervention, Division, n.d.). For the purpose of this study, the term “children” will also refer to children between birth and three years of age.

Presenting

Presenting is defined as existing in something mentioned or under consideration (Merriam-Webster, n.d.). For the purpose of this study, the term “presenting” will also refer to the existence of something, specifically a developmental delay or disability.

Individualized Family Service Plan (IFSP)

Individualized Family Service Plan (IFSP) is the written plan for providing Early Intervention services to an eligible infant or toddler and the infant or toddler's family in accordance with federal regulations and with the Massachusetts Department of Public Health Early Intervention Operational Standards (Early Intervention Division, n.d.). For the purpose of this study, the "Individualized Family Service Plan (IFSP)" will refer to the document utilized by the early intervention agency to outline specific family goals, action plans, and additional services being utilized by the family.

Service Coordinator

Service coordinator is a Early Intervention specialist assigned to: assist and enable an eligible infant or toddler and the infant or toddler's family to receive IFSP services in a timely manner; coordinate all Early Intervention services including evaluations and assessments; facilitate and participate in the development, reviews, and evaluation of the IFSP; facilitate the development of a transition plan; ensure families are aware of all rights and procedural safeguards available within the Early Intervention system; provide information on available resources; and support families ass needed to access resources (Early Intervention Division, n.d.). For the purpose of this study, a "service coordinator" will refer to the staff member who oversees a particular child's case and IFSP, managing and providing services.

Referral Sources - Any adult person is able to refer a child for Early Intervention services. This noncomprehensive list includes the most common sources of referral for Early Intervention services.

Parent

> *Parent* means a biological or adoptive parent of the infant or toddler' a foster parent; a guardian generally authorized to act as the infant or toddler's parent or make early intervention, educational, health, or developmental decisions for the infant or toddler; another person acting in place of a biological or adoptive parent (including a grandparent, step-parent, or relative with whom the infant or toddler lives who is legally responsible for the infant or toddler's welfare); or a surrogate parent, but does not include any parent whose authority to make educational decisions has been terminated under state law (Early Intervention Division, n.d.). For the purpose of this study, the term "parent" will be defined as the biological mother or father of the child. This term will also be used to include adoptive mothers and fathers of the child.

Guardian

> *Guardian* is someone who has the care of the person or property of another (Merriam-Webster, n.d.). For the purpose of this study, the term *Guardian* will refer to any individual who has current custody of the child whether that be a grandparent or another member of the biological family, or someone who is otherwise identified as the legal contact person for the child.

Caregiver

Caregiver is a person in whose care an infant or toddler may be temporarily placed, including but not limited to non-custodial relatives, baby-sitters, childcare providers, and nannies (Early Intervention Division, n.d.). For the purpose of this study, the term *caregiver* will refer to the individual that provides for the day to day needs of the child outside of the aforementioned parent or guardian and accepts responsibility for the child's overall wellbeing and care.

Other Referral Source

Referral is defined as the act, action, or an instance of referring (Merriam-Webster, n.d.)

For the purpose of this study, the term *Other Referral Source* will refer to a referral made by someone other than the parent, guardian, primary caregiver, Department of Child and Family Services or pediatrician. This may include other family members, friends, neighbors, day care providers, babysitters, etc.

Outcomes - According to the Webster dictionary an outcome is something that follows as a result or consequence (Merriam-Webster, n.d.). Two outcomes will be observed in this study.

Desirable outcome

For the purpose of this study, the term *Desirable Outcome* will refer to the following reasons for exiting the early intervention program. A child may be deemed no longer eligible for early intervention services due to no longer having the predetermined risk factors, or present with any developmental disabilities, this would be considered a desirable outcome. A child may also be deemed no longer

eligible for early intervention services due to turning three years old and aging out. The last desirable outcome is that a child may move out of the catchment area and be successfully set up for services near their new home.

Undesirable Outcome

For the purpose of this study, the term *Undesirable Outcome* will refer to the families who decide not to accept services, or those who no longer respond to outreach from early intervention. A child moving out of the catchment area without securing replacement services would also be considered an undesirable outcome.

Delimitations

This study will be delimited to children between birth and three years of age who are eligible in the state of Massachusetts for Early Intervention. Only children who had completed the intake process and had a working Individualized Family Service Plan (IFSP) managed by their service coordinator will be utilized. Additionally, the study will be delimited to cases that were closed during 2019.

Assumptions

A major assumption of this study is that the documents and records being utilized are accurate. There is an understanding that these records are utilized for insurance purposes, and are subject to regular government audits for quality insurance, leading the assumption of their accuracy to be reasonable. A secondary assumption is that the records utilized for this study have been correctly transcribed when they underwent the removal of all personal identifying information and were shared with the primary investigator.

Significance of the Study

Early Intervention was created through Part C of IDEA in order to provide services and assistance to children between birth and three years of age who are presenting with developmental delays or who have been identified as being at a greater risk of developing developmental delays or disabilities. Early Intervention aims to provide services and support for the child and their family with the hopes that this will help to diminish the need for services in the future through the educational system and Part B of IDEA. It also hoped that through these supports families will be less inclined to turn to institutionalization for assistance and relief. Determining if a relationship exists between the referral source and the outcome of services will allow for more tailored care, providing greater support to those who may be at a greater disadvantage from the beginning. Furthermore, better understanding of referral sources will allow for greater funding in areas that have greater amounts of particular referrals. The greatest significance of this study is that it can allow for children who are enrolled in early intervention to have a greater rate of success, promoting healthy and positive development.

Chapter 2

Review of Literature

The Individuals with Disabilities Education Act, also known as IDEA, was first enacted in 1975 and was known as the Education for All Handicapped Children Act (Dragoo & Library of Congress, 2018). The purpose of this act was to offer free and appropriate public education for those children with a developmental disability and in need of additional support. This act brought responsibility to the state to provide the tools necessary in order to ensure education to all children.

When the Act was first established, it focused primarily on children older than three or four years old; those who were enrolled in elementary school were the target demographic. This was a great beginning, but it left out significant demographics- the children who had not yet reached school age, those who were three years old and younger. In 1986 amendments were made which included the establishing of the IDEA that we are familiar with today. The creation of the Early Intervention program included children from birth to three (DOE, 2020). Increasing the age range of eligibility was extremely beneficial to those who have children that are presenting with either a developmental delay or disability, outside of the original catchment demographic which was school age children. Providing these services to these children and their families assisted in improving their developmental outcomes (DOE, 2020). This expansion also aided in the transition process into the public school system. Transitioning into the school system, as well as out of it, was a cumbersome task and often difficult to navigate. These amendments to IDEA assisted in addressing these transitional periods, making them less challenging. Greater support is to be considered a necessary tool to greater success.

This literature review will provide more information on IDEA; more specifically Part C which outlines Early Intervention Services and the benefits of these services for children, their families and the society that we live in as a whole. This review will dive into who is receiving services, what is necessary in order to be considered eligible for services, the reality of the referral process, the role played by our healthcare system and the quantity, variety, and quality of services provided by Early Intervention agencies. Part C of IDEA aimed to be inclusive, and universally attainable and beneficial. This literature review will explore the realization of this goal.

Part C of the Individuals with Disabilities Act

Early Intervention Programs are run on a state level. Each state is able to determine the criteria that they would like to utilize in order to determine eligibility for services. However, they have the goal of examining the child's physical abilities, cognitive skills, communication skills, social and emotional abilities, and their adaptive skills for possible delays. Each state receives support in creating these programs that are interdisciplinary and provide early intervention services to all children along with their families who are presenting with a developmental delay or disability in any of the above listed categories of physical and mental development (DOE, 2020). Generally eligibility is determined by a delay in one or multiple of the following: physical abilities, cognitive skills, communication skills, social and emotional abilities, or their adaptive skills. However, a physical and or mental diagnosis that may impact development and can potentially cause developmental delays may also result in an eligibility determination. Another considering factor in eligibility determination is the presence of greater risk for a developmental delay or disability due to environmental factors. As previously stated each state receives funding in order to provide these services, along with the US territories of Puerto Rico, American Samoa,

Guam, the Northern Mariana Islands and the Virgin Islands. Each area that receives funding is able to determine their own criteria for eligibility.

A unique component to early intervention services is the emphasis on services being provided in natural environments. Natural environments are described as the child's home, places in their community, or in childcare settings. These are the physical interpretations of the term natural environments. However, the IDEA also attached a more illustrative meaning to the word. More specifically they define natural environments as “settings in which the child would participate had he or she not had a disability” (Harjusola-Webb et al., 2013, p.43), with this definition a focus is placed on the caregivers as the individual or individuals who will be putting these various interventions into practice on a consistent basis, creating a more natural access to supports and interventions.

Developmental Assessments Utilized for Eligibility Determination

During the reauthorization of IDEA, in 1986, Part C was added and extended its services in order to also support children between birth and three years of age who have a developmental delay or disability and provide them with services (Dragoo & Library of Congress, 2018). This change allowed for early detection of developmental disabilities in infants and toddlers. Early detection allows for early intervention, possibly reducing the need for the utilization of services later on. In addition, this allowed families to gain the support needed to better care for and meet the needs of their child, hopefully reducing the need or desire to seek out institutionalization (Dragoo & Library of Congress, 2018). The specific service that is offered to these children and their families is Early Intervention, often referred to as EI. The main requirement of Early Intervention is to provide each child and family with a unique and individualized plan in order to meet their specific needs. Children that are eligible for Early Intervention services under IDEA

are children who are identified as having a developmental delay, have received a medical diagnosis or have a high likelihood of developing developmental delays later on down the line (Dragoo & Library of Congress, 2018). This idea of a developmental delay is not abstract or subjective, rather it is objective, specific and often determined utilizing developmental screenings.

There are a variety of developmental screening tests available that can be utilized in determining whether or not a child has any developmental delays. The Battelle Developmental Inventory is one of the most popular, and more often utilized in conjunction with Early Intervention when determining developmental delay and service eligibility. The Battelle Developmental Inventory (BDI) was developed in 1984 and evaluates the following five developmental domains: cognitive, adaptive, motor, communication, and personal-social (Berls & McEwen, 1999). These are the same domains that are listed in Part C of IDEA. The Battelle specifically covers an age range from birth - eight years old, this is a wider range than what is typically found in developmental inventories for infants.

There are many unique features to the Batelle that make it propitious for utilization in Early Intervention. When administered, the inventory can be broken up into its separate domains which allows for different members of the team to work concurrently during what is standardly a 90 minute administer time (Berls & McEwen, 1999). There are three administrative formats available to those administering the Batelle; they are able to utilize structured administration, observation, as well as parental/guardian interviews. Early Intervention services are ideally provided in a natural environment, which is often the home. The different administration formats allow for administrators to consider their setting, and the other elements that exist in the home and select the most suitable format for the situation. A level of flexibility is also available

through the option for parental/guardian interview for situations when the child may refuse to perform structured activities, or is performing grossly below what is typical for them. Uniquely, the Battelle also gives administrators the opportunity to adapt the inventory when necessary for children with disabilities (Berls & McEwen, 1999).

The Battelle was standardized with 75% of the children living in an urban area and 25% living in a more rural area. In the sample a majority of the children were white, at 84% and the remaining 16% consisted of mostly African-american and Hispanis-American children. Neither gender nor race had a significant difference amongst their scores (Berls & McEwen, 1999). No concerted effort was made to control for the socioeconomic status of the participants, neither was information collected regarding the occupations, income, or the education received by the parents of the children utilized for the standardization process (Berls & McEwen, 1999).

Three additional developmental screening tools are the Developmental Profile II (DP-II), Denver-II (DO-II) and Battelle Developmental Inventory Screening Test (BDIST). The DP-II has five different categories that it observes: physical, self-help, social, academic and communication. These categories were normed for children between the ages of 0 and 9 ½. This test is administered through a parental report along with child observation of specific behaviors. DP-II provides a developmental age when subtracted from the actual age which shows whether or not a child is advanced, average, borderline or delayed in their development. Unfortunately, there are some shortcomings of the DP-II. When the DP-II was normed, it was limited to children in the geographic location of Washington and Indiana. Additionally, only “Blacks and Whites" were utilized (Glacose & Bryne, 1993). However, DP-II is often used in health-care settings as a developmental screening tool because of its reasonable administration time of ten

minutes, its optional direct administration option, and the variety of scores it offers providing program eligibility scores (Glacose & Bryne, 1993).

The Denver-II is the newer and more updated version of the Denver Developmental Screening Test-Revised often referred to as DDST-R. This developmental screening had been standardized in 14 countries and translated into over 40 different languages (Glacose & Bryne, 1993). Similarly to the DP-II, the Denver-II also utilizes a combination of parental report, direct elicitation and observation. DP-II provides a single score placing an individual in any of the following categories: abnormal, questionable, untestable, or pass on the following domains: fine motor-adaptive, personal-social, and gross motor. Unfortunately, Denver-II mirrors DP-II's shortcomings by being normed in a limited geographic location. The population utilized for standardization was solely in Colorado, a limitation along with the lack of validity testing by the authors was a concern (Glacose & Bryne, 1993).

Battelle Developmental Inventory Screening Test (BDIST), is different from the Battelle Developmental Inventory as it has a more rapid administration, however it is an often utilized developmental screening tool. The BDIST has seven subsets that it measures, which are personal-social, adaptive, fine motor, gross motor, expressive language, receptive language and cognitive skills. Due to the ability to utilize BDIST when determining eligibility, it is very popular and used often with special educators (Glacose & Bryne, 1993). Unlike the previous two developmental screening tests, the BDIST takes at least 30 minutes and sometimes longer with older participants. The BDIST was standardized on a nationally representative sample; however, there were rumors that the inventory overproduced failing scores to its younger participants leading the authors to calibrate their norms (Glacose & Bryne, 1993).

Glacose and Bryne (1993) conducted a study in order to examine the accuracy of these three developmental screening tests. The results of their study showed that the academic scale of the DO-II was rather unsuccessful and did not identify many of the students who were in fact having difficulties. Fortunately, the DP-II was more sensitive and better able to identify children with developmental delays and disabilities. This being said, though the DP-II was more successful than the DO-II when grouping the questionable passing scores, the DP-II still failed to identify approximately half of the children with disabilities. When the opposite approach of grouping questionable failing scores, the results tilted in the opposite direction identifying more children with disabilities than accurately. Of the three developmental screening tests discussed in this review, the most successful one utilized is the BDIST. However, it is not without its flaws, and inaccuracies do occur. In order for it to be the most useful and accurate, the 1.5 level was recommended to be the most utilized cut off as it resulted in more accurate detection of children presenting with a developmental delay or disability (Glacose & Bryne, 1993).

Developmental screening tools are utilized in order to determine eligibility for services under part C of IDEA. For this reason, their accuracy is extraordinarily important. If the developmental screening tool does not identify a child with a developmental delay or disability, that child is not eligible for services, leaving them and their family without the necessary support and services that they may need. This may lead to a more difficult transition into the school system and special education services. Early Intervention services were developed to provide services to all eligible children, which is not possible when eligibility is skewed due to a lack of representation when standardizing the tool or when the tool being utilized lacks reliability and validity.

Pediatrician Competence and Awareness of Early Intervention

The very first step that needs to be taken in order to receive Early Intervention services is the completion of a referral. Referrals are made to specific Early Intervention agencies on behalf of a child and their family. Once the referral has been completed, the agency can make an attempt to contact the family and arrange to determine if the child is, in fact, eligible for services. Referral sources vary, and there are not limitations on who is able to make a referral. However, common referral sources are the child's parent/guardian, their pediatrician or primary care provider, the department of child and family services, or a family friend. One of the more common referral sources, and arguably one of the more impactful referral sources, is the pediatrician or primary care provider. Pediatricians and primary care providers are highly regarded and respected; it is hoped that they have the respect and trust of the child's family and the community. It is also often assumed that pediatricians and primary care providers have a wealth of knowledge regarding child development and have the skills necessary to identify possible delays and diagnosable developmental disabilities. In summary, pediatricians and primary care providers are on the front lines and have a very important role in referring children and their families to Early Intervention services when appropriate.

In order to become a doctor, there is extensive schooling and training. Specifically, when becoming a pediatrician, you typically undergo a pediatric residency where you are trained and mentored by pediatric residency training directors and experts in the field. Edwards (2018) researched the role that these mentors play when educating future pediatricians on Early Intervention and the services that they provide. She sent out a survey to the Pediatric Residency Training Directors the list of which was available through the American Medical Association website. The survey aimed to determine the Pediatric Residency Directors' understanding of

Early Intervention, the role they feel they play in earlier referrals, and lastly, their perceived adequacy of training efforts. Unfortunately, most participants reported having minimal knowledge of Early Intervention Services, feeling unfamiliar with Part C of IDEA (Edwards, 2018). This lack of awareness and understanding of Early Intervention held by the Residency Training Directors removes any likelihood that they are educating future pediatricians on Early Intervention Services, their benefits, or the referral process. Early Intervention has been proven to be very successful; however, their success relies on their utilization. This lack of awareness gets passed down to the pediatric residents as they absorb the information that they are given, focusing on the things that had the greatest emphasis during their residency. Unfortunately, this perpetuates the cycle of lack of familiarity and utilization of Early Intervention Services diminishing the likelihood of impactful referrals.

A gap is seen between identifying a developmental delay in the primary care setting and starting Early Intervention Services (Conroy et al., 2018). It is reasonable to think that the information above may have an impact on this unfortunate observation. It should be noted that pediatric and primary care practitioners' responsibility is not to conduct Early Intervention evaluations or screenings, but instead to refer the children and their families to Early Intervention Services and assist them in making a valuable connection with Early Intervention Services. Conroy (2018) saw this gap and felt it important to embark on a quality improvement study with the following objectives: a better system in order to encourage families to connect with Early Intervention, create clear referral pathways towards specific Early Intervention agencies, and lastly a system in order to track referrals after the fact in order to determine the families that are failing to connect with Early Intervention. Conroy (2018) hoped to ensure that the agencies would evaluate most families referred to these Early Intervention agencies. Through concrete

changes, such as creating an electronic referral system that allowed for direct and accurate referrals to Early Intervention agencies along with improved communication between the primary care facility and the Early Intervention agencies. Creating an Early Intervention registry allowed for follow up when barriers and difficulties arose for the family (Conroy et al., 2018). The effort shown through this quality improvement study is ideal. Hopefully, other primary care facilities will utilize this information to make changes and allow for better communication with Early Intervention agencies, decreasing the gap in identifying developmental delays and the referral process for Early Intervention services.

Though, at times, it may be difficult to accept disparities in the medical field, and pediatricians are not an exception. Overall it is highly recommended that pediatricians screen for autism spectrum disorder in all children. The hope is that early screening will allow for early detection. Identifying autism spectrum disorder early on allows for earlier interventions; similarly to other developmental delays and disabilities, early detection, and early intervention is key. Intervening early on allows for better development in the future, a large motivation for the American Academy of Pediatrics to recommend universal screenings for all children (Wallis et al., 2020). This being said, though encouraged to screen all children for autism spectrum disorder and other possible developmental delays, a disparity still exists between those children who have received this diagnosis and the children who have received interventions such as Early Intervention in minority children (Wallis et al., 2020). Wallis et al. (2020) completed their study to better understand this disparity and shed light on the unfortunate situation. It was found that though a majority of the children associated with this large primary care network were receiving developmental and autism spectrum disorder-specific assessments. However, the number of referrals to Early Intervention, along with other developmental supports were rather low (Wallis

et al., 2020). The rates of Early Intervention referrals differed based on sex (male or female), family's primary language spoken in the home, developmental presentations, socioeconomic status, and race. The reason behind these differences was not clear; however, what was clear was the lack of equity in regards to Early Intervention referrals after an autism spectrum disorder diagnosis or the determination of a developmental disability or delay. It is extremely important that pediatricians and the facilities they work for are ensuring that they are evaluating and aware of their implicit biases and are consistently working towards equity in all aspects of their work. However, it is especially important when considering the well being of children. These pediatricians should be champions of these children, actively working against their implicit biases to ensure that they are being referred to Early Intervention, as opposed to acting as a barrier to receiving these services. Pediatricians are placed on a pedestal similarly as other healthcare providers, and it is presumed that they are all-knowing and can do no wrong. Realistically this is far from the truth; pediatricians and other healthcare providers are still individuals; individuals that are flawed, that hold implicit bias and capable of making mistakes and unknowingly operating off their biases.

Early Intervention services are not limited to children diagnosed with a developmental diagnosis. To be eligible for Early Intervention services, you must be considered eligible, and eligibility is determined by any current developmental delays, diagnosis, and specific risk factors. This broad categorization of eligibility exists to allow for more interventions early on to prevent future needs for services. Tang et al., (2012) decided to look into neonatal follow-up programs in California and their referral practices. For the infants that are a part of these neonatal follow-up programs, a majority of them would most likely be eligible for Early Intervention Services as they are currently presenting with developmental delays or concerns for possible

developmental delays, hence the need to be a part of the neonatal follow-up program. This being said, not every infant associated with this program was referred to Early Intervention Services. Through their work, Tang et al., (2012) found that after the first follow-up appointment, many of the practitioners prescribed to the school of thought that more time was needed and that things would improve with that additional time and without intervention. High-risk infants or those that had failed their developmental screening did not receive a referral for Early Intervention services. The researchers thought that referral rates would most likely increase after the second follow up visit when things did not improve independently and without intervention. However, the proportions for the number of infants not referred after their first follow-up visit remained the same even after the second follow-up visit, despite the lack of evident progress (Tang, et al., 2012). As the child aged, their window of opportunity for Early Intervention Services decreased along with the potential for impactful interventions and beneficial developmental growth. By not intervening and providing an Early Intervention referral, pediatricians in this case were a barrier for these infants and their families from receiving beneficial services and support.

Barriers to family-centered services, such as Early Intervention were explored by Shannon (2004). One of the primary barriers discovered was the physician's office. Both professionals and families felt that practitioners were barriers to Early Intervention services (Shannon, 2004). Shannon's research highlighted several barriers related to the physician's office. The first was that physicians often utilized a "wait-and-see" approach, expressing that with time delays will diminish, or the child would outgrow them. Families reported returning to the practitioner's with their concerns, and consistently being met with this ideology. Often they would either receive a referral to Early Intervention services, months or years down the line. At times they would never receive a referral from their pediatrician, missing the window to utilize

Early Intervention services entirely (Shannon, 2004). Families reported feeling intimidated by the practitioners, stating that the practitioners would utilize medical terminology that was often confusing and isolating. This created a barrier to their communication, and led families to not stray away from advocating for their child's needs. In instances where families did advocate for the needs of their child, or disagreed with their practitioners' suggestions, they were considered difficult and received a negative reputation (Shannon, 2004).

Shannon's study illuminated how Early Intervention professionals perceived the barriers to services erected by the medical professions. Early Intervention professionals described the medical practitioners as lacking in a family centered approach. Specifically they noted that the practitioners did not take the time to hear the families concerns. Physicians in this study highlighted their experiences as well. The practitioners indicated their limited time with families, and that a majority of the time, in their opinion, children would outgrow a delay. Practitioners described delays often being subtle and that parents were overly concerned about developmental milestones (Shannon, 2004).

Racial Disparities in Accessing and Utilizing Early Intervention

Racial disparities have been clearly identified and documented through Early Intervention and have an impact on several levels. The first place where racial disparities begin is within the home of families in need of Early Intervention services for their child or children who are presenting with developmental delays or disabilities. Early Intervention is uniquely a voluntary program; families are not mandated in any way to engage and utilize services and can terminate services at any time. This being said, the family buy-in is incredibly important. Magnusson, et al., (2017) conducted a study where they worked to gain a better understanding of the beliefs of African American and Hispanic Mothers who are considered to have a low socioeconomic status

in regards to developmental delays and Early Intervention. For their study, they conducted in-depth interviews with willing mothers who utilized one of the two urban pediatric primary care clinics used in this study. These interviews led to several themes that could be considered impediments on the mothers seeking services. The mothers described being able to notice if their child was delayed by comparing them to other children around. However, many noted that children age and develop at different rates and possible delays did not bring out major concerns. Where there were concerns mothers felt comfortable relying on their own social networks as opposed to seeking out other services or utilizing suggestions made by their pediatrician, though not due to lack of trust. When Early Intervention was considered, there just seemed to be other social and financial needs that took precedence. Accessing services was also difficult; information was either confusing or felt inaccessible (Magnusson et al., 2017). If and when mothers decided to engage or participate in Early Intervention, it seemed due to external pressure or perceived pressures and not because they truly wanted to or saw the possible benefits for their child. This forced engagement tended to feel like an inconvenience, and the mother was still not engaged in a way that would be beneficial to either them or their child, reducing their likelihood of remaining in Early Intervention (Magnusson, et al., 2017). One way in which to decrease this disparity, and to see greater levels of minority children involved in Early Intervention, would be to educate the mothers and families. This could be done by engaging them in a conversation about the needs and benefits of these services, providing them with information on how these services can be beneficial and supportive while giving clear and concise information on how to actually access these services.

Minority children are typically disproportionately underrepresented in Early Intervention (Morgan et al., 2012). This is seen consistently, with many contributing factors. Having family

engagement and buy-in is one of those factors; however, this is not the only one. Being appropriately referred to Early Intervention services by your pediatrician or primary care provider is also a factor that contributes to underrepresentation in Early Intervention when these providers are disproportionately making referrals, or in other words, not referring minority children for services. By forty-eight months, minority children (such as black or latinx) were not only disproportionately underrepresented in Early Intervention, but they were also not being evaluated by professionals in regards to communication, attention, or learning problems at levels comparable to their white counterparts (Morgan et al, 2012).

Without question, there are racial disparities in Early Intervention. Confusion may lie in how and why these disparities exist, but consistently minority children are underrepresented in Early Intervention from the time of referral, eligibility, and in the receiving of services. Additionally, time progression plays a role in these disparities. Feinberg, Silverstein, Donahue, and Bliss (2011) found that at nine months, only 9% of children received Early Intervention services that were eligible to do so. Though this percentage was low, it was noted that there were no racial differences or disparities when looking at the services received. In comparison, at 24 months, 12% of the children that were eligible received services; sadly, black children at this age were five times less likely to receive services. These results indicate that disparities grow and develop over time (Feinberg, Silverstein, Donahue, & Bliss, 2011). The reasoning behind this disparity remains unclear. Be that as it may, a trend was identified. It appears that greater racial disparities occurred in children's receipt of services that were related to whether or not they were receiving Early Intervention Services based on a perceived developmental delay or a medical diagnosis or medical condition (Feinberg, Silverstein, Donahue, & Bliss, 2011). This thought that services and disparities exist due to diagnosis is one that was also looked into by Javalkar

and Litt (2017), who found that those children who had a developmental delay as opposed to a diagnosis that were partaking in Early Intervention Services were less likely to receive the services that they need, and would be more likely to abandon services altogether despite still being eligible to receive services. Unfortunately, the families of these children eligible due to a developmental delay instead of a diagnosis also had greater levels of being dissatisfied with services. In comparison, those children and their families who were receiving Early Intervention services due to medical diagnoses were generally more satisfied and had their needs met through services provided by Early Intervention (Javalkar & Litt, 2017).

McManus et al., (2020) did not set out in their study to investigate racial disparities in Early Intervention, nevertheless as they examined characteristics of Early Intervention referral gaps, characteristics of Early Intervention access gaps, and characteristics of Early Intervention service type gaps, they were able to see that white children were more likely to receive an Early Intervention referral in comparison to black children in similar situations. The results of the black children and their families screening results are not as likely to be attributed to a clinical risk in need of a referral, but instead a social concern (McManus et al., 2020). Additionally their study showed that there was also a gap between socioeconomic status, those with higher income potentially having greater discernment to champion their children and acquire appropriate services. Consistent with other studies it was also seen by McManus et al., that those with greater needs due to severe conditions, were more likely to be referred.

Early Intervention services represent an umbrella under which a variety of services are provided. These different services include speech therapy, physical therapy, occupational therapy, music, and art therapy, along with many other services. Enrolment in an Early Intervention agency opens the door to many different possibilities and supports. Racial

disparities in Early Intervention Services continue to vary along with the number of services received. Black non-Hispanic children were less likely to receive physical therapy in comparison to their white peers, and if they did, the intensity of the therapy they received was considerably less. (Khetani, Richardson, & Mcmanus, 2017). Differenciences in socioeconomic status also play a role in disparities in services offered by Early Intervention. Those families with larger incomes were able to access physical therapy along with occupational therapy with greater intensity than those with lower incomes. The work done by Khetani, Richardson, and Mcmanus (2017) also found a difference between those who had public insurance compared to those who had private insurance. The families that had private insurance received more intensive speech therapy. This was a curious discovery as Early Intervention is a free service that is able to be accessed regardless of health insurance and at no cost to the parent as an attempt to alleviate discrepancies based on socioeconomic status; unfortunately, the disparities still exist despite these efforts.

Summary

This literature review first takes a look at the Individuals with Disabilities Education Act, also known as IDEA and how that came about, and the population it originally aimed to support, which was school age children. IDEA has since grown to encompass individuals with developmental delays from birth to 21 years of age. Part C of IDEA, which specifically outlines Early Intervention services that are offered to children from birth to three years of age who present with a developmental delay or disability or are considered to be at a greater risk for developmental delay or disability. In this review the services are outlined, along with the goal of Part C, which is to provide services to all those who are eligible at no cost. Open and universal accessibility was the driven ideal behind Early Intervention.

Though this is how the act was written, the truth is that this was not the case when it came to practice. Three barriers were identified as standing in the way of Early Intervention being universally accessible to eligible children and their families. The first barrier was the determination of eligibility. The tools utilized in order to determine whether or not a child was eligible for services were flawed. These developmental screenings often inaccurately evaluated the child, especially minority non-white children. In order to combat this, it was suggested that different developmental screening tools be utilized in order to determine eligibility for Early Intervention, or perhaps stepping away from relying so heavily on these tools that do not always provide accurate information. Adjusting these instruments so that they may be more accurate is also a serious consideration; however, assessment tools often vary in their reliability and validity, often carrying their own biases.

Referral sources were also investigated, more specifically, those referrals coming from pediatric and primary care facilities. Most families utilize these offices, and they are equipped and able to identify the presence of developmental delays and disabilities. For this reason, they are often referral sources for Early Intervention Services. However, the research shows that they tend to fall short when it comes to this responsibility in a variety of ways. First, pediatricians and primary care providers do not seem to be as knowledgeable in Early Intervention as one would assume. Many reported being unfamiliar with services and the referral process as a whole, turning to fellow staff members with questions. This, in turn, limited the number of referrals being made and the number of children presenting with a developmental delay or disability who were able to access these resources. Pediatricians and primary care providers also delayed reaching out to Early Intervention in hopes that developmental delays would resolve or improve on their own without intervention. This lack of knowledge and understanding also transferred to

families when referrals were made, leaving caregivers to feel hesitant and unlikely to move forward in seeking out services. Pediatricians and primary care providers have a unique relationship with their patients and the families of their patients, one that is often held in high regard. It is important that they are knowledgeable about Early Intervention, the services they provide, and the referral process as a whole. It would behoove these facilities to make a greater effort in educating their staff on the role of Early Intervention and the benefits they offer to their patients. Developing working relationships with their local Early Intervention agency would also improve communication and increase the likelihood of successful referrals and program enrolment. Bridging this gap between pediatricians and primary care facilities and Early Intervention agencies should be paramount.

Lastly, the disparities in representation and services provided for non-white children and low-income households needed to be addressed. These disparities existed throughout assessments in order to determine eligibility, the referrals made by pediatricians and primary care providers, as well as in services received from Early Intervention services. The reasons behind these disparities and the gross underrepresentation of minority children in Early Intervention need to be further investigated. However, work can begin now to rectify these discrepancies in care. It is important that both Early Intervention providers and pediatric and primary care facilities are doing the work necessary to become more culturally competent by realizing that adjustments may be necessary, for example, when working with different cultures and with individuals with different socioeconomic backgrounds.

The development of Part C of IDEA was remarkable. The fact that families are able to receive support and services such as speech and language therapy, physical therapy, and occupational therapy is extraordinary. The unique approach of offering services to the family as

opposed to solely the child has far-reaching benefits. However, as a society, it is our responsibility to continue to question and criticize these social programs, holding them accountable for the promises that they have made. More can and needs to be done in order to ensure that Early Intervention is living up to its ideals to provide quality and universal services to children and their families who may be presenting with a developmental delay or disability or are considered to be at a greater risk. In doing so, we will be able to continue to uplift our children, allowing them to reach their full potential and take advantage of every opportunity.

With this being said this particular study will further investigate the relationship between referral sources and the outcome of services. In doing so the hope is to provide additional knowledge and information on how the referral source may impact the outcome of services. The results of this study will provide Early Intervention agencies with greater context, and understanding on how the outcome of their services are being impacted and what if anything can be done from the very beginning to ensure greater success. This literature review does establish some difficulties that exist with referral sources, however, a quantitative study is still needed in order to more clearly determine the relationship between different referral sources and different outcomes of services.

Chapter 3

Methodology

Research Design

The purpose of this qualitative research study was to gather better understanding on whether or not the source of referral: Parent, Primary Care Physician/Pediatrician, Hospital/NICU, Department of Child and Family Services, Child Care Center, Community Agency, Early Intervention Agency, or "Other" is in any way related to the possible reasons for discharge for the children enrolled in an Early Intervention agency in Boston, Massachusetts. There are several possible reasons for discharge. A child could either age out of services, move out of the service catchment area, or no longer have a qualifying developmental delay or disability. These outcomes are considered to be positive. When a family chooses to refuse services or are no longer responsive to agency outreach, this is considered to be a negative outcome.

A retrospective quantitative comparative research design was utilized for this study. The present study was done through a secondary analysis where data had already existed, due to the recording and documentation process within the Early Intervention agency. Necessary agency documentation includes a record of the original referral source, along with the reasoning behind the conclusion of services. Utilizing a secondary analysis was more cost effective and time efficient. This research design allowed for existing data to be utilized, in order to compare the

impacts of different referral sources and compare them to the different outcomes of children enrolled in an Early Intervention Agency.

Sample

In order to be enrolled in the Early Intervention Agency utilized in this study, an initial intake meeting needed to take place. Once the intake is complete an assessment is done and eligibility is determined. If a child is eligible for services, an Individualized Family Service Plan is created and services may begin. The participants utilized in this study were children who were determined to be eligible for services and had created an IFSP. Those who were referred for services but were determined ineligible, or had not yet created an IFSP were not utilized in this study. The participants were sampled from all the cases closed in 2019. Participants were not limited based on their gender, race, ethnicity, socioeconomic status, length of program enrollment, or services received.

An agency employee extracted all personal identifying information from the data. For the purpose of this study identifying information was defined as the child's full name, child's social security number, and home address. This study collected data from 270 participants.

Procedure

Marywood University's IRB's Exempt Review Committee Application was completed and an Exempt Review was granted (Appendix A). After receiving IRB approval, a contact letter was drafted and emailed to North Suffolk's Harbor Area Early Intervention Agency. This email

described the purpose, intent, and benefits of this study to the agency (Appendix B). North Suffolk's Harbor Area Early Intervention agreed to participate in this study, and approved the utilization of their data (Appendix C). An agency employee obtained the data from 270 of the children's case files that fell within the parameters outlined in the sample section.

The data retrieved from the child's case files were the following: referral source, reasons for referral, age at referral, age at discharge, duration in Early Intervention, discharge reason, written language, spoken language, gender, race, ethnicity, and culture. Demographic information was limited to the child's age, gender, race, ethnicity, and the primary language spoken in the home. This demographic information was utilized in the supplemental analysis. After the data was collected and reviewed it was analyzed utilizing SPSS.

Analysis of Data

Subproblems

1. What are the outcomes of referrals made by the parent for a child enrolled in an Early Intervention agency, was analyzed using a frequency distribution.
2. What are the outcomes of referrals made by the primary care physician for a child enrolled in an Early Intervention agency, was analyzed using a frequency distribution.
3. What are the outcomes of referrals made by the hospital/NICU for a child enrolled in an Early Intervention agency, was analyzed using a frequency distribution.
4. What are the outcomes of referrals made by the department of child and family services for a child enrolled in an Early Intervention agency, was analyzed using a frequency distribution.

5. What are the outcomes of referrals made by a child care center for a child enrolled in an Early Intervention agency, was analyzed using a frequency distribution.
6. What are the outcomes of referrals made by a community agency for a child enrolled in an Early Intervention agency, was analyzed using a frequency distribution.
7. What are the outcomes of referrals made by an Early Intervention agency for a child enrolled in an Early Intervention agency,was analyzed using a frequency distribution.
8. What are the outcomes of referrals made by "other" for a child enrolled in an Early Intervention agency, was analyzed using a frequency distribution.
9. What is the relationship between the different referral sources i.e, parent, primary care, hospital/NICU, all outside agencies, and the discharge reasons for children enrolled in an Early Intervention agency, was analyzed utilizing a Chi Square test of independence analysis.

Supplemental Analysis

1. Is there a difference among reasons for referral and duration of services, was analyzed utilizing a multiple linear regression.
2. Is there a relationship between gender and the reasons for referral, was analyzed utilizing a Chi Square test of Independence.
3. Is there a difference in gender for duration of services, was analyzed utilizing an independent-samples *t* test.
4. Is there a relationship between age at referral and reasons for discharge, was analyzed utilizing a Chi Square test of Independence.
5. Is there a relationship between age at referral and reasons for referral, was analyzed utilizing a Chi Square test of Independence.

6. Is there a difference between age at referral and reasons for discharge, was analyzed utilizing a one-way ANOVA.
7. Is there a relationship between language spoken at home and reasons for discharge, was analyzed utilizing a Chi Square test of Independence.
8. Is there a relationship between “late” referral ages and the referral source, was analyzed utilizing a Chi Square test of Independence.
9. Is there a relationship between the language spoken at home and the referral source, was analyzed utilizing a A Chi Square test of Independence.
10. Is there a relationship between ethnicity and reasons for referral, was analyzed utilizing a Chi Square test of Independence.
11. Is there a relationship between ethnicity and the referral source, was analyzed utilizing a Chi Square test of Independence.
12. Is there a relationship between ethnicity and reason for discharge, was analyzed utilizing a Chi Square test of Independence.

Chapter Four

Data Analysis

Introduction

An Early Intervention agency located in Boston, Massachusetts was selected to be utilized for this study. This particular agency services the greater Boston area, which consists of a diverse population with a large variety of races, cultures, and socioeconomic statuses.

The data utilized for this study was collected by a long-time employee of the agency. This employee used a random number generator in order to select 270 closed cases. This number was predetermined based on what a recommended sample size would be for approximately 800 cases, which was the total number of cases that had been closed during the year 2019. Once the cases had been randomly selected, this employee removed all identifying information. After which she placed the requested data into a spreadsheet. The spreadsheet was sent via email to the primary investigator of this study. It was then uploaded into SPSS by the primary investigator.

Once the data was uploaded into SPSS, all string variables were recorded into numeric variables. Additionally, values were assigned to all categorical and nominal variables. All missing data points were coded as zeros. After the data had been appropriately reviewed and examined for quality, it was possible to run the appropriate tests and analyze the results.

Demographic Information

The data utilized in this study was collected from an Early Intervention Agency located in the greater Boston area of Massachusetts. During the year 2019, approximately 800 children were exited from this particular agency's services for a variety of reasons. The tables below outline the demographic information of the children and their families utilized in this study.

Table one displays the very large variety of races of the children whose data was utilized for this study. The three largest races represented were white with a frequency of 61.5%, American Indian/Alaska with a frequency of 12.2% and Black or African American with 9.3%.

Table 1: Frequency of Represented Races

Race	Frequency	Percent
White	166	61.5%
Black or African American	25	9.3%
Asian	7	2.6%
American Indian/Alaska	33	12.2%
Native Hawaiian or Pacific Islander	2	0.7%
Black or African American & White	12	4.4%
Black or African American & American Indian	1	0.4%
White & Asian	1	0.4%
White & American Indian / Alaska Native	12	4.4%
Total	259	95.9%

Table two displays the variety of cultures represented by the children whose data was utilized for this study. Majority identified as being American from either the United States of America or Canada with a frequency of 18.1%. Many identified as Central American at 16.3% and Salvadoran at 14.4%. African American had a smaller representation with a frequency of 5.6%. Please view Appendix D for a larger table containing a further breakdown of “other”.

Table 2: Frequency of Represented Cultures

Culture	Frequency	Percent
American (USA & Canada)	49	18.1%
South American	28	10.4%
Central American	44	16.3%
Salvadoran	39	14.4%
Dominican	12	4.4%
Puerto Rican	15	5.6%
Asian Indian/Pakistani	5	1.9%
Middle Eastern	2	0.7%
European	4	1.5%
African American	15	5.6%
African	15	5.6%
Haitian	2	0.7%
Brazilian	4	1.5%
American & African American	3	1.1%
American & Central American	4	1.5%
Salvadoran & Central American	2	0.7%
Other	11	4.1%
Total	254	94.1%

Table three displays the number of male and female children represented in the collected data set. Males represented the majority of this data set with a percentage of 64.1%.

Table 3: Gender Breakdown

Gender	**Frequency**	**Percentage**
Male	173	64.1%
Female	97	35.9%
Total	270	100%

Table four displays the languages utilized in the home. A majority of the households utilized either English, Spanish, or a combination of both. This was evident in both verbal and written communications. English and Spanish were recorded as the spoken language in the home at an equal frequency of 44.8% indicating that almost 90% of the languages spoken in the home were English and Spanish. When looking at written language, English remained to be the largest written language at a frequency of 43.3%, closely followed by Spanish at 34.8%.

Table 4: Languages Utilized in the Home

Spoken Language	**Frequency**	**Percentage**
None recorded	11	4.1%
English	121	44.8%
Spanish	121	44.8%
Portuguese	5	1.9%
Arabic	8	3.0%
Chinese	1	0.4%
Other	3	1.1%
Total	270	100.1%
Written Language	**Frequency**	**Percentage**
None Recorded	54	20%
English	117	43.3%
Spanish	94	34.8%
Portuguese	4	1.5%
Other	1	0.4%
Total	270	100%

Table five displays the ethnicities of the children whose data was utilized for this study, a majority of which were Hispanic/Latino at 57.4%.

Table 5: Frequency of Represented Ethnicities

Ethnicity	**Frequency**	**Percentage**
Hispanic/Latino	155	57.4%
Not Hispanic/Latino	104	38.5%
Total	259	95.9%

Table six identifies the various areas of observed or perceived delay that led to a referral for Early Intervention services. An observed or perceived delay in communication skills was the number one reason for a referral to Early Intervention services making up 48.1% of the reasons for referral. Communication was followed by an established condition as a reason for referral with a frequency of 10.4%.

Table 6: Reasons for Referral

Referral Reason	**Frequency**	**Percentage**
Adaptive	2	0.7%
Communication	130	48.1%
Motor	23	8.5%
Social/Emotional/Behavioral	9	3.3%
Overall Development	15	5.6%
Premature/Traumatic birth	19	7.0%
Established Condition	28	10.4%
At Risk Concerns	17	6.3%
Total	243	89.9%

Table seven outlines the different referral sources recorded in the data collected for this study. Though there were a variety of referral sources, the most prevalent referral source was the primary care physician with a frequency of 54.4%, followed by the parent of the child at 14.4%. Many referrals were also made by the Hospital/NICU at 7.8% and the Department of Child and Family Services at 10%.

Table 7: Referral Sources

Referral Source	**Frequency**	**Percentage**
Parent	39	14.4%
Primary Care	147	54.4%
Hospital/NICU	21	7.8%
DCF	27	10.0%
Child Care Center	1	0.4%
Community Agency	3	1.1%
Early Intervention Agency	4	1.5%
Other	28	10.4%
Total	270	100%

Table eight outlines the different outcomes or reasons for discharge. A majority of the cases have no contact/lost contact as the reason for discharge at 24.8% closely followed by a familial choice to decline services at 24.4%.

Table 8: Reasons for Discharge

Discharge Reason	**Frequency**	**Percent**
Three Y/O__LEA Referral	53	19.6%
Three Y/O Not Eligible for LEA__ No Referral Made	26	9.6%
Three Y/O Not Eligible for LEA__ Referrals Made	14	5.2%
Family Choice___ Declined Services	66	24.4%
Less Than Three Y/O__Not Eligible	28	10.4%
No Contact/Lost Contact	67	24.8%
Transferred to another MA EI Program	6	2.2%
Child Moved Out of State	10	3.7%
Total	270	100%

Subproblem One

Subproblem one, what are the outcomes of referrals made by the parent for a child enrolled in an Early Intervention agency, was answered by using a frequency distribution.

Table nine shows the outcome frequencies of those who were referred by a parent. The largest outcome with a frequency of 35.9% was the child turning three years old and being referred to special education as eligibility for early intervention ends at age three. The second outcome with the greatest frequency was the families choice to decline services with a frequency of 17.9%. Both the child moving out of state or being transferred to another MA Early Intervention program were the outcomes with the least amount of frequency, at 2.6% each.

Table 9: Outcomes of Parental Referral Source

Outcomes	**Frequency**	**Percentage**
Three Y/O__LEA Referral	14	35.9%
Three Y/O Not Eligible for LEA__ No Referral Made	5	12.8%
Three Y/O Not Eligible for LEA__ Referrals Made	2	5.1%
Family Choice___ Declined Services	7	17.9%
Less Than Three Y/O__Not Eligible	5	12.8%
No Contact/Lost Contact	4	10.3%
Transferred to another MA EI Program	1	2.6%
Child Moved Out of State	1	2.6%
Total	39	100%

Subproblem Two

Subproblem two, what are the outcomes of referrals made by the primary care physician for a child enrolled in an Early Intervention agency, was answered by using a frequency distribution.

Table ten shows the outcome frequencies of those who were referred by their primary care physician. The outcome with the greatest frequency was a family choice to decline services at 23.8%, followed by a loss of contact at 21.1%, and then a referral made to special education at three years old with a frequency of 19.7%.

Table 10: Outcomes of Primary Care Physician Referral Source

Outcomes	**Frequency**	**Percentage**
Three Y/O__LEA Referral	29	19.7%
Three Y/O Not Eligible for LEA__ No Referral Made	15	10.2%
Three Y/O Not Eligible for LEA__ Referrals Made	11	7.5%
Family Choice___ Declined Services	35	23.8%
Less Than Three Y/O__Not Eligible	15	10.2%
No Contact/Lost Contact	31	21.1%
Transferred to another MA EI Program	5	3.4%
Child Moved Out of State	6	4.1%
Total	147	100%

Subproblem Three

Subproblem three, what are the outcomes of referrals made by the hospital/NICU for a child enrolled in an Early Intervention agency, was answered by using a frequency distribution.

Table eleven shows the outcome frequencies of those who were referred by the hospital or NICU. The outcome with the greatest frequency was a loss of contact at 38.1%, followed by a family choice to decline services at 23.8%.

Table 11: Outcomes of Hospital/NICU Referral Source

Outcomes	**Frequency**	**Percentage**
Three Y/O__LEA Referral	1	4.8%
Three Y/O Not Eligible for LEA__ No Referral Made	1	4.8%
Family Choice___ Declined Services	5	23.8%
Less Than Three Y/O__Not Eligible	4	19.0%
No Contact/Lost Contact	8	38.1%
Child Moved Out of State	2	9.5%
Total	21	100%

Sub Problem Four

Sub problem four, what are the outcomes of referrals made by the department of child and family services for a child enrolled in an Early Intervention agency, was answered by using a frequency distribution.

Table twelve shows the outcome frequencies of those who were referred by the Department of Child and Family Services. Family decision to decline services was the greatest outcome with a frequency of 33.3%. The second most frequent outcome was a special education referral at three years old with a frequency of 22.2%.

Table 12: Outcomes of Department of Child and Family Services Referral Source

Outcomes	**Frequency**	**Percentage**
Three Y/O__LEA Referral	6	22.2%
Three Y/O Not Eligible for LEA__ No Referral Made	3	11.1%
Three Y/O Not Eligible for LEA__ Referrals Made	1	3.7%
Family Choice___ Declined Services	9	33.3%
Less Than Three Y/O__Not Eligible	3	11.1%
No Contact/Lost Contact	5	18.5%
Total	27	99.9%

Sub Problem Five

Sub problem five, what are the outcomes of referrals made by a child care center for a child enrolled in an Early Intervention agency, was answered by using a frequency distribution.

Table thirteen shows the outcome frequencies of those who were referred by a childcare center. Only a single case in this study fell under this category and the outcome resulted in a referral to special education at three years old.

Table 13: Outcomes of Child Care Center Referral Source

Outcomes	**Frequency**	**Percentage**
Three Y/O__LEA Referral	1	100%
Total	1	100%

Sub Problem Six

Sub problem six, what are the outcomes of referrals made by a community agency for a child enrolled in an Early Intervention agency, was answered by using a frequency distribution.

Table fourteen shows the outcome frequencies of those who were referred by a community agency. There were three cases in this study that identified the referral source as being a community agency resulting in discharge reason of turning three with no special education referral, familial decision to decline services, and a child who had moved out of state.

Table 14: Outcomes of CommunityAgency Referral Source

Outcomes	**Frequency**	**Percentage**
Three Y/O Not Eligible for LEA__ No Referral Made	1	33.3%
Family Choice___ Declined Services	1	33.3%
Child Moved Out of State	1	33.3%
Total	3	99.9%

Sub Problem Seven

Sub problem seven, what are the outcomes of referrals made by an Early Intervention agency for a child enrolled in an Early Intervention agency, was answered by using a frequency distribution.

Table fifteen shows the outcome frequencies of those who were referred by an early intervention agency. Of those that were referred by an early intervention agency, 50% received a referral for special education at three years old.

Table 15: Outcomes of Early Intervention Agency Referral Source

Outcomes	**Frequency**	**Percentage**
Three Y/O__LEA Referral	2	50%
Three Y/O Not Eligible for LEA__ No Referral Made	1	25%
No Contact/Lost Contact	1	25%
Total	4	100%

Sub Problem Eight

Sub problem eight, what are the outcomes of referrals made by “other” for a child enrolled in an Early Intervention agency, was answered by using a frequency distribution.

Table sixteen shows the outcome frequencies of those who were referred by “other”. A majority of these resulted in an outcome of no/lost contact at 64.3%.

Table 16: Outcomes of “Other” Referral Source

Outcomes	**Frequency**	**Percentage**
Family Choice___ Declined Services	9	32.1%
Less Than Three Y/O__Not Eligible	1	3.6%
No Contact/Lost Contact	18	64.3%
Total	28	100%

Sub Problem Nine

Sub problem nine, what is the relationship between the different referral sources i.e, parent, primary care, hospital/NICU, all outside agencies, and the discharge reasons for children enrolled in an Early Intervention agency, was analyzed utilizing a Chi Square test of independence analysis. In order to run an effective Chi Square analysis that did not violate the assumptions, and therefore the integrity of the statistical analysis, the data was reorganized into more concise groupings.

A Chi Square test of independence was calculated comparing whether the type of referral source and the reasons for discharge were related. A significant relationship was found, (X^2 (6) = 13.75, p <.05). The results show that 53.8% of those children whose parents made the referral were significantly more likely to have a child who was discharged because a child turned three compared to 28.2% whose child was discharged due to family declining services as well as 17.9% of those children who were discharged because they were not eligible. They were more likely to be discharged because the child turned three as opposed to those whose family declined or the child was no longer eligible. Of the children who were discharged because they turned three years old, they were more likely to have been referred by primary care 59.1%, parent 22.6%, or outside agencies 16.1% compared to referrals made by the hospital/NICU at 2.2% (Table 17). The effect size was small (Cramer's V = .165). Thus, the null hypothesis, that there was no relationship between the referral sources and the reasons for discharge, was rejected.

Table 17: Results of Chi Square test of independence analysis

		Discharge Reason		
Referral Source		Family Declined	Child Turned 3YO	Not Eligible
Parent	% Within Referral Source	28.2%	53.8%	17.9%
	% Within Discharge	10.4%	22.6%	16.3%
	Adjusted Residual	-2.1	2.2	.0
Primary Care	% Within Referral Source	44.9%	37.4%	17.7%
	% Within Discharge	62.3%	59.1%	60.5%
	Adjusted Residual	.4	-.4	.0
Hospital/NICU	%Within Referral Source	61.9%	9.5%	28.6%
	%Within Discharge	12.3%	2.2%	14.0%
	Adjusted Residual	1.7	-2.8	1.4%
All Agencies	%Within Referral Source	45.7%	42.9%	11.4%
	%Within Discharge	15.1%	16.1%	9.3%
	Adjusted Residual	.2	.6	-1.1

Supplemental Analysis

Question one, is there a difference among reasons for referral and duration of services? A multiple linear regression was calculated predicting a child's duration of services based on their reason for referral. The regression equation was not significant ($F(6, 45.300) = .095$, $p > .05$. The reason for referral is not a significant predictor of a child's duration of services.

Question two, is there a relationship between gender and the reasons for referral? A Chi Square test of independence was calculated comparing the reasons for referral and gender. No significant relationship was found (X^2 (6) = 5.373, p>.05). Reasons for referral and Gender of the child appear to be independent of one another, with no significant relationship.

Question three, is there a difference in gender for duration of services? An independent-samples *t* test comparing gender and duration of services showed a significant difference between the two groups ($t(268) = 2.506$, $p < .05$). The mean of the duration of services for males (M = 9.8, *sd* = 8.239) was significantly higher than the mean of the duration of services for females (M = 7.38 , *sd* = 7.113). There was a small to moderate effect size (Cohen's d =.318).

Question four, is there a relationship between age at referral and reasons for discharge? A Chi Square test of independence was calculated comparing the age at referral and the reason for discharge. A significant interaction was found, ($X^2(4) = 28.92$, $p <.05$). Those who lost contact were 62.7% more likely to have been an early referral compared to late referrals at 29.6%. The effect was small (Cramer's V = .231).

Question five, is there a relationship between age at referral and reasons for referral? A Chi Square test of independence was calculated comparing the age at referral and the reasons for referral. A significant interaction was found ($X^2(6) = 84.89$, $p <.05$). Early referrals were 58.8%

more likely to be due to a communication referral compared to late referrals at 41.2%. The effect size was large (Cramer's V = .674).

Question six, is there a difference between age at referral and reasons for discharge? A one-way ANOVA comparing age at referral and reasons for discharge was utilized. A significant difference was found among ages at referral ($F(2,267) = 15.569$, $p < .05$). Tukey's HSD was used to determine the nature of the difference between the age at referral and the reasons for discharge. This analysis revealed that children who were referred later were more likely to be ineligible for services ($M = 45.47$, $sd = 4.325$). The effect size was moderate ($eta^2 = .104$).

Question seven, is there a relationship between language spoken at home and reasons for discharge? A Chi Square test of independence was calculated comparing language spoken in the home and reason for discharge. No significant relationship was found ($X^2(4) = 2.321$, $p > .05$. There does not appear to be a relationship between the language spoken in the home and the reasons for discharge.

Question eight, is there a relationship between "late" referral ages and the referral source? A Chi Square test of independence was calculated comparing late referrals and referral sources. No significant relationship was found ($X^2(1) = 1.82$, $p > .05$. There does not appear to be a relationship between those who were referred later and the source of referral.

Question nine, is there a relationship between the language spoken at home and the referral source. A Chi Square test of independence was calculated comparing the relationship between the language spoken at home and the referral source. A significant interaction was found ($X^2(3) = 16.742$, $p < .05$) Homes where Spanish was the primary language spoken were more likely (72.1%) to have the primary care as their referral source, than homes where English was the primary language spoken. The effect size was small (Cramer's V = .273).

Question ten, is there a relationship between ethnicity and reasons for referral? A Chi Square test of independence was calculated comparing the relationship between ethnicity and reasons for referral. No significant relationship was found (X^2 (5) = 1.149, p >.05). There does not appear to be a relationship between ethnicity and the reasons for referral.

Question 11, is there a relationship between ethnicity and the referral source. A Chi Square test of independence was calculated comparing ethnicity and the referral source. No significant relationship was found (X^2 (3) = 5.833, p >.05). There does not appear to be a relationship between ethnicity and referral source.

Question 12, is there a relationship between ethnicity and reason for discharge. A Chi Square test of independence was calculated comparing the relationship between ethnicity and reasons for discharge. No significant relationship was found (X^2 (2) = 1.857, p >.05). There does not appear to be a relationship between ethnicity and reasons for discharge.

Chapter Five

Discussion

Summary

This study investigated a possible relationship between different referral sources and the reasons for discharge among children enrolled in an Early Intervention program in Boston, Massachusetts. It was hypothesized that there was a relationship between the different referral sources and the reasons for discharge for a child enrolled in an Early Intervention program. Results found that there was a significant relationship between the different referral sources and the discharge reasons for children enrolled in an Early Intervention program in Massachusetts. The null hypothesis, which stated that there was no relationship between the different referral sources and the discharge reasons for a child enrolled in an Early Intervention program, was rejected.

Discussion

The Early Intervention program that was utilized for this study is located in Boston, Massachusetts and services the greater Boston area. This area is very diverse, with a multitude of races, ethnicities, and cultures. A list of the different cultures of the families utilized in this study can be found in Appendix X. Though the majority of the races weren white, with a frequency of 61.5%, there were over five different races and combinations of races recorded. When examining ethnicity, Hispanic/Latino represented the majority with a percentage of 57.4%. It was identified that many of those enrolled in the program spoke both English and Spanish in the home. A great opportunity for future research would be determining what relationships exist amongst diversity and Early Intervention as it pertains to referral reasons, sources, and discharge reasons among the children enrolled.

Based on the research findings there was no significant relationship between the language spoken at home and reasons for discharge. This is vital when discussing if language can create a barrier to accessing services. However, it is important to note the environment. Since so many of those enrolled in this particular agency spoke both English and Spanish in the home, language may not have been a barrier for this particular location and demographic. This provides an excellent opportunity for additional research on whether or not language can be a barrier to receiving or providing Early Intervention services, more specifically in less diverse environments. In this environment, those who identified their primary language spoken at home as Spanish were more likely to have their primary care physician as their referral source. With this knowledge, Early Intervention agencies can make adjustments accordingly which may include hiring multilingual staff, and communicating with referral sources in the area such as primary care physicians and child care centers with materials in both English and Spanish.

When examining referral sources, over 50% of the referrals were made by the child's primary care physician. This is a great indication of the value of the primary care provided when discussing Early Intervention and the referral process. However, this is a startling percentage when taking a look at what Edwards (2018) uncovered, which was that a majority of Pediatric Residency Training Directors had minimal knowledge of Early Intervention or understanding of the process. This would undoubtedly trickle down to the pediatricians that they are training. When one lacks knowledge and understanding it is difficult to provide accurate information. Many families depend on their primary care provider to act as a resource and a guide for them as they care for their child, wanting to ensure that they are providing them everything they need in order to grow and develop. The results of this study also show that when a child is referred by

their primary care provider, familial choice to decline services is the highest reason for discharge. This is not only alarming, but unacceptable.

In Tang et al., (2012) we see the way in which pediatricians adopt this "wait and see" phenomenon, thinking that with time perceived developmental delays will self-correct. However, the data shows that when a child has an early referral, they are more likely to be discharged due to a loss of contact. When discharge occurs due to a loss of contact, the child is no longer utilizing services that they are still eligible for, making this an undesirable outcome. This school of thought shared by the pediatrician that waiting is best leads indirectly to less services for children, despite the attempt at an earlier intervention with an early referral. Future studies can further investigate discharge reasons due to a loss of contact in order to determine ways in which to bolster retention within Early Intervention agencies.

As the largest referral source, physicians hold a great amount of responsibility. Increasing education, awareness, along with improving referral channels for primary care physicians will hopefully diminish this outcome. Overall, child care centers, community agencies, the Department of Child and Family Services had far lower referral rates. Working to educate these entities, and providing them with clear and easy avenues to make these referrals could assist in providing more children and their families with this opportunity to receive these beneficial services.

Though far fewer parents were seen as referral sources they were in fact the next greatest referral source in frequency after primary care physicians. Increasing parent education, and exposure can assist in increasing this percentage from 14%. When the parent was the referral source the discharge reason that had the greatest frequency was ineligibility due to the child turning three years old. This is a far better outcome, as it shows utilization of the services until

they were no longer available. When considering ways in which to support Early Intervention, increasing parent education, and increasing parental referrals would have the largest benefit. As this would in turn increase the number of children who are remaining within Early Intervention as long as they were eligible. Studies by researchers such as Magnusoon, Minkowitz, Kuhlthau, Caballero, and Mistry (2017) have worked to investigate familial buy in, and understanding, and Early Intervention services and maintain enrollment. Determining how to increase parental referrals could go a long way in increasing the number of children being serviced and receiving support. This is beneficial for the child, their family, the early intervention agency as well as the community as a whole.

Once a child is enrolled with an Early Intervention agency there are a variety of reasons why they may be discharged from services. Ideally ineligibility would be the highest reason for a child to be discharged. However, the data showed that a majority of those discharged in 2019 were due to no/loss of contact at 24.8%. This is followed closely by the familial choice to decline services at 24.4%. These are both the most undesirable reasons for discharge, as they do not fully take advantage of the services available. One of the unique aspects of Early Intervention is that it is voluntary, no child and their family is mandated to partake in these services. However, it is startling to see such a large number of families have made the choice to forgo support towards achieving their goals, which is the purpose of Early Intervention. The results of this study can be utilized to further investigate the high rates of familial decline, along with no/loss contact. Addressing this would hopefully increase familial involvement in services and in turn decrease the amount of children who are being discharged before no longer being eligible.

There are universal benefits in receiving Early Intervention services, regardless of the reasons why a child might be enrolled in services. When examining why a child is referred for

services and how long they remain in the program there is no significant difference. One can infer that the referral source plays a greater role as opposed to what developmental delays they have when looking at how long services are utilized. Many believe that gender plays a large role when looking at children who are presenting with a developmental delay or disability. Results of this study show that there is no relationship between gender and the reasons for referral, indicating that males are not more likely to be referred to services due to a communication delay for example than female children. Future studies would be best focused on educating referral sources as opposed to factors such as reasons for referrals and differences amongst genders when investigating how to increase enrollment retention.

When examining when a referral was made and how that possibly related to the reason they were discharged it was seen that those who were referred later were more likely to be discharged because they were no longer eligible for services. This diminishes the time they are able to receive services, and makes the referral process to special education more difficult as the service coordinator has less time to assist and support in this transition. Early Intervention services must end at three years old which does not provide much time for late referrals to build connection and support.

Implications

There are many implications of this study. The acquisition of this information could allow for an adjustment in how Early Intervention agencies equip their staff members to support those enrolled in Early Intervention services. Once a referral is received, agencies can guide their employees to utilize targeted strategies indicative of the different supports needed due to a particular referral source. An example of this would be if a referral is made by a source other than the parent, the agency staff could implore additional strategies to garner greater familial

buy-in. The results of this investigation highlighted the difference when a family was in fact the referral source. Families who were not active in the referral process may need additional information in order to understand the full scope of services available to them, and the benefits that are possible if they remain engaged in services.

The knowledge captured by this study could be utilized to open doors to program development with the goal of servicing families enrolled in Early Intervention services resolved to building relationships with others in similar situations. This opportunity could allow for families to have connections with others who are navigating similar situations, determining how best to utilize the new and considerable services available to them.

When investigating Early Intervention agencies and services, the information gathered is valuable to each of the stakeholders involved. These stakeholders include, but are not limited to, the child enrolled in Early Intervention along with their family, the agency that provides them with services, the varying referral sources, the education system, and our society as a whole. When a community invests in their children they reap the benefits for generations. Children and their families are able to gain a greater level and quality of services when their needs are being understood and prioritized. If a family is entering services with the knowledge and understanding of what is available to them, and how to access these resources they are more likely to walk away from services having the tools and skills necessary to achieve their goals.

However, in order to achieve this level of success; attention and dedication must be paid throughout the process, beginning with referral sources. This study shows how valuable a referral source from the parent is, having the largest yield of children who remain in services until they are no longer eligible. Primary care physicians and pediatricians are also a critical resource for families, and much more is needed so that they are able to appropriately guide them

to access and utilize Early Intervention services. Early Intervention agencies and their staff are capable, and able to support these children and their families, but it is necessary that they have the support of their local community. Early Intervention agencies are better equipped to support children and their families when they have the opportunity to anticipate their needs. This study provides some insight into that, by giving agencies the ability to garner greater understanding of the impact of the referral source. With this information efforts can be made to create greater connections with local primary care and pediatric practitioners, which are common referral sources. Strategic and conscientious efforts can be made to follow up with these primary care and pediatric practitioners and the families after a referral is made in hopes to maintain relationships, and retention within an agency's program. This potential to work collaboratively is a new opportunity allowing for elevated support for these children and their families.

As Early Intervention agencies gain greater success in their efforts to support children and their families, there is an understanding that the special education system will also benefit. Those who are receiving and consistently utilizing services earlier on may alleviate the need to utilize special education services in the future. This would diminish the strain felt by the special education system to support incoming students with a variety of needs with less than ideal access to resources. The “wait and see” ideology leads to delays in service access and symptoms becoming pervasive. There becomes an increased need for intervention and access to resources as time continues to elapse. The results of the “wait and see” ideology are discordant to what could be possible if early detection was supported and there were proactive efforts made. This study highlights this, and its implications can extend beyond Early Intervention agencies and into the special education sphere.

Limitations

The first limitation that the investigator identified was the location of the study. The agency utilized for this study is located in Boston, Massachusetts. The investigator highlighted that since a singular agency was being utilized it would limit the generalizability of the findings. When considering how these results would relate to agencies in differing neighborhoods, as well as different states this remained a limitation of the study. The investigator also identified that the study would be unable to account for some possible unknown factors that may contribute to various reasons for discharge such as a change of address, or an inability for the service coordinator to successfully contact the family. This also remained a limitation. A limitation that was not previously anticipated was the impacts of a smaller sample size. In general, there was not enough saturation in each cell in order to run a Chi Square analysis that did not violate assumptions. For this reason, utilizing data from a singular year was a limitation.

Future Research

There are many possibilities for future research, this field is a relatively under researched one and this study, though fruitful, is only the beginning. One option for future research would be conducting the exact same study, while looking at closed cases from multiple years. This change would allow for a greater number of cases to examine. Increasing the amount of years where data was collected would allow for a more robust data set, and greater opportunity for Chi Square analysis without needing to combine, or collapse some of the categories. There is also a possibility that investigating numerous years could also uncover trends throughout the years. These trends could be compared to changing local initiatives, fluctuating governmental trends, differences in governmental funding, and more. This would bring to light the diverse elements possibly impacting referrals and outcomes within the Early Intervention Agency. As a non-profit,

government supported agency, Early Intervention is intrinsically connected to its community. It would be serviceable to the public for future research to explore these connections further.

Utilizing different Early Intervention agencies from different cities and states would also be an excellent opportunity for future studies. It is clear from the demographic information in this study that the particular agency utilized contains a lot of diversity. A separate study could investigate to see if diversity plays a role in familial involvement and commitment to Early Intervention services. It is possible that variations could be seen when comparing different cities, states, along with different regions. This insight might allow for future investigations on how to consider demographic information when working to increase familial involvement and commitment to Early Intervention services. A version of this study with a greater focus on demographic information could also aim to investigate if language significantly impacts familial involvement and commitment in Early Intervention services.There are a variety of personal information that could be considered such as socioeconomic status, immigration status, and familial make up when exploring future research possibilities. These qualities in particular have large impacts on individuals and are often considered large parts of a person's identity, making it worthy of further investigation in this context.

The current study was a quantitative study, which provided a great overview of the situation at hand. However, for as much insight as it provided, it also left many questions unanswered. A qualitative study would be a great approach for future research, this form of analysis would provide rich context that is not always available when utilizing a quantitative methodology. There are two valuable routes that could include a qualitative methodology. The first is conducting a study that focuses on the referral sources. Investigating what led the referral source to make their referrals, and what, if any, follow up they had after making referrals.

Interviews could seek out to better understand what the referrals expectations were, and if they made continuous efforts maintain relationships with local Early Intervention Agencies. Greater understanding of the referral source could lead to more poignant referrals. The second is to speak directly with families on their perceptions of their time in Early Intervention and the reasons why they have chosen to terminate services despite remaining eligible. This particular study could assist in determining what barriers exist for families in regards to accessing Early Intervention services, and what might be impacting their ability to commit or invest in services. The more that is learned about the familial experience, allows for greater and more poignant efforts to improve this experience and decrease any barriers to full utilization of the services available.

Another option for future research is one that is focused on Early Intervention agency staff and administrators. Both a quantitative and qualitative study involving Early Intervention staff and administrators would be fruitful and informative. There is potential that this research could provide an opportunity to better understand the relationships that are built between referral sources. How do they think the referral sources impact their relationships with those enrolled in services, as well as perceived benefits and barriers regarding referral sources. A future study with a focus on staff and administrators at an Early Intervention agency would also be able to explore their relationships with those enrolled in services, and how they differ between those that remain enrolled and those who choose to not utilize services despite remaining eligible. Specifically, what experiences do these employees have with familial decline, and loss of contact? What suggestions would they have for families, referral sources, and other stakeholders? There would be immense value in investigating the employee's experiences and their sentiments involving their field. Considering questions such as: How do employees at an Early Intervention agency discuss concerns involving resources, burnout, and staff turnover rates? Early Intervention is a

growing field that requires more investigation and research in order to continue to deliver on the commitment it has made to society's children and their families. Early Intervention requires societal commitment, and one way to do this is through investment in research to better develop its success.

A great continuation of this study would be one that centers around those who were referred to the education system. A goal of such a study could be to investigate how prepared were these individuals for the education system considering their time utilizing Early Intervention services. Both a quantitative and qualitative investigation would be beneficial in determining the role that Early Intervention played on their transition into the special education system. Were there benefits to their utilization of Early Intervention services? Could there have been a more successful transition if there had been a previous utilization of Early Intervention services? This study would be able to focus on those that were enrolled in Early Intervention and are currently navigating this transitional time. Focus could be directed to those employed within the special education system, and could illuminate their perceived differences between those who had utilized Early Intervention resources, and those who had not.

If a future student was interested in adding on to this present study, an interesting and potentially fruitful extension of this investigation could explore the utilization of services during, and or immediately after the Covid-19 pandemic. This study was purposeful to exclude dates that coincided with the pandemic. However, the impact that such a pandemic would have on services such as Early Intervention are undeniable. During the pandemic efforts were undoubtedly made to alter the way services were accessed by those enrolled in Early Intervention agencies and an exploration of the outcomes of these alterations would contribute a great deal to the literature. As time moves further and further away from the pandemic, its impact still lingers. A study could be

conducted to examine the differences in referral sources, along with the utilization of services both during and after the pandemic. If this exact study was replicated utilizing cases that were closed after the pandemic, the results could be compared to the results of this study, providing some insight on what, if any impact occurred. By extending this study to investigate the times during and after the pandemic, a unique opportunity for the agency would be uncovered; allowing them access to evaluate the success of their efforts to maintain continuity in the services that they provided for those enrolled in their agency. This unique opportunity could inspire this specific agency, other Early Intervention agencies, and the committed stakeholders.

Conclusion

There are many families who are not taking advantage of the services available to them through Early Intervention. This study indicated that families are ending services despite being eligible to receive them, while others are entirely unresponsive to agency outreach. It is paramount that this number decreases, as these are children and families where a need has been identified, that ultimately remains unmet. This unfortunate situation must be mitigated. There is so much benefit to be had by properly educating referral sources, along with families of the possibilities for support and guidance through the utilization of Early Intervention services. Children are struggling with their overall development, their communication skills, and more; while families are struggling to provide them with the support they need. There is value to be had in addressing this concern.

This study has shown how beneficial it would be to take the time to educate our communities about Early Intervention, and its value to our children and furthermore our society. More can be done to engage pediatricians, and primary care physicians in supporting child development outside of the medical model. These medical professionals have the ability to foster

familial relationships that extend beyond their offices. However, this means that time needs to be taken by these medical providers in order to better understand the resources available. Only with better understanding, and a greater sense of value and appreciation for these entities, specifically Early intervention can they appropriately share and guide families to better understand these resources and their benefits. In doing so they can strengthen community ties, and promote interdisciplinary care.

In conclusion, the importance of Early Intervention, and its impacts on children, their families, and our society is undeniable. However, in order to continue its positive impact it must be nurtured. This study investigated some of the barriers that exist in utilizing Early Intervention to its greatest capacity, and has provided options and opportunities to address these barriers. Children are quite literally our future, and are deserving of societal resources and individual care. We, as a society, are able and capable to provide this when we take a closer look at what is needed, i.e., education and stronger lines of communication. Though voluntary, Early Intervention has universal benefits for children and their families, working to make this experience one that is desirable and valued is of the utmost importance.

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Appendices

Appendix A

Marywood
UNIVERSITY
EXEMPT REVIEW COMMITTEE

MARYWOOD UNIVERSITY
EXEMPT REVIEW COMMITTEE
Immaculata Hall, 2300 Adams Avenue, Scranton, PA 18509

DATE:	October 10, 2022
TO:	Keshia Vilchert
FROM:	Marywood University Exempt Review Committee
STUDY TITLE:	[1792942-1] *The exploration of Early Intervention Referral Sources and Their Possible Relationship to Early Intervention Outcomes*
MU ERC #:	2022-E031
SUBMISSION TYPE:	New Project
ACTION:	NOT RESEARCH INVOLVING HUMAN SUBJECTS
DECISION DATE:	October 10, 2022

Dear Keshia Vilchert:

Thank you for your submission of an Exemption Request for this project. Marywood University's Exempt Review Committee has reviewed your submission and determined that while it meets the definition of research, it is **NOT RESEARCH INVOLVING HUMAN SUBJECTS** covered by 45 CFR part 46 (see Human Subject Regulations Decision Chart 1). This is because:

- ☐ The activity does not meet the federal definition of research, which is a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge.
- ☒ The activity meets the federal definition of research, but not the federal definition of human subject [46.102(e)(1)], because:
  - ☐ it does not involve living individuals.

☐ it involves living individuals and secondary activities, but will obtain, use, study, analyze, or generate public, not private, information or biospecimens.

☒ it involves living individuals and secondary activities, and will obtain, use, study, analyze, or generate private information or biospecimens, but information or biospecimens will be gathered by the record holder, HARBOR AREA EARLY CHILDHOOD SERVICES, which is unaffiliated with the research, in such a manner that the investigator(s) or research team will be unable to individually identify or associate identities with the information or specimens. This is because:

- ☒ the investigator(s) will receive completely de-identified data (non-PHI) and will not be given keys or links to coded data, even temporarily. Also, no re-identification via deduction (e.g. combination of demographics with a small population) will be possible.
- ☐ the data or specimens will be coded, but the investigator(s) and record holder will enter into an agreement prohibiting the release of the key to the investigator(s).
- ☐ the data or specimens will be coded, but the record holder has written policies for a repository or data management plan that prohibits the release of the key to any investigator(s).
- ☐ the data or specimens will be coded, but there are other legal requirements prohibiting the release of the key to the investigator(s).

This determination means that no further review is required by our ERC. You may proceed with this project so long as it has not been disapproved by officials of the institution. If any activities or procedures change within the described project, review requirements may be affected, so please notify us prior to initiation of such changes.

If you have any questions, please contact the Research Office at 570-348-6211, x.2418 or irbhelp@marywood.edu.

Please include your study title and IRBNet ID number in all correspondence with this office.

Regards,
Exempt Review Committee

Appendix B

Dear North Suffolk's Harbor Area Early Intervention Program,

My name is Keshia Vilchert and I am a current doctoral candidate at Marywood University. I am working towards receiving a doctorate degree in Human Development. In order to complete the dissertation requirements necessary I am conducting a study in which I look at the relationship between Early Intervention referral sources and Early Intervention outcomes.

This study hopes to shed light on a possible relationship between Early Intervention referral sources such as: pediatricians, parents, the department of child and family services, and primary caregivers; and the relationship that these referrals might have with the outcome of services whether that be due to the child no longer being eligible for services or an exit from services despite still being eligible. Better understanding of these possible relationships will allow for Early Intervention agencies to provide a more tailored approach when crafting Individualized Family Service Plans. This would hopefully allow for better and more consistent outcomes, providing more appropriate services leading to greater and more robust success. Identification of a relationship could be extraordinarily beneficial to Early Intervention agencies along with the families that they so diligently work to serve.

I am reaching out to you and your agency in order to request utilization of your agency's data regarding referral sources and outcome of services. Allowing access and utilization of this data for this study will be the first step in accessing this useful information to be utilized by your agency in order to move forward with this study.

As a previous employee of Harbor Area I am very familiar with all that your agency provides to the community. Through this particular research study I would like to assist in increasing all that your organization provides for the families and the community as a whole. I look forward to hearing from you at your convenience, and hope that we could have the opportunity to work together.

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Sincerely,
Keshia Vilchert

Appendix C

Keshia Vilchert Marywood University- Request for non-PHI data

Early Intervention Referrals and Discharge reasons April 2022

Letter of Agreement

Harbor Area Early Childhood Services, North Suffolk Mental Health Association, Inc.
130 Condor Street
East Boston, Ma 02128
(617) 569-6560

Marywood University
2300 Adams Ave
Scranton, PA 18509

Keshia Vilchert, student at Marywood University and Ph.D. dissertation candidate, and former North Suffolk/Harbor Area EI Developmental Specialist, has requested a partnership agreement. North Suffolk Mental Health agrees to share a one-time data set of Harbor Area Early Intervention Client System non-PHI data set inclusive of Referral source, and Discharge Reasons.

Ms. Vilchert is a Ph.D. candidate at Marywood University located in Scranton, Pennsylvania. Her area of study is Human Development with a concentration in Health Promotion. Currently, Ms. Vilchert is working on her dissertation titled "An Examination of the Relationship between Referral Sources and the Reasons for Discharge". During her research, Ms. Vilchert identified a gap in the literature. When looking at participation in early intervention services there was minimal information pertaining to referral sources and their relationship with service participation. However, when looking at ways to optimize participation in early intervention the research has neglected to examine the relationship between referral sources and early intervention outcomes. This has brought Ms. Vilchert to her dissertation topic as she plans to examine this relationship with the hopes of finding a meaningful correlation. Doing so can allow for new approaches to services and hopefully create an opportunity to gain a greater understanding of the process in order to further support families.

North Suffolk's Harbor Area EI program will be providing Ms. Vilchert with the data outlined in the table below. This data will be taken from those who were discharged from the program during the year 2019.

The data will be collected by Aliza Llovet, a current NSMHA Harbor Area employee, from the Department of Public Health System, specifically through its client extract function. From the available data within the previously outlined parameters, Ms. Llovet will utilize a random number generator in order to identify a small sample size determined by the table of recommended sample size, which can be found attached to this letter. Once the sample has been determined, Ms. Llovet will strip it of all its PHI data and share it with Ms. Vilchert. This data will be collected and shared on a single occasion.

Ethnicity	Written Language
Age at Referral	Spoken Language
Duration in Program	Race
Age at Discharge	Culture
Discharge Reason	Referral Source
Gender	Reason for Referral

The study will be beneficial not only for the Harbor Area Early Intervention Program, but many other early intervention programs. A better understanding of the relationship between referral sources and various discharge reasons can allow for new and greater understanding which can lead down a path of innovative support. Supporting families is the ultimate goal, and research such as this provides an opportunity to find these innovative ways to further this meaningful work.

The one time data set extract from the Early Intervention Client System (EICS) NSMHA Harbor Area EI is attached to this agreement letter for authorization. The data set has been reviewed and approved by Rachael Cracknell, Program Director of Harbor Area Early Childhood Services, Sandra Heath, Director of Quality Management NSMHA, and by North Suffolk legal counsel as meeting all requirements of De-identification of Protected Health Information in accordance with the Health Insurance and Accountability Act (HIPAA) Privacy Rule, 45 CFR 164.514.

Rachael Cracknell, LICSW/MPH April 19, 2022

Program Director
Harbor Area Early Childhood Services

Judi Lemoine, RN Date: April 25, 2022

Chief Operating Officer/Authorized Representative

North Suffolk Mental Health Association, Inc.

Appendix D

Culture_Recoded

	N	%
No Response	16	5.9%
American (USA & Canada)	49	18.1%
South American	28	10.4%
Central American	44	16.3%
Salvadoran	39	14.4%
Dominican	12	4.4%
Puerto Rican	15	5.6%
Asian Indian/Pakistani	5	1.9%
Middle Eastern	2	0.7%
European	4	1.5%
African American	15	5.6%
African	15	5.6%
Haitian	2	0.7%
Brazilian	4	1.5%
Other	1	0.4%
American & African American	3	1.1%
American & Central American	4	1.5%
American & Puerto Rican	1	0.4%
African American & African	1	0.4%
African American, African, & Middle Eastern	1	0.4%
African & Middle Eastern	1	0.4%
Other & Asian Indian/Pakistani	1	0.4%
South American & African American	1	0.4%
Central American & African American	1	0.4%
Central American & Dominican	1	0.4%
Salvadoran & Central American	2	0.7%
Salvadoran & Puerto Rican	1	0.4%
Dominican & African American	1	0.4%