2013

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Carla Swanson
University of Rhode Island, caswanson@verizon.net

Recommended Citation

Swanson, Carla, "ATTRITION FROM EARLY INTERVENTION: ASSOCIATIONS WITH SEVERAL CHILD CHARACTERISTICS" (2013). *Open Access Master's Theses.* Paper 175. https://digitalcommons.uri.edu/theses/175

ATTRITION FROM EARLY INTERVENTION:
ASSOCIATIONS WITH SEVERAL CHILD CHARACTERISTICS

BY

CARLA SWANSON

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE
IN
HUMAN DEVELOPMENT AND FAMILY STUDIES

UNIVERSITY OF RHODE ISLAND
2013

MASTER OF SCIENCE THESIS

OF

CARLA SWANSON

APPROVED:

Thesis Committee:

Major Professor	Karen McCurdy
	Jaime Dice
	Amy Weiss

Nasser H. Zawia
DEAN OF THE GRADUATE SCHOOL

UNIVERSITY OF RHODE ISLAND
2013

ABSTRACT

Objectives. This study tested for associations between attrition from Early Intervention programs and a child's age at referral, race, home language, referral source, functioning, and insurance status and explored the relative predictive power of these individual child characteristics.

Methods. Data from the Rhode Island Department of Human Service's Early Intervention Data Management System were examined using *t*-tests and logistic regression techniques.

Results. Overall, EI non-completers tended to be younger and non-white. They were more likely to have had public insurance and they had significantly higher developmental functioning scores at entry. Non-completers were more likely to come from Spanish speaking families; and children who were referred to EI by a medical provider or who transferred from one provider to another were more likely to drop out than children who were referred to EI because of DCYF involvement.

Conclusions. This study provides new information about child characteristics that are modest predictors of attrition. Retention efforts should focus on the sustained engagement of younger, publicly insured, non-white, Spanish-speaking, and medically referred children, acknowledging that some non-completion can be explained by the preemptive nature of EI referral policies. Finally, attrition is an important phenomenon from a program evaluation perspective because drop-outs can skew outcome assessments

ACKNOWLEDGMENTS

I would like to thank my major professor Karen McCurdy for introducing me to Early Intervention, helping me identify and develop a pressing, “real world” research question, and sharing with me her own expertise on the topic of attrition. Her measured guidance, calm reassurance, and statistical know-how were consistent, and consistently needed, all the way through. I would like to thank the rest of my committee, Dr. Amy Weiss and Dr. Jaime Dice, for their careful reading of my proposal and later drafts - their insightful comments enriched my work.

I would like to express a separate set of thanks to Karen McCurdy and Jaime Dice for the invaluable course content and graduate work experience I gained from each of them. The experiences I gained as their student and graduate assistant were springboards I needed to launch myself into the exciting, important and new (to me) field of program quality improvement in early learning. Thank you.

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CHAPTER 1

INTRODUCTION

Congress established the Infants and Toddlers with Disabilities Program (Part C/Early Intervention) in 1986 as an amendment to the *Education for All Handicapped Children's Act of 1975 ("35 years," 2010).* As described in Sec. 631 of the Act's 2004 reauthorization, the implementation of Part C includes Congressional commitment to: (a) enhance the development of infants and toddlers with disabilities and minimize potential developmental delay; (b) support families of disabled children; (c) maximize the potential of people with disabilities to live independently; (d) reduce educational costs by minimizing the need for special education services; and (e) help states to ensure that all eligible infants and toddlers are identified and served including those from minority, low-income, urban, rural, and foster care families.

Early Intervention is federally administered by the Office of Special Education and Rehabilitation Services (OSEP). OSEP makes formula grants to individual states that are responsible for statewide, interagency administration and implementation. States engage local service providers who offer screenings and services to infants and toddlers who have or are at risk for developmental delays. Services are typically provided at no cost to participants[1].

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[1] States may adopt a "payment policy," which must be approved by the US Secretary of Education. In these states, families who do not meet the state's definition of inability to pay may be required to pay for some services (U.S. Dept. of Education, n.d.). In Rhode Island all EI services are provided at no cost to families (RI Dept. of Human Services, n.d.)

Between 2008 and 2012, 6,257 infants and toddlers in Rhode Island enrolled in and exited from Early Intervention programs (“EI Data Management System,” 2012). These infants and toddlers met eligibility criteria for developmental delay or for a set of conditions known to cause delay. Of those, 22.9 % made unplanned exits prior to meeting agreed-upon goals (n=1,435) (“EI Data Management System,” 2012; D. Novak, personal communication, November 2012). Nearly one quarter of the children enrolled in a no-cost program designed to slow or altogether stop a developmental delay failed to complete it.

Attrition and Child Outcomes.

Children who enroll in Early Intervention because of an existing or predicted delay and then drop out prematurely do not receive the full benefit of therapeutic services. These children are less likely to see the developmental gains they might experience if their delay had been comprehensively addressed in infancy or toddlerhood (Shonkoff & Phillips, 2000). Over the last twenty years empirical evidence has mounted documenting the risks to all children when opportunities for optimal brain development are deficient (Center on the Developing Child at Harvard University, 2008; National Scientific Council on the Developing Child, 2007). In the seminal 2000 report “From neurons to neighborhoods: The science of early childhood development” Jack Shonkoff and Deborah Phillips use findings from neuroscience to articulate the relationships between a child’s early experiences and later child and community outcomes. The report draws many associations between less than optimal brain development in infancy and a range of poor developmental and societal outcomes and notes that when children who have or are at significant risk for delay are denied appropriate therapies, the negative impact on development can be significant and lasting (Shonkoff & Phillips, 2000).

While brain development occurs throughout life (Pascual-Leone, Amedi, Fregni & Merabet, 2005), episodes of vigorous neural connectivity occur at several discrete periods. Infancy and toddlerhood are two of these sensitive periods during which time the developing brain is exceptionally responsive to environmental effects. In particular, these periods are optimal times for shaping brain architecture that controls functions such as vision, hearing and language (Knudson, 2004; Center on the Developing Child at Harvard University, 2008).

When a child is removed prematurely from Early Intervention and services are not sought elsewhere, potentially beneficial treatments are not applied at an early age, when they may have been most effective. Many higher-order brain functions develop as a result of earlier, scaffolding capacities. If formative neural circuitry is not "wired" properly, future capacities may be negatively impacted (Hadders-Algra, 2001; "A Science-based Framework," 2007). Delaying intervention services decreases opportunities to alter the long-term developmental trajectories of delayed or high-risk infants and toddlers (Center on the Developing Child at Harvard University 2007; Shonkoff & Phillips, 2000).

Attrition and Program Evaluation

Beyond the negative developmental effects on the individual child, attrition also has negative effects on the validity of outcome evaluations. The United States Office of Special Education Programs (OSEP) is charged by Congress with federal oversight and evaluation of Early Intervention (IDEA, 2004, §616 & 642). OSEP monitors state agencies charged with administration of EI to ensure that they meet program requirements, particularly those that relate to improving outcomes for infants and toddlers. States must provide evidence that children receiving Early Intervention services under IDEA are making gains (Hebbeler, Barton & Mallik, 2008). Children who leave Early Intervention prematurely circumvent formal discharge procedures. Exit data is not collected from these children, and they are not included in state reporting (D. Novak, personal communication, November 2012). These children may have received intervention services for many months, or even years, before dropping out and may or may not have shown improvements in functioning. If the number of non-completers is significant and they are not included in outcome reporting, the data set cannot be considered complete. As a result, local programs may overstate or understate the aggregate effects of their services. When reports are generated from that data at the state and national level, the findings may not reflect a comprehensive or accurate picture of Early Intervention's efficacy.

Little is known about why families leave Early Intervention early. The unexplained phenomenon of attrition in Early Intervention programs warrants investigation given the human and capital costs of lifelong developmental delay as well as taxpayer investments[2] that support state implementation (Ganz, 2007; "The Foundations of Lifelong Health," 2010;). I explored relationships between a failure to complete Early Intervention and a child's age at enrollment, race, language, developmental functioning at entry, referral source, and insurance status in an attempt

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[2] $438,548,146 FY2011 in grants made to states plus an additional 500,000,000 in ARRA funds (**www2.ed.gov/programs/osepeip/funding.html**)

to identify some of the characteristics of children most likely to exit Early Intervention prematurely.

CHAPTER 2

REVIEW OF LITERATURE

Early Intervention and Child Outcomes

The Early Intervention system of supports is intended to engage with babies as soon as a disability or delay is known or suspected – in some cases from birth. Newborns may be found eligible for services before leaving the hospital because of a specific condition or because they experience significant prematurity, low birth weight, illness, or surgery soon after birth. Other babies may be referred and found eligible as soon as they are observed to be developing more slowly than or differently from other children. The benefits of addressing developmental delays early are well-established in the health and social science literature.

Studies from the speech, language and hearing fields highlight the risks of delaying treatment for any communicative disorder (McLean & Cripe, 1997; Ward, 1999; “Roles and Responsibilities,” 2008). In 2007, the Joint Committee on Infant Hearing recommended that infants be screened in the first month of life. Infants who do not pass the screening should receive services no later than three months of age (Busa et al., 2007).

These recommendations were made in the wake of growing empirical support for the benefits of early intervention to hearing impaired babies. In several published studies, Yoshinaga-Itano and her colleagues demonstrated that infants who are deaf or hard of hearing will perform 20 to 40 percentile points higher on a range of school-related measures (vocabulary, articulation, intelligibility, social adjustment, and behavior) if they receive intervention services prior to six months of age (Yoshinaga-Itano, 1995, 2004; Yoshinaga-Itano et al., 1998; Yoshinaga-Itano, Johnson, Carpenter & Brown, 2008). Moeller (2000) explored an association between the timing of an intervention and outcomes in deaf and hard-of-hearing children. She found that babies who were enrolled before 11 months of age had better vocabulary and verbal reasoning scores at five years old than did children who enrolled in intervention services when they were older.

Autism diagnoses have steadily increased over time (Kuehn, 2007) and the syndrome is now estimated to affect one in 88 children in the United States (Baio, 2012). Once considered a disorder with an extremely poor prognosis (DeMyer, Barton, DeMyer, Norton, Allen & Steele, 1973; Howlin, 1997), recent research reflects a sea change in autism treatment and outcomes. That is, Rogers (1998) provided a review of studies indicating that early detection and intervention, before the syndrome is fully manifested, can result in "satisfying gains" for young children with autism (Rogers, 1998).

In a 2003 review of Autism Spectrum Disorders research and evidence-based practice, Woods and Wetherby (2003) concluded that, despite clinical challenges to early diagnosis, delaying diagnosis and treatment deprives children of the chance for maximizing gains. More recently, Dawson (2008) described studies that found between 75% and 95% of children with ASD who receive intense intervention in infancy and toddlerhood develop useful speech by age five, and some children who receive early, intensive treatment no longer display evidence of any disability

(Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Sallows & Graupner, 2005). Dawson further suggested that autism may be prevented if infants at risk are detected and appropriate treatments implemented while the brain is still in early development (Dawson, 2008).

The Zero to Three Policy Center cites a Mathematical Policy Research publication that found when infants and toddlers who score below national norms on a range of developmental functioning scales do not receive intervention services, they frequently move into the lowest functioning group (Oser & Cohen, 2003). A review of research on children with Down syndrome and their Early Intervention experiences resulted in the overall conclusion that therapeutic interventions in infancy can have positive effects in children with this syndrome (Nilholm, 1996). A review of research on the effects of early intervention on motor development reported mixed findings. Some studies found no positive correlation between early intervention and motor development of delayed pre-term and full term infants. However, other studies reported that age-specific therapies applied to pre-term or young infants can have positive effects on motor development (Blauw-Hospers, & Hadders-Algra, 2005; Blauw-Hospers, de Graaf-Peters, Dirks, Bos & Hadders-Algra, 2007).

Early Intervention and Attrition

One challenge to any study of attrition is defining the phenomenon. Researchers typically describe attrition as “premature” or “early” termination (Davis, 1999; Kazdin 1990; Smith, K. J., Subich, L. M., & Kalodner, C., 1995; Daro, McCurdy, Falconniera & Stojanovic, 2003). However, “termination” may be defined differently from one researcher to the next. An individual may be considered “terminated” if they enrolled but never engaged in services. More often, some level of services was received and participation subsequently stopped at the will of the individual and without professional advisement. In cases where children are participants, as in Early Intervention, it is the parent or caregiver who decides that the child will drop out. However, what is considered a “dropout” in one study may be considered a “completer” in another (Kazdin, Stolar & Marciano, 1995). For example, in a 2011 study of race and participation in Early Intervention, Feinberg et al. noted, tangential to his study, that 79% of children in his study “dropped out,” which he defined as children who began but did not continue EI services. However, he does not differentiate between children who leave the program because they have met their goals, children who formally transition into other programs and children who make unplanned exits prior to meeting stated goals. [3]

It is the latter of those three definitions to which this study attends. At its base level, attrition means *leaving*. Studies that expressly explore attrition typically look at why participants leave a program to which they had made a commitment before reaching an agreed upon or natural stopping point. A careful review of the literature yielded research and reports exploring associations between child characteristics such as race, socioeconomic status, insurance type, maternal education and place of residence and access to or enrollment in Early Intervention services (Peterson, Wall, Raikes, Kisker, Swanson, Jerald,... & Qiao, 2004; Rosenberg, Zhang & Robinson, 2008; Wang, Elliott, Rogowski, Lim, Rather & Schuster, 2009; Feinberg, 2011). However, these studies contain limited or no discussion or analysis of why children

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[3] I elected to use the term “non-completer” to avoid negative connotations associated with the term “drop-out” when used in other contexts.

leave Early Intervention. I discovered no published research dedicated to the study of attrition or retention in Early Intervention programs.

Home visitation and psychotherapy are two somewhat analogous fields in which research on attrition has been conducted. A literature review revealed many studies that explore why participants fail to complete home visitation or child psychotherapy programs. There are similarities between these fields and Early Intervention in that all involve parental commitment to sustained engagement over time. Research that explores why some parents commit and begin to engage in home visitation or child psychotherapy services and then make unplanned exits may therefore provide some insight into the phenomenon of attrition from Early Intervention.

However, there are significant differences among the fields. During an Early Intervention home visit the visiting practitioner (for example, a speech, occupational, or physical therapist) provides services to the child. Families may be involved in the session, as practitioners often share strategies and techniques for caregivers to employ as part of the family's daily routine, but parents are not the service recipient. An EI home visit could be conducted between the practitioner and the child without any parent involvement. This is not the case with traditional home visiting programs. Home visitation programs work directly with parents providing parenting support and child abuse prevention strategies (McCurdy et. al, 2006; McCurdy, Gannon & Daro, 2003; McCurdy & Daro, 2001).

There are also important differences between the Early Intervention model and pediatric psychotherapy. Pediatric psychotherapists are similar to EI practitioners in that they work directly with children. However, psychotherapy services are not provided in the home where most Early Intervention therapies occur. Notable differences in delivery models must be taken into account when attempting to draw analogs among the home visitation, pediatric psychotherapy and Early Intervention fields.

Factors Associated With Attrition

Attrition and race. Minority children are at greater risk for dropping out of psychotherapy than are white children (Miller, Southam-Gerow & Allin, 2008; Kazdin, Mazurick & Bass, 1993; Kendall & Sugarman, 1997). Kazdin, Stolar & Marciano (1995) note that certain characteristics found disproportionately in black families present barriers to program completion. These include poverty, stress, and residing in a single-parent family. Additionally, the service delivery model may make sustained participation less likely for black families if they are receiving psychotherapy services from non-black professionals (Allen & Majidi-Ahi, 1989; Roger & Cortes, 1993).

Conversely, studies of retention in home visitation programs generally find minority families more likely to complete service regardless of the race of the service provider. McGuigan, Katzev & Pratt (2003) and Dumka, Garza, Roosa & Stoerzinger (1997) found Hispanic parents were significantly more likely to remain in services. Navaie-Waliser et al. (2000) found higher retention rates for African American mothers as did Daro, McCurdy, Falconnier and Stojanovic (2003). McCurdy, Gannon, and Daro (2003) again found Hispanics and African American families more likely than White families to remain engaged. Acknowledging differences between findings in the psychotherapy and home visitation literature, I based my hypothesis on findings from home visitation given the greater similarities in delivery model. Early Intervention and home visitation models do not typically involve issues inherent to keeping external appointments (accessing transportation, transport time, childcare for other children). Psychotherapy programs include these potential challenges that are not expected in an Early Intervention setting. I developed this hypothesis around the research findings in what I determined to be the most analogous setting – home visitation. I therefore expected to find that White children were more likely than Black or Hispanic children to drop out of Early Intervention.

Attrition and primary language. Prior studies have not exclusively explored an association between primary language and home visitation or child psychotherapy program completion. However, in 2003 McCurdy, Gannon & Daro reported their findings on the role of ethnicity in home visitation participation patterns. Acknowledging the small number of non-English speaking participants in the study, they report associations between attrition and a poor participant-provider language match. While Hispanics were more likely to remain in service overall, non-English speakers receiving services from English-speaking providers received 16 fewer visits and ten fewer months of service.

Additionally, there is a significant body of research in the health and preventive care literature that documents disparities between English and non-English speakers in health care treatment and use. This research is relevant because most EI services are health care services. Audiology, speech therapy, physical therapy, occupational therapy, nursing and psychological services, nutrition counseling and medical screenings are all healthcare services.

A 2007 study of 12,704 Whites and 5,500 Hispanics found that Hispanics who did not speak English at home were at risk for not receiving recommended health care services (Cheng, Chen & Cunningham, 2007). A 2005 National Institute of Health Public Health Report found that individuals with language barriers are less likely to have a regular source of medical care, receive fewer preventive services, and are less likely to adhere to prescribed medications. They are also the most likely to leave a hospital against medical advice (Flores, Abreu & Tomany-Korman, 2005; Flores, 2006). These findings support the hypothesis that Spanish speakers are less likely to maintain health care enrollment. I hypothesized that families that spoke Spanish at home were more likely to leave services prematurely than English speaking families.

Attrition and child functioning at enrollment. McCurdy & Daro (2001) cite Olds & Kuzman's (1993) findings that parents of medically fragile babies were more likely to remain engaged in parenting programs. An earlier study by Fontana, Herschmann, McCarton, Meltzer & Ruff (1988) found that babies identified as "at-risk" influenced parents' decisions to remain engaged in an intervention program. Duggan, Windham, McFarlane, Fuddy, Rohde, Buchbinder & Sia's 2000 study of Hawaii's Healthy Start Home Visiting program found that mothers of low-birth weight pre-term babies were more likely to stay in service than were mothers of infants with no special healthcare needs. These findings suggest that babies with more intensive medical needs are more likely to complete a course of treatment than babies who are less medically fragile. Put another way, the greater a parent's perception of need for services – as reflected by the severity of the child's medical condition – the more likely they are to complete the program. Based on those findings, I tested whether the severity of a child's disability when the child enrolled in EI predicted attrition. I expected to find higher-functioning infants and toddlers more likely to drop out of Early Intervention.

Attrition and referral source. Based on the theories previously cited associating a parent's perception of need for services with attrition, I also explored a possible association between how a child is referred to Early Intervention and whether or not the child completes the program. Children may be referred to EI from many sources with varying degrees of parental involvement. Parents who independently perceive a need for services may make a referral themselves. On the other end of the parental involvement spectrum are Department of Children Youth and Families (DCYF) referrals. DCYF policy requires that all babies and toddlers referred to child welfare are also referred to EI under the "at risk for delay" proviso. These referrals are typically made free of parental input or influence (although custodial parents must ultimately give written consent to evaluate). In between are referrals made by medical, education and social service providers and the small number of children who are referred by way of transfer when they move to Rhode Island from another state.

I interpreted perception of need in terms of the degree of autonomy associated with the referral source. I expected parent and medical referrals to represent those children with the greatest parental perception of need for services. I expected DCYF referrals to be the referral type with the least degree of parental perception of need. Based on prior research on attrition and severity of disability I expected to find that the babies and toddlers most likely to drop out were those children from families with the least parental engagement in the decision to seek services. These are compulsory referrals made when a child becomes involved the Department of Children Youth and Families (DCYF). Based on research positively associating parental influence with program completion, I hypothesized that children referred with the least parental involvement – compulsory/DCYF referrals – were the most likely to drop out.

Attrition, socio-economic status and health insurance. Based on theoretical constructs proposed in studies of race and attrition – that challenges faced by families in poverty predispose them to difficulties completing treatments and services (Miller, Southam-Gerow & Allin, 2008; Kazdin, Mazurick & Bass, 1993; Kendall & Sugarman, 1997) – it is important to consider whether socioeconomic status influences retention in EI. The psychotherapy and home visiting literature testing associations between race and attrition typically explore race explicitly and then nest race within the larger context of socio-economic status (SES) (Lanier, Kohl, Benz, Swinger, Moussette & Drake, 2011; Attride-Stirling, Davis, Farrell, Groark & Day, 2004; Kazdin, 1996). However, the Rhode Island DHS dataset does not include income, education or occupation variables – information typically used to assess a family's socio-economic status. Thus, SES effects must be tested by using an available variable that can represent SES.

I used insurance status as an SES proxy. The database contains four selectable values for insurance status – Medicaid, RIte Care, private insurance and no insurance. Based on federal eligibility requirements, children covered by RIte Care, Rhode Island's Medicaid managed care program, live below 250% of the Federal Poverty

Level (FPL). In Rhode Island, 96% of uninsured children live below 250% of the poverty level (*Children without health insurance*, 2013). Private insurance typically comes through parent employment or self-employment. I tested the hypothesis that children with lower SES – those with Medicaid or RIte Care or with no insurance – were more likely than children with private insurance to drop out of Early Intervention.

CHAPTER 3

METHODOLOGY

Sample and Procedures

Sample. This cross-sectional study used de-identified secondary data from the Rhode Island Department of Human Service's Early Intervention Data Management System (EIDMS). The Department of Human Services (DHS) collects demographic, participation, enrollment, and outcome information on every child enrolled in Early Intervention. My research questions attended to how children exit Early Intervention. DHS provided me with a subset of the EIDMS that included only infants and toddlers who enrolled in and exited from EI between 2008 and 2012 (n=6257). The database contained 49 variables including referral source, age at referral, age at discharge, reason for eligibility, reason for discharge, and other demographic factors.

For the current study, cases with missing or impossible data were removed as were cases outside the study's enrollment range[4] (n = 309). The study design required filtering out the small number of children that did not speak Spanish or English (n = 90) and children who did not fit the criteria for values of the dependent variable, "completion status" ("completer" or "non-completer"). These children fell into an "alternate exit" category and were not considered in this study (n = 446). There were 5412 cases in the final sample.

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[4] The enrollment period considered in this study was 2008 – 2012. DHS provided a dataset that included some children enrolled in 2006 and 2007.

The final sample (n = 5412) included 1344 non-completers (25%) and 4068 completers (75%). Following enrollment statistics nationally (NEILS, 2007), the study sample was disproportionately male. Nearly two thirds of the children were boys (n = 3493) and 35.5% were girls (n = 1919). Children came from every city and town in Rhode Island. Nearly 40% resided in Rhode Island's four core cities – Central Falls, Pawtucket, Providence and Woonsocket (n = 2161). Combined data from children residing in Charlestown, Exeter, Foster, Glocester, Jamestown, Little Compton, Narragansett, Newport, North Smithfield, Richmond, Situate and West Warwick accounted for less than 6% of the sample.

Procedures. When a child is referred to Early Intervention, caregivers are directed to a DHS-certified Early Intervention provider.[5] The provider initiates a screening and evaluation process to determine eligibility for services. Children who are found eligible are entered into the database by the provider overseeing the child's evaluation (D. Novak, personal communication, May 2013).

Programs devise their own data collection methods and tools. Of the seven database variables considered in this study (e.g., age at referral, discharge reason, race, language, "COSF scores", referral source, and insurance type), the child's age, referral source and form of insurance are provided at first contact with EI, typically over the telephone by the person making the EI referral. The child's language and race are typically provided by the parent during an intake assessment that may be over the phone or in person. Scores indicating functioning at entry and at exit are determined by a standardized rating process undertaken by a team that includes professionals such

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[5] During the period covered in this study there were ten certified providers: Children's Friend and Service, Easter Seals of RI, Family Resources Community Center, Family Services of RI, Hasbro Children's Hospital, James L. maher Center, Looking Upwards, Meeting Street Center, Seven Hills of RI and the Trudeau Center.

as doctors, speech and language pathologists, occupational and physical therapists, and others familiar with the child as well as family members (*Overview of the Child Outcome Summary Form*, 2009). Data are collected and entered into the database at enrollment and again at discharge. “Discharge reasons” are built into the database and are selected by the child’s service coordinator when the child exits Early Intervention. The reason for discharge is determined by the recommendations made in the child’s formal transition plan or, in the absence of a plan, based on the coordinator’s knowledge of family circumstances (e.g., moving out of the region?).

Completion status. My research questions explored differences between children who complete EI as planned and children who drop out prematurely. To establish group membership, I used the EIDMS variable “discharge reason.” This variable includes 15 values describing circumstances under which a child leaves EI. Six values represent children that ended their EI service because they moved out of state, switched to another provider, or died (7% of total sample): *Moved out of stat*e; *Exit (No IFSP) Family switched to another EI site*; *Exit (No IFSP) moved out of state*; *Deceased*; *Family switched to another EI site,* and *Child (No IFSP) did not qualify for EI was referred.* Children in these categories may or may not have completed their service plan prior to moving, transferring or dying. Because their completion status is unknown, they were excluded from this study.

The remaining cases were divided into two groups: completers and non-completers. Completers (70% of total sample) were identified by five values that described children who completed their service plan: *completion of IFSP prior to reaching maximum age for Part* C; *part B eligible*; *not eligible for Part B exit to other* *programs*; *not eligible for Part B exit with no referrals*; *part B eligibility not determined*. Non-completers (22.9% of total sample) were indicated by four values that described children who made unplanned exits with no transition planning: *exit (No IFSP) attempts to contact unsuccessful*; *exit (No IFSP) withdrawal by parent or guardian*; *withdrawal by parent or guardian*; and *attempts to contact unsuccessful*.[6]

Independent Variables

Race. The original data set included nine options for race. I created a category "other" and grouped 7.1% of the sample that were not Black, Hispanic or White (specifically, American Indian/Native Alaskan, Asian, Mixed, Native Hawaiian/Other Pacific Islander, and Unknown). Four categories were created with the regression comparison category coded first: (0) *White* (1) *Black* (2) *Hispanic* and (3) *other*.

Language. There were fourteen options for language in the original data set including English, Spanish, Arabic, French, Hmong and Portuguese. However, children speaking a language other than English or Spanish accounted for only 2.5% of the total. Given the small number of children speaking neither Spanish nor English, these cases were grouped as "other" and filtered from this study. The two languages were coded with the regression comparison category coded first: (0) *English* and (1*) Spanish*.

Functioning at entry. To explore if the severity of a child's delay at time of enrollment predicted whether the child would drop out of treatment, I used data from the Child Outcome Summary Form (COSF) rating scale.

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[6] I originally proposed to further divide the non-completer group into groups identified by whether or not they had entry IFSP scores. I was interested in comparing children who did not have entry IFSP scores to those that did working under the premise those children without IFSP scores contacted EI but never engaged. However, the number of children in this category is too small for a valid comparison.

The COSF was developed in 2005 by the Early Childhood Outcomes Center for use by states and local EI programs. COSF scores are standardized measures of a child's functioning in three domains: (1) social relationships, which includes getting along with other children and relating well with adults; (2) use of knowledge and skills, which includes thinking, reasoning, problem solving, and early literacy and math skills; and (3) taking action to meet needs, which includes feeding, dressing, self-care, and following rules related to health and safety (Outcomes for Children Served through IDEA's Early Childhood Programs, 2011).

The COSF is a 7-point rating scale used to assess a child's functioning in each of the three domains*:* 1 *(skills are not yet immediately foundational); 2 (occasional use of foundational skills);* 3 *(immediate foundational skills most or all of the time across settings and situations);* 4 *(occasional use of age-appropriate functioning, more behavior is not age appropriate than age-appropriate);* 5 *(mix of age appropriate skills and not age appropriate behavior and skills across settings and situations)* and 6-7 *(age expected skills)* (Greenwood, Walker, Hornbeck, Hebbeler & Spiker, 2007).

Eleven studies support the tool's validity (Greenwood et al., 2008). It is used by professionals who are assembled to work as a team to create an Individualized Family Service Plan (IFSP) for a single child. IFSP team members may include physicians, therapists, teachers or child care providers, social workers, or other individuals familiar with the child as well as the child's caregivers.

The COSF process happens twice – first, when a child is enrolled in EI and again when he or she exits the program. According to federal regulations a child must have a screening, initial evaluation, initial child and family assessments and initial IFSP meeting within 45 days of referral to Early Intervention (Individuals With Disabilities Education Act, 20 U.S.C. § 303.310 (2011). Children found eligible at the evaluation stage are enrolled in the program and then moved to the assessment stage which includes the entry COSF. Once the COSF is complete the child's scores are entered into the data base by program staff. The COSF process is meant to happen again when the child exits Early Intervention enabling staff to compare entry and exit COSF scores.

This study uses entry COSF scores as a measure of child functioning at enrollment. To create the new variable *functioning at entry* I first calculated the mean of each child's three COSF scores. This resulted in a single COSF score, "COSF at entry." I then created a categorical variable "Functioning at Entry" with three values: low *(scores ranging from 1 – 3.99*), medium *(scores 4 – 5.99)* and high *(scores 6-7).* Categorical variables made the data easier to interpret.

Referral source. The original data set included 21 possible values to indicate how a child was referred to Early Intervention. For this study, values were grouped into five categories and coded with the regression comparison category first: (0) *compulsory (DCYF)*, (1) *medical* (pediatrician/family practice, inpatient hospital, lead program, mental health center, neonatal intensive care unit/pediatric intensive care unit, outpatient hospital based programs, RI hearing assessment program, and Visiting Nurses Association/Visiting Nurse Services (2) e*ducation/social service*, (3) *parent/family*, and (4) *transfer/out of state/other*.

Insurance. Early Intervention providers collect information on children's insurance status when they are referred and they enter it into the EIDMS. Programs require this information in order to bill for services. The DMS has four values for insurance type – Medicaid (MA), Rite Care, private insurance and no insurance. I combined "Medicaid (MA)" and "Rite Care" into one group, *public,*
and considered the two remaining values, *private* and *uninsured*, separately.

Statistical analyses. Statistical analyses were performed using SPSS version 21. Statistical tests were 2-sided and a *P* value of less than 0.05 was considered statistically significant. Initial data analysis of all variables ensured that the number of cases in each group was sufficient for analysis. Initial analyses also included calculation of mean and standard deviations of COSF ratings and age at referral and frequency distributions of the remaining categorical variables. Independent samples group t-tests were calculated to explore associations between COSF ratings and age at referral and outcome variables. A two-way contingency table analysis was conducted to evaluate possible associations between completion status and race, language, functioning at entry, referral source and insurance. Logistic regression analysis explored which of the independent variables were stronger predictors of attrition, controlling for age at referral. Odds ratios were calculated for each independent variable. Unfortunately, the variable *age at completion* was too skewed to include (nearly 50% of participants exit the program at 36 months).

CHAPTER 4

FINDINGS

As shown in Table 1, children in the study sample were referred to Early Intervention at every age during the first three years of life (0 – 35 months) with a mean enrollment age of 18.56 months. Children enrolled as newborns and young infants accounted for almost 18% of the sample while only 12% were referred during the last six months of eligibility (30 – 35 months). More than half the sample fell into the “medium functioning” category at enrollment (entry COSF scores of 4-5). Just over one quarter received COSF scores of three or below at the time of enrollment; the remaining 14% were “high functioning” (COSF scores of 6 or 7). Children were enrolled for an average of 293 days. Although the mean age at discharge was 29.91 months, nearly half the sample exited Early Intervention in the 36th month. Nearly one quarter of the sample was Hispanic. The largest proportion of the population was white (61.9%), and Black children accounted for only 7.2% with around the same number of children falling into the “other” races category. Most of the sample spoke English; fewer than ten percent came from Spanish speaking homes.

Table 1. Characteristics of Early Intervention Participants by Program Completion Status

Variable	Completer (n = 4068)	Non-completer (n = 1344)	All children (n = 5412)	$\chi 2$ or *t* test
Mn Age at referral (SD)	20 (9.1)	14.22 (9.5)	18.56 (9.57)	*t(*2210) = -19.43, p>.000
Mn COSF at referral (SD)	4.46 (1.27)	4.63 (1.19)	4.5 (1.25)	*t*(2428) = 4.553, p<.005
Race %				103.331, <.000
Black	6.3	34.5	7.2	
Hispanic	21	33.7	23.8	
White	66.2	19.6	61.9	
Other	6.5	31	7.1	
Language %				
English	8.5	10.3	9	4.059, p<.05
Spanish	91.5	89.7	91	
Functioning at entry %				13.073, p<.001
High (COSF 6-7)	13.8	15.5	14.2	
Med (COSF 4-5)	59.1	62.4	59.9	
Low (COSF 1-3)	27.1	22.2	25.8	
Referral Source %				130.803, p<.000
DCYF	10.3	5.8	6.9	
Medical	40.2	32.7	34.6	
Ed/Social Service	3.1	3	3	
Parent/Family	35.3	51.9	47.8	
Transfer/Out of State/Other	11	6.6	7.7	
Insurance Status %				202.577, p<.000
Public (Medicaid/Rite Care)	69.9	48.3	53.7	
Private	27	49.2	43.7	
Uninsured	3.1	2.5	2.6	

Abbreviations: COSF, Child Outcome Summary Form

Nearly half the children in the sample were referred to EI by a parent or family member. Referrals from sources related to health and well-being accounted for 34.6% while referrals from education or social service entities (other than DCYF) accounted for only 3% of the total. Seven percent of the sample was referred by DCYF (n = 374). Very few children in this sample had no insurance. Slightly more than half of the children were covered by Medicaid or Rite Care and the remaining 44% had private insurance.

Bivariate Analyses

Table 1 also presents a comparison of completers to non-completers on the independent variables and covariates. An independent samples group t-test compared the mean age at referral and COSF scores at entry for non-completers and completers. For mean age, data were non-normally distributed as assessed by Shapiro-Wilk's test (p>.05) and negatively kurtosed (.862, SE .067). Given the kurtosed distribution, data transformation was considered. However, converting age to z-scores would have resulted in a loss of interpretive value and so original data were used. Non-completers were significantly younger at referral than completers ($p < .000$) and had significantly higher COSF scores at entry ($p < .000$).

A chi-square analysis tested for associations between the dependent variable *completion status* and the independent variables *race*, *language*, *functioning at entry*, *referral source*, and *insurance type*. There were statistically significant associations between completion status and race ($p < .000$); language ($p < .044$); referral source ($p < .000$); functioning at entry, ($p < .023$) and insurance type ($p < .000$). While significant, all associations were small: completion status and functioning at entry, Cramer's V = 0.049, $p = .023$; completion status and race, Cramer's V = 0.155, $p = .000$; completion status and insurance type, Cramer's V = 0.193, $p = .000$; completion status and referral source, Cramer's V = 0.155, $p = .000$; completion status and language, $\varphi = 0.027$, $p = .044$.

Logistic Regression

A logistic regression model was developed to determine how well the independent variables explained the probability of dropping out. Overall, the model was statistically significant, ($p < .000$). Nagelkerke's R2 of .163 indicated a modest relationship between prediction and grouping, explaining 16% of the variation in completion status. Prediction success was somewhat improved with the addition of the independent variables, including age at referral. The final model predicted 76.3% overall, correctly classifying 95.2% completers and 19.3% non-completers.

Odds-ratios for each independent variable tested which values significantly predicted attrition. Of the five predictor variables, all were significant (see table 2). Non-white children were more likely to drop out of EI than white children ($p < .000$). African American children were 1.67 times more likely to leave EI early ($p < .000$) and Hispanic children were almost twice as likely to drop out ($p < .000$). Spanish speaking children were 1.56 times as likely to leave EI as were English speakers ($p < .001$). Functioning overall was predictive of attrition ($p < .005$). However, rates of non-completion were not significantly different for medium ($p < .127$) or low functioning ($p < .367$) children as compared to high functioning children.

Table 2. Logistic Regression Predicting Attrition from Early Intervention programs
(n = 5412)

Variable (Referrent)	β	*SE* β	Wald's χ2	*df*	*p*	OR	95% CI for EXP β	
							Lower	Upper
Constant	-.76	.19	15.8	1	.000	.47		
Age at referral	-.06	.00	261.6	1	.000	.94	.93	.95
Race (White)			68.4	3	.000			
Black	.51	.12	16.93	1	.000	1.67	1.3	2.13
Hispanic	.69	.09	54.73	1	.000	1.99	1.66	2.4
Other	.57	.13	19.89	1	.000	1.76	1.37	2.26
Language (English)								
Spanish	.45	.13	11.65	1	.001	1.56	1.20	2.01
Functioning at Entry (High)			10.76	2	.005			
Medium	.15	.10	2.33	1	.127	1.16	.95	1.42
Low	-.10	.12	.81	1	.367	.90	.71	1.13
Referral Source (DCYF)			15.9	4	.003			
Medical	.37	.13	7.7	1	.006	1.44	1.11	1.87
Ed/Social Services	.31	.22	1.87	1	.171	1.36	.87	2.11
Parent/family	.14	.14	1.08	1	.300	1.15	.88	1.5
Transfer/other	.43	.16	7.00	1	.008	1.54	1.12	2.11
Insurance Type (Medicaid/Rite Care)			89.47	2	.000			
Private	-.74	.08	88.38	1	.000	.47	.41	.55
Uninsured	-.05	.2	.06	1	.815	.95	.65	1.4

Of the five referral sources, three were significant predictors of attrition: DCYF (*p* = .003), medical (*p* = .006), and transfers/other (*p* = .008). Contradicting my hypothesis, DCYF referrals were the least likely to drop out of service. Medical referrals were 1.44 times as likely and transfers/others 1.53 times as likely to leave Early Intervention as DCYF referrals. I expected to find parent referrals to be less likely to drop out, however parent/family and education/social service referrals did not add significantly to the predictive power of the model. While insurance status overall was significant (*p* = .000), uninsured status did not have significant predictive value compared to children with public insurance (*p* = .815). However, supporting my hypothesis, children with private insurance were somewhat less likely to drop out than children with public insurance.

CHAPTER 5

CONCLUSIONS

The intent of this study was to help identify characteristics that contribute to EI non-completion among a large sample of EI participants. One quarter of the infants and toddlers in this sample dropped out of EI early and without a plan for continued services. Overall, children who were withdrawn early from EI tended to be younger at referral and they had significantly higher COSF scores at entry. They were more likely to be non-white and to have public insurance Non-completers were more likely to come from Spanish speaking families, and medical referrals or transfers were more likely to drop out than DCYF-involved children.

I had not expected to find minority children to be significantly more likely to drop out than white children. This phenomenon did not prevail in the home visitation literature, where Hispanic families were often the least likely to leave a program early. However, in child psychotherapy literature, minority status has been shown to be a positive predictor of attrition, and disparities in minority access to health care are well documented (Weinick & Krauss, 2000). It is possible that the analog between home visitation programs and Early Intervention – where Hispanics were nearly twice as likely to drop out as Whites – is too weak to inform the questions asked in this study. EI services are typically medical or therapeutic treatments. It is possible that studies exploring associations between race and medical care are better suited as references when considering effects of race on engagement in Early Intervention. A 2011 study found eligible black children are as much as five times less likely to be enrolled in EI than eligible white children (Feinberg, Silverstein, Donahue & Bliss, 2011). It is possible that the same or similar factors that contribute to an enrollment disparity also contribute to disparities in retention. For example, clinician bias is suggested as one explanation for under-enrollment of eligible black toddlers in Early Intervention (Wang, Rogowski, Lim, Ratner & Schuster, 2009). The authors point to prior findings of racial differences in rates of identification of children with developmental delays (Mandell et al., 2009). If practitioners are less likely to identify and refer non-white children to EI it is reasonable to consider that they might also be less likely to monitor and support EI engagement among non-white children who do enroll in the program.

Findings about language were supported – in the direct assessment of program completion among Spanish speakers and in the assessment of attrition among Hispanic children. Study findings – children from Spanish speaking families are more likely to drop out of EI – are not surprising. A 2004 study that examined data from the 2001 National Survey of Children with Special Health Care Needs found that children with special health care needs who have non-English speaking parents were more likely to have an unmet need for family support services, and to lack a personal doctor, nurse, usual source of care or family centered care (Yu, Nyman, Kogan, Huang & Schwalberg, 2004). Children from families with limited English proficiency also have significantly greater odds of not being brought in for needed medical care (Flores, Abreu & Tomany-Korman, 2005).

Referencing the 2003 McCurdy, Gannon & Daro study in which a provider-client language match was critical to sustained service duration, it would be instructive to know the degree to which EI services are provided in the family’s home language. Communication barriers and cultural considerations inherent with any discussion about language must be considered when addressing access and utilization barriers faced by non-English speaking families seeking medical treatment.

Regarding referral source as a predictor of attrition, I viewed DCYF involvement as the least autonomous way a family could become involved in EI. I considered this method of referral juxtaposed to the literature supporting parent referrals as most likely to complete a treatment plan. However, a positive association between DCYF referral and attrition was not supported. It may be that some DCYF-involved children are more likely to complete their service plan because regular participation is managed by an external, accountable provider such as a social worker or foster family. These children may be more likely to complete treatment given the extra layer of support and accountability social services provides over and above the parents. It would be useful to examine associations between DCYF referrals and characteristics not explored in this study, including reasons for referral or improvement over time, to look at other ways DCYF referrals differ from children referred through other sources. It is possible that clinicians who work with DCYF-involved children engage in certain practices that differ from those of other referral sources that, in turn, lead to more sustained EI engagement. If this is the case, a fuller understanding of those practices could be a benefit to program staff considering retention strategies.

Taking a broad look at attrition, it is possible that some non-completion can be explained by the preemptive nature of EI referral policies. Children may be referred to EI at birth or as very young infants not because of a presenting disability but because of multiple risk factors or as a result of DCYF involvement. Neither of these referral conditions always leads to delay. Preemptive referral policies may explain why younger referrals and significantly higher COSF scores at entry were more likely to dropout. Infants and toddlers entering EI through a preemptive referral rather than a presenting delay would likely have higher scores. Parents may withdraw their child when a subsequent lack of need is perceived or becomes apparent.

This may help explain why medical referrals are more likely than DCYF referrals to drop out. Perhaps medical and therapeutic practitioners employing a prevention model are making preemptive referrals for delays that are not always accurately predicted. Attrition among this group could be an indication of the sensitivity of various child screenings.

That children with public insurance are more likely to non-complete than children with private insurance is a finding that would benefit from more research. I used insurance status as a proxy for SES – however, the role of public insurance itself – Rite Care and Medicaid – cannot be discounted. There may be factors associated with insurance type that impacts a family's decision to stay in EI. The proxy relationship is also important to examine. This study found that children who meet income eligibility requirements for pubic insurance are more likely to leave than families who have private insurance. However, while public insurance is a solid proxy for low income families, private insurance cannot be considered a proxy for higher income families. Some low income families have private insurance and so are accounted for in the "privately insured" yet may still fall within federal poverty levels.

This study was constructed around a question framed as a deficit – why nearly one quarter of children determined eligible for EI withdrew prematurely. The question could have been framed conversely. An “unacceptable” attrition rate is subjective. It is also fair to say that Early Intervention in Rhode Island has a 75% retention rate. It would be instructive to make a comparison with attrition rates in other states, although inconsistencies in state data collection criteria and methods would make accurate comparisons difficult.

This study had several limitations. The dataset was secondary, and it did not contain variables with direct connections to prior research. There are many studies that test associations between attrition and socioeconomic status, maternal education, or family structure, but the RI EI Data Management System does not collect data on those child variables. Finally, this study cannot be generalized as the sample is from a single state and is not nationally representative.

The effect size (16%) shows a small but reliable relationship between predictor variables and attrition. The small explanatory power is likely attributable to the large sample size. This study provides new information about some child characteristics that modestly predict attrition. Early Intervention clinicians may wish to be mindful of the possibility that publicly insured, uninsured, and non-white children are more likely to drop out, with Hispanic children the most likely to withdraw. Clinicians and program managers may wish to also pay special attention to referrals of younger children (perhaps those under 14 months), understanding that some attrition is “acceptable” given that not all children referred to EI will experience an actual delay.

Attending to EI non-completers is important from a program evaluation perspective. Failing to capture the outcomes of non-completers truncates the population under investigation and threatens to skew the results of evaluations that claim to assess program efficacy but do not consider non-completers. Federal and state governments spend well over half a billion dollars a year on Early Intervention services across the country (www2.ed.gov). It is important to know that those funds are well-spent.

The need for further research into additional predictors of attrition is pressing and more data collection and analysis is required. The RI Department of Human Services could collect additional data from participants that would allow for a deeper look into factors that are associated with attrition. It would be useful to have more information about the specific condition(s) that led to the child's referral; family income; family composition; maternal education; more detailed race and ethnicity information and immigration status. It would also be instructive if programs collected data on providers - ethnicity, language, work experience and type and amount of training. This would allow an exploration into whether the issue of "provider match" is contributing to attrition.

Information about EI program sites can inform a fuller exploration of the attrition phenomenon. It would be useful to know how consistent COSF training s are from team to team and program to program. Intra-state implementation was one area in which researchers failed to find validity in use of the COSF tool (Greenwood et al., 2008).

The Service Coordinator role might also be examined. As the child’s assigned “gatekeeper,” the Service Coordinator may be best positioned to maintain consistent contact with families while enrolled with the intent of supporting sustained engagement. The Service Coordinator may also be in a position to follow up with families who leave – a key component of a full exploration of this topic. Program staff should work diligently to track down and interview families who leave to hear what they have to say about their experiences while enrolled as well as details about their reasons for failing to complete the program. Capturing this primary data is perhaps the most important step in preparation for developing strategies to enable EI practitioners to retain more families for the full course of recommended therapy.

Finally, programs at the local and state level must have the resources to collect, aggregate and analyze data to create an accurate and meaningful assessments of Early Intervention’s implementation and efficacy.

Findings from this study should encourage further research. Meanwhile, Early Intervention administrators and program staff may begin to consider tailored initiatives designed to support black and Hispanic families, in particular Spanish speaking families, non-DCYF referrals, younger referrals and children with public insurance in “staying the course,” thereby increasing the likelihood that disabled and at-risk children will receive maximum benefit from the treatments and services to which they are entitled under IDEA.

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